

DNA DAY 2012

1st Meeting of ORPHANET-Portugal on Rare Diseases and Orphan Drugs and Regulation of Genetic Testing

20 APRIL | 14h00 - 18h00
IBMC AUDITORIUM | PORTO
FREE ENTRANCE



ORPHANET-Portugal was recognised by the Portuguese Ministry of Health as the official portal for information on rare diseases and orphan drugs

Organization: ORPHANET-PORTUGAL:
Jorge Sequeiros (national coordinator) Jorge Pinto Basto (projector manager) and Sandra Peixoto (information scientist)
Location: Instituto de Biologia Molecular e Celular | Rua do Campo Alegre, 823, 4150-180 Porto | tel: +351 22 607 49 00

DNA DAY 2012

1st Meeting of ORPHANET-Portugal on Rare Diseases and Orphan Drugs and Regulation of Genetic Testing

20 APRIL | IBMC AUDITORIUM | PORTO | FREE ENTRANCE

11h00-13h00 Meeting of the Scientific Advisory Board of ORPHANET-PT followed by snack-lunch and discussion: reserved to ORPHANET team and its SAB members

14h00-14h20 Official Opening

Secretário de Estado Adjunto do Ministro da Saúde, Dr. Leal da Costa
Presidente da ERS (Entidade Reguladora da Saúde), Prof. Jorge Simões
Diretor-Geral da Saúde, Dr. Francisco George
Vice-Presidente da ACSS (Administração Central do Sistema de Saúde), Dr. Rui Santos*
Presidente do INSA (Instituto Nacional de Saúde Dr. Ricardo Jorge), Prof. Pereira Miguel
Presidente do INFARMED (Autoridade Nacional do Medicamento e Produtos de Saúde I.P.), Prof. Jorge Torgal
Ordem dos Médicos, Membro da Direção da SRN
Presidente da FCT (Fundação para a Ciência e Tecnologia), Prof. Miguel Seabra
CEIC (Comissão de Ética para a Investigação Clínica), Drª Margarida Lima
Diretor do IBMC, Prof. Claudio Sunkel

I. RARE DISEASES AND NATIONAL PLANS FOR RARE DISEASES IN PORTUGAL AND IN EUROPE

14h20 ORPHANET and EUCERD and the National Plans for Rare Diseases and Orphan Drugs in Europe
Keynote speaker: Pr. Ségolène Aymé, INSERM, France; Founder of ORPHANET, Director of EUCERD (EC)
(moderator: Profª Heloísa Santos)

Round-table: Rare Diseases and Orphan Drugs in Portugal (moderator: Dr. Francisco George)

14h50 National Plan for Rare Diseases in Portugal, Centres of Reference and RD Cards - Enfª Fernando Guerra (Dir.-Geral Saúde)

15h00 Regulation of Orphan Drugs in Portugal - Prof. Jorge Torgal (Presidente, INFARMED)

15h10 Research Programmes in Portugal on Rare Diseases and Orphan Drugs - Drª Anabela Isidro (FCT)

15h20 General Discussion with the participation of Pr. Ségolène Aymé, health authorities, regulators, professionals and federations of patients' associations

16h00 Coffee-break

II. QUALITY AND REGULATION OF GENETIC TESTING IN PORTUGAL

Round-table: Regulation of Offer and Quality of Medical Genetic Testing in Portugal (moderator: Prof. Jorge Torgal)

16h15 OCDE BP Guidelines for MGT and the CoE Additional Protocol on Genetic Tests for Health Purposes - Prof. Jorge Sequeiros (ORPHANET-PT)

16h35 Quality of genetic testing - Prof. Manuel Teixeira (President, Sociedade Portuguesa de Genética Humana)

16h45 Licencing and accreditation of medical genetics laboratories - Dr. João Gonçalves (Molecular geneticist, INSA)

16h55 Quality of Medical Genetics Services - Profª Purificação Tavares (Colégio de Genética Médica, Ordem dos Médicos)

17h05 Regulatory aspects - Dr Nina Sousa Santos (Jurist, Direção-Geral Saúde)

17h15 General Discussion with the participation of health authorities, regulators, professionals, patients associations representatives (Aliança and FEDRA) and representatives of parliament political parties (PSD- Dr. Miguel Santos*, PS- Drª Maria de Belém Roseira, CDS-PP - Dr. João Moreira Pinto, PCP*, BE- Dr. João Semedo, PEV, Drª Heloísa Apolónia*)

18h00 End of the meeting and “Douro de Honra”: presentation of “Prize Rola-Braz” and launch of Douro wine “Quinta de Remostias”

Organization: ORPHANET-PORTUGAL
Jorge Sequeiros (national coordinator) Jorge Pinto Basto (projector manager) and Sandra Peixoto (information scientist)
Location: Instituto de Biologia Molecular e Celular | Rua do Campo Alegre, 823, 4150-180 Porto | tel: +351 22 607 49 00

* to be confirmed



PARCERIAS



APOIO

