

International Groups Six Monthly Reports

DebRA UK July –Dec 03

Fundraising and events

Final accounts for 2003 are in preparation but the estimated income is around £3.5 million (€4.8 million). Income came primarily from individuals, companies, charity shops and charitable foundations. Our objective is to double income within 3 years and we have made a number of new appointments to enable this to happen, including a new Director of Fundraising and Communications, Mark Smith, who has joined us from a large UK children's charity where he was Head of Corporate Fundraising. A number of new events are planned, including a joint venture with McDonalds – a 12 hour trek over hilly country – to raise funds for the Ronald McDonald Children's Charity and ourselves.

Whilst exact figures are hard to obtain, we believe that, in terms of income and charitable expenditure, we are the biggest skin charity in the UK (4-5 times bigger than our nearest rival) and number 3 in genetics.

Sadly, one of our trustees with a severe form of RDEB, Jonny Kennedy, died from a SCC at the end of the year. However, knowing that he was dying, he was determined to use this to increase awareness of EB and the last few months of his life were filmed by a TV company. This programme will be broadcast on national TV at peak time, probably in March 2004, and DebRA UK is organising an awareness and direct mail programme around this. We anticipate that this will have a considerable impact. If possible, we will send every national group a video of the programme.

During the course of 2004 we anticipate a particular growth in direct mail and face-to-face fundraising, as we lay the foundations for future income growth.

Special Projects

DebRA UK's website, www.debra.org.uk, has now been updated and a redesign is planned for later in the year.

International work continues, both on behalf of DebRA Europe and DebRA UK. DebRA UK has awarded funding to DebRA Croatia and DebRA Hungary to allow them each to appoint a nurse. The DebRA UK/DebRA of America relationship has led to some joint work on public awareness and close collaboration in putting a team of runners in to the New York Marathon. Periodic contact is made with most national groups, mainly by email.

In the case of DebRA Europe, we are working closely with I.E.B. Debra Germany on the 2004 DebRA International Conference and with DebRA Scandinavia on the second symposium for Scandinavian health professionals.

Planning for the next meeting of the DebRA Europe Board in April is underway. It has been suggested that the time is now ripe for another organisational development workshop to focus on PR, communication and promotion. We will also be considering the programme for 2004/5. *Comments on either of these would be welcome.*

The DebRA International website, www.debra-international.org, is in need of updating and work will commence within the next few months. *Any comments/ideas will be appreciated.*

On a more parochial level, we have outgrown our existing offices and we are in the process of buying the neighbouring office as well. DebRA UK now employs approximately 60 full-time equivalent staff, just over half of whom work in our shops.

Conferences and meetings

DebRA co-hosted EB 2003 in conjunction with the Institute of Child Health (Great Ormond Street Hospital's academic wing), which brought together clinical teams with expertise in EB from around the world to pool their expertise and to develop protocols for best practice. *The proceedings of the meeting are in preparation and will be available from DebRA UK for £15 plus postage.*

DebRA UK's annual conference will be held on 15 May 2004 in Stoke on Trent. *Anyone who is in the UK at the time will be welcome if they let us know in advance.*

During the second half of 2003 I attended meetings of DebRA Europe, Eurordis, EPPOSI and several research meetings.

I will be attending the E.B.A.E. General Assembly at Genethon in March and the Swiss experiential meeting in June.

Research and medical news

During 2003 DebRA UK approved new research projects with a total value of approximately £800,000 (€1.11 million), primarily concentrating on gene therapy and cancer in EB. DebRA Ireland is a partner in the cancer programme and DebRA Netherlands also made a welcome financial contribution.

In December 2003 DebRA UK brought together the Principal Investigators on existing projects to consider the future development of our research work. It was recommended that a number of new schemes be adopted, including a) longer-term project grants for 5 years to enable more substantial packages of work to be undertaken, b) Non-clinical Research Fellowships to allow promising younger scientists to take on their own projects and c) clinical research aimed at symptom relief. The trustees have accepted these recommendations and the new schemes will be introduced during the second half of 2004 at the pace that funding permits.

The programme grants will require considerable funding, in the region of £1 million (€1.4 million) over five years for each programme. An expression of interest for a cancer programme has already been received.

We hope to be able to appoint a dedicated Research Manager sometime during 2004.

On behalf of DebRA Europe we have worked with a number of research groups who have submitted applications to the European Union's FP6 research grant programme. We understand that three applications have been submitted for gene therapy in RDEB (DebRA Europe is a partner in two and has a working relationship with the third) and two more general applications on genetic skin conditions (DebRA Europe is a partner in one).

DebRA UK's teams in direct contact with people living with EB now comprise 8 nurses and 5 social workers. The social work team that was established in the first half of 2003 has become well-established and it is apparent that an increase in staffing is needed. Ideally, existing staff's hours will be increased and 4-5 less well qualified assistants will be recruited. The timing of this will depend on the pace at which funding becomes available. In Scotland, we are seeking funding to appoint another 1.5 nurses and a social worker.

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