



**Candidates for the Eurordis Board of Directors**  
**General Assembly, Athens, Greece, Friday 8<sup>th</sup> May 2009**

*In 2009, 4 Directors will be elected for a 3 year mandate*

**Association Française contre les Myopathies – France, represented by Beatrice de Montleau**

My name is Beatrice de Montleau. I am 44 years old and have 3 children: Esther (17); Constantin (15) and Axel (12). My youngest being affected by a Duchene Muscular Dystrophy (with a very rare deletion), doing well at school and happy in his life, trying to be as independent as he can.

Due to my professional background, as former Head of Internal Audit and now Head of Sustainable Development, I began my volunteer involvement within AFMs' financial committee. Then, I took more responsibilities by:

- being a Board member (since 2006), and then General Secretary (since 2008)
- being active in the International Commission (and now responsible for it), which main priorities are networking; patients registers and help
- being member of the AFM Multidisciplinary consultation Commission, also in charge of Competence centers
- organizing Telethon of financial institutions.

I also recently attended the first DMD conference in Asia, organized by UPPMD and with AFM as a sponsor, which took place in Bangalore in February.

I am used to working in an international network (65 countries) and am convinced that the culture mix is the best way to enhance good ideas. I also have a good knowledge of European Union functioning.

Due to my personal overview of all projects going on worldwide into rare diseases, I have the feeling that Eurordis objectives are the best ones. Being a strong pan-European community of patients and dealing with orphan drugs status and patients registers are some of the ongoing key subjects.

I am positively impressed by all the work done by Eurordis and by its successful story. I will do my best to maintain the efficient links between Eurordis and AFM. I will try to do as well as my predecessor Pierre Birambeau did.

I would be very proud of serving Eurordis and honored if you accept me in the Board. I will put my personal energy and my professional skills to help you in fighting rare diseases.

**Behçet's Syndrome Society, United Kingdom, represented by Richard West**

I am Richard West, 53 years of age and since 1995 I have been living with Behçet's Syndrome, which is a rare, complex and lifelong illness.

- 1996 - I joined the Behcet's Syndrome Society which is a UK based Charity that gives help and support to people living with this illness and their carers.
- 2002 - I was elected to be Secretary and Trustee of the Behcet's Society and still hold this voluntary position.
- I have helped organise the Annual General meetings of the Behcet's Society where Doctors specialising in the illness are invited to talk to sufferers and carers.
- I have attended and taken part in the Behcet Patient's International Conferences in Turkey, Portugal and Austria. I am involved in the organisation of the Behcet Patient's International Conference in London in 2010, where we hope to formalise an International Patient's Organisation for this illness.

I was a senior UK Police Officer and since 2000 I have been working as an Investigator for Solicitors and Insurance Companies mainly investigating road accidents.

I have in the past been a Governor at a Secondary School in the UK and I am used to Committee work through this position and that of a Trustee of the Behcet's Society.

I am a patient representative on the National Voices Service User panel in the UK. National Voices is a new umbrella group for national voluntary organisations representing users of health and social care in England to give them a stronger voice in policy making.

In 2008 I attended a Summer School in Barcelona organised by Eurordis which gave training for Rare Disease Patient Advocates in Clinical Trials and Drug development. Following this I am now one of the patient members of the Eurordis Task force involved in Drug Information Transparency and Access. I have also attended the European Platform for Patients Organisation Science (EPPOS) workshop on Clinical Trials and the one day Eurordis Paris Conference on National Plans for Rare Diseases.

All my working life I have been involved in investigative work, so I am well practiced in asking pertinent questions, listening, analyzing facts and drawing rational conclusions.

I have seen at first hand the excellent work of Eurordis and I would like to volunteer to be a Director of the organisation. I would work enthusiastically on behalf of everyone with a rare disease. I would actively seek out new members to join Eurordis, especially those organisations that do not have many members. I feel that they have an uphill struggle to be recognised as a group with a rare disease and be represented at a National or International level and that Eurordis is best placed to help them.

### **Federazione Italiana Malattie Rare (UNIAMO), Italy, represented by Paola Zotti**

My name is Paola Zotti from Italy. I am a cultural anthropologist. Rare diseases came into my life on March, 30 1990 when my unique daughter was born.

I hadn't heard of RD before and suddenly it became my primary area of interest. From RD I've learned that life is always surprising and statistics are not a theoretical matter. Very soon I understood that RD, in spite of their multiplicity, represent a paradigm of approach and a challenge for our problem solving skills.

On January 1995 thanks to intuition, I started one of the first Italian web sites dedicated to a RD. And this is due to the particular nature of our umbrella-organization of reference, DEBRA, I gained the confidence to work within an international set.

