

EURORDIS SUMMER SCHOOL ALUMNI 2008 to 2017

lumn1	Name	Last name	Country	Association	Year
1	Nikkie	Aarts	Netherlands	Erasmus University Rotterdam	2016
2	Marzia	Abenante	Italy	Tuberous Sclerosis Italian Association	2012
3	Karen	Aiach	France	Sanfillipo	2009
4	Zoe	Alahouzou	France	EURORDIS	2013
5	Gonzalo	Aldeanueva Serrano	Spain	Behcets disease Spain	2014
6	Claudio	Ales	Italy	Pten Italia Cowden Sindrome	2017
7	Xochitl Guadelupe	Alvarez Rodriguez Desch	Spain	D'Genes	2014
8	Inês	Alves	Portugal	ALPE Foundation	2017
9	Alba	Ancochea	Spain	Feder	2015
10	Leo	Andeweg	Netherlands	St. Klankboard	2012
11	Kim	Andrvez	Canada	CurePSP Canada	2017
12	Anna	Arellanesova	Czech Republic	Czech Association for Rare Diseases	2015
13	Manuel	Armayones Ruiz	Spain	Asociacion Espanola de Sindrome de Lowe	2012
14	Tobias	Arndt	Belgium	EDRIC	2016
15	Sharon	Ashton	France	EURORDIS	2011
16	Dimitris	Athnasiou	Greece	MDA Hella	2014
17	Antoinette	Attard	Malta	Breast Care Support Group Europa Donna	2012
18	Vida	Augustiniene	Lithuania	Lithuanian Diabetes Association	2012
19	Hatijah	Ayob	Malasia	Malaysian Rare Disease Association	2017
20	Hana	Ayoob	United Kingdom	AKU Society	2013
21	Stefania	Azzali	Italy	Ring 14 International	2017
22	Claudie	Baleyrier	France	French Association against Friedrich Ataxia	2008/2010
23	Renza	Barbon	Italy	UNIAMO	2015
24	Eglantine	Barents	Netherlands	Diabetesvereniging Nederland	2012
25	Beata	Barna	Hungary	HUFERDIS - and Williams Syndrome Association	2009
26	James	Barrow	United Kingdom	Cystic fibrosis UK	2016
27	Lucia	Bartoloni	Italy	Associazione Italiana Kartagener	2008
28	Luisa	Basset	Spain	Federacion Española de padres de niños con cancer (FEPNC)	2008
29	Eva	Bearryman	France	EURORDIS	2016
30	Simona	Bellagambi	Italy	UNIAMO	2011
31	Britta	Berglund	Sweden	Swedish EDS Association	2009/2010
32	Cecilia	Bjargo	Sweden	Prader-Willi Syndrome Association in Sweden	2009/2010
33	Ignacio	Blanco Guillermo	Spain	Instituto Catalanian National Cancer Institute	2015
34	Philip	Bloom	France	Association Française des Malades de Myeloma Multiple (AF3M)	2012
35	Liz	Blows	United Kingdom	Stiff Person Syndrome	2016
36	Anne-Mary	Bodin	France	EURORDIS	2011

37	Agnese	Bonfiglio	Italy	A.Ma.Po	2012
38	Jill	Bonjean	France	EURORDIS	2011
39	Maria	Borrell	Spain	ASEM Catalunya	2016
40	Manon	Bosch	Netherlands	Byniervereniging NVACP	2013
41	Brigitte	Bosman	Netherlands	Lung cancer Netherlands	2012
42	Mathieu	Boudes	France	EURORDIS	2014
43	Guy	Bouguet	France	Lymphome Espoir	2014
44	Marcelle	Bousbaci	France	Association HNPCC Syndrome de Lynch	2014
45	Sandra	Brasil	Spain	Centro de Biología Molecular Severo Ochoa	2017
46	Arnd	Brauer	Germany	Alliance for Chronic Rare Diseases ACHSE	2008
47	Fernando	Brocca	Italy	HHT Onlus	2017
48	Virginie	Bros-Facer	France	EURORDIS	2016
49	Joanne	Bullivant	United Kingdom	John Walton Muscular Dystrophy Research Centre	2017
50	Catherine	Burgess	United Kingdom	Pseudomyxoma Survivor	2012
51	Edward	Callus	Italy	Associazione Italiana dei Cardiopatici Congeniti Adulti (AICCA)	2012
52	Sara	Carrabba	Italy	Aisac Onlus	2014
53	Raquel	Castro	France	EURORDIS	2014
