

**Magic Bullets with Butterfly Wings:
The Cooperation between Experts and Lay People in the Patients'
Association Debra Austria and its Research Initiatives**

D I P L O M A R B E I T

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0 Preface

Writing a thesis such as this involves many more forms of debt and reasons to be grateful than can be expressed by following citation standards.

In that sense, I would like to thank all my colleagues at VIRUSSS¹, and all participants of the VIRUSSS summer schools for the discussions on my work and on many other related topics. This thesis would be of much poorer quality without these spaces of reflection. Especially, I am indebted to Philipp Haydn, Astrid Mager and Brian Wynne for their comments on (partially much) earlier versions of this work.

Karen-Sue Taussig, Rob Hagendijk and Annemiek Nelis generously gave me the opportunity to have a glimpse of their ongoing work, and thus made orientation in the complex theoretical field I was entering easier.

Most of all I would like to thank Ulrike Felt, for continuing intellectual and practical support, for allowing me the freedom to shape this thesis the way I wanted, even though I never really knew how I wanted it until it was finished, and most of all for providing such an inspiring environment to work in.

Furthermore, I would like to express my gratitude to my mother, without whose support in many ways this thesis as well as the studies it completes would not have been possible.

And last but not least, this is written for Nora, because it took much more of our time than it should have done.

That all said, it goes without saying that all errors of fact, interpretation, grammar and spelling are my own.

¹ Vienna Interdisciplinary Research Unit for the Study of (Techno)Science and Society, www.univie.ac.at/wissenschaftstheorie/virusss

1 Introduction

It is a beautiful warm and sunny October morning, and golden sunlight floods the lobby of the conference centre. As I am registering for Debra Austria's² annual meeting, a group of children races by so rapidly that I can hardly spot the white of their bandages which, for me, signifies that they actually also belong to the meeting. It is quite an illustrious group that has gathered below the already snow-covered mountains surrounding the city. Besides a slightly disoriented sociologist, people affected by the rare inheritable skin disease Epidermolysis Bullosa (EB) have come from all over the country, from neighbouring countries, and some even from the rest of Europe. There are adults affected by the disease, there are many children playing in the hallways, some affected, some not. Parents and relatives of affected children are also present, as are medical doctors, molecular biologists, and nurses.

I receive a name sign and a quite thick package of materials, on the cover of which a butterfly proudly spreads its wings. As I look for my room, still slightly disoriented by the many new faces, I wonder what actually has brought me to this meeting of people affected by a nearly unknown disease, their relatives and scientists.

To give a first explanation, one can take the long way round. For nearly twenty years now, the relationship between science and society, or between scientists and lay people, has been on the political, and also on the social scientific agenda.³ The question to ask here is how lay people and scientists understand each other and the science in question. More recently, after it had been noticed that the communication of science to lay audiences goes beyond the filling of information deficits, and that those lay groups might actually have something to contribute to producing a better knowledge a new question, that of how lay people may influence research, has been added to the agenda.

And what better setting could there be to observe these questions than medicine, more concretely the context of a self-help group? It can be suspected and argued that hardly any other science affects and changes the daily lives of those touched by it so deeply. What more pressing reason for trying to understand, and also to engage science could there be than being affected by a severe disease?

² Debra stands for Dystrophic Epidermolysis Bullosa Research Association, a patients' association of people affected by the rare inheritable skin disease Epidermolysis Bullosa.

³ See chapter 3.3 for details;

This, in a nutshell, is what this thesis is about. It is about how all the people that have gathered in a Salzburg hotel this morning interact to build the framework in which the experts and laypeople organized in Debra discuss, do and maybe even change science.

And myself? This might be the short way round. Being a sociologist with a strong background in medical sociology, a fascination in science studies and the incautious wish to do empirical work in his masters thesis, what might be more logic than researching a self-help-group/patients' association⁴ and their relation to medical science. Or at least that is what one thinks looking back...

This thesis starts with a short introductory portrait of the group of people I am writing about, Debra Austria, and the condition, Epidermolysis Bullosa, they are affected by. As far as this is possible in the narrow margins of this first chapter, it is thought to provide a first impression what the thesis will be about and serve as a background for the next chapters. This is followed by a chapter on theories. Drawing on insights from science studies, medical sociology, medical anthropology and a number of related case studies, this chapter is supposed to provide the grounding on which the empirical picture of Debra will be painted, and it also will provide the "outside" to which the conclusions I will draw from my empirical material will be related.

The next chapters are concerned with how this thesis was done. First, I will relate my "theoretical tools", the group of theories I used to think about and theorize my research. In a next step, the concrete set of research questions to be answered by the empirical chapters will be explained. Finally, a traditional "method" chapter describes how the data for this thesis was gathered and analyzed.

The main empirical part of this work starts with a short chapter on "living with EB", which aims at giving an insight into the daily lives of people affected by EB and the problems they face. The remainder of the empirical part is divided into three large chapters, the first of which deals with the founding of the association and how the people involved in it managed to build a cooperation across the "expert-lay divide". In the second part, I will deal with Debra's research, and with the question of in how far and how the affected lay people shape this research. The third chapter is devoted to how the money needed for sustaining Debra's activities is raised, and which identities are created and contested in this process. Every one of this chapters is followed by a sub-conclusion which relates the

⁴ See chapter 3.2.1 for some definitional remarks on these terms.

findings of this chapter to the general framework of the thesis. In a last chapter, final conclusions will be drawn.

As should have become clear by now, this thesis, though the empirical research it bases on was done in German, is written in English. There are a number of reasons for doing so, the main one being that nearly all the literature this thesis is based on is in English, and thus, the process of translating concepts would have been a tiring and also conceptually dangerous one. All quotations used in the text are translated by the author, the original quotations are to be found in annex 1.

2 Debra Austria and Epidermolysis Bullosa: a short introductory portrait

Finding a suitable setting to study the interactions between experts and lay people and the latter's engagement with research in the medical domain is not easy in the Austrian context⁵. One of the first steps of my fieldwork thus had to be to find a patients' association which was, in short terms, both patient-led and research-oriented. A first survey of the websites of possibly relevant organisations quickly revealed that both criteria were not easy to come by, let alone their combination. First of all, many Austrian associations seemed very little "patient"- and very much "professional"-led. Furthermore, an active engagement with research that went beyond being interested in the progress of science was to be seen in nearly none of the surveyed associations⁶.

Debra proved to be the exception to this rule. As much of this thesis will be dedicated to describing Debra and living with Epidermolysis Bullosa, the task of this chapter only is to provide some short introductory information. Founded in 1995 in Salzburg, Debra is, relatively speaking, a newcomer to the Austrian self-help landscape. Roughly, the association has 160 full members, about half of which are directly affected by the disease, the remainder being relatives and other interested people. Already its name "Debra", which is imported from a similar group in the British context, hints at its interest in fostering research. Debra stands for Dystrophic Epidermolysis Bullosa Research Association. Consequently, Debra sees fostering research towards a cure for EB as one of its main goals, besides securing optimal health care for people affected by the disease, informing them and raising their quality of life, also by doing communication activities to reach a better societal integration.

Epidermolysis Bullosa itself is an inheritable disease⁷, or rather a group of closely related diseases of genetic origin⁸. Characteristic of the disease is that the slightest mechanic irritation of the skin can lead to the forming of blisters. In its more severe forms, this blistering can also occur on mucous membranes, such as in the throat, the mouth or under

⁵ And in this sense I am doubly indebted and grateful towards the people involved in Debra Austria, one the one hand for supporting my project, and on the other for their engagement which enabled me to write this thesis on such a thrilling story.

⁶ See chapter 6 for more details.

⁷ For more detailed information, see <http://www.debra.org/>

⁸ There are also rare cases of acquired, auto-immune EB.

the eyelids. Furthermore, blistering can lead to a joining of extremities, such as the fingers, which can only be corrected by surgery.

Epidermolysis Bullosa has three main forms, EB simplex, dystrophic EB and junctional EB, which vary in the seriousness of the respective symptoms and affect different regions of the skin (see graphic 1).

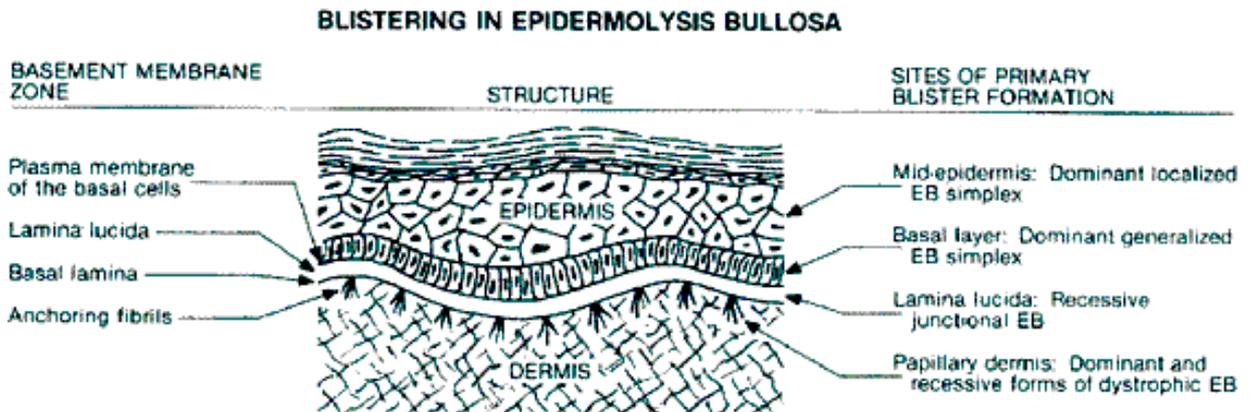


Image 1⁹:

EB simplex¹⁰ is the most common form of EB, seventy percent of all cases being affected by this variant. Affecting only the upper regions of the skin, it is also the least severe of the three forms, and affected patients may even lead a nearly symptom-free life. The simplex form of EB is inherited in an autosomal dominant pattern, meaning that it will appear even if only one of the inherited traits is affected by EB. This in turn means that EB simplex tends to “run in the family”.

The junctional form of EB is the most rare, affecting ten percent of all cases. It is recessively inheritable, which means that it appears unexpectedly in most of the cases. Its symptoms are very severe, the infant mortality within the first life year being approximately fifty percent. Only very few patients with junctional EB survive the first three years of their lives.

The dystrophic form, which shows in around twenty percent of all cases, can be inherited both dominant and recessive. Compared with the junctional form, the dystrophic form has

⁹ Source:

<http://www.debra.org/modules.php?op=modload&name=News&file=article&sid=2&mode=thread&order=0&thold=0>

¹⁰ <http://www.debra.org.uk/abouteb/types.htm>

a wider range concerning the severity of symptoms, but it still is much more grave than EB simplex. Characteristic of the dystrophic form of EB is the joining of extremities like fingers or toes.

Because the condition does not only affect the skin, but also for example mucous membranes in the mouth, the throat and even the lungs, health care for people affected by EB is complex, and has to involve specialists from a number of different disciplines.

3 Framings: Contexts and Theories

Every story needs to be told against a background, and if it is a scientific story these backgrounds are called “contexts” and “theories”. The aim of this chapter is to provide a frame for what will be written about Debra in the empirical part of this thesis, first of all in the sense of pointing to facts that lie outside the narrow focus of my empirical work but which are nevertheless important to be able to compare this description with what has happened elsewhere and at other times – this is what is usually called contexts. On the other hand this part of the thesis will provide models of explanation and different ways of thinking about the phenomena concerned, for example the expert-lay interaction describing different theories that deal with the issues discussed.

But why not separate contexts and theories, and put them in two distinct parts? The main reason for this is that, considering this option, I strongly felt that every theory also has a context, and in science, many contexts are told to explain or strengthen a theory. For example, understanding the early theories of self-help without considering the context of the phase of the self-help movement they were written in is nearly impossible, or at least misleading. Separating contexts and theories thus would have been a little like showing pictures without frames, and then frames without pictures.

Thus, I have decided to structure this chapter by three topical blocks that roughly correspond with the three different scientific fields involved in this work on the one hand – medical sociology, science and technology studies, and what I would like to call “cultural studies of medicine and society” -, and which on the other hand treat questions that run parallel to those of the three main empirical chapters of this thesis. These three blocks will be preceded by a short introduction to the concepts of modern society that lie behind many discussions touched in this chapter. The first block will deal with the question of understanding self-help, mainly from the perspective of medical sociology. Main questions to be discussed will be the history of self-help and different ways of understanding/describing it. The second block introduces the main perspective of this thesis, the possible contribution of science and technology studies to the issue of self-help and the involvement of patients’ groups in research. Science studies¹¹, an transdisciplinary

¹¹ The transdisciplinary field of science studies has many names, other well known labels are STS (science, technology, society) or the sociology of scientific knowledge;

field, has a long standing tradition of critical research into the relations between experts and laypeople, or sciences and their publics. Ways of conceptualising the relation between lay people and knowledge production will be the second related focus of this block, which is especially relevant to the questions of this thesis. The third block will deal with the cultural relations between medicine and society, with the identities that are produced and reproduced by medical practices and their place in society. This strand of research¹², which is strongly associated with medical anthropology, has gained momentum with the discussion of the impact of the “new genetics”.

These three different disciplinary perspectives also point to another function of writing a contexts and theories-chapter, which I would explicitly like to mention here. To describe what one sees as relevant contexts and theories is also to describe one’s own standpoint, the point of view from which this thesis is written.

¹² Though it can be traced back to writers like Michel Foucault, see Foucault 1975

3.1 Is modernity over after it has never really begun? Changing concepts of society at the beginning of the 3rd millennium

To talk about theories of society in the brief space available for the theory part of this thesis a little seems like trying to squeeze an enormous discussion into a few pages. The number of macro-sociological theories and theories of society is steadily growing, indeed the running gag that there are as many societies as there are sociologists, even though of course still quite an exaggeration, probably has a grain of truth in it. But still, I believe that many of the claims made by different authors in later parts of this chapter cannot be fully understood without at least mentioning some of the models and discussions on how modern society and modernity itself can be conceptualized. In the following I have chosen to outline the three theories of modernity that from my point of view are most central concerning the issues at hand¹³. Niklas Luhmann's monumental theory of modernity serves as an important background for the discussions about the meaning of self-help, as well as a starting counterpoint for Ulrich Beck's and Anthony Giddens' conception of reflexive modernity. The discussion between those two theories plays an important backstage part in the reflections about the new forms of interaction between science and society¹⁴. Finally, Bruno Latour's fundamental challenge of the category "modernity" echoes in much of science studies work and thus also deserves to be mentioned here.

3.1.1 Modernity as functional differentiation – Niklas Luhmann

Complexity can be seen as one of the keywords to Niklas Luhmann's theory of modern society¹⁵. What differentiates modern society from pre-modern-societies, e.g. the agrarian societies of the middle ages, is an enormous rise in internal complexity, to be measured in the number of specialised communication systems. This increase is made possible by a change of the basic mode of the organisation of society. According to Luhmann, while earlier societies were made up by homogenous units¹⁶ that were organized either in a

¹³ This of course implies omitting a number of theories that are not quite so, but still rather important concerning some aspects that will be discussed. For example the work of Jürgen Habermas has a strong relevance for the discussion about self-help in medical sociology.

¹⁴ Nowotny et al. 2001

¹⁵ Luhmann 1998

¹⁶ For example villages or tribes for societies characterised by segmentary differentiation.

segmentary or later in a hierarchical¹⁷ form of differentiation, modern society is characterized by functional differentiation. This means that modern societies are comprised of a number of highly specialised subsystems, each fulfilling a certain function for society as a whole. Examples for these subsystems would be the economy, politics, law, and two especially important systems for the topic of this thesis: science and health care¹⁸. Each of these systems follows a certain binary code¹⁹ that defines its identity as well as a number of highly specialised programmes²⁰ that guide its actions. Furthermore, each of the subsystems is highly autonomous, follows its own logic and cannot be directly influenced from the outside. For the science system, autonomy in this case also means that knowledge is seen as being produced only according to the internal rules of the system, relatively uninfluenced by other systems like the economy or politics²¹.

As a result of functional differentiation modern society has no “centre” and thus many problems of modernity²² can be traced back to the fact that each system pursues its own goals without seeing the whole of society. Luhmann has always rejected claims of a transition to a post-modern society, arguing that as long as functional differentiation prevails, our society can only be called modern.

For the issue of self-help, besides the fact that it according to Luhmann is the process of functional differentiation that makes the enormous complexity and thus capability of science and medicine possible, the most important aspect of this theory is the place of the individual in the process of modernisation. The emergence of a large number of highly complex systems means that it is impossible for the individual to fully grasp the different logics and knowledge systems of each of these systems. Thus two new groups of roles arise, a limited number of people in functional or expert roles in a functional subsystem, e.g. doctors or scientists, and the large majority of people as audience or lay people that only have very limited possibilities of action in the respective system, e.g. patients²³. From my point of view, it is only this knowledge divide that makes it sensible to talk about self-help, because the concept of self-help as something special implies that it is normal to be

¹⁷ For example in the advanced civilizations of ancient Egypt or the kingdoms of the middle ages.

¹⁸ Luhmann 1990a, Luhmann 1990b

¹⁹ For example true/false in case of the science system.

²⁰ In the case of science, theories

²¹ A claim that could be easily criticized considering the findings of STS-studies.

²² Luhmann 1986 provides an interesting example for environmental problems

²³ Stichweh 1988; A further example of these role pairs would be consumer/producer for the economy.

helped by others, for example the specialists of a certain subsystem. The very idea of self-help is dependent on a complex, differentiated society.

Thus, the polarization of expert and lay roles is a result of functional differentiation – and according to this theory the system (in this case medicine or science) would not only be expected to be autonomous towards other systems, but also to be uninfluenced by the large number of people in its “audience”.

3.1.2 Re-Thinking Society? The concept of reflexive modernisation

Ulrich Beck and Anthony Giddens, the two main authors to be associated with the concept of reflexive modernisation²⁴, agree with Luhmann that contemporary societies should not be labelled post-modern. But opposing his systems’ theory they claim that a major shift in the structure of modernity has indeed taken place in the second half of the 20th century, a shift that is large enough to call the present state of society a “new modernity”. The key difference between the concept of reflexive modernisation and most ideas of post-modernity lies in the fact that this shift is not presented as a revolutionary transition, but rather as a gradual process that is rooted in the very foundations of modernity itself – reflexive modernisation is modernity turned upon itself. It is the success of modernity and most of all its unexpected side-effects that cause and structure the transition. According to Beck for example, the side effects of modern science²⁵ are mainly responsible for the changing attitudes of the public towards science, the change of attitude being from a state of unconditional trust to one of public distrust.

The concept of reflexive modernisation does not negate the diagnosis of functional differentiation as a central structural feature of modernity, but it claims that functional differentiation is becoming less clear-cut and rigid in the process of reflexive modernisation. On the one hand, the monopolies of functional subsystems on their respective field of action are weakened and new forms of action arise from within society. The most important example of this process is what Beck labels “sub-politics”. Sub-politics describes political actions taken outside the traditional political system, for example by environmental or self-help-groups. Sub-politics thus includes individuals in the functional subsystems and broadens the scope of actors in the wider political arena²⁶. On

²⁴ Beck 1992, Beck 1997; Giddens 1990

²⁵ The Chernobyl disaster being his most notorious example of a „side“ effect; Beck 1992

²⁶ And thus the political arena itself;

the other hand, as the separation and autonomy of the subsystems is decreasing, links and fusions between codes become visible. For science, this means an self-opening of the monopoly on truth²⁷.

The theory of reflexive modernisation has been criticized from the side of science and technology studies, on the one hand as being too simplifying in its assumption of a state of unconditional trust of lay-people in simple modernity and thus underestimating the complexity of the expert-lay-relationship²⁸, and on the other for being too optimistic in its estimation of the chances of sub-politics to influence functional subsystems, for example scientific knowledge production²⁹. Still, its basic conception of the change of modernity often remains unchallenged even in these criticisms.

3.1.3 What if we never have been modern? On Bruno Latour's theory of modernity

While authors like Luhmann and Beck might argue whether we are entering a new phase of modernity, or whether we are still “simply modern”, Latour offers a seemingly disturbing thesis: he claims that in fact we have never been modern at all³⁰. The key to this argumentation is the fact that the author, coming from a background in science and technology studies, defines modernity quite differently than the theories discussed before. The essence of the modern constitution according to Latour is the rigid separation between a factual, unanimated and “cool” nature on the one hand, and society or the political, populated by values and opinions, on the other. This separation produces a realm of things that always speak truly, but cannot speak for themselves and thus need to be spoken for by science, and a realm of human politics that is separated from these processes, comprised of a lot of talk with little factual basis. Drawing on comparative anthropological evidence, Latour claims that this separation only exists in the modern western world, thus making it the defining criterion of modernity.

While this separation exists in the semantics of modernity, it cannot be observed on the level of everyday practises. There, a proliferation of objects that are simultaneously natural and social, which Latour calls “hybrids” is to be observed.

²⁷ Beck 1997; 112

²⁸ Wynne 1996, see also chapter 3.3

²⁹ Nowotny/Scott/Gibbons 2001; see also chapter 3.3.2

³⁰ Latour 1993

“The ozone hole is too social and too narrated to be truly natural; the strategy of industrial firms and heads of state is too full of chemical reactions to be reduced to power and interest; the discourse of the ecosphere is too real and too social to boil down to meaning effects; Is it our fault that networks are *simultaneously real, like nature, narrated, like discourse and collective, like society?*”³¹

The political is too important in the formulation of epistemological “facts” and the natural is too influential in the realm of politics – thus it is not possible to hold the distinction made in the “great divide” between nature and politics in observations of the modern world; but still it exists in social reality. In fact, the argument is that this very divide is a political construction: it cuts the political short by the “power of the facts”, but on the other hand re-imports political values into the production of these facts through the back door. Latour proposes a political theory that attempts to handle these processes consciously and thus more democratically³².

What seems most important concerning the use of this theory for the issue of this thesis is its calling into question of the relation between politics and nature. While natural “facts” and technological solutions can determine political solutions, they themselves are seen as contingent and influenced by social factors, for example imagined user groups in the case of technologies³³. The question thus is whose values and competences are integrated into the production of scientific and technological artefacts, and which natural/political solutions can be arrived at through this process. It has been argued in this context that the integration of the experiences and values of user groups, from drug users to patients can lead to qualitatively better arrangements³⁴. In any case, taking this theory as a point of departure, systematic research into the interactions between sciences and lay groups is needed.

³¹ Latour 1993; 6; emphasis in original

³² Latour 2001

³³ Bijker 1995a

³⁴ Stengers 1998

3.2 Understanding Self-Help

To write about self-help is a bit like travelling back in time. Not only the peak of the self-help-movement itself can be seen in the late 70ies and early 80ies of the previous century, also most of the sociological publications treating self-help as a social phenomenon date from this period. But while the number of self-help groups has stabilized on a relatively high level, the sociological attention towards self-help has actually decreased. Thus, many of the theories that will be presented here are nearly two decades older than most of the other literature used in this thesis. So, in a way this chapter not only follows self-help back through time, it also follows sociology back through time. For the reader of today, accustomed to a much “cooler” sociology, the nearly enthusiastic style of writing and the hopes and sympathies that are projected into the phenomenon self-help seem puzzling, because they take place in the context of a different discussion about the relationship between society and the individual. But still, these writings offer the most thorough insights into the phenomenon of self-help and can help to re-think it beyond the narrow ways in which it is often treated today³⁵. These theories and their backgrounds will be discussed in the second part of this subchapter, after a short history of self-help groups and patients’ associations and a discussion of these two terms.

3.2.1 Self-help groups and patients’ associations: some definitional remarks

Both the terms patients’ association and self-help group are used in this thesis, sometimes in very similar meanings and circumstances. While the two terms are in fact of course closely related, their use in this thesis, especially to describe Debra, still depends on some quite crucial differences.

The maybe most often cited definition of self-help groups is given by Katz and Bender:

“Self-help groups are voluntary, small group structures for mutual aid and the accomplishment of a special purpose. They are usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem, and bringing about desired social and/or personal needs. The initiators and members of such groups perceive that their needs are not, or cannot be, met by or through existing social institutions. Self-help groups emphasize face-

³⁵ That is, focussing exclusively on the individual coping dimension of self-help.

to-face social interactions and the assumption of personal responsibility by members . They often provide material assistance, as well as emotional support;”³⁶

This definition of self-help can include a wide range of activities and actors, from lonely parents to people affected by catastrophes, for example an hurricane. Leaving these aside, I will restrict the use of the term self-help-group to groups that relate to a certain medical problem or disease. Note that, in contrary to how the term is often used, the social-psychological dimensions - mutual aid and emotional support - though they are of course important elements of the definition, are seen as by far not sufficient to describe a self-help group. A second important dimension is the active perception of a gap in the existing social institutions, and the taking of collective actions to change this. These actions can of course take various forms, depending on the specific group. For example, feelings of alienation and anonymity that might be experienced by patients can be answered either by forming a very inward-oriented support group to alleviate the distress caused by this, or by taking actions to change the health care system in order to solve the problem at the “supply side” – or of course by doing both at the same time. A further important criterion Katz and Bender describe is the spontaneous origin of self-help-groups³⁷. A genuine interest to form the group should exist from within, the organizational structures should not be imposed from the outside. This serves to delineate patient-led groups from groups led and controlled by professionals like medical doctors. Of course, doctors can be stimulators of self-help-groups, but they should not dictate their structures. In empirical work, especially considering groups in which both patients and professionals like doctors and scientists play an important role – as it is the case for Debra -, drawing this boundary is very difficult, and the dichotomy between patient-led and professional-led is often of little analytic value³⁸. This has led to the creation of new terms like “hybrid forum”³⁹ to describe collective efforts of professionals and patients⁴⁰.

The term patients’ association, though widely used in recent literature, has not been defined as exactly as self-help group⁴¹. The term association suggests, used in analogy to for example an association of consumers, an active engagement to promote the interests of

³⁶ Katz/Bender 1976; 9

³⁷ Katz/Bender 1976; 9

³⁸ Wood 2000; 21

³⁹ Rabeharisoa/Callon 1998

⁴⁰ See chapter 4.2 for a detailed discussion of this topic;

⁴¹ Wood 2000

its respective constituency, a fact that, as discussed above, poses a difference to some self-help groups, though not necessarily to all. Furthermore the tendency to represent a large majority, if not even all people affected by a specific disease is implicit, even though often a number of associations exist for a single disease⁴². Patients' associations thus tend to be larger than self-help groups, and cannot necessarily be described as "small group structures". On the other hand, the possible number of members is limited by the number of people affected by the respective disease, which means that for rare diseases such as Epidermolysis Bullosa, the number of people in a patients' association might actually be quite low and comparable to large self-help groups.

In my argumentation, the most central criterion that marks the difference between a self-help group and a patients' association is thus not only its size and its stronger out-group-activities, but the relative degree of professionalisation⁴³. The wider scope of activities of patients' associations, for example the goal to inform about the disease or to do lobbying for better health care call for different structures that can only much harder be based on the principle of spontaneous organization. These professionalized structures show some affinities to a formal organization like a business company, but I would still hesitate to employ the term "self-help-organization"⁴⁴, which is widely used in the German speaking literature. The main reason for this is that in comparison to formal organizations, the level of spontaneous organization and voluntary work is still very high in patients' associations. While the line between the two terms cannot be easily drawn because of many overlapping issues, I will restrict the use of the term self-help group to the internal activities of mutual aid and discussion, while I will describe the out-group activities like fund-raising or funding research as those of a patients' association. The self-help group is thus one part of the patients' association – a definition that also fits the self-perception Debra's members have of the structure of their group.

⁴² Wood 2000

⁴³ see Wood 2000 for a comparison of the different degrees of professionalisation in different national contexts

⁴⁴ Trojan et al. 1986

3.2.2 Self-help groups and patients' associations: a short historical overview with special attention to rare diseases

The historical roots of **medical self-help groups** can be traced back to immigrant support groups and workers' self-help movements in the United States, as well as to associations of disabled, chronically ill veterans of the many wars of the 20th century⁴⁵. One of the first, and still one of the largest, medical self-help groups to be founded was the AA, Alcoholics Anonymous, established in the 1930's, the years of depression. Two important features of these early groups were a high valuation of "experiences" on the one hand, and a distinct mistrust in the will and ability of public agencies to solve their pressing problems on the other.

Self-help groups catering to specific diseases only came up in larger numbers after the second world war, in the 1950's and 1960's⁴⁶. In this period, the feminist health movement contributed much to the development of the idea of self-help and its societal dimensions⁴⁷. After a steady growth in the US, the self-help movement reached Europe in the early 1970's⁴⁸, accompanied by societal and scientific discussions about the meaning of the phenomenon. In the 1990's, the estimated number of self-help groups in Germany was one group per 1000⁴⁹ people in urban and one per 1800 in rural areas.

The situation in Austria cannot be easily characterized, for the scientific attention to and the interest in researching self-help always seems to have been less than in other countries, a fact that is itself in part attributed to the generally lower level of self-help activity⁵⁰. Using the data of the self-help group registry at the Fonds Gesundes Oesterreich⁵¹ a masters thesis⁵² estimates the total number of self-help-groups in the mid 1990s to be 731. Considering Austria's total population of roughly 8 million people, this would result in one group per roughly 47000 people, which is between 47 and 26 times less than the figures reported for Germany. Part of this enormous discrepancy can probably be explained by the differing quality of the raw data, especially because the Austrian registry operates on a

⁴⁵ Rapp 2000; 193

⁴⁶ Rapp 2000

⁴⁷ Klawiter 2000

⁴⁸ Söllner 1996

⁴⁹ von Ferber 1993

⁵⁰ Svoboda 1989

⁵¹ www.fgoe.org

⁵² Hribernik 1998

voluntary basis and a number of smaller groups might actually not be included. But even then these numbers indicate a by far lower level of activity.

The reasons for this situation may on the one hand be seen in the general development of the relations between science and society in Austria⁵³, which never provided a solid background for grassroot activities, and more specifically in the little financial and organizational assistance offered by the state⁵⁴. It cannot be seen as a coincidence that Eurordis, an umbrella organisation of 199 patients' associations from 16 European countries⁵⁵, including two member organisations from Iceland, has not got a single Austrian member association. Furthermore, by far not all of the registered groups can be called grassroot groups, in the sense that they are initiated by citizens/patients in a bottom up-approach. Rather, it is not necessarily the exception that self-help groups are initiated and sometimes even lead by doctors.

Patients' associations have only very recently attracted the attention of scientific research, which makes it hard to find publications on their historic development. But it can be safely said that these associations, and also their engagement with medical research and care, are not a new phenomenon. In fact, Angela Creager's account⁵⁶ of the development of the vaccine against polio in the early 20th century, which illustrates the important role lay philanthropies played in the development of one of the most important medical innovations of the 20th century, may serve as an indicator that the influence of lay groups on 20th century medicine could be quite underestimated. Further examples are the American National Tuberculosis Association, founded in 1904, and the American Cancer Society, founded 1944. After the second world war, the work of the Huntington society⁵⁷ which played a decisive role in the discovery of the genes causing the disease, deserves to be mentioned.

A quite rapid increase in the number of patients' associations can be observed in the 80s and 90s⁵⁸, roughly a decade after the growth phase of self-help groups. At least for the Anglo-American countries, for which this issue has been studied, it can be stated that patients' associations have become quite an important political factor in the health systems

⁵³ Felt 2003a

⁵⁴ Svoboda 1989

⁵⁵ <http://www.eurordis.org/QSN/QSN-ang/QSNliste-ang.htm>

⁵⁶ Creager 2002; chapter 5

⁵⁷ Wexler 1995

⁵⁸ Wood 2000

of the respective countries. Wood⁵⁹ estimates that roughly two percent of the American and British population are organized in patients' associations. The financial power of these bodies also is quite impressive: twenty percent of the associations studied in the United Kingdom had an annual budget of over one million British pounds, another third lies between 100.000 and a million⁶⁰. The annual turnover of patients' associations in the United States alone was an estimated 10 billion Dollars⁶¹ in 1990. These figures on the one hand point to the enormous potential financial, social and political power of these associations, and on the other hand explain the processes of professionalisation necessarily involved.

No comparable evidence exists for Austria, but judging from their appearances in the media and the number of newly founded associations, a slight growth can probably also be witnessed here. Besides Debra, examples of other active patients' associations would be the Austrian society for muscular research⁶², or the cystic-fibrosis-society⁶³.

The probably most successful, and also most researched patients' association in an European context is the French AFM⁶⁴. Initially the successor of a number of small scale support groups, the AFM quickly grew to be one of the main funding institutions of molecular-biological research in France in the 1980's. This was especially aided by the invention of the Telethon, an annual TV-fundraising campaign that followed the model of the American Jerry Lewis-Foundation, and which was and still is extraordinarily successful.

While the implications of the AFM's cooperation with state laboratories and biotech-companies will be discussed in chapter 3.3.1, it is the very structure and fact of its existence that is of interest in this chapter. The AFM does not represent a single disease, but a group of rare or "orphan" diseases. An orphan disease is a condition that statistically affects less than one in 20.000 persons⁶⁵. While the number of people affected by such diseases may be small, the 6000 orphan diseases taken together affect a significant proportion of the population. Thus, the patients' associations representing a single orphan

⁵⁹ Wood 2000; 56

⁶⁰ Wood 2000; 63

⁶¹ Wood 2000; 6

⁶² See http://www.arcs.ac.at/news/events/science-talk/docs/muskelforschung_broschuere.pdf

⁶³ <http://www.ms-ges.or.at/>

⁶⁴ Association française contre les myopathies; Rabinow 1999, Rabeharisoa/Callon 1998, Rabeharisoa/Callon 1999; see chapter 3.3.1 for a discussion of the AFM's influence on biomedical research

⁶⁵ <http://www.cord.ca/2what.asp>

disease historically tended to be quite weak. But recent years have seen a number of networking activities, both nationally and cross-nationally, in order to build groups that have a certain “critical” mass. These networks of groups often are initiated by a particularly successful example. In the case of Epidermolysis Bullosa, the first Debra group was founded in 1978 in the United Kingdom. Today, Debra UK⁶⁶ is an extremely successful charity organization with its own professional staff. From the start, one of Debra UK’s goals, besides providing support and improving the health care conditions for those affected by the disease, has been to fund research to find a cure. Until today, Debra UK has served as a role model for 36 independent groups in 32 countries, from Mexico via Romania to Hong Kong, including the Austrian group. These groups are organized in an umbrella organization called Debra International⁶⁷ whose main task is to coordinate the independent groups, organize communication, for example in annual meetings and conferences, and to do political lobbying work, especially on the level of the European Union.

Umbrella organizations representing a single disease, a group of closely related diseases or even rare diseases as a whole like EURORDIS⁶⁸ have established themselves as actors in the European Union’s health policy process. Results of this involvement include the establishment of EPPOSI⁶⁹ - a European Platform for Patients’ Organizations, Science and Industry - and a community action programme on rare diseases⁷⁰. Recently, the European Commission has initiated the creation of an European Health Forum to include all stakeholders in the policy arena.

One of the notable features of this “rare disease movement” is its international structure and mode of organization. While self-help activities historically tended to be locally or nationally oriented, these networks derive their very strength from their globalized, trans-national structures. They may as well be one of the first examples of the globalization of lay interests in health care and medical research⁷¹.

⁶⁶ <http://www.debra.org.uk/index.htm>, see also Rapp/Heath/Taussig 2000

⁶⁷ <http://www.debra-international.org/index.htm>

⁶⁸ European Association for Rare Disorders, www.eurordis.org

⁶⁹ <http://www.epposi.org/>

⁷⁰ http://europa.eu.int/comm/health/ph_threats/non_com/rare_diseases_en.htm

⁷¹ For a further example, the case of breast cancer, see Klawiter 2000

3.2.3 Theorizing self-help

For the sociology of the late 70's and early 80's, the enormous increase in self-help activities posed quite a theoretical challenge. What were the causes and effects, the individual motives to join, and what were the societal backgrounds of this new phenomenon, of this new social movement? These were the main questions of a large research project, comprising of both a quantitative survey and a number of qualitative interviews, that was conducted in Germany⁷².

