

International Groups Six Monthly Reports

DEBRA Germany

Fundraising and events

- no fundraising.
some donations on occasions as birthday parties and funerals

Special projects

- actualizing some booklets
- we completed two new booklets: Eye care at EB and EB simplex
- we sent applications to several health insurances
- we participated in seminars and workshops related to changes in the healthcare in Germany, in some commissions we are member.
- More and more doctors and therapists asked for information.
- We visited newborn babies and children in hospitals and families in northern as well as in southern Germany to support professionals and parents
- searching for sponsors to set up a mobile service
- preparing the international meeting in October in Stuttgart
- search for a second person in our office

Conferences and meetings

- September 2003 International DEBRA Meeting in Neuchatel
- October 2003 board meeting at Duderstadt with subjects: a. The situation of sisters, brothers and parents in a family with EB
b. Fundraising
c. The law of succession.
- October in London: International Meeting „Clinical management of EB“
- one meeting in the region of Baden/Württemberg (BW) and one in Nord-Rhein-Westfalen (NRW)

Research and medical news

- We sponsored Dr. Holm Schneider at University of Erlangen. He is doing research at EBJ and is giving medical care to a number of patients with EB junctional
- Last year we got a grant of the Government for research and care. Our centre in Freiburg (research and care special at EBD) is doing very well. In Cologne (Research and care at EBS) Dr. Korge urgently needs assistance
- The projekt of searching international literature on EB is finished.
Now that student of the University Witten/Herdecke is collecting medical reports not having been published yet.