54	Antonella	Celano	Italy	People Association with rheumatic diseases (APMAR)	2012
55	Irina	Cepinac-Ban	Serbia	National Association of Childhood Cancer Parent Organizations of Serbia (NURDOR)	2008
56	Oksana	Chalenko	Ukraine	Association of Handicapped Children with Progressig Muscular and Neuromuscular	2013
57	Lara	Chappell	France	EURORDIS	2015
58	Stamatine	Cheilari	Austria	COST	2016
59	Gema	Chicano Saura	Spain	Asociacion de Afectados por Displasia Ectodermica (AADE)	2012
60	Andrada	Cicua	Romania	Romanian Association of Huntington's Disease	2017
61	Claudio	Cinquemani	Germany	support group "Neutrino" – families affected from inherited neurotransmitter aciduria	2017
62	Chiara	Ciriminna Swan	Switzerland	Black Swan Foundation	2017
63	Rob	Collin	Netherlands	Radboudumc	2015
64	Maria Daniela	Corvo	Italy	Associazione Italiana Sindrome e Malattia de Behçet (SIMBA)	2008
65	Denis	Costello	France	EURORDIS	2009
66	Sandra	Courbier	France	EURORDIS	2016
67	Antonella	Cravero	Italy	Associazione Sclerosi Tuberos (AST)	2011
68	Claudia	Crocione	Italy	HHT Onlus Teleangiectasie Emorragica Ereditria	2014
69	Jordi	Cruz	Spain	Spanish MPS Society	2012
70	Maria Jesus	Cuesta	Spain	Dravet Foundation	2017
71	Etelka	Czondi	Romania	Romanian Prader Willi Association (APWR)	2008
72	Avril	Daly	Ireland	Genetic Rare Disorders Organisation	2015
73	Dorica	Dan	Romania	Romanian Association for PID patients	2014
74	John	Dart	United Kingdom	DEBRA International and DebRA UK	2009/2010
75	Lutgarde	De Baere	Belgium	Belgian Organisation for Metabolic Diseases	2008/2010
76	Johan	De Graaf	Netherlands	Nederlandse Hypofyse Stichting	2016

77	Béatrice	de Montleau	France	AFM Telethon	2017
78	Evanina	de Morcillo Makow	Spain	Asociacion de Epidermolisis Bullosa de España	2008
79	Nicola	de Nittis	Germany	Deutsches Thalassamei Forum	2014
80	Aida	Decaj	Albania	Albanian Asociacion of rare deseases-Gaucher disease	2017
81	Mihaela	Despa	Romania	Myelom Euronet Romania	2009/2010
82	Rebecca	Dimond	United Kingdom	University of Cardiff	2016
83	Barbara	Dissauer	Austria	DEBRA Austria	2013
84	Vladimir	Dolejs	Czech Republic	Czech Society of Haemophilia	2008
85	Vanessa	dos Reis Ferreira	Spain	Asociacion Espanola Sindrome CDG	2011
86	Ivo	Dostal	Czech Republic	Klub Nemocnych Cystichou Fibrozou	2014
87	Jose	Drabwell	United Kingdom	Internation Patient Organisation for Primary Immunodeficiencies (IPOPI)	2008
88	Aldona	Droseikiene	Lithuania	Lithuanian Multiple Schlerosis Union	2013
89	Karen Topaz	Druckman	Switzerland	CH-HHT	2016
90	Genvieve	Dubois-Flynn	Canada	Canadian Institutes of Health Research	2017
91	Davor	Duboka	Serbia	National Organisation for Rare Diseases Serbia	2014
92	Yolaine	Dupont	Canada	PVNH Support and Awareness	2013
93	Sonja	Durinck	Canada	World Alliance Pituitary Organization	2017
94	Jana	Dvorackova	Czech Republic	Czech Haemophilia organisation	2011
95	Norbert	Eckelmann	Germany	Selbsthilfegruppe Glykogenose Germany	2014
96	Guenter	Eibel	Germany	Gaucher Gesellschaft Deutschland	2009/2010
97	Zoe	Elliott	United Kingdom	cf/Aware	2017
98	Monica	Ensini	France	EURORDIS	2013
