



## EURORDIS MEMBERSHIP MEETING 2021

SHAPING THE NEXT 10 YEARS OF RARE DISEASE POLICIES:  
EUROPE'S ACTION PLAN FOR RARE DISEASES

#30millionreasons

### LIST OF PARTICIPANTS

LAST NAME	FIRST NAME	COMPANY/ORGANISATION	COUNTRY
Abdelhadi	Rayene	International Pharmaceutical Students' Federation (IPSF)	Netherlands
Ábele	Maria	European Federation of Associations of Patients with Haemochromatosis (EFAPH)	Hungary
Acălinei	Arabela	Neuro Move CMT Association	Romania
Acaralitei	Maria	Romanian Prader Willi Association (RPWA)	Romania
Adamopoulou	Mary	95, Rare Alliance Greece	Greece
Agius	Mariella	National Alliance for Rare Diseases Support – Malta	Malta
Alahouzou	Zoe	EURORDIS	France
Aleksandrova	Oksana	Association of Patients with Pulmonary Hypertension	Ukraine
Aleksovska	Vesna	Association of Citizens for Rare Diseases "Life with Challenges"	Macedonia
Aligiannis	Kostas	EURORDIS	Belgium
Almasi	Zsuzsa	Romanian Prader Willi Association (RPWA)	Romania
Almendariz	Maria Elena	Federación Peruana de Enfermedades Raras (FEPER)	Peru
Amadio	Jessica	Mitocon	Italy
Aminoff	Dalia	AIMAR – Associazione Italiana Malformazioni Anorettali	Italy
Ancochea	Alba	Federación Española de Enfermedades Raras (FEDER)	Spain
Andersen	Jeanette	Lupus Europe	Belgium
Andersen	Mai	MCADD patient group	Denmark
Andersen	Terkel	EURORDIS	Denmark
Antoniou	Eleni	Thalassaemia International Federation (TIF)	Cyprus
Arellanesová	Anna	Rare Diseases Czech Republic	Czech Republic
Arnesen	Astri	European Huntington Association	Norway
Ashton	Sharon	EURORDIS	United Kingdom
Aslanian	Anne-Laure	EURORDIS	Spain
Atakay	Deniz	PKU Family Association	Turkey
Athanasiou	Dimitrios	World Duchenne Organisation (WDO) / 95, Rare Alliance Greece	Greece
Atzori	Walter	Alexion	Belgium
Aumont	Pierre	SILLC – Association de Soutien et d'Information à la Leucémie Lymphoïde Chronique et la maladie de Waldenström	France
Bakker	Suzie-Ann	World Duchenne Organisation (WDO)	Netherlands
Balekjian	Eduardo	ESB	Belgium
Baleyudier	Claudie	Association Française de l'Ataxie de Friedreich (AFAF)	France
Ballagh	Peter	Sickle Cell and Thalassaemia Ireland (SCTI)	Ireland
Barea	María	Vascular Anomaly Patient Association (VASCAPA)	Belgium

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Barreiros	Céu	Associação Portuguesa de Osteogénese Imperfeita (APOI)	Portugal
Barros	Ana	Raríssimas – Associação Nacional de Deficiências Mentais e Raras	Portugal
Bartès	Beate	Vivre sans Thyroïde (Living Without a Thyroid)	France
Basset	Luisa	Federación Española de Padres de Niños con Cáncer	Spain
Bellagambi	Simona	Uniamo FIMR (Federazione Italiana Malattie Rare)	Italy
Benvenuti	Stefano	Fondazione Telethon	Italy
Bergholtz	Jana	European Cavernoma Alliance (ECA) / Rare Diseases Sweden	Sweden
Bergna	Martina	EURORDIS	France
Berjonneau	Erwan	EURORDIS	France
Bernardi	Alessia	Zavod Bernardi Ventrella	Slovenia
Bettuzzi	Marcello	Associazione Fondazione Italiana HHT "Onilde Carini"	Italy
