



MEMBERS' NEWSLETTER

EUROPEAN DYSTONIA FEDERATION

JANUARY 2011

Message from Monika Benson, EDF President

Dear Friends,

The time has once again come to summarise the year that has gone by and welcome a new one. It has been another busy and exciting twelve months in the life of our Federation.

2010 started off with a generous invitation from the Dystonia Medical Research Foundation (DMRF) for our Executive Director and me to attend their annual conference in Scottsdale, Arizona in February. We were able to observe their Medical and Scientific Advisory Committee's process for selection of applications to receive research awards for 2010, and to spend time talking to the scientists as well as the members of the DMRF Board.

In May EDF was also represented at the Dystonia Treatment Congress in Hannover. Here we had an exhibition booth to distribute our leaflets and the announcement of the Barcelona 2011 medical conference. We also took advantage of the great opportunity to meet company sponsors, other patient organisation representatives and many dystonia specialists. EDF provided a member of the panel for the final discussion of the conference.

I was very happy when the board agreed to my idea of holding the EDF annual conference and General Assembly in Malmö in Sweden. I truly enjoyed the whole process of finding the venue, choosing menus, contacting speakers, selecting a social event, raising local funds and all the other work that came along with it. And I was very pleased to see so many participants: speakers, sponsors, delegates, and members of the Swedish and Danish dystonia associations – all together, 60 people participated in the three-day-event.

I was also very pleased that former president of EDF, Didi Jackson and her husband Barry joined us in Malmö. Due to Didi's long-time commitment and dedicated work for people with dystonia, she was appointed an Honorary Member of EDF. She received a diploma as well as flowers from EDF and from our German member organisation Deutsche Dystonie Gesellschaft.

At the formal General Assembly in Malmö, I was again honoured to be elected to the Board of EDF for a second term of three years. At the Board meeting, following the GA, I was re-elected as President for this period. I would like to thank you once more for your support and trust which allows me to continue to work for dystonia patients through our Federation.

In October I attended the Dystonia Coalition's Annual Meeting in Atlanta, to confirm its partnership with EDF for the Barcelona symposium in 2011, and to publicise the event to the scientists in the Atlanta audience. You can read more about the Coalition later in this newsletter.

At its recent meeting in November, the EDF board was sorry to receive Alan Tamlyn's resignation. Alan has been a Board member of The Dystonia Society for many years and has supported the activities of EDF during that time. He was elected to the EDF Board in 2009 and we thank him warmly for all of his work for dystonia patients over many years but, especially for his efforts as an EDF Board member during the past year, and for his earlier support. We offer him our best wishes for the future.

Ahead of us is another exciting year for EDF with the upcoming **5th International Dystonia Symposium** in Barcelona in October 2011. The arrangements are well under way, although many tasks are yet to be completed. A report can be found later in this Update.

Our **EDF 2011 Annual General Assembly** will take place in Barcelona on Sunday 23 October, following the medical symposium. More details will be sent to member groups in the spring.

I know that the individual members of your organisations are grateful for all the dedicated work you do on their behalf and I would like to thank you – the leaders of our member groups - for your support for your Federation. The activities at the national level and at the European level complement one another to benefit dystonia patients. I hope that you will see clearly, from the list attached to this newsletter, just how much EDF has done for the benefit of your members in the past few years.

I look forward to working with all of you in the twelve months ahead and, on behalf of the board of EDF, I wish you all a successful and fulfilling year in 2011.

Monika Benson
President

EDF NEWS in BRIEF

Philip Eckstein leaves the Dystonia Society

Thank you Philip! - In November The Dystonia Society organised a party for Philip Eckstein who, after almost 6 years as their CEO, is moving on. The event took place in the TDS premises in London and was attended by all of their staff and board members as well as me and Alistair Newton from EDF, plus many others of Philip's colleagues and contacts.

The first time I met Philip was 4 years ago at a meeting of the European Dystonia Federation in Brussels and he was then co-opted secretary to the board of EDF. The following year I was also on the board and we were in the same team working together for people with dystonia all over Europe. And I had fun working with Philip!