99	Maria	Escudero	Spain	Fundacion Menudos Corazones	2009/2010
100	Antonella	Esposito	Italy	Angeli Noonan Italian Association for Noonan Syndrome	2009
101	Alexander	Exner	Germany	German federal association of vascuular birth deformities	2013
102	Ouarda	Fareh	Italy	SIMBA (Behcet)	2009
103	Christina	Fasser	Switzerland	Retina International	2015
104	Isabel	Fernandez Aldeguer	Spain	Spanish Federation of Rare Diseases	2013
105	Pisana Maria	Ferrari	Italy	PHA EUROPE	2017
106	Kristina	Ficeriova	Slovakia	Debra Slovakia	2014
107	Holger	Fischer	Germany	ZNM Zusammen Stark!	2016
108	Carla	Fladowski	Italy	Associazione Sclerosi Tuberosa (AST Onlus)	2009/2010
109	Katharine	Foda	France	Association for Parents of Children with Cancer (ISIS)	2008
110	Elisabetta	Fortunati	Italy		2015
111	Corinne	Fourrier	France	Association Nationale du Syndrome Xfragile "Le Goeland"	2009/2010
112	Rita	Francisco	Portugal	APCDG	2017
113	Fridrik	Fridriksson	Iceland	Unique Children	2014
114	Juan	Fuertes Guillen	Spain	Asociacion Nacional de Hipertension Pulmonar	2011

115	Ilaria	Galetti	Italy	GILS	2016
116	Costin Radu	Ganescu	Romania	Asociatia Persoanelor cu Talasemie Majora	2011
117	Manuel Angel	Garcia Chicano	Spain	Displasia Ectodermal	2016
118	Maria	Gardsater	Sweden	Rare Diseases Sweden	2009
119	Elisabetta	Gecchele	Italy	Acondroplasia Insieme per Crescere Onlus	2013
120	Sylvie	Genet	France	Association Française contre les Myopathies	2012
121	Markus	Georg	Germany	Pro Retina Dutschland	2012
122	Chandu	George	India	Indian Organisation for Rare Diseases	2016
123	Francoise	Germain	France	Association Huntington France	2011
124	Vlad	Ghiga	Romania	My Child Heart Association	2017
125	Margaret	Giuliani	France	Vaincre les Maladies Lysosomales (VML) France	2017
126	Greetje	Goossens	Belgium	Belgian Myeloma Patient Organisation	2008
127	Sean	Gordon	Israel	ult Polyglucosan Body Disease Research	2017
128	Aurelie	Goyenvalle	France	COST UVSQ Versailles	2016
129	Christina	Grabowski	Germany	Morbus Osler Selbsthilfe e.V.	2015
130	Sorin	Gradinaru	Romania	My Child My Heart Association (ACMIM)	2012
131	Lesley	Greene	United Kingdom	Cystinosis and Metabolic Disorders	2009/2010
132	Andrea	Gressani	Italy	Associazione Immunodeficienze Primitive ONLUS	2011
133	Jasjote	Grewal	Germany	CELLS - Centre for Ethics and Law in the Life	2015
134	Anke	Groenen	Netherlands	Dutch Association for neuromuscular diseases	2014
135	Juergen	Grunert	Germany	Deutsche Ehlers-Danlos-Initiative e.V.	2017
136	John	Gurhy	United Kingdom	Ataxia UK	2009
137	Helma	Gusseck	Germany	Pro Retina Dutschland	2013
138	Emina	HadzhiasaOvic	Bosnia	Udruženje gradjana oboljelih od plućne hipertenzije "DAH"	2017
139	Rob	Hagen	Netherlands	Parkinson Vereniging VSOP	2016
140	Ann	Hale	United Kingdom	Global Organisation for Lysosomal Diseases (GOLD)	2008
141	Rachel	Hansen	France	Prader-Willi France	2012
142	Adriana	Harja	Romania	Romanian Myasthenia Gravis Association	2017
143	Tess	Harris	United Kingdom	PKD Charity	2013
144	Patrick	Heijne	Netherlands	Dutch Association for Addison and Cushing	2011
145	Anja	Helm	France	EURORDIS	2016
