EURORDIS GENERAL ASSEMBLY
15 MAY 2025

CANDIDATES TO THE BOARD OF DIRECTORS' ELECTION

JOHN GERBILD, RARE DISEASES DENMARK/ ATAXIA & HSP ASSOCIATION, DENMARK

My journey in the world of rare diseases began 23 years ago, when my wife was diagnosed with Spinocerebellar Ataxia type 3 (SCA3) – a rare, inherited neurological disorder for which there is currently no cure or treatment. Following her diagnosis, we joined the Danish Ataxia and HSP Association (DK-A&HSP). Five years ago, one of my daughters was also diagnosed with SCA3. This profoundly deepened my commitment to the association even further. Since then, I have devoted nearly all my time to the shared effort of pursuing treatment options for this disease. In the meantime, I have also worked to improve the quality of life for people affected by all types of Ataxia and HSP. Over the past five years, we have grown DK-A&HSP's membership from 200 to 380 – more than half of all those diagnosed in Denmark. I came to realize that the sense of distance and isolation experienced by people living with rare diseases in Denmark is also a reality in other Nordic countries. This poses an additional challenge in driving progress in the rare disease field. Motivated by this, I joined EuroAtaxia 10 years ago as a board member. This has been an invaluable source of knowledge and connection to the wider European patient community. Since 2019, I have also represented EuroAtaxia within EFNA (the European Federation of Neurological Associations) and have participated in initiatives such as the EURORDIS Open Academy on Medicines Research and Development, among others. I am also an EPAG (European Patient Advocacy Group) representative within the European Reference Network for Rare Neurological Diseases (ERN-RND), contributing to the development of patient journeys.

For the past 10 years, I have also dedicated time to Rare Diseases Denmark – the Danish National Alliance for rare diseases, encompassing 55 rare disease associations (covering around 600 rare diagnosis) and supporting between 30,000 and 50,000 people living with a rare disease in Denmark. Among other things, I am involved in advocating for increased attention from the political and scientific communities to help establish robust healthcare structures for testing new treatments – beyond national borders. One tangible outcome of this advocacy has been the successful establishment of a validated clinical trial site at

Rigshospitalet in Copenhagen. In 2020, I was elected for the Executive Committee of Rare Diseases Denmark, and recently, I was elected vice-chair. I am due to my commitment often invited to speak at key venues – including the EU Parliament, the Danish Parliament, scientific conferences such as the International Ataxia Conference, and more. Since 2024, I also represent Rare Diseases Denmark in the EURORDIS Council of National Alliances (CNA).

In my professional life, I now work with the DK-A&HSP association, supporting people with ataxia and HSP in navigating daily challenges and improving their quality of life – from assisting with healthcare forms to helping them and their caregivers stay motivated and engaged. Previously, I worked with the installation, teaching, and implementation of telemedicine solutions. Before that, I worked in the shipping industry and business sector for a Danish company. I truly believe that the work of EURORDIS is making a significant difference for people living with rare diseases across Europe, and I would be honored to contribute to that mission.

KIRSTEN JOHNSON, FRAGILE X INTERNATIONAL, UNITED KINGDOM

It has been a privilege to serve on the Board of EURORDIS for the past three years. In that capacity, I have been involved as the Board Lead for EURORDIS' Mental Health & Wellbeing Initiative; been on the Newborn Screening Working Group; been a Screen4Care advisor; and have spoken at many events as a board member, including EMMs, ECRDs, ERTCs and at the Re(ACT) Congress. I am a Commissioner for the Lancet Commission on Rare Diseases, nominated by EURORDIS.

I am President of Fragile X International, an international charity registered in Brussels which represents fragile x country organisations around the world. I have two daughters with Fragile X Syndrome, and I live with the fragile x premutation. I also Chair the Council for Rare Diseases International, which is currently leading on the adoption of a World Health Assembly Resolution on Rare Diseases.

I have a wealth of boardroom experience and will bring to EURORDIS expertise in setting strategy, hiring staff, governance, budgets and overseeing organisations. In regard to the person specifications, I am self-employed and able to give the time required to this position; I am willing to encourage membership of EURORDIS from other organisations; I enjoy working as part of a multicultural team; I have extensive public speaking experience; and I have chaired and convened numerous online meetings.