Bianca Ioana	Coca	Romanian Prader Willi Association (RPWA)	Romania
Biller	Ruth	ARVC-Selbsthilfe e.V.	Germany
Bloom	Lara	Ehlers-Danlos Society	United Kingdom
Bodin	Anne-Mary	EURORDIS	France
Bogaerd	Owen	SAS	Netherlands
Boiteux	Marie-Claude	Cutis Laxa Internationale	France
Bok	Amanda	European Haemophilia Consortium (EHC)	Belgium
Bolz-Johnson	Matt	EURORDIS	Germany
Bonaparte	Adriana	De Neu	Argentina
Bonjean	Jill	CF-Europe	Belgium
Borgards	Petra	Bundesverband Angeborene Gefäßfehlbildungen e.V. (German Association of Congenital Vascular Malformations)	Germany
Borhan	Mirela	Asociația Persoanelor cu Glicogenoză (APG Romania)	Romania
Bork	Cher	Alagille Syndrome Alliance	United States
Borrell	Maria	EURORDIS	Spain
Borroni	Simona	Dravet Syndrome European Federation	France
Boselli	Simone	EURORDIS	Belgium
Bottarelli	Valentina	EURORDIS	Belgium
Braga Menéndez	Florencia	ALAPA – Alianza Argentina de Pacientes	Argentina
Brambilla	Isabella	Dravet Italia	Italy
Břečtan	Rene	Rare Diseases Czech Republic	Czech Republic
Breza	Marianthi	University of Athens	Greece
Brites	Joaquim	APN – Associação Portuguesa de Neuromusculares	Portugal
Brook	Angela	Pseudomyxoma Survivor	United Kingdom
Bros-Facer	Virginie	EURORDIS	Spain
Bruegmann	Petra	Netzwerk Hypophysen und Nebennierenerkrankungen e.V. (Pituitary and Adrenal Network) / European MEN Alliance (EMENA)	Germany
Brunetti	Alessia	Associazione Italiana Sindrome X Fragile	Italy
Buttigieg	William	National Alliance for Rare Diseases Support – Malta	Malta
Bwomono	Concy	European Sickle Cell Federation (ESCF)	Sweden
Çakir	Zeynep	Rare Diseases Network (Turkey)	Turkey

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Calabrò	Michele	European Patients' Forum (EPF)	Belgium
Calcarella	Serena	APMARR – Associazione Nazionale Persone con Malattie Reumatologiche e Rare	Italy
Camaradou	Jenny	Rethink Funding	United Kingdom
Camerini	Alessandra	Fondazione Telethon	Italy
Camp	Rob	EURORDIS	Spain
Campabadal	Marta	EURORDIS	Spain
Cardoso	Maria Júlia	Associação Qe (Quinta Essência)	Portugal
Carvajal Arjona	Susana	ERKNet	Spain
Casamayor	Manuel	Asociación Gaucher de México	Mexico
Castilho	Rosemeire	FEVER – Associação Brasileira de Enfermidades Raras	Brazil
Castro	Raquel	EURORDIS	Spain
Caubo	Irene	NFVN – Neurofibromatose Vereniging Nederland	Netherlands
Cayuela Solano	Francesc	Federació Catalana de Malalties Minoritàries (FECAMM)	Spain
Cederroth	Helene	Wilhelm Foundation	Sweden
Chalandon	Anne-Sophie	Sanofi Genzyme	France
Chansard	Audrey	CF-Europe	France
Chappell	Lara	EURORDIS	France
Charlet	Anne	Lupus Europe	France
Ciobanu	Anca	HAE Junior	Czech Republic
Coombes	Charlotte	EURORDIS	France
Cooper	Graham	Aortic Dissection Charitable Trust	United Kingdom
Cornet	Alain	EURORDIS	Belgium
Cosmina	Festeu	Romanian Prader Willi Association (RPWA)	Romania
Coupe	Marlène	AVML – Association Vivre Mieux le Lymphoœdème	France
Courbier	Sandra	EURORDIS	France
