

List of contributors to the public consultation

138 contributions were received. Contributors are listed in alphabetical order for each of the eight possible categories maintaining the self-classification made by them. Some of the contributors could have been classified under different categories.

1. Academic/public health and healthcare specialised institution/organisation (33)

- ✓ *Attikon Hospital, Greece*
- ✓ *Berufsgenossenschaftliches Unfallkrankenhaus Hamburg, BG Trauma Hospital Hamburg
BG= German Social Accident Insurance Institution for trade and industry),Hamburg,
Germany*
- ✓ *Centre de Référence des infections ostéo-articulaires complexes pour l'Inter-région Nord-Ouest, France*
- ✓ *Children's Heart Center, Skane University Hospital, Lund, Sweden*
- ✓ *Clinica Pediatrica Università degli Studi dell'Insubria - Ospedale di Circolo Fondazione Macchi - Varese – Italy*
- ✓ *Clinical Neurosciences Department, Neurology Unit, Italy*
- ✓ *Coordinating Centre for Rare Pediatric Diseases, Lithuania*
- ✓ *Croatian National Institute of Public Health. Croatia*
- ✓ *Department of Clinical Sciences, Lund University, Plastic and Reconstructive Surgery, Jan Waldenströms gata 18, Skåne University Hospital, SE-20502 Malmö, Sweden*
- ✓ *Department of Neurosurgery, Lithuanian University of Health Sciences and Hospital of Lithuanian University of Health Sciences; Neuroscience Institute, Lithuanian University of Health Sciences. Lithuania*
- ✓ *DNV Business Assurance, Norway*
- ✓ *Erasmus MC, Center for lysosomal and metabolic diseases, Netherlands*
- ✓ *European network of paediatric research at the European Medicines Agency (Enpr-EMA)*
- ✓ *European Union of Medical Specialists, Belgium*
- ✓ *Fondation René Touraine: an international Foundation for Dermatology*
- ✓ *French Reference Center for Rare Iron Overload Diseases of Genetic Origin. France*
- ✓ *German Mesothelioma Register. Germany*

- ✓ *Hospital La Fe, Spain*
- ✓ *Institute of Child Health, Greece*
- ✓ *IRCCS - Istituto Ortopedico Rizzoli - Department of Medical Genetics and Rare Orthopaedic Diseases, Italy*
- ✓ *Istituto Ortopedico Rizoli, Italy*
- ✓ *National Center for Tumor Diseases (NCT) Heidelberg, Germany*
- ✓ *Neuromuscular Disorders Clinic, Neurology Department, Hospital General Universitari Vall d'Hebron, Spain*
- ✓ *North of England EU Health Partnership, United Kingdom*
- ✓ *RCCRD, University Hospital of Udine, Italy*
- ✓ *Red cell pathology unit, Hospital clinic-university of Barcelona, Spain*
- ✓ *Regional Coordinator Centre for Rare Diseases of the Friuli Venezia Giulia Region-Italy*
- ✓ *Riga East University hospital stationary "Infectology Center of Latvia" (RAKUS LIC), Latvia*
- ✓ *Scientific Institute Public Health, Belgium*
- ✓ *Slovak Radiological Society, Slovakia*
- ✓ *SWEET e.V., Germany*
- ✓ *The Centre for Disease Prevention and Control, Latvia*
- ✓ *University Medical Center Hamburg-Eppendorf, Germany*
- ✓ *University of Glasgow, United Kingdom*

2. Health professionals' organisations (29)

- ✓ *Association of Speech Language Pathologists Malta*
- ✓ *Centre de Références des Infections Ostéoarticulaires Complexes (CRIOA)/Referral Centre for Complex Bone and Joint Infections, France*
- ✓ *Centres de référence des infections ostéoarticulaires graves et complexes (CRIOA)/Regional Referral Center for Complex Bone and Joint Infections, France*
- ✓ *EuroDSD Consortium*
- ✓ *European Board of Urology, EBU (Urology section of the UEMS)*
- ✓ *European Federation of Nurses Associations*
- ✓ *European Region of the World Confederation for Physical Therapy (ER-WCPT)*
- ✓ *European Society for Medical Oncology*
- ✓ *European Society of Cardiology*

