

## RD-ACTION, European Medicines Agency, and DG SANTE Workshop:

### How ERNs can add value to clinical research in rare diseases and highly specialised domains

Dates: 29<sup>th</sup> - 30<sup>th</sup> May 2018

Venue: European Medicines Agency, London

#### ERN Representatives

PARTICIPANT NAME	ERN REPRESENTED
Simone Barsotti	ERN RECONNET
Antonio Carcas	ERN TRANSPLANT-CHILD
Catherine Champseix	ERN-SKIN
Li Chan	ENDO-ERN
Jose Drabwell	ERN RITA
Teresinha Evangelista	ERN EURO-NMD
Rosalie Ferner	ERN GENTURIS
Jean Michel Heard	MetabERN
Stéphane Lejeune	ERN EURACAN
Bart Leroy	ERN-EYE
Eduardo López Granados	ERN TRANSPLANT-CHILD
Andrea Mazzanti	ERN GUARD-HEART
Giovanni Mosiello	ERN EUROGEN
Rima Nabbout	EpiCARE
Karoline Noworyta	ERN PAEDCAN (observer)
Antonio Piga	EuroBloodNet
Niels Qvist	ERNICA
Alessandra Renieri	ERN ITHACA
Luca Sangiorgi	ERN BOND
Maurizio Scarpa	MetabERN
Claire Shovlin	VASCERN
Ans van der Ploeg	ERN-CRANIO

**ePAG (European Patient Advocacy Group) representatives**

PARTICIPANT NAME	ERN REPRESENTED
Alain Cornet	ERN ReCONNET
Johan De Graaf	ENDO-ERN
Christina Fasser	ERN-EYE
Ilaria Galetti	ERN ReCONNET
Andrea Gressani	ERN RITA
Gergely Meszaros	ERN LUNG
Sara Perez	ERN CRANIO
Beverley Power	ERNICA
Cathelijne Van Doorne	ERN-RND
Russell Wheeler	ERN-EYE

**European Medicines Agency Experts**

PARTICIPANT NAME	EMA AFFILIATION
Stiina Aarum	EMA - Human Medicines Research & Development Support Scientific Advice
Enrica Alteri	EMA - Human Medicines Research & Development Support Division
Dimitrios Athanasios	EMA - Paediatric Committee (PDCO) Member
Patrick Celis	EMA - Inspections & Human Medicines Pharmacovigilance - Scientific Committees Secretariat
Lucia D'Apote	EMA - Advisory Functions - Scientific Committees Regulatory Science Strategy
Monica Ensini	EMA – Stakeholders and communication - Public engagement department
Ana Hidalgo-Simon	EMA - Human Medicines Research and Development Support - Specialised Scientific Disciplines

Sheila Kennedy	EMA - Inspections, Human Medicines Pharmacovigilance & Committees - Surveillance & Epidemiology
Xavier Kurtz	EMA - Inspections, Human Medicines Pharmacovigilance & Committees - Surveillance & Epidemiology
Kristina Larsson	EMA - Human Medicines Research & Development Support Division - Orphan Medicines
Maria Mavris	EMA – Stakeholders and communication - Public engagement department
Isabelle Moulon	EMA - Senior Advisor on stakeholder engagement
Daniel O’Connor	EMA – COMP member UK
Elias Péan	EMA - Human Medicines Evaluation - Oncology, Haematology & Diagnostics
Laura Pioppo	EMA - Inspections, Human Medicines Pharmacovigilance & Committees - Clinical & Non-clinical Compliance
Guido Rasi	EMA - Executive Director
Catalin Rolea	EMA - Stakeholders and communication - Public engagement department
Ivana Silva	EMA - Stakeholders and communication - Public engagement department
Fergus Sweeney	EMA - Inspections, Human Medicines Pharmacovigilance & Committees

### **European Commission - DG SANTE and DG Research Representatives**

<b>PARTICIPANT NAME</b>	<b>ERN REPRESENTED</b>
Iiro Eerola	DG Research and Innovation Unit E2 (Innovative and Personalised Medicine)
Hélène Le Borgne	DG Sante Unit B3 (Cross-border Health Care and eHealth)
Anneli Torronen	DG Sante Unit B5 (Medicines: policy, authorisation and monitoring)

### Project/Domain Experts and National Representatives

PARTICIPANT NAME	AFFILIATION
Valentina Bottarelli	EURORDIS / RD-ACTION
Victoria Hedley	RD-ACTION / Newcastle University
Ines Hernando	EURORDIS / RD-ACTION
Ralf-Dieter Hilgers	Integrated DDesign and Analysis of small population group trial (IDeAI)
Virginie Hivert	EURORDIS
Daria Julkowska	E-RARE /European Joint Programme Co-Fund Proposal
Yann le Cam	EURORDIS / RD-ACTION
Joanne Lee	Newcastle University
Monika Preuss	Board of Member States Representative, UK
Ana Rath	Orphanet / RD-ACTION
Eileen Treacy	Board of Member States Representative, Ireland
Mark Turner	University of Liverpool / Conect4Children