



EURORDIS Membership Meeting (EMM) 2023

25 - 27 May 2023
in Stockholm

List of Participants by Company/Organisation

Family Name	First Name	Country	Company/Organisation
Acalinei	Arabela	Slovenia	EAMDA
Agius	Mariella	Malta	National Alliance for Rare Diseases Support Malta
Ajdal	Lahsen	Morocco	Pharmacie Cascades Ouzoud
Aleksandrova	Oksana	Ukraine	Association of patients with pulmonaty hypertension
Amir	Boucherok	Algeria	Hospital
Andersson	Tove	Sweden	CSL Behring
Andersson	Ammi	Sweden	RBU (Rörelsehindrade Barn och Ungdomar)
Andreas	Jarblad	Sweden	Swedish Cystic Fibrosis Association
Antalova	Anna	Slovakia	Slovenská aliancia pre zriedkavé ochorenia (SAZCH)
Antonopoulou	Katy	Switzerland	Sjogren Europe
Arellanesová	Anna	Czech Republic	Rare Diseases Czech Republic
Ashton	Sharon	United Kingdom	EURORDIS - Rare Disease Europe

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Asikainen	Katri	Finland	HARSO ry
Athanasίου	Dimitrios	Greece	World Duchenne Organization
Atzori	Walter	Sweden	Alexion Astra Zeneca Rare Disease
Augoustides-Savvopoulou	Persephone	Greece	KRIKOS ZOIS Society for Patients and Friends of Patients with Inherited Metabolic Disease
Augucēviča	Marta	Latvia	Rare Disease Association Caladrius
Bäckström	Silvia	Sweden	Takeda
Badirgali	İpek	Slovenia	EAMDA
Baijet	Judit	Spain	EURORDIS - Rare Disease Europe
Bellagambi	Simona	Italy	UNIAMO- Rare Diseases Italy / EURORDIS - Rare Disease Europe
Bergholtz	Jana	Sweden	European Cavernoma Alliance
Bergna	Martina	France	EURORDIS - Rare Disease Europe
Bertoletti	Monica	Italy	AIBWS ODV
Bladh	Helena	Sweden	Takeda
Blichfeldt	Susanne	Denmark	Danish PWS association
Bloom	Lara	United States	The Ehlers-Danlos Society
Bloor	Janet	United Kingdom	Self-Employed
Bohlin	Emma	Sweden	Rare Diseases Sweden
Boiko	Hanna	Belgium	EURORDIS - Rare Disease Europe
Bolz-Johnson	Matthew	Germany	EURORDIS - Rare Disease Europe
Borgards	Petra	Germany	Bundesverband Angeborene Gefäßfehlbildungen

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Bori	Barbara	United Kingdom	BioMarin
Boselli	Simone	Belgium	EURORDIS - Rare Disease Europe
Bottarelli	Valentina	Belgium	EURORDIS - Rare Disease Europe
Boucherok	Amir	Algeria	Muhammad Dandan public hospital
Brites	Joaquim	Portugal	APN - Associação Portuguesa de Neuromusculares
Broun	Denis	Spain	Menkes International General Secretary
Brunlid	Gabriella	Sweden	Biogen
Butcher	Rachel	United Kingdom	EURORDIS - Rare Disease Europe
Byk	Guillaume	Belgium	European Commission
Cabral	Emerson	Spain	Alexion
Campabadal	Marta	Spain	EURORDIS - Rare Disease Europe
Capone	Donatella	Italy	NANA ETS
Carletti	Samantha	Italy	PKS Italia Aps
Casamayor	Manuel	Mexico	Asociación Gaucher de México
Castro	Raquel	Spain	EURORDIS - Rare Disease Europe
Croitoru	Adrian	Romania	DMD Care Association
Daly	Avril	Ireland	Retina International
Dan	Dorica	Romania	RONARD
de Graaf	Johan	Netherlands	Dutch Pituitary Foundation
de Graaff	Laura	Netherlands	Erasmus MC Rotterdam

