

## **International Groups Six Monthly Reports**

DEBRA Sweden September 2003 – February 2004

### **Fundraising and events**

- Ongoing fundraising all year round: butterflies and “Bingolotto” (TV-lottery)
- Lecture on EB at conference in Stockholm for school doctors in September.
- Tennis match in October; Mats Wilander v/s Stefan Edberg, which raised ~ 10 000 €.
- Article published in the magazine “Vi föräldrar” (Us Parents) in November, written by EB-mum Jessica Hammarlund.
- 3<sup>rd</sup> EB-family week at Ågrenska foundation in Gothenburg, February. 7 families attended (max. 10 families). The 1<sup>st</sup> EB-week was in 1995 and the 2<sup>nd</sup> in 1998.

### **Special Projects**

Planning of the 2<sup>nd</sup> Scandinavian EB-conference for healthcare professionals (Stockholm, April 2005). Meetings with the scientific and organizing committees in September and November.

### **Conferences and meetings**

- Board meeting in Stockholm in October (+ monthly telephone meetings)
- Ophthalmic surgeon Gabor Koranyi attended the EB-conference in London in October. DEBRA Sweden supported his travel costs and conference fee.
- Chairmen’s meeting at Swedish Association for Rare Disorders in Stockholm. The meeting agreed to develop a national center of excellence (non-medical) for rare disorders together with Ågrenska Foundation in Gothenburg.

### **Research and medical news**

Outreaching work: “The newborn on call duty” (EB-mum and nurse Lotta Lindgren) paid a visit at Karlstad Hospital, where a boy was born with R-DEB Halleopaeu Siemens in November. Lotta met both the family and the healthcare professionals.