Being the 'captain' of our team, I was very sad last year when I heard about his resignation and my team losing such an important fellow player. He was one of our key Board members and we miss his excellent ability with the pen, his creative ideas and good advice, his ambition to move forward, his positivity and enthusiasm.

On behalf of the EDF board and all of our members I thank Philip for all the work and time he has dedicated to dystonia patients and to our Federation, and we send him our best wishes for the future.

Monika Benson

Didi Jackson receives Honorary Membership of EDF

At the 2010 General Assembly in Malmö, EDF's former President Didi Jackson was elected as our first Honorary Member. She and her husband Barry were EDF's guests, and travelled from Hamburg to be with us. Didi said that it had been an honour to serve as EDF President, and she looked forward to seeing EDF continue to progress and continue its international activities to support the work of the national groups.

Future Annual EDF Member Conferences and General Assemblies

Apply now to host the EDF annual meeting - Following the success of the 2010 Annual conference and GA in Malmö, the EDF Board has decided to hold the annual conferences and General Assemblies in the different countries of its member groups. Your group can now apply to host the EDF annual meeting and General Assembly in the autumn of 2012. The application should state suggestions for venue, social event and possible speakers of your country.

Do not miss this opportunity of showing your country, your city, your culture and having some of your national dystonia specialists on the speakers' list. Submit your application to Monika Benson by April 30th 2011 at monika.benson@telia.com

Important new dystonia research initiative in Belgium

FDR and Belgian Government in joint dystonia research funding agreement

The Foundation for Dystonia Research (FDR), based in Antwerp, Belgium, has initiated the most ambitious research programme in Europe so far, in an agreement with the University of Leuven and the Belgian government. This will provide joint funding of €2M to establish a new department at the world-renowned University. The new department will concentrate on research to establish the cause of dystonia, and the process of recruiting a principal investigator is currently under way. Greet Ruelens and Lieve Van Gorp, the Directors of FDR, act as EDF's Research Advisers and spoke enthusiastically about the project at EDF's 2010 General Assembly in Malmö. It is a very serious and well-structured project to lift dystonia research in Europe on to a higher platform. EDF warmly wishes FDR all success in this venture.

For more information follow this link:

<http://www.vib.be/en/news/Pages/Ruelens-Van-Gorp-Foundation-and-VIB-K-U-Leuven-establish-chair-for-research-into-the-neurological-disorder-dystonia.aspx>

The Dystonia Coalition – What is it?

The Dystonia Coalition – EDF's partner in the 5th International Dystonia Symposium, 2011

The Dystonia Coalition is a collaboration of medical researchers and patient advocacy groups, and is supported by the Office of Rare Diseases and The National Institute of Neurological Disorders and Stroke at the National Institutes of Health (NIH) in the USA. Its mission is to increase the speed of progress in dystonia research, to find better treatments and a cure. It will also promote the development of better approaches to diagnosis and other aspects of medical investigation.

The work of the Coalition is co-ordinated in Atlanta, Georgia, and already includes more than 30 specialist clinical dystonia centres in North America, with several in Europe. These are: Hannover, Milan, Bari, Brussels, Paris, London, Leipzig, Lübeck. More centres are expected to join in the near future.

The Coalition has the supporting membership of nine US patient advocacy groups and European Dystonia Federation has now joined them. This will ensure that EDF's member groups are represented in this extremely important international dystonia research forum. <http://rarediseasesnetwork.epi.usf.edu/dystonia/>

EDF Medical and Scientific Advisory Board

As mentioned in the summer 2010 Update, EDF has begun to restructure its panel of medical and scientific advisers, and some new appointments were made during the late summer of 2010. The current list of members of this board is shown at the end of this newsletter. Further appointments are planned in 2011 and will be reported in due course.

