

## 1<sup>st</sup> Conference of 'EB-CLINET – Clinical Network of EB Centres and Experts' October 5-7, 2012 - Salzburg, Austria

### EB-CLINET INAUGURAL MEETING

106 participants from 33 countries, amongst them lead clinicians and other senior staff from different Epidermolysis Bullosa specialist centres worldwide, gathered at the General Hospital, Salzburg on 5-7 October 2012 for the inaugural meeting of EB-CLINET. Organised by the Academy of the EB House Austria and funded by DEBRA Austria with additional sponsorship from the city and the county of Salzburg as well as from the companies Interspar, Flen Pharma and PolyMem, the meeting formalised the establishment of the European (and international) Reference Network for EB.

The meeting was opened by Walter Steidl, member of the county government of Salzburg, and the host, Prof. Helmut Hintner, who outlined the EU criteria for a Centre of Expertise and noted that already several of the international EB clinical centres meet these requirements. A formal collaboration between these centres could form the basis for a European Reference Network (ERN), for which EU funding will be available in coming years. The inaugural meeting of EB-CLINET would provide the opportunity for the participating centres to get to know each other and their facilities better and indicate synergies for collaborations.

Prof. Hintner was followed by Stephen Lynn who spoke about an existing network for neuromuscular diseases, TREAT-NMD, which could serve as a model for how EB-CLINET could develop. It was stressed that the focus of the network was on infrastructure, creating the tools for clinical trial readiness and enabling clinicians to collaborate better. These tools included patient registries, outcome measures, standardisation of animal models and care guidelines, all of which are priorities for EB research and clinical care and where work is currently taking place. There was a strong positive reaction from the participating centres that the TREAT-MND model provided valuable examples and experience.

Since a major objective of the meeting was to understand better the range of services and activities undertaken at the existing clinical centres, each EB centre or EB expert (in total 31 centres/experts from 26 countries, out of those being 22 centres/experts from 17 EU member states) made a short presentation, in a standardised format, on their work. It is beyond the scope of this summary to describe each presentation in detail but the presentations can be accessed on the website [www.eb-clinet.org](http://www.eb-clinet.org) (Section Meetings / EB-CLINET Meetings).

Cumulatively, the centres participating in the meeting had over 6,600 (!) patients with EB in their care, although it was acknowledged that in many countries people with EB might be treated at a non-specialist centre and so not be included in the patient lists of the specialist units. Patient numbers varied greatly between the centres, partly reflecting population size and partly as a function of how well-established each centre was. In some countries, such as Germany, Italy and the UK, there is a strong national network linking two or more clinical centres; in others one centre provided the centre of expertise for the whole country (and sometimes surrounding countries as well). The centres with the largest numbers of patients tended to

be the longest established and/or had been designated nationally as the specialist centre for EB. These centres, such as the ones in Austria, France, Germany, Italy, The Netherlands and the UK, had at least 350 patients treated at each unit. At the other end of the spectrum, some national centres were treating 20-60 patients each. Whatever the size of the centre, all expressed a deep commitment to treating patients in the best possible way and to developing and sharing their expertise.

Participating centres were asked about diagnostic pathways and there was a common core adopted by virtually all of them in coming to a diagnosis, including the clinical features, immunofluorescence mapping and electron microscopy. Mutation analysis was undertaken by a significant number of centres with prenatal diagnosis available at some. In the case of some smaller countries, all or some of the more complex diagnostic procedures were performed on a contract basis at a foreign centre.

Centres also reported on the mode of patient care they adopted. All provided multidisciplinary, or interdisciplinary care, although the numbers of specialisms included varied between the centres. A number of centres emphasised the importance of the specialist EB nurse in the team, spanning hospital and community care. All centres provided patient and family education about EB during the course of clinical appointments and sometimes by patient workshops and other meetings. The Salzburg EB House presented their patients' handbook, which is designed to answer the most common questions raised by patients in lay terms but with real depth – this handbook can be translated and adapted by other centres for their own patients.

Many of the centres offered training opportunities to other professionals, often on an individual basis to enable shared care for specific patients. However, some centres offered structured training courses and visits of observation on a regular basis. The London units (Great Ormond Street Hospital and Guy's & St Thomas' Trust) used this meeting to announce the launch of an online, modular training programme, tailored to different specialities, which now has funding and will be available during 2013. In a separate session, an update was given on the progress of the current best clinical practice guidelines in cancer as well as pain management, wound care and nutrition. Another session introduced the English translation, funded by DEBRA Austria, of the guide to occupational therapy produced by the OT team at the EB House.

