

**RD-ACTION Workshop Co-Organised with DG SANTE:
How can ERNs generate, appraise and utilise clinical practice guidelines, to
enhance the impact of consensus guidelines in national health systems?**

Dates: 6th and 7th December 2017

Venue: Istituto Superiore di Sanita

Aula Marotta, National Centre for Rare Diseases

ERN Representatives

| PARTICIPANT NAME | ERN Represented |
|-------------------------|------------------|
| Ahmad Amin | GUARD-HEART |
| Eva Åström | BOND |
| Simone Baldovino | ERK-NET |
| Cinzia Bellettato | MetabERN |
| Ignacio Blanco | GENTURIS |
| Melanie Brunhofer | PAEDCAN |
| Antonio Carcas | TRANSPLANT-CHILD |
| Alexandra Carls | ERK-NET |
| Fabio Dardi | ERN-LUNG |
| Lorenzo D´Antiga | TRANSPLANT-CHILD |
| Carlo Dionisi | MetabERN |
| Hélène Dollfus | ERN-EYE |
| Maya El-Hachem | ERN-SKIN |
| Teresinha Evangelista | EURO-NMD |
| Francesco Fascetti Leon | ERNICA |
| Antonella Gambale | EuroBloodNet |
| Andrew Gennery | ERN-RITA |
| Bronwyn Kerr | ITHACA |
| Teia Kobulashvili | EPI-CARE |
| Kristiina Kyrklund | ERNICA |
| Dominiek Monserez | EURACAN |
| Peter Mossey | CRANIO |
| Luca Persani | ENDO-ERN |
| Karin Plass | EUROGEN |
| Ursula Plöckinger | MetabERN |
| Carola Reinhard | ERN-RND |

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|-------------------|----------|
| Muriel Rogasik | EURACAN |
| Savino Sciascia | ERK-NET |
| Maurizio Scarpa | MetabERN |
| Andrea Sodi | ERN-EYE |
| Rosaria Talarico | RECONNET |
| Corine van Lingen | MetabERN |
| Federico Vigevano | EPI-CARE |
| Carola Zillikens | BOND |

ePAG (European Patient Advisory group) representative

| PARTICIPANT NAME | ERN REPRESENTED |
|------------------------------|--|
| Peter Verhoeven | ERN-RITA (and RARE-Bestpractices) |
| Geske Wehr | SKIN-ERN (and RARE-Bestpractices) |
| Juan Fuertes | ERN-LUNG |
| Isabelle Manneh-Vangramberen | EURACAN (and JARC and European Cancer Patient Coalition) |
| Anita Kienesberger | PaedCan (and JARC and Childhood Cancer International – Europe) |
| Anne Hugon | MetabERN |
| Mary Kearney | ERN-RND |
| Claudio Ales | GENTURIS |
| Christina Fasser | ERN-EYE |
| Amanda Bok | EuroBloodNet |

Project/Domain Experts, EC Experts, and National Representatives

| PARTICIPANT NAME | AFFILIATION |
|-------------------------|---|
| Matthew Bolz-Johnson | RD-ACTION / EURORDIS |
| Anna Carta | DG SANTE |
| Paolo Casali | JARC (Joint Action for Rare Cancer) |
| Stefano Cianfarani | European Society of Paediatric Endocrinology |
| Olaf Dekkers | European Society of Endocrinology |
| Victoria Hedley | RD-ACTION |
| Primiano Iannone | Italian ISS and National Representative (Italy) |
| Paola Laricchiuta | RARE-BestPractices |
| AnneSophie Lapointe | Assistance Publique – Hôpitaux de Paris (APHP) |

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|-----------------------|---|
| Béla Melegh | UEMS and national representative (Hungary) |
| Agata Polizzi | RARE-BestPractices |
| Ana Rath | RD-ACTION/ Orphanet |
| Zuleika Saz Parkinson | Joint Research Centre (European Commission) |
| Rumen Stefanov | National Representative (Bulgaria) |
| Domenica Taruscio | RD-ACTION/ RARE-BestPractices |
| Till Voigtländer | Chair of the ERN Board of Member States and national representative |
| Lenja Wieje | EURORDIS |
| Ariane Weinman | RD-ACTION / EURORDIS |