# EURORDIS GENERAL ASSEMBLY
# 17 MAY 2023

# Candidates to the Board of Directors

## Alain Cornet, Lupus Belgium

In 2004, my wife was diagnosed with Systemic Lupus Erythematosus, a diagnosis that changed our lives.
As a Senior Finance Executive in a large multinational, I had the opportunity to build skills in the area of Finance & Accounting, Strategy, Organization Management, External relations,... So for my part, I increasingly tried to contribute those skills in the lupus community. I later moved to part time, and finally left my work to re-center my life more fully to support organisations and projects that I have passion for. I am currently General Secretary of LUPUS EUROPE, Treasurer of EURORDIS and support multiple organisations on Governance, Finance or strategy matters. I am further building my skills by following an master's in business coaching and organization development. I am engaged in many projects including ERN ReCONNET EPAG, EJP-RD WP20 on Clinical trials, Patient panel organisation, as well as leading research on patient related lupus topics or advocacy projects such as the lupus100.org website creation. I would be more than happy to continue using my experience, skills and knowledge to serve the rare Diseases community as Treasurer for EURORDIS

## Dorica Dan, Romanian Prader Willi Association, Romania

My name is Dorica Dan and I am the mother of Oana, born with PWS in 1985 and late diagnosed at 18 years.
I am representing RPWA - Romanian Prader Willi Association, coordinator of NoRo center, president of Romanian Association for Rare Cancers and Romanian National Alliance for Rare Diseases and I would like to re-apply as a board member of EURORDIS.
As a Board member, I would bring my knowledge and experience of initiating National Plan for Rare Diseases in Romania, building, organizing and fighting for sustainability and development of a resource center in a low economic environment like our country, a Center of Expertise part of ERN ITHACA, but also, my experience as an advocate for patient's access for their rights at national and EU level.
My achievements:
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- Initiated RPWA (Romanian Prader Willi Association) in 2003 and established RONARD (Romanian National Alliance for Rare Diseases) through a project funded by CEE Trust in 2007 and established the Romanian Association for Rare Cancers;.
- Opened the first Centre for Information about Rare Genetic Diseases in Romania and initiated the National Plan for Rare Diseases in Romania.
- Became board member of EURORDIS and ambassador of IPWSO as a former board member (International Prader Willi Syndrome Organization) since 2007;
- EURORDIS EUROPLAN advisor and coordinator of WP6 on Specialized Social Services for RD of EJA for RD;
- EUCERD & CEGRD member – European Union Committee of Experts in Rare Diseases;
- Established NoRo Center and became coordinator of NoRo Center since opening in 2011;
- Member of NCRD – National Council for Rare Diseases (A commission of MoH in Romania) and Economic and Social Council in Romania.
- member of the Romanian Social Economic Council for 2 years;
- member of working groups for rare diseases for Ministry of Health Romania;
- Member of the steering group of RareResourceNet and vice-chair.
- Ashoka fellow since 2018;

## DANIEL DE VICENTE, FEDERACIÓN ESPAÑOLA DE ENFERMEDADES RARAS (FEDER), SPAIN

With a degree in Pharmacy, I have over 20 years' experience in community pharmacy. I am firmly committed to non-profit entities up to the point of focusing my postgraduate course in management and strategic planning in this field. As for today, I work as Freelance Health Consultant in management, developing strategic planning for pharmacies and health establishments. To the fact of being a professional in the pharmacy field it was added my personal condition as RD patient, brining me this advantageous dual perspective.

I would remember my childhood as a normal one if it was not for countless visits to doctors, specialists and hospitals. For better or worse, I know by first-hand how frustrating and exhausting is to receive a late diagnostic. I was 36 when I was diagnosed: I suffer from Acid Sphingomyelinase Deficiency (ASMD), a genetic, degenerative illness affecting about two thousand people around the world, although some specialists suggest that this is an underestimated data. Later on , my sister was also diagnosed and we have been participating in a clinical trial for 6 years, with the aim of finding a safe and effective treatment.

