



Launch Event
28-mai-15
Hotel Rafael Atocha, Madrid
Participants List

Zoe	Alahouzou	EURORDIS	
Vesna	Aleksovska	Ass. Life with Challenges	R. Macedonia
Alba	Ancochea	Feder	Spain
Terkel	Andersen	Danish Haemophilia Society	Denmark
Nasir Alam	Ansari	GBS / CIDP Foundation NEPAL	Nepal
Sharon	Ashton	EURORDIS	
Bianca	Barbis	AFAG	Brasil
Renza	Barbon	UNIAMO	Italy
Luisa	Basset	CCI, Childhood Cancer International	Netherlands

Lieven	Bauwens	International Federation for Spina Bifida and Hydrocephalus	Belgium
Eva	Bearryman	EURORDIS	
Rene	Brectan	CAVO	Czech Republic
Lily	Cannon	CARD	Cyprus
Rosa	Cedeno	Instituto de Genetica Fundacion Venezolana de Hipertension Pumonar	Venezuela
Lara	Chappell	EURORDIS	
Denis	Costello	EURORDIS	
Antoine Souheil	Daher	AFAG	Brazil
Avril	Daly	Fighting Blindness/GRDO	Ireland
John	Dart	DEBRA International	UK
Hawa	Drame	FITIMA Foundation	Burkina Faso
Christina	Fasser	Retina International	Switzerland
Shirley	Feider	ALAN -maladies rares Luxembourg	Luxembourg
Alain	Fontaine	Alliance Maladies Rares	France

Megan	Fookes	Rare Voices Australia	Australia
Fabris Stéphan	Fowe	Associacion De Hemofilicos Del Camerun	Cameroon
Pamela	Gavin	NORD	USA
Paul	Gi-menès	Alliance Maladies Rares	France
Dora	Gimes	Rare Diseases Hungary	Hungary
Androniki	Grypari	Greek Alliance for Rare Diseases	Greece
Robert	Hejdenberg	Agrenska Foundation	Sweden
Anja	Helm	EURORDIS	
Marta	Jacinto	Rare Diseases Portugal	Portugal
Maria Cecilia	Jorge Branco	AFAG	Brazil
Alastair	Kent	Genetic Alliance UK	UK
Oleg	Kvlividze	Georgian Foundation for Genetic and Rare Diseases (GeRaD)	Georgia
Jose Carlos	La Plata	FEBER	Brazil
Marianna	Lambrou	Greek Alliance for Rare Diseases	Greece
Anne	Lawlor	GRDO	Ireland

Ines	Leal de Faria	Rare Diseases Portugal	Portugal
Yann	Le Cam	EURORDIS	
Flaminia	Macchia	EURORDIS	
Stansilaw	Mackowiak	Polish Orphan	Poland
Fabio	Marques De Freitas	AFAG	Brasil
Irina	Miasnikova	NGO "Help to cystic fibrosis patients"	Russia
Christine	Mundlos	ACHSE e.V.	Germany
Ramaiah	Muthyala	Indian Organization for Rare Diseases	India
Yukiko	Nishimura	Japan Patient Organisation	Japan
Vanessa	Peberdy	IFPMA	Switzerland
Wellington Luiz	Pegorari Hamann	AFAG	Brasil
Jose-Luis	Plaza	AEDAF (Asociación Española Angioedema Familiar)	Spain
Manuel	Posada	Research Institute for Rare Diseases	Spain
Johan	Prevot	IPOPI	UK
Jörg	Richstein	ACHSE e.V.	Germany

Kevin	Rufang Huang	Chinese Organisation for Rare Diseases	China
Françoise	Salama	AFM	France
Peter	Saltonstall	NORD	USA
Rosa	Sanchez	Aniridia Europa	Spain
Jean-Marc	Sfeir	EURORDIS	
Danijela	Szili	HUFERDIS	Hungary
Leire	Solis Garate	IPOPI	UK
Antonie	Souheil Daher	Casa Hunter	Brasil
Dean	Stardelis	PEPSA	Greece
Helga	Süli-Vargha	HUFERDIS	Hungary
María Delfina	Tay	Association Procrece Guatemala	Guatemala
Paloma	Tejada	EURORDIS	
Marina	Terekhova	Russian patient organization of Gaucher disease	Russia
Sharon	Terry	Genetic Alliance	USA
Alfredo	Toledo	ALIBER-Alianza Iberoamericana de Enfermedades Raras	Uruguay

Nathalie	Triclin	Alliance Maladies Rares	France
Rainald	Von Gizycki	PRO RETINA Deutschland	Germany
Durhane	Wong-Rieger	Canadian Organization for Rare Disorders	Canada
Anna	Zannetou	Cyprus Alliance for Rare Disorders	Cyprus
Mirosław	Zielinski	Polish Orphan	Poland
Baiba	Ziemele	Latvian Alliance for Rare Diseases	Latvia
Vlasta	Zmazek	Debra Croatia	Croatia