Board of Director's elections
EURORDIS - General Assembly – 19 May 2017
Candidates

Alba Ancochea, Spanish Federation of Rare Diseases (FEDER), Spain

I have almost a decade of experience and commitment in implementing planning policies, programs and socio-health projects in the field of Rare Diseases in Spain.

Since 2009, I've been involved with the Spanish Federation of Rare Diseases (FEDER), which gathers 338 patient organisation. For the last 4 years now I have the privilege of being FEDER's CEO and leading a team of more than 40 professionals in charge of the development of 25 specialized projects aimed at improving the quality of life of PLWRD. I am currently leading the Federation's boost towards an international level by promoting the creation and current functioning of the Ibero-American Alliance of Rare Diseases, besides representing FEDER in RDI, and in the CNA. I'm also member of DITA Task Force. My degrees in Psychology and in teaching for Special Needs, a MA in Administration and Management of Foundations, Associations & NGO, Master in Clinical Psychology, Master in Mediation and Advanced Diploma in Family relationship, among other qualifications, enable me to represent Spanish people with rare diseases in a dozen of Work Committees and national and international projects regarding National Strategy, Centers of Expertise, access to Orphan Medicinal Products , treatment and research on RD. I really believe in the role of Patient organizations (PO) in making changes happen and I want to contribute even more in strengthening the capacity of POs and RD patient advocacy by being part of EURORDIS Board of Directors. I would really be honored to contribute to EURORDIS' mission and to a broader and stronger Rare Diseases community in Europe, by providing new perspectives and experiences, as well as bringing enthusiasm, commitment and true dedication.

Dimitrios Athanasiou, United Parent Projects Muscular Dystrophy, Greece

Dear Members, I am Dimitrios Athanasiou, father of Hermes, a boy with Duchenne MD, an incurable and terminal disease. Since my son's diagnosis I have become a full time patient advocate and drug access activist for Rare Diseases in Europe.

I trained in the EURORDIS Summer School, graduated from the 14th months training of EUPATI Patient Academy and I am an EMA-nominated patient expert, participating in Scientific Advice, SAG and CHMP Meetings in the UK. I hold a BA and an MBA in

Financial Management, speak English, French and Greek and have worked for over 25 years' in business development across Western, Eastern Europe and the Middle East.

I strongly believe that time for us is too precious and we should leave no one behind. For this reason, I want your support to join the board of EURORDIS, in order to bring my passion, skills and hard work for the development and access to drugs for people with rare diseases wherever they live inside but also outside Europe.

Lieven Bauwens, International Federation for Spina Bifida and Hydrocephalus, Belgium

Lieven Bauwens is the Secretary General of the International Federation for Spina Bifida and Hydrocephalus (IF -www.ifglobal.org), and the chair of both Child-Help Belgium and Child-Help International (www.child-help.be), a charity dedicated to help children with SB/H in developing countries. In those capacities, he is a global advocate for the rights of persons with the disabilities while engaging actively in primary prevention of these impairments. He is a board member of the Food Fortification Initiative (www.ffinetwork.org), of the International Disability Alliance (http://www.internationaldisabilityalliance.org/en), and a founding partner of the global alliance for Spina Bifida and Hydrocephalus, PUSH! (www.pu-sh.org), and Child-Help in Belgium, Germany, France and the Netherlands.

A background in Architecture and Business Administration, Lieven got involved in IF as brother of a young man with Spina Bifida and Hydrocephalus. He brings to Eurordis yearlong experience in international advocacy and organizational development.

Dorica Dan, Romanian Prader Willi Association, Romania

I am a mother of a daughter of 32 years with PWS, board member in Eurordis for 10 years. During this time, I have initiated the National Plan for Rare Diseases in Romania and I am member of the National Committee for Rare Diseases – a commission for rare diseases at Ministry of Health Romania. My organization opened the Pilot Reference Center for Rare Diseases "NoRo" through a project implemented in partnership with Frambu Norway and funded by Norway Grants. Our center became a center of expertise part of a national reference network that became member of ERN ITHACA. I am also one of the ePAGs.

I was one of the EURORDIS Europlan advisors for Romania, Hungary, Slovakia and Bulgaria and I had the opportunity to collaborate with different organizations and national alliances, to learn more and improve my skills and knowledge about cooperation and collaboration of patient organizations with different stakeholders.

I have represented EURORDIS at International Conferences throughout Europe and as a member of EUCERD and CEGRD for the last 6 years, I was involved as a Work Package

leader of the EUCERD Joint Action Working for Rare Diseases (EJA), Work Package 6 focusing on Specialised Social Services and promoted the RECOMMENDATIONS TO SUPPORT THE INCORPORATION OF RARE DISEASES INTO SOCIAL SERVICES AND POLICIES. I am also coordinating the WP 6 from INNOVCare project.

I have been personally awarded by Medica Academica, different medical Galas, ex: The voice of the patients in Romania, Collaboration and bringing together all the stakeholders in the field of rare diseases or for Innovation in health care.

I would like to continue my activity as a board member and I think that during time I proved that I am a good team member and that I am able work in a national and international environment.

Marie-Noelle Gaveau Glantin, Association Française Des Syndromes d'Ehlers-Danlos, France

I am candidate for the EURORDIS Board of Directors election. I have created the AFSED in 1997, the first Patients Organization in France about EDS. I have been the chairwoman since 2000.My sons both have the rare disease, Ehlers-Danlos Syndrome as my dead husband. I've been a medical doctor; a psychiatrist. I have a private office in Le Havre. Europe's building is my great idea, my aim from my adolescence and for my whole life. I have friends everywhere in Europe. I like to travel around the world. I am interested in Genetics and medicine.

