

**THE MINUTES OF THE BOARD MEETING OF DEBRA EUROPE HELD ON 14/15  
SEPTEMBER 2002 AT THE SHEPPERTON MOAT HOUSE, UK**

**Present:**

**Austria**

Rainer Riedl

**Belgium**

Ingrid Jageneau

Mats Waktare

**Croatia**

Vlasta Zmazek

**Finland**

Liina Harkonen

**France**

Patrick Gazin

Elie Nombalais

Guy Verdot

**Ireland**

Michael Griffiths

**Italy (Puglia)**

Carol Dilley

Imelda Santacroce

**Netherlands**

Jan Doldersum

**Norway**

Kris Aaseth

Heidi Silseth

Kare Silseth

**Spain**

Carolina Bech

Inigo de Ibarrando

**Sweden**

Jessica Hammarlund

Henrik Lindgren

Malin Netz

**Switzerland**

Lisa Huber  
Kurt Schmocker

**U.K.**

David Bendor-Samuel  
Philip Evans  
Graham Marsden  
Scott O'Sullivan

**USA**

Martin Hassner

**In attendance**

John Dart (UK)  
Jackie Denyer (UK)  
Lesley Haynes (UK)  
Liz Pillay (UK)  
Sarah Quinn (UK)  
Fiona Shave (UK)  
Bob Snookes (UK)

**1. WELCOMES**

Short welcoming addresses were given by Inigo de Ibarra, President of DEBRA Europe, and Philip Evans, Chairman of DEBRA UK. A report on activities during the past year and accounts for 2001 were circulated.

**2. OBJECTIVES OF THE MEETING**

**2.1** John Dart, Director of DEBRA Europe, introduced the objectives of the meeting. The 2001 meeting had agreed that the 2002 meeting should concentrate on internal issues of enabling DEBRA Europe to undertake its work more effectively and to identify priorities. Accordingly, there would be no scientific or clinical sessions.

**2.2** The aim of the meeting would be to define what DEBRA Europe must do and what it would like to do and then to consider how these activities should be undertaken, who should do them and how they should be paid for?

**2.3** Several issues had been identified, prior to and during the consultation held earlier in the year, as being important. These included:-

- a) the current diverse (too diverse?) range of activities
- b) 'ownership' of DEBRA Europe
- c) limited resources in terms of staff and finance
- d) limited involvement of member groups
- e) unclear relationship with DEBRA International

**2.4** To set the scene, the current wide range of activities undertaken by DEBRA Europe was described. These are detailed in Appendix I.

**2.5** The format for the sessions was then outlined and agreed. Each session would focus on a particular area of work or need and would be opened with a short introduction by one of the delegates. The major part of each session would be devoted to group discussion, followed by agreement on the priorities within that area of work. At the end of the meeting, general priorities would be established.

### **3. SESSION 1 - COMMUNICATION**

**3.1** This session was led by Malin Netz (Sweden). She identified the following issues for discussion:-

- a) What information should be communicated?
  - from central office to the member groups
  - between member groups
- b) How should information be communicated?
  - website
  - email tree
  - quarterly reports

**3.2** In discussion, a key issue identified was what the audience was, i.e. did DEBRA Europe need to communicate with all members of the national groups or only with the officers/opinion formers?

Many delegates felt that individuals and families living with EB were too busy getting on with their day to day lives to be concerned with international issues. DEBRA Europe should work behind the scenes, assisting and facilitating the officers of the national groups in their work.

Other delegates felt that, whilst there were champions for DEBRA Europe in each group, there was often not a whole-hearted commitment to the organisation for the national group as a whole. The value and relevance of DEBRA Europe should be communicated to all levels within the national groups, particularly if a subscription is to be paid by each national group.

**3.3** A further issue debated was whether the focus of the organisation, and hence the communications, should be internal or external. There was considerable consensus that, although there was a need to have consistent external communication with external agencies such as the European Union, the main focus for DEBRA Europe was internal.

**3.4** There was considerable agreement about the types of information to be communicated. This included:-

- a) clinical care and management of EB
- b) research news
- c) sharing of information between member groups on how they were faring, e.g. fundraising, member involvement and activities, political activities. What works for our national group may work for others.

**3.5** In order to be effective and sustainable, communication methods must be simple, become a habit and require as little extra work as possible. It must be the responsibility of named individuals.

- a) Each member group should appoint one person to be responsible for communications with DEBRA Europe and its member groups.
- b) One member of the Executive Committee should be responsible for communications policy and overseeing staff compliance with agreed procedures.
- c) Each member group should produce a six monthly report on its activities in a standard format for circulation by the central office to all member groups.
- d) Each group should put their newsletters on their own website and provide an electronic copy to DEBRA Europe for inclusion on the DEBRA Europe website. Those newsletters in languages other than English should be accompanied by a brief summary or table of contents in English.
- e) A small editorial committee should be established to oversee the DEBRA Europe website.

