

ED09

International Conference on the
Multidisciplinary management
of Ectodermal Dysplasia and Severe Hypodontia



Berg en
Dal/Nijmegen
The Netherlands
May 14-15, 2009

International Conference on the Multidisciplinary Management of Ectodermal Dysplasia

All the participating patient support group leaders thank NobelBiocare for their sponsorship to assist their attendance at the above conference.

The International Conference on the Multidisciplinary Management of Ectodermal Dysplasia and Severe Hypodontia in Nijmegen was built on the successes of the past meetings in Malmö (2002), London (2004) and Copenhagen (2006). The meeting was organized by the Radboud University Nijmegen Medical Centre, in collaboration with the Dutch Association for Prosthetic Dentistry and Orofacial Pain (NVGPT).

During the ED09 conference the latest scientific achievements and most relevant knowledge on the management of ectodermal dysplasia (ED) and severe hypodontia were discussed. A broad spectrum of topics were covered, including genetic aspects, impact on quality of life and future possibilities for management of ED and hypodontia. The Conference was an inspiration to both clinicians and researchers leading to a greater understanding of the disorder and possible treatment for individuals with Ectodermal Dysplasia.

The conference was excellent and well organised with presentations from experts in the fields of dentistry, ophthalmology, genetics, speech and language, patient support organisations, to name but a few. Each presentation was both informative and well delivered.

For the support group leaders the conference provided an opportunity of meeting professionals from all around the world as well as many of the leaders of the supporting groups thereby creating an Ectodermal Dysplasia network. Such a network will enable us to assist our member families in providing them with information that we are able to obtain from each other. We as patient support organisation leaders were also privileged to have been invited to such a conference where we were able to learn of new research, new dental implant methods and the possibility of gene therapy. Whilst we were able to learn of new research the conference provided the wonderful opportunity of bringing awareness to the medical professionals of the day to day management of Ectodermal Dysplasia

experienced by patients, their quality of life and how ED affects the whole family and not just one individual.

Diana Perry (England), Andrea Burk (Germany), Giulia Fedele (Italy), Rob Heij (The Netherlands), Ulrike Holzer (Austria), Monica Jacobsen (Norway), Helen Kenzler (Sweden), Olivia Niclas (France),
Mary-Kaye Richter (USA), Andrew Williams (Australia), Izzet Yavuz (Turkey)