



## Annual Meeting 2019 – List of Participants

	<b>First Name</b>	<b>Last Name</b>	<b>Organisation</b>
1.	Fabio	Almeida	Instituto Vidas Raras
2.	Inês	Alves	ALPE Foundation
3.	Alba Amelia	Ancochea	FEDER
4.	Terkel	Andersen	EURORDIS
5.	Roberta	Anido de Pena	FADEPOF
6.	Nizam	Assaf	Amman Center for Human rights Studies
7.	Uzma	Atif	Takeda
8.	Amira	Awada	Instituto Vidas Raras
9.	Hatijah	Aybob	Malaysian Rare Disorders Society
10.	Simone	Azevedo	Bioverativ, a Sanofi Company
11.	Liberato	Bautista	CoNGO
12.	Lieven	Bauwens	International Federation for Spina Bifida and Hydrocephalus
13.	Eva	Bearryman	EURORDIS
14.	Matthew	Bellgard	Queensland University of Technology
15.	Johanna	Berglein	Soma e.v.
16.	Lara	Bloom	The Ehlers-Danlos Society
17.	Nicole	Boice	Global Genes
18.	Jill	Bonjean	Rare Diseases International
19.	Kym	Boycott	University of Ottawa, Care4Rare Canada
20.	Mladen	Bozic	Takeda
21.	William	Buttigieg	The National Alliance for Rare Diseases Support - Malta
22.	Jane	Cai	China Rare Disease Organization (CORD)
23.	Manuel	Casamayor	Asociacion Gaucher de Mexico a.c.
24.	Mbengue	Cheikh Ahmed Tidiane	Association Humanitaire de Lutte Contre Les Maladies
25.	Penney	Cowan	International Alliance of Patient Organizations
26.	Deepa	Dahal	DKI Health
27.	Avril	Daly	Retina International & EURORDIS
28.	Dorica	Dan	Romanian National Alliance for Rare Diseases & EURORDIS
29.	Fulvio	D'Angelo	Collagene VI Italia ONLUS
30.	Polianne	Delmondez	NGOs Committee on the Status of Women & Committee on Mental Health
31.	Migdalia	Denis	PH Latin Society
32.	Karen	Dindial	DKI Health
33.	Kelly	du Plessis	Rare Diseases South Africa
34.	Florence	Duguet	AFM-Téléthon
35.	Hamid Reza	Edraki	Rare Diseases Foundation of Iran
36.	Luciana	Escati Peñaloza	FADEPOF
37.	German	Escobar	PROPACIFICO
38.	Khalifa Babacar	Fall	Association humanitaire contre les maladies



39.	Fernando	Ferrer MBA	AMAVI
40.	Ryan	Fischer	Parent Project Muscular Dystrophy
41.	Brenda	Fix	Microsoft
42.	Patricia	Furlong	Parent Project Muscular Dystrophy
43.	Regina	Garcia Prospero	Instituto Vidas Raras
44.	José E.	Garcia-Ortiz	OMER
45.	Safiyya	Gassman	Pfizer
46.	Pamela	Gavin	NORD
47.	Jayne	Gershkowitz	Amicus Therapeutics
48.	Pamela	Graves-Moore	Sanofi Genzyme
49.	Rajendra Pratap	Gupta	Disease Management Association of India
50.	Femida	Gwadry-Sridhar	Pulse infoframe Inc.
51.	Sobia	Hamid	World Economic Forum
52.	Marc	Hanauer	Orphanet
53.	Robert	Hejdenberg	Agrenska
54.	Anja	Helm	EURORDIS
55.	Clara	Hervas	EURORDIS
56.	Claudia	Hirawat	Voz Advisors
57.	Kevin	Huang	CORD China
58.	Dawn	Irish	Takeda
59.	Julia	Jenkins	EveryLife Foundation for Rare Diseases
60.	Margaretha	Jones	International Humanist and Ethics Union
61.	Barbara	Kucsera	Permanent Mission of Hungary to the UN
62.	Yukiko	Kuroda Nishimura	ASrid
63.	Oleg	Kvividze	Georgian Foundation for Genetic and Rare Diseases
64.	Anna	Lambertson	Hairy Cell Leukemia Foundation
65.	Yann	Le Cam	EURORDIS
66.	Pedro	Lendinez	Mas Visibles
67.	Ronald	Lennon	Patient family member
68.	Bette	Levy	Soroptimist International
69.	Robert	Long	Uplifting Athletes Inc.
70.	Patricia	Lucki	ANGEL
71.	Flaminia	Macchia	Vertex
72.	Cynthia	Magdaraog	Philippine Society for Orphan Disorders
73.	Dora	Maradiaga	NCD Alliance
74.	Amalia	Maranhao	Abahe-Brazilian Association of Hereditary Diseases
75.	Rose	Mbede nga mvondo	infomaladierare
76.	Angela	McCoy	Takeda
77.	Paul	Melmeyer	NORD
78.	Irina	Miasnikova	Russian association for rare diseases
79.	Claire	Murphy	Terrapinn



80.	Ramaiah	Muthyala	Indian Organization for Rare Diseases
81.	Jesus	Navarro	ALIBER
82.	Kunihiro	Nishimura	NPO ASrid
83.	Olga	Oikonomou	Greek Alliance for Rare Diseases
84.	Anders	Olauson	Agrenska
85.	Diana Goretty	Oviedo	Federacion Colombiana de Enfermedades Raras
86.	Antonio	Parenti	EU delegation
87.	Linn	Parrish	Takeda
88.	Johan	Prevot	IPOPI
89.	Harsha	Rajasimha	Organization for Rare Diseases India
90.	Ana	Rath	Orphanet
91.	David	Rintell	BridgeBio
92.	Ana	Rios	OMER
93.	Jessica	Riviere	Biogen
94.	Jennifer	Rollo	Genetic Alliance Australia
95.	Carolina	Sanchez	EU delegation at the UN
96.	Lisa	Sarfaty	NORD
97.	Annalisa	Scopinaro	APW Italia Onlus - UNIAMO FIMR Onlus
98.	Eda	Selebatso	Botswana organisation for Rare Diseases
99.	Lineo	Seleki	Mara NPO
100.	Eliana Marcela	Sepúlveda Bedoya	FECOER
101.	Parinaz	Shahvand	Rare Diseases Foundation of Iran
102.	Tracy	Shaw	Immune Deficiency Foundation
103.	Stuart	Siedman	Bioerativ, a Sanofi company
104.	Katie	Smith	Tuberous Sclerosis Alliance
105.	Michael	Smyth	Kyowa Kirin
106.	Marshall	Summar	Children's National Medical Center & NORD
107.	Ryan	Taft	illumina Cambridge Ltd
108.	Paloma	Tejada	Rare Diseases International
109.	Foteini	Theiakou	Greek Alliance for Rare Diseases
110.	KP	Tsang	Hong Kong Alliance for Rare Diseases
111.	Laudeci	Vieira Dos Santos	Amavi Associação Mariavitoria de Doenças Raras e Crônicas
112.	Pedro	Villela Chavez	George Mason University
113.	Charlene	Waldman	Rare Bone Disease Alliance
114.	Alain	Weill	World Federation of Hemophilia
115.	Hartmann	Wellhoefer	Takeda
116.	Durhane	Wong-Rieger	Canadian Organization for Rare Disorders
117.	Rachel	Yang	Chinese Organization for Rare Disorders (CORD)
118.	Shuyang	Zhang	Peking Union Medical College Hospita
119.	Vlasta	Zmazek	Debra & EURORDIS