#### **4. SESSION 2 - RESEARCH**

**4.1** This session was led by Michael Griffiths (Ireland) who set the scene by showing a video of Prof. John McGrath that described the main areas of current research activity, i.e.

- a) clinical research
- b) genetics and gene therapy
- c) cancers in EB
- d) wound healing

The video was supplemented by information on the clinical trial being undertaken by Dr De Luca in non-lethal JEB.

**4.2** It was noted that, although individual member groups are responsible for providing the funding for research (if they so choose), the system of international peer review managed by DEBRA Europe, provides robust central evaluation and support.

**4.3** There was unanimity that member groups were interested in receiving regular, reliable information on EB research. It was agreed that regular six monthly expert research reports be commissioned by DEBRA Europe and circulated to all member groups. These reports should be written to be understood by the interested layman.

**4.4** There was some debate about the relevance of the results of the research to date to daily life. It was acknowledged that there has been progress and that patient funded research has made a difference, e.g. in nutrition, diagnosis and other areas.

**4.5** There was unanimity that research should be funded on the basis of quality rather than location, i.e. that funding should be concentrated on the highest quality work undertaken by the research groups with the best track records.

However, it was accepted that some groups, for local reasons, could only fund research in their own countries. Whilst no DEBRA Europe research fund exists, there have been moves to 'internationalise' national schemes:-

- a) DEBRA UK will fund research outside of the UK
- b) DEBRA Ireland has committed £100,000 over three years to the DEBRA UK managed programme on skin cancer.

**4.6** In debate it was recognised that not all member groups aspire to fund research themselves, having other priorities and making their international contribution in other ways. Within DEBRA Europe there is a body of groups who wish to fund research and they are able to collaborate within the organisation without necessarily involving all the other groups.

**4.7** Attempts have been made to establish a lay research interest group to relate to the EB researchers. It was felt that an optional session of each annual meeting should be devoted to a lay group meeting with the author(s) of the six monthly research reports.

## **5. SESSION 3 – PROFESSIONAL EDUCATION**

**5.1** This session was led by Kris Aaseth and Heidi Silseth (Norway) who had organised the DEBRA Scandinavia symposium for professionals in April 2002. DEBRA Scandinavia is a loose alliance within DEBRA Europe.

**5.2** It was acknowledged that all member groups wanted health care professionals to be knowledgeable about EB and able to provide high quality care. It was felt that national groups must take the lead on this but there was a supportive role for DEBRA Europe.

**5.3** Heidi Silseth described her experience in organising the Scandinavian symposium and the lessons that she had learned (see Appendix 2). The contribution of DEBRA Europe had been:-

- a) to identify international speakers and to make the invitations
- b) to give credibility/authority to the national group(s) in their dealings with professionals and the scientific committee
- c) to provide consultancy throughout the process

**5.4** DEBRA Europe manages the professional forums, i.e. the Nurses' Forum and INDEB (dietitians). These forums enable professionals from a particular discipline with an interest in EB to relate to each other, share experiences and to promote best practice. As a result of funding made available as a result of the Scandinavian symposium, a Nordic Forum website, [www.nordicebforum.org](http://www.nordicebforum.org) has been established and further forums started for other health professionals. These forums will be integrated into the DEBRA Europe structure.

## **6. SESSION 4a – ORGANISATIONAL DEVELOPMENT**

**6.1** This session was led by Rainer Riedl (Austria). He suggested that the scope of this session was to clarify:-

- a) how to strengthen the existing network.
- b) how to extend the network to new countries

**6.2** DEBRA Europe has, in the past, organised workshops on organisational development, particularly in the field of fundraising. Three national groups (Austria, Ireland and UK) had tried to organise a fundraising workshop in 2002 but had found little interest from member groups.

**6.3** The question was posed concerning what member groups wanted from DEBRA Europe in terms of organisational development?

- a) Groups want to learn from each other by having good information about activities undertaken. The proposals made in the communications session would assist considerably in this.
- b) Many important issues are decided at a European (or wider) level and this external environment can affect the ability of member groups to achieve their objectives. DEBRA Europe, by working at a supra-national level, is better placed to influence these issues than the national groups.
- c) The promotion of best practice can give guidance and strength to national groups.
- d) The annual conference is important in bringing the national groups together and providing formal and informal opportunities to learn from each other.
- e) Workshops on particular topics, e.g. the use of volunteers, may be helpful. It is not necessary for every group to participate in every workshop – a meeting of 2-3 groups that meets their needs is a success.