European Year of the Brain

Many of EDF's member groups responded immediately to a call for support of the European Brain Council's efforts in Brussels for 2013 to be allocated as European Year of the Brain (EYOB). This process involves lobbying with all Directorates-General of the European Commission, to find a 'champion' and then get more support from other D-Gs, before persuading the Parliament itself and the Council of Ministers. It is a long and complicated business, which is not well-understood by any of those involved - even the EU officials, and success is not yet assured.

For practical reasons, and to give a longer time to prepare activities and projects for EYOB, the European Brain Council (EBC) and its supporters are now pushing for 2014. Much support has been shown already by various sections of the European Commission and in the Parliament. A European Year of the Brain would bring enormous benefits for dystonia patients, as there would be much more funding available for international research and all EU member countries would be involved in organising events, awareness and research at the national level. EDF will bring you more news of this tremendous initiative as it happens! EDF will bring you more news of this tremendous initiative as it happens! www.europeanbraincouncil.org

The European Brain Council has become an important and useful collaborator with the European Commission and has succeeded in substantially increasing the amount of funding available for research into all aspects of the brain, including dystonia. Over the past 10 years, EDF's Executive Director has been closely involved with the activities of EBC and works alongside the many academic institutions and the pharmaceutical and medical device industries which are EBC members. Another important area of influence in which dystonia is promoted.

Patient leaders' workshop – November 2010

Medtronic Foundation – Patient group leaders' workshop – Brussels, November 2010

The Medtronic Foundation held the third in its series of workshops (2006, 2008 and 2010) to provide practical assistance to patient group leaders across Europe. Our Executive Director was again a member of the organizing committee and attended the workshop with the EDF President and the leaders of EDF groups from Italy, Germany, Norway, Switzerland and

UK. A report has been provided by Merete Avery, Chairwoman of Norsk Dystoniforening, and is published later in this newsletter. <http://www.medtronic.com/foundation/index.html>

Children's dystonia day in London

Children's Dystonia Day – The Dystonia Society, UK - In October, 2010, TDS held a successful one-day event in London for parents and children – the first for ten years in the UK, and a full report is provided later in this edition of Update.

What's happening in 2011?

The 2011 **Movement Disorder Society Congress** takes place in Toronto, Canada, in June and, if funding allows, EDF and its member groups will have a booth there to publicise your work and the Barcelona symposium.

<http://www.movementdisorders.org/congress/congress11/>

EFNS Congress – Budapest - Every year, EDF also has a booth at the **congress of the European Federation of Neurological Societies (EFNS)**, where we are involved through our work in EFNA (European Federation of Neurological Associations). The 2011 congress will take place in Budapest. In 2012, in Stockholm, EDF and its members will feature strongly at the best-attended session of the congress – The Good Life. There, the programme will focus on musician's dystonia, with Professor Eckart Altenmueller of Hannover, leading the event.

<http://www.efns.org/15th-EFNS-Congress-Budapest-2011.286.0.html>

International dystonia medical conference, Barcelona - EDF and the Dystonia Coalition have entered a partnership to organise the **5th International Dystonia Symposium – Barcelona, 20/22 October 2011**. The Dystonia Medical Research Foundation (DMRF) is also providing support for the organisation of the meeting. The collaboration - proposed by the Dystonia Coalition has brought even more scientific 'weight' to the meeting which EDF was already planning, and we believe it will be a major event in the history of dystonia in Europe. This revival of the original series of International Dystonia Symposia, which began in 1976, will bring together several hundred dystonia specialists and will provide enormous stimulus for dystonia research across the world. Fifty three distinguished dystonia experts from Europe, North America and Japan have accepted invitations to make presentations or chair sessions, over the three days of the symposium.

We expect this to be a really exciting event, which will build on the success of our last medical conference in Hamburg, 2008, and push forward the dystonia research effort across the world. Website information at:

www.internationaldystoniasymposium.org

EDF Annual General Assembly - Will take place in Barcelona, on Sunday 23 October 2011, after the 5th International Dystonia Symposium.

