European Reference Network
for rare or low prevalence complex diseases

Network Neuromuscular Diseases (ERN EURO-NMD)

EURO-NMD MEETING

FREIBURG
29-30 NOVEMBER 2017

PATIENT ADVISORY BOARD BOOKLET

EURO-NMD TERMS OF REFERENCE

The Patient Advisory Board is responsible for identifying and making suggestions regarding patients concerns and expectations on the remit of EURO-NMD. The PAB will establish their own rules of procedures and Terms of Reference.

Membership:

Members include those elected via EURORDIS who constitute the European Patient Advocacy Group for NMD (RNMD-ERN ePAG). Members from umbrella organisations (MDUK; VSN and DGM) will join the Patients Advisory Board by invitation.

ePAG representatives:

- François Lamy (AFM-Téléthon, France),
- Jean-Philippe Plançon (French Association against Peripheral Neuropathies: Guillain Barre syndrome-Chronic inflammatory demyelinating polyneuropathy, France),
- Evy Reviers (ALS Liga Belgium),
- Judit Varadine Csapo (Angyalszarnyak Hungarian Muscle Dystrophy Association),
- Marisol Montolio (Duchenne Parent Project Spain),
- Piero Santantonio (MITOCON ONLUS, Italy).

Other NMD patient representatives:

- Inge Schwersenz (DGM; Deutsche Gesellschaft für Muskelkranke; Germany),
- Ria Broekgaarden (VSN; Dutch Patient Society of Neuromuscular Diseases),
- Madelon Kroneman (VSN, Dutch Patient Society of Neuromuscular Diseases),
- Nic Bungay (Muscular Dystrophy UK).

The members of the PAB will commit to assist in the following:

- Governance of the ERN: The ERN Board will include the patient representatives that are part of the Patient Advisory Board. One representative of the PAB will also be part of the Executive Committee (see *Board Terms of Reference*).

- Activity Groups and Advisory Boards: Patient representatives will also be nominated by the Patient Advisory Board to be part of each Activity Group and Advisory Board.

- Guideline development: The PAB members will be central to the development of clinical and specialised social services guidelines and outcome measures, ensuring these instruments meet patient needs. For this they will engage with patient representatives beyond the network to appoint the best person for each task.

- Ethics: PAB members will be involved in ethics activities and one representative to the Ethics Committee will be appointed by the PAB as chair.

- Research: PAB members will contribute to the definition of research priority areas based on what is important to patients and families and will ensure that patients are embedded in the research activities of the network.

- Evaluation: PAB members will play a key role in network evaluation, ensuring feedback based on patient experience and evaluating ERN performance by reviewing quality indicators and making recommendations.

- Training and dissemination: PAB members will commit to disseminate information about the network and its initiatives to their organisations and to other patient groups not currently part of the PAB. Will develop educational materials for patients and families and healthcare professionals and participate in teaching activities.

EURO-NMD PATIENT ADVISORY BOARD POSTER

European Reference Network

PATIENT ADVISORY BOARD

The Voice of Patients with Rare Neuromuscular Diseases

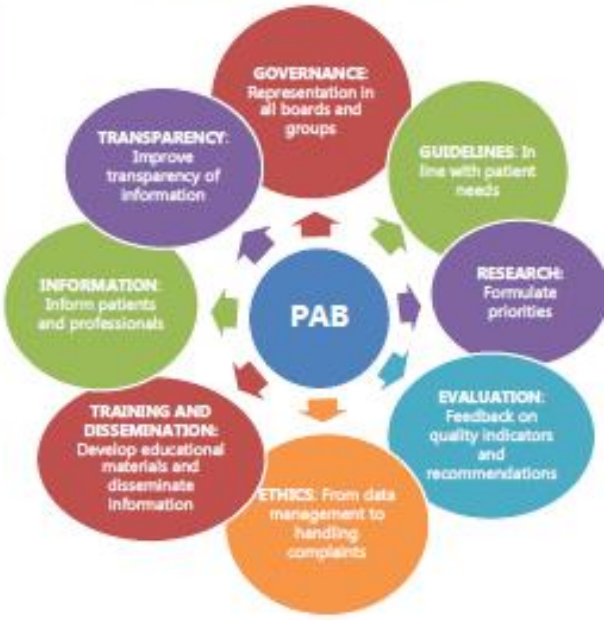
What is the Patient Advisory Board?