**6.4** The establishment of best practice, validated by DEBRA Europe, can empower national groups in obtaining the best care/services for people with EB.

- a) It was suggested that the professionals' forums be asked to periodically (annually?) publish a statement of best practice in their field and to make this readily available to the member groups.

**6.5** The importance of providing basic core funding to less well established groups was recognised as a future objective.

## **7. SESSION 4b – SUPPORT TO LESS FAVOURED COUNTRIES**

**7.1** Vlasta Zmazek (Croatia) introduced this part of the session illustrating the position of countries in economically less favoured areas of Europe using her experience in Croatia and examples from Bulgaria.

**7.2** As is well known, Croatia and neighbouring states suffered devastation during the war following the collapse of former Yugoslavia. The economic situation has still not fully recovered. DEBRA Croatia was established in 1996 and since then has developed a number of services including:-

- a) A comprehensive team of medical specialists able to provide a high quality treatment.
- b) Support to families in obtaining appropriate dressings.
- c) Payment of some specialist medical provision by the State.

- d) A special float for the use of families at Zagreb Children's Hospital.
- e) The provision of an office and the funding of a secretary/administrator.

7.3 DEBRA Croatia's current income is approximately €15,000 p.a. If funding were available, the following services would be developed.

- a) Employment of a nurse at a cost of approximately €7,500 p.a.
- b) Opening a specialist rehabilitation/holiday centre on the Dalmatian coast. The Croatian Government has offered a building free of charge but the renovation costs would have to be paid. The centre would be open to people with EB throughout Europe.
- c) Croatian EB services are already open to people with EB from surrounding countries such as Bosnia, Slovenia, Serbia, Montenegro and Macedonia. Secure funding would enable provisions to be further developed.

7.4 DEBRA Bulgaria faces severe financial problems, with many Bulgarians with EB unable to afford the cost of travelling to see a doctor.

7.5 DEBRA Hungary wishes to employ a specialist nurse but are unable to afford the €7,500 it would cost.

7.6 In discussion, it was noted that fairly small amounts of money could make a great difference to groups in these countries. Whilst, as in Croatia, the leadership of the national group has to show the ability to innovate, DEBRA Europe should seek to raise a development fund for these services.

7.7 National groups from less economically favoured countries should be encouraged to establish a special interest/lobbying group within DEBRA Europe.

## 8. **SESSION 5 – CONSTITUTIONAL ISSUES**

8.1 This session was led by Inigo de Ibarra (Spain), including proposals previously submitted in writing only by Jan Doldersum (Netherlands).

8.2 The issues identified for consideration/revision were:-

- a) the legal personality of DEBRA Europe
- b) improved representation of member groups
- c) the situation of those countries where more than one group exists
- d) the relationship with non-European national groups and the ambiguous status of DEBRA International.

8.3 DEBRA Europe is currently a project of DEBRA UK and derives its legal personality from the UK group under UK law. All member groups acknowledge that, when possible, DEBRA Europe should be a separate NGO in its own right. The previous consultation process and discussion at the meeting suggested:-

- a) The link with the UK did not cause immediate problems and gave the organisation some financial stability.
- b) The Executive Committee should seek to establish conditions conducive to independent status as soon as is practicable.

- 8.4** All member groups have a vote in the Executive Committee elections but the status of all the member groups meeting together is unclear in the present Constitution. It was agreed that:-
- a) Each member group should nominate one person to serve on the Board of DEBRA Europe.
  - b) The Board should meet once a year during the annual meeting and be the governing body of DEBRA Europe.
  - c) The Board should elect the Executive Committee which is charged with day to day responsibility for the management of DEBRA Europe.
- 8.5** In a very small number of countries, more than one group exists that can apply for membership of DEBRA Europe. A revised Constitution should:-
- a) Define how applications for membership should be determined
  - b) Ensure that, if more than one group from a country is in membership, that country only has the same voting strength as countries represented by one group.
- 8.6** A sample revised Constitution had been circulated by Inigo de Ibarra. The Executive Committee was charged with presenting a draft revised Constitution for consideration at the 2003 meeting.
- 8.7** Elections are due for the Executive Committee. The Director was instructed to organise an election in line with the current Constitution, taking into account the proposed changes previously authorised.
- 8.8** Martin Hassner (USA) spoke about the relationship with non-European EB support groups. There was consensus that collaborations outside Europe were of value. It was noted that the consultation previously undertaken had shown that non-European groups were happy to attend DEBRA Europe events and did not feel excluded. It was felt that:-
- a) DEBRA International should be formally constituted when feasible with its own constitution.
  - b) However, member groups believed the first priority was to revise DEBRA Europe's constitutional arrangements before embarking on the wider issue of DEBRA International.
  - c) In the interim, DEBRA International should remain a virtual organisation.