146	Sally	Hicks	United Kingdom	The Fragile X Society	2009
147	Nanda	Holm	Sweden	Rare Diseases Sweden	2011
148	Ulrike	Holzer	Austria	Selbsthilfe Gruppe Ektodermale Dysplasie EV	2014
149	Kristine	Hovhannesyann	Armenia	Center of medical genetics and primary health care	2017
150	Jiri	Hruda	Czech Republic	Czech Huntington Association	2011
151	Anne	Hugon	France	Association Francophone des glycogenoses	2013
152	Megan	Hunter	South Africa	Rare Diseases South Africa	2017
153	Glenn	Irvine	United Kingdom	Advocacy for Neuroacanthocytosis Patients	2011
154	Julian	Isla Gomez	Spain	Dravet Syndrome Foundation	2013

155	Ivan	Ivanov	Bulgaria	Thalassaemics' Organisation in Bulgaria	2011
156	Ingrid	Jageneau	Belgium	DEBRA Belgium	2011
157	Jovana	Jasnic Savovic	Serbia	Institute for Molecular Genetics and Genetic Engineering	2015
158	Katarzyna	Jesionkowska	Poland	Child's Heart Foundation	2011
159	Joanna	Jesionkowska	Poland	Dina Radziwillowa Child's Heart Foundation	2010
160	Xun	Ji	China	Chinese Organisation for Rare Disorders	2015
161	Sigurdur	Johannesson	Iceland	Alternating Hemiplegia association of Iceland (AHCAI)	2012
162	Alexandra	Johnson	United Kingdom	Joining Jack	2014
163	Stephanie	Joker Neilsen	Denmark	Rare Disorder Denmark	2014
164	Marija	Joldic	Serbia	Association for help and support of people with Hunter Syndrome MPS II in Serbia"	2014
165	Margreet	Jonker	Netherlands	Breast Cancer Society	2012
166	Yvonne	Jousten	Belgium	Association Belge du Syndrome de Marfan	2008
167	Chloe	Joyner	United Kingdom	Ciliopathy Alliance	2016
168	Trenholme	Junghans	United Kingdom	Cambridge University	2016
169	Laura	Kanapieniene	Lithuania	Rett Syndrome Europe	2016
170	Mary	Kearney	Ireland	Friedreich's Ataxia Research Alliance Ireland	2017
171	Ann	Kennedy	Ireland	Federation of European Scleroderma	2011
172	Borbala	Keszthelyi	Hungary	Hungarian Haemophilia Society	2011
173	Sheila	Khawaja	Italy	World Alliance Pituitary Organization	2017
174	Anja	Kladar	Croatia	Croatian Alliance for Rare Diseases	2015
175	Carmen Miranda	Kleinegris	Netherlands	NET groep Foundation	2013
176	Anna	Kole	France	EURORDIS	2009
177	Natascha	Kolland	Germany	I.E.B. Debra Deutschland	2012
178	Dragana	Koruga	Serbia	International Patients Organisation for Primary Immunodeficiencies	2011
179	Lisa	Kotschi	Germany	Arbeitsgemeinschaft Plasmozytom/Multiples Myelom	2012
180	Tom	Koukoulis	United Kingdom	UK Thalassaemia	2015
181	Anastasija	Kovaliova	Lithuania	Plautine hipertenzija	2015
182	Inna	Krulko	Ukraine	Ukrainian Union of Patients Organisations	2013
183	Oksana	Kulish	Ukraine	Pulmonary Hypertension Ukrainian Rare Disease Association- PH URDA	2015
184	Krzysztof	Kusidlo	Germany	Polish Society of MPS	2016
185	Oleg	Kvlivdze	Georgia	Georgian Foundation for Genetic and Rare	2011
186	Henk-Willem	Laan	Netherlands	Marshall Smith Syndrome Research Foundation	2011
187	Peter	Lack	Switzerland	Childhood Cancer Foundation Basel	2013
188	Laiticia	Laich	France	AFM -FRANCE-	2017
189	Michael	Längsfeld	Germany	Pro Retina Deutschland ev	2014
190	Anke	Lanser	Netherlands	Spierziekten Nederland VSN	2013
191	Anne-Sophie	Lapointe	France	Vaincre les maladies Lysomales	2016
