

## **The *Frauenselbsthilfe Krebs* (Women's self-help association cancer)**

The *Frauenselbsthilfe Krebs* (FSH), a self-help association for women with cancer, was founded in 1976. Since then, change is the only constant. In all those years, we went through numerous changes in the fields of society, politics and medicine which we took as an opportunity for further development. This is how a group of 15 women after breast amputation in Mannheim became a national self-help organisation composed of one central, federal association, 11 regional associations and 300 local groups. In these groups, about 30.000 people suffering from cancer get advice and help.

Right from the beginning, we followed a 5-point program which also served as a common guideline and link within the association. This program, which was completed by a 6<sup>th</sup> point, the representation of health care interests, in the year 2001, has an impact on our work down to the present day. Basically, our program can be summarized as follows:

**Being there** - and helping handle the shock of diagnosis

**Informing** – about support for coping with the disease

**Accompanying** – and helping adjust to life with or after cancer

Our special interest is to strengthen the competence of patients in order to enable people with cancer to act as well informed and mature patients and self-confident partners face to face with medical professionals. Furthermore, people should learn to make use of the structures and benefits of our health care system as far as needed.

The aim and content of our work is exclusively determined by the interests of people having cancer. The most striking fact is that all members of the association suffer from cancer and - at the same time - play an active role. They all work on a voluntary basis. All positions and functions are filled by non-professionals following democratic elections. All levels of the association are neutral, independent and open for other people with cancer at any time.

Thanks to the auspices and financial support given by the *Deutsche Krebshilfe* (German Cancer Aid), we can fulfil our fundamental work and essential duties without any restrictions. We also co-operate with compulsory health insurance companies which support self-help organisations on an individual and on a collective basis. We are represented in bodies of various national self-help federations such as *Bundesarbeitsgemeinschaft Selbsthilfe BAG*, *Deutsche Arbeitsgemeinschaft Selbsthilfegruppen* and *Paritätischer Wohlfahrtsverband*. Within these bodies, we share our experiences with other self-help associations and organisations.

We represent the interests of patients and take an active part in preparing medical directives for the treatment of cancer and participate in meetings of the *Gemeinsame Bundesausschuss* (federal joint committee dealing with national

health issues). We attend the meetings of several working groups of the Ministry of Health aiming at the implementation of the *Nationale Krebsplan* (National Plan for Fighting Cancer). We also take part in the commission which certifies cancer centres and we entered into more than 100 co-operation agreements with Breast Cancer Centres.

The central office of the FSH is located in the so-called *Cancer Self-help House*. Together with nine other national self-help organisations, we aim at utilizing synergies and strengthening our position in the field of health care politics. With a view from the outside, our advisory board makes sure that we get better inside our association.

In order to prepare our members on regional level to meet the changing demands, we developed a qualification program. The training aims at a good quality of advice, a differentiation towards professional advice, a review of self-conception, the consolidation of common identity, a smooth running of the daily routine within a self-help group and the identification of future strategic aims.

Furthermore, we provide a training for regional board members in which we impart knowledge in the fields of organisational development, comprehension of leadership, personnel management, team building, conflict management, public relations, personal competence and succession assurance.

We publish numerous brochures, DVDs and the quarterly magazine called *perspektive*.

In written guidelines, we collected the know-how and experience how to lead a national self-help association acting on a voluntary basis. This publication shall encourage the exchange between self-help organisations. Furthermore all professional co-operation partners are welcome to look behind the curtain of the *FSH* in order to notice that we do not only ask for quality in the health care system but also offer quality ourselves.