David Marsden Award 2011 - The next David Marsden Award will be decided in the summer of 2011, and the Award will be presented by the EDF President at the 5th International Dystonia Symposium in Barcelona, on October 22nd. EDF began the series of Awards in 2003, and these have continued every two years, with our Medical and Scientific Advisory Board adjudicating on research papers from young scientists. The prize will be €5,000 in 2011 and the winner will make a presentation at the Barcelona symposium.

Details of the Award can be found on the EDF website and EDF member groups are asked to make sure that all dystonia centres are encouraged to enter papers for adjudication. <http://www.dystonia-europe.org/europe/>

ARTICLES

The Medtronic Foundation Workshop held in Brussels, 10 – 12 Nov. 2010

"The Turning Point for your organization. How Patient Groups Evolve and Grow"

This was The Medtronic Foundation's third Patient Link Workshop, primarily geared towards cardio-vascular diseases, pain, diabetes, and movement disorders. The priorities of the workshop agenda were to empower patients to become active partners in their health care and to include partnerships and collaborations in the sponsorship programs.

The agenda was very promising and one of the first speakers was Mary Baker, President of the European Federation of Neurological Associations. Mary Baker's organizational experience was very inspirational.

Dr. Panos Kanavos, Senior Lecturer in International Health Policy, London School of Economics spoke about Health Technology Assessment (HTA). We learned how important it is to keep the aspect of HTA in mind when you want to bring up a case in The Health Care Debate or to politicians, remember that there are budgets, and try to justify “value for money” and sometimes justify “additional cost”. If you can point out, that not only your group, but also other groups or patients in general, can benefit from the “case” you are promoting, you will more likely be heard and have a stronger case. Cost effectiveness can be that with a certain treatment patients are able to still work or take care of themselves. Also, HTA bridges the gap between researchers and decision-makers.

Jérôme Boehm, Policy Officer Health systems, Health and Consumers Directorate General, European Commission provided information on HTA cooperation in the European Union. Among many things HTA means patients’ satisfaction, cost containment and reward for innovation. Gérard Raymond, CEO French Diabetes Association gave us an interesting HTA-related testimonial.

On day 2, there were 3 speakers from different organizations giving us examples of how their organizations reached a Turning Point where they made significant progress. There were many great ideas given and - just to mention a few of these:

To support your volunteers and find out what people are interested in and like to work with. Most people work better with something that they really care about.

Bring in more volunteers or board members when needed instead of overloading a few.

Integrate young people in your organization

Make sure that tasks for board members and volunteers are clear and outlined for example by written work descriptions.

On both days there were breakout groups to discuss different topics presented in the workshop. In these groups we learned more about how other organizations work. Some of the group work focused on what skills are needed in your organization and how to identify skills that are lacking so you can implement those. There were also discussions on legal aspects and responsibilities of organizations. In some countries, criminal background checks are done, and this is mandatory in the UK.

The collaborations and sharing of information, between patient organizations, national and international, is much more beneficial economically than each organization working alone. In addition to the financial aspect, the benefits to the patients and caregivers will be tremendous.

As a newly elected chairwoman, it was very rewarding to meet others in the same or similar positions and exchange information, get ideas and ask questions on how other organizations solve certain problems and how they work. Some of the speakers had a lot of experience and great advice.

I have learned a lot from this workshop and am very grateful that I had the opportunity to attend. I have many new ideas that I strongly believe can improve our organization. I will also keep in touch with some of the people I met for further collaboration and exchange of information.

Merete Avery
Chairwoman – Norwegian Dystonia Association

Medical Congress – “Treatment of Dystonia” – Hannover, May 2010

After the success of EDF’s “Dystonia-Europe-2008” in Hamburg, the response from dystonia specialists was clear. *“We like conferences which concentrate on dystonia alone. It is too easy for dystonia to be lost among the demands of other ‘bigger’ illnesses at general neurological meetings or even at Movement Disorder congresses, where the concentration is on Parkinson’s Disease.”*

So – some prominent doctors in Hannover decided to hold a medical conference on “Treatment” in 2010 and EDF was well-represented by the President and Executive Director, with a booth in the exhibition hall and plenty of opportunity to ‘network’ with other patient organisations - Deutsche Dystonie Gesellschaft, Benign Essential Tremor Association (USA), and Dystonia Medical Research Foundation (USA) - many dystonia specialists and most of the companies which have been our sponsors over past years.

