

# EUROPEAN DYSTONIA FEDERATION



## EDF Activities and Projects 2003 - 2010

**EDF annual conferences** – The Annual Conference brings together the leaders of national dystonia patients groups to hear international speakers on various useful topics, to participate in discussions and to learn from the experiences of their colleagues. The delegates are then able to bring this information back to their ‘home’ groups. Discussions at an EDF annual conference a few years ago brought together several Scandinavian national groups, who created a project to study dystonia in children and young people. This has been running for two years and is a good example of direct EDF member collaboration.

**David Marsden Award** – This award started in 2003 and is presented every two years. It has raised considerable interest among dystonia researchers which encourages more research on dystonia for the eventual benefit of patients. In addition, the Award presentation ceremonies at the very large-scale EFNS congresses [www.efns.org](http://www.efns.org) (more than 5,000 neurologists register for this congress) brings much good publicity for EDF, its member organisations and dystonia itself. The Award will be presented for the 5<sup>th</sup> time at the International Dystonia Symposium in Barcelona, in 2011.

[http://www.dystonia-europe.org/europe/Link\\_Awards/2010\\_awards.htm](http://www.dystonia-europe.org/europe/Link_Awards/2010_awards.htm)

**Medical and Scientific Advisory Board** – For many years, EDF has had a small Medical Advisory Board, which has provided assistance with occasional scientific advice and in the adjudication of the papers submitted for the David Marsden award. The membership of this group of advisers is being increased over the next year, to bring in more expertise and cover more specialist areas. Currently, the members are: Prof Alberto Albanese, Milan; Prof Alfredo Berardelli, Rome; Prof Kailash Bhatia, London; Prof Andres Ceballos-Baumann, Munich; Prof Joachim Krauss, Hannover; Prof Maja Relja, Zagreb; Prof Eduardo Tolosa, Barcelona; Dr Tom Warner, London.

**Stem Cell research** – In 2005, EDF was centrally involved with EFNA in organising a conference for 500 representatives of all pan-European ‘stakeholders’ in the stem cell research debate. “Stakeholders” included patients, scientists, religious groups, politicians and the media. We also organised a survey of neurological patients across Europe. The European Commission gave a grant of €500,000 to EFNA for the project. The aim was to give stakeholders proper information about all aspects of stem cell research, and ensure that the views of neurological patients were properly represented to political decision-makers.

Between 85 and 90% of those who attended the conference or returned the survey voted for stem cell research to continue to be supported. EDF has no position on this matter but merely presented the results of the survey and the conference voting, to the Commission and to the Members of the European Parliament over several years following the conference.

These results helped to ensure that stem cell research continued to be supported at the EU level, reflecting the wishes of the huge majority of neurological patients across Europe, including many with dystonia.

**Threat to the continuation of MRI scans across Europe - EU Directive on electromagnetic radiation exposure** - In partnership with the European Society of Radiologists and a number of Members of the European Parliament, EDF and EFNA campaigned on behalf of the patients who would be affected by a 2004 EC directive from D-G Employment. This directive was designed to protect employees by imposing limits on occupational exposure to electromagnetic radiation, but it also had the unintentional effect of making it impossible for healthcare specialists to carry out MRI and other diagnostic scans from the original date of implementation in 2008.

After lobbying from the patient/radiologists partnership, the Commission announced a delay of the implementation of the directive until 2011 to allow assessment of more up-to-date research on the subject. MRI scans are often used for a variety of reasons, by dystonia specialists.

[http://www.myesr.org/cms/website.php?id=/en/eu\\_affairs\\_research/alliance\\_for\\_mri.htm](http://www.myesr.org/cms/website.php?id=/en/eu_affairs_research/alliance_for_mri.htm)

---

**Paediatric Movement Disorders Symposia** – EDF has sponsored sessions at two of these symposia over the past few years, to stimulate interest in dystonia in children.

**Hamburg conference – 2008** – This was the first international medical conference in Europe for 15 years, solely on dystonia, and was organised by EDF. Its success has stimulated much interest in research into the illness, with a number of other international meetings now being proposed.