Crampe	Jean-Joseph	VHL France	France
Crist	Debi	Rare Patient Voice	United States
Crocione	Claudia	HHT Europe	Italy
Crocione	Claudia	HHT Europe	Italy
Croitoru	Adrian	DMD Care Association	Romania
Crookston	Megan	Brittle Bone Society	United Kingdom
Culcear Kiss	Ingrid	Romanian Prader Willi Association (RPWA)	Romania
Daccord	Magdalena	FH Europe	United Kingdom
D'Alessio	Barbara	Lega Italiana Ricerca Huntington (LIRH Foundation)	Italy
Daly	Avril	Retina International (RI)	Ireland
Dan	Dorica	Romanian National Alliance for Rare Diseases	Romania
Davoudian	Yaser	Rare Diseases Foundation of Iran (RADOIR)	Iran
de Graaf	Johan	Nederlandse Hypofyse Stichting (Dutch Pituitary Foundation)	Netherlands
De Keyser	Hilde	CF-Europe	Belgium
Delaye	Julien	EURORDIS	Belgium

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Demir	Mehmet	SMA Hastalığı ile Mücadele Derneği (Association for Fighting SMA)	Turkey
de Montleau	Béatrice	AFM-Téléthon	France
De Schepper	Bea	European Federation of Neurological Associations (EFNA) / European Huntington Association	Belgium
De Sousa	Dina	European Hematology Association (EHA)	United Kingdom
Digneffe	Toon	Takeda	Belgium
Dobai	Levente	Romanian Prader Willi Association (RPWA)	Romania
Dobrzewski	Günter	Morbus Osler Selbsthilfe e.V. (Osler's Disease Self-Help)	Germany
Dror-Azurial	Orly	Rare Disease Coalition Israel	Israel
Druckman	Karen	HHT Swiss	Switzerland
Dubief	Jessie	EURORDIS	France
Duboka	Davor	EURORDIS	France
Duguet	Christophe	AFM-Téléthon	France
Duguet	Florence	AFM-Téléthon	France
Dumitras	Aliona	Asociația Obștească "SOS AUTISM"	Moldova
Dumitriu	Iuliana	Association of Children with Mitochondrial Diseases	Romania
Dutac	Michèle	Alliance Arthrogrypose	France
Economides	Christina	Children's Tumor Foundation (CTF) Europe	Belgium
Edraki	Hamid Reza	Rare Diseases Foundation of Iran (RADOIR)	Iran
Erdal	Emre	Happy Faces Association	Turkey
Ernst	Stephanie	TAPS Support Foundation	Netherlands
Espasandin	Natalia	AEPEF – Asociación Española de Paraparesia Espástica Familiar	Spain
Faust	Gabi	Deutsche GBS CIDP Selbsthilfe e.V.	Germany
Fechete	Mădălina	Romanian Prader Willi Association (RPWA)	Romania
Feider	Shirley	ALAN – Maladies Rares Luxembourg	Luxembourg
Fernández	Emiliano	Asociación de Pacientes de Gaucher del Paraguay (APAG-PY)	Paraguay
Ferrie	Monica	Victorian Clinical Genetics Services (VCGS)	Australia
Fogarassy	Eszter	Hungarian Federation of People with Rare and Congenital Diseases (HUFERDIS)	Hungary
Fowler	Catherine	Aortic Dissection Charitable Trust	United Kingdom
Fowler	Keith	Aortic Dissection Charitable Trust	United Kingdom
Frank	Charissa	Bindweefsel.be – Vlaamse Vereniging voor Erfelijke (Flemish Association for Hereditary Diseases)	Belgium
Galbraith	Heike	Pfizer	Belgium
Galetti	Ilaria	FESCA (Federation of European Scleroderma Associations) / GILS (Gruppo Italiano Lotta alla Sclerodermia)	Italy
Galvin	Liam	European Idiopathic Pulmonary Fibrosis and Related Disorders Federation (EU-IPFF)	Belgium