The EURO-NMD Patient Advisory Board (PAB) aims to ensure true and equitable representation of the patient voice in the European Reference Network.

It strives to create a bridge between EURO-NMD and the rare neuromuscular patient community so as to ensure that the needs of patients are included in the strategic and operational delivery of the ERN, and to ultimately improve access to high quality diagnosis, care and treatment.

To this end, patient representatives are also nominated for each of the EURO-NMD Specialist Groups and Advisory Boards.

What does the PAB do?



Who are the PAB members?

The EURO-NMD Patient Advisory Board comprises **10 members** from **8 countries**:

- **Chair**: François Lamy (AFM-Téléthon)
- Ria Broekgaarden (Dutch Patient Society of Neuromuscular Diseases)
- Nic Bungay (Muscular Dystrophy UK)
- Madelon Kroneman (Spierziekten Nederland, Neuromuscular Association Netherlands)
- Marisol Montolio (Duchenne Parent Project Spain)
- Jean-Philippe Plançon (French Association against Peripheral Neuropathies)
- Evy Reviers (ALS Liga Belgium)
- Piero Santantonio (MITOCON ONLUS)
- Inge Schwersenz (Deutsche Gesellschaft für Muskelkranke)
- Judit Varadine Csapo (Angyalszarnyak Hungarian Muscle Dystrophy Association)

François Lamy, Chair of the PAB

EURO-NMD PATIENT ADVISORY BOARD MEMBERS

FRANÇOIS LAMY

Chair of the Patient Advisory Board
Member of the Executive Board
Member of the Muscle Diseases Specialist Group
Contact: flamy@afm-telethon.fr

François Lamy is the father of a 10 year-old boy with Duchenne Muscular Dystrophy. He has been elected as a member of the Board of Directors of the AFM-Téléthon since 2012, and currently serves as its Vice-President in charge of research. François Lamy also serves on the Board of Directors of the Center for the Study of Stem Cells (I-Stem CECS) and the Rare Disease Information Services (MRIS).

RIA BROEKGAARDEN

Member of the Patient Advisory Board
Contact: ria.broekgaarden@spierziekten.nl

Ria Broekgaarden is a representative of Vereniging Spierziekten Nederland (VSN), a Dutch neuromuscular patient organisation. She coordinates diagnostical bound groups and is a project leader for SMA, Pompe Disease and Duchenne Muscular Dystrophy. She is also a Founder, Board Member and adviser of the International Pompe Association, a former FSHD Board Member and Founder of FSHD Europe. Currently, she serves as a Board Member of SMA Europe. She is a former ENMC Board Member and President. Ria Broekgaarden has been involved in TREAT-NMD. She has experience with EU projects and drug development, from first development to availability.

NIC BUNGAY

Member of the Patient Advisory Board
Contact: N.Bungay@musculardystrophyuk.org

Nic Bungay joined Muscular Dystrophy UK in 2007 and is the current Director of Campaigns, Care and Information. He is responsible for the development of specialised health care policy for people with neuromuscular conditions, among other things. He set up and oversees the charity's 20 regional neuromuscular patient support and information groups which guide the charity's policy development and highlight ways that service users feel specialised neuromuscular services could be improved. Nic Bungay is also a public member of the NHS England Neuroscience Clinical Reference Group, a member of the Multi-Systems Disorders Clinical Reference Group and the Paediatric Neurosciences Clinical Reference Group.

MADELON KRONEMAN

Member of the Patient Advisory Board
Member of the Ethics Committee
Member of the Muscle Diseases Specialist Group
Contact: madelonkroneman@gmail.com

Madelon Kroneman was diagnosed with Myofibrilar Myopathy (Desminopathy). Her disease started at the age of 33. She is presently a member of the diagnosis working group "Muscular dystrophies and distal myopathies" of Vereniging Spierziekten Nederland, a Dutch neuromuscular patient organisation. She chaired this working group between 2002 and 2016. She is now the editor of the working group newsletter. She also follows scientific developments and is involved in reviewing scientific research concerning muscular diseases, both for funding bodies and for research requiring the involvement of members.

