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Patient advocacy in Germany



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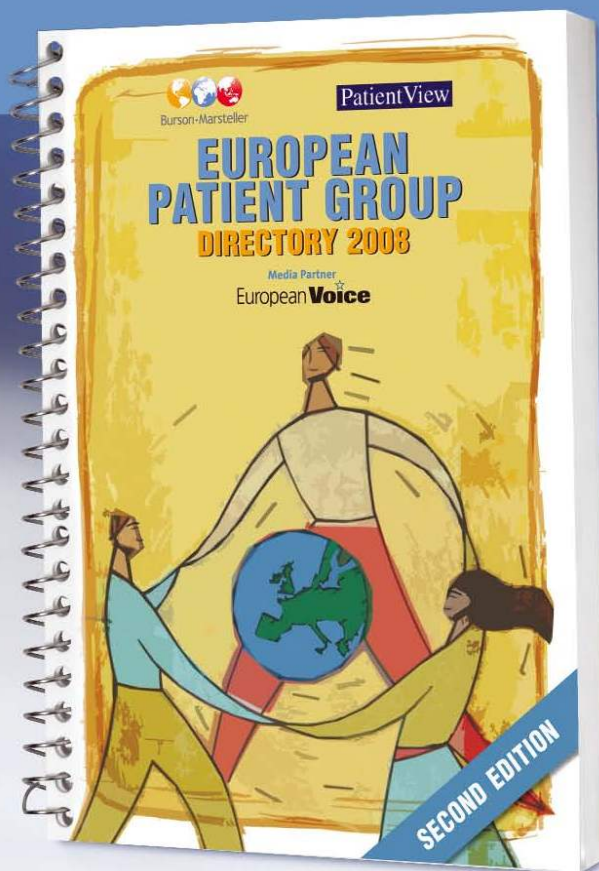


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THE 2008 EUROPEAN PATIENT GROUP DIRECTORY IS AVAILABLE NOW



Burson-Marsteller is proud to publish the second edition of the European Patient Group Directory. The directory, produced in cooperation with PatientView, is intended to be a resource for all who work on European health policy, including patient groups, politicians, officials, companies, NGOs and others. This edition contains not only updated information on the groups featured in last year's directory, but also profiles of some 45 new patient groups.

If you are interested in obtaining a copy of the directory, you can either download it at www.bmbrussels.eu or get a hard copy by sending a request to bmbrussels@bm.com

Patient advocacy in Germany



Ever since Otto von Bismarck, 19th-century Chancellor of Germany, created sickness insurance funds to supply the population with access to healthcare, Germany has championed its national health system as a model of success. Other countries replicated the insurance-based scheme. Today, though, the once-impressive German healthcare system is in crisis. German citizens now pay more for their healthcare than the inhabitants of any other European nation (bar Switzerland), and yet Germans on lower incomes no longer seem to benefit greatly from the services provided by the system. Life expectancy in this rich country has fallen below that of Austria, Italy, Ireland, Spain, and the UK. German patients feel victimised by their government, by industry, doctors, and pharmacists. Patients suspect that these are cosy cartels passing ever-rising costs on to consumers, and are aggrieved. For years, patients in Germany have felt that they have nowhere to turn to for help, and no one to fight their corner. Hardly surprisingly, the fragmented German patient movement is on the rise.

In this 42nd issue of *HSCNews International* we examine the forces that led to an expansion of the German patient movement in 2007, which seems set to continue its growth in 2008. We consider the form and scope of that expansion. We look at the one campaign area in which patient groups across Germany are unilaterally lobbying for change: the country's healthcare system. Finally, we include interviews with six patient groups that represent the interests of patients at a national, regional or local level. They are:

- ❑ Arthrose Selbsthilfegruppe (national).
- ❑ Deutsche Gesellschaft fuer Versicherte und Patienten eV (national).
- ❑ Kartagener Syndrom und Primaere Ciliaere Dyskinesie eV (national).
- ❑ Polio Allianz eV (national).
- ❑ Hepatitis Selbsthilfegruppe Hückelhoven (regional).
- ❑ Prostatakrebs Selbsthilfegruppe Giessen (local).

A few words about the financial side of the German healthcare system

Latest-available figures show the German healthcare system making a total expenditure of Euros 234 billion [US \$367bn] in 2006. The highest share of this spend was on the treatment and care of heart and circulatory illnesses (15.2%), followed by the digestive system (13.2%), musculo-skeletal (10.7%), and mental health (9.4%). Germans aged over 65 accounted for 43% of the total healthcare costs, even though they represent only 17% of the population.

In Germany, workers purchase mandatory insurance from government-appointed sickness insurance funds (in much the same way as drivers are legally obliged to buy vehicle insurance). When the scheme was first drafted (and for many decades after) employers would typically match their employees' financial contributions. But, as technology has become more expensive, and the demands of the chronically ill have risen, employers have gradually clawed back their donations. Today, employees are often paying the higher share.

Four different types of insurance cover exist in Germany:

Compulsory sickness insurances (GKV)

GKV provides service for around 90% of the population. The amount each individual pays depends upon personal income. A subscription covers family members, who are insured free (with certain limitations). GKV health services have one great advantage for patients: they are not dependent on the level of a person's subscriptions. On the other hand, GKV services are seen as being only "adequate".

Private insurance

9% of the population are privately insured. The amount they pay in insurance contributions depends upon the types of services to be delivered, and the person's health, sex, and age when they sign on. All private insurers require that individuals set aside savings as part of the subscription, so that they have funds to pay for the rises in subscription charges that occur after an insured person reaches pensionable age. In effect, then, subscription costs when signing-on are held artificially low, to attract new customers, but then radically increase later in life. One commonly-levelled criticism of the arrangement is that young people feel encouraged to opt out of the state system and go private, attracted by the latter's lower subscriptions. Then, after

these people have passed the age of 55, they can no longer opt back out of private insurance, and return to the state system—even if their private subscriptions are too high for them. State sickness insurers do not accept anyone who is over the age of 55. The only alternative for such people is to pay Euros 640 [US \$1,000] a month in subscriptions to their private insurer.

Other insurance schemes

2.3% of the population are insured through other systems, aimed either at recipients of social security, but mostly at professionals (for instance, members of the armed forces).