The first and maybe best researched of these questions lies at the intersection between sociology and social psychology – What causes people to join a self-help group? On an empirical level, Trojan et al. identified four main reasons⁷³:

- The wish to learn from other affected people (97 percent)
- Coping with problems caused by the disease (73 percent)
- Coping with problems of everyday life (73 percent)
- Shortcomings and deficiencies of the professional care system (44 percent)

These results are, as most survey results, quite general and thus cannot be easily interpreted. While the two “coping” answers are what might be usually expected to be the function of self-help groups, the fact that mutual learning as a function of self-help groups is mentioned by nearly all participants of the study, and by twenty-five percent more than the “coping reasons”, seems a bit surprising. Thus the exchange of knowledge and experiences is perceived to be the most important task for self-help groups. The forty-four percent that name shortcomings of the professional system as reasons for forming a group point to the inherent protest character of self-help groups. Alas, the exact nature of these shortcomings and deficiencies remained unexplored. Still, the fact that nearly half of the self-help group members positioned their group as a result of deficiencies shows a quite high potential of conflict between the professional system and the lay self-help groups.

The social-psychological literature on self-help focuses on the “coping”-function of self-help groups. The main reason for joining or founding a self-help group is seen as a solution strategy for the stress caused by the disease and its consequences⁷⁴. A similar model,

⁷² Trojan et al. 1986, Trojan 1989

⁷³ Trojan et al 1986; 57; it was possible to name multiple reasons;

⁷⁴ Schwarzer 2000

developed by Martin Seligman⁷⁵, stresses the importance of self-help in overcoming a feeling of helplessness which is caused by the subjective feeling of a loss of control over one's own life circumstances. In this model, the fact that the professional system tends to leave no or very limited responsibility with the patient leads to negative consequences for her or his psychic health. Self-help groups offer a way of comparing alternative paths of action, open possibilities for choice and thus enable to do something oneself. While the loss of possibilities to control one's own life circumstances can even lead to death in extreme cases⁷⁶, Seligman stresses that the contrary effects self-help groups have not only has measurable positive effects on the psychic, but also on the physical well-being of the concerned person.

The loss and regaining of control over one's own life circumstances also plays a central role in Trojan et al.'s sociological theory of self-help groups⁷⁷. Their model goes beyond the narrow psychological dimension of self-help, criticizing the social-psychological accounts for being too focussed on the coping dimension and leaving others aside. According to their argumentation, nearly eighty percent of the population would have one or more reasons to join a self-help group, while the real participation rates are much lower, often as low as one to five percent of the affected constituency⁷⁸. Thus, the function of coping with social and psychological problems is a necessary, but not sufficient reason to join or found a self-help group. The central question in their model is why there are not much more self-help groups. This on the one hand reflects the high valuation of the authors for self-help and their implicit wish for a growth of this model, but it poses an interesting analytical question on the other hand, especially in the Austrian context with its low self-help activity.

Developed out of a series of qualitative interviews with members of self-help groups⁷⁹, three central factors for the founding of a self-help group are identified:

- Disease-related physiological, psychological and social burdens
- Perceived shortcomings and deficiencies of the professional care system
- A certain amount of "counter-experience"⁸⁰

⁷⁵ Seligman 1995

⁷⁶ For example in war prison camps

⁷⁷ Trojan et al. 1986

⁷⁸ Trojan et al. 1986; 47

⁷⁹ The interviews were conducted in the same study as the survey mentioned above. Trojan et al 1986

⁸⁰ German: Gegen-Erfahrung; Trojan et al. 1986

According to the results of the interviews, nearly always all three factors are present, though in different proportions, in the founding of a self-help group.

The first factor points to the importance of the “coping” function of self-help groups for the individual participant, as it has been discussed in connection with the social-psychological theories. The presence or absence of “counter-experience” is important for the question whether a group of people affected by a certain problem will or will not form a self-help group. Two dimensions can be separated in the concept of “counter-experience”. On the one hand it relates to the material, psychological and social resources of a potential group member or the group as a whole. A certain amount of material resources is needed to provide the infrastructure, e.g. a room, for the group meetings, even for a small self-help group but much more for a patients’ association. Furthermore, the members need to be able to free the necessary amount of their time to join the group meetings. Psychological resources point to the issue that a minimal amount of psychic self-competence must remain to actually take action, which cannot always be taken for granted. Finally, a certain amount of social resources like general contacts are necessary for finding other people affected by the same problem in the first place. How difficult this is is of course related to the prevalence of the specific (health) problem. The availability of each of these three types of resources is crucial for forming a self-help group.

The second dimension inherent in “counter-experience” is the possibility to imagine and develop alternatives to the status quo, or in other words to initiate a counter-discourse. Prerequisites for this counter-discourse can be seen in actual experiences of a different “order of things” on the one hand, and in the availability of cultural forms to voice protest and dissent on the other. The lack of a tradition for bottom-up political engagement in Austria⁸¹ can thus be seen as one of the reasons for the weakness of its self-help movement.

Today, under different conditions, by a different medical sociology, a concept quite similar to counter-experience is being discussed in the discourses around health promotion⁸². The concept of empowerment⁸³ aims at providing people with the necessary resources to start a process of self-help, without determining this process on the other hand. To help people to ultimately help themselves is thought to have indirect structural consequences and even challenge the established balance of power.

⁸¹ Pelinka/Rosenberger 2000

⁸² WHO 1986

⁸³ Raeburn/Rootman 1998

Finally the perception of deficiencies in the professional system, together with the two other factors counter-experience and disease-related burdens, completes the trias of decisive factors necessary for founding a self-help group. The fact that the founding of self-help groups is also related to deficiencies of the professional care system allows to view self-help from the perspective of another group of sociological theories. Even though it is hardly associated with this tradition today, at the peak of its scientific discussion self-help was often described as a social movement⁸⁴. The reason this connection is negated today mainly lies in the fact that a notion of (more or less open) protest is required as one defining criterion of social movements. Especially in Europe, which never has had much of a tradition of overtly controversial self-help groups and patients' associations⁸⁵, this criterion was not seen as being fulfilled. In my opinion, the fact that deficiencies in the professional system and strategies for countering them are main reasons for founding these groups is sufficient for them to be seen as protest groups. After all, throwing stones is not the only way to voice protest.

Steven Epstein, whose work on the American Aids action groups will be discussed in a later chapter⁸⁶, has argued that viewing self-help through the lens of social movement theories can be very rewarding⁸⁷. Following the anglo-american tradition of movement research⁸⁸, three main lines of theorizing social movements can be distinguished: the resource-mobilization paradigm, social constructivism and finally the theory of the "new social movements".

Rooted in a functionalist tradition and strongly influenced by organisational sociology, resource-mobilization theories construct social movements as having fixed preferences arising out of social problems. Goals and motivations of social movements are given problems that exist in society, the fact that not all social problems lead to the forming of social movements is explained by the thesis that some movements are successful in mobilizing their resources, while others are not. The focus of these theories thus is not on how goals are chosen and shaped, but rather on by which strategies they are achieved.

⁸⁴ Katz/Bender 1976; 28

⁸⁵ This is quite different in the United States, see chapter 1.3.1

⁸⁶ See chapter 3.3.1;

⁸⁷ Epstein 1996; 20;

⁸⁸ Della Porta / Diani 1999, European approaches would e.g. include systems theory

Following this paradigm it is of interest how self-help groups and patients' associations raise money, recruit new members and organize their internal structures⁸⁹.

Oriented towards the theories of social interactionism, the social constructivism-paradigm⁹⁰ argues that the goals as well as the ways they are reached cannot be taken for granted or as "existing out there". The central research question of this school of movement research is how identities are constructed and common goals are framed by social movements. The framing of the movement goals often is conflictual, because many social movements are heterogeneous and different groups may have different visions of the group's goal⁹¹.

The discussion of the new social movements finally leads us back to more macro-sociologically oriented theories. Building on the work of Jürgen Habermas, new social movements⁹² are seen as post-materialist counterparts to the classical movements like the worker's movement. Not the division of capital and labour, but a multitude of cultural conflicts about the "grammar forms of life" are the reasons for the birth of new social movements. Especially the colonisation of the "Lebenswelt", that is, the space of everyday experience which is structured by language, by systemic, e.g. monetary logics, becomes target of the attacks of the new social movements. In another terminology, that of Niklas Luhmann, they are fighting the side-effects of functional differentiation.

3.2.4 The expert-lay-relation in self-help theory

In their comments on the societal implications of self-help groups Trojan et.al present an argumentation similar to that of new social movement theory⁹³. They stress the importance of knowledge about one's own disease and of the power effects that can be caused by an unequal distribution of this knowledge. In their view, it is the monopolization of expertise by professional experts, the so called "expertocracy", that causes the helplessness that leads to the forming of self-help groups. Self-help is thus conceptualised as an anti-expert movement that seeks to de-monopolize and offer alternative forms of knowledge. Implied in this conceptualisation is a positive normative valuation of the authors towards self-help,

⁸⁹ See Indyk/Rier 1993 for the application of this theory on grassroots AIDS groups

⁹⁰ Buechler 2000; 42

⁹¹ See chapter 3.4 for a discussion of these processes of identity construction.

⁹² Epstein 1996; 20

⁹³ Trojan et al. 1986

which they saw as a hope for re-gaining social coherence they felt to be lost in the process of modernization.

Trojan et al.'s expertocracy resembles what the cultural philosopher Ivan Illich at approximately the same time has termed "cultural iatrogenesis"⁹⁴. He argues that the lay cultural forms of coping with death and disease have been repressed and destroyed by modern biomedicine, and that it is the absence of such forms that causes the distress that ultimately leads to the forming of self-help groups.

These quite dramatic oppositions must be seen and understood in the light of the experiences of the early self-help movement. Maren Klawiter⁹⁵ offers an impressive example of the change of the patient role from a objectified docile body to an active subject caused by breast-cancer self-help groups. Until the 1980's, the standard procedure for treating women with a suspicious breast lesion was to do a surgical biopsy under full anaesthesia. If the lesion was diagnosed as being malignant, then the surgeon would immediately perform a radical breast amputation, still under anaesthesia. These practises were the target of self-help group activism in the early 80's. They on the one hand voiced their protest against these practise and thus offered many women, who were previously isolated and without a sense of contingency, a discourse to speak back. Furthermore, these groups acted as fora where information about physicians, and about different, alternative ways of treatment could be and were distributed. This enabled the patients to develop their role from that of an objectified body to active consumers. In turn, the engagement of the breast cancer self-help movement changed the face of breast cancer treatment, by a separation of diagnosis and surgery, and by a rise in alternative theories.

Even though they may be fitting for many examples of the early days of self-help, the theories of expertocracy draw quite simplified, schematic visions of the relations between experts and lay people. Experts are portrayed very negatively as maximising their power by monopolizing knowledge, and lay people are seen as devoid of having their own cultural forms of understanding.

A second strand of medical sociology research treats the knowledge of lay people and their relationship to experts from a different perspective.⁹⁶ One of the most important terminological distinctions in medical sociology is the difference between "illness" and

⁹⁴ Illich 1975

⁹⁵ Klawiter 2000

⁹⁶ Busby/Williams/Rogers 1997

“disease”, the term disease denoting the biomedical, scientific, abstract definition of a particular condition, while illness refers to the subjective individual interpretation and experience of the patient. Researching and writing about lay “beliefs” about illness, this space of lay experiences often carried the connotation of superstitions and misinformation. “Wrong” lay beliefs, even though they may be culturally rooted, were seen as a possible endangerment of the “compliance” of the patients with the correct and true biomedical diagnosis and treatment. This model is quite fundamentally different from the conceptualisation of the expert/lay-relationship in early self-help research related above, especially in its implicit value judgements. Experts and professional expertise are portrayed as positive and beneficial, the lay world is not seen as populated by too few cultural forms of coping with disease, but rather by too many. The crucial question here is whether the beneficial expert knowledge will be understood and accepted by the patients. What both models share is their definition of the lay social world and especially of science as being very homogenous. To put it bluntly, science is either good or bad, with little space left in between. This quite undifferentiated view of science and its relation to lay people has been criticized⁹⁷, and recently, the knowledge of lay people has also been conceptualized as being of equal worth to expert knowledge⁹⁸. Still, these new theories, though altering the implicit value judgements again, have little to offer to provide a more heterogeneous and complex account of science and its lay publics. Thus it has been argued, and I would like to follow this line of argumentation in this thesis, that medical sociology could benefit much from the broader discussion about the relationships between science and society carried out in different arenas, especially in the context of science studies⁹⁹. This will be the subject of the next chapter.

⁹⁷ Busby/Williams/Rogers 1997

⁹⁸ Busby/Williams/Rogers 1997

⁹⁹ Busby/Williams/Rogers 1997

3.3 Theorizing the interactions of sciences and society

The relationship between lay people and experts in particular, and between science and society in general, has not only been on the agenda of medical sociology. It has also been discussed in sociological theory¹⁰⁰, as well as in the political arena. As mentioned in the first subchapter, the theory of reflexive modernisation diagnoses a damaged relationship between science and society, caused by the negative side effects of modernisation. Before that, under the conditions of simple modernity, an unconditional trust in the institutions of science is assumed, which then changes to a state of distrust under the impression of side effects like pollution, environmental catastrophes, or simply increased public dispute among experts. Implicit in this conception is a notion of betrayal of the public's trust¹⁰¹.

The reason for the attention of the political sphere towards this question may be seen in the same perception of the public's growing suspiciousness of science. Quantitative surveys of attitudes towards science as well as of knowledge about science indicated growing distrust of the public, and this mistrust that disturbed the relationship between science and society found¹⁰² its expression in a growing number of public controversies as well as in decreasing numbers of science students. Since science and innovation were and still are seen as vital for the economic development and position of a country, politicians felt that actions needed to be taken¹⁰³. The first and probably the most famous and most criticized, example of such an action plan is the report of the British Royal Society "The Public Understanding of Science"¹⁰⁴. This report mainly followed the so called "deficit model", which was developed in the context of the survey research on attitudes towards science¹⁰⁵. It assumes that the public's distrust is mainly rooted in the fact that it is too less informed and thus ignorant about science. In this model, distrust and fear are produced by a shortage of information that can easily be solved by doing the appropriate communication activities. These communication activities are to be designed in a very linear fashion, following a clear sender/receiver logic. Communicating science is seen as a mere simplification of the complicated scientific discourse, and in delivering these simplifications to the public,

¹⁰⁰ Giddens 1994, Beck 1992

¹⁰¹ Wynne 1996

¹⁰² And still finds;

¹⁰³ See Felt 2003 for a detailed history of Public Understanding of Science politics

¹⁰⁴ Royal Society 1985

¹⁰⁵ Felt 2003b

which is merely waiting for this information to solve their fear and mistrust. This way of conceptualising the relationship between scientists and lay people resembles the model that has been discussed in the last chapter in the context of medical sociology. Science is presented as intrinsically benevolent, while its lay audiences are represented as rather disoriented, or essentially as an information void¹⁰⁶ to be filled.

The assumptions and also the empirical basis of this model was criticized by a number of qualitatively oriented studies, which in depth explored how people react to and how they position themselves in relation to science and technology¹⁰⁷. A main target of criticism, for methodical reasons¹⁰⁸, were the survey studies that form the empirical basis of the deficit model. Why should the failure to know about the birth date of Carolus Magnus be a valid indicator of a ignorance towards science? And most of all: Which science?

The assumed homogeneity of science in the deficit model, but also in the other models of the relationship between science and the public discussed so far, was put in question by a number of authors. Jean-Marc Levy-Leblond¹⁰⁹ has suggested to view science not as one single “unknown” continent, but rather as a number of islands scattered along a shore which represents society, some grouped, some lonely, some closer to the shore and some more distant. The basic argument underlying this metaphor is that modern science is so differentiated and internally so different that it does not make sense to treat disciplines as different as marine ecology and particle physics alike.

A study on the meaning of science to lay people conducted by Mike Michael¹¹⁰ supports this argument. Drawing on a number of in-depth interviews, his main finding is that people differentiate quite clearly between “science in general” and “science in particular”, meaning one particular scientific discipline, scientist or context of the application of scientific knowledge. Seemingly paradoxically, his interviewees would be able to explain complex relations and voice strong opinions about a particular scientific discipline which touches their lives in any way, but still claim to know nothing and would be ignorant about “science in general”.

¹⁰⁶ Only that this void is again connotated differently – in this case as to be filled by science while it was supposed to have been caused by science in the model of Trojan et al. 1986 or Illich 1975

¹⁰⁷ Wynne 1992, Michael 1992, Michael 1996

¹⁰⁸ Wynne 1995

¹⁰⁹ Levy-Leblond 1992

¹¹⁰ Michael 1992

The ignorance perceived by the surveys thus is seen as an effect of a meaning-shift between “science in particular” and “science in general”, that leads people to believe that in order to know something about “science in general”, it is necessary to know about everything, from cosmology to molecular genetics – which in fact of course completely impossible, even for any scientist¹¹¹. Furthermore, being ignorant of a certain science is not necessarily a state of passivity and a lack of information, but can even be an active choice depending on strategic considerations, e.g. a cost/benefit calculation or trust in a institution who is expected to manage the respective issue¹¹². Lambert and Rose¹¹³ have shown that people affected by a genetic metabolic disorder, which causes high cholesterol levels that can lead to heart attacks, but has no symptoms otherwise, are highly selective concerning which part of the relevant scientific information they want to explore further, and which they leave aside. They develop an interpretative form of “situated knowledge”, a way to integrate the scientific knowledge, for example the treatment advice given to them, into their daily life circumstances. The fact that they do not follow medical advice to the last extent thus is not a lack of understanding of the information given to them, but rather a conscious choice between optimal therapeutic effects and their own quality of life, a conscious choice rooted in a situated understanding of these facts. Similarly complex processes lie behind the question whether the scientific information is trusted, or not. Surprisingly¹¹⁴, a higher level of knowledge among the patients was observed to lead to less, not more trust in the given information, because the more informed lay people were aware that the scientific information given to them was itself not uncontroversial.

Differences between the situated lay understanding of a phenomenon and the scientific explanation can also lead to conflicts. In a study of people affected by musculoskeletal rheumatic disorders, Busby, Williams and Rogers found quite dramatic differences in the medical explanation of rheumatic conditions between lay understandings and the expert discourse¹¹⁵. While the expert system, met by the affected people in primary care, explains the pain mainly to come from ageing processes and has very little to offer in terms of therapy, or even remedy, the affected patients on the other hand see their condition as a result of “wear and tear”, and link it to complex stories of working lives, hard manual

¹¹¹ Wynne 1995

¹¹² Michael 1996

¹¹³ Lambert/Rose 1996

¹¹⁴ From the point of view of the deficit model.

¹¹⁵ Busby/Williams/Rogers 1997

labour and deprivation. They often can draw parallels between the intensity of labour and the seriousness of their symptoms at a given point in time. Simple ageing seems a too less complex and unsatisfying explanation compared to their own accounts. This, coupled with the inability of the practitioners to provide a cure or remedy, leads to mistrust and can seriously burden the relationship between doctor and patient.

But how can we treat these two different accounts in terms of epistemology – can the expert story really be seen as superior, or do the complex “beliefs” of the affected people actually have something to contribute to a better understanding of the disease?

Brian Wynne¹¹⁶ has analysed the interactions between Cumbrian hill farmers and radiation scientists after the Chernobyl accident. Immediately after the incident, high radiation values were reported from the hill soils, and the government placed a ban on the slaughter and sale of sheep from the affected areas. Initially, this ban was promised to be raised within three weeks, this period of time being based on the radiation experts’ prediction of the half-life period of the radioactive material. This short period of time was socially vital to the farmers who relied on being able to sell their surplus of lambs to secure their income. Unfortunately, the localized character of the knowledge on the biological half-life – the initial observations on which this knowledge was founded had been made on a different soil type - had been overlooked by the scientists, and the three weeks proved to be quite an underestimation. In the months to come, the area affected by the ban was gradually decreased, until finally a crescent shaped area around the infamous nuclear facility Sellafield remained. While the experts ensured that the contamination had nothing to do with Sellafield, earlier experiences of denials of accidents at the plant as well as the institutional “body-language” of the authorities caused mistrust among the farmers. A further cause for this distrust was the fact that the scientists ignored the farmers’ specialist knowledge of the environmental conditions in the hills and the behaviour of their sheep. For example, they compared different measuring points the farmers knew where not comparable because of different prevailing soil and/or weather conditions. In another instance, they experimented with substances to lower the radiation rate in the sheep, put a number of sheep into different fenced pens and treated the soils with different concentrations of bentonite which was supposed to bind the radioactive isotopes so the sheep would not be contaminated. While this seemed like a perfectly controlled experiment

¹¹⁶ Wynne 1992, Wynne 1996

to the scientists, the farmers knew that their hill sheep were not used to be kept in pens and thus would panic. This led to a rapidly accelerated metabolism that rendered the experiment senseless from the very beginning.

Drawing on this and other case studies, Wynne argues¹¹⁷ that lay people's trust in science is a far more complex issue than the simple dichotomy of trust/distrust used by reflexive modernisation theory suggests. Instead of following a simplifying logic of trust, betrayal and mistrust, trust must be seen as a complex and locally contextualised process in which, as mentioned above for the lay understandings of science, a number of locally contingent factors play important roles. In the sheep farmer case, previous experiences with the Sellafield authorities were as important as the actions of the scientists or the economic dependence of the farmers to sell their lambs as fast as possible. Trust can thus not be seen as a dichotomous variable, but rather as an equilibrium of different locally contingent factors. This in turn means that a seemingly small shift in one of these factors can cause a quite dramatic change from trust to distrust. Given the strongly contextualised nature of trust and its rootedness in a number of very specific experiences, it must also be taken into account that trust means something very different to different groups. Thus it makes as little sense to treat "the public" as an homogenous whole, as it does for science. For example, the workers in Sellafield will have totally different reasons and backgrounds on which to trust or not trust the very same experts on the same question the sheep farmers mistrusted them in. Even patients affected by the same disease can by no means assumed to have similar backgrounds and experiences – differences in age, income, place of residence, or ethnicity can lead to radically different experiences. To have AIDS as an injection drug user has a completely different meaning than to have AIDS as a homosexual, well situated middle-class employee¹¹⁸.

Wynne¹¹⁹ also argues that conflicts between experts and lay people not only arise because of different truth claims, as for example whether the radiation comes from Sellafield or not, but also and most importantly have a strong hermeneutic dimension.

"I would argue that far from *emptying* indigenous lives of meaning, the expert knowledges are typically importing *dense but inadequate meanings*."¹²⁰

¹¹⁷ Wynne 1996; 49-55

¹¹⁸ Epstein 1998

¹¹⁹ Wynne 1996; 60-61

¹²⁰ Wynne 1996; 60; emphasis in original

I cited a typical example for the import of such inadequate and thus contested meanings in the study Busby et al. conducted on musculoskeletal disorders – the assertion that the pain came from “simple” ageing instead of a hard life of labour was unacceptable for the lay people. In Wynne’s argumentation¹²¹, the abstract truth claims of expert knowledge are dependent on tacit assumptions of social relationships, values and patterns of behaviour – or on a “naïve sociology”. Applying these knowledges without considering the local context thus leads to a prescription of a implicit, naïve political model of the social. In the case of the sheep farmers, much of the conflict was caused by the fact that the scientists were completely ignorant of the fact that their knowledge was actually developed for a completely different area, and they also paid no attention to the farmers’ problems. Taking this a step further, it can also be argued¹²² that the failure or success, the very truth of expert knowledge, even depends on the necessity to put the social relations it implicitly depends on into place.

Furthermore, the case study shows that the farmers actually possessed a different, historically rooted body of expertise, which was ignored by the scientists but would have been an important addition to their knowledge in order for the experiments to be successful. Besides from having complex situated understandings of science, groups of lay people can thus also possess different kinds of “experience based expertise”¹²³ they can possibly contribute to scientific knowledge production. To say this does by no means implicate to devaluate scientific expert knowledge, but rather to acknowledge its limitations and contextual factors. A romanticisation of “local” knowledge must be seen as at least as problematic as unconditional trust in expert systems¹²⁴.

Finally, the use of the term “local” needs to be discussed. As in the sheep farmer case, lay knowledge is often portrayed as local and contextual, while expert knowledge, even though of course produced under similarly contextualised circumstances, is seen as abstract, de-contextualised and global. The notion of “lay expertise” being rooted directly in contextualised experience is the core of this argumentation, but the term “local” can be seen as rather misleading¹²⁵, for it suggests a certain geographical limitation. Given the

¹²¹ Wynne 1996; 68

¹²² Wynne 1996; 59; see also Latour 1987

¹²³ Collins/Evans 2002

¹²⁴ Wynne 1996

¹²⁵ Michael 2002

possibilities of modern communication, especially the internet, this “local” experience based contextualisation can as well be as global as science itself. The global discussion fora for patients affected by specific diseases, as well as the global character of a number of patient groups¹²⁶ may be seen as examples.

Considering the findings of this chapter, the relationship between science and society, between experts and lay people must be seen as much more complex than the previously discussed models suggest. It seems sensible not only to ask what impact expert knowledge has on lay people, but also if there is any influence of lay groups on the production of scientific knowledge. Also on the political level¹²⁷, the focus has shifted from the public’s understanding of science to the public’s engagement with science and technology, thus attributing a much more active role to lay groups. In the political sphere, this has been operationalised by developing a number of participatory methods, of which the Danish consensus conference is the best known¹²⁸.

In the context of this thesis, especially the influence of lay people on medical science is of interest. Which case studies exist that tell of lay people “talking back” to science? To which changes in scientific practice can the engagement of these lay knowledges with science lead? And generally, how can this relationship between experts and lay people, the influence lay groups have on science and technology, be conceptualized? These questions will be the topic of the next two subchapters.

3.3.1 Case studies of lay engagements with biomedicine

Even though the engagement of lay groups in biomedical research and practice can be traced back to at least the turn of the 19th century¹²⁹, only surprisingly few studies have explored the influence of these lay movements on and their relations to science. In this chapter, a number of case studies will be discussed, with special attention to the question how these lay movements influenced biomedicine, what their reasons for doing so were and how they achieved their goals.

¹²⁶ See chapter 3.2.2

¹²⁷ Felt 2003b

¹²⁸ See Felt/Fochler/Müller 2003 for a discussion of the social/political dimensions of participatory methods in 8 European countries;

¹²⁹ See chapter 3.2.2

The first case study is situated in Woburn, Massachusetts, in the mid- 1980's¹³⁰. At this time, Woburn had unusually high rates of childhood leukaemia. From the perspective of a number of residents, the incidence of a number of cases in a short period of time, where there had been much less before, indicated that there had to be a reason beyond mere chance. The health authorities and their experts denied to act, arguing that the increase of cases was nothing but a statistically not significant chance event. Initiated by a mother whose child had died of leukaemia shortly before, and drawing on the social relations of the local parish priest, a group of people started to chart the cases of leukaemia. The inhabitants of Woburn also suspected a possible reason for these cancer cases: their water. They had for a long time noticed that their water had a foul smell and bad taste, on some days worse than on others, and sometimes could not even be used when cooked. Unofficially, two large chemical plants nearby were made responsible for these pollutions. The parents' group was able to collect data that in their view proved that the vast majority of cases occurred in houses that actually drew their water from one single well. By forming successful alliances with a number of different scientists they were able to prove that the water was in fact contaminated by high levels of industrial waste carcinogens. The causal links between those carcinogens and the leukaemia cases was finally officially acknowledged, action was taken and the suspectedly responsible companies were sued. Even though the causal relationship between the waste dump of these companies and the leukaemia cases could never be fully established, still the Woburn movement must be seen as exceptionally successful. Phil Brown has used the term "lay epidemiology" to describe the actions of this movement¹³¹. In his view, this case demonstrates that lay people are capable of collecting and analyzing evidence in order to explain the strangely high number of cancer cases. While they were successful in collecting data themselves and drawing their conclusions, it should be noted that they still needed to recruit "friendly" scientists to attain the necessary authority in the public sphere, and especially in court. Linking this case studies to what was discussed in the last chapter, it can very well be seen how this movement was rooted in the conflict between an abstract, denying official expert narrative and the complexity and drama of the local experiences. The parents of the Woburn children knew that their water was smelling strangely, they had heard many stories about the practices of the companies and knew their "institutional body language", they were

¹³⁰ Brown 1987

¹³¹ Brown 1987

aware that there were many more cases than before, and most of all: their children were dying. This, confronted with the statement that this was just a “normal” rise in the figures, was what started the Woburn movement. In terms of its relation to medicine and science in general, the main goal of the movement was to make a certain problem which was felt by the residents but not acknowledged by the experts visible and accepted. Gaining credibility by recruiting their own experts played an important role in this process. The “discovery” of black lung disease, a miner’s disease that was denied by employers and professional medicine alike, by a social movement in West Virginia in the 1960’s poses a similar case¹³².

The achievement of credibility and the question of lay expertise also plays an important role in the second case study to be presented. In a much acclaimed book¹³³, Steven Epstein has related the story of American Aids treatment activism and its impact on AIDS research. One special feature of the AIDS treatment activism movement was that it mainly comprised of quite well-off middle-class employees and members of the gay sub-cultures, while at the same representing people affected by a highly stigmatized disease. The cultural capital of this group proved to be quite important in getting entry into the conference rooms where decisions on research and treatment were made. Contrary to the Woburn activists, the AIDS treatment movement did not try to highlight a hidden problem and to put in on the scientific agenda. AIDS of course was a huge subject of research, but it was the way this research was conducted that sparked the activists’ protest. Instead of just collecting their own evidence to support a claim, they directly engaged the methodical foundations of biomedical research, and carried the protest to the street. Among others, one site of the protest activities was Harvard medical school, one of the most high ranked institutions of American medicine, where the activists proclaimed: *“We are here to show defiance / for what Harvard calls good science.”*¹³⁴ The “good science” the affected people were rallying against was nothing less than the standard procedures for developing and distributing medical drugs. Faced with the prospect of a possibly quite near death, the AIDS activists felt that time was crucial, and they had no acceptance whatsoever for the bureaucratic drug regulation policies of the FDA¹³⁵. While new drugs were illegally

¹³² Smith 1990

¹³³ Epstein 1996

¹³⁴ Epstein 1996; 1

¹³⁵ Food and Drug Administration

imported from Mexico by some activists, others tried to get enrolled in new drug trials. In these studies, activists found the practice of double-blind experiments quite cynical, because it meant that a person hoping for a cure would only get a placebo in half of the cases, without even knowing it. Backed by the organisational structure of the movement, the participants of various studies pooled their medications to ensure that everybody would at least get fifty percent of the new medicine, thus destroying the design of the experiment. A further contested regulation was the “pure subject”-rule that allowed patients to enter only one clinical trial in a lifetime, and often only when they had not taken certain medicines earlier on. This “clean” science was heavily protested against by the activists, who claimed that this practice in fact kept people from treating their disease at an early stage, because they were trying to keep their “pure subject” status as long as possible in order to wait for their “best chance”. In sum, what the activists demanded was less attention to scientific criteria and more to the situation of the people affected.

To reach their goals the AIDS treatment movement did not only rely on taking their cause to the street. In order to really have an impact on the relevant agencies’ policies they soon realized they had to engage these institutions from within, and to do so they also, like the citizens of Woburn, had to employ a number of credibility tactics¹³⁶. One of the most important aspects of these tactics was to learn and master the language of biomedicine, and to understand the concepts involved. Furthermore, the activists cleverly took sides in already existing disputes about clinical trials, and they yoked their methodical arguments with moral ones. By successfully establishing their claim to represent all people with AIDS they also managed to establish themselves as an “obligatory passage point”¹³⁷ for the researchers, because they controlled a vital resource the scientists needed for their drug tests: research subjects. By employing these tactics, the AIDS treatment activists managed to have quite a substantial impact on the policies of the relevant institutions, and on the design of the clinical studies. Epstein thus concludes¹³⁸ that lay people are capable of mastering the complex language of biomedicine, of engaging with the epistemological core of biomedicine, and of effecting substantial changes according to their own interests. At the same time he emphasizes the complexities involved in this process. First of all, “learning the language” of biomedicine was far from being an easy process. A large

¹³⁶ Epstein 1995; 417-427

¹³⁷ Epstein 1995; 420

¹³⁸ Epstein 1995; 427-430

amount cultural capital as well as time was necessary for those activists who did this. Furthermore, by learning this language, these “lay experts” also took over some of the scientific logic. Thus, their argumentation moved closer to that of the experts, which on the other hand endangered their position within the movement where they were they were accused of siding with the establishment. In sum, a miniaturized version of the expert/lay divide opened within the treatment activists.

A characteristic feature of the AIDS treatment activism is its successful blend of spectacular protest action on the one hand, and negotiation on the other. In a similar effort, in the early 1980’s a group from Debra US¹³⁹ started their “bloody babies march” to capitol hill. By presenting their blistered babies to the senators, they succeeded in securing federal funding for basic research into Epidermolysis Bullosa. This preference for conflict strategies can be seen in a number of case studies from the United States¹⁴⁰, while the European examples often favour strategies of cooperation. Debra UK¹⁴¹, for example, refrained from aggressively lobbying parliament, and concentrated on raising funds by developing a successful private charity organization¹⁴².

One of the first studies of the cooperation between scientists and a self-help-movement¹⁴³ from a science studies perspective was von Gizycki’s work on the cooperation between researchers and the German retinitis pigmentosa society¹⁴⁴. Founded in the late 1970’s and modelled after an American sister organisation, the DRPV encountered a quite unfavourable environment: health care for those affected by retinitis pigmentosa, a form of retinal degradation that can eventually lead to blindness, was poor and virtually no research was done into the rare disease, neither by public nor private institutions. The DPRV started to formulate patients’ demands toward researchers and began building a framework for RP-research in Germany by lobbying federal bodies for funds, organizing a conference, establishing a scientific fund for funding research projects, a scientific advisory board, and finally by disseminating information about the international status quo of RP research and developing an integrated RP research programme. These activities were successful and managed to attract the attention of a number of, mostly young, researchers. Soon, the

¹³⁹ Heath/Rapp/Taussig 2000

¹⁴⁰ See also Klawiter 2000

¹⁴¹ Heath/Rapp/Taussig 2000

¹⁴² These differences of course also mirror different political systems and political cultures.

¹⁴³ In the terminology of this thesis: a patients’ association

¹⁴⁴ von Gizycki 1987

DPRV funded a number of projects. Besides money, they were able to offer another crucial resource: retinal tissue, that large numbers of DPRV members donated after their death. Von Gyzicki concludes¹⁴⁵ that the success of the DPRV is on the one hand to be attributed to a number of “semi-professionals”, patients who worked their way into the subject and then acted as mediators between the research community and the patients’ interest, and on the other hand to the fact that there was no established research community with fixed interests. He cites a number of other cases of similar societies who could not establish a comparable influence on research, because a research community already existed.

Another European case study shows that, given the right strategies, the effect a patients’ association can have on a research community, even on the research landscape of an entire country, does not need to be small. Rabeharisoa and Callon¹⁴⁶ have undertaken an in-depth study of an association that rose from a number of dispersed small patients’ associations for different rare muscular dystrophies in the early 1980’s to the probably most influential patient group in Europe, and a main pillar of French genome research: the AFM¹⁴⁷.