The scientific programme was very full, but opportunities were taken to distribute EDF literature and information about our own conference for medical specialists in Barcelona 2011.

Alistair Newton

The Dystonia Society – Parents and Carers Conference

On 9th October we welcomed 80 parents and carers to a conference at the Wellcome Collection in London. Attendees were treated to presentations and a range of workshops on childhood dystonia, whilst children were entertained by a team from Great Ormond Street Children's Hospital.

Dr Jean Pierre Lin, Paediatric Neurologist at the Evelina Children's Hospital started by asking "what is dystonia?"

With many causes and manifestations of dystonia, to answer this question we need to look at the common features and processes – the "involuntary, sustained, patterned repetitive muscle contractions of opposite muscles causing twisting movements and abnormal postures during motor tasks."

Looking at the origins of movements that we all express in childhood helps us to understand how people with dystonia can produce this fantastic range of extraordinary postures and movements. In any learning process, the body overuses muscles that it does not need to use. As babies develop they go through a range of abnormal postures which require the use of all muscles. This is part of developing movement and fine motor skills and in time the movements become more refined and more varied postures are developed.

Dr Lin suggested that, in developing dystonia, the brain has too many options. Instead of choosing one option for muscle control it wants them all, resulting in a multiple pile up of motor strategies. The brain seems to revert to the original state, with all muscles turned on, resulting in the postures and movements that we see in dystonia.

Dr Lucinda Carr is a Consultant Paediatric Neurologist at Great Ormond Street Hospital. She presented the Robert Surtees Memorial Lecture, and discussed the current practice in treating childhood dystonia.

She stated that for doctors the big question needs to be whether or not you should treat the dystonia. The doctor needs to balance the positives and negatives of each treatment – the effect that dystonia has on the child, what the treatment entails, whether there are any side effects and the time and cost implications of treatments. You need to take into account how the condition affects the child's quality of life – does it affect communication or education and are there any other medical problems to consider? She says that, without making these considerations it is not possible to consider how they should be treated.

Hortensia Gimerno is senior Occupational Therapist on the complex Motor Disorders Team at the Evelina Childrens Hospital. She talked about the importance of enabling children with dystonia to develop and learn skills and how she helps to develop these "life skills".

Children learn through their experiences and everyday opportunities; however, children with dystonia often do not get opportunities to learn through doing – with dystonia, the more you try to do something, the worse the dystonia gets. This can have a major impact on independent living, self confidence and self esteem.

Occupational Therapists empower children by giving them the skills that they lack. This may be by providing equipment or modifying tasks to make them more accessible. She stated that one of the most important things a parent can do is to set up a daily activity that is accessible to the child.

We also invited Ruth, Jackie and Amy-Belle to talk.

Ruth's son, Mattie, is 14. He has been severely disabled since birth, with dystonic atheroid cerebral palsy, which has had a major impact on his quality of life. A couple of years ago Mattie was told he would need rods put in his back due to problems with his spine; however the severity of his dystonia meant this surgery would not be possible. Mattie was put forward for an ITB pump to help reduce his dystonia spasms, which has had a positive impact on Mattie's quality of life – he is now in less pain, happier, more communicative and his personality has improved; however, as the spasms have reduced he has gained weight.

Jackie's daughter Ellie is 16 years old. She has had a severe form of dystonia since birth. Ellie uses a communication aid and is totally care dependent; however, she has full cognitive ability. Jackie talked about the importance in seeing Ellie as a child first – she is given every opportunity to enjoy life, going on holidays and pop concerts like any 16 year old. She emphasises the importance in having fun with your children and not letting a medical label overshadow that. You need to think about what your child can do, not what they can't.