- ✓ *FMA Finland*
- ✓ *Hellenic Society for the study of inborn errors of metabolism (HSSIEM), Greece*
- ✓ *Hospital Carlos Haya. Malaga. España*
- ✓ *Hospital Universitario Fundación Alcorcón, Spain*
- ✓ *INCCI (National Heart Institute in Luxembourg)*
- ✓ *IVAA International Federation of Anthroposophic Medical Associations*
- ✓ *Lithuanian Child Neurology Association*
- ✓ *Lithuanian Society for Paediatric Gastroenterology and Nutrition*
- ✓ *Lithuanian society of pediatric oncology and hematology*
- ✓ *Malta Association of Physiotherapists*
- ✓ *Ordem dos Enfermeiros, Portugal*
- ✓ *Paediatric Rheumatology International Trials Organisation (PRINTO at <http://www.printo.it> or www.pediatric-rheumatology.printo.it)*
- ✓ *Pediatric Orthopaedic Unit. National Reference Unit in pediatric orthopedics. CSUR. Orthopedic Surgery and Traumatology. Faculty of Medicine. University of Murcia. University Hospital "Virgen de la Arrixaca". Department of Health. Murcia Health Service. Spain.*
- ✓ *Polish Nurses Association*
- ✓ *Radboud University Nijmegen Medical Centre, department of Neurology, Netherlands*
- ✓ *Servicio de Neurocirugía Pediátrica. Hospital Universitario 12 de octubre, Spain*
- ✓ *Slovenian Association of Radiology*
- ✓ *The European Glaucoma Society*
- ✓ *The Standing Committee of European Doctors (CPME)*
- ✓ *UEMS. Section/ European Board and College of Obstetrics and Gynaecology*

3. Patient organisation/association (26)

- ✓ *APDP - Associação Protectora dos Diabéticos de Portugal*
- ✓ *Asociacion de pacientes de Hemocromatosis (AEH). Spanish Hemochromatosis Patient Association*
- ✓ *Associação Portuguesa de Hemocromatose*
- ✓ *AZZURRA Associazione Malattie Rare Onlus, Italy*
- ✓ *Brittle Bone Society*

- ✓ *Cyprus Federation of Associations of Patients and Friends*
- ✓ *Cystic Fibrosis Europe (CFE)*
- ✓ *DEBRA International*
- ✓ *EFAPH – European Federation of Associations of Patients with Haemochromatosis*
- ✓ *EFAPH European Federation of Associations of Patients with Haemochromatosis*
- ✓ *EURORDIS – The European Organisation for Rare Diseases*
- ✓ *Hoffnungsbaum e.V. Verein zur Förderung der Erforschung und Behandlung von NBIA (vormals: Hallervorden-Spatz-Syndrom), in English: Tree of hope, Association dedicated to foster research and treatment in NBIA (formerly: Hallervorden-Spatz-Syndrome), ACRONYM: HoBa*
- ✓ *International Federation for Spina Bifida and Hydrocephalus*
- ✓ *International Federation for Spina Bifida and Hydrocephalus (IF)*
- ✓ *International Patient Organisation for Primary Immunodeficiencies (IPOPI)*
- ✓ *Krikos Zois (=LIFE-LINK) Greek Society for Patients and Friends of Patients with Inherited Metabolic Diseases*
- ✓ *Lithuanian association of people with genetic neuromuscular diseases "Sraunija"*
- ✓ *Madrid Spina Bifida Association (Asociación Madrileña de Espina Bífida), Spain*
- ✓ *Malta Health Network*
- ✓ *MITOCON insieme per lo studio e la cura delle malattie mitocondriali ONLUS, Italy*
- ✓ *PHA EUROPE - European Pulmonary Hypertension Association*
- ✓ *Rare Disorders Denmark*
- ✓ *SHINE- Spina Bifida.Hydrocephalus.Information.Networking.Equality*
- ✓ *The ESPKU -The European Society for Phenylketonuria and allied disorders*
- ✓ *Udruga osoba i roditelja djece sa spinom bifidom "Aurora", Croatia*
- ✓ *VSH vzw, Belgium*

4. Healthcare provider (23)

- ✓ *AZ Vesalius, Belgium*
- ✓ *Department of Clinical Genetics, University and Regional Laboratories, Region Skane, Lund, Sweden*
- ✓ *Department of Medical Biochemistry, Oslo University Hospital, Rikshospitalet, Oslo Norway*