As so many of the examples described above, the AFM was born out of a feeling of personal despair. The parents of the children affected by muscular dystrophies encountered ignorance or at best helplessness among the medical profession and, because every single of the different muscular dystrophies is an orphan disease, neither state nor industry invested in finding a cure. A charismatic lead person managed to unite the different associations representing the muscular dystrophies, and at the beginning of the 1980’s, the AFM was born and made an important strategic decision: their path to a cure for the muscular dystrophies would be genomics, the identification of the genes causing the disease and finally, gene therapies. In 1987 they introduced the Telethon, an annual TV-fundraising campaign that followed the model of the American Jerry Lewis-Foundation. This campaign proved to be an enormous success, raising an annual average of 50 million US Dollars over the next years¹⁴⁸. The success of this campaign, Rabeharisoa and Callon argue¹⁴⁹, in part was due to the clever strategic choice of the gene as a symbol. By concentrating on genome research, the AFM was able to link the particularity of the tragic, but few, cases of muscular dystrophies, to the national research interests of France. Indeed,

¹⁴⁵ von Gyzicki 1987; 87-88

¹⁴⁶ Rabeharisoa/Callon 1998, Rabeharisoa/Callon 1999, see also Rabinow 1999

¹⁴⁷ Association française contre les myopathies

¹⁴⁸ Rabinow 1999; 40

¹⁴⁹ Rabeharisoa/Callon 1999

the AFM would be a major agent in French and international genome research over the next decade, and it would even be part of the cooperation that published the first physical map of a human chromosome in 1993¹⁵⁰.

Rabeharisoa and Callon¹⁵¹ describe the process of knowledge production initiated and sustained by the AFM as one of mutual learning. The AFM has itself defined research as a process that should start at the needs of the patient, and eventually return to them by proposing a solution. To reach this goal, according to Rabeharisoa and Callon, the patients and other lay people involved in the AFM and the respective scientists have developed an “intermediary discourse” that enables them to talk about the process of research and take strategic decisions without descending into the highly technical details of the research process that would exclude the lay interests. By doing so, the AFM is described by the authors as having invented a third model of research that combines features of the two classical models of public action and the market. The model of public action means that the state finances research and defines its boundary conditions, but it does not specify the exact goals of this research. These are subject to the scientific autonomy of the researchers that actually carry out the respective research. In the model of the market these goals are specified by the private actor financing the research, leaving only very little room to the scientists. The new model Rabeharisoa and Callon describe oscillates between those two poles – the AFM cannot and does not want to afford to leave the complete control over the goals with the scientists, but it on the other hand also isn’t capable to define those goals technically as detailed as to determine the scientists’ actions. The result is a reflexive process of interaction in which both sides define the goals and proceedings of research in an intermediary discourse.

Because the dense interaction between experts and lay people in the AFM supersedes the traditional categories of self-help groups, companies or universities, Rabeharisoa and Callon propose a new term to capture this quality: that of the hybrid forum or collective. The defining criterion of such a group is that it consists of experts as well as of lay people who embark on a “collective experiment”, and who are in a permanent dialogue about their goals, and about the results they obtain.¹⁵²

¹⁵⁰ Rabinow 1999; 45-46

¹⁵¹ Rabeharisoa/Callon 1998, Rabeharisoa/Callon 1999

¹⁵² Rabeharisoa/Callon 1999; 49

Summing up, two different groups of strategies can be distinguished in the case studies of patients' engagement with biomedicine. First, strategies of protest that employ a political discourse of equity and participation were described. To be successful, groups following this route have to establish themselves as credible actors towards science and politics. A number of credibility tactics have been described, the most important of which probably are the appropriation of the scientific language, and the self-establishment as an obligatory passage point, for example by monopolizing resources needed for research.

The second group of strategies, focused on cooperation, rather stresses the importance of private action over the employment of a political discourse. A crucial part of these strategies is being able to negotiate an agreement with a number of scientists who are willing to listen to the patients' concerns and interests. Thus, it are not credibility tactics that play a central role, but rather tactics of negotiation. Still the resources used in both groups often are similar. For example, the ability to provide ample supply of material needed for research can as good as an argument in a negotiation as it can be as a form of pressure.

3.3.2 New relations between science and society: between democratisation and contextualisation

The case studies of the previous two chapters have shown that it no longer can be seen as viable to conceptualize science as a purely interest-free and autonomous enterprise, and the public as pure recipients of the knowledge produced. Patient groups and other lay formations enter scientific knowledge production, causing different kind of effects, sometimes actively challenging the very epistemic core of science¹⁵³, sometimes just creating favourable conditions for certain kinds of research and stating their interests¹⁵⁴, sometimes inventing completely new forms of expert/lay relationships and research financing¹⁵⁵. Delineating science and society has become difficult in those hybrid forums. As Bruno Latour argues¹⁵⁶, standing on the ground floor of the AFM's building in Paris, who could say where science and where society is? He thus argues that the relation between science and society has shifted from a state of an autonomous science clearly separated from society to research as a much more close and involving relationship

¹⁵³ Epstein 1998

¹⁵⁴ von Gizycki 1987

¹⁵⁵ Rabeharisoa/Callon 1999

¹⁵⁶ Latour 1998

between science and society. Instead of a detached and cold science, research is “warm, involving and risky”¹⁵⁷. The patients no longer wait for the results of science to reach them, they actively take part in shaping and producing them. The imagined autonomy of science is replaced by a conscious commitment to problem-solving.

But how can this transformation from science to research, this encounter of the supposedly¹⁵⁸ previously so clearly separated domains of science and society be understood and conceptualized? From my point of view, two basic models of describing and framing this change can be discerned within science studies: on the one hand, there is a discussion about a **democratisation** of science and technology, or a **participation** of lay people in knowledge production; on the other hand, while the first debate is relatively old, a new concept has recently entered the arena, that of a *contextualisation* of science and technology, and of *socially robust knowledge*.

It has always been a core theme in science studies that scientific and technological innovations are also influenced by social factors, and most of all that they are contingent. The optimal form of a technological artefact or the “correct” scientific solution only is a retrospective construction¹⁵⁹. In the production context, a number of contingent choices are made that affect the final design of the artefact, but that may also be taken another way without making the construction impossible. This can best be illustrated by referring to the social construction of technology¹⁶⁰ paradigm, which argues that real and also imagined user groups play an important role in the design of a technology. What is the ideal bicycle? A high, daring construction with which young, sportive upper-class men can show their artistic skills – or a stable vehicle with two wheels of an identical size which can also serve an old lady in taking her groceries home? Of course, there is no answer to this question. The design depends on which real or imagined user groups are implicated in the design. In turn, the example shows that scientific and technological solutions and artefacts also carry and represent a certain model of the social. Technologies can be used to prescribe and standardize certain forms of social relations¹⁶¹. Framing science and technology this way nearly automatically raises questions of power and political order. What about those not

¹⁵⁷ Latour 1998, 208

¹⁵⁸ Whether the temporalities involved can really be described in the linear fashion Latour suggests is to be doubted.

¹⁵⁹ Latour 1987

¹⁶⁰ short: SCOT, Bijker 1995a

¹⁶¹ Latour 1991

implicated in the designs, what about the excluded? Exclusion can happen in many ways, from not being able to use a train because one has to use a wheelchair¹⁶² to just wanting a quick snack and being allergic to onions¹⁶³.

The step from these observations to a normative commitment only is a small one. If political orders are inscribed in technologies¹⁶⁴, if certain groups are favoured over others, why not open scientific and technological development to democratic decision making¹⁶⁵? From this point of departure, could the influence of patients' groups on medicine be seen as a democratisation?

Richard Sclove¹⁶⁶ has developed a model of "democracy and technology". He bases his model mainly on Benjamin Barber's model of a "strong democracy", which assumes that traditional representative democracy is "weak" and alienating, and needs to be replaced by a more participatory form of decision making. Thus, Sclove argues for a strongly locally rooted participatory form of decision making on science and technology, that largely mirrors the processes used in consensus conferences. A group representing the larger population participates in and finally decides on issues of science and technology. Sclove's model can be and has been criticized for a number of reasons, for example concerning the possibility of local governance in a global world. But most importantly it can be argued that he employs a naïve view of democracy, following one specific theory and uncritically imposing its model to reach an ideal solution. But are models of the social not implicated in theories of democracy as they are in technological designs? Alan Irwin¹⁶⁷ and Mike Michael¹⁶⁸ both have argued that exercises of participatory democracy in science and technology, as the consensus conferences are, must also be seen as constructing specific roles and ascribing them to the lay people engaged in them. They can be described as "technologies of community"¹⁶⁹ that produce social orders as well as sciences and technologies do.

¹⁶² Moser/Law 1999

¹⁶³ Star 1991

¹⁶⁴ For the classical formulation of this argument see Winner 1980

¹⁶⁵ Bijker 1995b

¹⁶⁶ Sclove 1995

¹⁶⁷ Irwin 2001

¹⁶⁸ Michael 1998

¹⁶⁹ Irwin 2001

It has been recently recognized by science studies authors that employing different concepts of democracy can also lead to quite different conclusions¹⁷⁰. Most discussions of a democratisation of science and technology, as well as most of the actual experiments in democratising science and technology at least implicitly follow the model of deliberative democracy¹⁷¹. Deliberative democracy highlights the importance of a discourse between equal participants, and of mutual learning. In a process of rational deliberation, free of power-effects, the ideal solution for all participants is finally to be arrived at. Because this model favours consensus, and the fiction of an ideal solution for all, the issue of representation is very pressing: Can all people possibly affected by a new technology be integrated in the decision making? Taking this concept of democracy as a yardstick, can the involvement of patient groups in research be seen as a democratisation? Viewed on a narrow scale, it of course can, because it represents an opening of the space of deliberation to a new, and arguably very important group. On the other hand, it seems imaginable that the interest of a patient group might be in conflict with other groups in society. For example, the AFM's strong involvement with gene therapy research might not be looked upon favourably by disability rights groups.

This conflictual dimension of democracy and of political life in general, is taken seriously by another theory of democracy, which Elam and Bertilsson propose to be helpful in analyzing patient activism: that of radical democracy¹⁷². Theorists of radical democracy deny the possibility of lasting consensual solutions given the complexity of modern societies. Democracy then rather resembles an open discussion of and struggle about contingent problems, for which there are no "rationally correct" solutions. Patient groups would then be active actors in the shaping of the relationship between science and society, but not necessary agents of a transformation towards a more "democratic" science.

What the exact relationship between science and democracy is and what impact the actions of patients' groups do and should have on it does not need to be resolved in this thesis¹⁷³. At this point it seems important to see that in all those theories, framing the relationship between science and lay people in terms of democratisation means asking for more participation of lay people in science and technology. This first of all means that the

¹⁷⁰ Elam/Bertilsson 2002

¹⁷¹ Elam/Bertilsson 2002; 21

¹⁷² Laclau/Mouffe 1985

¹⁷³ The remarks made above should have made clear that this is far from being a simple question which would warrant a separate thesis to be treated at least roughly.

transition taking place is conceptualised as a unidirectional movement: society enters science, while before science and society were two separated entities. Science itself does not actively change, it is changed by the “democratic invasion” of society.

Furthermore, especially in the dominant deliberative model, participation means exerting a conscious, rational influence on science in order to fulfil the interests of the own group. Speaking of “participation” in science and technology thus implies a very direct causal link between the conscious interests of the participating groups and the effects this participation has on science and technology. For instance, the aids activists¹⁷⁴ did clearly participate in AIDS-research because they even altered the methodological procedures applied, but what about the case of the German retinitis pigmentosa society? The patients involved there altered the boundary conditions of research to promote scientific interest in their own disease, but they did not consciously participate in the actual process of knowledge production. Does this mean that the knowledge actually produced under these circumstances does not differ from knowledge that has been produced for example in a university laboratory? Or are there other, less direct forms of influence that the terminology of democratisation is unable to grasp?

Nowotny, Scott and Gibbons¹⁷⁵ have proposed the term “contextualisation” to describe the new processes of interaction between science and society. Instead of portraying this as a move only of society towards science, they describe the ongoing changes as a complex, co-evolutionary process. Their assertion of an increasing contextualisation of science, or that society increasingly “speaks back to science”¹⁷⁶ is based on the diagnosis that modern society as a whole, including science as its sub-system is undergoing a fundamental transformation. Partly following Beck’s argumentation¹⁷⁷ they claim that the principle of functional differentiation of autonomous subsystems¹⁷⁸ is dissolving. Previously clearly differentiated entities like the market, politics or culture become transgressive – economic imperatives and rationalities enter politics as well as science and culture, and vice versa. Thus, it becomes increasingly difficult to treat science and “society”, both undergoing a transformation, as separated entities.

¹⁷⁴ Epstein 1998

¹⁷⁵ Nowotny/Scott/Gibbons 2001

¹⁷⁶ Nowotny/Scott/Gibbons 2001

¹⁷⁷ See chapter 3.1.2

¹⁷⁸ See chapter 3.1.1

“[...] it has become more difficult to regard science as a distinctive sub-system of society [...], because all systems and sub-systems are in flux and have become transgressive.”¹⁷⁹

Viewed against this background it becomes clear that the process of ongoing contextualisation must be analyzed as a transformation of *both* science and society, and is taking place along a number of complex, e.g. economic and cultural rationalities that have to be taken into account to support the political logic employed by the democratisation model.

Concretely, the process of contextualisation is described as following three underlying tendencies: First, the science system itself is seen as progressively changing from a “segregated” model of internal organisation to an “integrated” model. This means that individual working patterns as they are common in molecular biology become more important than modes of knowledge production that involve a large number of equal researchers. The former condition supports and asks for a more entrepreneurial role of the scientist that is important because of the second tendency. Given the increasing complexity of the relationship between science and society, uncertainties proliferate, and, to give an example, funding for research can no longer be taken for granted, forcing the individual scientists to actively look for different contexts from which he or she can acquire resources. Thirdly, and partly as result of the former processes, people can claim a more important place in the produced knowledge, *“as actors whose needs whose needs, wishes and desires are listened to, and possibly responded to, if not anticipated”¹⁸⁰*.

Contextualisation is not a one-sided movement imposed upon science, but “by contrast, strong contextualisation occurs when researchers have the opportunity, *and are willing*, to respond to signals received from society”¹⁸¹. The process of contextualisation is characterised by intense communication between both sides, which leads to a shift in the respective problem definitions, to mutual learning and finally to a common definition of the problem. This mutual learning process does not necessarily rely on the explicit communication of preferences, instead, it is multi-layered. *“Explicit messages are communicated, interpreted and re-interpreted as well as implicit or yet-to-be-articulated preferences, needs and desires.”¹⁸²*

¹⁷⁹ Nowotny/Scott/Gibbons 2001; 58

¹⁸⁰ Nowotny/Scott/Gibbons 2001; 131

¹⁸¹ Nowotny/Scott/Gibbons 2001; 131; emphasis in original;

¹⁸² Nowotny/Scott/Gibbons 2001; 134

On a larger scale, Nowotny, Scott and Gibbons claim that this contextualisation of knowledge production will also lead to a different form of knowledge, for which new quality criteria are needed. Their thesis is that this new constellations of knowledge production will lead to a “socially robust” knowledge, that is recognizable for a wider proportion of society. Relating this to the prior discussion of expert-lay relationships in this chapter¹⁸³, this means that conflicts between science and lay life-worlds are less likely to arise, because the contested meanings are co-produced contextualised with these relevant lay-publics. Still, considering the discussion of a democratisation of science and technology earlier in this chapter leads to the question: For whom, for which groups will the knowledge be socially robust? May it be the case that a socially robust solution for one group could be highly controversial for another? For the case of biomedicine, given the complexity of the cultural relations between medicine and society, this does not seem unlikely. Exploring these complexities will be the task of the next chapter.

¹⁸³ e.g. Wynne 1996

3.4 Patient groups and the cultural and social implications of modern biomedicine – politics of identity

While the last two chapters have dealt with the interaction of medicine and society from different viewpoints, that of medical sociology and that of science studies, they share the focus on how society has spoken to medicine. The question of how medicine has affected and changed society has so far only been dealt with concerning the debate around the Public Understanding of Science, and only in a quite narrow fashion. This chapter will put its emphasis on exactly this question: How can we understand and describe the broader cultural and societal changes induced by modern biomedicine, for example genomics research?

Traditionally, medical sociology has dealt with the cultural impact of medicine on society under the label of “medicalization”¹⁸⁴. The concept of medicalization mainly describes the expansion of medical jurisdiction, or the integration of more and more previously differently defined conditions into the realm of medicine. Because many of the examples of early medicalization research concerned medical attention towards phenomena that were previously defined in terms of deviance and often seen as crimes, this transition was also described as going from “badness to sickness”. While this assertion holds for many examples, one of the most prominent being that of mental illness, medicine has also integrated many other conditions that previously had not been termed “deviant” in a criminal sense, but regarded as different in other ways, as in the case of hyperactive children¹⁸⁵. Medicalization can not be seen as a homogenous process, but in many cases rather as an ongoing cultural struggle, with controversies arising and cross-cutting processes of de-medicalization. For example, homosexuality historically clearly has moved from badness to sickness¹⁸⁶, and was then relatively de-medicalised. Today, considering discussions about “gay-genes”¹⁸⁷, it can be argued that this controversy is again gaining force.

Micro-studies¹⁸⁸ have revealed that it often is not the basic fact that a certain condition is discussed under the terms of sickness at all that is controversial, as it is the case with

¹⁸⁴ Conrad 1992

¹⁸⁵ Clarke et al. 2003

¹⁸⁶ Foucault 1990

¹⁸⁷ Miller 1995

¹⁸⁸ Rapp 2000, Taussig/Rapp/Heath 2003

homosexuality, but rather the specific identity ascribed by the medical system and its practitioners that is disputed by affected people¹⁸⁹. Medicine must thus also be seen as producing and ascribing identities – identities that can be transformed and contested by the ascribed, but also identities that can be welcomed. For the parents of children affected by Down syndrome, it is not so much the fact that the condition is labelled as a medical problem at all that is felt to be repulsive, but the many subtexts woven into the complex medical narrative that portray a child affected by this condition to be un-human¹⁹⁰.

In a recent article¹⁹¹, Adele Clarke and a number of co-authors have challenged that the concept of medicalisation still is capable of adequately describing the relations between medicine and society. The claim that, propelled by an increasing techno-scientification of biomedicine, the new genomics and also the increasing use of information technologies in health care, medicalization has intensified, but also has changed to what they call “bio-medicalization”. A central distinction that separates bio-medicalization from medicalization is that while medicalization mainly sought to control the medicalized identities it produced, bio-medicalisation is capable of actively shaping and transforming these bodies and identities. Technoscientific interventions can produce new medical-techno-scientific identities. The case of deaf children, researched by Stuart Blume¹⁹², can serve as an example here. The cochlear implant, a relatively new medical device, can be used to “cure” deafness in young children, albeit with a number of quite serious side-effects. For example, even the small hearing capabilities present are destroyed during the implantation, making the child completely dependent on the implant. To the surprise of many medical doctors and scientists, the introduction of this implant, though also welcomed by some, was fiercely opposed by parts of the deaf community, who saw deafness not as a disability, but as a subculture of its own, with its own language and traditions. This culture was perceived to be threatened by the erasure of deafness implicitly promised by the cochlear implant. Furthermore, the children treated with the implant were not simply transformed to “normal” children, because the technology was not able to completely restore their hearing ability. Rather, their new techno-scientific identity put

¹⁸⁹ Again, this can also be seen as science importing „dense, but inadequate meanings“, Wynne 1996; See also chapter 3.3

¹⁹⁰ For example one of the clinical diagnostic criteria for trisomy 21 is the „simian-crease“ at the back of the hand; See Rapp 2000

¹⁹¹ Clarke et al. 2003

¹⁹² Blume 1997

them in a precarious third place between the “normal” world and the deaf-community, who implicitly viewed the act of implantation as treason.

Similar constellations can be found in the bioethical debates on the impact and potential consequences of the development of the new genetics. The sequencing of the human genome, the increased effort of research into possible genetic causes of many diseases, and the still distant promise of gene therapies as a cure can be seen as one of the most dramatic medical revolutions of the 20th century and have caused fierce debates about their possible social consequences. The metaphors and images of genetics have entered deeply into the cultural context of everyday life¹⁹³ and the genetic discourse has become so dominant that selected authors speak of a “geneticization” of society¹⁹⁴. “Geneticization” implies that all aspects of human life, be they social, psychological or physical, are increasingly seen in terms of genetic inheritance and causality. While a genetic determinism is seen as eliminating all other kinds of influences on human life and human behaviour, geneticization is also seen as an individualizing process in which the individual is again and again thrown back on his own genetic inheritance. Viewed from this perspective, the new genetics would need to be seen as a very scary enterprise – which is the goal of the critics. From the perspective of the empirical social sciences, and especially medical anthropology, this account has albeit been criticized as being too simplistic.

First, studies in Public Understanding of Science research have shown that lay people’s understandings and views of the new genetics are far more complex and far less deterministic than assumed by geneticization-theory¹⁹⁵. As in the case studies described in the last chapter, the discourse of geneticization is broken a myriad times in the concrete context of lay life-worlds. In the context of the human genome-project, three medical anthropologists¹⁹⁶ studied the impact of the new genetics in a number of different affected constituencies, from the “Little People’s Association of America” to Debra US. What can be learnt from their work is that the local processes of “geneticization” are highly contingent and dependent on the values, history and identity of the respective group. While the LPA¹⁹⁷ reacted quite similarly to the deaf communities researched by Stuart Blume,

¹⁹³ Nelkin/Lindee 1995

¹⁹⁴ Lippman 1991

¹⁹⁵ Condit 1999, Kerr/Cunningham/Burley/Amos 1998

¹⁹⁶ Taussig/Rapp/Heath 2003

¹⁹⁷ Little People’s Association of America

the members of Debra perceived genome research and the possibility of gene therapy as an enormous chance to heal themselves or their children.

Carlos Novas and Nikolas Rose¹⁹⁸ have argued that, given the number of genetic support groups, new self-help groups and research oriented patients' associations that have sprung up with the advent of the new genetics, describing its impact on society as individualizing seems quite partial. On the contrary, genetic identity has become a point of crystallization for social group structures.

*"[...] it is not hard to imagine groups formed around the chromosome 17, locus 16,256, site 654,376 allele variant with a guanine substitution. Such groups will have medical specialists, laboratories, narratives, traditions, and a heavy panoply of pastoral keepers to help them experience, share, intervene and "understand their fate."*¹⁹⁹

Paul Rabinow has termed this new form of societal organization "biosociality"²⁰⁰. He argues that the new genetics will likely re-shape society, but this does not imply that society will be short-cut and determined by biology. Instead

"[...] in biosociality nature will be modelled on culture understood as practice. Nature will be known and remade through technique and will finally become artificial, just as culture becomes natural."

The transition is thus portrayed as a two way process – while social identities are all of a sudden rooted in biological facts, those ascribed these identities themselves become active agents in forming these new identities, as well as the very roots they depend on. The participation of patients' associations like the AFM can serve as an excellent example here. While the AFM today may be seen as a group gathered around a number of genetic anomalies, it was the association itself that put this very identity into existence by investing in genome research.

What will be the relationship between these new, biosocial, and traditional identities? While the critics of geneticization had assumed that they would eventually supplant and endanger traditional forms of conviviality, ethnographic studies show that these new forms of identity cross-cut and interact with traditional forms of identification to complex identity practices. Rayna Rapp²⁰¹ has investigated the meanings attributed to prenatal diagnosis among various communities. She found that religious, ethnic, class, gender and biomedical technoscientific identities are woven into a complex network that eventually frames the individual decisions taken.

¹⁹⁸ Novas/Rose 2000

¹⁹⁹ Rabinow 1996; 102

²⁰⁰ Rabinow 1996; 99

²⁰¹ Rapp 1998

What relevance do these observations on the changing nature of the relationship between medicine and society resulting from the „genomic revolution“ have for studying a patients' association? If we assume that the production and negotiation of identities plays a major part in shaping the interface between medicine and society, then self-help groups and patients' associations clearly must be seen as very important agents in this process. It was already mentioned in the first subchapter of this part of the thesis that the self-help-movement played a crucial part in transforming the patient role from that of a passive object to an active subject. Similarly, many patients' groups are consciously or unconsciously active in formulating and communicating their view of their disease and the identity constituted by it.

Identities do not simply exist, they need to be performed and reiterated²⁰². In the case of patients' groups, these performances often involve the bodies affected by the disease and its specific symptoms, making the respective identity an embodied one. Deborah Heath has studied these practices of “identity work”²⁰³, the performances, counter-performances and embodiments of identity for the American National Marfan Foundation, a patients' association of people affected by Marfan syndrome, also a rare genetic disorder²⁰⁴. The main health issues for people with Marfan syndrome are cardiovascular problems. Undetected heart problems can lead to death at relatively young age, otherwise the syndrome is largely asymptomatic and therefore often goes undetected, increasing its dangerousness. People with Marfan-syndrom do however have a characteristic phenotypic appearance: they tend to be very tall and have quite long arms, legs and fingers. Visualisations of this “Marfan-appearance” play an important role in the identity politics surrounding the disease. The classical medical images used by scientists and doctors at conferences, but also in public lectures, are black and white photographs of nude bodies or body parts, with the usual anonymizing black bar across the eyes. Marfan activists resist these forms of the depiction of their disease, because in their eyes it constitutes a pathologizing discourse that focuses only on the clinical symptoms, but not on wider aspects of their “Marfan identity”²⁰⁵. In other terms, they feel this to be an unjustified de-

²⁰² Heath 1998

²⁰³ See chapter 3.2.3 for a discussion of identity work in social movement theory

²⁰⁴ Heath 1998

²⁰⁵ Heath 1998

contextualisation of the syndrome that abstracts it from the actual everyday practises it is enacted in.

Contrarily, people affected by Marfan syndrome have developed a rich assortment of symbols and metaphors to represent themselves beyond the medical discourse. One of these practices is relating to famous persons also suspectedly affected by the disease – in the case of the American group Abraham Lincoln, whose tall stature suggests Marfan syndrome, and who thus has become nearly an icon for the affected people. Furthermore, the symptoms and embodiments of the disease are often discursively linked to works of art, for example to sculptures of Rodin or Giacometti. This discursive link adds a notion of beauty to what would otherwise only be perceived as a telltale-sign of a anormal condition, thus playing an important role in the activists' identity politics.

But the pictorial and symbolic visualizations of the disease not only play an important role in symbolic identity politics, they also have their part in communicating to the public about the disease. Beside their positive symbolic connotation, which is important also in this respect, they are often designed to convey messages about the disease. For example, the symbol of the National Marfan Foundation is the heart²⁰⁶, which stands for the heart problems of those affected by the disease. At the same time, this positive symbol is used in awareness and fundraising campaigns – one important date for the activities of the National Marfan Foundation is Valentine's day.

Campaigning for funds is where the mobilization of resources and the construction of identities meet. This can work out well, as in the Marfan case, but it can also lead to conflicts when the identity the patients' group or a fraction of the group wants to display is not the identity that "sells best". In the case of a Cystic Fibrosis patients' association²⁰⁷, conflicts arose because the information and fundraising campaigns focussed only on small children, because they were suspected to be better advertising media. Older affected people disputed this form of identity politic, criticizing that their problems and points of view would be omitted. Thus, it seems rewarding to pay attention to the two possibly conflicting goals of identity politics and resource mobilization.

²⁰⁶ Heath 1998

²⁰⁷ Stockdale 1999

4 Theoretical Tools

This chapter uneasily sits between theory, research questions and methods. In a way, it even is not supposed to be there, because I have talked about theories, and shortly, I will talk about methods. But this chapter is about neither, and it is about both. It comes into existence because I believe that there is more than one way of using theory and more than one concept of method. Theories, in the classical sociological sense of the word, provide explanations of how the (social) world works. They assemble different elements from empirical research to build a coherent model of a particular phenomenon. At least I have learnt that the best way to classify them is that there are small theories, that explain only a tiny fragment, then there are those that explain a little more, and then there are the big ones, which explain (nearly) everything²⁰⁸. But you cannot be sure whether the last ones are in fact theories or some strange kind of metaphysics. I have used this way of doing theory in the last chapter, to explain, to frame, and to describe²⁰⁹. This chapter is about the uneasiness incorporated in the “big theories”, even though it mostly is about a small theory. This uneasiness comes from the fact that “big” theories do something else beside explaining in an obvious way, they provide you with a way to look at the world, and this perspective cannot be derived solely from empirical research. Of course this is true for every theory, because every theory favors certain elements over others. There are no complete (or total) descriptions, even at the middle or small range. But some theories handle this issue reflexively, whereas it just happens to others.

So theories have at least two functions: they explain by drawing on empirical results, and they provide perspectives. While it may not be possible to separate these two functions when describing a theory, I think it is worth trying to do so in the use of theories.

This chapter is also about a method. But again, it is not about a method in the classical sense, it is not about doing interviews or documenting observations. It is about the way the subject of research is shaped in the research process by the way it is looked at, by the way it is described. One could say it is about methods, of thinking, not methods of acting²¹⁰.

²⁰⁸ To be correct: theories of small, middle, and long range.

²⁰⁹ Although at least some theories of the last chapter can be used in the way theory is used in this chapter too – e.g. the theories of social movements. The fact that I use them as contexts is my theoretical choice, and it is grounded on the reasons outlined in this chapter.

²¹⁰ But thoughts of course guide actions, and that is the link to the „real“ methods. Mol/Mesman 1996

A good method (and also a good theory) should be a guide through problems of field work²¹¹. Because of this, I have structured this chapter by four questions which are central to conceptual issues of this thesis. First, I will briefly sketch a perspective, which does not answer these questions, but which can be used to turn them into productive thinking, and then I will apply this perspective to my questions. This perspective is a theory that does not want to be a theory²¹², and it goes by the strange acronym ANT, which means Actor-Network Theory. Unfortunately, it is not possible to describe ANT in the way I have described theories in the last chapter²¹³. ANT has no bible, but it has many prophets. What ANT is, then, is a lot of productive texts and a few basic beliefs. Borrowing from John Law it can be said that there is more than one ANT, but less than many²¹⁴. And in the language of symmetry, they are all different, but they are in a way also all the same. They are partially connected. ANT thus cannot be used as a coherent model to explain the world of a social²¹⁵, its goal is not to finally answer questions, but to find ways to productively address them. This is how I intend to use it, as a toolbox, picking some elements that seem useful to matters at hand while leaving others to others. I am in no way claiming this is a “correct” use of a theory, but it is very good for building a perspective. At some points the tools provided by ANT might not fit the shape of the problems at hand completely. I will then relentlessly borrow from other people’s toolkits, especially from interpretative sociology.

4.1 Perspectives on ANT

ANT was born in France, and it started out telling stories about researchers, scallops and electric vehicles²¹⁶. The best way to describe its theoretical roots is probably that it represents a “ruthless application of semiotics”²¹⁷. Semiotics in its original form is about language, or more generally speaking, about signs. It is about how meaning is created. Structuralist linguists negated the notion that there is a “necessary” link between the sign and what it signifies, a link that would determine the form of the sign. Instead, the meaning of signs is produced by differences and relations to other signs. Poststructuralists agreed

²¹¹ See Mol/Mesman 1996 for a good example;

²¹² Latour 1999

²¹³ Law 1997

²¹⁴ Law 1999; 12

²¹⁵ Latour 1999

²¹⁶ Callon 1986, Callon 1999

²¹⁷ Law 1999; 3

with them, though they did not agree with the structuralist thesis that even if the single sign is arbitrary, the structure of language can tell us something about the things “behind it” (anthropological constants, for example)²¹⁸. Michel Foucault showed that making relations of signs also means ordering the world²¹⁹, and that this is an act of power²²⁰. He was also the first to introduce material elements and practices into semiotics²²¹. This, and some other mainly French philosophical traditions²²², is where ANT comes from.

This short excursion into the history of ideas might be helpful in understanding the name itself. The term network was never meant the way it could easily understood, today, in the “network society”. It did not simply designate a number of linked entities like one might imagine the World Wide Web, and it isn’t a topographical metaphor either²²³. It is about ontological relations, about how actants mutually define / are defined and on how this is expressed in and related to material relations. Or, it is simply a way of saying structure (in the semiotic sense) and adding contingency and materiality²²⁴.

That might also be the reason for the hyphen. The word Actor-Network embodies a tension, it does not describe two entities, the actor and its network (around it). Instead, it describes one entity, in two ways, maybe like physics has described light as a wave and a particle²²⁵. An actor is an actor, for example if the influence it might have on other actors is described, but it is also a network, for it cannot have meaning and identity standing alone. Its agency is produced and constrained by the way it is defined in relation to others.

But in ANT these relations are everything but fixed. Its second and maybe more fitting name, the sociology of translation tells this story too. Translation is about building links between actor/networks, about narrating a possibility of order between them. Translation also embodies a tension²²⁶. To translate also is to betray, in the sense that it is to pretend to make things, which are different, the same. ANT did this by making the bold statement that

²¹⁸ Stäheli 2000

²¹⁹ Foucault 1994

²²⁰ Foucault 1990

²²¹ Foucault 1995

²²² Like the work of Michel Serres, to whom ANT maybe owes most, including the notion of translation. See Serres/Latour 1995

²²³ Latour 1999

²²⁴ Law 1997

²²⁵ Latour 1999

²²⁶ Callon 1986

it does not matter at all whether an actor is human or not in these networks²²⁷. ANT deconstructs the boundary between nature and culture. This, even though it has been often accused to be one, is not at all a constructivist position²²⁸, neither is it a realist one. Rather, by deconstructing the boundaries between the natural and the cultural, ANT also dissolves the ground on which constructivist and realist arguments are usually made.

Enrolment is an aspect of translation²²⁹. Enrolment means to put someone in a role, or to be described in a particular role by others. But enrolment also has a quite Machiavellian notion to it. To enroll is to recruit allies, or, if we put an even stronger emphasis on the agency of the entity enrolling, to put others in your version of ordering the world. It was this Machiavellian line of ANT that was quite successfully told in some of its most famous pieces. Latour's work on Pasteur and the title of his article "Give me a laboratory and I will raise the world"²³⁰ maybe illustrates this best. Stories were told from the viewpoint of the princes, on how they enrolled, on how they raised worlds. By focusing on the successful, other voices were lost, or made invisible²³¹, and the tension of translation, the notion of betrayal, was lost. The actors built their networks much more than they were built by them. ANT at some points became totalizing and fixed, as the otherness of the enrolled became absorbed in stories of success²³². All of this made it far too easy to understand ANT as the actor and his (!) network²³³.

This was accompanied by a special rhetorical move of deploying the symmetry principle in the language of liberal political theory²³⁴. Latour certainly has a way of describing the silenced masses of objects scratching at the doors²³⁵. This way of putting it does two things, first, as Michel Serres has observed²³⁶, it again erases the tension of otherness for the sake of liberation. Furthermore it deploys a different political theory than that of

²²⁷ This is maybe the most contested move of ANT (Collins/Yearley 1992). But of course, in my reading, they never said they were the same. As so often, they are the same in a fundamental way that they define and are defined, but they empirically are not in many others.

²²⁸ Sociology, especially its German version has shown quite some obduracy to accept this. Even in places where one would expect a somewhat more differentiated reaction, like in environmental sociology, ANT is portrayed as a version of completely crazy hyper-constructivism (Diekmann/Preisendörfer 2001). While this could be easily put aside as academic ignorance, my suspicion is that something more serious is at work here. After all, what ANT does is simply ignoring the difference Durkheim based sociology on.

²²⁹ Callon 1986

²³⁰ Latour 1983

²³¹ Star 1991

²³² Lee/Brown 1994

²³³ Latour 1999

²³⁴ Lee/Brown 1994, Mol/Mesman 1996 for a criticism of this rhetoric;

²³⁵ But shouldn't the door scratch too? And who will open it? © See Latour 1988

²³⁶ Serres/Latour 1995

semiotics, that of liberalism²³⁷. While the politics of semiotics is about showing contingency and multiple possible ways of ordering the world²³⁸, liberalism cares very little about these complexities. It is about the free and the oppressed.