No cover

Just 0.1% to 0.3% of the population have no insurance cover.

In addition to insurance

The German healthcare system draws on other forms of finance apart from insurance contributions. Additional fees or subsidies are increasingly given by the state or by charities. A thriving private healthcare market has also grown up in Germany outside the insurance-based systems, offering alternative therapies, anti ageing, cosmetics, fitness, plastic surgery, and wellness services.



The forces compelling change

Rising costs and patient dissatisfaction

The signs of decline within German healthcare system are well evident. To begin with, the costs of the system have spiralled out of control, putting greater pressure on the purses and wallets of German citizens.

A study on national healthcare expenditure, published in 2005 by the Organisation for Economic Co-operation and Development (OECD), looked at the OECD's 30 members (which include the major economies of the world), and ranked Germany as the fourth-highest spender in terms of the percentage of GDP dedicated to healthcare.

German citizens lay the blame for their high insurance payments directly at the door of their government, which, they think, has been compelling health insurers to take on additional staff. This boost in staff numbers has occurred at a time when the government has publicly called for greater

productivity and belt-tightening by employers.

In 2007, the insurance company Marschollek, Lautenschläger und Partner AG (MLP) and the Institut für Demoskopie Allensbach (Institute for Opinion Research, Allensbach) polled German citizens to determine their views on the state of the national healthcare system. The survey's findings makes bleak reading, and include:

- ❑ Well over half of German citizens consider their healthcare services to have worsened during the previous three years.
- ❑ Just over three quarters of Germans feel that current national and local government policies are ineffectual in supplying good-quality, long-term, universal healthcare.
- ❑ Three quarters anticipate a partitioning of the healthcare system into a sector that services the needs of the poor (the state system), and

another that looks after the rich and the elites (such services are those funded by private insurers, and those supplied to civil servants, who have their own special professional insurance scheme). This two-tier system would weaken the principles of social solidarity that have underpinned the German healthcare system since founding.

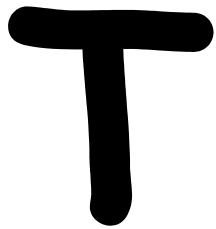
- ❑ Nearly two thirds think that the services supplied by private-sector insurance are superior to the services provided by insurers within the government scheme, especially for acute episodes (such as a broken leg, or cataract operations). These sentiments are shared both by citizens benefiting from the private sector and those limited to the compulsory state healthcare system. The private patients gain ready access to medical

specialists, and to state-of-the-art treatments.

The grim conclusion of this 2007 report was that inequalities in Germany's healthcare services would diminish life expectancy among the less well-off, who account for 57% of the total German workforce. The remaining 43% higher-income employees are assured a better outlook. Many have opted out of the state system and signed up for private insurance.



The growth of the German patient movement



he evolution of the patient movement

Dissatisfied with the level of service obtained from the country's healthcare system in general (and from sickness insurances specifically), patients are banding together. They aim to not only provide support and information to fellow patients, but also to create a more potent patient voice within the healthcare system.

Although no one has any precise figure as to the number of patient groups nationwide, the consensus among the patient groups interviewed for this issue of *HSCNews* is that 70,000 is about the right total. New groups are forming all the time. Some operate at Federal level, others at regional (state), and/or at local (city) level.

The larger patient groupings are to be found working on behalf of the most disenfranchised sections of the patient population. For example, some 5,000 patient groups are said to represent

the needs of patients with an inherited disease. Many different kinds of rare diseases exist, but, when pooled together, this element of the patient movement makes for a formidable force.

The rare-disease patient community argues that the patients they represent are neglected by the national healthcare system, that levels of medical information on their illnesses are inadequate, and that doctors are ill-educated about this medical field.

Patient groups that have built up large databases of specialised information on their subjects have gained recognition among the medical profession, who capitalise on the groups' knowledge. To add to their gravitas, patient groups have, in turn, appointed medical professionals onto their boards, secure in the knowledge that groups with this facility cannot be ignored by the medical profession.

Germany's expanding network

German patient groups have also learned the value of networking with their peers. In doing so, they have scaled up their ambitions.

Virtually all German patient organisations (irrespective of their current size) had humble beginnings. Typically, they start life by holding local meetings attended by concerned families or afflicted patients. Once more confident of their status, they begin to cooperate with other similar groups in their region, or with a centrally-organised national organisation, keen to build its branch networks.

In principle, such collaborations should result in vast expanding networks of contacts spreading across the nation, capable of reacting quickly to a new piece of government legislation, or a new policy decision. This has not yet happened, and many patient groups remain parochial,

setting their sights within the boundaries of their own neighbourhood, supporting their own immediate community.

Nonetheless, the German patient group population increasingly recognises that benefits are to be gained from contact with peers. Although exchanges between patient groups have generally been limited to sharing valuable data, the view that “together, we are stronger” is gaining ground.

Definite signs are appearing that patient groups are becoming part of the establishment. Whereas before, local and regional groups operating in isolation were reliant on volunteers for their very existence, once banded together, they have the economies of scale to be able to employ full-time, skilled managers.

Professional managers, in turn, have introduced marketing and promotional expertise into the patient group movement. These trained, experienced managers are particularly skilled in knowing how to tap into low-cost publicity drives aimed at the media. They can organise conferences, public events,

seminars, and know best how to lobby the public, medical professionals, and government.

The German patient movement is thus maturing, in all manner of ways. One limiting factor is, of course, money. German groups want—and need—to expand, but are finding the necessary funding hard to attain.

Sources of income

Until recently, membership fees have formed the mainstay of income for the German patient groups. Members of the groups are often seen out on the streets, distributing flyers to recruit more patients as members. The problem for ambitious patient organisations with an eye on the national agenda is that expansion inevitably distances them from their grassroots. Raising income through membership subscriptions then no longer remains feasible. Conversely, smaller local and regional groups usually stay successful at retaining their membership base.

Aside from revenue earners like publications and public donations, patient groups are also free to apply for

subsidies from the sickness insurers, which, by law, are obliged to pass about 1% of their revenues to patient groups. These so-called ‘comprehensive funds’ do not amount to much, however, once they have been distributed to the multitude of beneficiary patient groups. The criteria for entry are also so strict and demanding that applications often end up being rejected. This lack of guarantee of gaining any return for the work involved in applying has dissuaded a considerable body of Germany’s patient groups from coming forward for comprehensive funds.

