



Rare 2030 Panel of Experts

Full Membership List

Surname	First Name	Type of Stakeholder **	Country
Agius	Francis	National/Regional Competent Authority (National policy maker)	Malta
Aleksovska (Stojmirova)	Vesna	Patient advocate	Northern Republic of Macedonia
Alves	Ines	Patient advocate	Portugal
Amin	Ahmad	ERN Coordinator/ERN Healthcare Provider representative	Netherlands
Aminoff	Dalia	Patient advocate	Spain
Anastasiadou	Violetta	National/Regional Competent Authority (National policy maker)	Cyprus
Ancochea Díaz	Alba	Patient advocate	Spain
Andersen	Terkel	Patient advocate	Denmark
Andrew	Mandy	Social care and social innovation experts	United Kingdom
Antoniou	Eleni	Patient advocate	Cyprus
Ardigò	Diego	Pharmaceutical Industry and other health-related industries	Italy
Are Aksnes	Stein	National/Regional Competent Authority (National policy maker)	Norway

Arellanesová	Anna	Patient advocate	Czech Republic
Arzimanoglou	Alexis	ERN Coordinator/ERN Healthcare Provider representative	France
Athanasίου	Dimitrios	Pharmaceutical Industry and other health-related industries	Greece
Azzopardi	Miriam	National/Regional Competent Authority (National policy maker)	Malta
Barić	Ivo	National/Regional Competent Authority (National policy maker)	Croatia
Barisic	Ingeborg	Individual experts involved in the European Joint Actions for Rare Diseases	Croatia
Battye	Michelle	ERN Coordinator/ERN Healthcare Provider representative	United Kingdom
Bauwens	Lieven	Patient advocate	Belgium
Baynam	Gareth	International initiatives	Australia
Bellagambi	Simona	Patient advocate	Italy
Berkholz	Dieter	National/Regional Competent Authority (National policy maker)	Germany
Biller	Ruth	Patient advocate	Germany
Blay	Jean-Yves	ERN Hospital Manager	France
Bloom	Laura	Patient advocate	United Kingdom
Bodemer	Christine	ERN Coordinator/ERN Healthcare Provider representative	France
Borras	Josep M	Individual researcher	Spain
Brambilla	Isabella	Patient advocate	Italy
Brectan	René	Patient advocate	Czech Republic
Bros-Facer	Virginie	European research networks and infrastructures	France
Brüggmann	Petra	Patient advocate	Germany
Brunetta	Angelo Loris	Regulatory Experts	Italy
Bucsics	Anna	HTA bodies/reimbursement authorities	Austria
Buske	Orion	Individual Researcher	Canada
Carraro	Vittoria	Pharmaceutical Industry and other health-related industries	Belgium

Castro	Raquel	Social care and social innovation experts	Spain
Cattaneo	Ivana	Pharmaceutical Industry and other health-related industries	Italy
Chantelot	Emmanuel	Pharmaceutical Industry and other health-related industries	Belgium
Cisarik	Frantisek	National/Regional Competent Authority (National policy maker)	Slovakia
Dallapiccola	Bruno	National/Regional Competent Authority (National policy maker)	Italy
Daly	Avril		Ireland
D'Amato Sizonenko	Loredana	Patient advocate	Switzerland
Dan	Dorica	Patient advocate	Romania
Dedeu	Toni	Health Economist	United Kingdom
Del Mar Mañú - Pereira	Maria	ERN Coordinator/ERN Healthcare Provider representative	France
Dollfus	Hélène	ERN Coordinator/ERN Healthcare Provider representative	France
Driessens	Mariette	Pharmaceutical Industry and other health-related industries	Netherlands
Eichler	Hans-George	Regulatory Expert	Netherlands
Eleftheriou	Androulla	Patient advocate	Cyprus
Evangelista	Teresinha	ERN Coordinator/ERN Healthcare Provider representative	France
Evers	Pauline	Pharmaceutical Industry and other health-related industries	Netherlands
Facchin	Paola	National/Regional Competent Authority (National policy maker)	Italy
Feider-Rohen	Shirley	Patient advocate	Luxembourg
Feitz	Wout	ERN Coordinator/ERN Healthcare Provider representative	Netherlands
Fonfría Solabarrieta	Marta	Social care and social innovation experts	Spain
Fonseca	Valter	National/Regional Competent Authority (National policy maker)	Portugal
Galetti	Ilaria	Patient advocate	Italy
Gatermann	Ruediger	Pharmaceutical Industry and other health-related industries	Germany