Although I can see difficulties, I consider this as a significant opportunity for us, as Europeans, to provide a European perspective on RD: I'm proud to be European, I really believe in a European way which will enable us to unite solidarity, welfare and economics.

At present, my principal fields of interest are precisely two: school and research.

In my opinion, formation represents a crucial step for social integration of RD people and to increase awareness in a civil society. I'm sure if your desk fellow is suffering from a RD and the school system offers useful tools to face this situation, the vision of RD can change deeply and in an exponential way.

Research: the present economical situation in Europe is difficult. Research funding requires more attention regarding the assignment of funds. The point of balance between basic and translational research projects is hard to establish.

I thoroughly believe that a strategic role can be played by the Patients' Associations, the first to believe that research is ultimately, the way forward in therapy.

I would like to add my enthusiasm and experience to the European context of RD.

### **Genetic & Rare Disorders Organisation, Ireland, represented by Avril Daly**

I have worked for the Irish Charity Fighting Blindness since June 2000. In my position as Head of Public Affairs I am responsible for raising awareness of genetic and rare retinal diseases among the general public, health care professionals and policy makers. I am the spokesperson on all matters relating to the charity's events, campaigns and policies.

Over the past nine years I have been an active member of GRDO – The Genetic and Rare Disorders Organisation, which is the Irish national alliance supporting families affected by genetic and rare disorders. I was elected chair in 2008.

I am also a member of both The Medical Research Charities Group (MRCG) and The Irish Platform for Patient Organisations Science and Industry (IPPOSI) who are working closely with GRDO to campaign for the establishment of a National Plan for Rare Diseases in Ireland in the shortest possible time frame. I represent Retina International and Retina Europe on the Board of The European Platform for Patients Organisation Science and Industry (EPPOSI) and am a member of the AMD Alliance International.

Upon my graduation I worked on the production of a number films and television programmes and contributed to local radio as a commentator. I then worked for a Publishing company for over three years and was responsible for the editorial content and promotion of a monthly Communications magazine. In that time I also devised and successfully launched a title dedicated to the telecoms sector in Ireland.

As a student I taught drama to children and young adults with special needs and worked as a volunteer with the Irish Wheelchair Association.

I was diagnosed with Retinitis Pigmentosa in 1998 and am registered as Vision Impaired.

I am married and live in Dublin.

### **The Croatian Society of Patients with Rare Diseases, Croatia, represented by Mirando Mrsić**

My name is Mirando Mrsic, 49 years old, married, Hematologist and since many years involved in the field of rare disease in the countries of South East Europe.

Due to my medical background and political work as member of the parliament I am very well aware of the challenges of rare diseases from a legal, infrastructural and clinical point of view.

As medical director of the Leukemia and Lymphoma Patient Organisation and one of the founders of the fundation „Ana Rukavina“ , I introduced a country wide campaign to establish an unrelated bone marrow donor registry and umbilical cord blood bank with the main goal to increase the chances of cure for leukemia and lymphoma patients.

In order to make therapies for Rare Diseases available to patients, I believe that it is of utmost importance to create an infrastructure based on equal patient rights, diagnostic possibilities and fundaments for reimbursement of Orphan Drugs, in developed - as well as transition economies with a less fortunate economic situation, as it is the case in the majority of Central and Eastern European countries.

I see the stimulation of an environment where Research and Development create new possibilities and provide a perspective to patient's lives as one of the key activities.

I believe that a lot of experience and knowledge can be mutually shared on a European level leading to a better understanding and improvement to access therapy and to provide education on Rare Diseases to a broader public, as well as to medical and scientific community.

I would be very glad to significantly contribute with my knowledge and enthusiasm to the continuation of the successful work of Eurordis.

### **Tuberous Sclerosis Association, Greece, represented by \*Marianna Lambrou**

I am the mother of Katerina (40 years old), who suffers from Tuberous Sclerosis.

President of the Tuberous Sclerosis Association (TSA) of Greece since her foundation in 1992.

TSA of Greece is an active member of the National Confederation of Disabled People and member of the European Disability Forum. Also president of the Greek Alliance for Rare Diseases which was officially established in 2003. Since 2002 I am member of the Board of Directors of Eurordis.

At this point among other activities, I am networking with representatives of associations of Rare Diseases in order to join us in the Alliance and at the same time to persuade them to become members of Eurordis. Being a member of the Board of Directors is an important experience and I am glad to share the knowledge I gain, with the patient associations in my country in order to work together and improve the quality of life for our patients and their families.

I strongly believe that Greece should continue to have a place in the Board of Directors with my presence in order to obtain the good practice of other countries but also represent the different mentality and needs of South Europe. As a member of the Board of Directors I feel that I would have better chance and authority in my efforts to accomplish our goals at the national level.

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