But the story does not end with these criticisms. There is life after traditional ANT, a life or a body of work that tries to overcome these shortcomings by reviving some of the forgotten foundations of the sociology of translation, but also fusing it with other influences from, for example, feminist theories. It is this body of work²³⁹ I will base upon most of the perspective I am setting out to describe. It is about reclaiming the tension originally built into ANT. Its definition of symmetry as a rule of method might be phrased as seeing and knowing that things are the same²⁴⁰, but they are also different²⁴¹.

4.2 Four Questions

Question 1: The unit of analysis

The first question really seems to be quite simple. It is about describing my unit of analysis. So, how can we properly represent Debra? In my title, I have taken the easy and maybe a bit sloppy approach to call it a patients' association and in the third chapter I have reflected on the differences between self help groups and patients' associations. But is that really a good way to describe it? After all it is not only the patients who associate. When Debra's board meets, actually the majority of people in the room are not patients, and even in a plenary meeting, they might be slightly missing the fifty percent cut. First of all, there are the scientists and doctors, who are as board members or simple members, but in most cases as very active members anyway, clearly a part of Debra. And then there is a quite prominent group which are neither patients nor scientists, but relatives, in most cases parents, of affected people. These of course have the strongest links to the affected people, but still, taking one group out of three to name your unit of analysis seems to be a quite asymmetric.

In the language of ANT Debra is an actor, but it is also a network. It can be clearly described as speaking and acting with a single voice in a charity concert, but on the other

²³⁷ Mol/Mesman 1996

²³⁸ Mol 1999

²³⁹ Law/Hassard 1999

²⁴⁰ Thus retaining the strength of "classic" ANT.

²⁴¹ To reclaim the tension.

hand, as will be described in later chapters, it is a network, in which at least three groups sometimes have quite different definitions of it.

ANT offers a word to describe such associations: a hybrid forum²⁴². The essence of the concept of the hybrid forum is that an association consisting of heterogeneous groups (experts and laypeople) embarks on a “collective experimentation”, meaning that they have common goals and discuss the results of their progress and its results.

The concept of the hybrid forum, even though it stresses heterogeneity, puts an emphasis on the common, not the different by deploying notions like “collective experimentation”.

Another concept that might remind us of the differences is that of the boundary organization²⁴³. A boundary organization is situated between (at least) two different social worlds²⁴⁴, it involves the participation of actors from both sides of the boundary. It constructs common boundary objects²⁴⁵, but at the same time the two social worlds divided by the boundary might have quite different views and expectations of what the boundary organization is supposed to do. By satisfying both of these expectations, a boundary organization also constructs and stabilizes the boundary²⁴⁶ between the both worlds. It is thus engaged in simultaneous production of knowledge and social order²⁴⁷.

This concept also puts the emphasis on both the common and the different, but it makes a stronger point concerning the differences. Still, it has been mostly used to describe interactions between science and policy in formal organizations, and thus is not ideally suited for describing a patients’ association.

Question 2: Dynamics and Cohesion

While the first question was rather about naming the actor, the second is about describing the network. How to describe the various relations in the group, and also those to actors outside the group? And how to reflect the changes that take place over time?

The central concept to answer this question is enrolment, which captures the mutual forming of roles and ascribing of roles in the group. ANT would not be necessarily needed to describe this, it could also be done with symbolic interactionism, for example. But the

²⁴² Rabeharisoa/Callon 1998

²⁴³ Guston 2001

²⁴⁴ The concept of boundary organizations has been developed for analyzing the boundary between politics and science, but it can and has been transferred to other boundaries as well.

²⁴⁵ See question 2 for the concept of the boundary object, Star/Griesemer 1999

²⁴⁶ On boundary work see question three.

²⁴⁷ Guston 2001

important element of enrolment that distinguishes it from other approaches is the strategic notion. Enrolment also means finding allies to reach a goal. This can help to see the tensions embodied in enrolment procedures, as long as enrolment is conceptualized as *mutual* enrolment, not as an act of strategy by some Machiavellian prince. Of course all the actors in Debra have a common goal, to find a cure for EB. But on the other hand, the visions and connotations of this goal are quite different.

The strategic notion also helps to understand changes over time. To reach a goal needs resources, and the need for resources can lead to the enrolment of new actors in the network. Thus, for example, the most common thing that is needed is money. A traditional way to raise money for a patients' association is to enroll the media to do fundraising. But one does not only enroll the media, one is also enrolled by it. Looking for change with ANT puts the focus on how the entire network changes with the enrolment of a new actor. While change and also the mutual forming of roles can be well described using ANT, I found it somewhat different to describe the mechanisms of cohesion, that which binds the group together and forms common identities. To address this, I will borrow from symbolic interactionism's toolkit and import the concept of boundary objects. Partially, this is about explaining the paradox of translation, and about the question of how translation can work if the interests of the parties involved are different.

Susan Leigh Star and John Griesemer²⁴⁸ have introduced the concept of the boundary object to describe how different social groups co-construct²⁴⁹ an object (in their case a museum) without agreeing completely on its definition and its purpose (or without even being interested in that). A boundary object has the capability of integrating different views and definitions of an object, but also different interests and needs. At the same time, it is diffuse enough to be defined differently by the parties involved, but solid enough to retain coherence. One way of seeing it would be as a way of minimizing the problems of translation by employing a (non-human!) translator.

²⁴⁸ Star/Griesemer 1999

²⁴⁹ The restriction of the term boundary object to co-construction seems important to me. As Peter L. Berger has noted in his invitation to sociology (Berger 1966), the basic element of the "art" of sociology is being able to switch between different frames of reference and take different points of view. If the term boundary object is used for *viewing* an object differently too, then a well socialized sociologist will see everything, from bicycles to tulips, as a boundary object. This way, the term loses its analytical potential.

Question 3: The social and the natural

One of the most disputed elements of ANT is its deconstruction of the difference between human and non-human actors. The agency of non-human actors has not been of much concern to me, because it was my choice not to focus my research on developing an account of the trajectory of the possible development of a gene therapy or any other technology. I was mostly concerned with the social side of the relations between the actors. But the nature/culture divide plays an important part in understanding the strategies the members of Debra discuss, and their differences. To explain this, I would like to draw on the concept of passages²⁵⁰. A passage is a “movement between specificities”²⁵¹, it is about being able or being dis-abled. Law and Moser explain this by the example of Liv, a woman unable to move her arms and legs who “controls” her life via a joystick she moves with her chin. For Liv, there are good passages from one specificity to another, like opening her front door with a few moves of her head, and there are bad passages, like writing a letter with her special word processor, which takes her an entire weekend. For someone affected by EB, a typewriter might be a bad passage, because the mechanical strain it puts on the fingertips makes working with it impossible. And this is a very bad passage indeed, because it can bar entrance to the labor market. It is different with computers. And of course the worst passage of all is working in an Austrian labor market project for disabled people, because the only thing people do there is produce wooden toys.

The concept of passages of course does not only apply to disabilities, it applies to all of us, because moving between specificities is what we do every day. At the moment of writing this in Maastricht, for example, I have a little plastic card with a rather strange photo of myself and a microchip on it. This card lends my books, it opens doors, it opens and locks my wardrobe, it prints and copies, and it even pays for my meals in the university cafeteria²⁵². Now if that little microchip would decide to quit our interessement, quite a lot of passages would break down, and they would not be easy to replace without getting a new card. I would be quite dis-abled. This makes a more general point, which is similar to what Erving Goffman has written about stigma²⁵³. In the end, we all have our good and bad passages. This is by no means to say that the petty nuisance of a broken plastic card

²⁵⁰ Moser/Law 1999

²⁵¹ Moser/Law 1999; 200

²⁵² Not really, unfortunately.

²⁵³ Goffman 1986

compares to the daily experience of pain. Of course it does not, it is fundamentally different. But in a certain way, it is also the same.

There are many ways to achieve a better passage, to be able to move between specificities. For example, it is important for Liv to be able offer her guests some coffee, because that is the custom in Norway. There are (at least) two different ways of making that passage. One might be a coffee-machine that responds to her joystick and automatically makes coffee, the other is for the guest to go down to the cafeteria and get some food and drink – for free, because it is understood that Liv pays. We might call one solution a technological and the other an organizational or social solution.

There are also many ways of trying to solve the problems people with EB are faced with. They might be social ones, like fighting for rights for disabled people, or technological ones, like designing special shoes. Most of these are still strategies, or visions of passages. The biggest vision of all is the “passage of passages”, which is the gene therapy, that promises to solve all problems at once by making the disease disappear, as well as all the identities associated with it.

What ANT helps to see is that even if the “social” and the “natural” strategies are different, they are also the same, because they try to build good passages. The technological strategies have effects that could be labeled social as well as the social strategies have effects that could be labeled natural²⁵⁴.

Negating the a-priori-difference between the natural and the social world does not mean ignoring its prominence for the actors in the field. It has been shown that sometimes even the entire authority of an organization²⁵⁵ depends on maintaining that very difference, while it can at the same time be shown to constantly violate it in its daily operations. Using the differences built in the semantics of modernity²⁵⁶ can also be a strategy.

Question 4: Power

This last question returns to the problem of describing cooperation, but instead of asking about how coherence is established, it asks about power in the relationships between the different actor groups.

A common way to deal with this in the arena of patients’ groups is to frame the issue in

²⁵⁴ This is well researched for the effect of self-help-groups on individual health. Seligman 1995

²⁵⁵ Bal/Bijker/Hendriks 2002

²⁵⁶ Latour 1993

terms of colonization²⁵⁷. One group (always the professionals) with more power colonizes the other (always the lay people). In this framework, power is something an actor possesses²⁵⁸, not something that is performed. Colonization then is the use of this power to intentionally impose one group's interests on the entire association, while suppressing the other's. This is the classical sociological definition of power: Power is the chance to impose your will on other people²⁵⁹. There probably are cases²⁶⁰ where such a framework can prove to be useful, but I soon found out that for my case, it was not.

In a situation characterized by cooperation as described in question 2, any attempt to see power through the theoretical eyes of the classical model could only have resulted in ascribing power to one group²⁶¹ without any empirical background.

To propose a model of thinking about more subtle relations of power with ANT, I would like to return to the concept of enrolment. From a strategic point of view, knowing and understanding the actor to be enrolled is an advantage, and knowing about the actor means knowing about his network. This raises the issue of complexity. Influencing another actor or even taking part in its decisions requires to understand the complexity of the relations that enable and constrain that actor. And as the sociology of science knows, science, with all of its politics and actors, is quite complex. An important part of science studies has been to show, that it is in fact possible for lay people to master this complexity, but that it also takes a lot of resources to do so²⁶². These resources might be easily accessible for a large patient organization like the AFM, but for a small one this can raise an asymmetry that is unintended by both parties. At this point, the discussion returns to the considerations about a democratization or contextualization of science²⁶³. Only empirical research can show the possibilities and limitations of these processes.

²⁵⁷ Wood 2000

²⁵⁸ Interestingly enough it is hardly ever explained where the power comes from. Doctors just have it.

²⁵⁹ Star 1991

²⁶⁰ Probably quite a lot in Austria, I suppose.

²⁶¹ Guess who?

²⁶² Epstein 1996

²⁶³ See chapter 3.3.2

5 Research Questions

I hope that the last two chapters have helped to show and explain a few of the multitude of perspectives from which a phenomenon as multi-layered and as complex as the issue of patient groups and their relation to medical research can be perceived, analyzed and described. While it certainly would be worthwhile and desirable to pay ample attention to each of these dimensions in the empirical part of this work, the fact that this is a masters thesis sets quite narrow limits to what is possible. Because of this I have decided to choose once central problem perspective for both my empirical research, as well as the writing of this thesis. As this text is written in the sociology of science, this perspective is concerned with the relations between lay people and scientists or experts. Even a first short glance at their webpage²⁶⁴ reveals that Debra is an example of a quite close cooperation between lay people affected by the disease Epidermolysis Bullosa, and a number of experts in medicine and molecular biology. As was described in the theory chapters, such a cooperation between experts and lay people must be seen as more complex than might be expected. Case studies of controversies have shown that establishing a common interest and mutual trust is far from a trivial issue. Furthermore, it has been described that lay people's relationship towards science cannot be described in a general way, but is a multi-layered, locally contingent process depending on the individual life circumstances.

From this perspective, a number of questions can be asked with regard to Debra:

- What is the relationship between experts and lay people within the group?
- What form does the cooperation take, how is it maintained? Which respective benefits do the groups involved see?
- Which mutual perceptions of the respective other group exist?
- Are the “lay people” in Debra a homogenous group, or can a number of situated perspectives be discerned? And if so: Does this lead to different actions within the group?
- Finally, the theoretical question on how to conceptualize such a close interaction between lay people and experts has been brought up.

²⁶⁴ www.debra-austria.org

Furthermore, Debra's strong orientation towards research into a cure for Epidermolysis Bullosa, and the patients' engagement in this process, can be linked to the discussions on the epistemological, social and institutional consequences of lay people's engagement with science and technology.

- How do lay people and scientists perceive the reasons and effects of this engagement with medical research?
- How does the engagement actually take place? In which ways can the lay people actually influence research?
- Which processes and tactics enable them to do so? Are the lay people able to grasp the complexity of the research process, has an "intermediary discourse" that permits communication about the goals of research been developed?
- What is the balance of power or influence within the group? In how far are the patients capable of articulating their preferences towards research, and of turning those preferences into actual topics for research?
- From a theoretical perspective, can this process be described by models of "democratisation" or "contextualisation"?

While the issue of the expert/lay relationship is the main scientific focus of this work, another goal of this masters thesis must be to offer a detailed portrait of the activities, goals and history of Debra. Because of this, setting the focus on the details of the expert/lay-relationship cannot mean that other aspects are completely left aside. Rather, the perspective derived from science studies theory needs to be coupled with the other theoretical viewpoints introduced in earlier chapters to present a thorough account of Debra's activities. The conceptualisation of self-help in medical sociology draws our attention towards the fact that the forming of self-help groups is a complex process in which a number of factors play important roles. Considering that Debra is a "latecomer", it can be asked:

- What were the reasons for forming Debra?
- What factors can be identified that led to the relatively late founding of a EB self-help-group in Austria?

- How has Debra developed over time? Which changes have taken place in the group's goals and strategies?

Finally, the work on the relationship between medicine and society has shown the important role of the construction, negotiation and communication of medical identities. Concerning patients' associations which are active in raising funds and in other kinds of public relation activities, this identity work has been shown to have a sometimes precarious character, oscillating between the wish to represent the complex realities of the actual identities involved, and the goal to raise as much money as possible. Here, this body of research meets with the social movement perspective on self help activism.

- How does Debra "sell" the science it is supporting? How is the research done communicated to wider publics?
- What identities of the disease and those affected by it does Debra communicate in its activities?
- How does Debra mobilize the resources it needs to carry on? How is this linked to the processes of communicating identities?
- How are the communicated identities chosen and negotiated? Is this an issue within the group, and if, is it controversial?

Hopefully, by answering those questions it will be possible to shed some light on the complex and fascinating entity Debra is.

6 Methodological Approach

Choice of a basic methodological approach

When considering the methodological possibilities to explore the basic question underlying this thesis - the relationship between experts and lay people in medical research and the latter's possible influence on this research, in the Austrian context - it quickly became clear that doing a qualitative case study would be the most suitable approach in the framework of a masters thesis. I chose qualitative methodology²⁶⁵, because this thesis and my approach to it in general, is much more oriented towards building theory, than towards testing it. As I have indicated in the theory chapters, though case studies and theories exist concerning this topic, they come from quite different national and cultural contexts and also are far from being able to present a "coherent theory" of the influence of patients' associations on medical research. If one takes the findings of critical science studies scholars²⁶⁶ concerning the situatedness of the encounters between science and the public seriously, it also is to be seriously doubted whether such a theory could actually be formulated in a meaningful way. A qualitative approach with its focus on methodological openness thus seemed most suitable for doing an explorative case study in the Austrian context. Furthermore, qualitative methodology's focus on observing and describing specific social settings and their processes was fitting my intentions. In this special case, the qualitative approach was to build a "grounded theory"²⁶⁷, meaning a theory built from the data gathered, for the special case to be studied and then to relate this grounded theory to existing theoretical concepts and findings from other national contexts.

Choice of an association to study and field access

Finding an actual case to study proved to be more difficult than designing a basic methodological concept. The first step to identify possible field settings was an internet research to find possible patients' associations to study. Two criteria were important in this research and in the final decision which group to approach: First of all, the association had to be research-oriented, meaning that an active discussion, if possible even an active

²⁶⁵ Silverman 2000, Strauss/Corbin 1998, Flick 2002

²⁶⁶ See chapter 3.3, e.g. Wynne 1996

²⁶⁷ Strauss/Corbin 1998

financing of research, should be one of the main activities of the association. Secondly, I was looking for a patient-led association, meaning a group which was not clearly dominated by the interests of the medical professionals involved. While both points could of course only be identified very superficially by surfing their webpages, a large number of patients' associations could actually be ruled out from the start. In the end, Debra Austria was actually the only association which at first sight really fitted this criteria.

In a next step, contact was made to the association's president, whose office is located in Vienna, I presented my project and field access was negotiated. Debra's president agreed²⁶⁸ to play the role of a guide through the field. This was especially important given the sensitive nature of the terrain. Understandably, not all members of Debra were that keen to do an interview on their condition and their engagement in Debra. The president established contacts with those would did like to do so, and it can only be stressed that his help in finding interview partners has greatly contributed to the quality of my data material. As it was clear that this would take a significant amount of time, a scarce resource for a patients' association, I agreed to do some research on possible funding sources from foundations.

Data collection

The data used in this thesis was collected between March and November 2002.

The core of my data set consists of five qualitative interviews, two of which were conducted with parents of affected children, both very actively involved in Debra, one with an affected adult, and two with leading medical doctors and researchers. The number of interviews was limited by two factors: first of all, as I already indicated, the number of affected people actually willing to do an interview was limited. Secondly, as EB is a very rare disease, the people affected by it are spread all over the country, which means doing interviews involves quite a lot of travelling. Of the five interviews, only one was conducted in Vienna, three were done in Salzburg on two different occasions, and one in Innsbruck – spanning nearly the entire east-west extension of Austria.

²⁶⁸ And I have to thank him at this point for doing so, and doing so this well. I also would like to thank Ulrike Felt for her support in establishing access to this sensitive field.

Methodologically, the interviews were conducted as **semi-structured interviews**²⁶⁹. Using this method allowed me to retain a large degree of openness towards my interview partners' narrations, while at the same time being able to focus the interview on the dimensions relevant to my research questions. The interview guideline used was modified several times throughout the research process, on the one hand to reflect the different roles of my interview partners in the association, and on the other hand to test and refine findings obtained from earlier interviews. The length of the interviews ranged from thirty minutes to nearly two hours. All the interviews were taped and fully transcribed for later analysis.

This first set of data was supplemented by **ethnographic fieldwork**²⁷⁰ and participant observation²⁷¹. While the interviews could provide me with insights on the personal views and accounts of the interviewees concerning the topics of this study, doing participant observation enabled me to see how certain parts of the relevant social reality were enacted in "real life". On the one hand, the three days of fieldwork spent at Debra's annual meeting 2002 provided me with an excellent opportunity to see interactions between experts and lay people. Visiting a charity concert enabled me to get a better impression of Debra's fundraising activities in particular and their communication with a wider public in general. These two fieldwork experiences were documented in respective sets of field notes.

Thirdly, five issues of the association's **illustrated newsletter**, covering a time from July 2000 to July 2002, were used as an additional data source. The newsletter "Debra Aktuell" is an interesting collection of different kinds of articles. Letters and short stories written by affected people figure along with research reports, summaries of international conferences, and health care tips. Thus, the newsletters could give an overview of the different facets of Debra, and also an excellent impression of the development of the association over time. Furthermore, the cover images of the newsletters were the data for analysing Debra's "iconography", and the way it presents itself to wider publics.

This, and the association's **websites**²⁷², were sets of **data produced by the members of Debra itself, not by the researcher**, and thus were an important addition to the data set.

²⁶⁹ Flick 2002; 127

²⁷⁰ Baszanger/Dodier 1997

²⁷¹ Flick 2002 ; 199

²⁷² www.debra-austria.org, www.schmetterlingskinder.at

Data Analysis and Reflection

Grounded theory²⁷³ was the main method I used for analysing my data. The first reason for doing so is that grounded theory allows to combine different types of data in one process of analysis. Thus it was possible to compare and supplement interview passages with newsletter articles or observations made during fieldwork. This is because, contrary to many other techniques of data analysis, grounded theory was not designed for *one* specific type of data material. Secondly, grounded theory is a method of analysis designed for building micro theories. Its essential procedure is to inductively code the data material and group it into a number of defined categories. This category-system is then refined and relations between the different categories are analyzed. Thirdly, grounded theory has a high sensitivity for practical problems of doing research, and, contrary to many of the methods developed in a German speaking context, it does not claim that there can be an “objective” way of doing the one correct analysis²⁷⁴. Instead, it stresses that analyzing data is a highly contingent, but also creative process. This rejection of an objectified notion of science makes doing grounded theory highly suitable for doing science studies research, as a number of well known case studies show²⁷⁵.

Concretely, the transcribed interviews were chosen as a central data source and coded by open coding²⁷⁶, a technique in which one inductive coding is assigned to a sentence or a number of thematically related sentences. These codings are organized in a code plan, which as the coding process evolves, becomes more and more saturated. This means that new passages are increasingly likely to be coded by existing codes than creating new ones. In a second process, the codes hierarchies and relations between the codes are established, and some codings become sub-categories or dimensions of others. In sum, I assembled 22 main categories for my interview material, 9 of which had a total of 40 subcategories.

In the next step, the newsletter articles and field notes were assigned codings from the developed code system.

Finally, the codings were assigned to thematically related research questions, explicated and analyzed in order to answer the specified questions.

²⁷³ Strauss/Corbin 1998

²⁷⁴ See Lamnek 1995 for a number of these methods.

²⁷⁵ See Fujimura 1992 for an example.

²⁷⁶ Strauss/Corbin 1998; 101

Separately, the cover images of the newsletter were analyzed with a **semiotic method** of photo analysis²⁷⁷. In this method, the different elements of a picture are described, and their possible connotations are analyzed. In a next step, I compared the results of this picture analysis with other data (observations, interviews) I had collected and coded on Debra's public image and its construction.

In the last step, the findings from the data analysis were brought together and brought into a "storyline"²⁷⁸, which was then set into relation to the existing theoretical literature and case studies. The result is this thesis.

²⁷⁷ Hall 1998

²⁷⁸ Strauss/Corbin 1998

7 Living with EB

This first empirical chapter is dedicated to describing the daily life of people affected by EB, to the problems they face and the way they frame their own lives. It stands at the beginning of Debra's story and my findings, which will be narrated in the next chapters, for a purpose. I believe that is crucial to have an impression of the immense burden EB can sometimes be for a single individual or a family, of the hardships associated with it, of moments of pain and despair, but at the same time also of the moments of the joy and of the admirable strength with which people affected by EB lead successful and happy lives. As it was not the main task of my work to explore these dimensions of living with EB in detail, I can only draw on parts of the interviews I did to explore the main questions of this thesis. More concretely, this chapter is based on the experiences of two families with affected children and those of an affected male adult, supported by articles in the association's newsletter. Thus it is by no means intended to be a "representative" portrait of life with EB, but rather to give an impression about living with the disease. It is also not intended to describe the "average" person affected by EB, because – setting aside that they are affected by the same or a similar genetic mutation – the people affected by the disease are as different from each other as the rest of Austria's total population is. Furthermore, it has to be added that EB also is a highly individual disease, varying enormously in its symptoms and the way those symptoms affect the individual's life²⁷⁹. In this sense, I can provide only spotlights.

But still, even though I am sure that there are many different ways of perceiving the problems caused by EB and coping with them, my fieldwork has also convinced me that there is a similarity of the corporal, psychological and social problems associated with EB as a condition, and furthermore that the way these problems and their relative importance are perceived are related to the life circumstances the affected person or family is in. While there are probably many more variables, like for example wealth or religious beliefs, that have an influence on this, I will concentrate on describing²⁸⁰ one central distinction in this

²⁷⁹ How (some of) these individualities are transformed into aspects of a collective identity, while others are not, and what consequences this has would be a thrilling further research question.

²⁸⁰ This chapter, and all other who touch upon this issue in the remainder of this thesis, embodies two methodological tensions. The first is concerned with speaking for others. As always in social science, I am speaking for others here, for the affected adults who talk about themselves and their own affectedness, as well as for the parents who speak for their affected children. Thus, there are three layers of representation

thesis – that between families with children affected by EB and affected adults. The reason for this choice is that I found that the different perspectives these two groups have on EB and on Debra itself are important to understand many of the issues that will be discussed in the following chapters. To give just a short preliminary example, parents of affected children tend to be much more strongly interested in fostering medical research into a possible cure than older affected people, which may be one of the reasons why they are much more actively involved in Debra.

The three cases described in the following are all affected by the more severe forms of Epidermolysis Bullosa. As described in chapter two, three main forms of EB, varying in the severity of their symptoms and the patterns of inheritance, exist. While the most common forms of EB only carry lighter symptoms²⁸¹, the dystrophic and junctional types of EB can only be described as very serious and impeding conditions. This in turn means that of course not everybody affected by the disease will develop all of the symptoms described, but from my point of view it seems easier to abstract to less serious forms than it is to extrapolate to more severe conditions.

EB affects the body's largest organ, the skin. Briefly explained, the mechanism of EB is that even the slightest irritation of the skin can lead to the forming of blisters. As the skin is one of the main organs of the human body for sensing pain, these blisters also are very painful. As the forming of the blisters can be caused by even the slightest irritations, it is not easy to predict when blistering will appear and where. Waiting for new blisters to appear, and treating them early on structures the day of families with an affected child, as the mother of Olga, a primary schoolchild affected by the dystrophic form, told me. Olga²⁸² herself has not got much time to join me and her parents in our (I suppose) for her rather boring conversation, as she is much too busy racing around the hotel lobby with a bunch of other children present at the yearly meeting of Debra Austria. The most lasting contribution she makes to my research material are the loud cries of joy they leave on my tape when passing by, making the voices of myself and her parents unheard for a few seconds.

involved, and some of the differences related in this chapter may very well be due to the differences involved in speaking about oneself and about someone else. This methodological tension cannot be resolved, it can only be reflected.

Secondly, also as always in social science, there is a tension and a difference between talking about a phenomenon and thus enacting it in conversation, and enacting it in "real life".

²⁸¹ In relation to the cases described here, not in general terms.

²⁸² All names used in this text are pseudonyms.

Olga's mother (laughs):

“ Well, that starts in the morning, look everywhere, change the bandages, where do we have a blister? That blister is then punctured, squeezed out, well, and then again bandaged anew. Or apply some crèmes, because the itching of course, the itching is our biggest problem ”(Q1)²⁸³

Blisters can appear at all regions of the skin, and can accordingly affect daily life in an enormous variety of ways. Blistering of the hands can cause problems in playing, doing schoolwork, and many other things. At the feet, they can seriously impede the walking ability of the affected person. During my fieldwork, I was told a story of a young boy with EB simplex who can hardly wear shoes in summer²⁸⁴ and hardly is able to walk, his parents sometimes even having to carry him from the sunchair to the swimming pool. Blistering also causes pain in seemingly everyday activities, like bathing, or taking a shower.

It is not only constant pain and itching that impairs the life of a child affected by EB, but also the constant worry about causing the next blister. As blisters are caused by mechanic irritation, even the small injuries that frequently occur when children play nearly always lead to serious, painful blistering that can also result in a permanent scarring of the skin. Thus, parents but also children affected by EB can struggle with the dilemma of restricting the playing activities, or risking serious blistering.

In its more serious forms, EB does not only affect the normal skin, but also mucous membranes, for example in the mouth, the throat or under the eyelids.

„And sometimes it happens with her eyes, that she cannot open her eyes. It can occur in the morning, it actually already happens during the night, that an erosion at the cornea leads to a sealing of the eyes. The cornea is ruptured, and this friction leads to the forming of a blister under the eyelid. Actually it is a blister at the mucous membrane of the eyelid. And then it happens, then there's a sudden shrill shriek in the middle of the night, because that hurts incredibly. And in the morning, Olga comes and both her eyes are closed. And then she can't open them for a day at least, sometimes even two days.” (Q2)

But Olga does not only develop blisters in her eyes, her throat is also affected, making swallowing a daily ordeal. Because of this, her nourishment has to be supplemented by a gastrostoma that allows to add the nutrients she cannot take in during the day at night. A

²⁸³ All quotations translated by the author. Original quotations can be found in Annex 1.

²⁸⁴ The increased sweating further increases the blister building rate.

few months before our interview, Olga has had to undergo an operation to separate her fingers, which had joined – another typical symptom of dystrophic EB. After a complicated operation, for which a specialist had to fly in from the UK, she still has to wear splints at night to protect her fingers from joining again.

Living with EB means having to perform a large number of daily care activities, some of which would not be usually expected to be performed by lay people, from opening blisters and changing bandages to applying a gastrostoma. Thus, a considerable amount of care competence is needed on the side of the parents, or the affected person itself.

While these stories of pain and physical problems play the most significant part in parents' account of living with an affected child, accounts of social exclusion or other social problems play a rather peripheral role. School is going well, Olga says. Olga also has a special person to look after her needs in school. At first, the father of another affected child told me, the other children sometimes asked about the girl's skin, but they got used to it rather quickly.

This father also told me about social problems associated with the disease:

„actually the personal experiences are surprisingly positive. There are very few instances, where one could say, well that was bad for Mona now. Among the close friends and acquaintances, well, Mona grew up as normal as possible, with a lot of friends around. And if you know each other from such an early age, then nobody asks “What is that you've got there?”. Rather, that is normal, and we tried to make it as easy as possible for her. And in the kindergarten, at that age they don't ask. And then she actually moved on to primary school with the same group. And otherwise there were also relatively little repulsive experiences.” (Q3)

The protected environment of the school and stable peer groups can help to keep harassments as few and small as possible. In sum, even though there are quite dramatic stories of exclusion, as that of a boy that was banned from a public swimming pool in the main opening time, the importance attributed to these kinds of problems is far less than with adults affected by EB.

Ingo is a forty year old man, affected by a lighter form of the condition than Olga. It is a beautiful, hot summer day, and as he lives at the other end of the country than I do, after kindly picking me up from the train station, we sit in a café and talk. When I ask him what life with EB is like, he does not start by describing the bodily problems associated with a fragile skin. Instead, he stresses that the maybe most pressing problem for him is the way he is perceived by other people.

„Well, to say it roughly, the illness itself for me rather is a problem at a psychological level now. Just by your looks you are impeded in some way [...]. There are recurring confrontations with people who laugh about me, on the street, in pubs, wherever. And you have to cope with that in the first place, have to develop strategies to meet that. [...]and otherwise, finding a partner is difficult too. That remains a problem. Because, I think, the skin simply is the medium with which you step outside, more than someone who has heart problems. Nobody can see that. And, well, that makes it harder or is worse than the actual medical consequences.” (Q4)

Bodily problems do not pose a central concern to him, instead he has developed a way of managing the symptoms of his disease, in order for them to interfere as little as possible with his daily life. For example, he has discovered that he can “train” his feet by walking longer distances, so that they will not form blisters when walking on the concrete roads of the city he lives in. This of course does not mean that EB is not still a very painful, and also annoying condition. But it are rather the psychological and social problems caused by the disease than the experience of bodily pain that concern him. Psychological setbacks in everyday context are one aspect of this problem, the question whether one is accepted as a full member of society is another. For example, when Ingo was young, there were no special classes and professionals devoted to integrating handicapped people into the normal school system, but he was sent to a special school for the handicapped. This, coupled with the challenges EB poses, proved to be an enormous barrier for entering the labour market. Manual labour is hard for people affected by EB, and Ingo, even though he is a writer, had problems using a typewriter because it would cause blistering on his fingers – a problem that has disappeared with the ascent of the personal computer. He was not able to find “normal” work, and thus was sent to a “protected” working place for handicapped people, where cynically he had to work on plastic toys with a piece of wire – something for sure much less suitable for EB skin than operating a typewriter.

Today, Ingo is an employee of an university library, a job he enjoys very much, and he writes poems and short stories in his free time. The question of agency and rights of handicapped people concerns him very much, and he is active in groups on these subjects. He sees his story, and I can only confirm this point, as one of success, even though this success had to be paid in hardships he would not want anyone else to endure. On different scales and in different aspects, stories of other adults with EB are quite similar. For example, a man who is seventy years old now walked (!) through half the country in his youth, just because he had the dream of being a clockmaker – something one would

believe to be impossible for someone affected by a more serious form of EB. As it turned out, it was not.

Summing up the findings from my interviews, my conclusion is that even though the nature of the problem is of course the same, the perspective on the relative importance of certain types of problems shifts with the age of the person affected by EB I interviewed. While bodily problems were the focus of parents' narratives, the affected adult mostly was concerned with issues of social acceptance, and psychological problems.

Though there are differences in the respective problem perspectives, there is one assertion my interview partners shared: they resent viewing their or their children's condition as a disease.

But that's an interesting issue, we don't feel, or the affected people and relatives don't talk about illness. I mean, it is an illness, we don't need to talk about that, they are patients. But it kind of isn't, my daughter is not ill in that sense, even though she accompanies us. She is ill when she has a cold, or the flu, or something like that. (Q5)

This perspective, which is quite often found in self-help groups²⁸⁵, tends to be misunderstood. Far from being a loss of reality, it in my point of view rather is an rejection of the classical properties of the "sick role"²⁸⁶. Medical sociology has described the "privileges" of being sick, e.g. not having to work, but it has also described that these privileges, as we saw in the case of Ingo, can turn to be serious burdens for people affected by a chronic disease. They do not want to be seen as a permanent exception, and they wish to be allowed to find ways to function as members of society and draw their self-respect from doing so, just as everyone else does. Because work is one of the if not the most, central pillars of modern identity, chronically ill people want to work as far as they themselves see they can. But there are situations, be they a cold or related to their chronic illness, where they also wish to take the privilege of being "sick". This lies behind the two concepts of disease present in the above quotation. I for my part have tried to honour this by not using the word disease in relation to EB, except when talking about the scientific definitions and descriptions of the condition. But as with all conventions of writing, I am sure there will be mistakes. I apologize for them.

²⁸⁵ Heath 1998

²⁸⁶ Parsons 1951

8 Founding Debra, building the cooperation

One of the most surprising, but also the most rewarding experiences of field work is discovering that one has been asking the wrong questions all along. When I started inquiring about how Debra was founded, whose idea it was, what I was expecting was a narrative structured along the power line supposed to run between doctors and patients. Implicitly, I was looking either for an heroic narrative of patients building the group, or for the usual “Austrian story” of group induced by professionals – from above. I was naïve, and when I began asking, I was deeply confused to be offered a number of very different narratives by professionals and affected people. Everyone was telling me different stories, and it was absolutely impossible to personalise the “idea” for the association. As a sociologist, I really should have guessed it would be, because as I see it now, the founding of the association cannot be described as one idea one particular person or group suddenly had, but as a convergence of different narratives, which at one given point in time met to form what today is known as Debra. That point in time was 1995, and the place was the mountain-framed Austrian city of Salzburg.

From the affected people’s point of view, Debra is rooted in experiences of helplessness, despair and the wish to share one’s problems with similarly affected people. The founding of the association was mainly driven by parents of affected children, not by affected adults. As parents told me, having a child with EB in the context of the Austrian health system before Debra was founded could be quite a disturbing experience. It has to be considered that as EB is a very rare disease, the average physician is very likely to only have seen it in a textbook, if at all. Adding to the shock of having an possibly or obviously handicapped child – the initial symptoms of EB at birth range from a small blister to nearly totally missing skin - is the experience of helplessness and incompetence on the side of the treating doctors.