Goodhand	Peter	International Initiatives	Canada
Graessner	Holm	ERN Coordinator/ERN Healthcare Provider representative	Germany
Grentoft	Mette	Patient advocate	Denmark
Gschmeidler	Brigitte	Pharmaceutical Industry and other health-related industries	Austria
Guardian	Marcus	HTA bodies/reimbursement authorities	Netherlands
Guillén-Navarro	Encarna	Social care and social innovation experts	Spain
Haf Davies	Elin	Pharmaceutical Industry and other health-related industries	United Kingdom
Harris	Tess	Patient advocate	United Kingdom
Hivert	Virginie	Regulatory Experts	France
Holm	Birthe Byskov	Patient Advocate	Denmark
Holtgrewe	Ursula	Social care and social innovation experts/health economist	Austria
Holzer	Ulrike	Patient Advocate	Austria
Hughes-Wilson	Wills	Pharmaceutical Industry and other health-related industries	United Kingdom
Hugon	Anne	Patient advocate	France
Incerti	Carlo	Pharmaceutical Industry and other health-related industries	Netherlands
Isla Gomez	Julián	Pharmaceutical Industry and other health-related industries	Spain
Jacinto	Marta	Patient advocate	Portugal
Jain	Ritu	International activities	Singapore
João Freitas	Maria	Social care and social innovation experts	Portugal
Jondeau	Guillaume	ERN Coordinator/ERN Healthcare Provider representative	France
Julkowska	Daria	European research networks and infrastructures	France
Kaariainen	Helena	National/Regional Competent Authority (National policy maker)	Finland
Kolitsi	Zoi	Independent Researcher	Greece
Kotulska-Jóźwiak	Katarzyna	National/Regional Competent Authority (National policy maker)	Poland

Krutzinna	Jenny	Individual Researcher	Norway
Le Borgne	Hélène	EU policy makers	Belgium
Le Cam	Yann	Individual expert involved in the European Joint Actions for Rare Diseases	Belgium
Lindgren	Peter	Health Economist	Sweden
Lindsell	Sarah	Individual Researcher	United Kingdom
Lohse	Ansgar	ERN Coordinator/ERN Healthcare Provider representative	Germany
Lopez Granados	Eduardo	ERN Coordinator/ERN Healthcare Provider representative	Spain
Macek	Milan	National/Regional Competent Authority (National policy maker)	Czech Republic
Macchia	Flaminia	Pharmaceutical Industry and other health-related industries	Belgium
Magrelli	Armando	Regulatory Expert	Italy
Mann	Mirjam	Patient Advocate	Germany
Martin	Simona	EU policy makers	European Commission
Mathijssen	Irene	ERN Coordinator/ERN Healthcare Provider representative	Netherlands
Meade	Nick	Patient advocate	United Kingdom
Melegh	Bela	Individual experts involved in the European Joint Actions for Rare Diseases	Hungary
Meszaros	Gergely	Patient Advocate	Hungary
Miasnikova	Irina	Patient Advocate	Russian Federation
Mohr	Lisen Julie	Social care and social innovation experts	Norway
Moll	Nathalie	Pharmaceutical Industry and other health-related industries	Belgium
Montefusco	Maria	Patient Advocate	Sweden
Montserrat Moliner	Antoni	Patient advocate	Luxembourg
Mosca	Marta	ERN Coordinator/ERN Healthcare Provider representative	Italy
Muthyala	Ramaiah	International initiatives	United States of America
Nabbout	Rima	European research networks and infrastructures	France
Natz	Alexander	Pharmaceutical Industry and other health-related	Belgium