MARISOL MONTOLIO

Member of the Patient Advisory Board
Member of the Muscle Diseases Specialist Group
Member of the Research Board
Contact: research@duchenne-spain.org

With more than 15 years of research experience, Marisol Montolio is the Scientific Director of the Duchenne Parent Project Spain and Curator of the Patient Registry, promoting scientific research in Duchenne and Becker Muscular Dystrophy. Marisol Montolio is a Biologist and has a PhD in Neuroscience from the University of Barcelona. She has worked in the identification of drugs for neurological diseases, including genetic and degenerative diseases, and later acquired extensive experience in coordinating and executing research collaborations between academic groups, private companies, foundations and associations on the research of rare diseases. She is also adjunct professor at the University of Barcelona.

JEAN-PHILIPPE PLANÇON

Member of the Patient Advisory Board
Co-chair of the Educational Board
Member of the Peripheral Nerve Diseases Specialist Group
Contact: Jean-philippe.plancon@wanadoo.fr

Jean-Philippe Plançon suffers from rare peripheral neuropathy disease.
He founded the French Association against Peripheral Neuropathies in 2006 and the French Alliance of Rare Peripheral Neuropathies Patients Associations in 2016. For 10 years, Jean-Philippe Plançon worked as registered nurse and health manager. He holds an MSc and also conducted research in the role of adapted physical activity in patients suffering from chronic inflammatory demyelinating polyneuropathies. He taught at the Sorbonne Paris Cité University-Paris 13 (UFR Health, Medicine and Human Biology) and is a trained expert patient in therapeutic education program. He also holds a PhD in law with the Laboratory of Medical and Health Law, and works on the issue of fundamental rights to the protection of health in rare diseases.

EVY REVIERS

Member of the Patient Advisory Board
Member of the Ethics Committee
Member of the Motor Neuron Diseases Specialist Group
Contact: evy@alsliga.be

Evy Reviers is the daughter of a patient living with Amyotrophic Lateral Sclerosis (ALS). As CEO of ALS Liga Belgium since 2006, Evy Reviers performs the general management of the organisation and coordinates the support to Belgian ALS patients. She has obtained several priority procedures to increase the quality of life of ALS patients in Belgium. At the European level, she is the Chairwoman of EUpALS, the European Organisation for Professionals and Patients with ALS, and defends the rights of ALS patients in scientific advice procedures at EMA. She is also a member of the ALS Dream Tem, the Rare Diseases Organisation Belgium, the Drug Information Association, and euro. Between 2010 and 2016, she was a member of the Board of Directors of the International Alliance of ALS/MND Associations.

PIERO SANTANTONIO

Member of the Patient Advisory Board
Member of the Mitochondrial Diseases Specialist Group
Contact: P.Santantonio@igeam.it

INGE SCHWERSENZ

Member of the Patient Advisory Board
Contact: inge.schwersenz@dgm.org

Inge Schwersenz is the mother of two children with Spinal Muscular Atrophy. Her younger child passed away in 1984, at four years-old. Her older son is alive and a computer scientist. Inge Schwersenz is a retired medical doctor specialised in Anaesthesiology. In 2001, together with her husband, she founded the German initiative “Forschung und Therapie fuer SMA” within the Deutsche Gesellschaft fuer Muskelkranke. Their goal is to fund research in the field of SMA and educate patients and the public about SMA. One of its founding members in 2006, she is still a Board Member and Treasurer of SMA Europe. She is also a member of the Drug Information, Transparency and Access Taskforce at EURORDIS and a member of the Oversight Committee of the SMA Patient Registry.

