

## Rare 2030 Panel of Experts

### Membership List for Sub-Group 8: Accessing Healthcare\*

Surname	First Name	Type of Stakeholder**	Country
Amin	Ahmad	ERN Coordinator/ERN Healthcare Provider representative	NL
Aminoff	Dalia	Patient advocate	IT
Anastasiadou	Violetta	National/Regional Competent Authority (National policy maker)	CY
Ancochea	Alba	Patient advocate	ES
Andersen	Terkel	Patient advocate	DK
Are Aksnes	Stein	National/Regional Competent Authority (National policy maker)	NO
Arellanesová	Anna	Patient advocate	CZ
Asikainen	Katri	Patient Advocate	FI
Arzimanoglou	Alexis	ERN Coordinator/ERN Healthcare Provider representative	FR
Barić	Ivo	National/Regional Competent Authority (National policy maker)	HR
Barisic	Ingeborg	Individual experts involved in the European Joint Actions for Rare Diseases	HR
Battye	Michelle	ERN Coordinator/ERN Healthcare Provider representative	UK
Bauwens	Lieven	Patient advocate	BE
Baynam	Gareth	International initiatives	AU
Bellagambi	Simona	Patient advocate	IT
Berkholz	Dieter	National/Regional Competent Authority (National policy maker)	DE
Biller	Ruth	Patient advocate	DE
Bloom	Lara	Patient advocate	UK
Bodemer	Christine	ERN Coordinator/ERN Healthcare Provider representative	FR
Boltz – Johnson	Matt	ERN Coordinator/ERN Healthcare Provider representative	UK

Borras	Josep	Individual Researcher	ES
Bruijns	Christel	Pharmaceutical Industry and other health-related industries	CH
Brüggmann	Petra	Patient advocate	DE
Brunetta	Angelo Loris	Regulatory Experts	IT
Bucsics	Anna	HTA bodies/reimbursement authorities	AT
Butterworth	Sondra	Individual Researcher	UK
Carraro	Vittoria	Pharmaceutical Industry and other health-related industries	BE
Chantelot	Emmanuel	Pharmaceutical Industry and other health-related industries	BE
Cisarik	František	National/Regional Competent Authority (National policy maker)	SK
Dallapiccola	Bruno	National/Regional Competent Authority (National policy maker)	IT
D'Amato Sizonenko	Loredana	Patient advocate	CH
Dan	Dorica	Patient advocate	RO
Dooms	Marc	Individual Researcher	BE
Eleftheriou	Androulla	Patient advocate	CY
Evangelista	Teresinha	ERN Coordinator/ERN Healthcare Provider representative	FR
Facchin	Paola	National/Regional Competent Authority (National policy maker)	IT
Feitz	Wout	ERN Coordinator/ERN Healthcare Provider representative	NL
Fonseca	Valter	National/Regional Competent Authority (National policy maker)	PT
Freitas	Maria João	Social care and social innovation experts	PT
Goodhand	Peter	International Initiatives	CA
Graessner	Holm	ERN Coordinator/ERN Healthcare Provider representative	DE
Gschmeidler	Brigitte	Pharmaceutical Industry and other health-related industries	AT
Guillén-Navarro	Encarna	Social care and social innovation experts	ES
Harris	Tess	Patient advocate	UK