Amy-belle is 18. She was diagnosed with dystonia aged 4 when she found she couldn't lift her right arm. She has been seeing a doctor ever since and had DBS surgery earlier this year. Before the DBS her arm was moving uncontrollably, which she found incredibly frustrating. Although she says it was a difficult decision to have the DBS surgery, the surgery was very successful and she said that she would recommend it to anybody.

The Dystonia Society

EDF and other pan-European neurological groups

European Federation of Neurological Associations (EFNA)

General Assembly – Brussels, November 2010 - The EDF President was invited to attend the 2010 EFNA General Assembly in Brussels, and took the opportunity to network with the leaders of many other neurological illness federations, which are also EFNA members. As well as hearing about the many successful activities of EFNA, the

audience heard two external speakers make interesting presentations on two of EFNA's projects: A study of the health and quality of life of carers in neurological illness (Oxford University); and on the work of the MRI Alliance in persuading the Commission to change health and safety legislation which would prevent the use of MRI machines across Europe.

Health Technology Assessments (HTA) - For the past two years, EFNA has been running HTA courses for patient leaders and others, in partnership with the prestigious London School of Economics and, as the informed involvement of the medical profession is crucial, EFNA is now bringing the information to neurologists. HTA already exists in many countries and is spreading fast to all the others. As governments struggle to contain health budgets, they set up HTA authorities which decide the merits of different treatments, and how cost-effective they are. Already, many patients have been prevented from receiving treatment which has already helped them, when a national HTA body has disallowed its use in that country. Knowledge of the principles of the system allows patients, doctors and others to argue their case strongly.

EDF's Executive Director, Alistair Newton, has held the post of EFNA Secretary-General for the past 10 years, and EDF has played a central role in all EFNA activities, thus promoting dystonia and EDF's member groups to the wider international audience of policy and decision makers. EFNA continues to progress in a number of areas and has now appointed an Executive Director to support the work of the EFNA Board. EDF looks forward to continuing its close association with such an active and successful organisation, which has brought all neurological illnesses to the attention of policymakers in Brussels. www.efna.net

European Federation of Neurological Societies (EFNS)

Annual neurological conference - The European Federation of Neurological Societies (EFNS) holds very large-scale congress every year, with up to 6,000 neurologists attending. EFNA's close links with EFNS allow it to run two sessions at these congresses – one for the doctors (“The Good Life”) and one for patients and health professionals (“Awareness Day”). In Geneva, in 2010, the Awareness Day concentrated on explaining the relatively new concept of Health Technology Assessment (HTA). The Good Life provides a session based on performances of music and dance, with a specialist presenter who brings together the effects of the performance and how it benefits neurology and people living with neurological illness. www.efns.org

Alistair Newton

NOTES

5th International Dystonia Symposium – Barcelona, 20/22 October 2011

www.internationaldystoniasymposium.org

2011 EDF Annual General Assembly – Barcelona, Sunday 23 October 2011

EDF needs help to produce UPDATE twice each year – summer and winter. The work of editing, and publishing needs to be shared and volunteers are invited to contact the Executive Director, Alistair Newton, to discuss the activities involved. sec@dystonia-europe.org

Members' Directory – The EDF Members' Directory is about to be reprinted and if there are any changes to the contact details or the text of the entries for any member group, please let us know – so we can get things right! sec@dystonia-europe.org

GA – Malmö. Presentations from the General Assembly are in a separate document attached to this Update

EDF's successes – a roll-call of our activities over the past 8 years is attached in a separate document

**The Board of European Dystonia Federation
sends best wishes for success and good health in 2011 to all European dystonia groups,
to their Boards and their members,
to the EDF Board's advisers
and to our Medical And Scientific Advisory Board**

We thank you all for you efforts to support EDF over the past year

**The Federation gratefully acknowledges the generous support of its sponsors and we send
our best wishes to all of them for a happy and successful 2011**

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