192	Maureen	Latocki	Canada	MitoCanada Foundation	2017
193	Anne-Grethe	Lauridsen	Denmark	European Gaucher Disease	2015

194	Carmen	Lavin	United Kingdom	Myastherna Gravis Association	2014
195	Camelia	Lazar	Romania	Association Williams Syndrome Romania	2009/2010
196	Yannick	Le Henaff	France	COST Univ Rouen	2016
197	Rebecca	Leary	United Kingdom	John Walton Muscular Dystrophy research Center	2017
198	Kerry	Leeson-Beevers	United Kingdom	Alstrom Syndrome UK	2008/2010
199	Bryndis Maria	Leifsdottir	Iceland	Unique Children	2014
200	Pille-Katrin	Levin	Estonia	Union of Estonian MS Societies	2013
201	Michele	Lipucci di Paola	Italy	Associazione Veneta Lotta Talassemia (AVLT)	2008/2010
202	Orica	Lundgren	Sweden	Agrenska - National Centre of Rare Diseases	2008
203	Dorthe	Lykke	Denmark	Foreningen for Ataksi/HSP	2011
204	Shane	Lynam	France	EURORDIS	2009
205	Flaminia	Macchia	Belgium	EURORDIS	2012
206	Roanna	Maharaj	United Kingdom	UK Thalassaemia Society	2013
207	Helen	Malherbe	South Africa	Rare Diseases South Africa	2017
208	Mirjam	Mann	Germany	German National Alliance (ACHSE)	2011
209	Isabelle	Manneh-Vangramberen	Belgium	European Cancer Patient Coalition	2017
210	Stamatina	Manolias	Greece	Association of people with Genetic disorders	2008
211	Lali	Margvelashvili	Georgia	Society of Parents and Children with JIA (member of GERAD)	2015
212	Eva	Marin Bercial	Spain	Ring 14 Espagna osal	2016
213	Ramon	Marti	Spain	Vall d'Hebron Institute of Research	2015
214	Roberto	Martin	Spain	Spanish Association of Pulmonary Hypertension	2014
215	Susana	Martinez Cid	Spain	Somriures Valents, Asemcat	2016
216	Angela	Marzulli	Italy	AMAR	2016
217	Albert	Matevosyan	Armenia	"Neurohereditary diseases" Charity Association	2008/2010
218	Luc	Matthysen	Belgium	HTAP Belgique Asbl	2013
219	Vitaliy	Matyushenko	Ukraine	Kharkiv Charitable Foundation	2012
220	Graham	McCloy	United Kingdom	Oxford University	2015
221	Bonnie	McKerracher	United Kingdom	Chromosome 18 Registry and Research Society	2013
222	Aaron	McPeake	United Kingdom	Behcets Syndrome Society	2009/2010
223	Melanie	Meniar	Netherlands	European Waldenström's Macroglobulinemia Network	2015
224	Anna	Meriluoto	Finland	Fabry Internation Network, Finnish Fabry Association	2011
225	Gergely	Meszaros	Hungary	Tudoer Egylet PHA Hungary	2014
226	Marie	Meunier	France	EURORDIS	2017
227	Maria	Michelfelder	Sweden	Primary Immunodeficiency Organisations	2013
228	Jan	Mihule	Czech Republic	Czech CF Association	2011
229	Hanna	Milczarek	Poland	Dina Radziwillowa Child's Heart Foundation	2009
230	Flavio	Minelli	Italy	Unione Italiana Ittiosi (UNITI)	2008

231	Bijana	Mirceska	Republic of Macedonia	Save Liver of Patients SLAP	2017
232	Montse	Mireles	Spain	Fundacion Menudos Corazones	2009/2010
233	Bojana	Mirosavljevic	Serbia	LIFE association against child rare disease	2014
234	Marieke	Mol	Netherlands	Coeliac Association	2012
235	Fatemeh	Mollet Hosseinzadeh	Switzerland	NBIA Suisse	2017
236	Marisol	Montolio	Spain	Duchenne Parent Project	2017
237	Paula	Morandi	Italy	Mitocon	2017
238	Lise	Murphy	Sweden	Marfanforeningen	2009/2010