JUDIT VARADINE CSAPO

Member of the Patient Advisory Board
Member of the Muscle Diseases Specialist Group
Contact: juditcsapo@yahoo.com

Judit Varadine Csapo’s younger son was diagnosed with Facioscapulohumeral Muscular Dystrophy (FSHD) 8 years ago. After the genetic testing of the family, Judit Varadine Csapo learnt that she also is affected by the same disease. At the time, there was no information about

rare diseases in Hungarian and no patient organisation in Hungary. Subsequently, she founded Angyalszarnyak, the Hungarian Muscle Dystrophy Association. With approximately 500 members, the association aims at informing patients in Hungarian and helping them to find each other.

EURO-NMD PATIENT REPRESENTATIVES

BOBBY ANCIL

Member of the Educational Board
Contact: B.Ancil@musculardystrophyuk.org

DIMITRIOS ATHANASIOU

Member of the Advisory Committee
Contact: dathax@gmail.com

When his son was diagnosed with Duchenne Muscular Dystrophy, Dimitri Athanasiou became a fulltime international patient advocate in Duchenne and in rare diseases. Dimitri Athanasiou founded the Parent Project of MDA HELLAS in Greece. Currently, he is a Board Member of the United Parent Project Muscular Dystrophy (UPPMD), a European Medicines Agency Patient Expert in Duchenne Muscular Dystrophy, and co-chairs EFGCP's Children's Medicine Working Party (CMWP). He is DIA's EuroMeeting 2017 Program Committee Member. He is also a member of EURORDIS, a EUPATI fellow, and a member of EUPATI's Course Committee. He established the Greek EUPATI National Liaison Team.

MARTIN BOBROW

Member of the Genetics Specialist Group

Martin Bobrow became an Honorary Life President of Muscular Dystrophy UK in 2013. Professor Bobrow has made an outstanding contribution in the field of human genetics. He served as Chair of the Board of Trustees of the then Muscular Dystrophy Campaign from 1995 to 2010. He held senior roles in higher education and clinical posts within the National Health Service. He was Professor of Medical Genetics at the University of Cambridge from 1995 to 2005. He also served as a Governor of the Wellcome Trust, a Council member of the Medical Research Council, and was a founding fellow of the Academy of Medical Sciences. He was a member of the Department of Health's Gene Therapy Advisory Committee from 1989-1995 and Human Genetics Advisory Commission from 1996-1999.

SERGE BRAUN

Member of the Research Board
Contact: sbraun@afm-telethon.fr

Serge Braun is Scientific Director at AFM-Téléthon. He has 10 years of experience in academia and 10 years of experience in the biotechnology sector. He obtained his

degree in Pharmacy and a Ph.D. in Pharmacology from the Louis Pasteur University of Strasbourg, France. He was a postdoctoral fellow at the Neuromuscular Centre, School of Medicine of the University of Southern California in Los Angeles, USA, before going back to the University of Strasbourg. In 1995, he joined Transgene SA (Strasbourg, France), the largest French biotech company, where he became Vice-President in charge of Research and developed his career in the field of gene therapy of genetic diseases and of immunotherapy of cancer. He co-founded Neurofit, a contract research organisation specialized in preclinical testing of both the central and the peripheral nervous system. He was Vice-President of Alsace BioValley, the tri-national initiative, non-profit making organisation, for the development of a major biotech cluster in Europe. He is also a member of the French National Academy of Pharmacy.

JOAQUIM BRITES

Member of the Muscle Diseases Specialist Group
Contact: jbrites@me.com.pt

Joaquim Brites has a 26 year-old son with Duchenne Muscular Dystrophy. Joaquim Brites has been involved with APN, a Portuguese neuromuscular association, for more than 20 years. He was a member of APN's Board of Directors and became its President in 2012. APN focuses on direct support for neuromuscular disease patients and their families. Joaquim Brites is also the President of the General Assembly of the Portuguese Alliance of Associations of Rare Diseases since 2012 and represents Portuguese neuromuscular patients, in several European organisations. He represents Portugal in the Rare Diseases Platform ("Plateforme Maladies Rares") in France.