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de Ligne	Anne	Belgium	
de Moya Rubio	Elena	Germany	Marfan Hilfe (Deutschland) e.V.
de Vicente	Daniel	Spain	Federacion Española de Enfermedades Raras - FEDER
Delaye	Julien	Belgium	EURORDIS - Rare Disease Europe
Demirhan	Burcu	Turkey	Turkey SMA Foundation
Dillon	Annamarie	United Kingdom	Orchard Therapeutics
Drachmann	Danielle	Denmark	Ketotic Hypoglycemia International
Druckman	Karen	Switzerland	HHT Swiss
Dubief	Jessie	France	EURORDIS - Rare Disease Europe
Duboka	Davor	France	PTC Therapeutics
Ekholm	Katja	Sweden	Karolinska University Hospital
Eriksson	Lise-lott	Sweden	MPE - President / The Swedish Blood Cancer Association - CEO/Secretary General
Eriksson Piekert	Amanda	Sweden	Institut Produits Synthèse (IPSEN) AB
Espenakk Osvoll	Andrea	France	EURORDIS - Rare Disease Europe
Evans	Elsie	United Kingdom	FH Europe
Faccio	Nicole	United Kingdom	@facciolita
Fahlberg	Marie H.	Sweden	Svenska FOP-föreningen
Faust	Gabi	Germany	Deutsche GBS CIDP Selbsthilfe
Favresse	Roseline	France	EURORDIS - Rare Disease Europe
Faye	Fatoumata	France	EURORDIS - Rare Disease Europe

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Ferencz	Beata	Sweden	Roche AB
Francisco	Rita	Spain	EURORDIS - Rare Disease Europe
Gerbild	John	Denmark	Foreningen for Ataksi og HSP
Gheorghiu	Ana	Romania	Asociatia pentru Matei
Gonçalves	Paulo	Portugal	RD-Portugal (Rare Diseases Portugal)
Grände	Malin	Sweden	Rare Diseases Sweden
Grentoft	Mette	Denmark	The European Federation of Williams Syndrome
Grigorova	Nataliya	Bulgaria	Bulgarian Huntington Association
Grundstrom	Jonas	France	Sanofi
Grunert	Juergen	Germany	Deutsche Ehlers-Danlos Initiative e.V.
Grybek	Tomek	Poland	Foundation of Borys the Hero
Gumus	Gulcin	Spain	EURORDIS - Rare Disease Europe
Gunther	Penilla	Sweden	EU Cancer Mission Board
Gustafsson Bonnier	Kristina	Sweden	Riksförbundet Sällsynta Diagnoser
Gylfason	Guðmundur	Iceland	Einstök Börn - Support Group for Children with Rare Disorders
Hardardottir	Gudrun	Iceland	Einstök börn Stuðningsfélag
Havelange	Paul	Belgium	22q11 Europe
Helm	Anja	France	EURORDIS - Rare Disease Europe
Hernando	Ines	Spain	EURORDIS - Rare Disease Europe
Hoffmann	Angelika	Germany	Bundesverband Angeborene Gefäßfehlbildungen e.V.

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Högvall	Karin	Sweden	Rare Diseases Sweden
Holzer	Ulrike	Austria	EDIN Ectodermal Dysplasias International Network / Pro Rare Austria
Howard	Brian	France	EURORDIS - Rare Disease Europe
Hugon	Anne	France	AFG Association francophone des Glycogénoses (French GSD)
Hunt	Sara	United Kingdom	Alex, The Leukodystrophy Charity
Hurard	Marine	France	EURORDIS - Rare Disease Europe
Jansone	Kristine	Belgium	European Haemophilia Consortium
Jarblad	Andreas	Sweden	Swedish Cystic Fibrosis Association
Jensen	Lene	Denmark	Rare Diseases Denmark
Johnson	Kirsten	United Kingdom	The Fragile X Society
Jørgensen	Johnna Anita	Denmark	Landsforeningen for Multipel System Atrofi
Jung	Gila	Germany	Chiesi
Juran	Stephanie	Sweden	Rare Diseases Sweden
Kole	Anna	France	UCB
Kristoffersen	Kristian Emil	Norway	Stiftelsen Frambu
Krupsdahl	Gitte	Denmark	Rare Diseases Denmark
Kulesha	Tatiana	Ukraine	Rare diseases of Ukraine
Kulish	Oksana	Ukraine	CF "Sister Dalila" PHURDA
Kulish Skara	Oksana	Ukraine	PHURDA
Kupiec	Janna	Poland	MATIO Polish CF Foundation

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Kvlividze	Oleg	Georgia	Georgian Foundation for Genetic and Rare Diseases
Kwast-Hoekstra	Diana	Netherlands	Endo-ERN/Dutch Pituitary Foundation
Lakwijk	Peter	Sweden	Thyroid Federation International
Le Cam	Yann	France	EURORDIS - Rare Disease Europe
Lehtonen	Tiina	Finland	HARSO ry
Leijenhorst	Sayen	Netherlands	Stichting SpierKracht
Leijenhorst-Le Belle	Aleksandra	Netherlands	Stichting SpierKracht/LGMD CAB
L'Hévéder	Anne	France	EURORDIS - Rare Disease Europe
Lundgren	Mildred	Sweden	HHT Sverige/ HHT Europe
Lundin	Åsa	Sweden	Centre of Rare diseases southeast
Lundström	Erica	Sweden	Rare Diseases Sweden
Macchia	Flaminia	Belgium	Roche
Malinina	Jelena	Belgium	EURORDIS - Rare Disease Europe
Mangarov	Todor	Bulgaria	PHA Bulgaria
Mangelaars	Maartje	Netherlands	Janssen
Mann	Mirjam	Germany	ACHSE e.V.
Mäntylä	Fanni-Laura	Finland	
Marcetic	Andrea	Serbia	Bromologos
Marchi	Davide	Belgium	Vertex Pharmaceuticals
Marinova	Monika	Bulgaria	Association of Tarlov Cyst patients in Bulgaria