239	Liana	Murtazina	Russia	Association for assistance to Rett Syndrome Patients	2013
240	Irina	Myasnikova	Russia	Help to CF patients	2011
241	Begonya	Nafria Escalera	Spain	Asociacion Espanola de Sindrome de Lowe	2013
242	Lyubomir	Naydenov	Bulgaria	Bulgarian Society of Patients with Pulmonary Hypertension	2013
243	Gerard	Nguyen	France	Rett Syndrome Europe	2008/2010
244	Olivia	Niclas	France	AFDE - Dysplasies Ectodermiques	2009
245	Gisela	Nogades Nadea	Spain	IGTP Catalan	2016
246	Christel	Nourissier	France	EURORDIS	2008
247	Lesnik	Oberstein	Netherlands	LUMC Netherlands	2015
248	Michael	Oeschger	Germany	Skleroderma Selbsthilfe e.V.	2015
249	Iva	Omrcecm	Serbia	National Organisation for Rare Diseases Sebia (NORBS)	2017
250	Xavier	Ortega	Spain	Vall d'Hebron Institute of Research	2015
251	Anne	Oyewole	United Kingdom	The John Walton Muscular Dystrophy Research Centre	2017
252	Reet	Paloson	Estonia	Prader Willi Assoc of Estonia	2013
253	Maria	Panza	Ireland	Irish Fragile X Society	2014
254	Kay	Parkinson	United Kingdom	Alstrom Syndrome (UK)	2011
255	Marek	Parowicz	Germany	Polish Alternating Haemiglegia in Children	2013
256	Margit	Paul	Austria	Hepatitis Aid Austria	2016
257	Sandra	Pavlovic	Serbia	National Organisation for Rare Diseases Serbia	2015
258	Dore	Peereboom	Netherlands	Oscar Netherlands	2017
259	Sandra	Pereira Pinto	Spain	Spanish Association of CDG Sindrom (AESCDG)	2012
260	Sara	Perez	United Kingdom	COST	2016
261	Sara	Perez Martinez	Spain	Asociacion Nacional Sindrome de Apert	2008/2010
262	Martine	Pergent	France	IPOPI - Primary Immunodeficiencies	2009
263	Marie-Odile	Perrousseau	France	Association Huntington France	2009/2010
264	Lisa	Phelps	United States of America	National Organization for Rare Disorders	2017
265	Chris	Philips	United Kingdom	Behcets Syndrome Society	2014
266	Irene	Pitsillidou	Cyprus	EULAR	2016

267	Ieva	Plume	Latvia	PHA Latvia	2015
268	Ekatrina	Podushkina	Russia	Russian Association of rare Diseases	2017
269	Gabor	Pogany	Hungary	Rare Diseases Hungary (HUFERDIS)	2008/2010
270	Christoph	Poincilit	Switzerland	INPDA	2015
271	Veronica	Popa	Greece	Pending confirmation	2016
272	Jill	Prawer	United Kingdom	Lipoprotein Lipas Deficiency on RareConect	2013
273	Bernd	Quadder	Germany	Deutsche Sarkoidose	2008/2010
274	Blanca	Quijano Ruiz	Spain	FIBICO-IMIBIC_SCREEN (Spanish Clinical Research Network) ECRIN	2015
275	Chinar	Rahmattulla	Netherlands	Vasculitis Foundation	2014
276	Oli	Rayner	United Kingdom	Spit it out Cystic Fibrosis	2013
277	Patrice	Régnier	France	EURORDIS	2009
278	Hermien	Remmelink	Netherlands	Spierziekten Nederland	2017
279	Daniel	Renault	France	AIRG France FEDERG	2013
280	Evy	Reviere	Belgium	ALS Liga Belgium	2016
281	Mario	Ricciardi	Italy	Cystic Fibrosis Europe	2015
282	Rainer	Riedl	Austria	DEBRA Austria/ DEBRA International Pro Rare Austria	2012
283	Pedro	Rocha	Spain	Rett Syndrome Catalan	2016
284	Annelise	Roennow	Denmark	Fed European Scleroderma Association	2013
285	Claas	Röhl	Austria	NF Kinder	2015
286	Holger	Roloff	Germany	Deutsche Narkolepsie-Gesellschaft	2012
287	Olivia	Romero Lux	France	Association Française des hémophiles	2014
