

## Rare Diseases International 2nd Annual Meeting

May 25, 2016

ECRD 2016 Edinburgh

Zoe	Alahouzou	Europe	EURORDIS
Alba	Ancochea	Spain	FEDER
Terkel	Andersen	Denmark	Danish Haemophilia Society
Anna	Arellanesová	Czech Rep	Czech National Association for Rare Disease
Josette	Azzopardi	Malta	National Alliance for Rare Diseases and Si
Alain	Baumann	Canada	World Federation of Hemophilia
Lieven	Bauwens	Belgium	International Federation for Spina Bifida
Mark	Beckwith	USA	Naevus Global
Judit	Becskeházi-Tar	Hungary	HUFERDIS
Simona	Bellagambi	Italy	UNIAMO
Denis	Belyakov	Russia	Russian Union of patients' and patients' c
Valentina	Bottarelli	Europe	EURORDIS
William	Buttigieg	Malta	National Alliance for Rare Diseases and Si
Juan	Carrion Tudela	SPAIN	Alianza Iberoamericana de Enfermedades
Emmanuel	Chantelot	Belgium	IFPMA / Shire
Lara	Chappell	Europe	EURORDIS
Angela	Chaves	Colombia	FEDERACION COLOMBIANA DE ENFERME
Chiara	Ciriminna Swan	Switzerland	Blackswan Foundation
Sandra	Courbier	Europe	EURORDIS
Marco	Crimi	Italy	Ring 14 International
Avril	Daly	Ireland	GRDO
Dorica	Dan	Romania	Romanian Alliance for Rare Diseases
Emanuele	Degortes	Belgium	Biogen
Migdalia	Denis	USA	PH Latin Society
Annamarie	Dillon	Netherlands	Genzyme
Marija	Dimovska	Macedonia	National Alliance for Rare Diseases of R. M
Kelly	du Plessis	South Africa	Rare Disease Society of South Africa
Davor	Duboka	Serbia	National Organization for Rare Diseases
Caitriona	Dunne	Ireland	GRDO
Liro	Eerola	Belgium	European Commission
Heather	Etchevers	France	Association ANNA
Alain	Fontaine	France	Alliance Maladies Rares
Megan	Fookes	Australia	Rare Voices Australia
John	Forman	New Zealand	ICORD
Desiree	Gavhed	Sweden	ICORD / Orphanet Sweden
Elisabeta	Gecchele	Italy	UNIAMO
Melanie	Gibson	USA	NORD
Paul	Gimenez	France	Alliance Maladies Rares
Malin	Grände	Sweden	Rare Diseases Sweden
Jim	Green	UK	International Niemann-Pick Disease Allian

Nancy	Hamilton	Europe	EURORDIS
Anja	Helm	Europe	EURORDIS
Virginie	Hivert	Europe	EURORDIS
Birthe	Holm	Denmark	Rare Diseases Denmark
Ulrike	Holzer	Austria	Pro Rare Austria
Kevin	Huang	China	Chinese Organization for Rare Disorders
Ingrid	Jageneau	Belgium	RaDiOrg
Dart	John	UK	DEBRA International
Marija	Joldic	Serbia	National Organization for Rare Diseases
Marleen	Kaatee	Netherlands	PSC Patients Europe
Alastair	Kent	UK	Genetic Alliance UK
Marianna	Lambrou	Greece	PESPA
Annika	Larsson	Sweden	ICORD
Anne-Grethe	Lauridsen	Denmark	European Gaucher Alliance
Yann	Le Cam	France	EURORDIS
Mirjam	Mann	Germany	ACHSE
Toni	Mathieson	UK	International Niemann-Pick Disease Alliar
Olivier	Menzel	Switzerland	Blackswan Foundation
Snezhana	Mitina	Russia	Russian Union of patients' and patients' c
Ramaiah	Muthyala	India	Indian Organisation for Rare Diseases (I-C
Irina	Myasnikova	Russia	Russian association of rare diseases
Yukiko	Nishimura	Japan	Tokyo Research Center for Advanced Scie
Sanja	Njelic	Switzerland	Novartis
Letitia	O'Dwyer	New Zealand	NEW ZEALAND ORGANISATION FOR RARE
Anders	Olauson	Sweden	AGRENSKA
Cor	Oosterwijk	Netherlands	VSOP
Lisa	Phelps	USA	National Organization for Rare Disorders
Greg	Robertson	Switzerland	Shire
Jean-Louis	Roux	Europe	EURORDIS
Leire	Solis	UK	International Patient Organisation for Pr
Paloma	Tejada	Switzerland	Rare Diseases International
Rick	Thompson	UK	FINDACURE
Olivier	Timmis	UK	AKU Society
Alfredo	Toledo	Uruguay	Alianza Iberoamericana de Enfermedades
Vladimir	Tomov	Bulgaria	National Alliance of People with RD
Marina	Trenkova	Russia	Russian association of rare diseases
Nathalie	Triclin	France	Alliance Maladies Rares
Kin Ping	Tsang	Hong Kong	Retina International / Hong Kong Alliance
Silvia	Van Breukelen	Netherlands	VSOP
Marieke	van Meel	Netherlands	NephcEurope
Rainald	von Gyzycki	Germany	Retina International
Geraasimos	Voutsinas	Greece	PESPA
Elisabeth	Wallenius	Sweden	Rare Diseases Sweden
Ariane	Weinman	Europe	EURORDIS

Ingunn	Westerheim	Germany	Osteogenesis Imperfecta Federation Eurc
Durhane	Wong-Rieger	Canada	CORD
Rachel	Yang	China	Chinese Organization for Rare Disorders
Baiba	Ziemele	Latvia	Latvian Alliance for Rare Diseases
Vlasta	Zmazek	Croatia	Croatian Alliance for Rare Diseases

ases  
upport Malta  
and Hydrocephalus

rganizations with rare diseases

upport Malta  
s Raras (ALIBER)

DADES RARAS

Macedonia

ance (INPDA)

ance (INPDA)

organizations with rare diseases & MPS Russia  
(ORD)

ence and Technology

DISORDERS

(NORD)

Primary Immunodeficiencies

s Raras (ALIBER)

for Rare Diseases

ype (OIFE)