One key achievement in my experience as an advocate is in changing the name of the FMR1 gene. I co-authored an article in Cells which highlighted the stigma and discrimination attached to offensive language in the original naming of the gene, and because of our advocacy the gene and protein name were both changed. In 2024, I co-authored The Joys of Fragile X: Understanding the strengths of Fragile X and delivering a diagnosis in a helpful,

holistic way. I continue to work on building a more inclusive society for all those living with rare conditions, one which embraces each of us for the value we bring to society.

I believe in EURORDIS' mission and values and welcome the opportunity to continue to represent the interests of people living with rare conditions from all European countries. Thank you for considering my nomination for election to the Board.

TETIANA KULESHA, NGO "RARE DISEASES OF UKRAINE", UKRAINE

Chair of the Board of the NGO "Rare Diseases of Ukraine," and co-founder of the charitable foundation "Orphanni Synytsi." Born in Kyiv, I graduated from Borys Grinchenko Kyiv University. I taught English at one of the capital's schools. Initially, I combined teaching with public activism, but for over five years now, I have devoted 100% of my time to improving the system of care for people with rare diseases in Ukraine. My journey began with a diagnosis that changed everything. When my son Dmytro was 11 years old, he was diagnosed with a rare genetic disease — mucopolysaccharidosis. At that time, such diseases were not treated in Ukraine: there were no medicines, no national programs, and the cost of lifelong therapy was astronomical. Doctors gave us no hope. But I chose not to give up — and instead to change the healthcare system. I studied international experiences, communicated with patient organizations in other countries, and collected examples of effective legal frameworks. In Ukraine, I organized long-term advocacy campaigns, held rallies in front of the Ministry of Health and the Cabinet of Ministers, and raised awareness of the challenges faced by patients with rare diseases. In 2014, thanks to the persistence of the community, a law was adopted guaranteeing lifelong state-funded treatment for orphan patients. Ukraine also created an official registry of rare diseases, which currently includes about 300 entries. Today, my team and I are actively involved in implementing the Government-approved Concept for the Development of the Healthcare System for Patients with Rare (Orphan) Diseases for 2021–2026. An expanded neonatal screening program has already been launched; 22 reference centers have been registered; the Orphanet nomenclature has been translated into Ukrainian, and a full package of documents has been prepared to register it as the national classification of rare diseases. By the end of 2025, Ukraine is expected to officially adopt Orphanet as its national classifier. In 2024, I was elected to the EURORDIS Board of Directors — a role I am deeply honored to hold. It took time to fully embrace the responsibilities and opportunities that come with this position. But I have come to realize that focusing solely on the challenges and achievements of my own country is not enough. We must think and act globally, build bridges across borders, and support countries that are just beginning this journey. I am ready to continue this mission and sincerely hope for your trust to keep serving on the EURORDIS Board. As a mother of a child with a rare disease, I truly believe: an incurable diagnosis does

not mean the end of life. The motto of the organization I have led since 2014 — “Rare patients are a state priority” — is not just a slogan, but a guiding principle for everything we do. Every day, we work tirelessly — and beyond — to ensure that the needs of people living with rare diseases are prioritized in public policy and that they have access to effective treatment and a fulfilling life

MERVYN MORGAN, ITP SUPPORT ASSOCIATION, UNITED KINGDOM AND IRELAND

I joined the UK and Ireland ITP Support Association in 2016; and became the Chief Executive Office shortly after in 2017 reporting to the Chair of Trustee’s Prof Adrian Newland CBE and the Charity Trustee’s. The ITP Support Association is a UK registered charity which aims to promote and improve the general welfare of patients, and the families of patients, with Immune Thrombocytopenia. As CEO I have expanded the advocacy reach of the organisation with a growing number of Local and Regional ITP Patient Support Groups. This has included both in-person meetings and those in the virtual environment, all of which has encouraged participation from all four corners of the globe. I am also a Board member of the ITP International Alliance, which is the global organisation with over 30 ITP patient groups represented from around the world. The ITPSA is also a founding member of the ITP International Alliance, along with the Platelet Disorder Support Association from the USA. Since I became a board member of the ITP International Alliance, we have seen the creation of a Euro ITP patient organisation Subgroup which includes 15 European based ITP patient associations. In addition, I am also currently a member of the EHA ITP Guidelines Committee which is working on new guidelines for ITP, Immune Thrombocytopenia and I am also a member of the UK Paediatric ITP Registry ‘Study Steering Committee’. The ITPSA has also been supporting the various UK ITP Registries (Adult, Paediatric and Pregnancy) since the outset with an average of 50,000 Euro grant support per year. As a long standing patient advocate I was selected to take part in the latest EHA Advocacy Training programme, which involves working with other rare disease organisations from around Europe. I have also been a co-author of around 14 published ITP related abstracts and a member of several Advisory Boards. I have also attended and presented at a number of NICE technical assessment meetings for new treatments. I have attended both ASH and EHA Conferences and just recently I chaired an ITP Symposium at the British Society for Haematology at this year’s BSH Congress in Glasgow. In May I will also be chairing, along with Prof Newland, the ITPSA Annual Patient Convention in Manchester. Outside of Patient Advocacy I have the following experience: In addition to my role at the UK ITP Support Association I am also the Chair of the Hertfordshire Sports and Physical Activity Partnership (HSP) which promotes exercise and healthy living, again also working, in part, with the National Health Service, this organisation is part of the