There were great variations between the centres in the amount and nature of research that they could undertake. Virtually all of the centres were undertaking some clinical research into particular aspects of the management of EB, whilst many of the larger centres had well-established research laboratory facilities with extensive programmes focusing on gene, cell, protein and small molecule therapies.

Whilst the first meeting inevitably had a heavy emphasis on sharing the current situation in each centre of expertise, there was consensus that EB-CLINET offers the opportunity to work collaboratively on a number of projects, including professional training, best clinical practice, clinical trials and an international register. In order to maintain momentum, it was agreed that a small steering group would meet during the EB2012 conference to plan how to move projects forward and that a further meeting be held in Salzburg in 2013. Thereafter, meetings would probably be held every two years in different locations.

For further information please contact Gabriela Pohla-Gubo ([g.pohla-gubo@salk.at](mailto:g.pohla-gubo@salk.at)).

John Dart  
COO DEBRA International

List of EB Centres presenting their national situation:

- AT Austria**, Salzburg – EB House Austria, Department of Dermatology, Paracelsus Medical University  
**AU Australia**, Sydney – Department of Dermatology, St George Hospital  
**BE Belgium**, Leuven – University Hospitals Leuven  
**BG Bulgaria**, Pleven – DEBRA Bulgaria & Department of Dermatology and Venereology, Medical University Pleven  
**CH Switzerland**, Bern & Basel - University Hospital Basel/Department of Dermatology & University Hospital Berne/Department of Dermatology  
**CL Chile**, Santiago – EB House Chile  
**CN China**, Beijing - Department of Dermatology, Peking University First Hospital  
**CZ Czech Republic**, Brno - Dep. Of Pediatric Dermatology- Pediatric Clinic, University Hospital Brno  
**DE Germany**, Freiburg - University Freiburg – Medical Center, Department of Dermatology, EB Center  
**DK Denmark**, Aarhus - Department of Dermato-venerology, Aarhus University Hospital  
**ES Spain**, Madrid - Department of Bioengineering, Universidad Carlos III de Madrid (UC3M), CIEMAT- CIBER on Rare Diseases  
**FR France**, Paris - Department of Dermatology, Reference Centre “Maladies Génétiques de la peau (MAGEC)”, INSERM U781, Necker Enfants Malades Hospital, APHP  
**HR Croatia**, Zagreb - Department of Dermatology and Venereology, University Hospital Center Zagreb  
**HU Hungary**, Budapest - Semmelweis University Budapest, Department of Dermatology, Dermatooncology and Venerology  
**IE Ireland**, Dublin - National Service for Adults with EB, Department of Dermatology, St James’s Hospital & National Paediatric EB Centre Department of Dermatology, Our Lady’s Children’s Hospital Crumlin  
**IT Italy**, Bozen - Department of Dermatology and Venerology Central Teaching Hospital of Bolzano/Bozen  
**IT Italy**, Milan - Department of Dermatology and Department of Paediatric Science, University of Milan  
**IT Italy**, Rome - Bambino Gesù Children Hospital, IRCCS  
**IT Italy**, Rome -Istituto Dermopatico dell’Immacolata, Clinical Centre for Genodermatoses and Laboratory of Molecular and Cell Biology  
**IR Iran**, Tehran - EB House Iran, Shohadaye Tajrish Hospital  
**NL Netherlands**, Groningen - Centre for Blistering diseases, University Medical Centre Groningen  
**PL Poland**, Warsaw - Warsaw Medical University, Department of Dermatology & Institute of Mother and Child  
**PT Portugal**, Lisbon - University Clinic of Dermatology, Hospital de Santa Maria  
**RS Serbia**, Belgrade - Department of Dermatology, University of Belgrade  
**SI Slovenia**, Ljubljana - University Medical Centre Ljubljana; Department of Dermatovenereology  
**SK Slovakia**, Presov - Department of Dermatovenereology, Faculty Hospital Presov  
**UA Ukraine**, Kiev - National Medical Academy of Postgraduate Education, International NGO “Dermatologists for Children”, Debra-Ukraine  
**UK United Kingdom**, Birmingham - Birmingham Children's Hospital  
**UK United Kingdom**, London - Great Ormond Street Hospital  
**UK United Kingdom**, London - Guy's and St Thomas' NHS Foundation Trust  
**US United States**, Cincinnati - Cincinnati Children's Hospital