



RARE
DISEASES
INTERNATIONAL

RDI Membership Meeting
June 4, 2017
Barcelona

List of participants

1	Luz Victoria	Salazar Ceballos	ACOPEL
2	Alfredo	Toledo	ALIBER
3	Juan	Carrión	ALIBER/ FEDR
4	Gérard	Viens	Alliance Maladies Rares
5	Mónica Inmaculada	Tortosa Fito	Asociación de Enfermos de Fiebre Mediterránea Familiar y Síndromes Autoinflamatorios de España: FMF ESPAÑA
6	Aranzazu	Ormazábal	Asociación Catalana de Espina Bífida e Hidrocefalia
7	Chiara	Cirimmina	Blackswan
8	Eda	Selebatso	BORDIS
9	Durhane	Wong-Rieger	Canadian Organization for Rare Disorders
10	Greg	Smiley	Caring Voice Coalition
11	Jane	Coward	Chiltern
12	Cristina	Pindado González	Congenital Hyperinsulinism International
13	Marc	Pérez-Serra	EAT
14	Cathelijne	van Doorne	euro-Ataxia
15	Margaret	Giuliani	European Gaucher Alliance
16	Clara	Hervas	EURORDIS
17	Yann	Le Cam	EURORDIS
18	Paloma	Tejada	EURORDIS
19	Inés Alicia	Castellano	FADEPOF (Federación Argentina de Enfermedades poco Frecuentes)
20	Angela Patricia	Chaves Restrepo	FECOER
21	Alba	Ancochea	FEDER Federación Española de Enfermedades Raras
22	Luciana	Escati Peñaloza	Federación Argentina de Enfermedades Poco Frecuentes (FADEPOF)
23	Paulina	Pena	FEMEXER
24	Jose	Pena	FEMEXER
25	Carlos David	Peña Aragón	FEMEXER
26	Claudio	Cordovil-Oliveira	Fundacao Oswaldo Cruz
27	Martha	Herrera	Fundacion Colombiana para Fibrosis Quistica
28	Emma	Suardiaz	IFSBH

29	Sanaullah	Syed	Indian Organization for Rare Diseases
30	Christoph	Poincilit	INPDA
31	Saida	Ortolano	Instituto de Investigación Sanitaria Galicia Sur
32	Hatijah	Ayob	Malaysian Rare Disorders Society
33	Swati	Sharma	Medifirst
34	Nircia Isabella	Andrade Pereira	Menkes Brasil
35	Christine	White	National Gaucher Foundation of Canada
36	Iva	Omrčen	National Organisation for Rare Diseases Serbia (NORBS)
37	Lisa	Phelps	National Organization for Rare Disorders
38	Hanny	Poincilit	NPSuisse
39	Barbara Iwona	Wojcicka-Bartłomiejczyk	NUTRICIA
40	Waheed	Butt	Patient
41	Ali	Davoudian	Rare Diseases Foundation of Iran
42	Sirous	Eftekhari Maleki	Rare Diseases Foundation of Iran
43	Somayeh	NagahiTapeMolaie	Rare Diseases Foundation of Iran
44	Alireza	Tavakoli	Rare Diseases Foundation of Iran
45	Kelly	du Plessis	Rare Diseases South Africa
46	Megan	Hunter	Rare Diseases South Africa
47	Ekaterina	Podushkina	Russian patient union
48	Greg	Robertson	Shire
49	Migdalia	Denis	Sociedad Latina de Hipertension Pulmonar
50	María José	Rodríguez	Susac Syndrome Spain
51	Lara	Bloom	The Ehlers-Danlos Society
52	Denis	Belyakov	Union of patients and patient's organisations with Rare diseases
53	Alexander	Kosenko	Union of patients' and patients' organizations' with rare diseases
54	Galindo	Rodríguez	Weber Economía y Salud
55	Sonja	Durinck	World Alliance Pituitary Organization
56	Sheila	Khawaja	World Alliance Pituitary Organization
57	Mark	Brooker	World Federation of Hemophilia
58	Cristina	Arnau	