

**Workshop: Creating a Sustainable Environment for Holistic & Innovative Care for Rare Diseases & Complex Conditions
Frambu Resource Centre for Rare Diseases, Oslo, 12-13 April 2018
Participants**

| | Name | Organisation | Profile | Country |
|----|------------------------------|--|---------------------------------------|--|
| 1 | Aline Schnieder | EURORDIS - Rare Diseases Europe | Patient Representative | France |
| 2 | Anders Olauson | Ågrenska Resource Centre | Social Service | Sweden |
| 3 | André Gubbels | Federal Public Service for Social Security - SPF Sécurité Sociale | Public body/National | Belgium |
| 4 | Anica Ježić | Ministry of Social Policy and Youth | Public body/National | Croatia |
| 5 | Anja Frankenberger | Kindness for Kids | Social Service | Germany |
| 6 | Barbara Glinsner | ZSI - Centre for Social Innovation | Academic | Austria |
| 7 | Beatriz Martinez-Lozano | Regional Ministry of Health-Region of Murcia | Public body/Regional | Spain |
| 8 | Birutė Tumiene | Board of Member States for ERNs | Public Body/National | Lithuania |
| 9 | Bronwyn Kerr | Genomic Medicine, Manchester; ERN ITHACA (congenital malformations and rare intellectual) | European Reference Network | United Kingdom of Great Britain and Northern Ireland |
| 10 | Carolin Engelhorn | Kindness for Kids | Social Service | Germany |
| 11 | Christine de Kalbermatten | MaRaVal | Patient Representative/Social Service | Switzerland |
| 12 | David Bergsaker | Frambu Resource Centre for Rare Disorders | Social Service | Norway |
| 13 | Désirée Gavhed | Karolinska University Hospital, Karolinska Institutet; ERN RITA (immunodeficiency, autoinflammatory and autoimmune diseases) | European Reference Network | Sweden |
| 14 | Dorica Dan | Romanian Prader Willi Association - NoRo Resource Center | Patient Representative/Social Service | Romania |
| 15 | Edmund Jessop | National commissioning Group, National Health Service | Public body/National | United Kingdom of Great Britain and Northern Ireland |
| 16 | Eduardo Tizzano | Hospital Universitari Valle Hebron | Healthcare Provider | Spain |
| 17 | Emilia Severin | Universitatea de Medicina si Farmacie (University of Medicine and Pharmacy) | Public body/Regional | Romania |
| 18 | Esteban Frauca | La Paz University Hospital, ERN TransplantChild (transplantation in children) | European Reference Network | Spain |
| 19 | Graham Slater | The Federation of esophageal atresia and tracheo-esophageal fistula support groups e.V.; ERNICA (inherited and congenital anomalies) | Patient Representative | Germany |
| 20 | Gunilla Jaeger | Ågrenska Resource Centre | Social Service | Sweden |
| 21 | Helena Kääriäinen | National Institute for Health and Welfare Helsinki | Public body/National | Finland |
| 22 | Hélène Dollfus | Hôpitaux Universitaires de Strasbourg; ERN EYE (eye diseases) | European Reference Network | France |
| 23 | Ildiko Vajda | VSOP (Dutch Genetic Alliance) | Patient Representative | Netherlands |
| 24 | Irina Vana | Zentrum für Soziale Innovation (Centre for Social Innovation, ZSI) | Academic | Austria |
| 25 | Isabel Fernandez | Federación Española de Enfermedades Raras (Spanish Rare Disease Federation, FEDER) | Patient Representative | Spain |
| 26 | Isabella Brambilla | Dravet Italia Onlus - Dravet Syndrome European Federation; ERN EpiCARE (epilepsies) | Patient Representative | Italy |
| 27 | Jan Lubinski | Department of Genetics and Pathology, Pomeranian Medical University Szczecin; ERN GENTURIS genetic tumour risk syndromes) | European Reference Network | Poland |
| 28 | Joanna Das | University of Newcastle | Academic | United Kingdom of Great Britain and Northern Ireland |
| 29 | Juan Manuel Torres Canizales | La Paz University Hospital; ERN TransplantChild (transplantation in children) | European Reference Network | Spain |
| 30 | Judit Germuska | Great Ormond Street Hospital London; ERN EpiCARE (epilepsies) | European Reference Network | United Kingdom of Great Britain and Northern Ireland |
| 31 | Judit Váradiné Csapó | Muscle Dystrophy Association; ERN EURO NMD neuromuscular diseases) | Patient Representative | Hungary |