The final source of revenue for patient groups is industry (specifically, pharmaceutical companies, and businesses that service the needs of pharma). The pharma industry in Germany has proved a ready supporter, and is certainly willing to help the patient movement—particularly patient organisations with a large patient constituency.

However, an innate distrust born of decades of living under a health system whose administrators, providers, and suppliers have all contrived to work together to the apparent financial

detriment of patients, makes most German patient groups deeply suspicious of the pharma industry and its motives.

The major contention that the groups have with pharmaceutical companies is the fact that the latter, always conscious of the necessity to fund expensive research efforts, charge high prices for their products.

But hardened attitudes appear to be changing. Today, public debate in Germany is currently exploring the suitability of capitalist principles in situations where socialist attitudes might be more appropriate. The public accepts that the present political and economic system in Germany is a 'free-enterprise social democracy' in which pharmaceutical companies, all the same, have a positive role to play.



Campaigning

R

eforming the healthcare system

Though patient advocacy is still in its infancy in Germany, one subject that most patient groups want to tackle stands out above all others—reform of what is widely perceived to be an ailing healthcare system.

The overwhelming feeling among the German public today is that the healthcare system—and, specifically, the sickness insurers—exist more for the benefit of their staff than for the patients.

These beliefs are sustained by mounting evidence that while healthcare services are being cut back, the financial contributions that patients pay to fund these services are increasing.

Doctors, too, no longer enjoy the public's respect to the same degree as before. A common belief in modern Germany is that the medical profession is motivated more by personal economic gain than by any desire to look after patients.

Slashing red tape

But before any campaigning can begin, patient groups face the awesome task of unravelling and understanding the workings of the German healthcare system.

The German patient groups interviewed in this issue of *HSCNews* agree that their first—and unwelcome—task has been researching the system's many levels, hierarchies, and roles (as well as the appropriate procedures and committees). These feats need to be accomplished, not only if the groups are to be knowledgeable enough to conduct advocacy activities, but also even if they simply wish to find the correct entry point into the system for their patient constituency. A complex system mitigates against patients too weakened by their medical condition to conduct their own investigation, or who are from socially-deprived backgrounds and are unused to exploring bureaucracies.

German patient groups consequently spend a lot of time figuring out how the healthcare system works, who are the best people to contact, what paperwork is required, and what channels to follow, as well as assessing treatments and medicines, and discovering which medical professionals are the best ones for patients to consult. The system continually alters, as do its regulations and recommended treatments, and patient groups find themselves regularly involved in trying to understand these changes.

Gaining a seat at the table

A comprehension of the German healthcare has enabled patient groups in Germany to become more politically aware. They have proved themselves capable of examining government programmes in detail—and sometimes offer strong criticism to a media eager to print or broadcast their views. Patient group leaders

make frequent appearances on national television to comment on government policy. Patient groups take the view that, since patients are ultimately the main source of funding of the sickness insurance system, their representatives—the patient groups—should have the right to a say in decisions on public policy.

Politicians and the Ministry of Health [Bundes Gesundheits Amt; BGA] have preferred to largely ignore the patient lobby, and instead to continue to consult only with the administrators of sickness insurances and with the main service providers (doctors, hospitals, dentists).

That oversight is, in part, now being redressed. The present German government has reacted to public pressure about the lack of support given to patients by appointing within the BGA a commissioner for patients, whose brief is consumer protection.

Some patient groups report that they are pleased to receive invitations to Berlin to meet the commissioner, and to be able to put their opinions across—while adding that they are under no illusions as to whether

their comments will ever be acted upon.

The importance of being knowledgeable

The German public—reading between the lines of recent political statements—is convinced that the country's healthcare services are set for a further round of cut-backs, beginning in earnest in January 2009. Almost as bad, insurance subscriptions look set to increase, rather than decrease.

German patient groups regard their government's stance on healthcare as shambolic. Politicians seem unable to supply clear policy-making statements. Instead, they incline to announcements that are contradictory, vague, and, in many instances, badly-researched. The indecisiveness of the Health Minister, in particular, has fuelled the public view that government is untrustworthy.

This is, to some extent, why the German patient group movement gained a more powerful voice during 2007. Patient groups seem especially well-informed when contrasted with the government. Patient groups study the system, and know

how it works from the position of the affected parties, the patients (bottom-up knowledge). Government ministers are seen as not fully understanding of, or caring about, the consequences of their own actions (possessing only top-down knowledge).

To get an idea of the latest developments in patient advocacy, and patient groups' reformist goals for the German healthcare system, *HSCNews* interviewed a cross-section of German patient groups on a number of key issues. The following main topics were discussed by the six executives interviewed:

- What does your organisation specialise in? How long has it operated? Who founded it, what is its spread, and how many members do you have? Is the organisation growing?
- How is your organisation funded?
- What are the key issues and problems facing your organisation today?
- What are your achievements and your aims?
- Have you tried to influence public healthcare policy, and, if so, how? Did you succeed?
- How would you like the German healthcare system to change?



Six case studies

A rthrose Selbsthilfegruppe

HSCNews speaks to AS Spokesperson, Eckhard K. Fisseler.

HSCNews International: *What does your organisation specialise in? How long has it operated? Who founded it, what is its spread, and how many members do you have? Is the organisation growing?*

Eckhard Fisseler: “The Arthrose Selbsthilfegruppe is involved in raising awareness of the importance that proper diet plays in reducing the risk of arthritis and rheumatoid arthritis—as well as in lowering cholesterol, reducing high blood pressure, the risk of stroke, heart attack, and type-2 diabetes. The medical profession states that arthritis cannot be cured, only managed, and that a process of deterioration is normal and inevitable. The AS knows that this is the wrong attitude, caused by a lack of knowledge of the underlying issue of the raised level of acidity in modern diets, which attacks cartilage and bone, and of the money-oriented nature of the modern healthcare system (it is not in the interest of the doctors or the pharmaceutical industry to suggest that, if patients were to have a better dietary regime, patients would not in fact need their support).

