

# Meeting News

## Scandinavian Conference on Epidermolysis Bullosa in Oslo 21-23 April 2002

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This very successful meeting was initiated and organized by Scandinavian DEBRA, notably the Norwegian Epidermolysis Bullosa (EB) patient organization (project leader: Heidi Ellingsen Silseth), with the assistance of a scientific committee (co-ordinator: Kari Storhaug). The organizers had invited a number of the internationally renowned speakers covering nearly all aspects of EB, ranging from the molecular genetics and clinical classification to the treatment options and assistance in daily life activities. The audience (about 150 people mainly from the Scandinavian countries) consisted mostly of professionals involved in the health care of EB patients. There were dermatologists, plastic and orthopaedic surgeons, specially trained paediatric nurses, dieticians, physiotherapists, social workers and leading members of the various EB societies.

The meeting was held conveniently located in the centre of Oslo and was splendidly organized from both a scientific and social point of view. The programme (abstracts published in *Acta Derm Venereol* 2002;82: 227-240) began with Professor Robin Eady, London, who gave an overview of the history of EB diagnosis. He described



The organisers Heidi Ellingsen Silseth (*left*) and Kari Storhaug (*right*) opening the meeting.

the prevailing consensus regarding the classification of EB recently published in *JAAD* 2002;42: 1051.

Professor Leena Bruckner-Tuderman, Münster, focused in her presentation on the diagnosis of new-borns, giving an update on diagnostic possibilities and known molecular defects in EB.

Dr Dörte Koss-Harnes, Oslo, went on to describe the course of EB in early

childhood. She was complemented by a clinical nurse specialist from the UK, Jackie Denyer, who emphasized the role of nursing care in the early management of infants with EB. The organization of a multidisciplinary health care centre for young adults with EB was discussed by Professor John McGrath, London, who gave several examples of the benefits of a specialised department. The psychological aspects of EB, in both a patient and family perspective, was vividly dis-



Two of the lecturers, Dörte Koss-Harnes and John McGrath, in a discussion at the meeting.



Bryan Mayou, plastic surgeon from London, presenting one of his lectures.

EB, a project plan which has been debated together with Italian governmental officials for many years. In fact, approval to include the first patient in the trial was obtained only a few days before the meeting, which came as splendid news to the audience and especially to all junctional EB patients. Hopefully, in a year from now, we will know more about the results. Meanwhile, it is important to exercise all types of conservative treatment and plastic surgery, not least in order to prevent mutilation and cancer risk, a matter thoroughly presented by Dr Bryan Mayou from London.

cussed by Stefanie Mimra, a psychologist from Austria who is also the mother of a child with EB.

The non-cutaneous aspects of EB were covered in several presentations. Many dentists were present at the meeting as the oral cavity is a major health problem in many EB patients. Kari Storhaug presented an overview of oral treatment and prevention in EB. She pointed out the need to use non-traumatic cleaning, e.g. a specially designed mouth spray instead of a tooth brush to avoid laceration to the gingiva. A sometimes overlooked complication in EB is the ocular problem, which was covered by Dr Ken K. Nischal from London. In several workshops occupational therapy, physiotherapy and pain management in EB were discussed. The latter aspect is not least important, especially in connection with changing wound dressings in children.

The future prospects for EB patients was reviewed by Professor Jouni Uitto, Philadelphia, including the possibility of gene therapy. This was further extended by Dr Michele De Luca, Rome, who gave details of how ex-vivo gene therapy might work in junctional

How to run a high-quality and efficient EB clinic was further discussed by Dr. Marcel Jonkman, Groningen, who is in charge of one of the biggest centres for EB in Europe. In such efforts, nutritionists are very important and this aspect was covered by Lesley



Chris Aaseth (*right*), Chairman of DEBRA Norway and the author Anders Vahlquist (*left*), during a workshop on the role of patient organisations for affected patients and their family.



Tobias Gedde-Dahl, Jr. relating to his about 50 years of experience in the field of EB research, with special emphasis on the epidemiology of EB in Scandinavia.

Haynes, London, a specialist paediatric dietician for EB patients.

Two very well-received presentations concerned the personal experience of EB in conjunction with educational employment and the role of patient organizations, respectively. The former aspect was covered by Malin Netz, social worker and one of the founding members of DEBRA, Sweden, who combined her personal experience, wisdom and humour in an

excellent presentation. Similarly, Chris Aaseth, the father of an EB child and chairman of DEBRA, Norway, very convincingly emphasized the role of patient organizations for affected patients and their families.

Subsequently, Dr Tobias Gedde-Dahl Jr, Oslo, the Norwegian "godfather" of EB research, described in his very personal way the diagnosis and epidemiology of EB in Scandinavia.

The meeting ended with a demonstration of an atraumatic leg prosthesis in a patient with EB who had been amputated because of squamous carcinoma of the lower limb. Robert Fuglø, Hamar, a specially trained orthopaedic technician, showed a new principle for how to attach the prosthesis to the thigh so as to avoid painful blisters.

It is my firm impression that everyone returned home with new and broadened knowledge about this group of diseases, which will hopefully help many patients with EB in the Scandinavian countries. We were all grateful to the organisers and sponsors of this meeting, and there appeared to be a consensus that a new Scandinavian EB conference should be held again in 3-4 years.

The photos were provided by the organisers of the meeting.