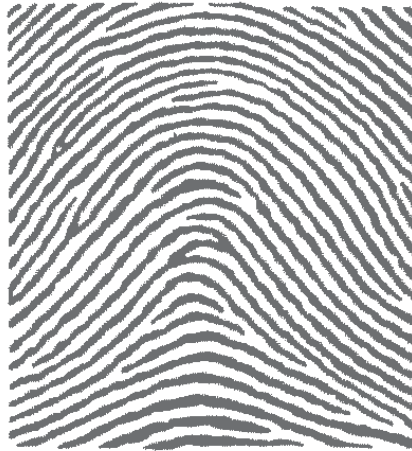


Self-Help Community Skin e.V.



2 m² Haut

**Skin cancer, occupational dermatitis
and other skin diseases**

***The reality of which we can speak is never reality
“per se” but a perceived reality.***

Werner K. Heisenberg

Courage from experience

The two square meters of skin represent the largest and most diverse of all human organs, but unfortunately also a weak point for many different disorders. The self-help community “Selbsthilfegemeinschaft Haut e.V.” is active supra-regionally and has set itself the task of offering advice and orientation to persons affected and their relatives: and this personally, confidentially, competently and free of charge. The target: to help people – suffering from chronic or occupation-induced skin disorders as well as from the various forms of skin cancer – to help themselves.

Anyone having to cope with these illnesses is quite often not only fighting with physical, but also with severe psychological and social problems. The members of the self-help community acting as volunteer staff know this only too well from their own experience. And they know ways of dealing with these problems.

In a supra-regionally linked network of various drop-in centres, they give advice on the most diverse issues related to skin diseases, their treatment and their consequences.

Our objectives are:

- **To target the “with and for one another”**
- **To help people to help themselves and to indicate external help**
- **To mutually encourage and support people in accepting and overcoming the illness**
- **To find new ways to recover together**
- **To exchange experience and information**
- **To clarify and create acceptance of the various skin diseases in society through public relations work**
- **As a patient representative group, to point out the lack of care for chronically sick persons and try to improve this in cooperation with various associations**
- **To motivate those affected – beyond the illness itself – to exercise influence on attaining possible improvements in the health system**

Implementation of our objectives

Specialist lectures and health seminars take place several times per year on current and informative issues surrounding the respective illness as well as group evening meetings. The schedule for these sessions can be seen on our internet site under www.shg-haut.de.

We offer self-help consultation hours for persons affected that have very individual worries and queries and who do not wish to discuss them in the community.

We participate at various health fairs and exhibitions as well as “self-help days” to inform those suffering, the general public, therapists, doctors and their staff about our self-help activities and the various skin diseases. In cooperation with various media, the general public and those affected are sensitized to these themes through telephone campaigns as well as reports in newspapers and TV regarding the various, chronic skin diseases.

What consultation/help do we offer?

By exchanging experience, in particular through information about responsible behaviour in dealing with the illness and with doctors, we help in achieving as favourable a progression of the disease as possible.

As a part of the self-help activities, the offices offer telephone advice and assistance.

Community evenings, self-help hours and health seminars/specialist lectures take place on acute and chronic skin diseases.

We provide information on helping people to help themselves, on specialist physicians, hospitals and convalescence centres. We provide advice on social welfare law issues by making specific use of our team of experts (also workplace relevant themes, applications to health insurance institutes, professional associations and similar).

Know what it is all about

The members of the “self-help community skin” are mainly confronted with the following illnesses and issues:

- Psoriasis
- Psoriasis vulgaris (e.g. on the hands)
- Hand eczema
- Occupation-induced skin diseases (also skin cancer)
- Skin cancer
- Neurodermatitis
- Rosacea
- Vitiligo (de-pigmentation of the skin)
- Other skin diseases

The main focus is on:

- Information on individual queries about the illness
- Practical questions regarding everyday life
- Legal issues associated with the illness
- Helpful aids
- Conveying contact addresses and contact persons
- Information on self-help
- Information material

Who advises you in the self-help consultation hours?

community “Selbsthilfegemeinschaft Haut e. V.” who – from their own experience with the illness – would like to pass on their knowledge about the many, diverse problems and possible solutions to them. They work as volunteers, but can count on support from the Experts’ Forum made up of doctors, therapists, social counsellors and lawyers.

