

CICATRIX e.V. – Community for People with Burns and Scars

Burns and scalding are the most frequent accident cause in Germany with 18,000 announced accidents. Around 2500 persons of those must be treated in a special centre for burn injuries. Experts estimate a dark figure of another 18.000 cases which are treated by family doctors.

Each number stands for a personal tragedy. Children and adults, often in mortal danger and always loaded with pains and scars on body and soul. But affected also are many thousand more lives of parents, husbands, colleagues and friends because such a misfortune leaves tracks, changes there life too.

Very often big financial problems hit the families. For example by the loss of the job, often remaining impediment with occupational disability or acquisition inability. Assurances do not pay at all, very late or only the smallest possible amounts. People who are responsible for the accident have their special problems on top of everything.

When Regina Heeß and Petra Lubosch met in 2004 they were both burn survivors with heavily scared bodies, faces and souls. Being successful business women before the accident and both responsible for two minor children they did not had the option of resignation. So they already led almost normal lives and they found their common goal to make it easier for all the new patients and their families. Since there was no real organization working all over Germany, no qualified information in the internet, no money for patients in need they decided to found a new charity organization for adult people with burns and all kind of scars. A name was pretty easy to find:

CICATRIX is Latin and means scar

Cicatrix or scars - they are typical for burn injuries, often conspicuously, growing rampant and disfiguring. Although a natural wound treatment, scars are experienced by most affected persons as a stigma because they bring public reactions like embarrassed looks, exclusion or refusal. In the worst case the affected persons retreat completely into isolation because together with the visible injuries of the skin the soul also is concerned.

Experience and scientific investigations show that scars can still change many years after the trauma. Numerous correction operations as well as various treatments and therapies follow almost always. Late damages to liver or kidney can appear.

Lifelong suffering is preprogrammed for many burn survivors. Some of the consequential costs are not covered by the insurance either private or from the state. With the renewed reform of the public health service in Germany more uncertainties originate.

CICATRIX wants to help in such cases with advice and contacts, with information about specialists, treatments, helping tools, medical development and networks. Our members, the executive board and our professional advisory board offer varied personal and professional experience and knowledge.

Our main instrument is the web-site www.cicatrix.de which has by now about 8000 visitors per month. The platform offers 200 different topics and a very active forum.

Today CICATRIX is working in Germany, Austria and Switzerland and with more than 800 members is one of the largest organizations for burn injured people in Europe.

We are providing a communication platform for affected persons, self-help associations, doctors, therapists, the industry and all institutions which are active with and for people with burns and scars.

CICATRIX informs very extensively about all aspects of burn injuries and scars. From prevention to treatment and problems up to tips and tricks how to live with scars. Information can save lives, hence, we also offer extensive information about all aspects of accident prevention and correct first aid.

We have two layers offering members help in regard of all juridical problems.

In all regions of Germany there are competent members willing to talk on the phone, meet with family members or patients and assist in finding doctors and therapists. In many cases we even accompany them to a new specialist or into a hospital for consultation.

We are supporting people in financial need with crèmes or pay directly for their therapy or find doctors who are willing to help if the insurance refuses to pay. One of our major charity projects is a little girl in Turkey named Buse. We invite her to Germany; she gets treated and operated if it is not possible in Turkey. We are supplying all necessary tools like crème, a wig and pay the medical bills.

This is possible through intensive public relation work, TV productions, talk shows and features, as well as giving speeches for Lions or Rotary Clubs. Members ask for money instead of birthday presents or funeral flowers to support our work. There is a donation hotline for Buse and lots of special occasions within the large Turkish population in Germany accumulating money for the girl.

Since last year we are funding an annual award for medical studies which are working on the prevention or treatment of scar tissue. The first price is 10.000 € and a second price is 5000 €.

All five members of the executive Board, as well as the 12 professionals on the advisory board are working for free. We do all the work alone via internet without an office or paid secretary so the overhead costs are minimal.

We educate ourselves and members through national and international congresses. Once a year we have our own one day congress for members and guests on a weekend, together with the annual members meeting and a very popular social event in the evening.

In 2011 we will follow one week the path of the famous "Jacob trail" from Bingen to Worms. After this pilgrimage we will have a service in the famous dome of Worms.

A large part of our work is giving lectures at educational institutes for nurses or first aid helpers or at internal programs for employees of the industry or insurance companies. Also we are getting more and more invitations to talk about burn injuries or living with scars at special medical congresses for example of plastic surgeons or wound care specialists.

We work in cooperation with other organizations with similar objectives in Europe or self help communities in Germany, as well as all the major medical organizations which are relevant for burn injured people.

So we are looking forward to work with all members of the EBCA and hope we can contribute for a better perspective for people who get injured right now.

Petra Lubosch
- Vice President –
Cicatrix e.V.

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