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| 32 | Juliet Tschank | Zentrum für Soziale Innovation (Centre for Social Innovation, ZSI) | Academic | Austria |
| 33 | Kristian E. Kristoffersen | Frambu Resource Centre for Rare Disorders | Social Service | Norway |
| 34 | Lenja Wiehe | EURORDIS - Rare Diseases Europe | Patient Representative | France |
| 35 | Lisen Julie Mohr | Frambu Resource Centre for Rare Disorders | Social Service | Norway |
| 36 | Mandy Andrew | NHS Lanarkshire | Public body/Regional | United Kingdom of Great Britain and Northern Ireland |
| 37 | Maria Beatrice Michelis | Istituto Giannina Gaslini; ERN BOND (bone disorders) | European Reference Network | Italy |
| 38 | Maria João Freitas | Raríssimas; Casa dos Marcos Resource Centre | Patient Representative/Social Service | Portugal |
| 39 | Mariangela Pellegrini | AP-HP Hôpital Saint-Louis; ERN EuroBloodNet (haematological diseases) | European Reference Network | France |
| 40 | Marta Fonfria | CREER (National Reference Center for people with RD and their families) | Public body/Social Service | Spain |
| 41 | Marta DeSantis | Istituto Superiore di Sanità | Academic | Italy |
| 42 | Mary Kearney | Irish College of General Practitioners; ERN-RND (neurological diseases) | Patient Representative/ERN | Ireland |
| 43 | Maud Le Graët | Finovatis | Academic | France |
| 44 | Michelle Battye | Sheffield Teaching Hospitals NHS Foundation Trust; ERN eUROGEN (urogenital diseases and conditions) | European Reference Network | United Kingdom of Great Britain and Northern Ireland |
| 45 | Monica Solomie | Ministry of Work, Family, Social Protection and Elderly | Public body/National | Romania |
| 46 | Oda Marie Jordal | Dermatology, Odense University Hospitals; ERN Skin (skin disorders) | European Reference Network | Denmark |
| 47 | Peter Lindgren | Karolinska Institutet | Academic | Sweden |
| 48 | Raquel Castro | EURORDIS - Rare Diseases Europe | Patient Representative | France |
| 49 | Rasmus Bruun | National Board of Social Services | Public body/National | Denmark |
| 50 | Rebecca Tvedt Skarberg | Norwegian National Advisory Unit on Rare Disorders; ERN BOND (bone disorders) | Patient Representative | Norway |
| 51 | Sara Perez | Asociación nacional Síndrome de Apert y otras craneosinostosis sindrómicas; ERN CRANIO (craniofacial anomalies ; ear, nose and throat disorders) | Patient Representative | Spain |
| 52 | Sebastian Ardelean | Salaj County Council | Public body/Regional | Romania |
| 53 | Silvia Manea | Veneto Region | Healthcare Provider | Italy |
| 54 | Stein Are Aksnes | Norwegian National Advisory Unit on Rare Disorders | Public body/National | Norway |
| 55 | Teresinha Evangelista | University of Newcastle; ERN EURO-NMD (neuromuscular diseases) | European Reference Network | United Kingdom of Great Britain and Northern Ireland |
| 56 | Tiina Stelmach | Estonian Ågrenska Foundation Resource Centre | Social Service | Estonia |
| 57 | Till Voigtländer | Board of Member States for ERNs. | Health Care Provider/ Public Body/National | Austria |
| 58 | Trine Tangeraas | Oslo University; MetabERN (hereditary metabolic disorders) | European Reference Network | Norway |
| 59 | Ursula Holtgrewe | ZSI - Centre for Social Innovation | Academic | Austria |
| 60 | Valentina Rupel | Institute for Economic Research | Academic | Slovenia |
| 61 | Veronica Wingstedt de Flon | National Agency for Rare Diseases | Public body/National | Sweden |
| 62 | Vibeke Sparring | Karolinska Institutet | Academic | Sweden |
| 63 | Victoria Hedley | University of Newcastle | Academic | United Kingdom of Great Britain and Northern Ireland |
| 64 | Vlasta Zmazek | Debra Croatia, Croatian Alliance for Rare Diseases | Patient Representative/Social Service | Croatia |
| 65 | Zsuzsa Almasi | Romanian Prader Willi Association - NoRo Resource Center | Social Service | Romania |

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