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Marszałek	Przemysław	Poland	Matio Polish Cystic Fibrosis Foundation
Matyushenko	Vitaliy	Ukraine	Children with Spinal Muscular Atrophy, Charitable Foundation Ukraine
Mayo	Concha	Spain	EURORDIS - Rare Disease Europe
Mazouch	Lubomír	Czech Republic	Pacientský Spolek pro Atypické parkinsonské syndromy (APS)
McKenna	Elizabeth	United Kingdom	Vertex Pharmaceuticals
Meade	Nick	United Kingdom	Genetic Alliance UK
Mees	Toni	United Kingdom	Metabolic Support UK
Mejat	Alexandre	France	AFM TELETHON
Meriluoto	Anna	Belgium	Fabry International Network
Meunier	Marie	France	EURORDIS - Rare Disease Europe
Micallef	Sebastian	Malta	AGORA Representative
Mihova	Rumyana	Bulgaria	CF Association Bulgaria
Milusheva	Polina	Bulgaria	National Association of Patients With Growth Hormone Deficiency
Minnis	Noel	Germany	Takeda
Mircheska	Biljana	Macedonia	Save Liver - SLAP
Moilanen	Katja	Finland	Finnish Association of People with Physical Disabilities
Montefusco	Maria	Sweden	Rare Diseases Sweden / EURORDIS - Rare Disease Europe
Mossler	Karin	Sweden	The JMR Foundation for persons with Smith Lemli Opitz syndrome
Murphy	Maura	Ireland	Rare Disease Ireland
Muscat	Michelle	Malta	National Alliance for Rare Diseases Support Malta
Nelken	Marzena	Poland	National Forum Orphan

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Nørhave	Gunhil	Denmark	Alfa-1Danmark - Alpha-1 Europe Alliance
Odrihocká	Adéla	Czech Republic	Rare Diseases Czech Republic
Olauson	Anders	Sweden	Agrenska Foundation
Orfanou	Evi	Greece	Together for Life
Ostapenko	Stanislav	France	EURORDIS - Rare Disease Europe
Ottesen	Lisbet	Denmark	The Wilson Patient Association Denmark
Parejo	Alba	Spain	AsoNevus
Paulsen	Inger-Margrethe Stavdal	Norway	The Norwegian Osteogenesis Imperfecta Association
Peeters	Lenny	Belgium	Janssen Pharmaceutica
Pehlivan	Ceren	Turkey	Türkiye SMA Foundation
Pender	Lorna	United Kingdom	Clinigen
Penfrat	Jan	Belgium	European Digital Rights (EDRi)
Pernet	Julie	Belgium	EURORDIS - Rare Disease Europe
Pernin	Lise	France	EURORDIS - Rare Disease Europe
Petroni	Angelo	Italy	Angeli Noonan Associazione Italiana Sindrome di Noonan Onlus-APS
Pirola	Claudio	Sweden	DysNet
Plume	Ieva	Latvia	Latvian Alliance of Rare Diseases
Pogány	Gábor	Hungary	HUFERDIS
Popa	Veronica	France	EURORDIS - Rare Disease Europe
Poulain	Julien	France	EURORDIS - Rare Disease Europe

Pradel	Alain	France	Association vivre mieux le lymphoedeme
Prawer	Jill	United Kingdom	FH Europe
Ramadan	Abdelhamid Hamdy	Kuwait	Moh
Ramos Patrício	António José	Portugal	ANDO
Ramstrom	Martin	Sweden	Immedica Pharma
Rataj	Janina	Poland	Polish Neuromuscular Diseases Association
Rataj	Michal	Poland	Polish Neuromuscular Diseases Association
Regnier	Patrice	France	EURORDIS - Rare Disease Europe
Rehman	Shoaib ur	Pakistan	University of science and technology Bannu Pakistan
Repo	Johanna	Finland	Inclusion Finland KVTL / Norio Centre of Rare Diseases
Rindner	Orit	Israel	Gorlin Syndrome Association
Rodríguez	María	Spain	Angeles de Susac
Roehl	Claas	Austria	NF Kinder / NF Patients United
Romundstad	Lars Nasset	Norway	Norwegian Federation for Ostogenesis Imperfecta (NFOI)
Ropert Conquer	France	France	MED13L Syndrome Association
Rosén	Evelina	Sweden	CDH Sweden
Rosillo Bebeyto	Laura	Belgium	International Federation for Spina Bifida and Hydrocephalus
Ross	David	United Kingdom	Rare Disease Male Mental Health Support Group
Rzepka	Kamila	Poland	Healthcare Education Institute
Samonenko	Nataliia	Ukraine	National Hospital Okhmatdyt
Schoeters	Eva	Belgium	RaDiOrg - Rare Diseases Belgium