Galvin	Orla	Retina International (RI)	Ireland
Gatermann	Ruediger	CSL Behring	Germany
Giacomelli	Andrea	Associazione Fondazione Italiana HHT "Onilde Carini"	Italy
Giacometto	Alessandro	EURORDIS	France
Gianni	Diana	ANACC (Italy)	Italy
Gilroy	Bernadette	PKU Association of Ireland (PKUAI)	Ireland
Gimenez	Faustino	Asociación Española de Familiares y Enfermos de Wilson (AEFEW)	Spain

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Giuliani	Margaret	Vaincre les Maladies Lyosomales (VML)	France
González	Estefanía	Fundación ALPE Acondroplasia	Spain
Gonzalez Coll	Juan Carlos	Asociación de Esclerodermia Castellón (ADEC)	Spain
Grabowski	Christina	Morbus Osler Selbsthilfe e.V. (Osler's Disease Self-Help)	Germany
Grabowski	Christina	Morbus Osler Selbsthilfe e.V. (Osler's Disease Self-Help)	Germany
Gradinaru	Sorin	ACMIM – My Child My Heart Association	Romania
Grech	Maria	Marigold Foundation	Malta
Gressani	Andrea	Associazione Immunodeficienze Primitive (AIP)	Italy
Grigorova	Natalia	Bulgarian Huntington Association	Bulgaria
Grunert	Juergen	Deutsche Ehlers-Danlos Initiative e.V.	Germany
Grybek	Tomasz	Foundation of Borys the Hero	Poland
Gumus	Gulcin	EURORDIS	Spain
Haase	Bine	FSHD Europe	Netherlands
Hamann	Anne	PRO RETINA Deutschland e.V.	Germany
Hanga	Diana	Romanian Prader Willi Association (RPWA)	Romania
Hanslik	Karolina	EURORDIS	Belgium
Harja	Adriana	Romanian Myasthenia Gravis Association	Romania
Hasan	Nida	Rare Diseases International (RDI)	France
Hedley	Victoria	Newcastle University, Translational and Clinical Research Institute	United Kingdom
Hees	Mark	Spierziekten Nederland (Muscular Diseases Netherlands)	Netherlands
Hejdenberg	Robert	Ågrenska	Sweden
Helm	Anja	EURORDIS	France
Hennessey	Claire	Max Appeal	United Kingdom
Hernando	Inés	EURORDIS	Spain
Hervás	Clara	EURORDIS	Belgium
Hivert	Virginie	EURORDIS	France
Hocfor	Agnes	International Prader-Willi Syndrome Organisation (IPWSO)	United Kingdom
Holm	Birthe	Rare Diseases Denmark (RDD)	Denmark
Holzer	Ulrike	Selbsthilfegruppe Ektodermale Dysplasie e.V. (Ectodermal Dysplasia Self-Help Group) / Pro Rare Austria	Austria
Houyez	François	EURORDIS	France
Howard	Brian	EURORDIS	France
Hughes	Marguerite	International Prader-Willi Syndrome Organisation (IPWSO)	United Kingdom
Hugon	Anne	AFG – Association Francophone des Glycogénoses	France
Hunt	Sara	Alex, The Leukodystrophy Charity	United Kingdom
Iles	Iulia	Romanian Prader Willi Association (RPWA)	Romania
Ionutas	Veronica	Romanian Prader Willi Association (RPWA)	Romania
Ireland	Dawn Marie	CDH International	United Kingdom
Isaic	Camelia	HAE Junior	Czech Republic
Ivory	John	Sanofi	United Kingdom
Jageneau	Ingrid	DEBRA Belgium	Belgium

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Jelen	Nejc	Viljem Julijan Association for Children with Rare Diseases	Slovenia
Jenner	Rebecca	Rett Syndrome Europe (RSE)	United Kingdom
Jensen	Lene	Rare Diseases Denmark (RDD)	Denmark