We have been operating for eight years now—which proves that we have a successful platform. The movement was founded by myself, Eckhard Fisseler, and is based on the pioneering work of Professor Lothar Wendt, who, in 1948, went public with his view that humans consume too much albumin, raising acidity, which, in turn, causes bone and cartilage to deteriorate.

ARTHROSE
SELBSTHILFEGRUPPE
(AS)

The Felsburg-based Arthrose Selbsthilfegruppe [Arthritis Self-Help Group] was founded in 2000 to draw attention to a controversial theory on the cause of arthritis. The group has 6 staff and 20,000 ‘participants’, and argues the importance of disease prevention.

[http://
www.arthroseselbsthilfe.de](http://www.arthroseselbsthilfe.de)

AS is run by six unpaid active volunteers who are all private citizens. We have no membership subscription.

The present 20,000 adherents or 'participants' are spread across Germany, but clustered in regional groups.

Evidence that there is an enthusiastic take-up of our ideas is seen in the number of books on the subject that we have been able to distribute. We are into our third print edition. We organise regional seminars, and these are open to the public."

HSCNews International: *How is your organisation funded?*

Eckhard Fisseler: "The AS is self financed through the sale of books and five healthy foods. We receive no funding from the pharmaceutical industry. We could, but we feel that our interests would be compromised, so we do not want, or seek, outside funding."

HSCNews International: *What are the key issues and problems facing your organisation today?*

Eckhard Fisseler: "Financing our work is an ever-present issue.

At conferences, we have noted that one third of the audience will take up our ideas enthusiastically, while the

"We have been operating for eight years now—which proves that we have a successful platform"

other two thirds will be sceptical (and some will even walk out in disgust).

One of the doctors who supported our work was put into prison for advocating the need for better diet through the reduction of acidity.

We tried to influence the sickness insurance companies to include articles about the activities of AS in their quarterly magazines, but they refused. We suggested to the Krankenkassen [German sickness insurers] that their patients do not actually need operations if they followed improved diets, but there is money to be made by the doctors and the sickness insurance system if they can prescribe medicines or artificial joints. The Krankenkassen pay out Euros 3 billion [US \$4.7bn] annually on such—we feel—unnecessary operations."

HSCNews International: *What are your achievements and your aims?*

Eckhard Fisseler: "We have had some success in raising awareness of proper diet among the public. The pharmaceutical industry is a formidable purveyor of supplements which are supposed to improve diets. But the type of pills provided are not fully absorbed by the human body, and wasted. We try to raise awareness of this factor, and of the

need for a proper intake of organic minerals through fruit, salads, and vegetables.”

HSCNews International: *Have you tried to influence public healthcare policy, and, if so, how? Did you succeed?*

Eckhard Fisseler: “We understood that doctors do not learn about the influence of diet during their university studies, so the aim of AS is to pressure the authorities to include this in the curriculum. We wrote to the Ministry of Health [Bundes Gesundheits Amt; BGA], asking why the better knowledge and insights that we have gained are not being passed on in the curriculum. But the Minister insisted that the BGA is not responsible for this, and that it is up to the universities to decide. The BGA did not even entertain an advisory role, or wish to influence policy. The AS has also approached the new Minister for Patients, Ms Helga Kuehn Mengel, and was invited to Berlin on April 10th 2008. It remains to be seen if this has an impact.”

HSCNews International: *How would you like the German healthcare system to change?*

Eckhard Fisseler: “The view of Athrose Selbsthilfegruppe is that there could be fundamental and massive savings in healthcare costs if the population were made more aware of the influence of proper diet.

We would like the doctors and Krankenkassen, as well as the Ministry of Health, to promote the idea of better diet. There is, however, a deeply-entrenched culture of making money out of the system, which the doctors, dentists, pharmacists, producers and fitters of artificial joints, and the pharmaceutical companies are all party to. So, it is difficult to raise awareness in the face of such formidable opposition.”

“There could be fundamental and massive savings in healthcare costs if the population were made more aware of the influence of proper diet”

D

eutsche Gesellschaft fuer Versicherte und Patienten eV

HSCNews speaks to DGVP Contact person, Manfred Pfeiffer.

HSCNews International: What does your organisation specialise in? How long has it operated? Who founded it, what is its spread, and how many members do you have? Is the organisation growing?

Manfred Pfeiffer: “The DGVP was founded in 1989, and is “open to anyone who is interested in a reasonable level of healthcare coverage”. Unlike ordinary patient groups, which are mainly focused on supporting patients with a particular disease or diseases, the DGVP is a political lobby—but it does primarily represent patients. We have some 35,000 members nationally. As the DGVP is a political lobby aimed at central government, we have no regional branches. The 30 staff running the DGVP are all volunteers.”

HSCNews International: How is your organisation funded?

Manfred Pfeiffer: “We have membership subscriptions, and we receive donations. The sickness insurances have a budget which they share out to patient groups, but getting such funds is difficult given the many conditions attached.”

DEUTSCHE
GESELLSCHAFT FUER
VERSICHERTE UND
PATIENTEN EV
(DGVP)

The Heppenheim/
Bergstrasse-based
Deutsche
Gesellschaft fuer
Versicherte und
Patienten eV
[German Society for
Insured Patients]
was formed in 1989
to advocate to the
country’s government
on behalf of German
patient issues. It has
30 staff and 35,000
members.

<http://www.dgvp.de>

HSCNews International: *What are the key issues and problems facing your organisation today?*

Manfred Pfeiffer: “Our membership is falling each year. The problem is that the general public doesn’t take much interest in health issues, as long as they are healthy. Only when they get sick, or are rejected by the healthcare system and they need help, do they want our support, and approach us.

We do not get enough new members to keep ourselves sufficiently funded. The sick who seek our help are already mostly socially disadvantaged, or have had bad experiences with the healthcare system, and feel vulnerable.

We expect the services provided by the German healthcare system to worsen next year. Services are being cut back, and we believe that waiting lists will lengthen.

We find that the budgets for each doctor are being reduced despite costs rising at the same time, and there is evidence that doctors are already deliberately extending waiting lists to reduce their financial losses.”