MENCIA DE LEMUS BELMONTE

Member of the Motor Neuron Diseases Specialist Group
Contact: menciadelemus@hotmail.com

Mencía de Lemus Belmonte is the mother of two children with Spinal Muscular Atrophy. Since her children's diagnosis in 2010, Mencía de Lemus Belmonte has been involved in activities related to patient organisations both at the national and international levels. She is the current President of the Board of Trustees of FundAME, therefore leading the organisation's strategy to better achieve its main goal of bringing a therapy to SMA patients as soon as possible while ensuring their quality of life and best care in the meantime. She is also Vice-President at SMA Europe. For the past 7 years, she has taken part to different initiatives promoting the patients' best interests such as ENMC workshops on standards of care or on clinical trials readiness, EMA workshops on SMA, national and international meetings, conferences and trainings.

EMMA DEL-REY

Member of the Mitochondrial Diseases Specialist Group
Contact: emma.delrey31@gmail.com

Emma Del-Rey has a daughter who was diagnosed with Mitochondrial Disease. Since 2008, she is the Vice-Chair of AMMI, a French Mitochondrial Disease Organisation. She organises meetings for

the regional delegate, provides information to hospitals and families, and organises events to raise funds for scientific projects and help affected families. She has also been a member of the Board of International Mito Patients (IMP) since 2011, and is in charge of an international project about pain for mitochondrial patients.

MARGUERITE FRICONNEAU

Member of the Neuromuscular Junction Defects Specialist Group
Contact: mfriconneau@afm-telethon.fr

Marguerite Friconneau was diagnosed with Myasthenia Gravis in 1985. She has been elected as a member of the Board of Directors of the AFM-Téléthon since 2007. She has also been a member of the French patient group on Myasthenia Gravis since 1987, and chaired that group from 1994 to 2009. The Myasthenia Gravis patient group is dedicated to patient care and advocacy with the scientific and medical communities as well as public authorities. Marguerite Friconneau was actively involved in the design of the French National Guidance Guide called PNDS in 2015.

MARIE-CHRISTINE OUILLADE

Co-chair of the Ethics Committee
Contact: marie-christine.ouillade@wanadoo.fr

Marie-Christine Ouillade has a daughter who has been diagnosed with Spinal Muscular Atrophy type II. Marie-Christine Ouillade has been actively involved in the activities of the AFM-Téléthon since 1996, and became a member of its Board of Directors in 2006, as well as a member of the Board of Directors of Genethon since 2007. She is also a member of the TREAT-NMD Project Ethics Council since 2007, a Board Member of the International Rare Diseases Research Consortium since 2011, and the President of SMA Europe. Between 2006 and 2012, she was a member of the Steering Committee of the French Biomedicine Agency.

FRANÇOISE PELCOT

Member of the Peripheral Nerve Diseases Specialist Group
Contact: francoise@marcy-pelcot.com

Françoise Pelcot founded the French Association against Amyloidosis together with a family friend in 1994, following the loss of Paulette. She was Vice-Chairman of the association and responsible for relationships with doctors, referral centres and pharmaceutical companies. Currently, she is a member of its Board of Directors and member of a working group of eight countries studying the creation of an international federation of associations fighting against hereditary Amyloidosis.

ALEJANDRA PEREDA

Member of the Advisory Committee
Contact: alepereda73@gmail.com

Alejandra Pereda has a son with Becker Muscular Dystrophy. She has been involved with Duchenne Parent Project Spain almost since the beginning of its reactivation 5 years ago, helping the investigation team and involved in the award of research grants as well as managing the international relationship of the association due to her international background. She has also been a board member of TREAT-NMD as a patient representative and remains a representative in EMA for the patient side on neuromuscular diseases.

FRANCISCO JAVIER PEREZ-MINGUEZ

Member of the Mitochondrial Diseases Specialist Group
Contact: javierperezminguez@gmail.com

Francisco Javier Perez-Minguez's son was diagnosed with Mitochondrial Encephalomyopathy with mutation in TK2 and passed away at 3 years old. In 2011, together with family members, Francisco Javier Perez-Minguez started the Ana Carolina Díez Mahou Foundation, to improve the quality of life of children with genetic neuromuscular diseases. At present, he is the Director of the Foundation. Since 2012, he has also been involved in the Association of Patients with Mitochondrial Pathology, and is part of its National Board of Directors as a vocal. He is the current Secretary of the National Board of Directors of the ASEM Federation, and promotes the new Strategic Plan for Neuromuscular Diseases (2017-2020). Francisco Javier Perez-Minguez has also been involved with the Spanish Federation of Rare Diseases (FEDER).

