

8th

INTERNATIONAL CONFERENCE ON ECTODERMAL DYSPLASIAS

PRELIMINARY PROGRAM 9th to 11th JUNE 2022

JUNE 09th

CITE INTERNATIONALE UNIVERSITAIRE DE PARIS
FIRST WORLD CONGRESS ON RARE SKIN DISEASES

13h - 14h

WELCOME ATTENDEES

Lunch

14h15 - 15h15

WORKSHOP 29 - ECTODERMAL DYSPLASIAS

Chairs : Smail Hadj-Rabia, Holm Schneider - confirmed

14h15 Introduction to the classification of ectodermal dysplasias
Angus Clarke (Cardiff, UK)

14h35 Ectodermal dysplasias : Management
Gianluca Tadini (Milan, Italy) - confirmed

14h55 Ectodermal dysplasias : Perspectives
Holm Schneider (Erlangen, Germany) - confirmed

15h15 - 15h30

COFFEE BREAK

15h30 - 16h

WELCOME TO ED2022 CONFERENCE

16h - 16h30

FAMILY TESTIMONIAL

Antoine Deschamps

16h30 - 18h

ECTODERMAL DYSPLASIA UPDATES

Chairs : Maranke Koster, Angus Clarke - confirmed

16h30 Update in clinics - *Smail Hadj-Rabia (Paris, France) - confirmed*

17h From clinical observations to molecular pathology of ectodermal dysplasias - *Maranke Koster (Greenville, NC, United States) - confirmed*

17h30 Ocular manifestations and management : Update
Serge Doan (Paris, France) - confirmed



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#ED2022



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8th

INTERNATIONAL CONFERENCE
ON ECTODERMAL DYSPLASIAS

9h - 9h15

WELCOME ATTENDEES

Welcome coffee

9h15 - 10h45

MUCOUS MEMBRANES

Chairs : Gianluca Tadini, Jannicke Liaaen Jensen - confirmed

9h15 Update in lower airways manifestations - Rola Abou Taam (Paris, France) - confirmed
- confirmed

9h45 Phonation in ED patients - Marion Semmler (Erlangen, Germany)

10h15 Dry mouth and oral health-related quality of life in various conditions including ED - Jannicke Liaaen Jensen (Oslo, Norway) - confirmed

10h45 - 11h

PARENT OBSERVATION

Claudia Alexa - confirmed

11h - 11h30

COFFEE BREAK

11h30 - 12h30

INCONTINENTIA PIGMENTI

Chairs : Christine Bodemer, Jacques Monnet - confirmed

PROGRAM TO BE DEFINE

12h30 - 13h30

LUNCH BREAK

13h30 - 15h30

DENTAL CARE SESSION

Chairs : Marie-Cécile Manière, Johanna Norderyd - confirmed

13h30 Dental care updates - Johanna Norderyd (Jönköping, Sweden) - confirmed

14h Pre-implant orthodontics - Brunilda Dharmo (Rotterdam Netherlands) - confirmed

14h30 Implant rehabilitation in patients with ectodermal dysplasia, digital surgery and virtual planning. Treatment strategies. Dr. José Ignacio Salmerón Escobar (Madrid, Spain) - confirmed

15h Perspectives in dental Care - Muriel de la Dure Molla (Paris, France) - confirmed

15h30 - 16h

COFFEE BREAK

16h - 18h30

WORKSHOP SESSION

16h Inspirational talk
Workshop introductions : Future collaborations for international community.

16h30 Workshop :

Workshop 1 : XLHED women carriers: diagnosis and management
Workshop 2 : Recommendations for P63-related ED management and care
Workshop 3 : Oral and mucosal issues in ED patients
Workshop 4 : Wound healing in ED patients

18h Conclusion of the day

JUNE 10th

INSTITUT IMAGINE
AND NECKER-ENFANTS MALADES HOSPITAL

TRAINING SESSION

9h30 - 12h30

Plenary session and training session are joint

13h - 15h

COURSES

13h Testimony - Alan Vermant

13h30 What are ectodermal dysplasias ?
Tim Wright (Chapel Hill, North Carolina, USA)

14h **ED : Clinical characterization and management**
1- Hypo / anhidrotic ED - Gianluca Tadini (Milan, Italy) - confirmed
2- P63 related ED - Smail Hadj-Rabia (Paris, France) - confirmed
3- Incontinentia Pigmenti - Christine Bodemer (Paris, France) - confirmed

15h30 - 16h00

BREAK

16h - 18h30

COURSES

16h Dental care - François Clauss (Strasbourg, France) - confirmed

16h45 Ophthalmological care and management - Serge Doan / Sarah Michel (Paris, France) - confirmed

17h30 ED : Perspectives - Holm Schneider (Erlangen, Germany) - confirmed

18h00 Conclusion - Virginie Counioux (Paris, France) - confirmed



8th

INTERNATIONAL CONFERENCE
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JUNE
11th

INSTITUT IMAGINE
AND NECKER-ENFANTS MALADES HOSPITAL

8h - 8h15

WELCOME ATTENDEES

Welcome coffee

8h15 - 9h30

DAILY LIFE SESSION

Chairs : Virginie Counioux, Jose Montoya, Mary Fete

8h15 Support parents of children with appearance affecting conditions and injuries / Stigma (supporting families & relatives)
Maia Thornton (UK)

8h45 Burden of disease and cost living : The example of Ectodermal dysplasias - *Dr. Ester Moreno-Artero (Madrid, Spain) - confirmed*

9h Reproductive decision making - *Busra Leo (Erlangen, Germany)*

9h30 - 10h20

PERSPECTIVE SESSION 1

Chairs : Encarna Guillen-Navarro, Smail Hadj-Rabia - confirmed

9h30 Next generation Sequencing: ED Diagnosis and new Genes
Encarna Guillen-Navarro (Murcia, Spain) - confirmed

9h50 Trials and perspectives - *Holm Schneider, Pierre Fabre, Esperare - confirmed*

10h20 - 10h30

COFFEE BREAK

10h30 - 11h15

PERSPECTIVE SESSION 2

Chairs : Ulrike Holzer, Smail Hadj-Rabia

WORKSHOP DEBRIEFS 10 MN PER DEBRIEF
+ 10 MINUTES DISCUSSIONS

11h15

NEXT ED CONFERENCE PRESENTATION

11h30

CONCLUSION