“When Olga was born, they transferred her to [the hospital of the regional capital, M.F.], and they treated her completely wrong there too. Because normally, they should have punctured the blisters, but they did nothing, and so they got bigger and bigger. And they bandaged them too, and if there’s pressure on them, that is not a good thing. I mean, they were the regional children’s clinic, I am sure they are good, but they have very little to do with EB, too. [...] It needs to be added that the first diagnosis was from

a biopsy. That was sent to Vienna, and the first diagnosis there was: Herlitz-type. The Herlitz type is the most severe form, which means that the children don't survive. And our daughter was in the hospital for three months after her birth. And all they talked about, as statement was, that hopefully she will be able to die. And then the question appeared, whether it wasn't Herlitz, but the dystrophic form [which is less severe, M.F.]. [...] But the experience for us was, that we had no one to turn to. And medicine itself did not react correctly, wrong diagnoses were made. (Q6)

This experience of being left alone by the medical system, the experience of incompetence, of bad care and wrong therapies, is something the parents I talked to made very quickly. It constitutes a breaking of trust and a shock to realize that the condition of one's child cannot be diagnosed and treated correctly, let alone cured in the medical centres of a country that claims to have one of the most advanced health systems in the world. As mentioned before, care for people affected by EB is complex, and parents of affected children have to and do acquire a range of skills, from bandaging to knowing when to open a blister. Without much support from the medical establishment, they had to develop those skills on their own. Being specialists in the care for their children, even more controversial encounters with the medical system ensue.

[...] but then the professor came, consultant's round, twenty people around. Did not say hello or something, no explanation what would happen next. "Now I'll show you how a blister develops." We went there with our child, four months old. And he said: "I'll rub until there is a blister". And we nearly fainted. To be fair, he didn't do it. He just opened a wound, explained a few things, and went away without saying goodbye. Just said "Nurse, bandage that". But she didn't manage. And after ten minutes of messing around I said: "Let me do it, I can do it better." Well, those are impressions, impressions not only we, but also others had. (Q7)

Furthermore, the treating doctors in the various hospitals were not interested in providing information on possible self-help-groups in Austria, nor did they suggest to build a self-help group. Faced with the experience of suboptimal health care and most of all the experience of being isolated in their problems, the parents wanted to know more about the condition, they wanted correct diagnosis, and they wanted to share their experiences, and started looking for a patients' association.

The founding of the association happened like this: first we looked, whether there already was an association or something. If you notice, that that [EB, M.F.] is something, which the people in the hospital know nothing about, then you start looking for something. (Q8)

Efforts to locate a group in Austria, both via hospitals as well as via the ministry of health proved to be futile, and thus the individual paths of the parents led outside the country. Olga's family, looking for the correct diagnosis for their daughter's condition, travelled to EB centres in Great Britain and Germany, where Olga's form of EB was diagnosed, but where they were also referred to a German self-help-group, the German chapter of Debra. Another family directly turned to Debra Germany for assistance and information, and both became members of the German association. Thus, one day in 1995, a small group of Austrian parents and their affected children met at the annual meeting of the German group in Dresden and decided to found an own group for Austria. But why a separate group for Austria? Would the German group not have been enough, considering the rare prevalence of EB, to discuss their experiences with the disease? The reason mainly lies in the fact that exchanging experiences was, though one of the most central, not the only concern involved in founding Debra Austria. Another important set of reasons relates to their experience of bad health care, and their will to change this.

So the idea was to found a self-help group in the first place, where affected people could find each other, communicate, and exchange experiences. And give help to new people who join, so that what happened to us does not happen to them. That no one knew anything. That no one knows anything, that you don't know, are you alone, or is there somebody else? [...] So the goal was not just the self-help group, to find each other and exchange experiences, but also good medical care. And correct diagnosis, that was the goal, so that what had happened back then wouldn't happen again. (Q11)

But how to change the Austrian health care system, starting from only a small number of families? Building on the models they had seen in Germany, and especially in the UK, the parents knew what they needed was a medical partner to establish one centre people affected by EB could turn to. Instead of taking the de-central approach, they decided to join forces with a team at the regional clinic in Salzburg, with which they had made positive experiences.

Then we founded this association in 1995, in Salzburg, because there there was someone, Professor [...], who had years of experience [with EB, M.F.], years of patient contact, and who was simply nice as a person. Contrary to the rather disastrous experiences we had at [large Austrian university clinic, M.F.]. (Q9)

As can be seen from this quotation, basing on their previous experiences with medicine, two factors were decisive in deciding which group of scientists they would cooperate

with. Competence and experience in treating EB on the one hand, and – maybe more importantly – experiences of a positive relation between the affected people and the respective experts.

Seven years later, I interview this partner at his office in the Salzburg clinic, and I ask the very same questions on the founding of Debra I have asked the parents of the affected children. Again, our conversation is led far beyond the narrow confinements of a small office in a small country, this time even beyond Europe to the United States.

The reason for organizing the entire thing was [...], to collect expertise for the patients and then finally also to get a centre. Not because we are especially important, or because we want to be a centre, but in principle, with rare disease, you have to go see people who know something about it. In America, I worked at the National Institutes of Health, and it was 82,83 the start of the AIDS [...] epidemic. And they collected patients from all over America, and brought them there by plane, because this at the beginning still rare disease was to be studied in a concentrated way. And that's the way it works with health care too, at the moment we have two children from Germany here, with their mother, who now virtually live with us for six weeks. That's a classical example for trying to get expertise. (Q10)

Here, the collection of expertise and the building of knowledge is central to the account of founding Debra. The perspective the doctor and scientist initially has had on the association is different from that of the affected people, as much as they may share the common vision of better health care. He sees the association also, rooted in his experiences of U.S. AIDS research, as a means, a focal point, to gather a large number of patients whose cases can be studied. Only this concentration of cases can contribute to the building of expertise for the patients, but also of scientific knowledge, on a disease as rare as Epidermolysis Bullosa. And in turn, this body of knowledge can then be the backbone for a “centre of excellence” that assures the best possible treatment for people affected by EB.

Working on the disease for now twenty-five years, he tells me that he had always thought there would be a need for a self-help-group. He also stresses the importance of having the right people to support and “carry” such a group, which does not seem to have been the case before 1995. As the parents of the affected children, he also mentions the German, and especially the British case as role models for building the Austrian association.

It should be noted that the expert emphasizes first and foremost that this collection of experiences is done for the patients, not for the sake of science itself. As will be discussed later, this focus on the interests and the wellbeing of the patients is one of the keys to

Debra's success, and considering the parent's decision to start the association in Salzburg, it was also one of the keys to its founding.

8.1 Building health care – collecting experience

Increasing the quality of health care for people affected by EB thus was one of the first and foremost goals of Debra. Because this goal is, as we have seen, rooted in the detrimental experiences parents of affected children had made, special effort was and is placed into helping affected parents and their children as soon after birth as possible.

In earlier times, it was not uncommon for a baby affected by EB to be kept in the hospital for as long as possible, sometimes even up to two years, as separated as possible from any outside influences, including even the parents.

And right after birth I was in the children's clinic for one and a half years, because the disease was not recognized. So they kind of said, let's see whether the child has chances to survive at all. And I was strictly separated from my parents, completely hygienic, I was kind of wrapped in cotton wool. That was pretty dramatic back then, I think. (Q12)

But even today, as described in the last chapter, the fact that EB is so rare can cause problems in an average hospital. Parents are left alone, no one can and does tell them how to handle the disease, how to properly take care of their affected child, because the necessary experience is not present at most clinics. Thus the learning process can be both physically as well as psychologically painful. The goal to alleviate this being one of its most important ones, Debra has taken two lines of action. First of all, a specially trained nurse is now available, funded in part by Debra, which can also travel to the place an infant with EB is born to aid the local hospital staff, but also and most of all to help the parents. The nurse will then also move with them into their home and spend the first few weeks with them, providing advice as they learn to take care of the special needs of their affected child.

But of course, the availability of this nurse alone is not enough, because the hospital or the parents have to be aware of that possibility to consult it. Thus, Debra also has to communicate its own existence and the services it has to offer. Besides a number of media activities, which will be treated in detail in chapter ten, it also sought to raise awareness for EB among physicians. For this task, a special leaflet was designed to be distributed among physicians via their professional association. Unfortunately, this project got stuck due to bureaucratic resistances within the professional association. This in turn may be one of the

reasons why even today, eight years after its founding, parents of affected children call after the latest TV feature on Debra, and everyone involved is surprised that no one had been able to tell them about the group when their child was born in a major Austrian hospital.

While the “mobile nurse” project is one devoted mainly to health care, improving the conditions for people affected by EB and making sure “that what happened to us does not happen to anyone else again”, other early activities of Debra are interesting crossovers between providing better health care and producing medical knowledge. For example, one of the first projects the clinic head of Salzburg brought into discussion at the founding of the association was to set up a so called “register” of all patients affected by EB. Modelled after EB registers in other states, especially the US, this register basically is a database consisting of all known people affected by EB in Austria, along with other medical information, such as the type and medical history of their condition. Initially, these registers are clearly a tool of medical knowledge production. They provide an opportunity for a systematic collection of data on the disease, as well as of course a resource with which the scientist’s claims can be legitimated in a publication, or, as I was told by a scientist:

Because if you state a claim on a certain type, it makes a difference whether you have one patient with that type of disease, or ten. That’s why we do that. (Q13)

The affected members of Debra acknowledge the interest of the scientists to set up such a register, but at the same time they also have a slightly different perspective on this database.

They also see it as a means to organise a proactive mode of individual health care, as providing the information necessary to inform patients which treatments or diagnostic tests they have to undertake in a certain period of time. For example, one common problem among the more serious forms of EB is that large moles can develop in spots where previous blistering has occurred. These moles have an increased probability of developing to malignant skin cancer. There recently have been several cases in Debra where the appearance of such moles had been neglected by affected people and their relatives, which in one case tragically even led to the amputation of an entire hand. The patient representatives hope that the register will provide a basis on which, ample resources provided, it will be possible to contact people affected by a certain form early on and inform them which tests they should take.

So we are building this register, who has which form and so on, quite a big one. After a model or a pattern from the United States. So that you can say, there are patients who have a specific form and someone should really call them and say: "Listen, you know, you got that specific form, you should come by every three months." (Q14)

Though the perspectives on and the expectations from this register are slightly different between lay people and professionals, the two goals are by no means contradictory. From the very beginning of the association a database has been built that can be used both for scientific purposes, as well as for those of active health care, making it a classical boundary object between the worlds of relevance of the affected people and the involved professionals.

Another central project in improving the health care situation for people affected by EB are the so called "general ambulances" which are held at the clinic in Salzburg twice a year. As was already mentioned, health care for people affected by EB is a complex and multidimensional issue that requires not only dermatologists, but also a large number of other professionals with special experiences in treating EB patients, such as dentists, ophthalmologists, gynaecologists, diet specialists and many more. Usually, treating EB thus means making a large number of single appointments and spending endless hours waiting in hospital ambulance floors. Furthermore, if even dermatologists experienced in treating EB are hard to come by, this even more applies to other medical specialities.

To alleviate this problem, professionals and affected people involved in Debra have started the general ambulance project. In quite an organisational effort carried out by the involved professionals mostly in their spare time, a special ambulance that caters only to people affected by EB is held. At these days, the affected people arriving from Austria, but also Germany, Switzerland and Italy can visit a variety of different specialists in one place without waiting time. Psychological counselling is also available.

While the general ambulances are an enormous benefit to the individual affected people, they also have an important function in gathering clinical knowledge, as they offer the possibility to see a large number of cases on a regular basis. Indeed, both patients and professionals told me that the quality of clinical care at the ambulances and at the clinic itself has quite substantially increased over the years.

The advantage in Austria is, that it is very centred. Germany on the other hand has a very federal organisation, very decentred. There is something there and something

somewhere else, which in this case is a big problem, because this way, for the disease is so rare, know-how, a pool of experience can never develop. At the beginning in Salzburg it was that way too, you came there [...], they wrote everything down, goodbye, and that's it. Meanwhile, after four or five years, they say: "Well, that has developed this way, we could do this or that, and in the other case, it was like that. Crosslinks develop, so to say. (Q15)

This experience-building function of the general ambulances is seen as one of the biggest advantages of this "Austrian model", compared to how EB care is organised in other countries. Experiences are not only collected concerning the dermatological aspects of EB, but also via the "Virtual Team" of around 15 specialists from various disciplines that take part in the general ambulances. Some very specialised medical interventions as for example surgery on the joined fingers characteristic for the dystrophic form cannot be done using local resources alone. In these cases, specialists from abroad are localized via the group's international contacts and then – after again a lot of organisational efforts – come to Salzburg to do the necessary interventions.

In sum, the general ambulances as well as the patient register reflect a successful balancing between producing clinical medical knowledge and fulfilling the needs of the affected people.

8.2 Seeing contingency, sharing experiences – benefits of Debra for its affected members

Besides the improvements in health care, what other benefits do the members of Debra who are personally affected, or relatives of affected people, see in joining the association? The standard answer for joining a self-help group is of course engaging in conversation about their shared fate – but in which ways does this actually help the engaged people?

When I asked for this, the answers I got is that one of the main, if not even the main task of the self-help group is to share experiences. The term experiences in this respect covers a wide range of issues, from care tips to psychological problems or to the general view of the disease itself.

Part of this exchange of experiences is seeing how different people handle the disease, and thus to gain a sense of contingency, of possible paths of action and of possible futures. How the condition of their child will eventually develop is an issue of highest interest for affected parents.

And then one asks, exchanges experiences. I can very well remember, as I saw a child back then who has these fingers, these joined fingers. And of course you ask. When did that start? And they say, well, it comes slowly and you cannot really tell when it starts. And then you hope that it won't come. And you increasingly see, that it will come. But exchanging experiences is extremely important for young parents, who have a newborn affected by the condition. For them, it is very very important, to come into the group early and see, how does that develop, which forms are there. There aren't just the severe forms, actually there are more lighter forms. (Q16)

As can be seen from this quotation, exchanging experiences is not always easy, it can also be quite frightening. EB does not only have different forms, it also tends to grow more severe as the children grow older. Doctors also alerted me to the dangers of seeing the contingency involved in the disease. They stressed the importance of informing affected people exactly about which type of EB they have and how it will develop, because they might otherwise misjudge their own situation in the face of the many forms of EB present in Debra, from nearly invisible light forms to extremely severe ones.

But exchanging experiences does also have a very practical dimension. It also means pooling the individual experiences on how to best treat the condition. It means talking about which bandages are best and which should not be used, which crèmes have the best healing effects on the blisters, which soaps can be used, and many other similar things. The

association's newsletter also features an impressive collection of practical tips on how to solve problems of daily life unexpected to someone with little experience with EB. Parents invent rubber coatings for pencils, so their schoolchildren will not develop blistered fingers. Someone else reports his experiences on using olive oil, and a young adult himself affected by EB writes about how to properly design and make shoes suitable for people affected by EB.

That's valuable, to get tips on a powder, a care product, a soap. [...] Well, yes, I would even say that that is one of the most important issues in the association, because I could get that from nowhere else. I can't know that from a doctor, who doesn't know that himself. (Q17)

The knowledge and expertise exchanged in the self-help group can only be provided by other people affected by the disease, not by professionals who have far less hands-on experience on these issues than the affected families themselves. Nevertheless, they can and do aid in collecting and systematizing these experiences. One example for this is a questionnaire started by Debra's nurse and the psychologist, herself mother of an affected child, on which care products the individual members use.

Besides care products, experiences with surgery or other medical interventions are also shared and discussed. Individuals or families try new forms of treating the condition in a quasi-experimental way and report their findings back to the group, thus contributing to the existing body of knowledge. One of the examples that was mentioned to me is the question whether homeopathic therapies work or not.

I mean, one hundred people make less experiences than a million. So there is no clear sign, whether homeopathy will actually help or not. One just tries. (Q18)

The issue of exchanging experiences, especially in its psychological dimension and in seeing potential trajectories of the condition, was more important to the parents of affected children I interviewed than for the affected adults, who in a sense already have seen how their condition has developed. Both groups equally stress the importance of sharing and exchanging practical experiences.

The self-help group itself thus can be described as a forum for collecting and pooling lay expertise. In a medical system that traditionally devaluates these forms of expertise, the question must be asked: How do the professionals involved react to this? Do they accept

these forms of experience based expertise? And more generally: how is the cooperation between experts and lay people in Debra negotiated?

8.3 Building an association, building a cooperation: the cooperation between experts and lay people in Debra

Judging from the case studies of the interactions between lay people and experts related in the theoretical part of this thesis, but also from the experiences the parents of affected children made in other medical contexts, it could be suspected that forming a successful cooperation between experts and lay people is far from an easy task. Still, in my fieldwork I never found a single instance where the difficulties for achieving such a basis for working together towards a common goal were mentioned – on the contrary, again and again my interview partners stressed how well the cooperation in Austria functions, especially in comparison to cases in other countries.

One reason for this success in the cooperation between experts and lay people must be seen in the fact that they have managed to construct objects, some in an institutional sense like the general ambulances, some in a more material sense like the patient register, that allow both sides to achieve the goals emerging from their respective perspective, while at the same time contributing to the overarching goal of “fighting EB”. Thus it is for example possible for the doctors and scientists to increase the quality of health care for the affected people and at the same time be able to collect data, to produce knowledge and to publish it. Still, as the head of the dermatology department at the clinic in Salzburg told me, one of the keys to success is to have a clear hierarchy in those goals.

If you always [...] put care for the affected people as a primary goal. [...] It's not science for it's own sake that's most important, but science for the affected people. And that's the way it has to be. The care, you have to be careful, to keep that first. So the affected people and their families will never have the impression that they're there, so that science can be done. Care has to go first. You have to heed that, because otherwise you can get carried away in science and then it gets so interesting that you forget your main goal. (Q19)

Putting the needs of the affected people first is not only something that is done in words, as I was able to observe when I attended the yearly meeting of Debra in Salzburg. An enormous personal effort is put into organizing health care, but also other things the

patients need. As we sit eating dinner at the first evening of the meeting, the head of the “EB-therapy-centre”, who in her “real” – paid – job is in charge of the molecular biology lab at the dermatology clinic, circles the table to inquire which additional health care appointments are needed. A young girl in primary school age sitting at my table has quite serious health problems coupled with pain, and needs a paediatrician. Finding an appointment in the short time –essentially a weekend - the family, who is from Germany, is in Salzburg is not easy. At approximately half past eight in the evening, the health care coordinator starts making phone calls to reach the head of the paediatric department. When she finally gets her on the phone, she is willing to do the appointment right now, but there is one big problem. She has no one to take care of her baby. The health coordinator offers to play babysitter while she comes to the clinic. Finally, after some discussion between the family, the paediatrician and the coordinator they agree on an appointment Saturday morning.

It is this access to experts that also plays an enormous role for the affected people. As I was told, it is also one of the main reasons why increasing numbers of people from neighbouring countries join the Austrian group. Debra Germany, for example, cooperates with one of the internationally most prominent EB-researchers, but still many affected people involved in the German group are not content.

And in top-science you're always travelling, on the road, and you have no patient contact any more. And that's what the Germans criticize: It's great, that Germany has a say internationally, but we don't get anything out of it anymore. We don't see this woman anymore, she's no longer available for us, so she has no effect as a doctor, because she is not there. That's why a lot of people come to us [to Austria, M.F.]now. (Q20)

The conclusion that can be drawn from this quotation is that the long term promise of influencing basic research to find a cure is less important to the affected people than the short term goal of ample access to good health care.

A further important dimension of the cooperation between experts and lay people in Debra can be found in the relationship between expert and lay knowledge. As I have already described, people affected by EB and their caring relatives hold a large body of knowledge on how to treat the disease, on how to organize care in an everyday context. One of the main functions of the self-help group also is to exchange this knowledge. The experts also contribute to these knowledge building processes by aiding them with organisational

support, but also for example by holding speeches on new developments in, for example, bandaging products at the annual meetings. Scientifically speaking though, as one researcher told me, these issues are of quite little interest, because his experiences had shown that the way the disease is treated has little or no effect on its development. But still, even if no long term cure may be achieved, the affected people are of course interested in techniques to ease their pain and their daily lives. What could be expected with a little experience in biomedical practices is that the experts would try to offer a standard best-practice recipe on care for EB, and prescribe that to the patients. But this is not the case. Instead, it is acknowledged by the experts that the affected people and their relatives hold a superior knowledge on their special case of the disease than the experts do. The following quotation is from an interview with a medical doctor, while we were talking about the general ambulances.

I've always been a supporter of, that, as soon as the parents take care of their children, then they will be the ones who know most about the disease in that specific case. That's the way it is, and you can give help in the beginning, but then..., and that's why they also exchange, when the self-help group meets.(Q21)

By saying this, the expert accepts that care for the disease in the situated context of everyday life is qualitatively different from standard medical practice in the clinic and thus requires different forms of knowledge, a knowledge that is to be found rather with the affected people and their parents than with the involved experts.

Assuming this perspective, the encounters between affected people and experts in the general ambulances, but also for example in the annual meetings of Debra, become instances of conscious mutual learning. The experts also are interested in the problems that arise out of everyday life with the condition, and also in the solutions affected people have found for them.

Accepting that affected people and their relatives also possess a knowledge base and a situated kind of expertise of their own right also implies accepting that they sometimes will do things that run afoul with the norms of modern biomedicine.

For example, alternative medicine plays a quite important part in the discussions within Debra, both in face to face interactions and in the associations' newsletter. Many alternative practices such as acupuncture or homeopathy today are accepted by biomedical practice and thus do not present much potential for conflict. But there are many more

practices people affected by EB, desperate because biomedicine is not able to offer a working cure, seek out in despair, sometimes spending enormous sums of money on them. Some of these cases involve clear elements of fraud and quackery, but besides that there are many other practices in the grey areas around biomedicine.

These alternative forms of medicine appear in Debra's newsletter, and speeches by alternative practitioners are held at the annual meetings along with those of biomedical experts. The affected people accept both types of knowledge alike, claiming that one would have to look what works, and what does not. Also the biomedical experts exert tolerance toward the alternative approaches, as one doctor told me.

For me it's very simple. If I know nothing about it, I don't talk about it. And if someone else has something to offer, which leads to success, then he was right. (Q22)

The decision on which experts to consult and which therapies to use is in the end left to the individual. The same liberty of discussion and decision applies to many other fields. For example, though this is an intensively discussed issue, the group has decided not to develop a common position towards issues such as prenatal diagnosis, in contrary to many other groups of affected or handicapped people.

8.4 Founding Debra – Conclusions

Summing up, how can the founding of Debra and its first activities be described in the light of the theoretical considerations already made? Debra Austria clearly is a latecomer in the self-help movement, especially if one takes the international level as a yardstick. Thus, one of the most interesting questions for me was to see whether the theories about the forming of self-help-groups, written nearly a quarter of a century ago and in different national contexts, would hold for the case of an Austrian group in the mid 1990s. Summarizing what was said in chapter 3.2.3, there are two main observations sociological theories of self-help made. First of all, the emphasis that coping with the problems of one's own disease is *the* central reason for founding a self-help group so often made in popular accounts and psychological theories is rejected. Even though this is of course an important motive, it forms just one aspect among others. For example, empirical surveys revealed that the motivation to learn from other members is mentioned more often than the coping motive. Secondly, three key factors were identified for the forming of a medical self-help-group: the presence of pressing personal problems caused by the disease, perceived shortcomings of the professional system and a certain amount of „counter-experience“.

It can also be said for my interviews with affected people involved in the founding of Debra that the coping motive, while important, did not play a central role in their accounts of their motivations. Rather, the intention to learn, to learn more about the disease by traveling to clinics in other countries, to learn more about the ways the condition can develop and to see the contingencies in living with it, was the key to the stories I was told.

Still of course, the personal burden identified to be the first of the three central factors that lead to the forming of a self-help group was clearly present in each of the individual stories. But it was not only the distress caused by having a seriously ill child that contributed to this burden, but also and much more the anxiety and uncertainty associated with the important role the second factor played: the obvious deficiencies of the professional care system to properly diagnose and treat this rare disease. It were these experiences of incompetence that on the one hand created feelings of helplessness and anxiety, and on the other led the parents of affected children to actions that finally led to the founding of Debra. But surely these experiences were not worse in the 1990s than they

were in thirty years before, when the adults affected by EB today organized in Debra were young. Why did they or their parents not decide to start a similar project?

Here the category of counter-experience comes into play. As can be seen from my interviews, the situation the affected parents found themselves in could not be considered favourable for starting a self-help-group. They were faced with a professional system that did not encourage them, let alone aid them to help themselves. The crucial point proved to be being able to find other people affected by the same disease. Because EB is that rare, finding a similar case in the same clinic or even town is highly improbable, and this poses a large obstacle for starting a self-help group. The disinterestedness the parents of affected children encountered when they inquired for information on possibly existing groups at clinics, but also at other institutions like ministries must be seen as characteristic of the lacking tradition and history of self-help in Austria in general. What finally made the difference, and started the process that finally resulted in Debra, did not come from within the country. The “counter-experience” necessary, the knowledge on how to form such a group and the possibility to finally meet other people affected by the disease, came from abroad, more concretely from the German chapter of Debra, which is itself modelled after the British original. It is thus the existence of a global rare disease movement in general, and of globally linked patients’ associations concerned with EB in particular, that provided the little extra resources, both on a cognitive and on a practical level, that were necessary to kick off Debra Austria.

Therefore, though it is rooted in extremely localized experiences of despair, Debra Austria must also be seen as part and result of a global social movement. This poses a challenge to self-help theory, which has so far conceptualised self-help mainly from the perspective of small group structures of spontaneous origin. Debra’s origin was spontaneous in the sense that it had not been planned by a professional to fulfil his own needs, but it still rests on a number of pre-existing structures on the international level. This existence of a global movement that aided the founding of the group may explain why it was this generation of parents of affected children that founded Debra, and not an earlier one, and that it were the parents of newly born affected children that started the enterprise, and not older affected patients who mostly had already slightly resigned after years of similar experiences.

This seemingly paradox encounters between highly situated experiences and global structures also shapes many of the activities of Debra. The general ambiances and the

patient register can be taken as examples: in these contexts, the internationalised system of producing medical knowledge, medical science, meets the situated health care needs of the affected people. The key to a successful cooperation, as I have argued, then is shaping these objects in a way that they can become boundary objects that can serve both purposes alike: the situated needs of the patients and the requirements of doing science.

But the collection and production of knowledge is not limited to the scientific domain only. One of the central functions Debra fulfils for its affected members is the pooling of individual experiences, both in a psychological and a practical sense. Especially the latter, the collection and discussion of different care methods, different health care products, but also the discussion in what ways the disease can develop, forms an independent forum of knowledge production that exists alongside the expert system. It is not necessarily a lay epidemiology²⁸⁷, the inquiry into the reasons of an inheritable disease being rather pointless, but it can certainly be considered to be a form of “lay medicine” – in the sense of a rather systematic collection and evaluation of ways how to best treat a given disease.

Given the difficulties described in the literature concerning the relation between such lay and expert knowledge systems, the harmony with which these both systems exist along each other in Debra seems remarkable. It is not even the case, as might be at first suspected, that the lay system goes largely unnoticed by the professionals. On the contrary, the respective forms of expertise are mutually acknowledged, and a mutual willingness to learn from the other side exists. This mutual respect, and the cleverly constructed boundary objects that link the two worlds of affected people and medical scientists, form the basis for taking the next step in the story of Debra: that of engaging in actual scientific research to find a cure for the disease.

²⁸⁷ Brown 1987

9 Magic Bullets – Debra Austria and its molecular-biological research

Even though the goal to actually finance research on EB was always implicated in the association's name and in the international models it was built after, Debra concentrated on building the self-help group and improving health care as the primary goals in the first years of its existence. This slowly started to change in the year 2000, when a scientist of the Salzburg clinic approached the association with the proposal to fund a specific project. He wanted to send one of his postdoc researchers to a company in the United States to learn more about a new method in gene therapy, which he had discovered in the literature. The patients' association made the basic decision to allocate part of its resources to financing research, as one of its most important goals had always been to play a part in finding a cure for the condition, and a separate organization for funding research, the "Forschungsverein" was set up. At the start-up meeting of this new organization, possible priorities for funding research were discussed. While reaching a cure for EB via gene therapy was decided to be the long term goal, the priority list also includes a number of other projects to be funded, including research on the typical cancers occurring in EB patients, on the healing of wounds, on nutrition and EB, on pain and itching and finally on the evaluation of medical products for EB. Out of a number of other projects, the gene therapy project was chosen to receive start-up financing.

The term gene therapy generally stands for the attempt to replace the sequence of the human genome suspected to be the cause of a certain disease. To do so, a "healthy" variant of the affected gene is introduced into the affected cells by a vector, often a retrovirus. By the replacement of the gene, the processes causing genetic diseases are thought to be interrupted. Even though high hopes are being put into gene therapy for many diseases of genetic origin, little success has so far been reported²⁸⁸. A number of studies which had been successful at first had to be aborted due to problems with the used viral vectors, which in some cases have even lead to casualties among the testing subjects.

The specific method researched by Debra Austria, called transsplicing, involves cutting out only specific mutated portions of a gene, the exons, instead of replacing the whole gene as is standard practice in other methods of gene therapy. Doing this also allows to manipulate

²⁸⁸ Stockdale 1999

genes which would be so large that they exceed the carrying capacity of the vectors used in other gene therapy approaches. This for example applies to the gene causing the dystrophic form of EB.

After the postdoc had returned, Debra continued to support the project by paying this specific researcher's salary. But why did the researcher actually approach Debra in the first place, at a time when it was unclear whether the Austrian group would actually be willing to support the project, and much more importantly when its financial basis was still quite small. Why did he not tap on the traditional public resources to finance medical research, or negotiate a contract with industry?

Indeed, the initial plan had been to use Debra's money only for a kickoff, to do the necessary travelling and research to gather sufficient data for writing a grant proposal and submit it to Austria's central research council for basic research, the FWF. The funding of the proposal was rejected twice, for a number of reasons as the leading scientists stresses. First of all, the funds of the council are getting scarcer and scarcer, making life harder for the individual scientist, as he told me.

it is of course not easy as a scientist. I believe they have a quota of 45 percent [of financed proposals, M.F.] at the FWF now, that's not bad, but it's for sure not easy for a scientist. (Q23)

There is no guaranteed public funding for medical research in general, and writing successful grants to acquire funds has become highly competitive enterprise that demands a high investment of resources. Furthermore, the special project they were proposing actually ran afoul to the council's focus on basic research. The "science of EB" has developed quite rapidly over the 1990s, fuelled by genomic research, and at the end of this period, the focus of the research has changed.

One thing's for sure, until five or ten years ago it was extremely hot. That was real basic science, finding the mutations that cause this diseases. That basically was 92 until 2000. And because we more or less didn't start before 2000, that wasn't an issue for the FWF anymore. And generally, gene therapy is very focussed, that's not really a basic science project. That's why you can't sell it to the FWF very well at the moment. So the only way is Debra. (Q24)

Developing the actual products that cure a disease, be they a pharmaceutical drug or as in this case, a certain form of therapy, is not seen as an enterprise of basic research to be funded by public money. Instead, the implicit expectation is that this last step of medical

research will be funded by private companies, who then expect to turn the revenues on the final products into their profits. But to make profit, a company needs a market that is large enough to warrant its investments into the development of the product. As EB is a rare disease, this is not the case. Furthermore it is far from clear whether a single form of therapy will actually be possible for all forms of EB. Current estimates are that it must be considered more likely that the therapy will have to be specific to the form of EB, or even to the specific genetic mutation in an affected family.

Of course, prevalence is one of the main issues for industry, and with EB, you haven't got that, even if you take it globally. In the end, it is an orphan disease, and no one from the industry is interested in it. So in the end it's only money from patients' associations. (Q25)

The fact that usually²⁸⁹ no public money or interest from the pharmaceutical industry is available is not restricted to Austria, making money from patients' associations and charities the prime source for research funding, and the ability to acquire this resources one of the prime attributes for successful EB researchers. The success of the currently leading Italian scientist, who has announced to be able to go into a trial stage with his gene therapy of a specific form of EB soon, is mostly attributed to his cleverness in raising funds. This dependency on money provided and raised by a patients' association also applies to the Salzburg laboratory, not only because of the general structural reasons mentioned above, but also because of the position of the lab in the Austrian research landscape.

Well, considering that we do a lot on EB in the dermatology laboratory now, it is of course very important that we do get money for that, too. Because our focus, so to say, is EB. And if you have a focus, it is important to get money for it. That's out of the question. On the other hand we just run along [the clinical work, M.F.], and we for sure aren't on a level to acquire international money, from the EU or national money from the FWF. So, from that point of view, that [getting money from Debra, M.F.] is essential for us. (Q26)

This quotation, voiced by a leading researcher, quite clearly self-situates the research group at the periphery of the Austrian, let alone the international research system. After the FWF had rejected their proposal, the research group requested funding for a similar project from Debra UK, which has a quite large budget devoted to funding only research on

²⁸⁹ There are also quite strange exceptions to this rule. Debra US has for example received a million dollar grant from the US department of defense, because the wounds occurring in EB are similar to those caused by chemical warfare.

Epidermolysis Bullosa. Even though bigger chances were expected for this proposal, considering that Debra UK funds only EB projects, it was again rejected, this time for methodological reasons. The procedures used were considered not to be state of the art by the scientific board.

The fact that the Salzburg lab is only an addition to clinical work, not an independent research unit, and the small basic funding mean that it is impossible to play with the “big players” on a national or international level. On the other hand, this peripheral position also offers advantages in cooperating with a patient group, because it leaves more space and time to meet the needs of the affected people – and thus form an attractive partner in the cooperation.

Thus something can be done for the EB-patients, which otherwise could be easily lost in normal everyday clinical practice. And there also are experiences, that it is lost. It is lost in [big clinic in Vienna], and all the patients from Vienna say, that that is a great hospital for sure, but they simply don't have time for special problems. And they [the patients, M.F.] have also noticed that. And that's why they're glad, that someone has been found who concerns himself with that. And has built this thing for the patients, so to say. (Q27)

Money is not the only resource the scientists acquire from the affected people for their research. For doing basic medical research on EB, as well as for developing possible cures, samples are required from the patients., be they tiny fragments of skin needed to do research on the skin cells, or fluid that forms in the blisters caused by EB. These samples are mostly collected during the general ambulances, sometimes a call to donate something is also published in the association's newsletter. In a rather comical moment during one of my interviews, an affected person remembered that he actually had kept a small vial of blister fluid in the back of his refrigerator for nearly two years, and wondered what to do with it now.

Such anecdotes set aside, the general ambulances held twice a year to which a large number of affected people of all types gather in Salzburg not only offer an excellent possibility to follow a large number of cases over a long period of time and document this process, but also to collect tissue samples.

While tissue samples and blister fluids are very material resources needed to do research, the information collected during the general ambulances also plays an important part in the research process. The data gathered are systematically collected in the patient register

described in detail in the last chapter, and can be for example used to back up claims made in publications.

Taken together, the fact that the scientists see a large number of affected people, and are able to collect data and tissue samples from them, can also be used as a valuable asset on the international level. Even though the group lacks the high standard equipment that would make them a valuable partner in technological terms, they can draw on a large number of patients and thus contribute patient data and samples.

And we're doing basic scientific investigations. We're collaborating with the Americans on that, the Americans in Washington and Philadelphia. We've done a lot of basic scientific projects with them. We see a lot of patients, and they have the expertise to do investigations we can't do here at all. A very good collaboration. (Q28)

In a certain way, thus, the weaknesses and the peripheral status of the laboratory can be turned from a disadvantage to an advantage by cooperating with the affected people. The resources provided by them allow them to make connections and enter cooperations also on an international level.

The affected people themselves are sometimes quite aware of these exchanges and their meaning for the scientists, as an affected adult told me:

And science too. That's important that the patients are involved in some way. Also the medical doctors have an interest in that, of course. They need people (laughs), so they can report on how they are doing. (Q29)

But in how far are the affected people really aware how and which research is done? How is science communicated within the association? Do the affected members of Debra try to influence the science that is being done, and if so, how do they do so? Does the engagement with lay people in the cooperation lead to a different kind of science being done? These questions will be the topics of the next chapters.

