EPPOSI
European Platform for Patients' Organisations, Science and Industry

# 10th WORKSHOP ON PARTNERING FOR RARE DISEASE THERAPY DEVELOPMENT
# 10 years after the Adoption of the EU Orphan Medicines Regulation: Where do we go to?

**Belgian Federal Parliament - Brussels, Belgium**
**-**
**Monday 26 - Tuesday 27 October 2009**

## PRELIMINARY PROGRAMME

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## MONDAY 26 OCTOBER

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| 13.00 | **Registration opens** |

### OPENING

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| 14.30 | **10 years of Partnering for rare disease therapy development**<br>Alastair Kent, Chair EPPOSI<br>HI&RH Princess Astrid of Belgium<br>Laurette Onkelinx, Minister for Social Affairs and Public Health |
| 15.30 | **Break** |

### SESSION 1 – IMPACT OF THE ECONOMIC CRISIS ON THE FIELD OF RARE DISEASES: WHAT IS THE IMPACT ON R&D, DIAGNOSIS AND ACCESS?

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| **Sessions Moderators:** | Alastair Kent, Chair EPPOSI<br>Erik Tambuyzer, Vice Chair EPPOSI |
| 16.00 | **Panel Discussion**<br>Terkel Andersen, EURORDIS - Denmark<br>Androula Vassiliou, European Commission<br>Jo De Cock, INAMI - Belgium<br>Willem van Weperen, to-BBB – the Netherlands<br>Timothy M. Cox, University of Cambridge (TBC)<br>Heinrich Schulte, Hamburg, Germany |
| 17.00 | **Discussion with the audience** |
| 18.00 | **End of Day 1** |
| 19.30 | **Reception and Dinner** |

## TUESDAY 27 OCTOBER

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| 8.00 | **Doors Open** |

### SESSION 2 – BUILDING ON THE POLICY BASE OF THE LAST 10 YEARS TO ADVANCE POLICY IN THE NEXT 5 YEARS

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| **Sessions Moderators:** | Yann Le Cam, EURORDIS<br>Giulia Del Brenna, European Commission (TBC) |

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| 8.30 | **Introduction/Overview**<br>Yann Le Cam, EURORDIS |
| 8.50 | **How to increase the number of Rare disease therapies under Research & Development to cover unmet medical needs?**<br>Kerstin Westermark, EMEA<br>Ségolène Aymé, Orphanet<br>**Panel:**<br>Ruxandra Draghia-Akli, European Commission (TBC)<br>Pauline Evers, Nederlandse Federatie van Kankerpatientenorganisaties (NFK)<br>Discussion with the audience |
| 10.00 | **Break** |
| 10.30 | **How to improve the success rate of OD Development between Orphan Drug Designation (ODD) and Marketing Authorisation?**<br>Katerina Kubackova, University Hospital of Motol (TBC)<br>Jordi Llinares, EMEA, (TBC)<br>**Panel:**<br>Tim Coté, FDA (TBC)<br>Discussion with the audience |
| 11.40 | **How to provide sustainable access to OMP at national level?**<br>Wills Hughes-Wilson, Genzyme<br>Andrea Rappagliosi, GlaxoSmithKline<br>**Panel:**<br>Mattias Neyt, KCE<br>Brian O'Mahony, European Haemophilia Consortium<br>Discussion with the audience |
| 12.50 | **Lunch** |

## SESSION 3 – RARE CANCERS

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| **Session Moderators:** | Paolo Casali, ESMO<br>Jean-Jacques Cassiman, ESHG |
| 14.00 | **Introduction**<br>Dominique Maraninchi, Institut National du Cancer – France (TBC)<br>Jean-Jacques Cassiman, ESHG |
| 14.10 | **How to address the needs of Patients with rare cancers? – Commonalities and differences with rare diseases.**<br>Paolo Casali, European Society for Medical Oncology<br>Kerstin Westermark, EMEA/COMP<br>Sandy Craine, CML Advocates Networ<br>Markus Wartenberg, Das Lebenshaus<br>Industry representative (TBI) |
| 14.35 | **Questions and Answers** |
| 14.45 | **Methodology, Clinical research and therapy development**<br>Jean-Yves Blay, Conticanet<br>Jan Lilliemark, Swedish Medicines Agency<br>Jan Geissler, ECPC<br>Industry representative (TBI) |
| 15.10 | **Questions and Answers** |
| 15.20 | **Break** |
| 15.50 | **Access (to information, timely and correct diagnosis, therapies including centres of excellence/HTA/reimbursement/multidisciplinary teams, patient mobility, etc)**<br>David Levy, Sheffield Teaching Hospitals<br>Alberto Costa, European School of Oncology (TBC)<br>Kathy Oliver, International Brain Tumour Alliance<br>Industry representative (TBI)<br>Nick Fahy –European Commission (TBC) |
| 16.15 | **Questions and Answers** |

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| 16.25 | **Discussion with the audience**<br>*Where are we? What have we achieved on the RT conference recommendations? What should we jointly do as next actions?* |
| **Chairs:** | Paolo Casali, European Society for Medical Oncology (ESMO)<br>Jean-Jacques Cassiman, ESHG |

## CLOSING SESSION

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| 17.00 | **Conclusions and Next Steps**<br>Alastair Kent, Chair EPPOSI<br>Erik Tambuyzer, Vice Chair EPPOSI |
| 17.20 | **End of the Workshop** |

For additional information about our activities:
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