HSCNews International: *What are your achievements and your aims?*

Manfred Pfeiffer: “Patient groups are too focused on their own specific disease issues, and have little idea how to promote themselves. They tend to be introverted, and highly specialised, so they have no chance of publicising any of the measures that

“We expect the services provided by the German healthcare system to worsen next year”

could make public policy more suitable. We at DGVP want to be the number-one lobby for patients. We have gained 20 patient groups as members. Considering that more than 70,000 patient groups exist in Germany, the potential for gaining more membership from among them is vast. Ideally, if each patient group were to be a member of our lobby, that would be of mutual benefit. We would also like other European patient groups to be members, so that a good information exchange can occur internationally.

We have achieved a high degree of acceptance in the media, and among employers’ associations, hospitals, doctors, and care workers. This is unusual because, in the past, we were only seen to represent patients. But, now, the providers of services are all equally affected by the government’s policies, and have increasingly accepted that our lobbying also reflects their concerns.”

HSCNews International: *Have you tried to influence public healthcare policy, and, if so, how? Did you succeed?*

Manfred Pfeiffer: “The 30 staff at the DGVP are a lobby that faces a

powerful political machine of 4,000 staff at the Ministry of Health [Bundes Gesundheits Amt; BGA]. Politicians and civil servants see us as disturbers of the peace. We have often found that the government's media spokespeople deliberately distort what we say—which shows us that they are deliberately trying to sabotage our lobbying.

“Politicians and civil servants see us as disturbers of the peace”

Our views are dismissed by politicians, whose new slogan is ‘economise and reduce costs’. But this cost-reducing hits services to patients, who have to pay more (and yet get less) just so that the healthcare system can keep funding its huge bureaucracy.

We have been invited to a meeting in Berlin with the Health Minister. We will put our views across, but we know that there is a clear procedure in which the government then ignores our position, demonstrating that the democratic process is just for show. The political coalition under Chancellor Angel Merkel wants to be the only decision-maker.”

HSCNews International: How would you like the German healthcare system to change?

Manfred Pfeiffer: “We seek a complete re-engineering of the German healthcare system. Ideally, we would like to see a referendum on the issue, much as in Switzerland.”

Kartagener Syndrom und Primaere Ciliaere Dyskinesie eV

HSCNews speaks to KSPCD Acting Chairman, Ralf Willi Frank.

HSCNews International: *What does your organisation specialise in? How long has it operated? Who founded it, what is its spread, and how many members do you have? Is the organisation growing?*

Ralf Willi Frank: “Our patient group was founded in 1997 for people with primary ciliary dyskinesia and Kartagener’s syndrome (PCD/KS), and their families. We have around 200 members. Most affected patients are based in Germany, Austria, Switzerland, and Italy, but we also have some in Great Britain and worldwide. German members are spread across the whole country, but clustered in regional groups.”

HSCNews International: *How is your organisation funded?*

Ralf Willi Frank: “We mainly get funded through our membership subscriptions, and from public donations. The sickness insurance system also provides funds occasionally. We get donations from a medical equipment manufacturer, Pari.”

KARTAGENER
SYNDROM UND
PRIMAERE CILIAERE
DYSKINESIE EV
(KSPCD)

The Ettlingen-based Kartagener Syndrom und Primaere Ciliaere Dyskinesie eV [Kartagener’s Syndrome and Primary Ciliary Dyskinesia Foundation] was formed in 1997 to provide information for, and advocate on behalf of, people with this rare respiratory disease. The group has a staff of 4-5, and some 200 members.

<http://www.kartagener-syndrom.org>

HSCNews International: *What are the key issues and problems facing your organisation today?*

Ralf Willi Frank: “Funding is a constant worry. We need it to keep our activities at the same level or expanding, and to help new patients. Secondly, no medicine has ever been specifically developed for this medical condition. So, with no pharmaceutical producer able to make money from treatments, no regular sponsorship from pharmaceutical companies is possible. In fact, the pharmaceutical industry plays no role with us. They have no interest, have not developed any specific medicine for our patients, put no funds up to do this, or to help us, nor do they have any seminars or conferences on the topic. This has the advantage that we remain independent of their influence, but the negative side is the lack of data from the very people who usually come up with some means of alleviating illnesses.

Some sickness insurances are difficult, too. They refuse to support our patients, even when doctors represent them. If we distribute flyers, or suggest to the insurances that patients could get inhalation treatments to alleviate distress, the sickness insurances are dismissive (though this does depend on the staff involved). Such lack of support is regrettable, but it doesn't put us off campaigning.”

“Some sickness insurances are difficult. They refuse to support our patients, even when doctors represent them”

HSCNews International: *What are your achievements and your aims?*

Ralf Willi Frank: “We have been able to distribute a magazine, organise an Internet forum, and run seminars and local meetings for patients. We have maintained our membership levels, and have been able to attract more patients, who have been identified through better diagnostic systems. We realise now that our condition appears to affect at least 1-in-20,000 people. We recognise that doctors could never know in detail about all 5,000-plus hereditary diseases, so we try to educate doctors through campaigns, through sending them flyers, and through arranging symposia and congresses. We have succeeded in getting some doctors onto our panel of activists. This is important, as doctors are more likely to listen to another doctor than to a member of the public.

Our main concerns are to set up a better patient register; to improve our website; to continue to campaign; to distribute flyers to doctors; and to inform more patients.

Overall, we feel that our activities have been a success. We have been

able to help patients by supplying them with informed medical data that allows them to better manage their condition.

We have been able to provide our panel doctors with the specialised knowledge that they lack on the subject. We also distribute educational flyers and publications to other doctors' surgeries, and to the sickness insurance offices."

HSCNews International: *Have you tried to influence public healthcare policy, and, if so, how? Did you succeed?*

Ralf Willi Frank: "We have not been active in larger campaigns aimed at government. We have relied for this on the Berlin-based Allianz Chronischer Seltener Krankheiten (ACHSE) [Alliance of Rare Chronic Diseases]. ACHSE consists of up to 70 small regional patient groups, and conducts political lobbying with press reports, and by appearing at events and seminars. We have been a member of ACHSE for the past three years. ACHSE helps each member patient group to feel that it is part of a bigger movement. It attracts more members, protects them, allows a better information flow back to each patient group, and each group can exchange data in a forum and at seminars. We will channel more of our activities through ACHSE wherever our aims coincide with those of other lobbies. ACHSE is, in turn, part of Paris-based EURODIS (the European

"We recognise that doctors could never know in detail about all hereditary diseases, so we try to educate them"

Organisation for Rare Diseases), the political lobby representing our interests in Europe.