288	Laura	Rooke	United Kingdom	Ataxia UK	2008
289	Joy	Rosario	South Africa	Primary Immunodeficiency Network of South Africa (PiNSA)	2012
290	Micaela	Rosenberg	Portugal	European Tuberous Sclerosis Association	2015
291	Anna	Rozek	Poland	Foundation helping people with muscular	2017
292	Chiara	Saba	Italy	AISW	2016
293	Valerie	Salamon	France	Inserm	2016
294	Joao	Salazar	Portugal	EMP- European Myeloma Platform	2009
295	Rebeca	Sanchez Calle	Spain	Asociacion de las mucopolisacarisis y sindromes relacionados	2015
296	Thomas	Sannié	France	Association Française des Hémophiles (AFH)	2008
297	Ketevan	Saralidze	Georgia	Georgian Foundation of Genetic and Rare	2013
298	Roberta	Savli	Belgium	European Federation of Allergy and Airways Diseases Patients Org	2013
299	Balthasar	Schaap	Netherlands	ADCA vereniging Nederland Euro-ataxia, EFNA	2011
300	Erica	Schenk	Netherlands	Fabry International Network	2009/2010
301	Hans	Scheurer	Netherlands	Myeloma Patients europe	2017
302	Ralf	Schmiedel	Germany	Pulmonary Hypertonie e.V.	2016
303	Cornelia	Schrauf	Austria	Debra Austria	2017
304	Yvonne	Schuller	Netherlands	COST Amsterdam Medical Centrum	2016
305	Inge	Schwersenz	Germany	Spinal Muscular Atrophy (SMA) within DGM	2009

306	Isabel	Sebastiao-Vieira	Portugal	Rarssimas Associacao nacional de deficiencias mentais eraras	2014
307	Christian	Seguin	France	Association pour aider et informer les syringomyelique Europeen Reunis (APAISER)	2009
308	Miriam	Selles	Spain	Fundacio catalana d'Esclerosi Lateral Amiotrofica	2011
309	Juliette	Senecat	France	EURORDIS	2013
310	Andriy	Shatillo	Ukraine	Children with Spinal Muscular Atrophy	2011
311	Raquel	Silva	Portugal	Associacao Portuguesa de Leucemias e Linfoma	2011
312	Joao	Silva	Portugal	Associação Portuguesa de Neurofibromatose	2017
313	Amy	Simpson	United Kingdom	Genetic Alliance	2015
314	Nick	Sireau	United Kingdom	AKU Society	2011
315	Dragomir	Slavev	Hungary	Thalassaemics' Organaisation in Bulgaria	2011
316	Rivka	Smit	Netherlands	Vereniging Spierziekten Nederland	2016
317	Francesc Cayuela	Solano	Spain	Asociation Espanola de Enfermos de Glucogenosis	2014
318	Špela	Sonjak	Slovenia	Society for patients with Fabry disease	2015
319	Christos	Sotirelis	United Kingdom	UK Thalassaemia Society	2009/2010
320	Adina Elena	Stanciu	Romania	Romanian Association for PID patients	2014
321	Katarina	Stepankova	Slovakia	Slovak Cystic Fibrosis Association	2009/2010
322	Georgiana	Stoica	Spain	ICIQ Institute of Chemical Research of Catalonia	2015
323	Dominique	Sturz	Austria	Forum for Usher Syndrome, hearing impairment and deafness - Usher Deafblind Austria	2017
324	Steffen	Suchert	Germany	Faun Stiftung	2014
325	Joanna	Swacha	Poland	Foundation UMIEC POAMAGAC - Mucopolysaccharoidosis (all types)	2012
326	Sanallah	Syed	India	Indian Organization for Rare Diseases	2017
327	Danijela	Szili	Hungary	Hungarian Federation of Rare Diseases	2011
328	Daniel	Tanesse	France	Association CMT-France	2017
329	Gillian	Thomas	United Kingdom	Rare Disease UK and Myeloma UK	2015
330	Oliver	Timmis	United Kingdom	AKU Society	2012