FRANÇOISE ROUAULT

Member of the Genetics Specialist Group
Contact: frouault@afm-telethon.fr

Françoise Rouault is the International Scientific Affairs Manager at AFM-Téléthon and represents the association in international scientific networks devoted to translational research in rare diseases and in neuromuscular degenerative diseases. She joined the Scientific Direction of AFM-Téléthon in 2009, and has over 25 years' experience in research in both academia and biotechnology companies. She studied Molecular Genetics at the Université libre de Bruxelles, Belgium, and performed her post-doctoral research within the Research Institute of Molecular Pathology in Vienna, Austria. Her research interests are around gene regulation and gene therapy, developing both non-viral and retroviral vectors for genetic disorders. In 1993 she joined Transgene SA in Strasbourg where her activity resulted in the first non-viral vector to be selected by AFM-Téléthon for clinical development for DMD.

JACQUES SALAMA

Member of the Neuromuscular Imaging Specialist Group
Contact: jsalama@hotmail.fr

Jacques Salama is the father of a young man with Duchenne Muscular Dystrophy. After his son was diagnosed with DMD in 1990, he joined the AFM-Téléthon. He later became its General Delegate for scientific policy, and joined the Board of Directors of Genethon in 1996. In 1999, he became the General Secretary of the Institute of Myology in France, an institute dedicated to research, care and education on muscle function and muscle diseases. There, he worked closely with the scientists developing medical imaging applied to muscle diseases. To this day, he appreciates the value of these new techniques of imaging to provide the possibility of non-invasive tools for diagnosis and follow-up of emerging therapies; they are of fundamental importance for the future development of drugs.

SANDRINE SEGOVIA-KUENY

Member of the Neurophysiology Specialist Group
Contact: ssegovia-kueny@afm-telethon.fr

Sandrine Segovia-Kueny is the Medical Director at AFM-Téléthon. She is a doctor of medicine, graduate of the University of Nice, France, and holds an Executive Advanced Master in Strategy and Management of Health Industries from the ESSEC Business School, France. Sandrine Segovia-Kueny also brings 15 years of experience in the public sector, including several years as a Deputy General Director in the Health Regional Agency in Lille, as an Environmental and Public Health Director in the Health Regional Agency in Orleans, as an Health Advisor in the French Ministry for sustainable development and a Medical Advisor in the General Health Direction in Paris. Sandrine Segovia-Kueny is also a Board and an Advisory Committee member in various public organisations.

DANIEL TANESSE

Member of the Peripheral Nerve Diseases Specialist Group
Contact: tanesse@free.fr

Daniel Tanesse and his wife both suffer from Charcot-Marie-Tooth. Daniel Tanesse first joined Charcot-Marie-Tooth France as a Regional Delegate 20 years ago. He later became its Referent for Congress and now serves as its Vice-President. He is also one of the founders of the CMT-Europe Consortium which aims, *inter alia*, at supporting all European CMT associations, enhancing patient representation, and helping researchers and laboratories to find volunteers for future therapeutics trials. He has himself been and still is involved in therapeutics trials for CMT: as a member of the ethical committee for the acid ascorbic trial (2004), as an investigator for the PXT-3003 trial (Phase III still current), and as a scientific and technical correspondent with the candidate drug called IFB-088 from InFlectisBioScience laboratory.

DIANA VAN DER MEIJ-KIM

Member of the Muscle Diseases Specialist Group
Contact: dvdmeij@yahoo.co.uk

Diana van der Meij-Kim has a son who was diagnosed with FSHD at the age of 10. She subsequently took an active position in promoting the research for FSHD and within a year she became a member of the FSHD working group of the Dutch patient organisation VSN and a Board Member of the Dutch FSHD Foundation. As a member of Dutch patient organisations, Diana van der Meij-Kim joined FSHD Europe and was elected its President in 2016.