It was at this point when my fight started, and my implication increased. Together with my sister, we came up with the idea of creating an association of our illness, which came into reality in 2019. I have been its president since then and, thanks to the flexibility offered by my work, I had the possibility of been engaged in the rare diseases' community needs at both the national (board member of the Spanish Federation for Rare Diseases since 2020) and international levels. It would be an absolute pleasure to share with you all the knowledge that I have acquired until now, including my time as Research Liaison Officer at the International Niemann-Pick Alliance and as European Expert at the European Medicine Agency. I also participate in the International Niemann-Pick Registry working group and in "Clinical Management Guidelines for ASMD" International working group.

My personal and professional knowledge will bring to EURORDIS' Board of Directors the advantageous value of relying on a person that has the experience of facing the obstacles that a person living with a

rare disease has to deal with. If you allow me, I will also mention the advantage that my previous experience at coping with affairs in the international arena could bring to this BoD, together with my enormous willingness and predisposition of working hand to hand with all of you with the aim of improving the life and conditions of every single person living with a rare disease.

## Tomasz Grybek, Foundation of Borys the Hero /Fundacja Bohatera Borysa (Metachromatic Leukodystrophy), Poland

Economist by training, Quality Assurance & Food Safety Manager by profession, Patient Advocate focused on strategic advisory for public entities by the necessity and passion of being a father of a child diagnosed with life threatening rare neurological disease.
My professional journey started with coordination of EU fund projects at the Regional Authority Office in Poland, followed by involvement in the Polish Aid advisory project in Moldova. Aforementioned experiences gave me fundaments to take managerial position in the food industry with growing interest in SDGs, One Health approach and Food Safety Culture phenomenon, which became my area of scientific research for my PhD studies. I graduated my economy master studies in 2007 and in the meantime our son, Borys, was born and few years later at the age of 5 he was diagnosed with rare disease.
Being a father of a child affected by rare disease gave me almost full spectrum of all shades of parental challenges related to patient journey. Starting with misdiagnosis, looking for a treatment around the globe, through the disability related issues, social & educational exclusion and ending with new-old personal life reality. All experiences created the opportunity to build my patient advocate dossier on a step wise approach, as I've started with local and regional advisory activities related to strategic planning of activities dedicated to rare diseases. These were followed by involvement in work of the drafting group of one of the draft versions of Poland's National Plan for Rare Diseases as well as work of external expert to the Plan related activities. Parallel I've become an ePAG for ERN ITHACA and Patient Board Member of MetabERN.
Subsequently, strengthened ties with EURORDIS led me to the European Commission's appointmentnto the European Medicine Agency Paediatric Committee (EMA PDCO) as a member representing Patients' Organizations and becoming a EURORDIS TAG Member. Variety of smaller and bigger initiatives, projects and cross co-operations within the aforementioned entities and establishments allowed me to gain quite a comprehensive set of perspectives of both bottom-up and top down approaches.
I strongly believe that my quite unique mix of professional background and personal experience gives me a perfect mandate to be the person in the Board of Directors thinking outside the box with the benefit of EURORDIS itself as well as its members. Moreover, due to my project working experience I'm used to working with documents, writing synthetic evaluations, working remotely with full utilization of the state-or-art IT tools. Last, but not least, my analytical skills together with the extrovert attitude ensure my ability to clearly present my independent point of view, both in writing and orally.
Having said that, I'd like to emphasize that I'm convinced that my life and work experience will allow me to serve EURORDIS' Members by ensuring that the Board of Directors' strategic decision making

process will be aimed for better aligning with patients' needs and focused on continuous Improvement of EURORDIS activity.

## Graham Slater, Esophageal Atresia Global Support Groups e.V (EAT), 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 (so far at least !) 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 lead TOFS' engagement with medical professionals and researchers. In January 2021 I was appointed a 'Public and Patient Voice' partner on the National Health Service of England's Clinical Reference Group for specialised surgery in children.

