

9:00 am WELCOME & OPENING REMARKS

9:00 am - 9:30 am (local time)

PONENTES

- Ignacio Para Rodríguez-Santana, Presidente, Fundación Bamberg (Spain)
- Stelios Kypouropoulos, Member of the European Parliament, Greece, (Belgium) *
- Fátima Matute Teresa, Consejera, Sanidad de la Comunidad de Madrid (Spain) *

9:30 am GOVERNMENT PLANS

National Plans, Policies and Government Initiatives Addressing Rare Diseases

9:30 am - 10:15 am (local time)

PONENTES

- Alexander Natz, Secretary General, European Confederation of Pharmaceutical Entrepreneurs (EUCOPE) (Belgium)
- Gianni d'Errico, Vice-Chair, ICPeMed – International Consortium for Personalised Medicine (Italy)
- Francesc Palau Martínez, Scientific Coordinator of the Strategy for Rare Diseases, National Health System (Spain)
- Domenica Taruscio, Former Director National Centre for Rare Diseases, President Study Centre KOS – Science, Art, Society, Istituto Superiore di Sanità Italia (Italy)
- Magdalena Daccord, Chief Executive, FH Europe Foundation (Switzerland)

MODERACIÓN

- Alexis Arzimanoglou, Coordinator European Reference Network on Rare and Complex Epilepsies, ERN EpiCARE

10:15 am SOCIAL & PATIENT

The Patient's Voice as a Driver for Access and Drug Approvals

10:15 am - 11:00 am (local time)

PONENTES

- Ilaria Galetti, VicePresident, FESCA (Federation of European Scleroderma Associations) (Italy)
- Marie-Christine Ouillade, French Muscular Dystrophy Association, AFM-Téléthon (France)
- Antoni Montserrat, VicePresident, ALAN Maladies Rares Luxembourg (Luxembourg)
- Jean-Philippe Plançon, Vice-Président, Alliance Maladies Rares (France)
- Sarah Khor, Director, EU Advocacy and Government Affairs Lead, Horizon Therapeutics, now part of Amgen

MODERACIÓN

- Alastair Kent, Chair of the UK Rare Disease Forum. Chair of the Rare Disease Advisory Group (RDAG) for NHS England, RDAG (United Kingdom)

11:00 am COFFEE BREAK AND NETWORKING

11:30 am TECHNOLOGIES OVERCOMING RD CHALLENGES

The Role of Technology in Rare Disease-Specific Registry and Diagnostic

11:30 am - 12:15 pm (local time)

PONENTES

- Antonio Alarcó, Catedrático, Director de la Cátedra de Telemedicina, Robótica y Telecirugía, Universidad de La Laguna (Spain)
- Miguel Segura, Neural Tumor Laboratory; Translational Research in Childhood and Adolescent Tumors, Hospital Universitario Vall D'Hebrón (Spain)
- Nuno Silverio, Grupo de Trabalho das Doenças Raras, Associação Portuguesa de Bioindústria (P-BIO) (Portugal)
- Marisol Montolío del Olmo, Director of Research Department and Technology Department Duchenne Parent Project Spain. Scientific Director of Cátedra Enfermedades Raras Universidad de Barcelona. ePAG ERN neuromuscular, Universidad de Barcelona (Spain)

MODERACIÓN

- Peter Fish, Digital Health and Clinical Innovation, CEO, Mendelian (United Kingdom)

12:15 pm ACCESS AND FINANCING

Innovation, Funding and Access to Orphan Drugs: Challenges and Opportunities

12:15 pm - 1:00 pm (local time)

PONENTES

- Maria Jose Sanchez, President, Spanish Association of Orphan and Ultra-Orphan Pharmaceutical Companies, AELMHU (Spain)
- Luisa María Botella Cubells, Responsible for Translational Research for Vascular Rare Diseases, Centro de Investigaciones Biológicas Margarita Salas (Spain)
- Adrien Samson, Healthcare Policy Senior Manager, EUROPABIO (Belgium)
- Elisabetta Zanon, Director, EU Public Affairs & Advocacy, European Alliance for Regenerative Medicine (Belgium)
- Enrico Piccinini, Head of Rare Diseases - Europe and Rest of World, Chiesi Global Rare Diseases (Italy)
- Matteo Scarabelli, Market Access Associate Director, EFPIA (Italy)

MODERACIÓN

- Fabrizio Checchia, Market Access & Government Affairs Expert, Independent consultant (Italy)

1:00 pm LUNCH AND NETWORKING

2:00 pm CLINICAL RESEARCH AND INNOVATION

Advances in Early Diagnostics and Treatment for Rare Diseases

2:00 pm - 2:45 pm (local time)

PONENTES

- **Mireia del Toro**, Rare Disease Coordinator and Metabolic Unit Coordinator, Hospital Vall d'Hebron (Spain)
- **Madeleine Durbeej-Hjalt**, Secretary General, Medicine and Health Sweden. Expert in Rare Muscle Diseases, Swedish Research Council (Sweden)
- **Beatriz Martinez Delgado**, Director of Human Genetics, Institute for the Research of Rare Disease (Spain)
- **Ian Rentsch**, Chief Commercial Officer & General Manager Pharma, Centogene (Germany)
- **Eduardo López-Granados**, Head of Immunodeficiencies-U767 Group, Spanish Rare Disease Network Research Center (CIBERER) (Spain)
- **Daniel de Vicente**, Vocal, Board of Directors, FEDER (Spain)

MODERACIÓN

- **Daniela Albero**, Regional Director, Blueprint Genetics (Spain)

Addressing Management of Rare Diseases. Research Networks & Reference Centers

2:45 pm - 3:30 pm (local time)

PONENTES

- **Michael Schlander**, Head of Division of Health Economics, German Cancer Research Center (Germany)
- **Alain Verloes**, Professor, Department of Genetics, Hospital Robert Debré. Coordinator, ERN ITHACA (France)
- **Eva Bermejo-Sánchez**, Director of the Institute for Rare Diseases Research (IIER), Instituto de Salud Carlos III (ISCIII) (Spain)
- **Mireia del Toro**, Rare Disease Coordinator and Metabolic Unit Coordinator, Hospital Vall d'Hebron (Spain)
- **Jill Praver**, Rare Disease Manager, FH Europe Foundation (United Kingdom)

MODERACIÓN

- **Grainne Crowley**, Partnerships and Development Lead, FH Europe Foundation (United Kingdom)

3:30 pm CLOSING REMARKS

3:30 pm - 3:45 pm (local time)

PONENTES

- **Alvaro Lopez**, Program Manager, Bamberg Health (Belgium)

FIN DE EVENTO

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Europe Rare Disease Summit 2024

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