

Conference: Advancing person-centred and integrated care for rare diseases and complex conditions across Europe
5th September 2018, Brussels

Participants List

Name	Organisation	Profile	Country
Stein Are Aksnes	Norwegian Advisory Unit on Rare Disorders	Public body/National	Norway
Zsuzsa Almasi	Romanian Prader Willi Association - NoRo Resource Center	Patient Representative/ Social Service	Romania
Terkel Andersen	EURORDIS - Rare Diseases Europe	Patient Representative	France
Eleni Antoniou	Cyprus Alliance for Rare Disorders	Patient Representative	Cyprus
Aitor Aparicio	CREER - National Reference Center PLWRD and their families	Public body/Social Service	Spain
Sebastian Ardelean	Salaj County Council	Public body/Regional	Romania
Iliana Argyriou	Permanent Representation of Cyprus to the EU	Health Attaché	Cyprus
Janina Arsenjeva	International Federation for Spina Bifida and Hydrocephalus	Patient Representative	Belgium
Ivana Badnjarevic	NORBS - National Organisation for Rare Diseases	Patient Representative	Serbia
Marta Balula	Raríssimas – National Association for Rare Diseases	Social Service	Portugal
Eva Bearryman	EURORDIS - Rare Diseases Europe	Patient Representative	France
Simona Bellagambi	EURORDIS - Rare Diseases Europe	Patient Representative	Italy
Valentina Bottarelli	EURORDIS - Rare Diseases Europe	Patient Representative	France
John Bowis	Former Member of British Parliament, UK Health Minister and Member of the European Parliament	Former Member of the European Parliament	UK
John Brennan	International Federation of Social Workers	Social Worker	Ireland
Raquel Castro	EURORDIS - Rare Diseases Europe	Patient Representative	France
Claire Champeix	Eurocarers	Civil Society	Belgium
Liliane Cocozza	Union Professionnelle francophone des assistants sociaux	Civil Society	Belgium
Alain Cornet	Lupus Europe	Patient Representative	Belgium
Sandra Courbier	EURORDIS - Rare Diseases Europe	Patient Representative	France
Dorica Dan	Romanian Prader Willi Association - NoRo Resource Center	Patient Representative/ Social Service	Romania
Chantal De Boevere	Council of University Hospitals of Belgium	Public body	Belgium
Hilde de Keyser	Cystic Fibrosis Europe	Patient Representative	Belgium
Davor Duboka	National Organization for Rare Diseases	Patient Representative	Serbia
Annette Dumas	EURORDIS - Rare Diseases Europe	Patient Representative	France
Diana Eriksonaité	European Commission, DG EMPL	European Commission	Belgium
Marta Fonfria	CREER - National Reference Center PLWRD and their families	Public body/Social Service	Spain
Esteban Frauca	La Paz University Hospital/ ERN Transplant Child	European Reference Network	Spain
Katie Gallagher	European Patients' Forum	Patient Representative	Belgium
Judit Germuska	Great Ormond Street Hospital London/ ERN EpiCARE	European Reference Network	UK
Irene Bertana	COFACE	Civil Society	Belgium
Encarna Guillen-Navarro	Hospital Clínico Universitario Virgen de la Arrixaca/ Health Council of the Region of Murcia	Healthcare provider	Spain
Victoria Hedley	Newcastle University	Academic	UK
Inés Hernando	EURORDIS - Rare Diseases Europe	Patient Representative	France
Clara Hervás	EURORDIS - Rare Diseases Europe	Patient Representative	France
Ursula Holtgrewe	ZSI - Centre for Social Innovation	Academic	Austria
Ulrike Holzer	Prorare Austria, Alliance for Rare Diseases	Patient Representative	Austria
Lisen Julie Mohr	Frambu Resource Centre for Rare Disorders	Social Service	Norway
Helena Kääriäinen	National Institute for Health and Welfare	Public body/National	Finland
David Koubi	Finovatis	Academic	France

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Oana Labo	Salaj County Council	Public body/Regional	Romania
Anne-Sophie Lapointe	Filière ANDDI-Rares – National Network	Academic	France
Margarida Laygue	Raríssimas – National Association for Rare Diseases	Social Service	Portugal
Maud Le Graët	Finovatis	Academic	France
Peter Lindgren	Karolinska Institutet	Academic	Sweden
Monica Lucia Avram	Salaj County Council	Public body/Regional	Romania
Silvia Manea	Coordinating Centre of Rare Diseases of the Veneto Region	Healthcare Provider	Italy
Beatriz Martinez-Lozano	Regional Ministry of Health-Region of Murcia	Public body/Regional	Spain
Giedrė Medziausaitė	Permanent Representation of Lithuania to the EU	Health Attaché	Lithuania
Marguerite Mormal	asbl Aidants Proches	Civil Society	Belgium
Anders Olauson	Ågrenska Resource Centre	Social Service	Sweden
Lidia Onofrei	Ministry of Health	Public body	Romania
Ana Carla Pereira	European Commission, DG EMPL	European Commission	Belgium
Ion-Gheorghe Petrovai	FreshBlood HealthTech Community	Academic	Romania
Gábor Pogany	HUFERDIS - Rare Diseases Hungary	Patient Representative	Hungary
Valentina Prevolnik Rupel	Institute for Economic Research	Academic	Slovenia
Vinciane Quoidbach	European Brain Council	Civil Society	Belgium
Ana Rath	Orphanet	Academic	France
Réka Ripszám	University of Pécs	European Reference Network	Hungary
David Sánchez	FEDER – Spanish Federation for Rare Diseases	Patient Representative	Spain
Katlijn Sanctorum	FAPA - Familial Adenomatous Polyposis Association	Academic/ Patient Representative	Belgium
Ester Sarquella- Casellas	Tunstall Healthcare	Healthcare Provider	Spain
Aline Schnieder	EURORDIS - Rare Diseases Europe	Patient Representative	France
Eva Schoeters	RaDiOrg - Rare Diseases Organisation Belgium	Patient Representative	Belgium
Annalisa Scopinaro	UNIAMO - Federazione Italiana Malattie Rare	Patient Representative	Italy
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Rebecca Skarberg	BOND ERN	Patient Representative	Norway
Monica Violeta Solomie	National Authority for Persons with Disabilities	Public body/National	Romania
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Irina Vana	ZSI - Centre for Social Innovation	Academic	Austria
Denica Velkovska	National Alliance for Rare Disease of R. Macedonia	Patient Representative	Republic of Macedonia
Till Voigtländer	Medical University of Vienna/ Board of Member States for ERNs	Healthcare Professional/ Public Body (National)	Austria
Ariane Weinman	EURORDIS - Rare Diseases Europe	Patient Representative	France
Frank Willersinn	Alpha-1 Plus asbl	Patient Representative	Belgium
Emilie Zingg	EURORDIS - Rare Diseases Europe	Patient Representative	France