The German government has set up a BundesAusschussGremium Selbsthilfegruppe [Federal Committee Panel for Self-Help Groups], a body designed to listen to lobbies like ours. So, in some ways, the patient movement as a whole has been successful in forcing this to happen. But, if opinions are to count at all, one has to be in a bigger lobby to make any impact."

HSCNews International: How would you like the German healthcare system to change?

Ralf Willi Frank: "Ultimately, we would like to see the government invest in a dedicated health centre for people with PCD/KS and their families. The centre should have specialist staff, and be properly funded from federal grants. This facility would reduce costs in the long run for the PCD/KS patient community, and would improve the accumulation of knowledge about the disease."

Polio Allianz eV

HSCNews speaks to PA Vice President, Andrea Eisele.

HSCNews International: *What does your organisation specialise in? How long has it operated? Who founded it, what is its spread, and how many members do you have? Is the organisation growing?*

Andrea Eisele: “Informally, we have been active for 20 years, though the Polio Allianz has only been formally structured as a patient group for the last five years. We have a national membership, with members clustered in regions. Some 100 of our members are afflicted with polio. We have found that at least 10,000 polio victims live in Germany, and interest in our work has increased substantially. Each year, we send more mail-outs to affected patients.”

HSCNews International: *How is your organisation funded?*

Andrea Eisele: “Our main source of income is annual membership subscriptions, followed by donations. Some money also comes in from the sickness insurances, but we have to make an application each time, and are never sure whether we will receive anything. We get very little from the pharmaceutical industry, but do not expect anything from that quarter, as there would be scant benefit to them in supporting our disease area.”

POLIO ALLIANZ EV (PA)

The Rheinstetten-based Polio Allianz eV [Polio Alliance] has 11 staff, 100 members, and was formally founded in 2003 as a self-help group specialising in acute polio and post-polio syndrome.

<http://www.polio-allianz.de>

HSCNews International: *What are the key issues and problems facing your organisation today?*

Andrea Eisele: “Our membership has expanded strongly since 1990, and includes both people with polio and family members. The merging of East and West Germany at that time was the catalyst for our formation, as the western European mass-immunisation programmes of the 1950s and 1960s did not happen in Eastern European countries. Germany is now seeing the result of that oversight, with a large number of affected people living in the country from places like Bosnia, the Czech Republic, Poland, and Russia.

Many of the victims of polio are socially disadvantaged. They are then approached by religious or political groups, who offer to help—but the victim gets no support. People with polio are only used by these groups for their own advantage. We try to come to the rescue of such victims.

A major hindrance to our work has been the task of trying to learn how the German healthcare network actually functions. It is an extremely complicated set up, and takes a long time to understand. The system is prone to complex changes at different levels, and in whole areas of service—changes that then have to be understood. The manner in which treatment and care is remunerated has, in particular, made many physiotherapists (whom we would rely upon) give up practicing altogether. Many doctors too, state

“A major hindrance to our work has been the task of trying to learn how the complex German healthcare network actually functions”

that they could simply not carry on, as the bureaucracy takes up so much of their time, and costs them so much to administer. We try to compensate for this by acting as a central resource, but it takes us a lot of time to learn about all the financial and bureaucratic processes.

Another key issue is that not many doctors know anything about polio, or how it acts on the body, or that that the condition brings about a progressive deterioration. Few doctors know, too, about the types of therapies that can make life more comfortable for victims. There is too much ignorance in the medical world about polio, and little data on the disease is available. Therefore, polio patients often get the wrong therapy, such as being treated for multiple sclerosis. Standard, known therapies are funded by the sickness insurances. Unfortunately, these can result in a worsening of the patient’s condition. One example is physiotherapy for the whole body, which can lead to a weakening of healthy muscle. We now know that a polio victim can only be loaded with 30% of the stresses that healthy people can take.”

HSCNews International: *What are your achievements and your aims?*

Andrea Eisele: “As part of our membership fee, we publish and circulate a magazine of six issues a year. Circulation is growing.

When our founder members started to try to get data together about polio, and find out who to turn to, accumulating sufficient information took them over eight stressful years. Their goal was to build on this learning experience, so that patients did not have to face the same difficulties.

We are proud to say that we can provide a full support background to affected polio victims within six weeks. We collect any data on polio, collate it, translate it (if necessary), and put it into a database. We find out which therapist can help, and keep contact details on file. We supply a handbook that collates all known facts about polio, and advises who to go to for the best support. Most patients are on low incomes, so we supply this data at cost. We also distribute informational flyers to doctors and sickness insurances, and take part in seminars and international congresses.

We make comparative studies. Therapists are invited to seminars to present their views. Many forms of therapy can help polio victims—anything from acupuncture to Kneipp cures, and vitamin preparations. We report on the best methods, where to get them, and what they cost. We describe medicines that are cheaper if

“Few doctors know about the types of therapies that can make life more comfortable for victims”

sourced from the Netherlands. We work with distributors who can source lower-cost preparations.

We do not just give advice to victims; we also give it to doctors, since doctors often come to us to gain more specialised knowledge. Certain chemical products, such as betablockers, are often prescribed by doctors, but can be bad for polio patients. We give advice on which pharmaceutical treatments are more suitable.”

HSCNews International: *Have you tried to influence public healthcare policy, and, if so, how? Did you succeed?*

Andrea Eisele: “We lobbied the German healthcare system to allow patients with polio to gain access to medicinal cannabis. We have found that it is accepted by the healthcare system when applied as a food additive, but not when applied as a drug.

The pharmaceutical industry cannot make money here, so the system does not encourage its use. We have not achieved acceptance of this therapy yet.”

***HSCNews International:** How would you like the German healthcare system to change?*

Andrea Eisele: “Our expectations are lowered by the knowledge that the pharmaceutical industry is not interested in supporting our disease area, either financially, or with drugs (the cost of research is too high relative to the patient base). We are keen to continue our work in contacting victims personally, and in supporting them as much as we can.”

