## 3RD MULTI-STAKEHOLDER

## Symposium

13-14 FEBRUARY 2019 CROWNE PLAZA HOTEL-LE PALACE BRUSSELS, BELGIUM ON IMPROVING
PATIENTS' ACCESS
TO RARE DISEASE
THERAPIES



Members of the Programme Committee:

**Athanasiou, Dimitrios** - DMD Patient Advocate, UPPMD Board Member, EMA Patient Expert in DMD

Bedlington, Nicola – Secretary General, European Patients Forum

Boselli, Simone – Public Affairs Director, EURORDIS

**Bucsics, Anna** - University of Vienna; Project Advisor, Mechanism of Coordinated Access to orphan medicinal products (MoCA)

**Gatermann, Ruediger** - Executive Board, EUCOPE, Director Health Policy & External Affairs Europe, CSL Behring, Germany

**Grimm, Bernard** – Healthcare Director, EuropaBio

**Hedley, Victoria** - Newcastle University - Rare Disease Policy Manager, Newcastle University John Walton Muscular Dystrophy Research Centre, MRC Centre for Neuromuscular Diseases, Institute of Genetic Medicine

**King, David** – EFPIA/EuropaBio Joint TaskForce on Rare Diseases & Orphan Drugs; Director, Regultory Policy and Intelligence, Shire

**Nestler-Parr, Sandra** – Managing Director, Rare Access; Associate, Head of Rare Diseases, Roboleo & Co

**Oosterwijk, Cor** – Board Member, European Patients' Forum/National Healthcare Institute (ZiN); Managing Director, VSOP

**Pirard, Vinciane** – Co-chair, EFPIA-EuropaBio Joint TaskForce on Rare Diseases & Orphan Drugs; Director of Public Affairs at SANOFI - GENZYME

**Treacy, Eileen** - ERN Board of Member States; Mater Misericordiae University Hospital, Clinical Professor, Paediatrics, Trinity College Dublin

**Upadhyaya, Sheela** - Associate Director of the Highly Specialised Technology programme, NICE

Advisors to the Programme Committee:

**Berntgen, Michael** – Head of Product Development Scientific Support, European Medicines Agency

**Bottarelli, Valentina** - Public Affairs Director & Head of European and International Advocacy, EURORDIS

**Dan, Dorica** – President of the Romanian National Alliance for Rare Diseases (RONARD); Chair, Romanian Prader Willi Association; EURORDIS Board Member

Hivert, Virginie - Therapeutic Development Director, EURORDIS

**Schaefer, Franz** – ERNKnet; Member, Scientific Advisory Board of RD-Connect; Head of Division of Paediatric Nephrology and KFH Children's Kidney Centre

Sotirelis, Chris – Patient Expert, EURORDIS / EMA