

# **International Groups Six Monthly Reports**

## **Ireland**

### **Fundraising and events**

The last six months have been busy. The Wicklow Challenge, now in its third year has gone from strength to strength and we have now been in the lucky position of turning people away. Over 50 teams took part in this year's 3 day trek sponsored by Lowe Alpine. A smaller group took on the more challenging trek of raising the funds for, and taking part in, our trek in the Drakensburg Mountains, South Africa. We are in the middle of planning our Ball, to take place next month and our 2004 challenges which are expanding to include two overseas treks, the Wicklow Challenge and a Kerry Challenge. On the corporate side, we have been lucky in being selected as charity of the year by Sodexo and by the Shelbourne Hotel, Dublin.

### **Special Projects**

We were deeply upset to learn of the death of Adam Graham, RIP on 4<sup>th</sup> August, 2003. Aged 10 years, a short life of pain lived with great courage, intelligence and character. He is deeply missed by his parents, Kevin and Alice, his sister Emma and all of us who were privileged to know him.

We have had two television exposures: Firstly, the hardships, fortitude and courage shown by Mary Naughton, mother of four children born with EB up to forty years ago was movingly featured on television recently. At that time, medical support was very limited and living conditions were more basic. Despite the huge practical problems, Mary courageously overrode advice and brought two of her boys with EB home where she cared for them. Thanks to her loving care, they enjoyed life at home until they died.

Then Emma Fogarty, a student with EB and her mother have just appeared on a TV afternoon show. Emma's determination, independence and beauty impressed everyone who watched the show.

### **Conferences and meetings**

We were delighted that so many EB staff from Our Lady's Hospital for Sick Children and St James's Hospital were able to attend the EB conference in London and also the Debra Europe meeting.

### **Research and medical news**

We currently fund two local research projects (Trinity College Dublin & University College Hospital, Cork) and contribute to the Cancer in EB campaign. We are currently considering other possible research options both in Ireland and internationally as we are committed to supporting EB research initiative.