Jiménez Fernández	Martín	Asociación HHT España	Spain
Jovović	Olivera	National Organisation for Rare Diseases of Serbia (NORBS)	Serbia
Julián	María Dolores	Freelance	Spain
Júlio	Filipa	European Huntington Association	Portugal
Kanapieniene	Laura	Rett Syndrome Europe (RSE)	Spain
Karakikla Mitsakou	Zoe	Lupus Europe	United Kingdom
Karatzias	Vasileios	Hellenic Friedreich's Ataxia Association	Greece
Kelday	Coreen	Brittle Bone Society	United Kingdom
Khandelwal	Shivang	Indian Institute of Technology Jodhpur (IITJ)	India
Khraiche	Joelle	CSL Behring	Belgium
Kinloch	Emma	Salivary Gland Cancer UK	United Kingdom
Kole	Anna	EURORDIS	France
Kontopidis	Dimitris	Hellenic CF Association	Greece
Korosec	Tadej	EAMDA – European Alliance of Neuromuscular Disorders Associations	Slovenia
Kovazh	Tamara	EURORDIS	Spain
Kulla	Hans-Dieter	pulmonale hypertonie e.V.	Germany
Kumra	Shuchi	Takeda	Switzerland
Kvividze	Oleg	Georgian Foundation for Genetic and Rare Diseases (GeRaD)	Georgia
Kwast-Hoekstra	Diana	Dutch Adrenal Society (NVACP)	Netherlands
Lakwijk	Peter	Thyroid Federation International	Sweden
Längsfeld	Michael	PRO RETINA Deutschland e.V.	Germany
Lascar	Sabine	VHL France	France
Lawlor	Anne	22q11 Ireland – Support Group	Ireland
Le Cam	Yann	EURORDIS	France
Leijenhorst	Aleksandra	SpierKracht Foundation	Netherlands
Leitman	Amy	NTM Info and Research (NTMir)	United States
León	Sole Sánchez	Asociación de Esclerodermia Castellón (ADEC)	Spain
Lepore	Angela	Associazione Italiana Sindrome X Fragile	Italy
Leru	Poliana	Colentina Clinical Hospital	Romania
Lewi	Dan	Cure and Action for Tay-Sachs (CATS) Foundation	United Kingdom
Louisse	Simone	Heart4Research (H4O)	Netherlands
Lourenço Marques	Manuela	andLINFAs – Associação Nacional de Doentes Linfáticos (National Association of Sufferers of Lymphatic Disorders)	Portugal
Lundgren	Mildred	HHT Sverige / HHT Europe	Sweden
Maeva	Natalia	Bulgarian Society of Patients with Pulmonary Hypertension (BSPPH)	Bulgaria
Maharaj	Romaine	UK Thalassaemia Society (UKTS)	United Kingdom
Malofii	Uliana	LCCF "Sister Dalila" Pulmonary Hypertension Ukrainian Rare Disease Association	Ukraine
Manaster	Lisa	CACNA1A Foundation	United States

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Manolopoulou	Penny	Solidarity	Greece
Marian	Alexandra	Romanian Prader Willi Association (RPWA)	Romania
Marinello	Diana	RIPAG	Italy
Marinou	Pamela	EURORDIS	France
Marshall	Jo	EURORDIS	France
Martínez Jiménez	Elvira	Federación Española de Enfermedades Raras (FEDER)	Spain
Marzulli	Angela	AIMAR – Associazione Italiana Malformazioni Anorettali	Italy
Mascetti	Marta	AISLA – Associazione Italiana Sclerosi Laterale Amiotrofica	Italy
Matyushenko	Vitaliy	Children with Spinal Muscular Atrophy (CSMA)	Ukraine
Mazouch	Lubomir	Spolek pro APS (APS Association)	Czech Republic
McEntegart	Tag (Mary)	Addison's Disease Self-Help Group (ADSHG)	United Kingdom
McGrath	Vicky	Rare Diseases International (RDI)	Ireland
