

## ***ED 09 - International Conference on the Multidisciplinary management of Ectodermal Dysplasia and Severe Hypodontia***

**Meeting: Ectodermal Dysplasia support groups**

**Friday May 15<sup>th</sup> , 2009, 16:45 – 18.00 h**

**Participants:**

**Chairman: Ulrike Holzer - Austria**

**Andrea Burk – Germany, Mary Kaye Richter – USA, Olivia Niclas – France, Diana Perry – U.K., Andrew Williams – Australia, Monica Jacobsen – Norway, Helen Kenzler – Sweden, Rob Heij and N.Heij – Netherlands, Dr. Izzet Yavuz – Turkey, Giulia Fedele – Italy, Henri ? – R.S.A., Birgitta Bergendal - Sweden, Johanna Norderyd - Sweden**

### AGENDA

1 Welcome (*Ulrike Holzer*)

Ulrike welcomes all participants, in different languages!

2 Approval of Minutes of previous Meeting 12th March 2008 Charleston USA (*Diana Perry*)

The brochure from last year is at the moment only available in pdf-format. Diana has been in contact with a company for opening the document.

One purpose with the brochure is that each organization can translate it into the own language and have it published on the homepage.

Diana is responsible for the content of the brochure and is also mastering changes. The Swedish and Norwegian logotypes are missing and will be sent to Diana.

3 State of affairs: new and ongoing research projects of every group (*everybody presents the most important projects of his country*)

Several countries have ongoing research projects. It's very important that all groups publish information (purpose, expected results and value, financing etc) about the ongoing projects in the country on the homepage, so that no new similar research projects start because of lack of information.

The NFED distributes information yearly about ongoing research projects – seven at the moment. The need for a global website with information about research projects is discussed and the issue will be on the agenda for next year.

The group in the Netherlands has developed and shows a cooling vest which freeze at 14C and stay cool for 2-4h.

One of the most important issues at the moment is registration, documentation and the establishment of a national database of the Ectodermal Dysplasia patients. There is an ongoing research project in the United States, based on the structure discussed at the consensus conference in Charleston last year. This issue is also on the agenda of EURORDIS. The meeting recommends the organization committee for the next ED conference (2012) to have the issue on the agenda and present the results.

4 Information sharing between the groups (*Andrew Williams*)

Has been mentioned in all the other topics

5 Formation of an International group: Are we ready for it? What would be the benefits? (*Diana Perry*)

The issue concerning an international group was discussed in Charleston last year. Mary Kaye sees no need or benefit for an international “umbrella” organization. If the groups in Europe want to go together is that not a question of international concern.

The most important thing is cooperation and concerning research it is essential. Birgitta refers to “Debra International”; an umbrella group whose members are the national associations representing people with EB in their countries. The main functions with DEBRA is to develop treatments for EB by coordinating the research programmes of the member groups and by facilitating close collaboration with the principal EB research teams. The main focuses of current research are gene therapy, cancer in EB, wound healing and clinical research aimed at symptom relief. (<http://www.debra-international.org/old/research.htm>)

The meeting decides to continue the cooperation between the countries and groups.

6 Information and Discussion: The new classification – what’s going on? (*Mary-Kaye Richter*)

The complete documentation from the classification conference will be distributed as soon as possible. The appointed group will meet, but due to lack of financing the time schedule is uncertain.

It is very important that all groups distribute the documentation to all known geneticists, dermatologists etc.

- 7 Centers of expertise - reference centers – where can we find them, do patients can use them beyond the borders? (*Olivia Niclas*)

Olivia has made the preparations for this issue, but had to leave very early for Paris. Ulrike will get the information and send it to all participants.

- 8 Next ED conference: Topics and Venue (*Ulrike Holzer*)

Professor Schneider announced some of the topics for the next ED conference. The meeting finds the following important issues to be taken into consideration for the next ED conference: dermatology, presentation of the research projects and results and Multi Center Collaboration.

Diana means that most lecturers start in the same way – with a summary of the characteristics of ED. It would be good if the conference starts with fundamental information about the diagnosis, and that all lecturers get that information in advance. The lectures can also be varied in time and the first lecture can start a bit earlier than 9.30.

If the advisory board of a group has any suggestions for an issue or theme, send an e-mail to Ulrike.

Birgitta points out that the next conference will be international and multi-professional (not only dentists) and that information about that must be very clear.

The meeting wants the organization committee to consider the date of the conference in 2012. (June is a very busy month in a lot of countries and May might be a better alternative. Ulrike & Birgitta)

Norway will arrange a conference on Quality of Life in 2015!

/HK