Hepatitis Selbsthilfegruppe Hüeckelhoven

HSCNews speaks to HSH Contact person, Karl Heinz Rauh.

HSCNews International: *What does your organisation specialise in? How long has it operated? Who founded it, what is its spread, and how many members do you have? Is the organisation growing?*

Karl Heinz Rauh: “Hep SHG Hüeckelhoven is a patient group that supports anyone who has blood disorders related to hepatitis C. We are also increasingly concentrating on patient issues to do with dialysis. We started out in 1999. We are now a regional body, operating independently, with 30 continuous members, and some 100 contacts annually with other affected patients. We are accessible to anyone who needs our advice. As we regionally based, our membership is stable, with any losses usually balanced by gains.”

HSCNews International: *How is your organisation funded?*

Karl Heinz Rauh: “Our members pay us an annual subscription. We are registered with the Finance Ministry to receive donations. We get some funding and some medical equipment from companies like Fresenius. We also cooperate with the pharmaceutical industry, and, now and again,

HEPATITIS
SELBSTHILFEGRUPPE
HÜECKELHOVEN
(HSH)

The Hüeckelhoven-based Hepatitis Selbsthilfegruppe Hüeckelhoven [Hepatitis Support Group of Hüeckelhoven] was founded in 1999. With a staff of 2 and 30 members, the group concentrates on providing information and help to people with the blood-borne virus, hepatitis C.

<http://www.hep-shg-hueckelh.de>

get some funds from them. But we have to make the approach—funding is never given spontaneously.

The sickness insurance systems are obliged to distribute 1% of their revenues to patient groups like us, and we have received some funding from this source. But its procedures are complex, and we have to justify what we spend the funds on. Often, the insurances attach qualifiers to any funds they may give—for instance, that it can only be used to subsidise seminars.”

HSCNews International: *What are the key issues and problems facing your organisation today?*

Karl Heinz Rauh: “Funding is the most difficult issue. There is increasing interest from patients in our activities, so funding services to them, and finding the time to help, are always problems. We are not happy about overall developments in the German healthcare system. Generally, we see a two-tier system developing, with private patients treated immediately, while the state-run sickness insurance patients have to wait up to three weeks for treatment. Our patients get a weekly allocation for treatment. This can, for instance, be Euros 500 [US \$787] for three dialysis treatments—which is only just enough. But German hospitals have fewer staff now, and the quality of their service is falling. So our patients feel inadequately cared for.

We recently organised a seminar, and wrote to 300 doctors. But only

“Funding is our most difficult issue”

three turned up. This was a major disappointment.

Another difficulty at present is that dialysis patients are mostly waiting for donated organs, and there is a shortage of donors.”

HSCNews International: *What are your achievements and your aims?*

Karl Heinz Rauh: “We have focused our promotional activities on advising, influencing, and educating our panel doctors. As a rule, doctors gain little knowledge about hepatitis through their own studies. Therefore, we also distribute flyers to many more doctors (as well as to the sickness insurance offices), and advise them that we can supply a large amount of the specialist information available on our subject. Doctors’ surgeries are receptive to our message. The treatment for the disease is now standard practice. Universities offer education on the topic. And we have found treatments and procedures that allow a 60% success rate in healing—we distribute information about patients who achieved full recovery within 60 weeks. In addition, we organise patient seminars that are well attended by patients.”

HSCNews International: *Have you tried to influence public healthcare policy, and, if so, how? Did you succeed?*

Karl Heinz Rauh: “There is a government body, the BundesArbeitsGemeinschaft Leber [Federal Labour Community for the Liver], which brings lobbying organisations in touch with policymakers. The government now has a lot of data on hepatitis C and dialysis, and recognises the need to support our activities. The main issue, in fact, is that the public itself does not know enough about the disease.”

“We find that responding to patients is far easier and quicker to if we remain small”

regionally based, and dedicated to assisting affected patients, and we want to leave larger bodies with the task of political lobbying and liaising with the Health Ministry.”

HSCNews International: *How would you like the German healthcare system to change?*

Karl Heinz Rauh: “We find that dialysis procedures, when done properly, take at least five hours in Germany. In the USA, treatments only require two-and-a-half hours. But while treatment is faster in the USA, this is at the expense of quality. There needs to be further research and development aimed at reducing dialysis times, and yet retaining quality levels.

As far as changing ourselves is concerned, we have contacts with the specialist medical associations, but we want to stay independent. We find that responding to patients is far easier and quicker to if we remain small. Larger patient groups build a massive administrative infrastructure, which then slows their response time. We remain

P

rostatakrebs Selbsthilfe- gruppe Giessen

HSCNews speaks to PSHGG Co-founder, Guenter Feick.

HSCNews International: *What does your organisation specialise in? How long has it operated? Who founded it, what is its spread, and how many members do you have? Is the organisation growing?*

Guenter Feick: “I founded this locally-based patient group in 2000. We now have five regional chapters, and 190 local, independent, city-based clusters. 90% of our participants are afflicted and seek advice. Every year, 20 new local self-help groups are set up.”

HSCNews International: How is your organisation funded?

Guenter Feick: “We have no membership fee. The affected pay for information booklets at cost. Our main sponsor is Deutsche Krebshilfe (DK) [German Cancer Help], founded by Mildred Sheel, the wife of a former President of Germany. DK is a philanthropic body that spends Euros 10m [US \$15.7m] each year. The donations are split among us and six other major cancer self-help groups. We accept that the pharmaceutical industry, too, would like to help—but it also wants to make a profit. So that no one can accuse us of being

PROSTATAKREBS
SELBSTHILFEGRUPPE
GIESSEN
(PSHGG)

The Pohlheim-based Prostatakrebs Selbsthilfegruppe Giessen [Prostate Cancer Support Group of Giessen] was founded in 2000 by patients with prostate cancer to provide more information to affected patients.

No website presence.

influenced, we have a policy of not accepting finance from the pharmaceutical industry.”

