



International Conference for Ectodermal Dysplasia

Session and Presentation Titles

Tuesday 10th June

Session One - Genetics, Taxonomy and “Other Types” of ED

Update on taxonomy

EDA pathway

Mechanistic insights and innovative therapeutic approaches in AEC syndrome

TSPEAR

Session Two – Dental Implants and Oral Health

Implants in ED

Results of the ED Dental/Oral Care study

Session Three - Thermoregulation throughout the lifespan - review.

Management of insufficient thermoregulation in young infants.

Thermoregulation in ED and controls.

Ectodermal dysplasia, thermoregulation and sleep difficulties.

Cooling strategies.

Wednesday 11th June

Session Four – Dermatology

Hair problems in the ectodermal dysplasias

Nail problems in the ectodermal dysplasias

How the Skin is affected in different types of ED

Session Five - Psychology and Social Science.

Lived experience - ‘patient voice’

An Introduction to the Work of Face Equality International

Supporting children and young people with Ectodermal Dysplasia: evidence-based family support

Challenges of living with ED

Caring for the Whole Person: Psychosocial Wellbeing in the Rare Disease Community

Session Six – Poster Presentations

Session Seven - Clinical services //MDTs

Talk on EB services as a model of MDT care

ENT aspects of ED

Transition to Adult Services

Clinical Guidelines on p63

Session Eight – Trials, Treatments and Databases

Update on EDELIFE clinical trial

Predicting the phenotypes from genotypes

NFED Databases

Prevalence Rates in Ectodermal Dysplasias

Rare diseases and public health: improving access to care for families affected by ED

Thursday 12th June - Families and Professionals

Session One – Focus on p63: EEC, AEC, Rapp-Hodgkin etc.

Session Two - Update from scientific meeting

Family/Sibling studies

Implants

XHED Trial

Session Three - Brief presentation followed by panel discussion, leading to a general discussion with Q&As

Speakers

Adam Jackson (Manchester, England)

Amanda Swanson (Columbus, Ohio)

Andrew Messenger (Sheffield, England)

Bertrand Richert (Brussels, Belgium)

Caterina Missero (Naples, Italy)

Celia Moss (Birmingham, England))

Clark Stanford (Iowa, USA)

Clayton Butcher (Missouri, USA)

Denis Headon (Roslin Institute, Edinburgh, Scotland)

Edvin Boije (virtual) (Indikator)

Filippo Cavallari (Italy)

Gabriela Petrof (UCL, London, England)

Giulia Volpato (Italy)

Hannah Harpin (England)

Heather Massey (Portsmouth, England)

Holm Schneider (Erlangen, Germany)

Kirsten Fitzgerald (Dublin, Ireland)

Laura de Rosa (Italy)

Lucie Griffon (Necker, Paris)

Maia Thornton (UWE, Bristol, England)

Marie-Louise Lovgren (Birmingham, England)

Mario Vincenzo Di Iorio (Italy)

Martin Barwood (Leeds Trinity, England)

Mary Fete (NFED, USA)

Michael Kuo (Birmingham, England)

Mike Harrison (Guy's and St Thomas's, London, England)

Mike Tipton (Portsmouth, England)

Nicolai Peschel (Erlangen, Germany)

Pascal Schneider (Switzerland)

Patricia Marik (Wisconsin, USA)

Phyllida Swift (Face Equality International)

Raquel Dias (Brazil and Canada)

Sarah McKaig (Birmingham, England)

Smail Hadj-Rabia (Necker, Paris)

Tess McPerson (Oxford, England)