9.1 Hopes and uncertainties: Engaging with and talking about science

Golden autumn sunlight floods through the panoramic windows into the conference room where the annual meeting of Debra Austria is taking place, making the Power Point slides that are being used by the leading researcher rather hard to read. He talks about the research that has taken place over the last year, both in Austria and internationally, and he explains how the projects funded by Debra are to proceed. Internationally, I learn from one of the slides, a number of research groups are developing gene therapies via different methods. Some of them are further advanced, one specific project in Italy is even about to be applied to a number of affected people. As EB is not a single disease, but rather a group of related diseases, each of these therapies only works for a certain type of EB. Before I have time to wonder, he explains that the method researched in Salzburg is still at such an early stage that it in principle can be applied to any of the three main forms. Safety is an issue, especially after a number of casualties have recently happened in other gene therapy trials. The problems are suspected to be caused by the viral vectors used, non-viral vectors are being considered. Someone asks what a non-viral vector is, but I don't understand the answer. My fieldnotes say something about insects and fish. The scientist goes on to explain, why a gene therapy of the skin will be less dangerous, essentially because the new skin cells are bred in the lab and then transplanted. Any cancerous developments could then easily be surgically removed.

As the presentation ends, a lively discussion ensues. At first, interest focuses on the different gene therapy trials going on. Affected people inquire which therapy will be possible for which form and how their chances of success are. The mother of an affected child wonders how the internal blisters will be treated by transplantation. The last and most intense part of the discussion is dedicated to the question of time. When will a cure be available? When will there be first results? The currently used methods are already developed quite far, the scientist responds, a breakthrough is to be expected within the next 10 years. Very little uncertainty can be heard from his words.

After the presentation, the last of the annual meeting, is over, I have a small coffee chat with the association's president. He tells me of the association's governing board meeting two days ago, where the research financing decisions were made. It was a long evening,

and the projects to be funded were explained to them in great detail. Still, he says, he and the other representatives of the affected people have the strong feeling that they do not fully understand what it is all about. It is all too complex. It is not just the purely scientific matters that contribute to this complexity, but all these strange links to science politics and other domains.

For many affected people presentations concerning the research into a cure for EB are one of the highlights of the annual meeting. The results to be announced are awaited with anxiety, because a lot of hope is put into an eventual success of the research efforts.

That's a feeling you always have, I think, that many people also go there [to see whether, M.F.], maybe there will be a solution this year. Other things are done on the side, but the most important thing to many people is the medical variant, concerning a cure. There is a part, where the most recent research results are presented, so that a lay person can understand them. With slides, partially with Power Point, to explain the effect of a gene or a molecule. As far as that can be explained to a lay person. That's difficult of course, but they try hard, not to use specialist terms, so that you might get a feeling hat they're talking and you don't understand anything. (Q30)

A large part of the success and the popularity of these presentations is that they are, as well as the research articles written by scientists in the association's newsletter, well prepared and designed. Quite some effort and thought is put into considering which findings might be of most interest to the affected members of Debra, and how they might be best communicated. Slides and images are designed to translate the basic principles of the scientific projects into everyday language. For example, the transsplicing project is described as a "gene-scissor" which cuts out and replaces the mutated parts of the gene.

As in the quotation above, most affected members and their families seem to be content with the information provided. The discussions at the annual meeting also show that the presentations enable the lay people to pose quite complex questions and to discuss central questions of the research process. Interestingly, the research process is discussed mostly in terms of abstract principles, or, even more often, in terms of expected results. No or only very little attention is attributed to the everyday practice in the laboratory. Other than in patients' associations in other countries²⁹⁰ the affected people show no interest to go into the lab, or to see "the enemy" in the form of the affected gene. The most interest is devoted

²⁹⁰ Rabeharisoa/Callon 1999

to the outcomes of the research projects, into which individual hopes of a cure are projected. But not all members of Debra share these high hopes equally – some, especially among the adult members of the association, are more suspicious whether the research efforts will actually lead to a cure for their condition.

“What do you expect from the medical research Debra funds?” was one of the central questions I repeatedly asked in my interviews and in other, more informal conversations. When talking to the parents of affected children, the answer was quick and brief:” A cure, of course. Via gene therapy.” Then a short pause, after which the complexity of the research process would be stressed and my conversation partners would point to the fact that the exact point in time when this goal would be reached would be still unclear. But it definitely exists. Research in the end is a linear process, even though of unknown length, which will eventually lead to the development of a cure for all forms of EB.

That means research is so complex. But until now we have high hopes, and thus we are allocating a certain amount of our budget to that. (Q31)

The term high hopes expresses the parents’ expectations of science best. Their motivation for engaging with science is the hope that their children will be cured, that their pain will come to an end, at some point in the near future.

The adults affected by EB adopt a more distant stance towards the research efforts. A recent small survey among the association’s members has revealed that quite a large proportion of its adult members, even though they do not openly oppose gene therapy research, would not want gene therapy used on themselves, even if it would be available. By the researchers and the parents of affected children, this is often attributed to the fact that the adult members have already “seen to much”, meaning that they have heard to many unwarranted and eventually unfulfilled promises of miracle cures by the medical establishment. They are suspected to adopt a rather inward looking orientation and concentrate on a personal and social reflection of their disease – an argument that is also used to explain why groups like Debra Germany, which is mainly led by affected adults – is far less active in promoting research than its neighbouring sister group.

When talking to adult members of the association, this is indeed one of the explanations they give for their slightly more distanced stance towards gene therapy. An affected adult told me about the many new medications he had tried, and the little effect they have eventually had.

But I've grown more sceptical in the meantime. I can remember, a few years ago, word was, yes, there is a gene therapy, and it will soon be at a level that something can be done. And that happens again and again. Recently I read a report that it is expected that something can be done in five years. But whether that is true then... (Q32)

Still, that does not mean that he rejects doing or funding gene therapy research. On the contrary, he tells me, he understands very well why other members of the association have such high hopes towards research – an understanding which shows that his stance towards gene therapy research is not only situated in the context of his own history and experiences with promised cures, but also in a reflection of the different life situations people affected by EB and their families can be in.

There are people who have got stronger expectations towards a cure. I can understand that. The parents of the children - I would have thought too, the best thing is if it can be cured. But through my long experience, I can handle the disease differently, I guess. For me it has been part of my life for a long time, because I was born with it (laughs). I'd be enthusiastic if something could be done about it too, but [it is even more so, M.F.] for an affected child, where the parents also suffer with the children. (Q33)

This quotation points to the second dimension inherent in the sceptical position of the affected adult. As described in more detail in chapter seven, the adult view of the condition may differ quite fundamentally from that of the parents of affected children. The pain and the bodily problems associated with EB are not as central to my adult interview partner as the social and psychological hardships that come with it. He has learnt to manage the daily health problems associated with EB, knows what he is able to do and what he should better omit. On the other hand, to put it very pointedly, a missing formal educational background which causes problems entering the first labour market, not the second, protected one reserved for handicapped people, can not be cured by a gene therapy. In the view of the affected adult I talked to, the emotional position of the parents of affected children is also a special, maybe more difficult one than that of an adult who has learnt to manage his or her disease, for they can only share the suffering of their child, often without being able to offer much relief.

Seeing this, he is in favour of funding gene therapy research, even though he would not be completely sure whether he would use it if it were available. Furthermore, he is very suspicious of the time horizons discussed in the association. Generally, the question of

time is the focus under which the research process is most discussed among the affected people, but also between them and researchers.

As already discussed, the focus of interest for the affected people in science is much more the result than the process. The process of scientific knowledge production is sometimes reduced to a simple representation of the time that still has to pass until a cure is discovered. Science is essentially portrayed as a linear process that leads to an outcome in a predictable amount of time. Questions on how long this will be, on how much (in temporal terms) research has advanced over the last year, are common place at the association's annual meeting. As in the plenary discussion on the research financed, scientists feel obliged to answer these questions. Doing so, for them, always means walking the thin line of how to properly represent scientific uncertainty. At the annual meeting, the researcher did so by stating that the methods were already quite advanced, and, if everything goes well, results are to be expected within the next few years. But what does this small disclaimer "if everything goes well" mean? To the patients, listening with ardent hope, this is only a minor footnote. What counts in their linear picture of science is the time it takes to reach the goal.

The only thing I understand as a lay person is, that ever since I've been part of it (for 10 years, M.F.) they keep saying, in five years there will be a cure or at least in five years the clinical trials will start. And that hasn't happened so far, but the five years sound more and more realistic. (Q34)

A major source of frustration, as is indicated with some irony in this quotation, cited by affected adults and parents of affected children alike, is that these deadlines seem to be regularly prolonged, betraying the hope of a linear process. What is the researcher's conception of this process, and how do they react to the expectations of the affected members?

I just keep saying that. You can't buy health and you cannot order positive scientific results. One has to see that. Because otherwise you could say, well people, I'll give you a hundred million dollars, function! But I can only function in my work, I can't function with the result. That's the way science is, and you have to tell that to someone, who does not know the tough life of a scientist (laughs). Because investing money doesn't mean there will be a result. You have to explain that honestly. Because otherwise happens, what the self-help groups, and also others, say: "Every five years you promise: In five years!" But you promise nothing, you explain. And on the other hand, if you don't play the lottery, you can't win. If you don't do science, it doesn't drop by by itself. (Q35)

This quotation, voiced by a leading scientist of the Salzburg research group, reflects a quite different view of the scientific process. Here, the results of medical research can never be guaranteed, let alone predicted. The high expectations of the affected people are confronted with the hardships of everyday science: trying things, which sometimes do work, and even more often do not work. Implicitly, there is some frustration with the view that science is something like a trivial, linear machine, a machine where money only needs to be added at the top, and results will come out at the bottom of the process. Instead, he claims that the research process is far from being a linear one. The image invoked is that of playing the lottery, which involves making random bets on quite low probabilities. Results are not guaranteed, for, as we all know, one can play the lottery for a quite long time without winning. Even though science is portrayed as the only way for reaching a cure, it is also a very uncertain way. Health cannot be bought, and science is not the method for doing so. In this storyline, gene therapy resembles the proverbial magic bullet, the impossible shot that somehow still manages to strike the hot spot.

In the quotation, the researcher claims wanting to communicate this uncertainty, this picture of doing science as playing a lottery. But still, talking to the affected members of Debra and their relatives, but also listening at the annual meeting, one gets a different picture: that of science as the trivial machine, the linear process. Interestingly, the uncertainty present in the scientist's account of their work is erased in the process of communication between experts and lay people. The statements I heard being voiced by scientists at the annual meeting were not invoking an image of playing lottery – probably on purpose -, but they did contain some elements of uncertainty, in “probably” or “if all goes well”. But in the ears of the affected members of Debra, these were stripped away and all that seemed to be left in the end were the black-boxes “five or ten years still to go”. Summing up, it can be said that even though the will to communicate risk and uncertainty is there on the side of the researchers, the process to do so is not very successful thus far.

9.2 Complexities: the affected people's influence on research

As we have seen, communicating the science done is often far from easy. But still, every year, when Debra's board meets for a long evening before the traditional annual meeting, the representatives of the affected people have to decide which of the projects proposed to them to fund, and which to leave aside. The prime criterion they have developed for this decision is the expected benefit the project will have for the affected people themselves. Thus, applied and problem-driven research is much more likely to be supported than projects without immediate or expected future applications. Also, the budget Debra can spend for supporting research is limited, for example, in 2003 around 20.000 Euro will be available, a small sum for doing research. Thus, choices on which project to support must be made wisely. But how easy is it to decide whether "Best practice methods to introduce genetic material into skin cells" or "Production of skin proteins by means of genetic engineering" will have more benefit for the lives of affected people, to quote two examples proposed at the first research board meeting in 2000?

But, to be honest, just yesterday doctor [...] explained that to us again, because he had proposed three research projects we were supposed to sponsor. The issue is so complex, I can't understand it, so that I could say, well, ten years ago they had that and now we're close to the goal. I can't say that as a lay person. Dr. C. said yesterday, that could take ten years, but that could also be next year, that there is a breakthrough. There are so many attempts, so many theories to approach that. (Q36)

In this quotation, the affected people's linear conception of science meets the complexity involved in actual scientific practice. Gene therapy research into EB is a highly diversified field. First of all, the different forms of EB have different genetic causes, demanding different methods of therapy. Furthermore, it is not even sure whether all people affected by one specific type of the condition can be treated by a single therapy, or whether this therapy will have to be tailor-made for the individual. Different gene therapy projects involve using different vectors, or, as the transsplicing or "gene scissor" project, target different regions of the affected gene. In sum, quite some literacy in molecular biology is necessary to understand the basic principles of the projects proposed. To offer this knowledge, a "crash course" in molecular biology is given by the researchers at the start of many board meetings. But even then, to understand the basics of a project does not mean being able to critically evaluate it.

When they say, let's do the project, let's do genome research, let's do that investigation. I couldn't say: No, that makes no sense, or something. Of course not. And the other's couldn't also. (Q37)

On a certain level, this is a problem for the representatives of the affected people, because they would of course like to have some control on how the money donated to them is spent. But it is not only the factual complexity of the science “behind the projects” that challenges the affected people, but also the social complexity of the research system. What other sources for money could be tapped, what alliances could be formed? What are the criteria for being awarded a certain grant? These are other questions the research board of Debra has to discuss. To give an example, several years ago, after the transsplicing project had been rejected by the FWF, it was submitted to the research fund of Debra International. After the project had also been denied there, the governing board of Debra International wrote a confidential letter to the president of the Austrian group, informing him that the project had been rejected because the methods used were out of date, but still encouraging him to fund it to get research on the topic started in Austria. Startled, the patient representative confronted the scientists with the question why their project would be methodologically out of date. The researchers responded by explaining that, even though Debra International is devoted to solely fund EB research, still a lot of groups compete for this money, and that it is hard to compete with the “big names” that already have their stand in the field. In short, the message was that not only the quality of a project contributes to its chances of being funded, but also the reputation of the researchers submitting it.

Explaining these processes and characteristics of the scientific field is also seen as a challenge by the researchers themselves.

Of course it's hard to explain what's going on in science. On the one hand in science itself, because that is a complex topic, especially gene therapy. But also concerning science policy, what the connections are, who awards the money, who decides on that. That's not easy, not to say impossible, to explain that to the patients' associations sufficiently. And it is the case for sure, and I keep hearing that, that they don't understand what exactly one is doing. You have to explain that in a simple way, what the gene scissor is. And how the connections develop in the research landscape. But that's a very hard topic, I keep noticing that. And you have to work on that. You have to present what is being done accordingly. (Q38)

Thus, in sum, the representatives of the affected people feel rather overwhelmed by the complexity presented to them. Even though they have some assistance in doing so through their international contacts, they do not really feel themselves to be able to make an informed decision on which projects to fund, or to control projects already running. They also do not see themselves as being able to exert a conscious influence on the research process or the knowledge produced. But what does this mean for the science being done? Is the research carried out by Debra the same that would be carried out in a university laboratory without the involvement of the affected people? Or does their engagement have other, more indirect effects?

A primary and rather direct effect is the mentioned focussing of the funded research projects on actual problems the affected people encounter, and their evaluation according to their expected benefits for their respective lives. Besides the mentioned molecular-biological projects, other smaller projects also try to solve problems that affect the daily lives of people with EB, like for example the terrible itching often caused by the condition. This focus on applied concerns is reinforced by a guideline issued by Debra International, which defines three main goals for EB research: the development of a gene therapy, research into the forms of cancer typically occurring with EB patients, and research on healing the wounds caused by EB. These guidelines, even though they only have binding character for projects financed directly by Debra International are acknowledged and heeded by the researchers I talked to.

As researchers stress, solving the problems of the affected people is their prime goal.

If you always [...] put care for the affected people as a primary goal. [...] It's not science for it's own sake that's most important, but science for the affected people. And that's the way it has to be. The care, and you have to be careful, to keep that first. So the affected people and their families will never have the impression that they're there, so that science can be done. Care has to go first. You have to heed that, because otherwise you can get carried away in science and then it gets so interesting that you forget your main goal. (Q19)

Here, an abstract, decontextualised science is pitched against a science that is designed to work for the people affected by EB. The quotation also indicates a slight conflict between the imperatives of science, and those of working for Debra. Doing science for science's sake is portrayed as creating a certain fascination, that can “carry the researcher away” from the actual goal of finding a cure or helping the affected people in other ways. This,

and creating the impression with the affected members of Debra that they are only used for the sake of science, is to be avoided at all costs. Thus, the cooperation with the affected people has already changed the knowledge production practices employed. Also, this cooperation does not allow the researchers to do “science as usual”.

But focussed science with a question...- very often science is done, where I can expect...; so, I have sponsor money, or a federal funding agency is expecting to know what happens with the money. Thus, of course I do science, so to say, where I can expect that I will have a result. I tell people to design something, that has to work. And then I have a result. Well done. But science where I have a question and have to try to answer this question by the available means. More difficult. More difficult.

M.F.: And that would be the case here?

We ask questions, and we try to have possibilities. But in science, there is no guarantee that there will be a result. That's the difficult thing. (Q39)

Researchers as well as affected people told me that one of the impacts of the lay people on research is creating a kind of moral pressure. The regular contact with the affected people, the “reporting” at the annual meetings, urges the researchers to do their research with the greatest effort and scrutiny. This also involves, as the quotation indicates, asking different question as one would possibly ask for getting public funding. As negative results are generally not honoured in science, asking “safe” questions, that promise less spectacular results, but also have only little danger of failure can be a quite viable strategy for securing future funding. With Debra, this is different, because the people affected by EB care only very little whether the scientific question of a project has actually been answered. Their interest is in results that can ease one of their problems or even contribute to finding a cure for their disease, and those are less likely to be found doing “safe science”. Thus, the cooperation with the affected people also changes the basic questions asked in the research projects carried out. But on the other hand, and this comes back to the issues discussed earlier in this chapter, these different questions involve a higher level of uncertainty.

9.3 Conclusions: New relations between science and lay people?

When they began their research efforts in the year 2000, Debra encountered a research landscape typical for an orphan disease. Virtually no research on EB was done in Austria, and none of the two “traditional” ways of financing research, either building a cooperation with industry via the market, or financing their research with public money provided by the state and its agencies, was a viable option. Thus, in a situation very similar to that of the German Retinitis Pigmentosa Society²⁹¹, it had to find alternative ways of funding and promoting research. But while the RP-society took the approach to start networking events and award prizes for respective research, in the case of Debra Austria the first initiative came from a research team, even though funding research had been Debra’s goal from the very beginning. Thus, while the RP-group had to create academic interest for their disease, the wish to cooperate with the patients’ association was already present in the case of Debra Austria. The reasons for this lie in the very same situation for EB research in Austria. Being denied public money as well as funding from the industry, the small research group focussed on EB basically had no other partner than Debra Austria to turn to. Entering this cooperation can thus also be interpreted as an entrepreneurial move by the researchers, as a way to do research which would not have been possible through traditional funding agencies. Von Gizycki²⁹² has argued that it was the weakness of the present research community that allowed the German RP society to enter the scientific arena. Also the laboratory now funded by Debra Austria defines itself as being at the periphery of the Austrian, let alone the international landscape. But, as we have seen, being at the periphery does not only have disadvantages. In this case, it offered the possibility to provide the services the affected people value so much, from the increased quality of health care to their strong involvement in research. Cleverly using this advantage, the research group can now very well play a role and be an attractive partner in international collaborations. What they have to offer is what is produced by their cooperation with the affected people. This one the one hand are tissue samples and other bodily resources, backed by the large number of documented cases of the rare disease they see because of Debra Austria on the other hand. Thus, even though an immense amount of voluntary

²⁹¹ Von Gizycki 1987

²⁹² Von Gizycki 1987

labour is involved from both sides, the scientists' cooperation with Debra must not be seen solely as a charitable one, but as one of mutual benefits for the involved parties.

Every Public Understanding of Science expert should be more than happy with Debra. It would probably be hard to find a constituency more interested in science, or a particular part of it, than the affected people, and scientists more dedicated to presenting and discussing their research with that constituency. But paradoxically, even though the scientists put quite some effort in conceptualising their presentations, the lay people feel that they do not really understand the science behind the research projects, or even the projects themselves. They feel overwhelmed by the complexity of different theories, methods, and the "jungle" of research politics. Furthermore, issues of uncertainty can not be successfully communicated within the association. Event though researchers stressed the non-linearity and complexity of the scientific process in my interviews and claim to communicate this to the affected people, those voice a very linear conception of science and hold the researchers accountable for not meeting certain deadlines. Compared to other cases²⁹³ the affected people also show very little interest in science as a process, for example in the daily laboratory work. What can be concluded from this? That science is so complex that it actually can not be properly communicated? I believe to properly understand this phenomenon we need to take into account what Lambert and Rose²⁹⁴ have described for their case: that lay groups have a special focus and interest when engaging science, and that ignoring things that lie outside this focus may be a conscious decision. The focus for the affected people in Debra clearly is to find a cure for EB. Thus, their interest is focussed much more on the result than on the process of science, which creates the bias inherent in their communication with the experts. Furthermore, the lacking tradition of critical engagement with science, or of science communication in general, in Austria, might contribute to the linearity of the model of science they invoke and the differences this shows to case studies from other countries.

But what about those actually deciding on the research to be funded, the board of Debra? The same holds true for them, they also, even though they have some help via their international contacts, feel that the scientific issues laid before them are too complex, both concerning their factual complexity, but also that of the (social) rules of the scientific game, for them to properly decide on new projects or to control the current ones. This sets

²⁹³ Rabeharisoa/Callon 1999, Heath 1998

²⁹⁴ Lambert/Rose 1996

them aside from the AIDS activists portrayed by Steven Epstein²⁹⁵, who successfully managed to learn the rules of the game, and also to use them to their advantage. Furthermore, the experts and lay people in Debra have developed no or only very little “intermediary discourse”²⁹⁶, which would enable them to talk about and decide on their scientific projects without entering into the technical details involved. But on the other hand, Steven Epstein has also shown that even though it is possible for lay people to master the scientific game, this is also a very hard process that involves a large amount of resources. Thus the question to ask is: Why do the representatives of the affected people in Debra not employ these resources? My answer to this is twofold. The first part projects into what will be the subject of the next chapter: running a research-oriented patients’ association and raising money is an enormously time-intensive business. Thus, when confronted with the choice to read a textbook on molecular biology or to visit a roundtable to do fundraising, I have no doubt what the representatives of the affected people would choose. This also is a key difference to the case described by Epstein, as raising funds was never really an issue in the conflict around AIDS research.

But this choice also relates to the second part of the answer: they trust their scientists. This trust is not an unconditional trust that would be expected to be arising out of an uncritical and naïve conception of science, for, as we have seen, there have been instances of quite serious mistrust. Much more, it is rooted in the success of the other parts of the cooperation, in the enormous work that has already been put in the common project of improving health care and offering a perspective to people affected by EB. Thus, the boundary objects constructing other parts of the cooperation also stabilize this relation.

But does the fact that the possibilities of the representatives of the affected people to directly influence science are quite limited mean that the actual science done is not different from that done in university or industrial laboratories? As I have discussed, the intense focus on possible applications that should have a benefit for the people affected by EB, does make the research done different. “But science is supposed to be pure. The data are supposed to follow their own course”²⁹⁷, one of her interlocutors told Deborah Heath in her study on Marfan activism. It was an upset scientist which had just returned from a meeting where Marfan activists had challenged her with the fact that they thought research

²⁹⁵ Epstein 1998

²⁹⁶ Rabeharisoa/Callon 1998

²⁹⁷ Heath 1997, 81

was progressing too slowly. The model of a pure science, which follows its own autonomous logic and course, has to be abandoned to do research in cooperation with a patients' association, and as can be seen from the quotations cited in this chapter, the scientists involved in Debra have already done so. The implicit moral pressure caused by discussing their research with the affected people, and by reporting to them on their progress, causes the researchers to ask different, potentially more risky questions.

In how far can the people affected by EB organized in Debra thus be said to participate in scientific research, and in how far can this be seen as a democratisation of science? As was discussed in chapter 3.3.2, the democratisation/participation model implies a very direct causal influence of lay people on the research done. For the case of Debra, this can only partially said to be the case. On the one hand, the affected people have a very direct influence on research in the sense that they demand it to be focussed on applied concerns and to have an expected benefit for people affected by EB. On the other hand, as we have seen, their ability to understand the dynamics of research and thus to really actively shape its direction are rather limited. Thus, the participation metaphor hold only in the "weak" sense of users voicing their needs, not in the "strong" sense of lay people engaging and actively altering scientific practice. The normative connotation of "democratisation" poses another question: Is the engagement of a group of affected people really a democratisation of science? A central question of democratic theory is, which groups are allowed/ have the possibility to participate, and which do not. The people organized in Debra, especially the parents of affected children, have a strong interest in the development of a gene therapy. As was described in this chapter, many affected adults take a more cautious and suspicious stance towards this development. It is easy to imagine that there would be other groups, for example some disability rights groups, who might be strongly opposed to gene therapy in general. But who does participate, and who does not? For the dominant deliberative model of democracy, with its focus on consensus this poses a problem, and the engagement of a certain lay group with science could thus not be considered a democratisation. For the model of radical democracy, this is not the case. Be that as it may, the focus of the democratisation model on the lay side of the expert-lay cooperation, from my point of view, greatly decreases its analytical power in the context of this thesis, when compared to the contextualisation model. First, the background of the contextualisation concept²⁹⁸,

²⁹⁸ Nowotny/Scott/Gibbons 2001

describes the processes described in this chapter in a far more complex way. Indeed it is not easy to discern whether science (the researchers) moved towards society (the affected people), or society towards science in the development of the research done in Debra. As described by Nowotny, Scott and Gibbons, changes in the research systems indeed do create entrepreneurial incentives for researchers to approach and form cooperations with lay groups. Research thus becomes contextualised, first of all in the sense that the concerns and wishes of the respective lay group are listened to and also heeded in the research process. But secondly, and this may even be the more important process, the scientific research process itself becomes situated in a completely different environment. In the case of Debra, this means the close connection of research activities with actions meant to provide better health care for the affected people. The patient register, the general ambulances, and a number of other smaller boundary objects link science to the immediate concerns of the affected people, thus situating it in completely different surroundings. As I have argued, there are indirect effects caused by this emergence of a new borderland inhabited by science as well as society, as the implicit moral pressure created by the affected people, as well as the dedication of the researchers to help “their” affected members of Debra. These indirect effects also lead to a different kind of science being done, to asking different and more risky questions.

It is to be assumed that this science will lead to a knowledge which is more socially robust for the affected people organized in Debra. But considering what was argued concerning the democratisation paradigm, does this mean that the knowledge will be generally more socially robust? What about less involved groups, such as the affected adults, or other societal groups? What is Debra’s relation to wider society in general? This will be the topic of the next chapter.

10 ...with Butterfly Wings: Debra Austria's Fundraising Activities

On a chilly, rainy October evening, the entrance to one of Vienna's smaller indoor concert locations is crowded. A lot of people have come to see the unusual line-up of different Austrian musicians, some more popular, some less so, some maybe stars of tomorrow, some certainly stars of times long gone. Someone comments that already the famous local rock musician which usually easily can fill entire stadiums is worth the money. So the hall is full. But this is not a completely regular concert. Young people with white t-shirts carrying the emblem of a butterfly cross the rows - they sell butterfly pins and lottery tickets. A small colour folder describing Debra and it's goals lies on every chair.

I scan the room, and crowded as it is, I do not see many familiar faces. Two scientists I know sit across the room, also, like the observing sociologist, in one of the back rows. I can spot some parents of affected children I know, but their children are not there, maybe because of the late hour – the concert will not end before midnight. Also, I cannot find any affected adults – but this may be due to the crowds and the dim lights.

The evening is hosted by a woman who usually presents the weather forecast on Austrian television and we learn that she, as well as all performing artists, does not charge her usual fee for the evening, as the net earnings of the concert go to Debra Austria. After a short introduction, the president of Debra steps onto the stage to welcome all those who have come, and to thank for their donations. He shortly explains what Debra is about, and that in the end, the reason for this concert is a serious one. The butterfly, he explains, is the symbol of Debra because the children affected by the disease have a skin which is as fragile as that of a butterfly. He continues to shortly relate some of the hardships associated with EB for those “butterfly children”, and he stresses that at present, there is no cure. Debra wants to change that, even though he gives no detail on how they intend to do so. But for now, though the reason is a serious one, he says, is is not the time to be serious, it is the time to be happy, celebrate, and enjoy the concert. Applause.

It is a very good concert indeed. During a break, paintings and drawings by an adolescent girl affected by EB are sold. The main topic of the paintings also are butterflies. After the break, a boy affected by EB joins a band playing the drums. And, even to my untrained ears, he does so more than well. The concert takes even longer than expected, with the

most famous performer taking his time at the end. As I leave before the end of the concert, I pass the father of an affected child, standing near the door, and talking on his mobile phone. He holds his phone towards the stage, then takes it back, and shouts “Do you hear that – Can you believe it, he is singing for us!”.

The next day I have coffee with a colleague, who, as Vienna is a small city indeed, by chance had also been at the concert. She did not really like the music though, but she is concerned about the butterfly children. It is tragic she says, but is it true that those children actually never reach adult age? I am surprised, and I explain, that, even though some very severe cases do not, many, if not even most, actually do. Well, she says, it’s because there were no affected adults present, and all the talk, all the material was only about children.

Financing research costs quite a lot of money. As the aspirations of Debra, both concerning the improvement of health care for people affected by EB, as well as concerning the financing of research to find a cure, go far beyond those of a “traditional” self help group, these activities can not be financed by the financial means of the organized members alone. Until 2001, the patients’ association had been mostly funded by its members, a number of regular donators, and by rather small local voluntary fundraising activities of some active members. But considering the high goals of Debra, more money was needed.

What would be one of the first places to turn to for funding a charitable organisation, as Debra is? It might be expected that some possibilities of public support for this kind of association might exist, especially in Austria, a country that is quite proud of having the highest density of private associations in the world. Also, other countries like for example the United Kingdom²⁹⁹ have special grants and budgets for helping starting patients’ associations. One of these models is the “startup grant” used in the UK, which comprises of a quite large basic funding which steadily decreases over a fixed period of years, and finally runs out. The idea of these grants is to empower the association to build its own infrastructure for raising money, and thus to be able to finance itself after the grant has run out.

Debra’s members quickly found out that there were little similar possibilities in Austria. At the federal level, where they had sent their project to a number of ministries, they were denied funding completely. Trying to get assistance at the federal level proved to be of

²⁹⁹ Wood 2000

great effort, civil servants in one ministry would quite often point to another, and in the end, a lot of letters had been written without much benefit. Approximately the same applies to the regional level of the federal states, and the cities where the association is located. Here, service points for self help groups exist, and they even sometimes do award small sums of money, even though it may be necessary to play some small tricks to get it.

In Vienna, there is a service point for self-help groups. And we got 20.000 Schillings [roughly 1500 Euro, M.F.] from there. But with a trick, because when I first said our association is located in Salzburg, they said, we won't get anything. Then I wrote a letter, with the heading "subgroup Vienna" and then we got the money. They have guidelines for funding [...]. And I said, I would like a printer, and then it was something extraordinary that I was allowed to buy a printer from a part of that money. [...] But it was clear that this was a one-time startup-grant and we won't get more. Maybe, if I was very clever, and write a lot of letters and go there very often we might get something between thousand and three thousand Schillings a year [70 and 220 Euro, M.F.]. [...] But that's nothing that could provide stability for us as an association. These are rather small sums, where you have to work a lot and fill out lots of forms to get the money. (Q40)

There are two stories in this quotation. One is about the difficulties of being a nationally, if not even internationally organized patients' association, and receiving public funding. Obviously, the expectation of the Austrian health care bureaucracy, is for a self-help group to be local. The predominant image is that of a group of people affected by a similar disease, meeting to talk in a specific location A or a location B. And since they meet in A or B, they quite probably also live there, so the authorities of A or B are responsible for paying any subsidies. But what about the case of EB and other rare diseases, where people have to travel across the country to have the "critical size" for talking about their disease? Obviously, that is not something that is expected. The second story is that these affected people actually do not need much, because they just come to talk. They might need a room, which is often provided, and sometimes they maybe would like to invite a medical doctor to learn more about their condition. Financial assistance is available for that. But what should they need a printer for? Why should they want to organize health care, when, as the Austrian law states, the scientifically best care is available for everyone? The activities Debra engages in are thus also beyond the scope of the expectations of the public funding agencies. For the president of Debra, who is also its leading fundraiser, this makes the issue quite simple. He is a pragmatic person. It is simply not worth his time, he says, writing so many letters for such small sums of money, sums so small, that they have little

effect on the association's total budget. Furthermore, he portrays the local self-help landscape as quite disparate, often even fighting about the small sums of money that are available, instead of stating a common case. He also does not really like to be involved in that.

A second possible source for funding a charitable association as Debra is, or charitable research in general, are charitable foundations. When Debra investigated this specific landscape in Austria, they quickly found out that there are virtually no Austrian foundations which support charitable associations or fund research. The main reason for this is to be seen in the Austrian foundation law, which, as opposed to similar laws in other countries, does not require foundations, which basically are a tax-saving way of parking large sums of money, to donate a certain percentage of their annual revenues to charitable causes. Thus, there are virtually no Austrian foundations funding charities or supporting research. The attempt to contact foreign foundations to receive support also proved to be futile, because many of those have a special national focus on their respective country. But it is not only the lacking of foundations that makes the Austrian tax law difficult for Debra. Furthermore a patients' association like Debra does not qualify as a body to which tax-deductible donations can be made. To counter this, Debra has had to set up a specific legal entity, dedicated only to the "fostering of EB-research" to allow for such donations, which are more attractive to the donators, to be made.

A third major source of funding for patients' associations are large national lotteries or charity campaigns, like the French Telethon³⁰⁰. A comparable Austrian counterpart to these international examples would be the large charity "Licht ins Dunkel", which is held every year on and around Christmas day. This campaign is supported by the Austrian broadcasting agency, which dedicates one of its two channels nearly entirely to "Licht ins Dunkel" on Christmas day. Traditionally, this charity is very successful. In 2002 alone, 12.5 Million Euro were raised³⁰¹. The money raised by the charity is basically divided into two budgets, one for supporting associations and groups, and one for individual charity. As so many other issues in Austria, the funds for organized groups are distributed in a corporatist way. A board made up of big charities, labour union representatives, and of other typical "social partners" decides on who will receive how much money. When they first approached "Licht ins Dunkel" Debra's hopes were high.

³⁰⁰ Rabeharisoa/Callon 1998

³⁰¹ <http://lichtinsdunkel.orf.at/news.html>

In the beginning we thought, wow, that's such a terrible thing we have, we'll go to Licht ins Dunkel and get three million. But no way. The first time you are not even noticed. (Q41)

While Debra received more money from this charity than it did from other public sources, the amounts were still very limited. Part of the reason for this, besides their attribution that the system puts newcomers at a disadvantage, is that “Licht ins Dunkel” is largely dedicated to an individual culture of charity. Recently, Debra encountered a similar case when one of the affected children appeared in a regional news programme, which caused enormous regional public response. Immediately local representatives as well as “Licht ins Dunkel” were willing to donate money – to the boy, not to the association.

And the funny thing is, after that TV-show in Tyrol, which caused a big stir regionally [...], the impression was, wow, now the big money is going to flow. [...] And they said, well we'll pay something for B., if he has any medical costs. But it's precisely not about giving a lot of money to one child. (Q42)

In the end, Debra's president argues, there is little an individual affected by EB, as severely affected he or she may be, could actually do with that large sums of money. Of course he could afford specialists, but after all, these specialists are already provided by Debra. And finding a cure can not be an individual project, it needs a collective effort. This is why it makes it little sense giving a lot of money to a single person. But obviously it seems to be by far easier to collect money for a single case, than for a group of people with specific goals, at least in the Austrian context.