Meade	Nick	Genetic Alliance UK	United Kingdom
Meszaros	Gergely	PHA Europe	Hungary
Meunier	Marie	EURORDIS	France
Miaouli	Elina	95, Rare Alliance Greece	Greece
Millman	Sue	EuroAtaxia	United Kingdom
Mirosavljevic	Bojana	Life, Association Against Child Rare Disease	Serbia
Mkhabela	Hlawulani	Rare Diseases International (RDI)	France
Mocutiu	Ramona	Romanian Prader Willi Association (RPWA)	Romania
Mohr	Lisen Julie	Frambu Resource Centre for Rare Disorders	Norway
Montefusco	Maria	Rare Diseases Sweden	Sweden
Montserrat Moliner	Antoni	ALAN – Maladies Rares Luxembourg	Luxembourg
Mumford	Jan	Genetic Alliance Australia	Australia
Murphy	Lise	Svenska Marfanföreningen (Swedish Marfan Association)	Sweden
Muscat	Michelle	National Alliance for Rare Diseases Support – Malta	Malta
Nafria Escalera	Begonya	Children's Hospital Sant Joan de Déu, Barcelona	Spain
Nett	Sabine	Deutsche GBS CIDP Selbsthilfe e.V.	Germany
Nguyen	Mai-Lise	Roche	Switzerland
Nisato	Giovanni	FH Europe	Switzerland
Noval Iruretagoyena	Susana	Fundación ALPE Acondroplasia	Spain
Oikonomou	Olga	Greek Alliance for Rare Diseases (PESPA)	Greece
Oliveira	Wanessa Garcia	FEBER – Associação Brasileira de Enfermidades Raras	Brazil
Onali	Michela	Associazione Gli Equilibristi HIBM	Italy
Oosterwijk	Cor	Patient Alliance for Rare and Genetic Diseases (VSOP)	Netherlands
Osborne	Patricia	Brittle Bone Society	United Kingdom
Ostapenko	Stanislav	EURORDIS	France
Osvoll	Andrea	EURORDIS	France
Ouillade	Marie-Christine	SMA Europe	France
Pakter	Philippe	Pierre Robin Europe Foundation	Netherlands

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Pallidis	Athanasios	LDL Greece	Greece
Panagouloupoulou	Nancy	Hellenic Friedreich's Ataxia Association	Greece
Pantea	Cristina Loredana	Children's Emergency Hospital "Louis Turcanu"	Romania
Papageorgiou	Labrini	Roche	Switzerland
Paraschiv	Corina	Medical Keto Diet Association	Romania
Pardo Gómez	Raquel	Asociación Miastenia de España (AMES)	Spain
Parowicz	Marek	AHC18+ e.V. / Polish Association for People Affected by AHC (ahc-pl)	Germany
Paslak	Bianca	ACHSE e.V. (Alliance for Chronic Rare Diseases)	Germany
Paulsen	Inger-Margrethe	Norwegian Osteogenesis Imperfecta Organisation (NFOI)	Norway
Pavanello	Stefano	Unione Triapiantati Polmone Padova – ODV	Italy
Pavlovic	Sandra	EURORDIS	Serbia
Petrutescu	Brindusa	Dr. Brîndușa Petruțescu – Activitate Medicală	Romania
Phair	Sandra	European Cavernoma Alliance (ECA)	Ireland
Philpott	Cara	Muscular Dystrophy Western Australia (MDWA)	Australia
Pineiro	Giancarlo	Alpha-1 Global	United States
Piñero Vegas	Mercè	Asociación Española de Esclerodermia (AEE)	Spain
Piryankova	Iliana	NAS – National Association for Sarcoidosis (Bulgaria)	Bulgaria
Pogány	Gábor	Hungarian Federation of People with Rare and Congenital Diseases (HUFERDIS)	Hungary
Popa	Veronica	EURORDIS	France
Puşcaş	Camelia	Romanian Prader Willi Association (RPWA)	Romania
