



International Conference for Ectodermal Dysplasia

**Scientific Programme for ICED25: 10th-11th June 2025, Birmingham
(Current Status as of 18th February 2025.)**

**Tuesday
10th**

Day One

09.30: Registration and Tea/Coffee/Pastries.

10.30 - 11.00: Welcome from Diana Perry CEO and Founder of the ED Society.

11.00 - 12.30: Session One

Genetics, Taxonomy and “Other Types” of ED (Chair: Professor Angus Clarke, Cardiff University, UK.)

11.00: Nicolai Peschel, Erlangen – Update on taxonomy.

11.20: Denis Headon at Roslin - On the EDA pathway.

11.40: Caterina Missero (Italy) – Mechanistic insights and innovative therapeutic approaches in AEC syndrome.

12.00: Adam Jackson – TSPEAR.

12.20: Discussion.

12.30-14.00: Lunch.

14.00 - 15.30: Session Two

Dental Implants and Oral Health (Chairs: Sarah McKaig, Mike Harrison, Kirsten Fitzgerald – UK.)

14.00: Clark Stanford, Iowa – New approaches in dental management of the Ectodermal Dysplasias.

1.45 Edvin Boije (virtual): the first results of the ED Dental/Oral Care study.

15.05: Mike Harrison (UK): UK Age and Region Implant Survey.

15.15: Discussion.

15.30-16.00: Tea/Coffee/Pastries.

16.00 - 17.30: Session Three

Thermoregulation throughout the lifespan (Chair: Professor Mike Tipton, Portsmouth University, UK.)

16.05: Professor Holm Schneider (Erlangen) - Management of insufficient thermoregulation in young infants.

16.25: Heather Massey (Portsmouth UK) - Thermoregulation in ED and controls.

16.45: Lucie Griffon (Necker, Paris) - Ectodermal dysplasia, thermoregulation and sleep difficulties.

17.05: Martin Barwood (Leeds Trinity, UK) - Cooling strategies.

18.00: Reception.

Wednesday Day Two

11th

09.00 - 10.30: Session Four

Dermatology (Chairs: Dr. Gabriela Petrof and Professor Celia Moss - UK.)

09.00: Andrew Messenger (Sheffield, UK) - Hair in the ectodermal dysplasias.

09.30: Bertrand Richert - Nails in the ectodermal dysplasias.

10.00: Dr. Gabriela Petrof and Marie-Louise Lovgren (UK) - How the Skin is affected in different types of ectodermal dysplasia.

10.30-11.00: Tea/Coffee/Pastries.

11.00 - 12.30: Session Five

Psychology and Social Science (Chair: Maia Thornton - UWE, Bristol.)

11.00: Hannah Harpin (ED Society UK Ambassador) - Lived experience/ 'patient voice'.

11.10: Phyllida Swift - An Introduction to the Work of Face Equality International.

11.30: Maia Thornton - Supporting children and young people with Ectodermal Dysplasia: evidence-based family support.

11.50: Raquel Dias - Challenges of living with ED.

12.10: Patricia Marik - "Caring for the Whole Person: Psychosocial Wellbeing in the Rare Disease Community".

12.30-13.30: Lunch.

13.30 – 14.40: Session Six

Poster Presentations.

14.45 - 16.15: Session Seven

Clinical services/MDTs (Chair: Professor Celia Moss - Birmingham, UK.)

14.45: Dr. Gabriela Petrof - Models of MDT care.

15.05: Michael Kuo - ENT aspects of ectodermal dysplasia.

15.25: Tess McPherson - Transition from paediatric to adult services.

15.45: Smail Hadj-Rabia – Clinical Guidelines on p63.

16.05: Discussion.

16.15- 16.45: Tea/Coffee/Pastries.

16.45 - 18.15: Session Eight

Trials, Treatments and Databases (Chair: Professor Holm Schneider - Erlangen.)

16.45: Professor Holm Schneider - Update on the EDELIFE clinical trial.

17.10: Pascal Schneider (Lausanne) - Predicting the *EDA* phenotype from genotypes.

17.35: Mary Fete (NFED) - Result of the international research conference and how we use our databases.

17.40: Clayton Butcher - Prevalence Rates in Ectodermal Dysplasias.

18.00: Amanda Swanson - Rare diseases and public health: improving access to care for families affected by Ectodermal Dysplasias.

19.00: Buffet Supper and Entertainment.