## **9. SESSION 6 – ANNUAL CONFERENCE**

- 9.1** Kurt Schmocker (Switzerland) reported on the plans for the 2003 conference to be held in Neuchâtel (see Appendix 3) on 11<sup>th</sup> –14<sup>th</sup> September.
- 9.2** It was noted that, in previous years, there had been limited time available at the Annual Conferences for DEBRA Europe business meetings. It was agreed that, at full-scale conferences, the programme should be arranged to allow the Board to meet on the first morning as a parallel session to the Conference presentations, with a final business meeting on the last morning.

**9.3** The annual meeting should follow a two year cycle, with a conference in one year and a business meeting (extended Board Meeting) in the other.

a) It had not been confirmed by DEBRA Germany that they wish to host the 2004 meeting. The Director was instructed to inform the German group that 2004 would be a business/Board Meeting and give the group the opportunity to either host the meeting or defer their turn until 2005.

## **10. SESSION 7 – IMMEDIATE PRIORITIES**

**10.1** This session was led by Graham Marsden (UK). The activities identified in previous sessions were classified as either essential or desirable.

**10.2** The following immediate priorities were agreed:-

### Essential

- Annual Meeting
- Revised Constitution
- International research coordination
- Establishment of robust communication
- Named Executive Committee members to take responsibility for communication and research
- Monitoring of EU decisions/actions
- Professional forums and cross-border training

### Desirable

- Increased responsibility at national level
- Best practice in health care
- Political activity
- Public relations
- Harmonisation of DEBRA Europe logo
- Appointment of a fundraiser
- Establishment of a fund to help groups in less economically favoured countries
- Establishment of a European research fund

## **11. SESSION 8 – PERSONAL ISSUES**

**11.1** This session was led by Mats Waktare and Ingrid Jageneau (Belgium). The priority list previously agreed was used as the basis for determining the allocation of responsibility.

**11.2** The following actions were agreed:-

- a) Annual meeting
- responsibility of the conference organiser named by the host country, in liaison with the Director. In 2003 the organiser is Kurt Schmocker.
- b) Constitution
- responsibility of the Executive Committee.
  - member groups to nominate Board member

- c) Intended research coordination - responsibility of the Director, reporting to the named Executive Committee member.
- d) Robust communication
  - each group to nominate person responsible for ensuring reports are submitted.
  - Director is responsible for circulation.
  - Named Executive Committee member to oversee compliance with procedures.
- e) Named executive Committee members responsible for communication and research
  - Executive Committee to nominate members for these roles (Rainer Riedl has volunteered for the communications role if elected).
- f) EU Membership
  - Responsibility of the Director
- g) Forums
  - Responsibility of coordinator of each forum and the Director

## **12 SESSION 9 - FINANCE**

**12.1** This session was led by Guy Verdot (France) who reported on the Executive Committee recommendation that each member group should pay a subscription to DEBRA Europe of 10% of its total membership fees or 1% of income, whichever is the greater (see Appendix 4).

- a) The principle of the payment of a membership fee was agreed.
- b) The preferred basis for calculation was 10% of national membership fees.
- c) Where this basis of calculation imposed an unreasonable burden on a member group, the Executive Committee is authorised to agree a variation.
- d) Payment of the subscription is mandatory from 1<sup>st</sup> January 2003 and voluntary in 2002.

**12.2** DEBRA UK has agreed to continue to make its existing contribution to DEBRA Europe. Subscription fees would constitute new income and the decision on how it is to be used was delegated to the Executive Committee.

**12.3** DEBRA UK has been chosen by Virgin Atlantic to receive the proceeds of in-flight coin collection for three months from November 2002. Virgin Atlantic will feature DEBRA's international work in the appeal materials and DEBRA UK acknowledge the need to use the funds raised in a similar manner.

## **13. SESSION 10 - CONCLUSIONS**

**13.1** This session was introduced by John Dart (Director).

**13.2** Some of the continuing themes throughout the meeting had been increasing ownership and accountability. The test of whether this meeting has been

successful is whether, by the time of the 2003 conference, more people are actively involved in DEBRA Europe and clear reporting structures are in place.

**13.3**

The 2002 meeting has been 'lower key' than recent conferences, held in less luxurious surroundings and with a more modest social programme. The organisation of future meetings is a matter for the host countries but member groups should not be inhibited from volunteering to host future meetings by any feeling that they could not provide sufficient hospitality.