

Symposium on Epidermal Differentiation Disorders 16-17 September 2025

Concept of program

Day 1 - 16 September – Expert meeting on epidermal differentiation disorders (EDD)

Location: Hotel Le Louis, Versailles

9:25–17:00h

9:25 Welcome

Julia Clabbers

09:30-12:30 What is important in EDD

09:30- 09:40 Session introduction

Angela Hernandez-Martin and Edel O'Toole

09:40-10:40 Overview of different topics relevant for EDD:

- Recent developments – most important literature 2020-2024 in overview – 10 min
- Knowledge gaps – what we don't know – 10 min
- Diagnostic challenges – 10 min
- Education goals – 10 min
- Patient perspectives – 10 min
- Research targets (psychosocial research, therapeutic research) – 10 min

10:40-11:10 and 11:30-12:30 Discussion on the abovementioned topics in small groups

(11:10-11:30 coffee break)

12:30-13:30 Core outcome set for ichthyosis.

Chairs: *Antoni Gostynski and Juliette Mazereeuw-Hautier*

- 12:30-12:45 Introduction of the project and the process
- 12:45-13:00 Information on the selected domains and outcomes
- 13:00-13:30 Group discussion on selected domains and outcomes for Round I of Delphi and Invitation for Delphi round 1

13:30-14:30 Lunch

14:30 – 17:00 Discussion

Chairs: *Eli Sprecher and Amy Paller*

- 14:30-16:00 Presentation on focus points from group discussions in the morning by table leaders and discussion per item
- 16:00-17:00 Finalize the goals for the upcoming years and brainstorming for new collaborative research initiatives

+/- 17:00-23:00 – Drinks, dinner, and social networking session



Organising committee

Drs. Julia Clabbers, Maastricht University Medical Center +, The Netherlands

Dr. Antoni Gostynski, Maastricht University Medical Center +, The Netherlands

Prof. Juliette Mazereeuw-Hautier, CHU Toulouse, France

Dr. Angela Hernández-Martín, Hospital Infantil Universitario Niño Jesús, Madrid, Spain

Prof. Edel O'Toole, Royal London Hospital, UK

Prof. Eli Sprecher, Tel Aviv Sourasky Medical Center, Israel

Prof. Amy Paller, Ann and Robert H. Lurie Children's Hospital of Chicago, USA

EADV venue

17th September

10:15-11:45

Edel O'Toole – EDD classification – introduction and palmoplantar EDDs

Judith Fischer – EDD classification – non syndromic EDDs and syndromic EDDs

Juliette Mazereeuw – new management guidelines and biologics

To be confirmed – New in EDD group – ATP2A2-nEDD and ATP2C1-nEDD

Fauve van Veen – Quality of life in EDDs and reproductive dilemma's

Amy Paller – Future therapies in EDDs

Eli Sprecher – summary from first EDDs symposium and future research agenda