Membership in other organisations

The Selbsthilfegemeinschaft Haut e.V. is an extraordinary member of the Professional Association of German Dermatologists (BVDD).

Member of the state working committee “SELF- HELP” for persons with disabilities and chronic illnesses and for their relatives: Nordrhein-Westfalen e.V. LAG SELBSTHILFE NRW e.V.

We exchange the most diverse information with other self-help groups such as e.g. German Heart Foundation, Restless Legs Syndrome, Asthma and Allergy, Fibromyalgia and Polyneuropathy.

Cooperation between the Roderbirken Clinic, rehabilitation centre for cardiovascular diseases, and the Selbsthilfegemeinschaft Haut e.V.

The fact that psoriasis – as a systematic inflammation – represents a risk for the heart and circulation as well as for the metabolism is so far one that is largely unknown. In this case, the Medical Director at the Roderbirken Clinic tries to ensure further clarification and understanding in joint lectures, discussion forums and media contributions.

In the meantime, regular self-help consultation hours have been established at the Roderbirken Clinic. They take place once a month and are eagerly attended by external visitors as well as patients in the rehabilitation centre. They complement one another ideally since the medical specialists come together with the living environment of those affected. A win-win situation thus evolves which is particularly beneficial for those persons severely suffering from skin illnesses. The highly-motivated relaying of dependable medical information at the layperson level is very

helpful in the communication between doctor and patient. Insofar this close cooperation has not only helped to clarify a little known medical phenomenon publicly, but has also had a positive effect in the specific individual consultations to the benefit of those affected. In this respect, we hope to be able to resolutely continue this cooperation.

Dr. med. Wolfgang Mayer-Berger

Medical Director of the Roderbirken Clinic

Internist – cardiology, psychotherapy, rehabilitation, social medicine, hypertensiology (DHL)



Dr. med. Wolfgang Mayer-Berger

Cooperation between the management of the BVDD and the Selbsthilfegemeinschaft Haut e.V.

Ms Christine Schüller and the Selbsthilfegemeinschaft Haut e.V., 42799 Leichlingen, practices successful cooperation with us dermatologists. I got to know this very active lady 4 years ago at the World Psoriasis Day and I was able to observe her fully-fledged and imperturbable way right up to the foundation of the self-help community in its present form.

Since the honorary services and particularly the consultation provided by Ms Schüller were characterised by a distinct separation from medical diagnosis, it was quite easy for me to meet the needs for dermatological consultation and to occasionally give lectures at regional meetings.

The Professional Association of German Dermatologists is grateful to the initiative and sustainability of Ms Schüller for the important

connections to health care politicians from North Rhine-Westphalia and the European Parliament. In this context, it can be repeatedly witnessed that politicians tend to believe those affected more than us doctors.

Dr. med. Erich Schubert

Speaker for the management of the BVDD



Dr. med. Erich Schubert

Cooperation between the Institute for Interdisciplinary Dermatological Prevention and Rehabilitation and the Selbsthilfegemeinschaft Haut e.V.

The main focus of activity in our facilities at the Osnabrück and Hamburg locations is the primary, secondary and tertiary prevention for patients with occupation-induced skin diseases. In terms of primary prevention, this means e.g. the conceptualisation and coordination of national and international prevention campaigns as well as quite practically specific, interdisciplinary company consultation; at the level of secondary prevention, outpatient medical care and also interdisciplinary training and at the tertiary prevention level, the implementation of special, inpatient, rehabilitation measures (“Osnabrücker Model”) for patients with occupation-induced skin diseases. Several affected persons from this group with severe, year-long occupation-induced skin diseases and the specific risk of an occupational illness emerging were informed of the prevention measures offered by our institute.

Patients with chronic occupational dermatitis and thereby with existential worries often display a great deal of uncertainty. Particularly in such cases, we have always considered it to be very positive for those affected that – from the side of the self-help community – appointments can be arranged directly in our institute and the insured persons can also be accompanied to medical examinations should this be requested. Normally, we continue to stay in contact with our patients that have gone through an inpatient course of treatment and offer them subsequent check-ups at regular intervals. In this respect, we are convinced that all the patients that were in the care of the self-help community benefited from the support of the self-help group that went well beyond the continued, outpatient co-support e.g. in the communication with social insurance institutes. This is something which very

much supports the measures we initiate and is to the advantage of the patients. Also at the very successful patient information days that they organise, at which we participate with contributions, it became evident just how much significance (but also impact) their honorary work has for persons affected.