		industries	
Noordhoek	Jacquelin	Patient Advocate	Luxembourg
O'Connor	Daniel	Regulatory Expert	United Kingdom
O'Donnell	Peter	Journalist	Belgium
Olauson	Anders	International initiatives	Sweden
Oliver	Kathy	Patient Advocate	United Kingdom
Oosterwijk	Cor	Patient Advocate	Netherlands
Özbek	Uğur		
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Palma	Ana	Pharmaceutical Industry and other health-related industries	Belgium
Parier	Eve	ERN Hospital Manager	France
Parker	Samantha	Pharmaceutical Industry and other health-related industries	France
Pereira	Alberto	ERN Coordinator/ERN Healthcare Provider representative	Netherlands
Petäjä	Jari	ERN Hospital managers	Finland
Peterlin	Borut	National/Regional Competent Authority (National policy maker)	Slovenia
Pirard	Vinciane	Pharmaceutical Industry and other health-related industries	Belgium
Plura	Marek	EU Policy Makers	Poland
Pogany	Gabor	Patient Advocate	Hungary
Posada De La Paz	Manuel	Individual experts involved in the European Joint Actions for Rare Diseases	Spain
Prats Monné	Xavier	EU Policy Makers	Belgium
Quinn	Casey	HTA bodies/reimbursement authorities	United States of America
Rath	Ana	European research networks and infrastructures	France
Richards	Tessa	Journalist	United Kingdom
Rui Santos	Ivo	Regulatory Experts	Portugal
Sándor	János	National/Regional Competent Authority (National policy maker)	Hungary

Sangiorgi	Luca	ERN Coordinator/ERN Healthcare Provider representative	Italy
Scarpa	Maurizio	ERN Coordinator/ERN Healthcare Provider representative	Italy
Schaefer	Franz	ERN Coordinator/ERN Healthcare Provider representative	Germany
Schlander	Michael	Health Economist	Germany
Schoeters	Eva	Patient Advocate	Belgium
Schuster	Ralf	European research networks and infrastructures	Germany
Scollen	Serena	European research networks and infrastructures	United Kingdom
Sepodes	Bruno	Regulatory Experts	Portugal
Severin	Emilia	National/Regional Competent Authority (National policy maker)	Romania
Slater	Graham	Patient Advocate	United Kingdom
Spink	Jayne	Patient Advocate	United Kingdom
Sproedt	Claudia	Patient Advocate	Germany
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Stevens	Sarah	Individual expert involved in the European Joint Actions for Rare Diseases	United Kingdom
Stoyanova-Beninska	Violeta	Regulators	Netherlands
Straus	Sabine	Regulatory Experts	Netherlands
Summar	Marshall	International initiatives	United States of America
Taruscio	Domenica	International initiatives	Italy
Tomov	Vladmir	Patient Advocate	Bulgaria
Trama	Annalisa	ERN Coordinator/ERN Healthcare Provider representative	Italy
Treacy	Eileen	National/Regional Competent Authority (National policy maker)	Ireland
Tumiene	Birute	National/Regional Competent Authority (National policy maker)	Lithuania
Tvedt Skarberg	Rebecca	Patient Advocate	Norway

Upadhyaya	Sheela	HTA bodies/reimbursement authorities	United Kingdom
Ussi	Anton	ERN Coordinator/ERN Healthcare Provider representative	Netherlands
Valdmane	Antra	National/Regional Competent Authority (National policy maker)	Latvia
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van Zelst-Stams	Wendy	National/Regional Competent Authority (National policy maker)	Netherlands
Verloes	Alain	ERN Coordinator/ERN Healthcare Provider representative	France
Voigtlander	Till	National/Regional Competent Authority (National policy maker)	Austria
Wagener	Yolande	Patient Advocate	Luxembourg
Wagner	Thomas	ERN Coordinator/ERN Healthcare Provider representative	Germany
Walani	Salimah	Patient Advocate	United States of America
Ward	Adrian	Pharmaceutical Industry and other health-related industries	Switzerland
Waszczuk	Antonina	Social care and social innovation experts	Germany
Weinman	Ariane	Patient Advocate	France
Wheeler	Russell	Patient Advocate	United Kingdom
Widenmann-Grolig	Anke	Patient Advocate	Germany
Wijnen	Rene	ERN Coordinator/ERN Healthcare Provider representative	Netherlands
Wilson	Petra	Pharmaceutical Industry and other health-related industries	Belgium
Wong-Rieger	Durhane	International initiatives	Canada
Wulffraat	Nico	ERN Coordinator/ERN Healthcare Provider representative	Netherlands
Yang	Rachel	International initiatives	Switzerland
Zain	Rula	Individual Researcher	Sweden
Zamorska	Tetiana	Patient Advocate	Ukraine
Zeriav Tanšek	Mag Mojca	National/Regional Competent Authority (National policy maker)	Slovenia

Zhang	Shuyang	International Initiatives	China
Ziemele	Baiba	Patient Advocate	Latvia

