International Conference on Ectodermal Dysplasias

A distinguished group of well vested international experts in Ectodermal Dysplasias (EDs) met for second time in Charleston, SC. Representatives from Italy, Norway, France, Sweden, Finland, Ireland, Wales, Germany, Brazil, Switzerland, USA come to discuss new classification approach for ED’s.

Dr. Carlos Salinas, Professor of the Division of Craniofacial Genetics of the College of Dental Medicine was the Chair of the Conference and the PI of the NIH Conference Grant. Mary Fete, Director of Research of the National Foundation for Ectodermal Dysplasias was the Co –Chair.

The Ectodermal Dysplasias is a clinically large and etiological heterogeneous group of genetic disorders characterized by abnormalities in tissues derived from the embryonic ectoderm such as hair, teeth, nails and sweat pores. So far there are over 180 disorders with Ectodermal Dysplasia.

This Conference is a follow up to the 2008 International Conference on the Classification of Ectodermal Dysplasias that was also held here in Charleston SC . Both conferences were supported by NIH-NIDCR Conference Grant and the National Foundation for Ectodermal Dysplasias.

“We clearly understand that the classification of complex disorders is a dynamic and long process. This is particularly true for diverse genetic disorders such as Ectodermal Dysplasias, a large and heterogeneous group of disorders, as we are constantly learning about the new advances in clinical and molecular genetics”.

Indeed the study of the human genome has accelerated the knowledge in gene identification and gene function making this time very appropriate to host a second international conference Salinas said.

“We are interested to further development of systematic approaches of an internet based bioinformatics model that can incorporate classification schemes that have different purposes but that pertain to the same clinical disorders.

Thus we envisioned that the clinical and molecular knowledge will be integrated by using an interactive internet based database that can be accessed by clinicians and scientists.

Salinas further explain; “This can be accomplished using a multi-axis system approach to include a Clinical/ Phenotype axis, a Gene based axis, and a Functional/ Pathways axis.”

The recognition that a multidimensional classification which could serve multiple purposes is a strong driving force in support of this effort. To this end an interdisciplinary group of clinicians and basic science investigators met here in Charleston.

We expect that the conference will result in a new classification that will foster a better understanding of ectodermal dysplasias and will also open up new fields of research. This
classification approach may also end up serving as a model for the classification of other complex disorders.

The Conference was quite successful because by consensus we were able to develop a new clinical criteria for the clinical classification based upon new evidences and we decided to implement the proposed three axis classification.

The implementation will be carried out with the NIH NCBI support and an international network of experts will act as Scientific Advisors.

We also learn from Dr. Kenneth Huttner about the advances made in the treatment approach of the Hypohidrotic Ectodermal Dysplasia X-linked which is the most common of the ED.s The goal here is to translate to humans what the molecular therapy has demonstrate possible in laboratory animals which is a permanent and significant correction of the disease.

Also Dr. Maranke Kostner presented a very sophisticated treatment approach for Hay Wells ( AEC) syndrome in which the goal is to develop new skin from cells from the affected patient and then replace the affected sections of skin with new and healthy skin that will not be rejected.

Both researchers emphasize the importance of implementing a classification approach that will serve the scientists by providing an intellectual and practical guide.

Furthermore we plan to publish the proceedings at the Am. J. Med. Genetics.

In addition to Dr. Salinas , Dr. Michael Kern, Associate Professor MUSC Department of Regenerative Medicine and Cell Biology and Dr Wenle Zhao, Research Associate Professor of the Division of Biostatistics and Epidemiology were invited participants. These faculty are active participants of the Center for Oral Health Research from the College of Dental Medicine.

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