Quadder	Bernd	Deutsche Sarkoidose-Vereinigung e.V. (German Sarcoid Association)	Germany
Radwan	Katarzyna	EURORDIS	Belgium
Rai	Myriam	Friedreich's Ataxia Research Alliance (FARA)	United States
Ramazina	Ayda	Rare Diseases International (RDI)	Belgium
Régnier	Patrice	EURORDIS	France
Restaino	Raffaella	Fondazione Alessandra Bisceglia ViVa Ale	Italy
Rigal	Loïc	Assedea	France
Rodrigues	Marta Sofia	Associação Portuguesa de Osteogénese Imperfeita (APOI)	Portugal
Rodríguez	Carolina	APERTcras – Asociación Nacional Síndrome de Apert y otras Craneosinostosis Síndromicas	Spain
Rogero	Cássia	FEVER – Associação Brasileira de Enfermidades Raras	Brazil
Romano	Laura	Fondazione Telethon	Italy
Ross	David	PTEN UK & Ireland (PTENUKI)	United Kingdom
Routledge	Sue	Pitt Hopkins UK	Netherlands
Ruano	Belén	ASINJOU – Asociación Española del Síndrome de Joubert	Spain
Ruez	Adrien	EURORDIS	France
Ruiz	Erik	EURORDIS	France
Ruszbach	Cristina	PKU Life Romania	Romania
Salama	Françoise	AFM-Téléthon	France
Sánchez de Vega	Rosa	Aniridia Europe	Spain
Scarabelli	Matteo	EURORDIS	France



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Schmidt	Fabian	Recordati Rare Diseases	France
Schmiedel	Ralf	Morbus Osler Selbsthilfe e.V. (Osler's Disease Self-Help)	Germany
Schmitt-Weese	Katja	TAPS Support Foundation	Netherlands
Schnettler	Sabrina	IEB DEBRA	Germany
Schultz	Robin	Hunter's CMT4B3 Research Foundation	United States
Schwarzer	Nicole	SoMA e.V.	Germany
Schwob	Céline	EURORDIS	France
Scopinaro	Annalisa	Uniamo FIMR (Federazione Italiana Malattie Rare) / Associazione Persone Sindrome di Williams (APW) Italia	Italy
Sestini	Sylvia	aimAKU – Associazione Italiana Malati di Alcaptonuria	Italy
Shahvand	Parinaz	Rare Diseases Foundation of Iran (RADOIR)	Iran
Siderius	Liesbeth	Shwachman-Diamond Syndrome Foundation (SDSF)	Netherlands
Skarberg	Rebecca	Osteogenesis Imperfecta Federation Europe (OIFE) / ERN BOND	Norway
Skibińska-Mamzer	Ilona	Polish Association for People Affected by AHC (ahc-pl)	Poland
Sluijmers	Annemarie	Lupus Europe	Netherlands
Smits	Rosanne	Radboudumc, Amalia Children's Hospital	Netherlands
Solis	Leire	IPOPI – International Patient Organisation for Primary Immunodeficiencies	Portugal
Somers	Amy	Lupus Europe	United Kingdom
Soykan	Olcay	PAHSSc – Pulmoner Hipertansiyon ve Skleroderma Hasta Derneği	Turkey
Spinou	Anna	Hellenic CF Association	Greece
Sproedt	Claudia	Cystinose-Selbsthilfe e.V. / Cystinosis Network Europe	Germany
Steele	Jenny	EURORDIS	France
Stefanovska	Gordana L.	Avatar	Macedonia
Steinecker	Karlheinz	AIRG France	France
Stoian	Irina	Federația pentru Drepturi și Resurse a Persoanelor cu Tulburări din Spectrul Autist din Republica Moldova (FEDRA RM)	Moldova
Stratieva	Petia	Retina Bulgaria	Bulgaria
Strehl	Thomas	IEB DEBRA	Germany
Sturz	Dominique	Pro Rare Austria / Usher Initiative Austria	Austria
Suluhan	Derya	University of Health Sciences (Turkey)	Turkey
Swiderski	Jan	Ipsen	France