331	Alan	Timothy	United Kingdom	EMBARC, ELF	2017
332	Vladimir	Tomov	Bulgaria	National Alliance of People with Rare Diseases	2011
333	Carole	Trowbridge	United Kingdom	Myasthenia gravis association	2011
334	Elja	van der Veer	Netherlands	Association for Muscle Diseases Netherlands	2011
335	Cathalijne	Van Doorne	Belgium	Euro-Ataxia	2017
336	Marieke	Van Meel	Netherlands	European Care for Nephrotic Syndrome	2011
337	Veronica	Van Nederveen	Netherlands	Stitching Patientenstem.nu	2017
338	Mary Lynne	Van Poelgeest-Pomfret	Netherlands	ICP Netherlands Interstitial Cystitis/ Painful bladder syndrome, chronic pelvic pain	2013
339	Ellen	Van Veldhuizen	Netherlands	Dutch Federation for Addison and Cushing patients	2009/2010
340	Floor	van Wiggen - Knuistingh	Netherlands	Duchenne Parent Project	2017
341	Gabor	Varga	Hungary	Hungarian Haemophilia Society	2009/2010

342	Gisela	Vasconcelosz	Norway	National Resource Centre for Oral Health in Rare Diagnosis	2017
343	Jonathan	Ventura	Belgium	RaDiOrg	2012
344	Peter	Verhoeven	Netherlands	Friedrich Wegener Stichtin	2012
345	Corinne	Verwer	Netherlands	Spierziekten Nederland (VSN)	2017
346	Gudrun Ruth	Vidarsdottir	Iceland	Hypoparathyroidism Europe	2008
347	Diana	Vitali	Italy	SOD Italia	2012
348	Rainald	Von Gizycki	Germany	Retina Europe/Pro Retina	2008
349	Elizabeth	Vroom	Netherlands	Duchenne Parent Project	2014
350	Jacques	Walch	France	Association Pemphigus - Pemphigoide France	2009
351	Kassandra	Walluks	Germany	Bundesverband Neurofibromatose e.V., Von Recklinghausen Gesellschaft	2017
352	Larry	Warren	Ireland	Alfa Europe and Alpha One Foundation (Ireland)	2008
353	Antonina	Waszczuk	Germany	TAKO centre - National Resource Centre in Oral Health in Rare Diseases - Lovisenberg Diaconal Hospital, Oslo Norway	2017
354	Tania	Webster	France	EURORDIS	2014
355	Geske	Wehr	Germany	Selbsthilfe Ichthyose e.V.	2016
356	Alain	Weill	France	Association Francaise des Hemophiles	2009
357	Ariane	Weinman	France	EURORDIS	2008
358	Richard	West	United Kingdom	UK Behcets Syndrome Society	2008/2010
359	Andrea	West	United Kingdom	BFDA UK	2016
360	Ingunn	Westerheim	Norway	Norwegian Association for Osteogenesis	2015
361	Russell	Wheeler	United Kingdom	Rare Disease UK	2012
362	Christine	White	Canada	National Gaucher Fondation of Canada	2017
363	Anke	Widenmann-Grolig	Germany	KEKS e. V and EAT e.V.	2015
364	Lenja	Wiehe	France	EURORDIS	2015
365	Frank	Willersinn	Belgium	Alpha-1 plus ASBL	2016
366	Durhane	Wong-Rieger	Canada	Canadian Organisation for Rare Diseases	2009/2010
367	Rose	Woodward	United Kingdom	Kidney Cancer Support Network and Rarer Cancers Foundation	2012
368	Arlene	Wuestner	Germany	ZNM Zusammenstark	2017
369	Anisha	Zaman	United Kingdom	Behcets Sydndrome Society	2013
370	Sandra	Zarina	Germany	European Gaucher Alliance	2016
371	Anastassiya	Zidkova	Czech Republic	Czech Society of Haemophilia	2015
372	Werner	Zinkand	Germany	German mpn-network	2017
373	Paola	Zinzi	Italy	European Huntington Association	2011
374	Vlasta	Zmazek	Croatia	Croatian Epidermolysis Bullosa Association	2008/2010
375	Lynne	Zwink	United Kingdom	The Fragile X Society	2010