



# 2<sup>o</sup> Simpósio de Genodermatoses

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

Secretariado Científico:

Dr.<sup>a</sup> 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

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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 Méditerranée, Fondation René Touraine, France*  
**Prof. Maria do Céu Machado**  
*Clinical Director of 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*  
**Diagnosis**  
**Prof. Christine Bodemer**  
*Hospital Necker Enfants Malades, France*
- 15h30 - 16h00 **Genodermatoses: From etiopathogenesis to prenatal diagnosis**  
**Prof. Ana Berta Sousa** (to be confirmed)  
*Department of Medical Genetics, Centro Hospitalar Lisboa Norte, Portugal*
- 16h00 - 16h30 **Coffee-break and “meet the experts”**
- 16h30 - 17h00 **Caring of ichthyosis skin - practical aspects**  
**Prof. Christine Bodemer**  
*MAGEC Coordinator, Hospital Necker Enfants Malades, France*
- 17h00 - 17h40 **Classification and overview of Epidermolysis Bullosa**  
**Dr. Jemima Mellerio**  
*Guy's and St Thomas' NHS Foundation Trust, St Thomas' Hospital, UK*
- 17h40 - 18h00 **Oral care in EB patients**  
**Dr. Paulo Nickel**  
*Hospital CUF Descobertas, Lisbon, Portugal*

### Workshop - Wound care in EB

Saturday, June 1st, 11h30 - 13h

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

Limited seats

## Saturday, June 1st

- 08h00 - 09h00 **Welcome**
- 09h00 - 09h40 **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*
- 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 - 10h20 **Electrochemotherapy in squamous cell carcinoma: IPO experience**  
**Dr. Vítor Farricha**  
*Instituto Português de Oncologia (IPO), Portugal*
- 10h20 - 11h00 **Wound care in EB**  
**Nurse Jackie Denyer**  
*Great Ormond Street Hospital, Debra UK, UK*
- 11h00 - 11h30 **Coffee-break and “meet the experts”**
- 11h30 - 11h50 **Living with ichthyosis**  
**Vera Beleza**  
*President of ASPORI - Portuguese Association of ichthyosis, Portugal*
- 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 **Gastrointestinal complications in EB (to be confirmed)**
- 14h30 - 15h00 **Nutritional support in EB**  
**Lynne Hubbard, Dietitian**  
*St. Thoma's Hospital, UK*
- 15h00 - 15h30 **Hand surgery in EB**  
**Dr. Gill Smith**  
*St. Thoma's 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*
- 16h45 - 17h00 **Coffee-break**
- 16h45 - 17h45 **Thematic round tables**
- 17h45 - 18h00 **Closing**