



2^o Simpósio de Genodermatoses

Lisboa, Vip Executive Art's Hotel
31 de Maio, 1 de Junho

Secretariado Científico:

Dr^a Carolina Gouveia

Prof. Carla Sá Couto

Dr. Vasco Sousa Coutinho

Comissão Organizadora:

Debra - Associação Portuguesa de Epidermólise Bolhosa

Aspori - Associação Portuguesa de Portadores de Ictiose

Centro Hospitalar de Lisboa Norte, EPE

Hospital CUF Descobertas

Inscrições:

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Sponsors:

 ISDIN

 Pierre Fabre

Secretariado:
 agimus
gestão de eventos

Programa Preliminar

Friday, May 31st



- 13h00 - 14h00 **Welcome and registration**
- 14h00 - 14h30 **Opening**
Prof. Américo Figueiredo
President of the Portuguese Society of Dermatology and Venereology, Portugal
Prof. Alberto Mota
President of the Portuguese Group of Pediatric Dermatology, Portugal
Prof. Louis Dubertret
President of Genodermatoses et Mediterané, Fondation René Touraine, France
Prof. Maria do Céu Machado
Clinical Director, Centro Hospitalar Lisboa Norte, Portugal
Prof. Jorge Mineiro
Clinical Director, of Hospital CUF Descobertas, Portugal
- 14h30 - 15h30 **Hereditary Ichthyosis**
Classification and Clinical Manifestations
Prof. Christine Bodemer
MAGEC Coordinator, Hospital Necker Enfants Malades, France
Caring of ichthyosis skin - practical aspects
Prof. Christine Bodemer
MAGEC Coordinator, Hospital Necker Enfants Malades, France
- 15h30 - 16h00 **Genodermatoses: From etiopathogenesis to prenatal diagnosis**
Prof. Ana Berta Sousa
Department of Medical Genetics, Centro Hospitalar Lisboa Norte, Portugal
- 16h00 - 16h30 **Coffee-break and "meet the experts"**
- 16h30 - 17h10 **Classification and overview of Epidermolysis Bullosa**
Dr. Jemima Mellerio
Guy's and St Thomas' NHS Foundation Trust, St Thomas' Hospital, UK
- 17h10 - 18h00 **Clinical manifestations and complications in newborns and children with EB: OPBG experience with multidisciplinary approach**
Prof. Maya El-Hachem
Ospedale Pediatrico Bambino Gesù (OPBG), Italy

Workshop - Wound care in EB

Saturday, June 1st, 11h30 - 13h

EB Nurse Jackie Denyer, Great Ormond Street Hospital, Debra UK, UK

Limited seats

Equipment kindly provided by Biomedical Simulation Center of Faculty of Medicine of University of Porto

Educative session for EB families (session in Portuguese/Spanish),

Saturday, June 1st, 14h-15h30

Nurse Joan Enric Torra (MSc), Iberian Clinical Manager of the Advanced Wound Care Division of Smith&Nephew

Limited seats

Offered by Smith&Nephew

Saturday, June 1st

- 08h00 - 09h00 **Welcome**
- 09h00 - 09h40 **Wound care in EB**
Nurse Jackie Denyer
Great Ormond Street Hospital, Debra UK, UK
- 09h40 - 10h10 **Skin cancer in the adolescents and adults with EB**
Dr. Jemima Mellerio
Guy's and St Thomas' NHS Foundation Trust, St Thomas' Hospital, UK
- 10h10 - 10h30 **Electrochemotherapy in squamous cell carcinoma: IPO experience**
Dr. Vítor Farricha
Instituto Português de Oncologia (IPO), Portugal
- 10h30 - 11h00 **Living with ichthyosis**
Vera Beleza
President of ASPORI - Portuguese Association of ichthyosis, Portugal
- 11h00 - 11h30 **Coffee-break and Vera Beleza's book launching venue**
- 11h30 - 11h50 **EB and ichthyosis organization in Spain**
Prof. Antonio Torrelo
Hospital Niño Jesús, Madrid
- 11h50 - 12h20 **Psychological aspects of having a child with a severe genodermatose**
Dr. Sandra Matos
Department of Pedopsychology, Centro Hospitalar Lisboa Norte, Portugal
- 12h20 - 13h00 **Ophthalmic aspects of genodermatoses**
Clinical manifestations and therapeutics
Dr. Lígia Cardoso
Centro Hospitalar Universitário de Coimbra, Portugal
- Ectropion surgery**
Dr. Miguel Correia
Hospital CUF Descobertas, Lisbon, Portugal
- 13h00 - 14h00 **Lunch**
- 14h00 - 14h30 **Oral care in EB**
Dr. Concepción Serrano
Private Practice, Valencia, Spain
- 14h30 - 15h00 **Nutritional support in EB**
Ita Saul, Dietitian
Our Lady Hospital for Sick Children, Dublin, Ireland
- 15h00 - 15h30 **Hand surgery in EB**
Dr. Gill Smith
Guy's and St. Thomas' NHS Foundation Trust, Great Ormond Street Hospital, UK
- 15h30 - 16h00 **Physical rehabilitation in EB**
Dr. Ana Cadete
Hospital CUF Descobertas, Lisbon, Portugal
- 16h00 - 16h30 **National registry of EB: preliminary results / Debra Portugal**
Prof. Carla Sá Couto
Faculdade de Medicina da Universidade do Porto, President of Debra Portugal, Portugal
- 16h30 - 16h45 **Coffee-break**
- 16h45 - 17h45 **Thematic round tables**
- 17h45 - 18h00 **Closing**