

**THE MINUTES OF THE DEBRA EUROPE EXECUTIVE COMMITTEE
MEETING HELD ON FRIDAY 15 OCTOBER 2004 AT THE HOLIDAY INN,
STUTTGART, GERMANY**

Present: Guy Verdot President
Vlasta Zmazek Treasurer
Fred de Gruil
Inigo de Ibarrodo
Graham Marsden

In attendance: John Dart Director

Apologies of absence: Michael Griffith
Rainer Riedl

ACTION

1. MINUTES OF THE LAST MEETING

The minutes of the meeting held on 16 April 2004 in Paris were agreed as a correct record and duly signed by the President.

2. MATTERS ARISING

2 Minutes of the meetings of the Medical and Scientific Advisory Panel had not been circulated to member groups but abstracts of successful research grant applications had been distributed.

4.3.2 Quarterly accounts are sent to the Treasurer. **JD**

6. The fundraising workshop had been held in Dublin on 29 September 2004, attended by fundraisers from Belgium, Croatia, Ireland and the UK. The workshop had recommended:

a) A review of DebRA's branding and a suggestion that the exercise start with DebRA Europe. **JD**

b) The establishment of a Fundraisers' Forum, on the model of the other forums, with an annual meeting and contact throughout the year by email and telephone. **Forum**

c) A directory of fundraising events organised by member groups be prepared annually so that participation can be opened up to groups other than the organisers. **JD**

3. DIRECTOR'S REPORT

A written report had been previously circulated. The following issues were discussed.

a) The funding of nurses in Croatia and Hungary had made a significant impact on the quality of life of

people with EB. It was agreed that, if the other member groups in the region wanted a nurse, DebRA Europe should make every effort to provide funding to make it possible. **JD**

b) The facilitation of training visits for clinicians and nurses to specialist EB treatment centres had been appreciated by all concerned. It was agreed that a list of specialist centres willing to take visiting clinicians be established so that the scheme could be expanded as an official DebRA Europe project. **JD**

c) The ambiguous nature of DebRA International was acknowledged and it was recommended that legal status be clarified, perhaps as a project of DebRA Europe. **JD**

d) The Director's work plan for 2004/5, which had been previously circulated, was approved with the additions above. **JD**

4. FINANCE

Audited accounts for 2003 and the draft budget for 2005 had been previously circulated. Management accounts for the nine months to 31.9.04 were distributed.

a) The accounts for 2003 were approved.

b) The 2004 management accounts were noted.
i) It was noted that some groups had not yet paid their subscription fee, although the sums outstanding were small, it was important that each member group made a contribution to provide 'ownership'. **VZ,JD**

c) The budget for 2005 was recommended for approval with the following additions.
i) An increase in the communications budget to allow a PR campaign to be mounted to promote DebRA Europe, using the successful FP6 applications as a springboard. DebRA UK will be approached to fund this. **VZ,GM,JD**

ii) An increase in the budget for the website to allow the annual redesign and updating. **VZ,JD**

5. COMMUNICATIONS

In Rainer Riedl's absence, the Director gave this report.

- a) Whilst still requiring considerable effort, the response rate for the six-monthly reports had increased. Janice Carrera was thanked for her effort. **JC**
- b) Discussion took place on the DebRA International website
- i) It was agreed that more contributions are needed from member groups.
 - ii) It was agreed to investigate whether economies of scale could be made by determining a common template for content that could be used by member groups for national sites.
- c) Twenty responses had been received from member groups [including those outside Europe] to the basic information questionnaire. These will be circulated to all groups so that synergies and common interests can be identified.
- i) Nearly three-quarters of the groups have an income of under €50,000 p.a.
 - ii) All except one were the only EB support group in their county.
 - iii) All member groups had under 1,000 members and over 40% had less than 100, 78% less than 250. Membership size seems to have little or not relationship to income.
 - iv) Half of the groups have no paid staff and 45% have either 1 or 2 staff. The two groups with the highest income had the highest staff numbers (6 and 104).
 - v) Seven of the groups funded research although two of these spent less than €2,000 p.a.
- d) A database of specialist EB clinical centres had been circulated to member groups. These will be updated as necessary. **JC,JD**

6. RESEARCH

In the absence of Michael Griffith, the Director gave

this report.

- a) The award of €4.8 million from the European Commission for EB and related research was welcomed. DebRA Europe's role is to act as the link between the researchers and the patients. **JD**
- b) A written update on the current state of EB gene therapy research has been commissioned from Mattias Titeux (Hovnanian group) and will be available shortly. **JD**
- c) An updated video on research, featuring Prof John McGrath will be shown at the conference and distributed to every member group. **JD**
- d) The proposal to use DebRA Europe as a means to allow groups to make a contribution towards the costs of specific research projects was endorsed and recommended to the membership. **JD**

7. QUALITY

A questionnaire on quality issues had been circulated to all member groups by Fred de Gruil. Eight responses had been received.

- a) Only one group was familiar with quality systems and less than half were involved in monitoring quality of EB health care systems.
- b) It was agreed that a specialist organisation in The Netherlands be asked to prepare a brief on quality systems and how they can contribute to improvements in care. **FG**
- c) It was felt that consideration should be given in future to commissioning specific research in this area. **All**

8. ANY OTHER BUSINESS

- a) A meeting has been organised during the conference for delegates from Eastern Europe. **VZ**

9. DATE OF NEXT MEETING

The next meeting will be held on Friday 22 April 2005 at 4.00pm in Stockholm, prior to the 2005 Annual Conference.