Candidates to the
EURORDIS Board of Directors
General Assembly 2014 - Berlin

Federación Española De Enfermedades Raras, Spain, *Gema Chicano Saura*

The opportunity presented of being member of EURORDIS board is certainly interesting and exciting, and I believe that my strong experience in rare diseases and patient alliance managing and education will make me a very competitive candidate for this position.

I am president of the association "Afectados por Displasia Ectodérmica" (A.A.D.E.) since 2004. My education in law has been very important for my association, other associations and patients with rare disease.
In my current job, as a lawyer and inspector I have accomplished the establishment of legal rules and procedures on several matters relating to my work. I have a higher education in human rights, disabilities and rare diseases. Furthermore, I have also completed training in clinical trials and have participated as an association in clinical trials for Ectodermal Dysplasia.
I would be sincerely pleased to bring this experience to the EURORDIS board and contribute to build a strong European community of patient organisations and people living with rare diseases, to be their voice at the European level, and to fight against the impact of rare diseases on their lives.

Greek Alliance for Rare Diseases, Greece, Dimitrios Synodinos

I was born in Aden, Yemen in 1949 and currently reside in Athens, Greece. I am married to Jan (Associate Professor of Genetics, Athens University) with three children and, recently, 2 grandchildren. Following university studies in economics, I work in the private sector. As a member of the Greek Alliance for Rare Diseases (PESPA) for the last few years, and having seen the huge problems that patients with rare diseases face, I have been involved with and have actively supported PESPA in organizing and participating in many different events in Greece and abroad.
I feel that my skills in communication and organization would be valuable to the EURORDIS Board of Directors in the promotion of EURORDIS activities and goals. Being from south-eastern Europe I will give the EURORDIS Board a view of the current situation and the needs of rare diseases in this region of Europe, and in return support the transfer of appropriate policies and information from the institutions of the European Union back to this region.

Rare Diseases Denmark (Sjældne Diagnoser), Denmark, *Birthe Byskov Holm*

I would be honoured being elected to serve patients and their families with rare diseases as a member of EURORDIS Board of Directors. Two years ago I became a member on the Board when Torben Gronnebaek passed away. It is my wish to contribute to this very important work in the years to come.

My personal experience of raising a son, born 1983 affected by osteogenesis imperfecta (OI) means that I personally have learned what life can be like when living with a rare disease. I joined the Danish Osteogenesis Imperfecta Society and served for several years as president/vice president and had the privilege to represent the Danish association when the European OI Federation (OIFE)

was established. As president (and co-founder) of the Danish National Alliance for rare diseases (Rare Diseases Denmark) I have experienced the importance of the European cooperation and the impact of this cooperation on national policy and governance. Rare Diseases Denmark became member of EURORDIS from its early start and is proud to work with EURORDIS on several projects

I have represented EURORDIS at meetings, conferences, seminars, in working-groups advocating for the cause of the rare people. Also, I have been fortunate to gain a profound understanding of the regulatory system, European legislation and knowledge on European and National institutions and of the interaction between the different stakeholders as a representative for the European patients in Committee of Orphan Medicinal Products (COMP), for 11 years. This experience has given me an understanding 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.

The importance of European cooperation in order to strengthen the national policy and governance of rare diseases is not to be underestimated. 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. We have gone a long way and made big achievements. But there is still a lot to be done and I wish to give my contribution by continuing to serve on the Board of Directors. I am a lawyer of education but now retired from professional work, serving as a full-time volunteer in Denmark and Europe.

Romanian Prader Willi Association (RPWA), Romania, *Dorica Dan*

I am Dorica Dan, the mother of Oana (29 years), and Alex (21 year). Oana has Prader Willi syndrome and she was late diagnosed. I am the president of the RPWA, RONARD and ARCrare. I have coordinated the NoRo project and established NoRo - the Centre for RD in Romania, HelpLine and www.edubolirare.

I initiated the work for a NPRD in Romania and became member of the National Council for RD, established by Ministry of Health Romania in order to advice Ministry in the implementation of the National Plan for Rare Diseases.

At EU level I am in the Board of Directors of EURORDIS since 2007 and in the European Committee of Experts for RD since 2010. I am one of the EURORDIS EUROPLAN advisors and a Work package leader for EUCERD Joint Action for RD – Specialized Social Services.

I understand the activities, mission, and vision of EURORDIS. I will continue to bring to EURORDIS my ability to work for the good of the organization as a whole, to acknowledge and help in the evolution of the realities of the Eastern European countries in this field, to have the strength given by my commitment and faith, and to continue to develop the activities that we have achieved.