



RARE
DISEASES
INTERNATIONAL

**RDI Membership Meeting
May 10-12, 2018
Vienna**

List of Participants

1	Bianca	Barbis	Afag	Brasil
2	Stephanie	Juran	Rare Diseases Sweden	Sweden
3	Lieven	Bauwens	International Federation for Spina Bifida and Hydrocephalus	Belgium
4	Mark	Brooker	World Federation of Hemophilia	Spain
5	Tamara	Kvas	Rare Diseases Croatia	Croatia
6	Sanja	Perić	Rare Diseases Croatia	Croatia
7	Irena	Žnidar	European Gaucher Alliance	Slovenia
8	Kelly	Du Plessis	Rare Diseases South Africa	South Africa
9	Marie-Claude	Boiteux	Cutis Laxa Internationale	France
10	Terry	Lai	Hong Kong Alliance for Rare Diseases	Hong Kong
11	KP	Tsang	Hong Kong Alliance for Rare Diseases	Hong Kong
12	Rainer	Riedl	Pro Rare Austria	Austria
13	Alba	Ancochea	Feder/Eurordis	Spain
14	HamidReza	Edraki	Rare Diseases Foundation of Iran	Iran
15	Sirous	EftekhariMaleki	Rare Diseases Foundation of Iran	Iran
16	Yaser	Davoudian	Rare Diseases Foundation of Iran	Iran
17	Mohsen	Sojoudi	Rare Diseases Foundation of Iran	Iran
18	Tetiana	Kulesha	Non-governmental organization "rare diseases of ukraine"	Ukrainia
19	Oksana	Aleksandrova	Non-governmental organization "rare diseases of ukraine"	Ukrainia
20	Tetiana	Zamorskaya	Non-governmental organization "rare diseases of ukraine"	Ukrainia
21	Larisa	Voloshina	Non-governmental organization "rare diseases of ukraine"	Ukrainia
22	Lut	De Baere	Boks	Belgium
23	Hilde	Ketels	Boks	Belgium
24	Anders	Olauson	Agrenska Foundataion	Sverige
25	William	Buttigieg	The National Alliance for Rare Diseases Support - Malta	Malta
26	Josette	Azzopardi	The National Alliance for Rare Diseases Support - Malta	Malta
27	Lara	Bloom	The Ehlers-Danlos Society	UK
28	Matthew	Harold	Pfizer Ltd.	United Kingdom
29	Annamarie	Dillon	ProQr	The Netherland
30	Irina	Miasnikova	Russian patients union, Russian association for rare diseases	Russian Federation
31	Dominique	Sturz	Usher Deafblind Austria, Pro Rare Austria	Austria

32	Mirjam	Mann	ACHSE e. V.	Germany
33	Christina	Waters	WuXi NextCODE	United States
34	Daria	Julkowska	ANR/E-Rare	France
35	Anita	Atema	Celgene	Nederland
36	Rainer	Riedl	DEBRA Austria, Pro Rare Austria	Austria
37	Mirjami	Tran Minh	Association of Cancer Patients in Finland	Finland
38	Ruediger	Gatermann	CSL Behring	Germany
39	Vinciane	Pirard	Sanofi Genzyme	Belgium
40	Qi	Sun	Chinese Organization for Rare Disorders(CORD)	China
41	Yann	Le Cam	EURORDIS Rare Diseases Europe	France
42	Juan	Carrión Tudela	Alianza Iberoamericana de Enfermedades Raras	España
43	Bertrand	Verwee	Roche	Switzerland
44	Gerard	Viens	Alliance Maladies Rares	France
45	Lindsay	Perera	Kyowa Kirin	United Kingdom
46	Yvette	Venable	Kyowa Kirin	United Kingdom
47	Dennis	Jackman	CSL Behring	United States
48	Verena	Dr. Wanker-Gutmann	I.P.W.S.O International Prader Willi Organisation	Austria
49	Zsuzsa	Almásí	Romanian National Alliance for Rare Diseases	Romania
50	Yukiko	Nashimura	ASRID / JPA	Japan
51	Eleni	Antoniou	CARD/ TIF	Cyprus
52	Christoph	Poincilit	INPDA	Switzerland
53	Ramaiah	Muthyala	I-ORD	India
54	Durhane	Wong-Rieger	CORD	Canada
55	Lisa	Phelps	NORD	USA
56	Ritu	Jain	DEBRA International	Singapore
57	Alfredo	Toledo	ALIBER	Uruguay
58	Migdalia	Denis	HP Latin Society	Venezuela
59	Clara	Hervas	EURORDIS Rare Diseases Europe	Belgium
60	Sandra	Courbier	EURORDIS Rare Diseases Europe	France
61	Hamann	Wellington	Afag	Brasil
62	Paloma	Tejada	Rdi	Switzerland