**Barcelona conference – 2011** – The EDF Board decided that a follow-up event to the Hamburg meeting should be held in 2011, and arrangements are well developed now for a symposium organised jointly with the Dystonia Coalition. This revives the original and definitive series of international dystonia meetings, which was started in 1976 by Professors David Marsden (London) and Stanley Fahn (New York). Such an important medical conference will give considerable impetus to developments in dystonia diagnosis and treatment and dystonia research generally. [www.internationaldystoniasymposium.org](http://www.internationaldystoniasymposium.org)

**Dystonia Coalition** - This is basically a network of scientific centres in North America and Europe, collaborating on dystonia research, and funded by a large grant from the USA National Institutes of Health (NIH). The patient groups based in North America are members of the Coalition, and EDF has also joined, to ensure that all EDF member countries are represented, and to show our support for such a worthwhile scientific dystonia initiative. <http://rarediseasesnetwork.epi.usf.edu/Dystonia/index.htm>

**Dystonia Management Guidelines** – The EDF Executive Director was invited to join the scientific panel which created the first European international guidelines for dystonia, in 2005. A revision was required in 2009 and the Executive Director was again invited to be a member of the review panel.

These guidelines are published for medical professionals by the Movement Disorder Society and the European Federation of Neurological Societies. They provide information from the latest scientific knowledge to encourage the highest standards of diagnosis and treatment of dystonia across Europe.

**European Federation of Neurological Associations (EFNA)** - is a high-level alliance of patient organisations, covering the spectrum of neurological illness. Its members and affiliates are the pan-European federations of national patient groups representing the different neurological disorders. Its mission is to provide maximum opportunities for people living with neurological conditions. EDF is an active member of EFNA.

EFNA achieves its aims by: promoting partnerships and projects with related organisations as well as with medical and healthcare professionals; by organising and participating in conferences; and campaigning to influence decision-makers at the European level. The concept of EFNA as a coalition of patient federations, which then addresses generic neurological issues with one voice, receives a positive response from politicians and others. [www.efna.net](http://www.efna.net)

**Measuring Health and Disability in Europe (MHADIE)** – The objective of this EC-funded project was to show that WHO ICF (International Classification of Functioning, Disability and Health) can be used with confidence internationally as a model for aspects of medical care, the production of reliable and useful disability statistics and social integration. EDF was prominent with EFNA in the work to disseminate the results of this scientific study. [www.mhadie.it](http://www.mhadie.it)

**European Brain Council (EBC)** - is a co-ordinating council formed by pan-European medical organisations in neurology, neurosurgery, psychiatry, basic brain research (neuroscience), as well as patient organisations and industry. It therefore represents a vast network of patients, doctors and scientists. The great breadth of the EBC membership allows it to work in close partnership with the European Commission, the European Parliament and the World Health Organisation (WHO), as well as other decision-making bodies.

Until 2003, Brain illness had not been considered to be as important for public health planning as heart disease, cancer or some other areas of medical research. In that year, EBC published its first study, showing conclusively that 35% of all health budgets is spent on Brain diseases. Since then, the amount of funding available for brain research (including dystonia) has increased substantially. In the EU Research

Framework Programme 6 the figure allocated to Brain research projects was €260M. In Framework Programme 7, it has exceeded €400M.

EDF is centrally involved in EBC, with our Executive Director being one of the EBC Officers.

[www.europeanbraincouncil.org](http://www.europeanbraincouncil.org)

**European Year of the Brain – 2014.** Starting in 2009, EBC began to raise support from many organisations, to convince the three European Institutions (Parliament, Commission and Council of Ministers) to denote a year to be “European Year of the Brain”. This will create a huge amount of interest in brain illnesses in each country of Europe, and will allow many projects to focus on all aspects of individual brain illnesses, like dystonia. It will also bring much greater opportunities for funding of research into dystonia and other neurological conditions.

The years 2011, 2012 and 2013 have been allocated to other concepts and the European Commission is now supporting proposals for a European Year of the Brain in 2014. Final confirmation is expected in late 2011.

**EFPIA Think Tank** - European Federation of Pharmaceutical Industries and Associations (EFPIA) is the federation of national pharmaceutical industry societies and holds quarterly meetings of patient group and company representatives (the “Think Tank”) to discuss matters of common interest. Great care is taken to ensure that there is no possibility of any conflicts of interest or undue influence arising as a result of this forum. EDF is represented by the Executive Director at these meetings.