10.1 Creating a Brand, Defining a Project: The Professionalisation of Fundraising

As the three ways for raising money described in the last chapter, public funding, charitable foundations and national charities or lotteries, can not provide a sufficient financial basis for Debra, the association has decided to concentrate on approaching “big” donators like service clubs or companies. But to do fundraising this way is a time-consuming business. Contacts have to be made, presentations of the association and its projects have to be prepared and held for every single donator. Even though this is quite a workload to fulfil operating on a voluntary basis, Debra’s presidents managed to collect quite a considerable sum of money this way. Then, at the beginning of 2002, a generous donator offered to pay a part-time salary for a professional fundraiser, an opportunity which Debra’s president himself decided to take. This offered the opportunity to invest much more time into doing professional fundraising, but it also created the necessity to develop a fundraising concept. Which groups should be addressed, via which media, and what contents should be communicated? Over the last two years, Debra has roughly been engaged in three types of fundraising activities: approaching bigger donators like service clubs personally, organizing charity events like concerts or auctions and finally addressing the general public via newspaper articles and appearances on television.

But which contents should the association concentrate on? What to tell the potential donators about how their money will be used? In the end, among the other activities of Debra, it will most likely be used to finance research on gene therapy, to find a cure for the condition. Thus one possible way would be to present Debra’s research projects, and to tell them about the “gene scissor”. Indeed, this was a first approach taken in the association’s fundraising attempts, but then, it did not take them long to find out that the science they were doing did not “sell” well at all. In sum, there was very little readiness among service clubs and other donators to actually fund research. This is attributed to the complexity of the subject to be communicated and to the public’s lack of understanding. Considering the findings of the last chapter, if even the representatives of the affected people struggle to grasp the complexities involved in their funded research projects, how should they communicate it in a way that people even less involved in the topic will understand?

Quite quickly we said: That's incredibly hard to sell. To go to the public and say: Well, give me money for research. [...] That's a subject-matter that's nearly impossible to understand even for people who know a bit about it, the more impossible to understand it is for sponsors and people who are completely outside. There we are back at the topic: how do I communicate science and results [...] How do I actually communicate what is being produced to an audience who does not understand that. (Q43)

Besides the difficulties of communicating the scientific projects, Debra's research also has another dimension which makes it difficult, if not even counterproductive, to talk about it in too much detail. Debra's research involves gene therapy, and thus genomics research in general, which has for long been a controversial issue in Austria. While this actually primarily applies to the agricultural use of genome research, the so called "green biotechnology", the people involved in Debra are afraid that the negative connotation associated with this type of research will spread to their topic and thus impair their chances for raising money. The negative image of green biotechnology, and of genome research in general in Austria, probably is to a considerable extent due to the extensive campaigns of Austria's largest tabloid newspaper, the "Kronenzeitung", against agricultural genome research. There also has been a very successful people's initiative³⁰² against green biotechnology in 1997.

Gene therapy has such a negative connotation to it, anyway; and probably, the normal reader of the „Kronenzeitung“ does not discern the red [medical, M.F.] and green [agricultural, M.F.] gene-thing. [...]. So we said, we have to define something, which can be sold in the sense of a thing that can finally be touched, and thus we came up with the EB-therapy-centre. (Q44)

Thus, Debra's fundraisers have concluded, if possible the exact content of their supported research should not be mentioned too often when communicating with the public. This is also why Debra's president did not mention gene therapy research, or genome research in general, in a single sentence when opening the charity concert. The solution to this dilemma for them was to define a different project for fundraising, a project that incorporates Debra's goals as well as the necessities fundraising imposes. Thus, the idea of the "EB-house" was born.

The centre for EB-therapy, which during my research period was renamed to simply „EB-house“ is a crystallisation of all of Debra's goals. First and foremost, it is planned to offer

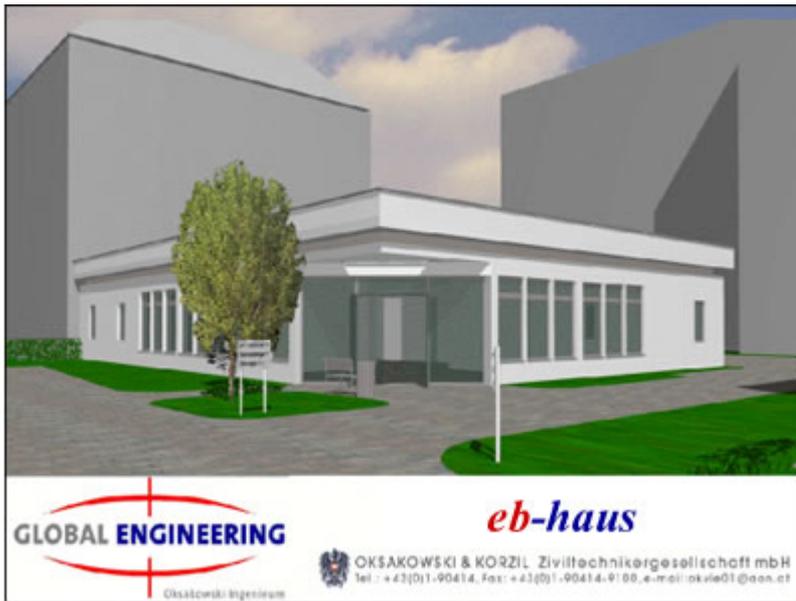
³⁰² Or Volksbegehren, an instrument of participatory democracy under the Austrian constitution.

an improvement in the health care situation for EB-patients. As more and more people, also from neighbouring countries, attend the general ambulances twice a year and also visit the clinic in Salzburg at other times, the capacities the dermatology clinic is able to offer are rapidly approaching their limits. Extra rooms for doing the complex and long bandaging process involved in EB-care in privacy are needed, as well as special infrastructure for the integrated care people affected by EB need, like for example a dentist's chair. Furthermore, rooms for medical consultations are planned, as well as for psychological counselling, for at the moment these conversations often have to be carried out under suboptimal conditions, sometimes even in the hallways. With this infrastructure, the house is supposed to serve as a "centre of excellence" and a role model for organizing EB health care for all of Europe.

A second important goal and function of the house also relates to improving health care: special lecture rooms are included in the layout of the house, which is also planned to function as "EB-academy". Here, doctors and nurses could be educated on EB as a disease and on the special needs of people affected by EB. This on the one hand is thought to alleviate the situation of missing knowledge on the rare disease among professionals, and prevent the resulting mistreatments which among other things had been one of the main reasons to form Debra Austria. On the other hand, general practitioners who treat members of Debra in their regional setting, can receive a special training in EB medicine and care.

And last but not least, ample space is reserved for a "EB-laboratory", and for all the equipment a modern molecular biological laboratory needs, for the house should also serve as a research centre. Currently, Debra's EB research is done in the rather small laboratory of the clinic of dermatology.

Thus, the house itself is a metaphor of Debra's goals and of the reasons for its existence, and it can be used for explaining and presenting these goals. But this quality of the metaphor is not the only advantage this project has for doing fundraising. The most important thing about it is, as I was repeatedly told by experts and affected people alike, that it can be drawn, it can be shown, and in the end, it can be touched. Through a cooperation with a company, pictures of the house, which is actually not really a house, but an addition to the existing clinic of dermatology, already exist.

Image 2³⁰³

These pictures and plans can be used to illustrate to the donors where their money will actually go to, and it offers a – though distant – promise of recognition, because in the end, metal signs “Funded by...” will be attached at the entrance of the new house.

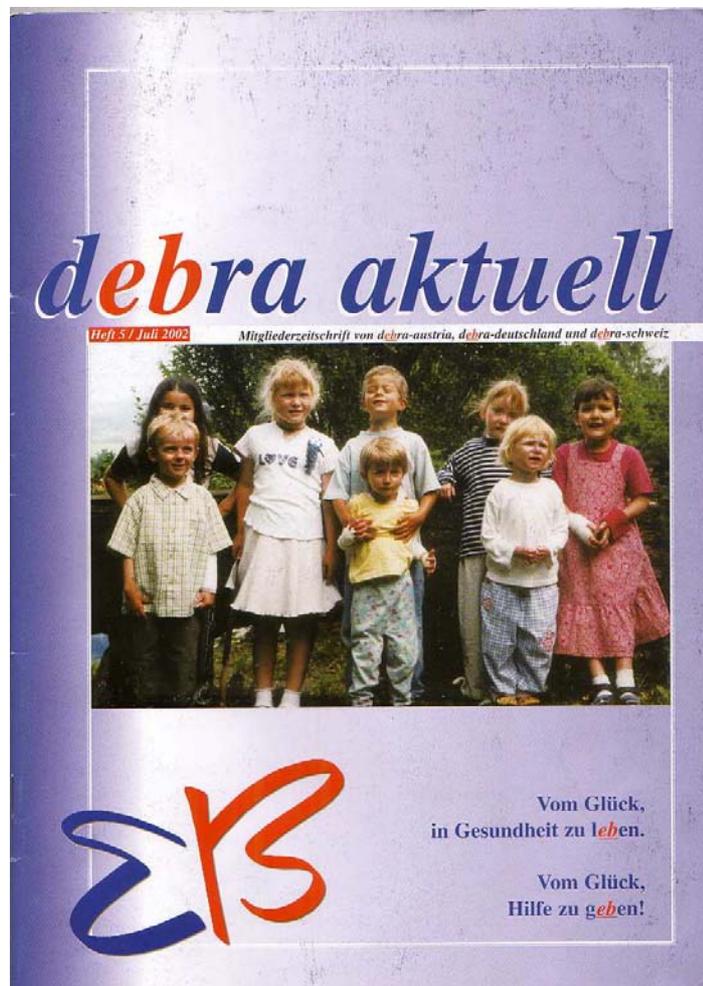
And I've always said, if I was a big sponsor and I'd give a lot of money. [...] I would like to see something when I spend money. I would like to see a brass plate, and written on it: Sponsored by.... (Q45)

Communicating science in fundraising thus for Debra is not so much a matter of simplification, but of creating metaphors, images and projects that build bridges between the public, its culture of charity, and Debra's own goals. While the EB-house is a metaphor for the goals Debra intends to reach, the butterfly that is the association's logo represents the disease itself, and the identity of those affected by it.

³⁰³ Source: www.debra-austria.org

10.2 Butterfly Images: Contested Identities

Contrary to the “EB-house” project, which is a genuinely Austrian invention, the butterfly logo is used by EB groups all over the world, making it an international symbol for the condition and the people affected by it. It is used as a logo attached to documents and newsletters, as a symbol printed on t-shirts or badges, and also as a label for the affected people themselves. Thus, affected children are often referred to as “butterfly” children, and Debra Austria has, after they had noticed that the butterfly symbol “works well” also in the Austrian context, even launched a webpage www.schmetterlingskinder.at.



Debra's newsletter with the butterfly symbol, which forms the letters “EB”, Image 3³⁰⁴

³⁰⁴ Source: Debra Aktuell 5, July 2002

But why the butterfly, and what does it signify? Why is it chosen to represent the condition, and also those affected by it to a wider public? When I asked the people organized in Debra this question, the answer would be that the skin of people affected by EB is as fragile as that of a butterfly, and that the butterfly could thus be used as a metaphor for explaining the condition and the way it affects the lives of those who have it. But, to ask a naïve question, why use a metaphor at all? On Debra's webpage, the disease is not only represented by the butterfly symbol, but also in other, in a way more straightforward ways. Under the subheading "Epidermolysis Bullosa", the detailed explanation of the condition is illustrated by a number of photographs, which differ quite dramatically from those used in other parts of the webpage.



Image 4³⁰⁵

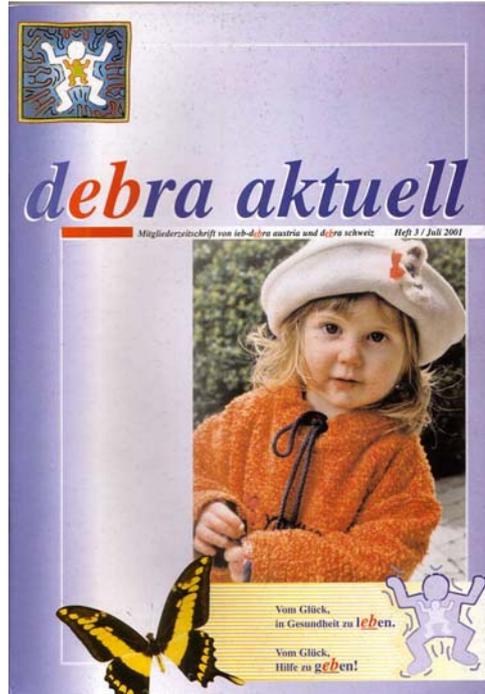
What is the focus of this picture? As the face of the newborn affected by EB cannot be seen, this is, as all other pictures used to "illustrate" the condition, an anonymous picture. Thus, the focus of the picture is not so much to show a person affected by a certain condition, but the condition itself, and its symptoms. But, to naively ask the same question again, why not use this picture to represent what EB is about to the public? One answer I was given is that actual detail pictures of the symptoms of the condition, which can be found on the association's webpage, but only if one wants to learn more about the disease itself and descends deeper into the structure of the page, should not be used to make a first contact, because some people may find them shocking. This statement has two dimensions. On the one hand, a "protection" of the public from too detailed images is implied. But on

³⁰⁵ Source: www.debra-austria.org

the other hand, the people organizing Debra's fundraising know, that such shocking images may also impress people and cause them to donate more money. Still, they do not use them on the front pages, not for reasons of protecting the public, but because the affected people themselves do not want them to be used, as they consider the symptoms and bodily problems caused by the disease as a private issue, which should not be "shown around" in public. For them, already the step to enter the public sphere and appear in a television show or a newspaper article is not at all an easy one, for after all, as was already described, there are also many social and psychological problems associated with EB.

So the butterfly is a way of saying things without showing too much (skin). But it also is much more than that. Many other things might also be used for symbolizing fragility, but a butterfly is also a symbol of beauty, and a symbol of hope. It enables Debra to cross the lines between medicine and art in its fundraising campaigns, as the butterfly as a symbol of beauty can also very well be depicted in paintings or other types of pictures. These paintings then, do not represent people affected by EB as medical subjects afflicted by a terrible disease, they also convey joy and hope. As a "side effect"; the butterfly symbol also works very well in connecting Debra with artists, offering excellent possibilities to do fundraising. Auctions of Austrian artists' paintings of butterflies have taken place, CDs have been produced and concerts held under the logo of the butterfly.

The crossover between communicating the disease and the hardships associated with it, and at the same time stressing the beauty and "normality" of those affected can be observed in many of Debra's publications and public appearances. For example, the typical image on the cover of the association's newsletter, which is not only an internal means of communication, but is also distributed among donators, will be that of an affected child.

Image 5³⁰⁶

But contrary to the photo of the newborn discussed before, one sometimes even has to look twice here to actually find hints and symptoms of the disease. First and foremost, these are typical children's photos, depicting happy children in "normal" situations. In a way, these images seem to intend to show that the everyday life of affected children, though often filled with pain, is also one of joy and happiness, and that they themselves, even though they have the disease, are as beautiful as the butterflies used as the association's symbol. The website dedicated exclusively to these children, www.schmetterlingskinder.at, resembles this. There are a number of photographs very similar to the one shown above, which link to pages portraying the individual affected child. There, a number of short questions are answered by each child, for example "What I want to become" and "What I like". Furthermore, he or she describes a typical day in his or her life. In these accounts and answers, the pain and difficulties caused by EB mix with accounts of joy, and dreams of possible futures. In a short and condensed way, this webpage portrays how EB is like in actual everyday lives and contexts, and also how individually different the children affected by the disease are. The texts describing everyday lives with the condition very much resemble the perspective of the affected children and their parents described in chapter seven. Describing the pain and problems caused by the blisters, and the

³⁰⁶ Source: Debra Aktuell 3, July 2001

complicated bandaging processes, they very much focus on the bodily problems caused by the disease, and less on the psychological and social ones.

In sum, the webpage design may be interpreted as a boundary object between the intention to show difference, to explain EB and also to touch people's hearts so they will donate money, and the wish to portray the affected children as happy and normal kids.

At this point it seems important to remember that, as was discussed in chapter seven, the affected people do not see themselves as being sick, they do not necessarily want to be treated as "exceptions", as people which should be treated differently because of their disease, in everyday life. This wish resonates in the "normality" of the stories told on the webpage of the butterfly children, but also in the front pages of the newsletter depicted above.

But that's an interesting issue, we don't feel, or the affected people and relatives don't talk about illness. I mean, it is an illness, we don't need to talk about that, it are patients. But it kind of isn't, my daughter is not ill in that sense, even though she accompanies us. She is ill when she has a cold, or the flu, or something like that. (Q5)

In doing fundraising though, this wish stands at odds with what is perceived to be the goal of communicating to the public. Creating a brand and raising money for it is about displaying difference, about giving reasons for donating money. Thus, there is an implicit conflict between the goal of fundraising and communicating the identity the affected people themselves have chosen, which makes stepping into the public a constant walk on a thin line. The webpages, stories and pictures which oscillate between normality and difference must be seen as an expression of this tension.

Internally, the way the association presents in the public sphere is not uncontroversial, especially among the affected adults. As can be seen from the examples described above, Debra's communication activities nearly exclusively focus on showing affected children and telling their stories, sometimes in a way that one even wonders if there are affected adults at all. But it is not so much that the adults would that much like to be in the media, that makes this controversial. They rather criticize the implicit message conveyed by this policy, and the light which is shed on the problems associated with living with EB. But it is not only the conscious choice of the association only to show children, but also the media which favour this decision, as one affected adult told me, when I asked him what exactly

he meant when he said that the association could do more to foster the integration of handicapped people.

But as I said before. [fostering, M.F.] integration would rather be to, rather to communicate an image in the media, more than you do with this compassion thing. Well, adults. Once there was this TV-show, which totally upset me. I was there in the audience [...]. And there was the son of X., and he talked a bit. And he was incredibly nice and cute. And then they showed a film, where wounds were taken care of, and so on. And everything a bit, to make people donate, you know. [...] It was pretty much ok. But she [the moderator, M.F.] didn't interview any of the adults in the audience, even though she knew they were there. Like, how are you doing with the disease, you know. It's always this thing with the children, always so much on compassion, you know, the poor kid, the poor Hascherl [poor thing]. You feel sorry for the kid, when it's on TV. But what people are doing twenty years later... When they go into a pub and have problems. That also happened to me, that I was thrown out. It would be important to talk about that. Especially on those programs, because a lot of people watch them. But always this pity-thing – I mean, it raised a lot of money. People donated, it was broadcasted shortly before Christmas. (Q46)

There are two lines of criticism concerning Debra's appearance in the media implicit in this quotation. The first and more obvious is that by focussing on the affected children and their stories, their problem perspective, which is quite different from that of the affected adults, is favoured. In the TV-show, stories about the pain associated with Debra were told, and a film about the bandaging problems was shown. But for the adult I talked to, other problems seem more pressing, especially the psychological and social problems associated with the disease. These are often problems of exclusion, be it from the labour market or a discotheque. He thinks that should be a topic too, because in his point of view, the only way to change these problems is by reaching a general change of consciousness toward people who are "different". But, even though adults would have been present at the show, none were interviewed, obviously because their story is less interesting to the media format than those of the affected children.

On a second level, the critique is associated with questions of agency. My interview partner is deeply disturbed by the helplessness by which the affected children are portrayed on TV, a notion which the untranslatable Austrian term "Hascherl", which means a small child with very little self consciousness, carries best. He does not like that, and for him this is a personal matter, for, as he says, he has gone a long way to free himself from these images of helplessness projected on him. For him, people with EB are not just sitting around in despair, waiting to be helped, but can be active and successive individuals as

well. And indeed³⁰⁷, he has many success stories to tell, and probably, he also would have liked to see those told on TV. At the same time, he is aware that it is this image of helplessness, especially in connection with the cute children, that “gets the money flowing”, for after all, money is rather donated to a helpless person than to a person who is successful and manages to live a good life anyway. Thus, he is not openly against doing these kinds of media appearances, but there is a certain kind of uneasiness associated with them, an uneasiness that is concerned with which image and which identity of people affected by EB is conveyed. For, to cite my colleague’s impression of the charity concert again, are really all people affected by EB cute but poor young children, and – to add my adult interview partner’s observation -, what about these children that have grown up, or even differently: What if these children will have grown up (and no cure will have been found)?

³⁰⁷ See also chapter 7

10.3: Conclusions: Mobilizing Resources, Constructing Identities

As, as we have seen, neither public funding, nor sufficient interest from industrial companies is available, the only way for Debra to finance itself and its research activities is by raising money through fundraising campaigns. It is surprising how little Austrian public bodies have to offer in terms of empowerment for patients' associations choosing this path. Neither ample startup-resources, nor other forms of assistance were offered to Debra. It seems that the agencies doing self help promotion still have a very fixed idea of what a self-help-movement should be like and what it should do. But also raising money from charities is not easy for a patients' association, as the expectation of the donators is often much more to help individuals in need, than to help a group of people to help themselves, as Debra has had to notice.

Thus, Debra has chosen that the most effective way for them to reach their goals is to mobilize their resources by doing professional fundraising, both from private charities and the public at large. To successfully do so, selective alliances with the media, but also with other actors with good links to the public, as for example artists, have to be built. Doing so involves an amount of work, which can only very hardly be carried out on a voluntary basis and thus the at least partial professionalisation of the associations' fundraising activities seems inevitable. But what is doing professional fundraising about? In its essence, it means re-formulating the association's goals and problems, so they can successfully (also in terms of financial return) be communicated via the media. Thus, the logic of the media, but also of the general Austrian public discourse on certain issues like for example genome research, have to be taken into account. And it is of course also learning by doing.

Thus, after some initial attempts, Debra decided that the best way for doing science communication for them, was not to communicate science at all. First, they encountered that there is very little readiness or tradition to donate money for doing research, in any case much less than for helping people, even if both may in the end be synonymous. Secondly, the concentration of Debra's research efforts on gene therapy strikes a nerve in the Austrian public discussion. Genomics, especially in the agricultural domain, have been subject of quite intense public controversy, and Debra fears that spill-overs from this debate may impair their own fundraising activities.

Instead, Debra has chosen the strategy to define metaphors and objects which stand for its goals, and at the same time fulfil the necessities imposed by engaging the public. The project “eb-house” summarizes the association’s goals in one project which can be depicted and presented, and which also offers the promise of a future return to possible donors. Butterflies or butterfly wings as a symbol for the condition itself and those affected by it are a metaphorical representation of the disease, as well as an excellent symbol for “enrolling” artists as well as the media into fundraising campaigns. This strategy can so far only be described as being very successful.

But, as the examples in the last part of this chapter show, to mobilize resources via public campaigning is also to mobilize identities. On the one hand, the identities of children affected by EB are carefully constructed in images and web pages, which seek to resolve the tension between showing their difference as being affected and handicapped by EB, and at the same time stressing that they too are happy and normal children. While this tension may be managed within the images and public appearances Debra does, the criticism of affected adults may not be resolved that easily. The identities produced in Debra’s fundraising campaigns may also be seen as those which fit best into the categories the media hold for raising donated funds. Thus, helpless and cute children fit better than affected adults and their problems, let alone their stories of success. But at the same time, an image of people affected by EB as being mainly children, and also as being helpless is communicated. Paradoxically, the agency the affected people organized in Debra show by forming the association, and by organizing and funding research to find a cure, has to be replaced by images of non-agency and helplessness to gain public money. Here, the need to mobilize resources creates tensions with the wish to produce and communicate identities which the affected people themselves consider fitting.

The cautiousness expressed by the affected adult cited in this chapter can also be seen as a slight disagreement in strategy. As was described in earlier chapters, the affected adults are generally much less enthusiastic and optimistic that a cure for the disease will soon be found, and their problems with the condition are different from that of affected children and their parents. Talking about issues of discrimination and exclusion in the media may be seen as a strategy to tackle these problems, but it at the same time endangers the chances of success of the strategy to cure the disease by gene therapy, because it is much less likely to raise funds. Thus, the choice which identities to stress in engaging the media

is also one of strategy, and one depending on the respective problem perspectives and the estimation of how likely a breakthrough by gene therapy really is.

11 Conclusions

In its essence, the goal of this thesis has been to develop a narrative. And as it has been told over all the chapters before, this story was that of the founding of Debra Austria, and of its quest for finding a cure for the inheritable skin disease Epidermolysis Bullosa. This story has taken us to a number of specific places, from conference rooms where decisions were made and speeches held to ambulance floors, into laboratories where the “magic bullets” of gene therapy research are produced and “fired”, and finally to concerts and charity events where they, in a way, receive their butterfly wings. It is a complex narrative, and at this point, it can only be hoped that it has been recounted well, in all its specificities. Telling about these specificities is an important, but not the only and sufficient goal of a scientific thesis. Another important task is to relate these specificities to things that lie outside that narrow scope of the actual empirical story, to make links, and to shift perspectives. This has already partially been attempted in the sub-conclusions following the empirical chapters, but this chapter is the place to again recount how the conceptual questions asked at the beginning of this thesis might be answered, and generally, what conceptual lessons might be learnt from Debra Austria’s story. In what follows I will group these conclusions into four subchapters.

Dissolving the expert/lay divide 1: Globalities/Localities

Both in medical sociology and in science studies theory, the difference between the globality of expert systems and the situated locality of lay experience and actions has been an important topos, and a powerful metaphor. As the story of Debra’s founding has shown, the central claims of both theories, that on the one hand the three factors, individual pressure caused by the disease, perceived shortcomings of the professional system and counter-experience, have to be present to start a self-help-movement, and that on the other hand this movement’s perspective on science and its own goals is structured by very concrete, situated experiences, have an impressive fit for describing and understanding Debra’s story. But, surprisingly, the categories of the local and the global cannot be discerned along the expert/lay divide. It was the very existence of a global rare disease movement in general, and other Debra groups in particular, that provided the counter-experience that made the local founding of the group possible. In many other instances,

global links of the lay movement are of high importance, as when it comes to evaluating certain scientific projects. Also, affected people as well as scientists have a system of international conferences where they meet and exchange.

For the scientists, the shifts and movements that are constantly taking place between the highly situated practices in the lab and the global structures of the science system, have long been acknowledged and described³⁰⁸. As this example shows, the question of how local and global influences mend also in the case of lay groups deserves the same kind of attention. For, as it seems, the “lay local” in the case of Debra Austria is at least in part also a “lay global”³⁰⁹ and thus transcends the dichotomy of lay/local - expert/global. Thus, the classical division between lay localities and expert globalities often made in both science studies³¹⁰ and self-help-theory³¹¹ cannot be sustained. But on the other hand, considering the important role of situated, local factors in Debra’s development, it would be more than premature to label it as a global social movement. As it is the case for science, the social in this patient group is located neither on the local, nor on the global level, but is created in an oscillation between those two different layers. This poses a fundamental theoretical question concerning the process of globalisation. If we cannot describe this process as a transformation from a local form of building and organizing the social to a global one, what meaning can then be attributed to these categories, and what role can they play in a scientific description of this oscillating phenomena³¹²?

In any case, even if it seems no longer viable to describe patients’ associations, self-help and other lay movements as purely local phenomena, caution and more conceptual work seems to be needed when describing them as “global” structures.

Whether this constellation of locality/globality of a lay movement is specific to the rare disease movement, or if it can be found in other domains, e.g. in environmental groups, is beyond the focus of this study, as is the question whether this is a new feature caused by processes of technological “globalisation”, or if it is not. Further research would be needed to answer these questions, and especially to learn more about the new relations between the local and the global in these movements, and their consequences.

³⁰⁸ Knorr-Cetina 1981

³⁰⁹ Michael 2002

³¹⁰ Wynne 1996

³¹¹ Trojan et al. 1986

³¹² See Law/Urry 2002 for a more detailed discussion of these issues.

Dissolving the expert/lay divide 2: Cooperation

A central focus and question of this thesis has been how the cooperation between experts and lay people in Debra can best be described. Closely related to this is the question on how to best describe my unit of analysis itself, Debra Austria. From the very beginning, I have called it a patients' association, which for the most part is correct. Still, the term patients' association denoted only the people affected by EB organized in Debra, only the lay people. But as it is, the scientists and medical doctors are also members of Debra, and they also actively take part in the decisions on the associations' goals and future actions. Thus, to be precise, another label is needed. A term that has already been used in the literature on patients' associations and scientific research³¹³ is that of the *hybrid forum* or *hybrid collective*. This term stresses that an entity like Debra is essentially made up of different (expert and lay) groups, who share a common goal and engage in common experimentations to reach this goal. The term thus very strongly focuses on the communalities of the involved parties, and of their future goals as compared to their current processes of operation. On a first level, this definition seems to fit Debra quite well, as, as has been described, it is made up of different groups (three main groups were identified: affected adults, affected children and their parents, and the scientists), who share a common goal, which is to find a cure for EB. On a second, more detailed level though, we have also seen that though these groups share a common long term goal, their short term goals are also quite different. The affected adults set a priority on tackling the problems of discrimination and exclusion in public life, the parents of affected children emphasize improving the conditions of health care for people affected by EB, and the scientist's priority is to do research, publish and establish international connections. I have argued that those goals, at least those of the dominant lay group of the affected children's parents and the expert groups, are mediated via boundary objects such as the general ambulances or the patient register, which allow for the involved groups to reach both goals at once. For example, the general ambulances greatly improve the quality of health care for people affected by EB, by offering concentrated possibilities of specialised, experienced care. At the same time, they are a medium for documenting a large number of cases on a regular basis for science. As in every good cooperation, both sides thus have something to bring to the table and to exchange, which is the first pillar on which the success of the

³¹³ Rabeharisoa/Callon 1998

expert/lay relation in Debra rests. The second pillar is a culture of mutual respect of the other group's respective expertise. Especially the expert's acknowledgement of lay expertise on the situated manifestation of EB in the everyday context is a feature seldom described in other case studies, which highly contributes to the success of the cooperation. Thus, I would like to argue that the dimension of the actual process of short-term cooperation, in which the goals of the involved parties are different, is far more important for properly describing their relationship than their common long term goals are. The term *hybrid collective* underestimates the differences underlying the experimentation towards a common goal, and it fails to grasp the complexity of the different goals different groups have on different time scales. Thus, another term which is suited better for grasping the differences and difficulties involved in coordinating the different groups in Debra is needed. The notion of the "boundary organization"³¹⁴ captures this process of building boundary objects to mediate the different expectations towards the cooperation and the common project very well. But the definition of the boundary organization also includes two elements that do not fit the case at hand. First of all, the term organization describes a very formalized and hierarchical social structure³¹⁵, which does not apply to Debra in particular or to many patients' associations and their cooperations with researchers in general. Secondly, a boundary organization is situated at the boundary of two social worlds. Case studies have thus far mostly described boundary organizations between two clearly structured social worlds, each carrying its own norms, traditions and logics of operation³¹⁶, the most famous examples being science and politics. Whether the same concept can be applied to describe the boundary between such a system, as science, and a "public", or a lay group, seems questionable and could thus be potentially misleading. Thus, to add to the present terminological confusion, I would like to propose the term "*boundary collective*", which stresses the common enterprise as well as the need to integrate different actor worlds and their different views and expectations into this process. A second and maybe empirically more fruitful way of describing the cooperation process in Debra is by viewing it as an actor-network, in which different groups, but also different goals and institutional objects as the general ambulances, are mutually constructed and re-shaped.

³¹⁴ Guston, see chapter 4.2

³¹⁵ Also see chapter 3.2.1.

³¹⁶ These could be compared to Luhmann's functional subsystems.

The success in creating these institutional boundary objects, as for example the general ambulances, creates benefits for all parties involved. While the affected people, which otherwise are marginalized within the Austrian health system, benefit from the creation of a centre for EB health care which increases the quality of care, the involved researchers, also located at the periphery rather than in the centre of the science system, can use the resources (data, tissue samples) obtained from their cooperation with the affected people to become attractive partners on the international level. The cooperation can thus be described as a *peripheral cooperation*, not only in the sense that it involves peripheral groups, but that it is made possible by resources and possibilities which exist only at the periphery, but not at the centre of the science system³¹⁷. This for example applies to the quite large amounts of time and voluntary effort the experts invest in offering the health care services the affected people value so much. This in turn means that being located at the periphery must not always be seen as solely a disadvantage. On the contrary, different possibilities and a certain freedom to do things not possible in the far more fast-paced centre exist.

While I have stressed the success of the expert-lay cooperation above, this case studies has also shown that there are many difficulties involved in successfully crossing this divide, some of which have been described in detail. For example, Debra has so far not been successful in creating an internal culture of communication in which the contents and processes of scientific research could be discussed. As I have shown for the question of the uncertainty of research, both parties stay immersed in their respective model of science, which is shaped by their own expectations and experiences. Thus, the lay people stay with a very linear model of science and mainly ask how long the road to success will be, while the scientists claim to try to communicate that this road is actually far less a highway than a labyrinth full of dead ends. Communicating science within the association must thus be seen as a very complicated process which also involves a number of misunderstandings.

³¹⁷ See chapter 9

Patient Power and a different production of knowledge?

But how does this cooperation between experts and lay people influence the process of knowledge production and the knowledge ultimately produced? Is this knowledge different, and if so, in what ways do the lay people influence science?

First, it has to be stressed that the production of knowledge in the sense of a systematic collection of facts and their testing through experimentation is not limited to the expert side. In a case similar to those described as “lay epidemiology”³¹⁸, the affected people in Debra pool and collect their experiences on different therapies, medications and alternative treatments and they evaluate new products or therapies by experimenting with them. Learning from others how to best treat the condition or some specific problem associated with it is one of the most important benefits of the group cited in my interviews. In this sense, a system of lay knowledge production exists alongside the expert system. The former is acknowledged by the latter, but, as far as I was able to observe, there is little transfer of knowledge from one system to the other.

On the side of the experts, clinical knowledge is produced in the general ambulances, and as far as comments of the medical doctors and the affected people go, this production has been quite impressive considering the improvements of the quality of health care over the recent years. Furthermore, molecular biological research is being done and financed by Debra to develop a gene therapy to cure the condition.

In the literature on lay engagements with scientific knowledge production, and the potential impacts this can have, two paradigms can be distinguished. On the one hand, this process can be viewed as a “democratisation of science and technology”³¹⁹, meaning that lay people can integrate their needs and wishes into the power structure built into scientific and technological artefacts. This model implies, as I have discussed, a unilateral move from society to science, and a very direct, causal taking of influence on the research process. On the other hand, the “contextualisation” model³²⁰ claims that multi-faceted changes are taking place both in the science system and society at large, which lead to a newly structured relationship between both sides. In this model, it is also science that moves towards society, because, as it for example is the case for the researchers associated

³¹⁸ Brown 1987

³¹⁹ e.g. Bijker 1995b, Latour 2001, Sclove 1995

³²⁰ Nowotny/Scott/Gibbons 2001

with Debra, changes in the science system force them to take an entrepreneurial role and look for funding outside the traditional categories. Contextualisation also allows for more indirect ways of mutual influence, and for the anticipation of tacit expectations.

Even though it has been shown to be possible to do so³²¹, the lay people deciding on which scientific projects to fund in Debra have not managed to master the “language” of biomedicine in a way which would enable them to understand the projects proposed as well as the general science system to an extent which would really enable them to make strategic decisions or to fully control ongoing projects. Neither have experts and lay people developed an intermediary discourse³²² which would allow them to tackle these issues without descending into technical details. Does this mean that there is an imbalance of power between experts and lay people? This is certainly the case, but it has to be taken into account that this imbalance is not created by intention, but by the complexity of the scientist’s actor-network. Not investing the time-resources needed to master this complexity is also a matter of strategic choice for the lay people involved in Debra. While they could spend weeks over textbooks, they prefer to spend their time raising funds for the common goal of finding a cure for the condition. This strategic choice is based on trust, a trust which is fostered by the success concerning the short-term goals of the cooperation and the boundary objects constructed.