Schwob	Céline	France	EURORDIS - Rare Disease Europe
Scopinaro	Annalisa	Italy	UNIAMO FIMR
Shi	Junyi	Germany	Chinese organization for rare disorders
Siladi	Joseph	Ukraine	Ohmatdyt
Singh	Jasvant	Georgia	Caucasus Medical Centre University
Sinica	Sanita	Latvia	Latvian Alliance for Rare Diseases
Skaara	Hall	Austria	PHA Europe
Skarberg	Rebecca Tvedt	Norway	OIFE and EURORDIS BoD
Skarberg	Knut Erik	Norway	Rebecca Tvedt Skarberg's assistant
Skölving	Björn	Sweden	Orchard Therapeutics Sweden AB
Smit	Cees	Netherlands	EHC
Sørensen	Peder	Denmark	Porfyriforeningen.dk , Porphyria association Denmark
Stocks	Cecilia	Sweden	Ågrenska
Stoyanova	Lilyana	Bulgaria	Association Of People Suffering By Acromegaly In Bulgaria
Stoyanova	Boryana	Bulgaria	National Association of Patients with Mitochondrial Diseases in Bulgaria
Stratieva	Petia	Bulgaria	Retina International
Sturz	Dominique	Austria	Usher Austria, Pro Rare Austria
Svarvar	Patrick	Sweden	Chiesi global rare diseases
Tallgren	Juha-Pekka	Finland	HARSO ry
Tanesse	Daniel	Belgium	European CMT Federation
Termander	Birgitta	Sweden	NOC

Theodorou	Georgios	Cyprus	Cyprus Association of Inherited Metabolic Diseases 'Aspida Zois'
Tomov	Vladimir	Bulgaria	Bulgarian Alliance of People with Rare Diseases
Tomova	Iskra	Bulgaria	National Gaucher Organization
Torquati	Fernanda	Italy	Associazione italiana gaucher
Tsymbal	Halyna	Ukraine	Joni and Friends, Agape Ukraine
Vakanas	Marios	Cyprus	Cyprus Association of Inherited Metabolic Diseases 'Aspida Zois'
van Breukelen	Silvia	Netherlands	VSOP Dutch Genetic Alliance
van den Bogaerdt-Rance	Sian	Netherlands	SAS
van den Bosch	Caroline T.	Netherlands	HEVAS
van der Heijden	Lex	Netherlands	CMTC-OVM
van Rijswijck	Huub	Netherlands	SMA Europe
Velkovska	Denica	Macedonia	Association for persons with Spinal Muscular Atrophy- Stop SMA
Velkovski	Jane	Macedonia	Association for persons with Spinal Muscular Atrophy- Stop SMA
Verbeke	Anne	Sweden	Low Countries Language Services AB
Veronese	Alessandra	Italy	AISED
Verstegen	Jose	Netherlands	Mevr.
Vitali	Diana	Italy	SOD ITALIA
Walls	Rhiannon	France	EURORDIS - Rare Disease Europe
Waslekar	Rahul	France	EURORDIS - Rare Disease Europe
Wehr	Geske	Germany	EURORDIS Board
Westerlund	Maria	Sweden	Rare diseases Sweden

Wigren	Johan	Sweden	Immedica Pharma AB
Wikström	Marie	Sweden	Föreningen för de Neurosedynskadade/EX-Center (Swedish Thalidomide Society, NGO / EX-Center)
Wilbur	Michael	France	EURORDIS - Rare Disease Europe
Williams	David	Netherlands	LGD Alliance Europe
Winter	Kym	United Kingdom	Rareminds
Wójtowicz	Paweł	Poland	MATIO Polish CF Foundation
Yamada	Aurelio	United Kingdom	BioMarin
Zacouris-Verweij	Wendy	Netherlands	NVLE
Živković	Stefan	Serbia	National Organisation for Rare Diseases of Serbia (NORBS)
Zygmunt	Aldona	Poland	Pfizer