GERARD WELLENBERG

Member of the Muscle Diseases Specialist Group
Contact: gerardwellenberg1@gmail.com

Within Gerard Wellenberg's family, the hereditary muscular disease Myotonic Dystrophy type-1 (MD1) has been diagnosed in 2001. From 2001 on, he lost one niece and one brother. His mother passed away in 1991 at the age of 58. Two other family members still suffer MD1. Gerard Wellenberg has more than 35 years of experience in the field of human and animal disease surveillance, control and eradication programs, epidemiology and the management of many research projects in the Netherlands and abroad. He has been active in the field of MD1 since 2012. He is the Chairman of the Dutch MD1 Action Team, which is involved in fundraising activities and raises Dutch citizens' awareness on the importance of MD1 research and on the impact of MD1 within families.

DOMINIC WELLS

Member of the Neurophysiology Specialist Group
Contact: dwells@rvc.ac.uk

Dominic Wells qualified from Cambridge University as a veterinary surgeon in 1984 together with a BA in Applied Biology. After several years in general practice in Nottinghamshire he attended the University of Wyoming where he obtained his Ph.D. in comparative physiology. In 2010 he became Professor in Translational Medicine at the Royal Veterinary College in London. His research activities focused on the physiology of the muscle and genetic transfer in the skeletal muscle, in particular within the ambit of development of therapies for Duchenne type Muscular Dystrophy. He also engages in experimentation concerning other potential DMD and amyotrophic lateral sclerosis therapies. Dominic Wells is also the Vice-Chair of Muscular Dystrophy UK's Medical Research Committee.

Board/Committee	Chair	Patient representatives
Executive Board	Kate Bushby	François Lamy (AFM-Téléthon, France) flamy@afm-telethon.fr
Ethics Committee	Jenny Versnel (Muscular Dystrophy UK) j.versnel@musculardystrophyuk.org Marie-Christine Ouillade (SMA Europe/AFM-Téléthon, France) mcouillade@afm-telethon.fr	Evy Reviers (ALS Liga, Belgium) evy@alsliga.be Madelon Kroneman (Vereniging Spierziekten Nederland) madelonkroneman@gmail.com
Advisory Committee		Dimitrios Athanasiou (MDA Hellas, Greece) dathax@gmail.com Alejandra Pereda (Duchenne Parent Project Spain) alepereda73@gmail.com
Educational Board	Andoni Urtizberea (APHP, France) ja.urtizberea@free.fr Jean-Philippe Plançon (AFNP, France) jean-philippe.plancon@wanadoo.fr	Bobby Ancil (Muscular Dystrophy UK) b.ancil@musculardystrophyuk.org
Research Board	Hanns Lochmüller hanns.lochmuller@newcastle.ac.uk	Marisol Montolio (Duchenne Parent Project Spain) research@duchenne-spain.org Serge Braun (AFM-Téléthon, France) sbraun@afm-telethon.fr
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Peripheral nerve diseases	Mary Reilly m.reilly@ucl.ac.uk	Jean-Philippe Plançon (AFNP, France) jean-philippe.plancon@wanadoo.fr Daniel Tanesse (CMT-France) tanesse@free.fr Françoise Pelcot (French Association Against Amyloidosis) francoise@marcy-pelcot.com
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Mitochondrial Diseases	Rita Horvath rita.horvath@newcastle.ac.uk	Piero Santantonio (MITOCON ONLUS, Italy) p.santantonio@igeam.it Emma Del-Rey (French Association for Mitochondrial Diseases) emma.delrey31@gmail.com Francisco Javier Pérez-Mínguez (Fundación Ana Carolina Díez Mahou, Spain) javierperezminguez@gmail.com
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Neuropathology	Bjarne Udd bjarne.udd@netikka.fi	
Genetics	Alessandra Ferlini fla@unife.it	Françoise Rouault (AFM-Téléthon, France) frouault@afm-telethon.fr Martin Bobrow (Muscular Dystrophy UK)

RED: members of the Patient Advisory Board