University of Hertfordshire (Voluntary position). The partnership is funded by Sport England and is one of a network of around 40 such partnerships in England. Mervyn has been on the HSP Board for around 15 years. I am also a Board member of the Hertfordshire Football Association and is the Safeguarding lead member on the Board. My earlier background was as a Senior Manager, Sector Operations Manager with around 1,000 staff and the Area Operations Programmes Manager with a responsibility for planning major projects, both with Royal Mail in the UK, I was with them for almost 30 years

CHRISTOPHE NORMAND, KOURIR, FRANCE

My daughter has suffered from juvenile arthritis since she was only 18-month-old. It was 13 years ago… We had learned to live with the disease, with the always present hope of healing and the ever-coming pain and sadness.

I joined the KOURIR organization to find support during difficult times, and now we give back what we received. I actively collaborate in organizing our annual family weekend, which provides a time for families, children, and health professionals to meet. This event helps everyone gain a better understanding of the disease, exchange tips, or simply feel less isolated.

As a board member of KOURIR, I represent the organization in the European Network of Children with Arthritis and Autoinflammatory Conditions (ENCA) and the European Reference Network for Rare Immunodeficiency, Autoinflammatory, and Autoimmune Diseases (ERN-RITA).

As a patient advocate, I represent our organization in various groups and think tanks that tackle more political and economic issues. For example, we advocate for the right of patients to receive appropriate treatments without economic bias.

As a patient representative, I am involved in research projects related to arthritis. I participate in some of these projects as an ethics board member or as an investigator, focusing on the optimized consideration of patient outcomes and on the socio-economic impacts of the disease on families.

GRAHAM SLATER, EAT (ESOPHAGEAL ATRESIA GLOBAL SUPPORT GROUPS E.V), UNITED KINGDOM

In 1953 I was born with esophageal atresia (EA), a congenital malformation affecting around 1 in 3500 live births. I am amongst the first survivors of this condition, and thanks to the

pioneering surgery of Mr Ambrose Jolleys at Manchester Children's Hospital, I have the good fortune to be alive. I have been fortunate to have had a relatively healthy life, not something that all survivors of this condition can say, as many suffer lifelong morbidities. In 2008 I became a Board member of TOFS (the UK EA patient group) and I continue to have a leading role in TOFS' engagement with medical professionals and researchers. In January 2021 I was appointed a 'Public and Patient Voice' partner on the National Health Service Clinical Reference Group for specialised surgery in children, and since 2023 I have also been a Board member of NEC (Necrotising Enterocolitis) UK. In 2011, together with colleagues from several other European EA patient groups, I was instrumental in founding an international federation, EAT (Esophageal ATresia Global Support Groups e.V), and I was privileged to be its Chair for ten years. I continue to support the federation as its Special Patient Advisor, in particular as a liaison with INoEA, an international multi-disciplinary group of medical professionals with a special interest in EA. Additionally from 2017 to 2023 I was Lead ePAG for ERN-ERNICA where I represented patients suffering from the range of congenital malformations within its clinical scope. I am a passionate advocate of international collaboration; it is vital that our patients can benefit from the sharing of good practice and the development of improved treatments and lifelong care. Importantly I have strived to promote patient representatives as equal and irreplaceable partners with clinicians and researchers. My efforts were recognised when I was honoured to be the recipient of the EURORDIS Volunteer Award 2022, and In May 2023 I was privileged to be elected to the Board of EURORDIS. I now offer myself for re-election. I would be honoured to serve for a further three years bringing both my personal experience as a PLWRD and my past professional experience to support the Board's important role of guiding EURORDIS in its support for, and representation of, all those suffering from, or affected by, rare diseases

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