Synodinos	Dimitrios	95, Rare Alliance Greece	Greece
Tanesse	Daniel	European CMT Federation	France
Tarrats	Núria	DEBRA Spain	Spain
Taruscio	Domenica	National Centre for Rare Diseases, Istituto Superiore di Sanità	Italy
Tesar	Michael	Curaplus	Austria
Theisen	Daniel	ALAN – Maladies Rares Luxembourg	Luxembourg
Thiollet	Hélène	Alliance Maladies Rares	France
Tincu	Iulia	Dr. Victor Gomoiu Clinical Children's Hospital	Romania
Tomsin	Robert	Vlaamse PBC-PSC-AIH patiënten vereniging (Flemish PBC-PSC-AIH Patient Association)	Belgium
Tontsch	Adriana	Association for Spina Bifida and Hydrocephalus	Germany
Tschida	Monika	PH Austria – Initiative Lungenhochdruck	Austria

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Usberghi	Lara	Associazione Italiana Sindrome X Fragile	Italy
Valenti	Marina	Associazione Sindrome di Alström Italia (ASSAI)	Italy
van der Heijden	Lex	CMTC-OVM	Netherlands
Van Poelgeest	Mary	WFIP – World Federation of Incontinent Patients	Netherlands
Vasseghi	Mary	TSC Ireland	Ireland
Veldman	Karin	Vereniging voor Ichthyosis Netwerken (Association of Ichthyosis Networks)	Netherlands
Velkovska	Denica	Stop SMA	Macedonia
Viala	Annie	Association Française Lesch-Nyhan Action (LNA)	France
Viala	Caroline	Association Française Lesch-Nyhan Action (LNA)	France
Virta	Sanni	Invalidiliitto	Finland
Vroom	Elizabeth	World Duchenne Organisation (WDO)	Netherlands
Wagner	Leona	Deutschsprachige Selbsthilfegruppe für Alkaptonurie (DSAKU) e.V.	Germany
Walsh	Lyndsey	RARE Ireland Family Support Network	Ireland
Wang	Mary	Fondazione Telethon	Italy
Waters	Fiona	Retina International (RI)	Ireland
Watson	Allison	Ring20 Research and Support UK	United Kingdom
Wehr	Geske	Selbsthilfe Ichthyose e.V. (Ichthyosis Self-Help)	Germany
Weigand	Elisabeth	Pro Rare Austria / ACHSE e.V. (Alliance for Chronic Rare Diseases)	Austria
Weinman	Ariane	EURORDIS	France
Westerheim	Ingunn	Osteogenesis Imperfecta Federation Europe (OIFE)	Norway
Wheeler	Russell	Leber's Hereditary Optic Neuropathy (LHON) Society	France
Wiegandt	Anna	ACHSE e.V. (Alliance for Chronic Rare Diseases)	Germany
Wiehe	Lenja	EURORDIS	Spain
Wilbur	Michael	EURORDIS	France
Willemse	José	Dutch Liver Patients Association (NLV)	Netherlands
Wogu	Lora Ruth	European Sickle Cell Federation (ESCF)	Ireland
Wójtowicz	Paweł	Polish CF Foundation MATIO	Poland
Woods	Dara	HHT Ireland	Ireland
Xuereb	Jennifer	Marigold Foundation	Malta
Yilmaz	Baha Ahmet	Hifoder (Association for Combatting Hypophosphatasia)	Turkey
Yordanova	Nikolinka	UMHAT "Sveta Marina" (Varna)	Bulgaria
Zakošek	Polona	DEBRA Slovenia	Slovenia
Zelinke	Demjen	Romanian Prader Willi Association (RPWA)	Romania
Ziemele	Baiba	Latvian Alliance for Rare Diseases	Latvia
Zinkand	Werner	mpn-netzwerk e.V.	Germany
Živković	Stefan	National Organisation for Rare Diseases of Serbia (NORBS)	Serbia
Zmazek	Vlasta	DEBRA Croatia / EURORDIS	Croatia
Zouva	Chrysanthi	Hellenic Friedreich's Ataxia Association	Greece
Zygmunt	Aldona	Pfizer	Poland