<http://www.efpia.org/Content/Default.asp?PageID=491>

**Innovative Medicines Initiative** – The Innovative Medicines Initiative (IMI) is Europe's largest public-private initiative aiming to speed up the development of better and safer medicines for patients. IMI is a joint undertaking between the European Commission and the pharmaceutical industry association, the European Federation of Pharmaceutical Industries and Associations (EFPIA). Each of the two partners (the EC and EFPIA) has provided €2Bn funding for projects.

IMI supports collaborative research projects and builds networks of industrial and academic experts in order to boost pharmaceutical innovation in Europe.

The EDF Executive Director was an invited speaker at several scientific meetings, during the early stages of this huge project to stimulate new medicines for Europe. His role, at the request of the European Commission, was to ensure that the scientists heard clearly that the position of patients in the IMI process is of paramount importance. [www.imi.europa.eu](http://www.imi.europa.eu)

**Dystonia Medical Research Foundation (DMRF)** – In recent years, contacts and collaboration between EDF and DMRF have been re-established and strengthened. As co-members of the Dystonia Coalition, DMRF is giving us strong support in the arrangements for the Barcelona conference in 2011. Further collaboration between our two organisations will be discussed soon. [www.dystonia-foundation.org](http://www.dystonia-foundation.org)

**Movement Disorder Society (MDS) – European Section** – Over several years, EDF has had a good relationship with this international medical organisation. This has allowed us to hold the presentation ceremonies of the David Marsden Award during their movement disorder session at the EFNS annual congress. They also have supported our medical conferences in Hamburg and, next year, in Barcelona – by circulating the information to their members and publicising the events.

EDF has had an exhibition booth at many MDS congresses, which enables us to promote the work of our members. It also allows us to circulate publications of interest to movement disorder specialists, especially to those of the country where the congress takes place. [www.movementdisorders.org](http://www.movementdisorders.org)

**European Federation of Neurological Societies (EFNS)** – EDF has been involved with EFNS for many years, and has had an exhibition booth at every EFNS congress since 1997. These congresses attract more than 5,000 neurologists every year, from all over Europe and beyond, including many movement disorder specialists. EFNS publicised our Hamburg medical conference in its newsletter and on its website, and will do so again for the Barcelona event in 2011.

Our Executive Director is a member of the EFNS Liaison Committee, and of its Education Committee.  
[www.efns.org](http://www.efns.org)

**EFNS - The Good Life** – Since 2006, EDF has worked within EFNA to organise the “Good Life” session at the annual EFNS congress. This event provides the neurologists with insight into the psychological aspects of music and dance which often help neurological patients to manage their illness more effectively. Often, this is achieved by re-discovering old skills or developing new ones in performance, or simply enjoying the performances of others.

At the Good Life session at the 2012 EFNS congress in Stockholm, the focus will be on dystonia patients, with Prof Eckart Altenmueller, Hannover, chairing the 2 hour event.

**Medtronic Foundation Workshops** – The Medtronic charitable Foundation has now organised three workshops for the leaders of patient groups in Europe, over the past 6 years. These concentrate on helping the principal officers of these groups to develop their practical skills in running their organisations. A few weeks ago, more than 50 patient group leaders, including 12 from EDF member groups, attended the latest of these events, over three days in Brussels.

The EDF Executive Director serves on the organising committee for these workshops.

**Medtronic Information for Dystonia Patients** – The second edition of Medtronic’s booklet of information for dystonia patients will be published soon. This has been compiled by a task force of medical and surgical specialists, as well as the President and Executive Director of EDF.

EDF was also involved in the preparation of the first edition some years ago, and our involvement is specially noted in each publication. The booklets will be issued in English and also translated into a number of other languages.

---

## **EUROPEAN DYSTONIA FEDERATION**

Secretariat: 69 East King Street, Helensburgh, G84 7RE, United Kingdom

Tel & Fax: +44 1436 678799

Email: [sec@dystonia-Europe.org](mailto:sec@dystonia-Europe.org)

[www.dystonia-europe.org](http://www.dystonia-europe.org)

Executive Director: Alistair Newton

---