- ✓ *Department of Medical Genetics, Medical School, University of Athens, Greece*
- ✓ *Department of Paediatric Neurology, Pendeli Children's Hospital, Athens, Greece*
- ✓ *Department of Pathology, University and Regional Laboratories, Region Skåne, Sweden*
- ✓ *Division of Inherited Metabolic Diseases, Centre for Childhood and Adolescent Medicine, University Hospital Heidelberg, Germany*
- ✓ *Groupe MGEN - Mutuelle Générale de l'Education Nationale, France*
- ✓ *Hemochromatosis Clinic at Santo António Hospital, Portugal*
- ✓ *Hospital General Universitario Gregorio Marañón, Spain*
- ✓ *Hospital Universitario de Getafe (Getafe University Hospital), Spain*
- ✓ *Kath. Kinderkrankenhaus Wilhelmstift gGmbH (Catholic Children's Hospital Wilhelmstift charitable non-profit Ltd), Germany*
- ✓ *Klinikverbund der gesetzlichen Unfallversicherung e.V. (association of clinics of the German Social Accident Insurance, KUV), Germany*
- ✓ *Multidisciplinary Endocrine Tumor Team, Skåne University Hospital, Lund, Sweden*
- ✓ *North German Epilepsy Center of Hamburg*
- ✓ *Openbaar Psychiatrisch Zorgcentrum Rekem, Belgium*
- ✓ *Phakomatoses Centre, Hospital of the Lithuanian University of Health Sciences Kauno klinikos*
- ✓ *Rehabilitation and MS-Centre Overpelt, Belgium*
- ✓ *Riga Centre of Psychiatry and Addiction Medicine, Latvia*
- ✓ *SB SOFT Italy*
- ✓ *Scandinavian Ear Reconstruction Centre, Dept of Plastic and Reconstructive Surgery,*
- ✓ *Schoen Kliniken group, Schoen Klinik Hamburg Eilbek, Dept. of neurology and neurorehabilitation, Germany*
- ✓ *VZW Jessa Ziekenhuis, Belgium*

5. Healthcare provider organisations (7)

- ✓ *Central Manchester University Hospitals NHS Foundation Trust, UK*
- ✓ *European Chiropractors' Union (ECU)*
- ✓ *Hospilim, Belgium*
- ✓ *Royal Free London NHS Foundation Trust, UK*
- ✓ *Unit for Patient Safety Capital Region of Denmark*

- ✓ *Verband der Privatkrankenanstalten Österreichs, Austria*
- ✓ *Zorgnet Vlaanderen and ICURO, Belgium*

6. Public authorities and government-appointed bodies (13)

- ✓ *Castilla y Leon Regional Health Service (Gerencia Regional de Salud de Castilla y Leon), Spain*
- ✓ *Directorate-General of Health / Ministry of Health, Portugal*
- ✓ *Entidade Reguladora da Saúde – ERS (Portuguese Health Regulatory Authority),*
- ✓ *Fundacion Rioja Salud, Spain*
- ✓ *Health Department, Campania Region - Italy*
- ✓ *Italian Technical Board of Regions for Rare Diseases*
- ✓ *Kassenärztliche Vereinigung Hamburg, KVH, Germany*
- ✓ *Ministère des Affaires Sociales et de la Santé, France*
- ✓ *Ministry for Health, the Elderly and Community Care, Malta*
- ✓ *Stowarzyszenie Chorych z Przepukliną Oponowo - Rdzeniową RP in Katowice, Poland*
- ✓ *The Norwegian Ministry of Health and Care Services*
- ✓ *VRCCRD - Veneto Region Coordinating Centre for Rare Diseases, Italy*
- ✓ *VSOP, Lupus Netherlands)*

7. Health insurer (2)

- ✓ *Deutsche Gesetzliche Unfallversicherung (German Social Accident Insurance, DGUV)*
- ✓ *Landsbond van Onafhankelijke Ziekenfondsen - Union Nationale des Mutualités Libres, Belgium*

8. Individual respondent (5)

- ✓ *Applus-novotec, Spain*
- ✓ *Assistance Publique Hôpitaux de Paris - Unité de Génétique des Maladies Cardiaques et Musculaires, France*
- ✓ *Dr mayka sanchez, Spain*
- ✓ *Foundation for Christianity, Hungary (2 contributions)*