

1ST ANDO CONGRESS

LEIRIA 2021

Lisbon Time
GMT+1

SKELETAL DISPLASIAS - THE PERSON AND SOCIETY

SATURDAY // SEPTEMBER 11

Visit Leiria

- 10H30 Tourist Route 1
- 11H30 Tourist Route 2
- 13H30 Congress Secretariat

14H30 Opening Session

Pedro Morouço (ESECS Director)

Inês Alves (ANDO Portugal)

Carolina Lemos (Scientific Commission)

- 14H45 Widening Horizons - ANDO Delegation in Madeira

Cláudia Aguiar

Session 1 - Clinical Centers with Expertise in Skeletal Dysplasias

Moderation - *Inês Alves*

- 15H00 The European Reference Network for Rare Bone Disorders - ENR BOND (EN)

Luca Sangiorgi (ERN BOND Coordinator) - Italy

- 15H25 Multidisciplinary Care for Skeletal Dysplasias Outclinic in 2 Main Hospitals (Pediatric & Adult)

Sérgio Sousa (Coimbra Pediatric hospital)

André Travessa (S. Maria Hospital - Lisbon)

Session 2 - Innovative Medicines Session

Moderation - *Carolina Lemos*

- 15H50 Stages and Process of Approval of Innovative Medicines for Skeletal Dysplasias (EN)

António Leiva (Quiron Hospital) - Spain

- 16H10 Impact on Quality of Life - Burosumab for XLH

Telma Francisco (Hospital D. Estefânia - Lisbon)

- 16H30 Coffee Break

Session 3 - Research in Skeletal Dysplasias

Moderation - *Inês Alves*

- 17H00 Pioneering Research in Collagenopathies Type 2 (EN)

Elvire Gouze (Innoskel CEO) - France

- 17H25 The QoLA Study - Experiences of Parents of Children with Achondroplasia (EN)

Julia Quitmann (Hamburg Hospital) - Germany

- 17H50 Functioning and Well-Being of Children with Achondroplasia - Global Study Outcomes (EN)

Alden Smith (Ascendis Pharma) - USA

- 18H20 Closure - Day 1

- 20H00 Congress Dinner



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SUNDAY// SEPTEMBER 12

Session 4 - Multidisciplinary Care in Skeletal Dysplasias

Moderation - *Inês Alves*

10H00 Everyday Mobility and Symptoms for Skeletal Dysplasias - **(EN)**

Penny Ireland (Queensland Children's Hospital) - Australia

10H30 New International Guideline for Achondroplasia - Lifelong Care

Sérgio Sousa (Coimbra Pediatric hospital)

André Travessa (S. Maria Hospital - Lisbon)

10H50 Orthodontics and Craniofacial Corrections in Skeletal Dysplasia

Ana Roseiro (Faculty of Dental Medicine - Coimbra University)

11H15 Coffee Break

11H40 Pregnancy in Skeletal Dysplasia

Speaker TBA

12H10 Peer Acceptance of Physical Difference in Children - National Project "It Is What It Is"

Sofia Duarte (Academia de Produtores Culturais)

12H45 Lunch

Session 5 - Open Conversations

14H20 Living the Diagnosis

Lia Silva (ANDO Portugal)

15H20 Influence of the Family in the Transition from Adolescence to Youth

Margarida Custódio dos Santos (Faculty of Psychology - Lisbon University)

16H20 Reflections and Clousure

Inês Alves (ANDO Portugal)