Hernando	Ines	ERN Coordinator/ERN Healthcare Provider representative	ES
Hivert	Virginie	Regulatory Experts	FR
Holtgrewe	Ursula	Social care and social innovation experts /health economist	AT
Holzer	Ulrike	Patient advocate	AT
Hugon	Anne	Patient advocate	FR
Jain	Ritu	International initiatives	SG
Jondeau	Guillaume	ERN Coordinator/ERN Healthcare Provider representative	FR
Kaariainen	Helena	National/Regional Competent Authority (National policy maker)	FI
Kotulska-Jozwiak	Katarzyna	National/Regional Competent Authority (National policy maker)	PL
Le Borgne	Hélène	EU policy makers	BE
Lohse	Ansgar	ERN Coordinator/ERN Healthcare Provider representative	DE
Macek	Milan	National/Regional Competent Authority (National policy maker)	CZ
Malniece	Leva	Individual Researcher	LV
Mañú - Pereira	Maria del Mar	ERN Coordinator/ERN Healthcare Provider representative	FR
Mathijssen	Irene	ERN Coordinator/ERN Healthcare Provider representative	NL
Melegh	Bela	Individual experts involved in the European Joint Actions for Rare Diseases	HU
Merkel	Bernard	EU policy makers	UK
Montserrat Moliner	Antoni	Patient advocate	LUX
Mosca	Marta	ERN Coordinator/ERN Healthcare Provider representative	IT
Oosterwijk	Cor	Patient advocate	NL
Özbek	Uğur	Individual Researcher	TR
Palau	Francesc	Individual experts involved in the European Joint Actions for Rare Diseases	ES
Petäjä	Jari	ERN Hospital Manager	FI
Pogany	Gabor	Patient advocate	HU

Popova	Jana	Patient Advocate	BU
Rath	Ana	European research networks and infrastructures	FR
Rui Santos	Ivo	Regulatory Experts	PT
Sandor	Janos	National/Regional Competent Authority (National policy maker)	HU
Scarpa	Maurizio	ERN Coordinator/ERN Healthcare Provider representative	IT
Schaefer	Franz	ERN Coordinator/ERN Healthcare Provider representative	DE
Schoeters	Eva	Patient advocate	BE
Slater	Graham	Patient advocate	UK
Sproedt	Claudia	Patient advocate	DE
Stevens	Sarah	Individual expert involved in the European Joint Actions for Rare Diseases	UK
Stewart	Rebecca	Patient Advocate	UK
Straus	Sabine	Regulatory expert	NL
Summar	Marshall	International initiatives	US
Taruscio	Domenica	National/Regional Competent Authority (National policy maker)	IT
Tomov	Vladimir	Patient advocate	BG
Trama	Annalisa	ERN Coordinator/ERN Healthcare Provider representative	IT
Treacy	Eileen	National/Regional Competent Authority (National policy maker)	IE
Tumiene	Birute	National/Regional Competent Authority (National policy maker)	LT
Tvedt Skarberg	Rebecca	Patient advocate	NO
Upadhyaya	Sheela	HTA bodies/reimbursement authorities	UK
Wagner	Thomas	ERN Coordinator/ERN Healthcare Provider representative	DE
Walani	Salimah	Patient advocate	US
Weinman	Ariane	Patient advocate	FR
Zain	Rula	Individual Researcher	SE



Zamorska	Tetiana	Patient advocate	UA
Zerjav Tanšek	Mag Mojca	National/Regional Competent Authority (National policy maker)	SI
Zmazek	Vlasta	Patient advocate	HR

(NB The following panel members were *assigned* to this group and may wish to change!)

Surname	First Name	Type of Stakeholder**	Country
Jondeau	Guillaume	ERN Coordinator/ERN Healthcare Provider representative	FR
Moll	Nathalie	Pharmaceutical Industry and other health-related industries	BE
Pereira	Alberto	ERN Coordinator/ERN Healthcare Provider representative	NL
Straus	Sabine	Regulatory Experts	NL
Valdmane	Antra	National/Regional Competent Authority (National policy maker)	LV
Voigtlaender	Till	National/Regional Competent Authority (National policy maker)	AT

\*Items under this heading include Centres of Expertise; integration of ERNs to health systems; Clinical Practice Guidelines; eHealth; access to specialised procedures or surgery

\*\*Many people in this Panel of Experts belong to numerous categories – the ‘Type of Stakeholder’ listed against each name represents the *primary* capacity in which experts were invited to this Panel.