Birthe Holm, Rare Diseases Denmark, Denmark

To be re-elected to serve patients and their families with rare diseases as a member of EURORDIS Board of Directors (BoD), would be an honor to me.

Who am I? My name is Birthe Holm. I have served on the BoD for five years and wish to contribute to this very important work in the years to come. I have also served as a representative for the European patients in Committee of Orphan Medicinal Products (COMP), for 12 years, signing out in 2016. I am a lawyer of education but now retired from professional work, serving as a full-time volunteer in Denmark and Europe.

My personal experience of raising a son, Michael, born 1983 affected by osteogenesis imperfecta (OI) means that I personally have learned what life can be like when living with a rare disease. Michael has lived through more than 3 decades, even though the prognosis at his birth was far less optimistic. Together with my life long work with the Danish Osteogenesis Imperfecta Society, Rare Diseases Denmark and in different connections linked to the European level, this has given me knowledge of and admiration for the great work done by patient representatives and volunteers all over Europe. But it has also given me an insight of the difficulties, the daily struggle, the unmet needs, inequalities and impact of the economic situation for rare disease patients throughout Europe.

My key issues. The importance of European cooperation in order to strengthen the national policy and governance of rare diseases is not to be underestimated. In order to be heard, we need to unify our voices I will focus on three key issues:

- Collaboration. To meet present and future challenges, we need a still stronger EURORDIS to advocate the rights and needs of rare disease patients throughout Europe. This has to be done on the basis of and together with all EURORDIS members – national alliances, federations and others.

- Solidarity. Even though our national systems differ, all rare people need access to diagnostics, treatment and social support. We must fight inequality and promote equal access for all.

- Sustainability. We have gone a long way and made big achievements. But progress is fragile and we have to ensure sustainability in order to build future achievements on solid ground.

A lot has to be done and I wish to give my contribution by continuing to serve on the Board of Directors.

Todor Mangarov, Pulmonary Hypertension Association, Bulgaria

Todor is a patient surgical treated in 2011, of chronic thromboembolic pulmonary hypertension (CTEPH). His rare disease is the only kind of Pulmonary Hypertension, potentially curable, without needing to resort to a lung transplant. He started in 2006 his struggle with the illness.

Todor is a soldier, for whom the rare disease Pulmonary Hypertension becomes a personal cause. The unconventional way, namely by bike tours in Bulgaria, Europe and the world, he inspires hope to the other patients that by early and timely diagnosis and appropriate therapy they will be able to improve their quality of life and to do everything that a healthy person could achieve.

Since 2007 Todor Mangarov is Vice-President of NAPRD. In 2010 he established the Pulmonary Hypertension Association – Bulgaria (PHA Bulgaria). It is a non-profit organization, which activities are aimed at helping people suffering from the rare disease pulmonary hypertension, providing assistance for the implementation of the communication between them, the association and the governing bodies and health institutions in Bulgaria and protects the rights of patients with this diagnosis, as well as its underlying conditions that descend from. cts with similar patient associations.

Todor Mangarov possesses leadership, coordination, planning, controlling, HR management skills. He is team player, who works under pressure. Mr. Mangarov organizes very well the work processes and administrates perfectly the complete project implementations. He acts as speaker during conferences and workshops.

Dimitrios Synodinos, Tuberous Sclerosis Association of Greece

Of Greek parentage, born in Aden, Yemen in 1949 and currently residing in Athens, Greece. I studied economics at the universities of Athens, Geneva and Reading, U.K. Married to Jan (Associate Professor of Genetics, Laboratory of Medical Genetics, Athens University) with three children and 4 grandchildren. Working in the private sector in Athens. As a member of the Greek Alliance for Rare Diseases (PESPA) for the last several years, having seen the huge problems that patients with rare diseases face, I have been involved with rare diseases and have actively supported PESPA in organizing many different events in Greece and abroad.

I feel that my skills in communication, organization and good people skills as well as my experience on the Board of Directors of Eurordis to date, will continue to be of value to the Eurordis Board of Directors in the promotion of Eurordis' activities and goals. Being from south-eastern Europe I will offer the Eurordis Board a view of the current situation and the needs of rare diseases in this region of Europe, and facilitate the transfer of appropriate policies and information to the institutions of the European Union.

Lex van der Heijden, CMTC-OVM, Netherlands

As father of a child with the rare disease CMTC (www.cmtc.nl/en) and founder/president of a global non-profit patient organisation I've gained a wealth of knowledge and experience for over 20 years. During the 2016 Eurordis conference I stepped on the soapbox and suggested to look at patients the holistic way. This means in this context that we should not only look at the patient from a medical point of view but also from the psychological and psychosocial points of view. We have in our organisation a medical psychologist for over 15 years and on our website we have also a number of articles regarding the psychological part of living with a rare disease.

My daughter had a medical problem during the weekend related to CMTC and in the hospital they didn't want to act because they didn't have access to her medical data. This is a common problem I've seen not only in Europe but also in eg. the USA. The patient has no complete medical record, which contains everything (data is spread over different hospitals, doctors, etc.) and has certainly no control who has access to HIS/HER personal medical data. Esp. with rare diseases this is risky for the patient!

My professional background is ICT and I've worked for eg. IBM Global Services for 16 years as Senior Project Manager.

My objectives are combining my 20+ years and 30+ knowledge/experience/skills on behalf of patients living with rare diseases to:

1.Raise awareness that patients must be treated and supported the holistic way.

2 Implement a patient health record that is controlled by the patient (or eg parents), which contains ALL medical data, is secure and is accessible from about any place.