HSCNews International: *What are the key issues and problems facing your organisation today?*

Guenter Feick: “The founders of Prostatakrebs Selbsthilfegruppe Giessen were patients who felt that insufficient data and support was available to people with prostate cancer. We collect and collate data on the disease, learn about the types of treatment available, and find out what the results have been. We discover how useful the pharmaceutical industry’s efforts have been by examining the types of treatment they offer, and the rate of success of each treatment. Our main issue is that we need to understand more about the influences on society that nurture the disease, and what to do to change things for the better.

The other issue for us is that the German healthcare system itself needs to be understood. It is a complex organism, and we have to work hard to make an analysis of the costs versus benefits of medicines, treatments, sickness-insurance costs and benefits, and the performance of doctors, and come up with the best advice for people affected, so that therapies can be extended, and unnecessary costs in treatment avoided. We find that the profits for service providers are often greater than the benefits to patients.

“The German healthcare system really presents a major problem to us”

The German healthcare system really presents a major problem. It has many levels, sections, decision routings, and consultation processes. Until we find out which consulting bodies are the ones we need to speak to, and maintain links with, it can be very tiresome to try to get a view on the whole network. So that our voice counts, we have to find out where it is necessary to be, and where to keep up to date with what is going on.”

HSCNews International: *What are your achievements and your aims?*

Guenter Feick: “We have had very positive results from doctors, hospitals, and specialist clinics, actively helping us by providing us with data. We can then collate the information, and feed it back to doctors who seek this more specialist knowledge. People with prostate cancer also report on their experiences, and we have built up an excellent database of doctors and clinics with a good reputation, and of the therapies that work best.”

HSCNews International: *Have you tried to influence public healthcare policy, and, if so, how? Did you succeed?*

“Since patients are the ones who fund most of the healthcare services, we want to have a voice in the final decisions made on policies”

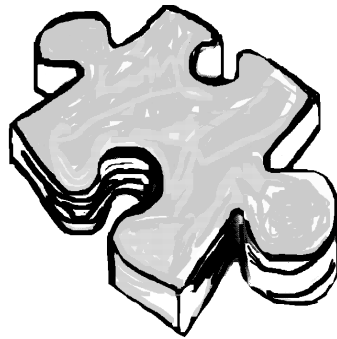
Guenter Feick: “We can show considerable success in our role of contributing towards government decisions made on diagnosis, treatment, therapies, and care, as well as on improving the physio-social environment of the patient. We feel that our work is valued by the government, and we have been able to influence—right up to the point of assisting on guidelines in healthcare regulations (such as on the correct diagnostic procedures, and therapies that the insured have a right to expect). We find that our suggestions and conclusions carry weight, and are accepted.

We also have continuous contact and cooperation with the Deutsche Gesellschaft Fuer Urologie [German Society for Urology], allowing good feedback, which, in turn, helps both sides to improve.”

HSCNews International: *How would you like the German healthcare system to change?*

Guenter Feick: “The biology of prostate cancer is still not adequately understood. 12,000 men die of the disease every year. If the disease were better understood, far

fewer deaths would occur. The German healthcare law Sozial Gesetzbuch [Social Code] 5 clearly specifies the obligations and rights of self-help groups. We are able to participate as advisers, and our voice is valued. However, we take the view that since patients are the ones who fund most of the healthcare services, we want to have a voice in the final decisions made on policies.”



Your emails on
HSCNews, issue 41, February 2008
'Winds of change?'



our emails

responding to HSCNews, issue 41, February 2008, 'Winds of Change?', which reviewed the growth and impact of patient advocacy worldwide

“Pity they had little to say about childbirth activism, which is the most active group of consumers of the lot!”

Beverley Beech,
Chair,
Association for Improvements in the Maternity Services (AIMS),
Surbiton, Surrey, UK.

“It HAD to be said, and I am glad that you are doing it! Many, many, feel and believe as you do, but most of us are afraid that we are the ONLY ones, and hesitate speaking out. You have done MEDICINE—in toto—a HUGE favour. The elephant is now out of the closet, and can no longer be ignored. It will, in the long run, spell a better future for ALL patients in all societies, and the wise doctors can now join ranks without being thought of as ‘traitors’ to their own colleagues. Good for you! Bravo.”

Robert Knutzen,
Chairman and CEO,
Pituitary Network Association,
Thousand Oaks, California, USA.

“Thank you for the 41st issue of *HSCNews*. It is such a ‘tool’ for all of us who fight for the rights of chronic patients that we feel more optimistic to go on fighting. After all, “togetherness makes the difference”. Don’t you think so?”

Jane Pittadaki,
Member of the Executive Board, and
Official Delegate of GHS to the World Federation of Haemophilia/
European Haemophilia Consortium (EHC),
Greek Haemophilia Society (GHS),
Athens, Greece.

“Many thanks for issue 41 of *HSCNews*, which is interesting and informative. We note that several topics remain unpopular even—and, perhaps, especially—among activists, namely the right to:

1. Not be a patient.
2. Be one’s own physician.
3. Receive non-medical care (for instance, care of the mentally disabled of all ages without drugs).
4. Unconditionally receive treatment for the affliction of choice (for instance, treatment for streptococcus or cancer in a person who tests HIV positive, but who elects to not take antiretroviral drugs).
5. Access laboratory tests and other medical services without referral.
6. Manage one’s own medical file.

Perhaps some of these issues will receive activists’ attention in the future. In fact, maybe PatientView would be interested in organizing an online debate on one of these issues?”

Mira de Vries,
Association for Medical and Therapeutic Self-determination (MeTZelf),
Amstelveen, the Netherlands.

“I find this issue [*HSCNews*, issue 41] very interesting. My question: why is the important movement of women (which came up in the 19th century in response to the big alcohol problem in industrialised countries) not mentioned? This became a strong movement for women’s rights (suffragettes), and was part of the new movements of abstainers. I think those abstainer movements were the first advocates for public health worldwide, and some of them still exist. Thank you for your attention, and kind regards.”

Hermann T. Meyer,
Alkoholpolitik,
Switzerland.

“Brilliant job. Thank you for sharing this. Patient activism has certainly made a significance difference for those of us with alpha-1-antitrypsin deficiency ‘alpha-1’ here in the US.”

John W. Walsh,
President and CEO,
Alpha One Foundation,
Florida, USA.

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