

Training Course on the management of EB

Monday 17 and Tuesday 18 March, 2008



Epidermolysis bullosa (EB) are genetic conditions that are characterized by blistering and erosions of the skin and mucous membranes after trivial trauma mostly starting at birth. Patients may suffer from symptoms of multiple affected organs. The last decade progress has accumulated in the management of EB. The most important one is the interdisciplinary approach. Therefore this course is dedicated to the care and clinical management of patients with EB.

In the Center for Blistering Diseases in The Netherlands, located at the University Medical Center Groningen, more than 280 Dutch patients with EB were diagnosed and treated. The optimal way to provide care for those with EB is within the context of an interdisciplinary team of health-care professionals. In this course we will share and discuss our opinions and practises. Participants will be given more insight in the different topics of the management of EB.

This two-day training programme is meant for healthcare professionals involved in EB (medical doctors, graduates, nurses or paramedics) who wish to know more about the clinical management of children and adults with EB. The sessions and workshops on the first day and a half are plenary and focus on different topics like infection and itch, wound dressings, gut problems, pain management, stress and EB, and ethical questions. On Tuesday afternoon there are hands on consultations in the interdisciplinary EB-clinic carousel. We will see six patients with various forms of EB. This EB clinic closes in an interdisciplinary meeting. The course ends with a dinner party on Tuesday evening.

Programme

Monday, 17 March 2008

- 08:30 Reception and registration
Chairman: Marcel Jonkman
- 09:00 Welcome and introduction
Marcel Jonkman
- 09:30 **Interdisciplinary approach**
José Duipmans
- 10:00 **Gut problems**
Anna Martinez
- 10:30 Coffee break
- 11:00 **Itch and infection**
Jemima Mellerio
- 11:30 **Nutrition**
Irene Herpertz
- 12:00 Lunch
- 13:30 **Introduction to workshops**
Marcel Jonkman
- 13:45 **Topical pain treatment**
Bouwe Molenbuur
- 14:15 **Developmental aspects**
Corinne van Scheppingen
Ida Mollema
- 15:00 Coffee break
- 15:30 **Groningen protocol life ending**
Eduard Verhagen / Han Mandema
- 16:00 **What's new in EB-management?**
Anna Martinez / Jemima Mellerio
- 16:45 Closing / Drinks
Photograph of the group
- 18:00 Experiencing Groningen

Tuesday, 18 March 2008

- 08:30 Welcome and coffee
- 09:00 **Organisation of diagnosis**
Marcel Jonkman
- 09:30 **Stress in EB**
Han Mandema
- 10:00 **Pain relief in terminal phase**
Bouwe Molenbuur
- 10:30 Coffee break
- 11:00 **Handsurgery: to operate or not?**
Peter Robinson / Karel Maathuis /
Melanie Eissens
- 11:30 **Introduction to EB-clinic**
José Duipmans
- 11:45 Lunch
- 12:30 **EB-clinic hands on**
- 16:00 Patient meeting
- 17:30 Closing
- 18:30 Dinner and fare well
Certificate of attendance



List of speakers

- Mrs. J.C. Duipmans, MScN RN, Nurse / consultant EB, UMCG
- Mrs. M.H. Eissens, occupational therapist, UMCG
- Mrs. C.E.M. Herpertz, dietician, UMCG
- Prof. M.F. Jonkman, MD PhD, dermatologist, UMCG
- Mr. C.G.B. Maathuis, MD PhD, rehabilitation physician, UMCG
- Mr. J.M. Mandema, MD, paediatrician, UMCG
- Mrs. A. Martinez, MBBS MRCP MRCPC, consultant paediatrician, Great Ormond Street Hospital for Children, London UK
- Mr. J.E. Mellerio, MD MRCP, consultant dermatologist, St John's Institute of Dermatology, St Thomas' Hospital, London UK
- Mr. B. Molenbuur, MD, anaesthesiologist, UMCG
- Mrs. I. Mollema, social worker, UMCG
- Prof. P.H. Robinson, MD PhD, plastic surgeon, UMCG
- Mrs. C. van Scheppingen, health psychologist, Dept. of Public Health and Health Psychology, UMCG
- Mr. A.A.E. Verhagen, MD PhD JD, paediatrician, UMCG

Organization

The Wenckebach Instituut in co-operation with the Department of Dermatology of the University Medical Center Groningen, The Netherlands.

Location

University Medical Center Groningen, Hanzeplein 1, Groningen, The Netherlands.

Registration

Registration is free of charge. You can register for the course on our website until February 15, 2008. The number of participants is restricted to 20. Registration includes coffee, tea, two lunches and a dinner party on Tuesday evening. Costs for travel, hotel accommodation and dinner on Monday evening are at your own expense.

More information

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