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.

In 2017 I became Lead ePAG for ERN-ERNICA in which I have been delighted to represent patients suffering from the range of congenital malformations within its clinical scope, and which led to my membership of the EURORDIS ePAG steering group.

I am a passionate advocate of international collaboration; it is vital that our patients are able to 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 together with my work in the UK, with EAT and with ERNICA internationally, I continue to support the remarkable efforts of EURORDIS in its support for, and representation of, all those suffering from, or affected by, rare diseases.

## Anna Spinou, Hellenic Cystic Fibrosis Association, Greece

I was diagnosed in the '80s at the age of six-months with Cystic Fibrosis (CF), a fatal childhood rare disease that mainly affects the lungs and the pancreas. Hopefully I managed to survive and here I am now, a proud 41 years old Cystic Fibrosis patient living in Athens with my husband and our two lovely cats.

I have graduated from the Department of Business Administration of Athens University of Economics & Business and I have been working during the last 15 years at University Hospital Administration. I

realized at a young age that I had to do my best to improve the healthcare conditions for Cf and rare diseases in my country and to fight for the rights of rare patients, so I decided to get involved in patient advocacy, resulting in my now 12 years' experience at patient advocacy.

Since 2018 I have been the President of the Hellenic Cystic Fibrosis Association, while I was on the Board of Directors of the Association as the General Secretary (2015-2017) and as a Board Member (2003-2005). In 2017-2019 I was the General Secretary of the Hellenic Federation of Associations for Rare Diseases (H.F.A.- R.D.) and since 2021 I am a Board Member of Rare Diseases Greece (RDG). I participate in working groups and meetings of European organizations CF Europe, ELF, ERS, Eurordis, European Transplant Patient Organizations (ESOT- ETPO). During my service as a patient advocate I have managed to improve the healthcare conditions and access to care and medicines for CF patients in Greece, while raising awareness for rare diseases. During my Presidency, the Hellenic CF Association was awarded in 2020 for the start of the early access program to the miracle CF triple therapy in Greece, which saved our lives and is gradually transforming CF from a fatal rare disease to a treatable chronic condition.

I would be very grateful to join the BOD of Eurordis. I am self-motivated with team spirit, strong organizational and interpersonal skills and a strong sense of responsibility. I believe that my personal skills in combination with my personal experience as a rare patient and my knowledge and experience as a patient advocate on a national level, will be useful tools for the European rare diseases community. It would be my pleasure to share my experience with the European rare community, in order to advocate all together for a better future for rare patients.

## Stefan Živković, National Organisation for Rare Diseases (NORBS), Serbia

I am a project coordinator at the National Organisation for Rare Diseases of Serbia, and a legal representative at the Foundation NORBS Plus – a charity organisation that was established with the main goal of raising funds for procurement purposes of necessary medical and technical aids for people living with rare diseases, which are not available at the expense of the health fund.

I have educational background in Political Science and International Relations, with a lot of non-formal education and training. I have volunteered/worked in various organisations in the field of youth and education, been involved in regional youth networks and have completed a traineeship at the European Parliament.

The reason for getting involved in rare diseases is my younger sister, who has cystic fibrosis. Since I started working in NORBS, I have been involved in many rare disease programmes and initiatives. I was part of Rare 2030 Young Citizens, participated in the EURORDIS Summer School on Medicines Research & Development, and am currently attending the Open Academy School on Scientific Innovation & Translational Research. Furthermore, I also took part in the Brussels Rare Disease Week in 2021 (online edition) and 2023 in-person programme.

I hope to bring my personal, professional and organisational experience and abilities to the EURORDIS Board of Directors to contribute to the European rare disease community and also to be a voice and bring youth perspective and perspective from the Southeast Europe/Western Balkans rare disease community to EURORDIS.

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