Thus, the notion of a democratisation of science describes the processes going on in Debra far less well than a contextualisation of science and technology. This also applies to the way the knowledge being produced is influenced by lay people. While very little direct influence, as for example in the criteria for choosing projects so they will have a maximum benefit for those affected by EB, can be discerned, there is strong evidence that the very constellation of the cooperation influences scientific knowledge production in an indirect way. Science is contextualised by the other activities of the association, like for example improving the quality of health care, but also in the constant discussion between experts and lay people on the subject of research. Through this, and through the communicated and anticipated expectations of the affected people, scientists are for example led to ask different, more risky, questions than they would have asked in a more “traditional” context. Thus, the process of contextualisation produces a kind of implicit moral pressure on the scientists which in turn influences their work.

³²¹ Epstein 1998

³²² Rabeharisoa/Callon 1998

Summing up, it must be stated that the lay people's engagement with science indeed changes the knowledge production process, but in less direct and straightforward ways than might be at first expected.

Identities and Strategies

Finally, this thesis has been concerned with how Debra steps into the public space to raise money for its efforts, and which identities of the condition itself and the people affected by it are created in this process. As I have argued, the creation of a public identity is strongly linked to the need to mobilize resources. Debra Austria has chosen the path of private initiative and fundraising rather than that of political lobbying for funds. This is interesting from a comparative perspective, because, rooted in different political cultures, this is true for all European case studies, while American patients' associations are much more likely to take "the political path".

Because of the logic of the media and the expected psychology of fundraising, images of young children affected by EB are nearly exclusively used in communicating with the public. This is not uncontroversial within the group, as especially affected adults criticize the connotation of helplessness that is created by using these images. But also for the parents of the affected children, doing this kind of media work goes with a certain unease. One important dimension of the identity all affected people like to claim for themselves is that they in fact are not ill. They or their children are affected by a condition which can be and is disabling in some situations, but they do not want to be treated differently all along because of this. Thus, communicating that people affected by the disease are in fact quite "normal" is an important issue to the affected members of Debra. This constant struggle between communicating this de-medicalized "normality" and at the same time communicating difference to give the public reason to donate echoes, as has been shown in the last chapter, in the web pages and images used by Debra.

What conclusions can be drawn from this? First of all, that identities are indeed constructed in networks. As we have seen, the "public image" of EB as a condition that mainly affects and concerns children is constructed in an interaction between the logic and interests of the media, Debra itself and an imagined image of "the charitable public". It differs from the image of living with EB constructed and told by the affected parents and

their children, and it differs even more from the EB in its everyday context described by an affected adult. Thus, my argument is that it is the enrolment of the media, and of an imagined “public” in general, which is necessary for raising funds, which produces this shift in the association’s construction of EB identity. This shift leads to the paradox that, even though the members of Debra are showing a level of agency unusual in the Austrian context, they still have to rely on images and identities of non-agency and helplessness to raise the resources necessary for maintaining this agency.

Adding up, at least three different identities of persons “living with EB” can be distinguished, one of which is performed “front stage” – the public image constructed in fundraising-, and two of which are performed “back stage”. The public image of EB mainly is that of helpless, but even though often happy, children affected by a terrible condition. Here, mainly the bodily problems associated with EB are mentioned. The same is true for the stories told by the parents of affected children, even though helplessness here is replaced by a strong will to change their situation. For the affected adult, the social and psychological dimensions of the condition are more important, as are problems of social exclusion. Thus, there are different perspectives on EB, which, to borrow a thought from ANT-writer Annemarie Mol³²³, can also be thought as actually being three different kinds of (enacting) EB. Also, because each of these EB’s has a different problem perspective, each of them also has a preferred “passage”³²⁴ or strategy. For the parents of the affected children, this is to find a cure which will solve the pain and the bodily problem caused by EB as fast as possible. To the affected adult, while this may also be a goal, it is less important, and, rooted in experiences of earlier promises of a cure, it also seems less likely. Instead, problems of exclusion and social discrimination are more pressing, and ask for a different kind of action. In essence, what creates the tension around the fundraising line of the association, is a conflict between a “social” and a “natural” strategy of coping with the disease. The “natural” strategy involves developing a cure via gene therapy. For this, funds are needed, and the identities constructed in the process of this fundraising are, though important, only temporary steps that will dissolve once the “passage of passages”, the cure is reached. In the adult perspective, precisely these identities are what is at stake and what is to be changed by a social strategy – that of identity work. Thus, from this perspective,

³²³ Mol 1999

³²⁴ Moser/Law 1999

different stories would need to be told and creating an image of helplessness is rather counterproductive.

Whatever images and identities are produced and communicated, they all are clearly related to the biomedical discourse, and in a way, they assemble around a biomedical definition, that of “Epidermolysis Bullosa”. Thus, Debra clearly forms an – rather active – part of what has been termed “biosociality”³²⁵. From this perspective, it is intriguing to review the multiple identities voiced, constructed and contested around this term, around this clinical symptoms, and around this group of genes. Far from being true too the “one gene, one identity”-policy simplifying theories of genetization might claim, an active forum of identity politics can be observed.

³²⁵ Rabinow 1999

12 A short epilogue

As I am writing this, it is nearly exactly one year after the sunny autumn day on Debra's annual meeting. The sun has left earlier this year, winter is approaching, and I realise that the story I have just written down is again already one year old. From the distance I have imposed on myself in order not to be too immersed in what's going on in Debra, and wanting to add just a little bit and then just another little bit to this thesis, I have still been able to observe that Debra's story has in fact been going on. There have been more and bigger fundraising events this year than ever before, and their webpage tells me that the group is in fact alive and well.

In sum, I strongly believe that Debra's story has been and will be a very important one to tell, for two reasons. The first is a political one: In a country with a profile so low on activism, the initiative and commitment, of all members of Debra, be they experts, affected people or relatives, is more than just remarkable. It is to be hoped that there will be more such examples in the future. Furthermore, from a scientific point of view, I am convinced that much (and much more than can fit between the covers of this thesis) can be learnt from Debra and its future development on the relations between experts and lay people, and on the kind of research that is produced in this cooperation.

Thus, I hope and I believe, this is only the beginning of a story. And, as I hope and wish the people in Debra: may it be a good story for all those involved. In that sense, this is only volume one.

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Annex 1: Original Quotations

Q1:

(lacht): Ja das fängt in der Früh an, überall schauen, Verband wechseln, wo haben wir eine Blase. Die wird dann aufgestochen, ausdrückt und so, und dann eben wieder frisch verbunden. Oder mit irgendwelchen Cremes einschmieren, weil Juckreiz natürlich, das ist unser großes Problem der Juckreiz

Q2:

Und mit den Augen haben wir auch ab und zu, dass sie die Augen dann nicht aufkriegt
 HF: Es kann sein in der Früh, das passiert dann schon während der Nacht, dass also eine Erosion an der Hornhaut zum Verschluss der Augen führt. Also da reißt die Hornhaut auf, und diese Reibung führt dann zu einer Blasenbildung unter dem Augenlid. Ja, da ist also praktisch da an der Schleimhaut des Augenlides ist eine Blase. Dann kommt es, dann gibt's einmal in der Nacht einen grellen Schrei, weil das irrsinnig weh tut. Und in der Früh kommt halt dann die Olga auf und hat beide Augen zu FF: Und bringt sie einen Tag nicht mehr auf. Einen Tag sicher nicht, meistens sicher nicht auf, kann auch sein zwei Tage

Q3:

dass eigentlich die persönlichen Erfahrungen überraschend positiv sind. Also es gibt sehr wenige Sachen, dass man sagt, also das war schlimm jetzt für die Mona. Also so im unmittelbaren Bekannten- und Freundeskreis, also die Mona ist sehr normal möglichst aufgewachsen, mit sehr vielen Freunden rundherum. Und wenn man sozusagen von Kindesbeinen aus der Sandkiste aufwächst, dann fragt auch keiner: „Was hast denn Du da?“, und so, sondern das ist normal und wir haben auch geschaut, ihr das zu erleichtern. Im Kindergarten ist es so, also so in dem Alter fragt keiner. Und sie ist dann eigentlich mit der Gruppe in die Volksschule übersiedelt, das heißt das war. Es gab auch sonst eigentlich relativ wenig so abstoßende Sachen.

Q4:

Und ja, so ganz grob gesagt, die Krankheit selber ist für mich jetzt eher auf der psychologischen Ebene ein Problem. Einfach durchs Aussehen ist man schon irgendwie beeinträchtigt. [...]. Da gibt's immer wieder Konfrontationen mit Leuten, die über mich lachen, auf der Straße, was weiß ich, oder in Lokalen eben, wo immer. Und das ist schon unangenehm natürlich. Und damit muss eben man erst Mal klarkommen. Muss sich Strategien entwickeln, wie man dem begegnet [...]und sonst ja, ich glaub' schwierig eben auch mit der Partnersuche. Das bleibt einfach alles ziemlich problematisch irgendwo. Weil ich denk' die Haut ist einfach jetzt das Medium, mit dem man nach halt außen tritt, mehr wie wenn man jetzt einen Herzfehler hat, was niemand sieht, und drum auch einmal, ja, dass es auch schwieriger ist oder schlimmer ist in der medizinischen Auswirkung halt, das dann.

Q5:

Das ist aber ein interessanter Punkt, wir fühlen uns, oder die Betroffenen und Angehörigen reden auch nicht von Krankheit. Ich mein, es ist eine Erkrankung, darüber brauch ma nicht reden, es sind Patienten. Aber es nicht sozusagen, meine Tochter ist nicht krank jetzt in

dem Sinn, obwohl sie uns begleitet. Krank ist sie, wenn sie Erkältung hat oder Schnupfen oder sonst was.

Q6:

Ich mein' wie die Olga, [...] auf die Welt gekommen, [...]ist, [ist, M.F.] sie nach [...] gekommen und dort haben sie sie auch total falsch behandelt. Weil die Blasen hätten sie normal aufstechen müssen und sie haben nichts getan und die sind natürlich immer größer und größer geworden. Und das ist eben durch das. Und haben das verbunden auch, und wenn da der Druck drauf ist, ist das nicht gut. Also es war so, in Linz in der Landeskinderklinik, ich mein, die sind sicher gut, da gibt's keine Frage, aber mit EB haben sie also auch sehr wenig zu tun. [...] Und man muss auch dazusagen, dass die erste Diagnose, die ist also von einer Biopsie, einer Hautentnahme, Die ist also nach Wien geschickt worden diese Hautprobe, und dort ist die erste Diagnose gewesen, Herlitz-Typ. Der Herlitz-Typ ist der schwerste Typ, das heißt da überleben die Kinder nicht. [...] Unsere Tochter war dann 3 Monate nach der Geburt im Kinderkrankenhaus. Sie haben dann nur mehr gesprochen darüber, eine Aussage war, hoffentlich kann sie sterben. Nein, es war ja so, dann ist die Frage aufgetaucht, ist es doch nicht Herlitz, ist es eine dystrophische Form. [...] Aber wenn wir damals, das war also für uns dieses Erlebnis, dass wir niemanden gehabt haben, an den man sich wenden kann. Dann die Medizin selber nicht richtig reagiert hat, falsche Diagnosen gestellt werden.

Q7:

[...] aber kam halt der Professor, Chefvisite, 20 Leut rundherum. Hat nicht Grüßgott oder irgendwas gesagt, oder irgendeine Erläuterung, was jetzt passiert. äJetzt zeig' ich Ihnen, wie eine Blase entsteht.“ Wir da mit unserem Kind halt hingangen, mit 4 Monaten. Und hat er gesagt:“ Jetzt reib ich da so lang, bis eine Blase kommt.“ Und wir uns ist ganz schlecht geworden. Er hats dann nicht gemacht, muss man fairerweise dazusagen. Hat halt nur, die Wunde, dies halt gegeben hat, aufgemacht, hat das ein bisschen erläutert und dann ohne Verabschiedung: weg. Hat dann gesagt:“ Schwester, verbinden Sie das.“ Die hat das dann nicht gescheit hingebracht. Und dann nach zehn Minuten so herumpackeln hab' ich dann gesagt: äLassens mich machen, ich glaub' ich kanns besser.“ Und, ich mein das sind so Eindrücke, die aber nicht nur wir gemacht haben, sondern andere auch.

Q8:

Also die Vereinsgründung ist eigentlich so gelaufen, dass wir mal geschaut haben, ob's da irgendeine Vereinigung oder sonstwas gibt. Wenn man, wenn man merkt, das ist etwas, wo sich im Spital die Leute nicht auskennen oder so dann schaut man na gibt's vielleicht irgendwas.

Q9:

Und dann haben wir 1995 diesen Verein gegründet, in Salzburg, weil dort eben mit Professor [...] jemand war, der seit Jahren Erfahrung hat, seit Jahren Patientenkontakt hat und auch einfach menschlich nett war. Im Gegensatz zu den Erfahrungen am [...], die eher desaströs waren.

Q10:

Der Grund war, das Ganze zu organisieren, [...] Expertise zu sammeln für die Patienten und dann letzten Endes auch ein Zentrum zu bekommen. Jetzt nicht weil wir besonders

wichtig sind, oder weil wir ein Zentrum sein wollen, sondern im Prinzip bei seltenen Erkrankungen musst Du hingehen zu Leuten, die was davon verstehen. Das haben wir in Amerika, hab' ich an den National Institutes of Health gearbeitet und da haben sie, ich war grad 82, 83 dort, da war gerade der Beginn der AIDS (...) Epidemie. Und da haben sie die Patienten aus Amerika zusammengefangen, mit dem Flugzeug hingebacht, weil man eine damals am Anfang seltene Erkrankung konzentriert studiert. Und genau so ist die Versorgung natürlich, wir haben jetzt gerade wieder 2 Kinder da aus Deutschland, die mit ihrer Mutter mehr oder weniger bei uns jetzt lebt für 6 Wochen, und das ist ein klassisches Beispiel, dass man halt versucht Expertise zu kriegen.

Q11:

Also das war so die Idee. Also einmal eine Selbsthilfegruppe zu gründen, wo sich die Betroffenen finden, wo sie eine Plattform haben, sich zu verständigen, Erfahrungen auszustauschen. Hilfestellung für Neue, die dazukommen, dass es diesen nicht so geht, wie's uns gegangen ist. Dass sich niemand ausgekannt hat. Dass sich niemand auskennt, dass man weiß, ist man alleine da, oder gibt's da noch jemand. [...] Das Ziel war also nicht nur die Selbsthilfegruppe, sich also zu finden und Erfahrungsaustausch, sondern auch medizinische Versorgung richtige. Und richtige Diagnose, das war also das Ziel, dass das nicht mehr passiert wie's damals war.

Q12:

[...] gleich einmal bei der Geburt bin ich eineinhalb Jahre in der Kinderklinik, weil ich, weil die Krankheit nicht erkannt genau richtig. A bisschen haben's so gemeint, warten wir einmal, ob das überhaupt Überlebenschancen hat, das Kind. Und ich war aber auch ganz strikt getrennt von den Eltern, weißt, ganz hygienisch halt eben, gell, ich bin da in Watte verpackt so irgendwie. Das war ziemlich dramatisch damals denk ich mir.

Q13:

Weil nur wenn man über einen gewissen Typ jetzt eine Aussage trifft ist es ein Unterschied, ob ich einen Patienten mit dem Typus Erkrankung hab' oder zehn. Deswegen machen wir das.

Q14:

Wir bauen also so ein Register auf, also wer hat welche Form und so weiter, ein sehr umfangreiches. Auch nach einem Modell oder nach einem Muster aus Amerika. Dass man sagt, da gibt's eben Patienten, die eine bestimmte Form haben und da sollte also wirklich jemand dort anrufen und sagen: „Pass auf, du weißt eh, Du hast die und die Form, Du solltest alle drei Monate mal vorbeischaun.“

Q15:

[...] was wir halt in Österreich, wo bei uns der Vorteil liegt, ist dieses Zentrierte. Deutschland ist halt sehr föderativ organisiert, sehr dezentral organisiert. Da gibt's da was und dort was und das ist in dem Fall ein großes Problem, weil sich damit aufgrund der Seltenheit der Krankheit sich nie so ein Know-How, ein Erfahrungspool entwickelt. In Salzburg wars am Anfang auch so, da ist man hingekommen. äAha, mmhm, so“, aufgeschrieben und auf Wiedersehen und das wars. Mittlerweile nach vier fünf Jahren ist es schon so, dass die sagen:“ Aha, das hat sich so entwickelt, da könnte man das machen und in dem anderen Fall war das so und sozusagen so Querbeziehungen entstehen.

Q16:

Und dann fragt man halt, und es kommt zum Erfahrungsaustausch, wie hat das, kann ich mich genau erinnern, wie ich dann schon ein Kind gesehen hab', die also mit diesen Fingern dahergekommen ist, verwachsen. Dann fragt man natürlich, wann hat das angefangen, ja. Naja, und die sagen, das geht ja schleichend, man kann ja nicht sagen, so, jetzt beginnt das. [...]. Ja, und dann hofft man halt, dass das nicht kommt. Und man sieht halt dann zunehmend, dass das dann tatsächlich kommt, ja. Also der Erfahrungsaustausch ist, also ganz wichtig ist es, finde ich, für junge Eltern. Die also ein Neugeborenes mit dieser Krankheit haben. Das ist also für die, ist es sehr sehr wichtig, dass man also frühzeitig in so eine Gruppe hineinkommt und sieht, was, wie entwickelt sich das, welche Formen gibt's da. Es gibt ja nicht nur die schweren Formen, es gibt ja eigentlich mehr leichte Formen auch.

Q17:

Das ist dann wertvoll, wenn man da so Tipps für ein Puder, ein Pflegeding, eine Seife, d[...]. Und, ja, wohl, doch, ich würde sogar sagen, dass ist eines von den wichtigsten Dingen, die der Verein hat, weil das kann ich mir sonst nirgendwo herholen. Das kann ich nicht von einem Arzt wissen, der weiß das ja selber nicht.

Q18:

, ich meine hundert Leute machen weniger Erfahrung als eine Million Leute. Und damit gibt's nicht einen klaren Hinweis, das Homöopathie nicht hilft, oder schon hilft, sondern man probiert's halt aus.

Q19:

Wenn man immer als das (...) Primum ansetzt, die Versorgung der Betroffenen. [...] Es ist nicht die Wissenschaft das Wichtige, an und für sich, sondern die Wissenschaft für den Betroffenen. Und so muss es sein. Die Versorgung, und man muss immer schauen, dass, dass man das vorn anhaltet. Dass niemals die Betroffenen und die Familien den Eindruck kriegen, sie sind dazu da, dass Wissenschaft gemacht wird. Das ist klar. Sondern, die Versorgung ist das Erste. Das muss man aber beachten [...] man kann sozusagen weggerissen werden in der Wissenschaft, und dann wird es so interessant, dass man das Hauptziel vergisst...

Q20:

Und in der Top-Forschung ist man halt nur mehr unterwegs und auf Achse und hat keinen Patientenkontakt mehr. Und das monieren die Deutschen. Super, toll, fein, dass Deutschland da irgendwo international mitredet, nur wir haben nichts mehr davon, wir sehen diese Frau nicht mehr, die ist nicht mehr verfügbar für uns, also die hat auch keinen ärztlichen Effekt mehr für uns, weil sie nicht da ist. Das heißt, es kommen jetzt sehr viele Leute zu uns.

Q21:

Wobei ich immer ein Anhänger war, wenn, wenn Eltern sich dann um die Kinder kümmern, wissen am meisten über die Erkrankung, in dem speziellen Fall sowieso die Eltern. So ist es einfach, und da kann man eben Hilfestellung geben, am Anfang, aber dann letzten Endes sind die, und darum ja auch, wenn sich die Selbsthilfegruppe trifft, machen die auch Austausch.

Q22:

„Für mich ist es ganz einfach. Wenn ich nichts versteh', red' ich nicht drüber. Wenn jemand anderer etwas anbietet, und, das bringt Erfolg, hat der andere Recht gehabt.“

Q23:

das ist natürlich nicht einfach als Wissenschaftler. Ich glaube 45 % Quote, dass sie haben im FWF derzeit, was nicht schlecht ist, aber es ist sicher nicht so, dass es einfach ist, nicht wahr

Q24:

Es war sicher so, dass es bis vor 5 bis 20 Jahren noch extrem heiß war. Da war's noch echte Grundlagenforschung, die Mutationen zu finden, die diese Erkrankung ausmachen. Neue Gene finden, die da beteiligt sind. Das war im Prinzip 92 weg bis 2000. Nachdem wir also erst mehr oder weniger 2000 angefangen haben, war das kein Thema mehr für den FWF. Und generell, die Gentherapie ist halt schon sehr fokussiert, das ist Thema, das nicht wirklich ein echtes Grundlagenforschungsprojekt ist. Deswegen ist das glaube ich dem FWF ein bisschen schlecht zu verkaufen, derzeit. Und daher kann's nur bei der Debra gehen.

Q25:

An sich ja, natürlich, die Prevalenz ist eines der Hauptthemen in der Industrie und das hat man mit der EB sicher nicht, auch wenn man's weltweit zusammennimmt. Das ist letzten Endes eine orphan disease, Und es gibt auch niemanden von der Industrie, der sich interessiert. Also es ist letzten Endes reines Geld aus Patientenvereinigungen, das da kommt.

Q26:

Naja, also, in anbetracht dessen, dass wir also im Labor der Dermatologie jetzt sehr viel für EB machen, ist es natürlich sehr wichtig, dass wir auch Geld dafür bekommen. Weil sozusagen unser Fokus ist die EB. Und wenn man sich schon dem Fokus widmet, ist es auch sehr wichtig, dass man dafür Geld bekommt. Das ist keine Frage. Andererseits laufen wir nebenher und da haben wir sicher nicht das Niveau, sozusagen internationale Gelder jetzt von der EU oder vom FWF, also national zu akquirieren. Insofern ist das für uns essentiell, das ist keine Frage.

Q27:

dass für EB-Patienten etwas geleistet wird, was im normalen Spitalsbetrieb ohne weiteres untergeht. Das ist auch unsere Erfahrung, dass es untergeht. Auch im AKH Wien geht es unter und das sagen uns alle Patienten, die aus Wien sind, dass das AKH sicher ein super Spital ist, aber für so Spezialprobleme haben sie einfach keine Zeit, und das haben sie auch mitbekommen. Und deshalb sind sie doch froh, dass sich jemand gefunden hat, der sich in der Provinz damit abgibt. Und das sozusagen aufgebaut hat für die Patienten.

Q28:

Und das andere ist, dass wir basiswissenschaftliche Untersuchungen. Da haben wir mit den Amerikanern zusammen, den Amerikanern in Washington beziehungsweise in Philadelphia haben wir sehr viele basiswissenschaftliche Untersuchungen gemacht, wobei

wir eben viele Patienten sehen und die die Expertise haben für Untersuchungen, die wir da gar nicht durchführen können.. Eine sehr gute Zusammenarbeit.

Q29:

Und sicher auch die Forschung denk ich, nicht. Das ist ja auch wichtig, dass die Patienten da irgendwie eingebunden sind. Da haben die Mediziner sicher auch ein Interesse daran. Das ist klar. Die wollen ja doch, man braucht eben Leut' (lacht), damit sie ja dann was berichten können, wie's ihnen geht.

Q30:

das Gefühl hat man schon immer wieder, wenn man schaut, ich glaub', das viele Leute auch hinfahren , vielleicht gibt's heuer schon eine Lösung.. Andere Sachen macht man halt so nebenbei, aber das wichtigste ist schon denk' ich für viele die medizinische Variante, was Heilung anbelangt, [Es gibt], so ein Teil, Nachmittag meistens, wo dann die neuesten Forschungsergebnisse [...] so, dass es ein Laie versteht. Das könnt' ich nicht sagen, so mit Dias, so mit Großraumprojizierenden, nicht. Power Point auch zum Teil, um da zu erklären, was da für eine Wirkung mit dem Gen und wie das Molekül. Soweit man das halt einem Laien erklären kann. Da ist schwierig natürlich, aber sie bemühen sich sehr, also nicht so abgehoben, Fachausdrücke verwenden, dass man das Gefühl hat, die reden da was weiß ich was und du kriegst überhaupt nichts mit.

Q31:

Das heißt also Forschung ist so komplex. Aber wir haben bis jetzt große Hoffnungen, und daher geben wir einen bestimmten Anteil unseres Budgets dort hinein.

Q32:

Und ich bin da mittlerweile skeptischer geworden. Ich kann mich erinnern, vor ein paar Jahren hat's geheissen, ja, es gibt eine Gentherapie, wird bald einmal so weit sein, dass man irgendwas machen kann eben. Und das kommt immer wieder. Heut hab' ich neulich in einem Bericht wieder einmal gelesen, ja, fünf Jahre rechnet man, dass man was tun kann. Also, ob das dann so ist

Q33:

Es gibt also Leute, die viel mehr Erwartungshaltungen haben in der Heilung. Das kann ich auch gut verstehen. Also bei den Eltern von den Kindern, dass sie da, hätt' ich mir auch gedacht. Das beste ist immer, wenn man's heilen kann, wenn man die Krankheiten heilen kann.. Ich bin da, aufgrund meiner langen Erfahrung so irgendwie und ich kann auch mit der Krankheit anders umgehen, wahrscheinlich. Für mich ist es schon immer, ziemlich lang eben Teil meines Lebens einfach, klarerweise, weil ich mit der auf die Welt gekommen bin und alles (lacht). Ich wär' natürlich auch voll begeistert, wenn man was tun kann dagegen, gell, aber, ich denk' eben gerad' einmal ein Kind eben, das die Krankheit hat und wo man eben ganz anders mitleidet als Elternteil, nicht.

Q34:

Das einzige, was ich mitnehme als Laie ist, dass sie seit ich dabei bin (for 10 years, M.F.) sagen, in fünf Jahren ist die Heilung da oder in fünf Jahren beginnen zumindest die clinical trials. Und das bisher nicht so passiert ist, wobei die fünf Jahre in diesem fünf Jahren immer realistischer klingen.

Q35:

Ich sag's nur immer wieder. Es gibt keine, man kann sich Gesundheit nicht kaufen und es gibt keine, keine positiven wissenschaftlichen Ergebnisse auf Bestellung. Das muss man sehen. Weil sonst könnte jemand sagen, so, jetzt geb' ich euch hundert Millionen Dollar, Kinder, funktioniert! Ich kann nur funktionieren in der Arbeit, aber ich kann nicht mit dem Resultat funktionieren. Dass muss man sehen. Wissenschaft ist, einer der nicht Wissenschaft macht, (...) und das zähe Leben des Wissenschaftlers kennt (lacht), dem muss man sagen, wie's ist. Weil sonst ist - Geld investieren bedeutet noch nicht das Ergebnis. Das muss man auch ehrlich darlegen. Weil sonst kommt's was, was auch die Selbsthilfegruppen, auch andere sagen. Alle fünf Jahre versprecht's ihr, in fünf Jahren. Und man verspricht nichts, man legt's dar. Nur auf der anderen Seite, wenn du nicht Lotto spielst, kannst du nicht gewinnen. Wenn du keine Wissenschaft machst, von selber schneit es nicht herein.

Q36:

Wobei, ich muss ganz ehrlich sagen, erst gestern bei unserer Vorstandssitzung hat uns der Dr. C. das wieder erklärt, weil er wieder drei Forschungsprojekte eingereicht hat, die wir sponsoren sollen. Das Thema ist so komplex, [...]. Ich blick' nicht durch, sag' ich ganz offen, dass ich jetzt sagen kann, ok, vor zehn Jahren waren sie so weit und jetzt sind wir schon knapp vorm Ziel. Das kann ich als Laie nicht sagen. Der Dr. C. hat gestern gesagt, das kann 1 Jahr, das kann 10 Jahre dauern und kann eigentlich schon in einem Jahr passieren, das der Durchbruch erzielt ist. Wobei es also so viele Versuche gibt, es gibt so viele Theorien, wie man das angeht.

Q37:

Wenn die sagen, machen wir das Projekt, machen wir die Genforschung, jetzt machen wir genau die Genuntersuchung. Ich kann nicht sehen, nein, das hat keinen Sinn oder so. Ist schon klar. Das können auch die anderen nicht sagen.

Q38:

Natürlich, das ist sehr sehr schwierig zu erklären, was in der Wissenschaft abläuft. Einerseits in der Wissenschaft selbst, weil es ja eben ein sehr komplexes Thema ist, gerade die Gentherapie. Aber auch was in der Wissenschaftspolitik abläuft, wie die Zusammenhänge sind, wer das Geld vergibt, wer das entscheidet. Das ist nicht leicht, um nicht zu sagen unmöglich, das den Patientenorganisationen letztendlich auch zur Genüge oft zu erklären. Und da ist es sicher so, und das höre ich auch immer wieder, dass sie nicht verstehen, was man genau macht. Da muss man sicher das erklären auf einfache Art und Weise, was die Genschere ist. Und wie sich die Zusammenhänge ergeben in der Forschungslandschaft. Aber das ist ein sehr schwieriges Thema, das merk' ich schon auch immer wieder. Und da muss man daran arbeiten letztendlich. Das man das dementsprechend präsentiert, was auch gemacht wird.

Q39:

Wobei gezielte Wissenschaft mit einer Fragestellung – sehr oft wird Wissenschaft gemacht, wo ich mir erwarte – also ich hab' Sponsorgelder oder der Bund wartet jetzt, was passiert mit dem Geld. Mach' ich natürlich jetzt sozusagen, Wissenschaft, wo ich erwarten kann, dass ich ein Ergebnis hab'. Ich lass was ausdenken, das muss gehen. Und dann hab'

ich ein Ergebnis. Brav. Viel schwieriger ist die Wissenschaft, wo ich eine Fragestellung hab' und dann mit den vorhandenen Mitteln ich schau, dass ich die Frage beantworten kann. Schwieriger. Schwieriger.

MF: Und das wär' sozusagen hier eher der Fall...

Wir gehen, wir gehen, wir stellen die Fragen und schauen dann, dass wir die Möglichkeit haben. Aber die Wissenschaft, da, da ist keine Garantie, dass was herauskommt beim Resultat. Und das ist ja das Schwierige.

Q40:

Da gibt's zum Beispiel in Wien, [...] eine Servicestelle für Selbsthilfegruppen[...]. Und da haben wir mal 20.000 Schilling bekommen, wobei mit einem Trick, weil ich zuerst gesagt hab, unser Verein sitzt in Salzburg, da hat's geheißen, nein, da kriegt's ihr nix. Dann hab' ich einen Brief hingeschrieben, wo draufgestanden ist, Landesgruppe Wien, dann hat sie gesagt, na gut, dann geben wir Euch ein bisschen ein Geld. Die haben also Förderungsrichtlinien, [...] Ich gab' dann gesagt, ich hätt' gern einen Drucker. Und das war dann ganz außergewöhnlich, dass ich einen Drucker kaufen durfte, also von einem Teil dieser 20.000 Schilling. [...]. Aber es war klar, mehr als das, das ist so eine einmalige Starthilfe, kriegen wir nicht. Vielleicht wenn ich sehr geschickt bin, und sehr viele Briefe schreibe und sehr oft hingehe, werde ich vielleicht tausend oder dreitausend Schilling im Jahr kriegen. [...] Aber das ist nicht etwas, wo ich sag, das stabilisiert uns als Verein. Das sind eher so kleine Beträge, wo man sozusagen viel arbeiten muss und viele Formulare ausfüllen muss, dass man was kriegt.

Q41:

Weil wir haben am Anfang gedacht, Pfau, wir haben so eine arge Geschichte, da gehen wir zu Licht ins Dunkel und dann kriegen wir 3 Millionen. Na Schnecken. Also beim ersten Mal wirst du gar nicht wahrgenommen.

Q42:

Und das lustige war nach dieser Fernsehsendung in Tirol, die dort regional sehr viel Staub sozusagen aufgewirbelt hat, [...]. Und dann war irgendwie so der Eindruck, na boah, jetzt fließen die großen Gelder[...] und die hat gesagt, na na, dass, also dem B. zahlen wir schon was, also wenn der jetzt da ärztliche Kosten hat, dann.. Es geht eben nicht darum, einem Kind jetzt viel Geld zu geben.

Q43:

Und relativ schnell waren wir dann dabei, dass wir gesagt haben: Das ist unheimlich schwer verkaufbar. An die Öffentlichkeit zu gehen und zu sagen: Na gebts mir Geld für die Forschung., [...], das ist einfach eine Materie, die ist selbst für Leute, die ein bisschen einen Einblick haben praktisch unverständlich, umso unverständlicher ist es für Sponsoren und Leute, die ganz draußen sind. Da kommen wir wieder zu einem Thema, wie vermittele ich einfach Wissenschaft und Ergebnisse [...] Wie vermittele ich eigentlich das was da produziert wird einem Publikum, das das eben nicht versteht.

Q44:

[...]Gentherapie hat sowieso einen negativen Beigeschmack, und wahrscheinlich der normale Kronenzeitungsleser unterscheidet auch nicht grüne und rote Gen-Geschichte. [...] Und jetzt haben wir gesagt: Wir müssen etwas definieren, was auch verkaufbar ist so im Sinne einer Sache, die man nachher angreifen kann und deshalb sind wir auf dieses EB-Therapiezentrum gekommen.

Q45:

Und ich hab' immer gesagt, wenn ich ein Großsponsor wäre und ich würde sehr viel Geld zur Verfügung stellen [...]. Ich würde gern, wenn ich Geld ausgebe', was sehen. Ich würde was dastehen sehen, wo eine Messingplatte drauf ist, wo steht: Gesponsort von XXXXX.

Q46:

Aber wie gesagt, Integration, wär' vielleicht eher die Richtung. (...) Oder auch so das Bild vermitteln in den Medien eben mehr, wie man es eben so macht mit diesen Mitleidsgeschichten. Erwachsene eben. Da war ja auch einmal eine Sendung, die hat mich total geärgert. Da war ich auch dort, als Zuschauer. (...) Und da war's halt dann auch so, da war so ein Sohn eben von der XXXX und hat halt erzählt ein bisschen. Und der war irr nett und lieb. Und da war auch ein Film eingeblendet, wo halt dann die Wunden gepflegt werden und alles, nicht. Und auch eine Spur, dass man spendet dann eben. [...]. Und es war ganz ok. Aber von den Zuschauern, dass sie von den Erwachsenen, die hat ja gewusst, dass die auch da sind, einen interviewt hätte kurz. So, wie geht's ihnen mit der Krankheit. Das ist immer das Ding mit den Kindern ist so ein Mitleidsding dann immer, gell, das arme Kind, das arme Hascherl. Das tut einem halt leid, wenn es da drinnen ist. Aber was die Leute dann zwanzig Jahre später machen. Wenn die dann wirklich in ein Lokal gehen und dort Probleme haben. Das ist mir selber passiert, dass ich aus dem Lokal rausgeworfen worden bin, Diskothek oder was. Eben, und das wäre ja auch wichtig zu thematisieren. Gerade in solchen Sendungen. Weil das ja viele Leute anschauen auch. Aber immer nur auf dieser Mitleidsding. [...] Das war eben dann doch. Hat auch ziemlich ein Geld gebracht. Die Leute haben gespendet, es war kurz vor Weihnachten ist es dann ausgestrahlt worden. Das kommt auch noch dazu. Irgendwie, ja.

Annex 2: Image Index

Image 1	Page 9	Source: http://www.debra.org
Image 2	Page 128	Source: www.debra-austria.org
Image 3	Page 129	Source: Debra Aktuell 5, July 2002
Image 4	Page 130	Source: www.debra-austria.org
Image 5	Page 132	Source: Debra Aktuell 3, July 2001

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