



RDI Global Meeting 2020 Participant List

Name	Last Name	Organisation
Nadiyah Hanim	Abdul Latif	Malaysian Rare Disorders Society
Mariella	Agius	The National Alliance for Rare Diseases Support - Malta
Silvia	Aguilera	Spanish Association for Antiphospholipid Syndrome
Samuel	Agyei Wiafe	Rare Disease Ghana Initiative
Vesna	Aleksovska	Association of citizens for rare diseases LIFE WITH CHALLENGES
Fabio	Almeida	Associação Brasileira de Paramiloidose
Rasha	Alnaibari	RDI
Zoi	Anastasa	Vasculitis UK
Alba	Ancochea Díaz	FEDER\RDI
Roberta	Anido de Pena	FEDERACION ARGENTINA DE ENFERMEADES POCO FRECUENTES
Eleni	Antoniou	Thalassaemia International Federation
Anne-Laure	Aslanian	EURORDIS
Uzma	Atif	Takeda
Hatijah	Ayob	Malaysian Rare Disorders Society
Josette	Azzopardi	National Alliance for Rare Diseases Support Malta
Alain	Baumann	WFH
Ruth	Billier	ARVC-Selbsthilfe e.V.
Lara	Bloom	The Ehlers-Danlos Society
Marie-Claude	Boiteux	Cutis Laxa Internationale
Thomas	Bols	PTC Therapeutics
Matt	Bolz-Johnson	RDI
Jill	Bonjean	Rare Diseases International
Valentina	Bottarelli	EURORDIS
Virginie	Bros-Facer	EURORDIS
William	Buttigieg	The National Alliance for Rare Diseases Support - Malta
Alessandra	Camerini	Fondazione Telethon
Rob	Camp	EURORDIS
Helene	Cederroth	Wilhelm Foundation
Anna	Chew	Malaysian Rare Disorders Society
Anil	Choubey	Indian Prader Willi Syndrome Association
Avril	Coelho	Local Government, Independent
Ellen	Coleman	VOZ Advisors
Denis	Costello	CML Advocates Network
Sandra	Courbier	EURORDIS
Caroline	Daly	Sarepta Therapeutics
Dorica	Dan	Romanian National Alliance for Rare Diseases
Carla	D'Angelo	IRDiRC
Yaser	Davoudian	Rare Diseases Foundation of Iran
Christine	de Kalbermatten	MaRaVal - maladies rares valais - seltene krankheiten wallis
Boel	De Paepe	Ghent University Hospital
Daniel	de Vicente	ASMD España
Migdalia	Denis	Sociedad Latina de Hipertension Pulmonar
Ratna	Devi	International Alliance of Patient Organisations
Ruggero	Di Maulo	Cloud-R Srl
Toon	Digneffe	Takeda
Marc	Dooms	University Hospitals Leuven
Vanessa	dos Reis Ferreira	Santhera
Orly	Dror-Azurriel	RD ISRAEL
Kelly	du Plessis	RARE DISEASES SA
Jessie	Dubief	EURORDIS
Davor	Duboka	EURORDIS
Sonja	Durinck	Canadian Pituitary Patient Network
Ege	Ercuar	PKU Family Association
Luciana	Escati Peñaloza	Federación Argentina de Enfermedades Poco Frecuentes (FADEPOF)
Christina	Fasser	Retina International
Alex	Felice	University of Malta
Monica	Ferrie	Genetic Support Network of Victoria
Laura	Florez	FECOER
Lisa	Foster	Rare Disorders NZ (formerly NZORD)
Paul	Freeman	Newcastle University
Safiyya	Gassman	Pfizer
Chandu	George	Seek a miracle Ataxia group
Rachel	Githinji	IAPO
Susana	Grosso	Alianza Retinosis Pigmentaria Argentina (ARPA) Miembro de la Federación Argentina de Enfermedades Poco Frecuentes (FADEPOF)
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Robert	Hejdenberg	Ågrenska
Ines	Hernando	EURORDIS
Tony	Holland	International Prader-Willi Syndrome Organisation
Paul	Howard	Amicus Therapeutics
Anne	Hugon	AFG patient organisation

Dennis	Jackman	RDI Faculty
Ritu	Jain	APARDO\RDI
Roselyn	Kanja	Rare Disorders Kenya
Sheila	Khawaja	WAPO
Ruediger	Krech	World Health Organization
Sivasangaran	Kumaran	Rare Disease Malaysia
Oleg	Kvividze	Georgian Foundation for Genetic and Rare Diseases (GeRAD)
Stalo	Kyriakidou	Unique Smiles
Terry	Lai	Hong Kong Alliance for Rare Diseases
Anna	Lambertson	Hairy Cell Leukemia Foundation
Yann	Le Cam	EURORDIS\RDI
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Nicolas	Lorente	SCN2A Europe
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Helen	Malherbe	Rare Diseases South Africa
Davide	Marchi	Vertex Pharmaceuticals
Fionnuala	Margreiter	European Huntington's Disease Network
Muriel	Marks	World Alliance of Pituitary Organizations
Eleonore	Mathe	Spark Therapeutics
Vitaliy	Matyushenko	Children with SMA, Charitable Foundation
Matthew	May	Roche
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Irina	Miasnikova	Russian association for rare diseases (Russian patients union)
Hlawulani	Mkhabela	RDI
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Lucia	Monaco	Fondazione Telethon
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Trudy	Nyakambangwe	Child Youth Care
Kay	Ode	Amicus Therapeutics
Godfred	Oduro	Thalassemia Foundation Ghana
Rose	Okoma	Association Aux Pas Du Coeur
Philippe	Pakter	Stichting Pierre Robin Europe (the Pierre Robin Europe Foundation)
Raquel	Peck	CZI
Alba	Pérez	Asociación Nacional de Hipertensión Pulmonar
Martine	PERGENT	IPOPI
Randel	Plant	Alpha-1 Foundation
Gábor	Pogány	HUFERDIS
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Regina	Prospero	Vidas Raras Institute
Alba veronica	Puddu	Private
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Laura	Quinn (Iliescu)	PRA Health Sciences
James	Radke	Zeal Access
Harsha	Rajasimha	IndoUSrare
Ana	Rath	OPHARNET
Paola	Ricci	Independent
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Maritza	Rodríguez	Organización de Pacientes con Hipertensión Pulmonar "Uapan Kallpa"
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Salwa	Sayd	Roche
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Parinaz	Shahvand	Rare diseases foundation of Iran
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Maureen	Smith	Canadian Organization for Rare Disorders
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Olcay	Soykan	Pulmonary Hypertension and Scleroderma Patients Association
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Sylvia	Sumargi	Indonesian Spinal Muscular Atrophy Community

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KP	Tsang	Hong Kong Alliance for Rare Diseases
Stephany	VARGAS	Ipsen
Caroline	Viala	Association Lesch-Nyhan Action
Mary	Wang	Fondazione Telethon
Anke	Widenmann-Grolig	EAT e. V.
Ienja	wiehe	EURORDIS
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Durhane	Wong-Rieger	CORD\ RDI
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Helen	Zhou	Illness Challenge Foundation
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