Against this background, we are looking forward to continuing cooperation with the self-help community and congratulate them on their commitment and dedication.

Prof. Dr. med. C. Skudlik

Permanent Deputy to the Head Physician
Specialist for dermatology and venereology,
allergology, nutritional medicine,
occupational dermatology (ABD)

Prof. Dr. med. S. M. John

Head Physician
Specialist for dermatology and
venereology, allergology, environmental
medicine, occupational dermatology
(ABD)



Prof. Dr. S. M. John

Cooperation between the Wuppertal Skin Clinic and the Selbsthilfegemeinschaft Haut e.V.

We have been working closely together with the self-help community for 5 years now. Cooperation ranges from making our library available for regular consultation hours organised by the self-help community to giving speeches and lectures at patient seminars offered by the self-help community.

In this context, a team spirit has developed over the years that is of great benefit to patients. The self-help community provides care and attention for the afflicted patients and thereby relieves the daily-stressed doctors enormously. It does not replace the medical work, but complements the provision of care. At regular intervals, a representative of the self-help community comes with patients who do not feel adequately supported and who have difficulties coping with their illness.

Even though these talks are occasionally challenging, it is possible to bring the patients forward and provide them with good advice to help them get along better with their often extremely restrictive condition. Here, communication takes on an extremely important role. Yet communication does not begin and end with the visit to the doctor, instead the self-help community spends many hours in communicating to the often helpless patients what has been diagnosed medically.

To sum up, it is an interaction of care for frequently testing patients requiring more attention than can normally be provided by general hospitals or in the practical everyday situation. In this respect, I fully appreciate the thoroughly committed work of the self-help community, also as a support for our medical care.

I trust that the energetic and dedicated work can be continued for many years to the benefit of all concerned.

Prof. Dr. med. Percy Lehmann

Director of the Centre for Dermatology,
Allergology and Dermatological Surgery
- Skin Cancer Competence Centre -



Prof. Dr. med. Percy Lehmann

Cooperation between those affected and the Selbsthilfegemeinschaft Haut e.V.

I have been suffering from psoriasis since I was 18. The self-help community has provided me with an opportunity of talking to others affected. Many in the community have not only had physical but also psychological problems because of the illness but do not know how to deal with the frequently negative attitude of other people.

Through talks in the self-help community and the exchange of experience, self-esteem is greatly enhanced. You learn how to accept the illness and how to cope with it positively.

You also gain more self-confidence towards the treating physicians in due course. Here, too, there is often uncertainty about the right course of treatment. Since treatments can have different effects on different patients, it is important to be informed about the numerous possibilities so as to find out the best one for any particular

individual. In the community, you have the chance to talk about successes, failures and possible side effects. The exchange between doctor and patient requires improvement. The acutely and chronically ill skin disease sufferers need a better lobby which is able to advance their interests and assert them if necessary. The more sufferers are actively involved in the committees of the Selbsthilfegemeinschaft Haut and other self-help organisations, the more influence they will have. In this respect every single person should make a contribution.

The self-help organisations should be firmly anchored in the health system as established institutions.

Z. M.

Köln

Cooperation between those affected and the Selbsthilfegemeinschaft Haut e.V.

I am a sufferer of psoriasis so to finally get my skin problems under control I followed-up on a report in the daily newspaper in 2009 and visited a meeting of the Selbsthilfegemeinschaft Haut in Leichlingen.

The chairwoman of the association immediately made a trustworthy and competent impression on me. It was very interesting and informative for me to meet other people affected and to talk to them about their skin problems and experience.

Other meetings followed, as did a symposium, various speeches from specialists as well as personal talks with volunteer staff members. They concerned themselves with my problems and worries in an exemplary manner, something I had missed till then at skin doctor surgeries. Besides psoriasis, which I had been suffering

from for years, I was diagnosed with basal cell carcinoma in 2010.

An operation was unavoidable and I was completely out of my depth with the many worries and fears I had. Thanks to the support from the self-help community and the good medical consultation, I was able to cope with the diagnosis and its consequences.

The volunteer staff accompanied me to doctor's appointments and also helped me during the preparation for the stay and operation at a skin hospital. Meanwhile, I am a member of the Selbsthilfegemeinschaft Haut e. V. myself and feel that I am in very good hands there.

J.C.

Leverkusen

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