

Annual Report 2012-2013

Message from President and Executive Director

"Achievement and Hope"

This year, 2013, is a very special year in the history of dystonia across our Continent, as we celebrate the 20th Anniversary of Dystonia Europe!

In 1993, eleven national group leaders formed EDF – the European Dystonia Federation - in Spoleto, Italy. Today - twenty years later - our organisation has grown to 18 members and the growth continues, with several new groups almost established.

Our activities have increased substantially since our founding twenty years ago and so has the interest in dystonia in general. After our very successful medical congresses solely on dystonia – in Hamburg 2008 and in Barcelona 2011 - the activities within dystonia research and development have boomed. The most significant move forward, and one with enormous potential, has been the forming of the new Dystonia Research Network which involves clinicians and researchers from all over Europe.

Looking back at the last year we gratefully acknowledge the many achievements: the collaboration with the Dystonia Europe Research Network and its activities such as the Training School in Bol, Croatia; the increased interest from patients and clinicians in countries with no dystonia patient groups, to try and establish one; stronger collaborative links with the industry; and the awareness efforts on the European level with the Dystonia Stories campaign and other communication activities. These activities have contributed to the improvements in research and treatment which give hope of a better future for dystonia patients.

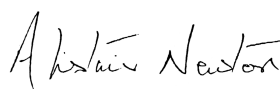
The continued growth and development would never have been possible if it weren't for all the very dedicated people involved over those twenty years: patient leaders from all over Europe, researchers and clinicians, industry partners and many more.

This year also marks the end of another *era* as we both end our current roles after six years working together as President and Executive Director. We will continue to be involved and serve Dystonia Europe and its members and partners, but in new areas of responsibility.

We would like to thank all of our member organisations, their board members and delegates, and our partners for their substantial contributions to the achievements of this year, but also for the efforts of past contributors to all of Dystonia Europe's activities since 1993. We look forward to our continued association with you all, and to another twenty years of Achievement for Dystonia Europe, and the Hope which that will bring to people who live with dystonia.

A handwritten signature in black ink, reading "Monika Benson".

Monika Benson
President

A handwritten signature in black ink, reading "Alistair Newton".

Alistair Newton
Executive Director

Board Review

Three board meetings were held during the year. Two in Brussels; in January and May, and one in Edinburgh, before the Annual Conference. Steps were taken to recruit new board members.

The President and the Executive Director held a 2-day-meeting on strategy in Lund in October.

Communication Resources

Newsletter

Winter and summer editions of Dystonia Europe News were issued by email to members and to our many contacts, and printed copies were distributed at various meetings and conferences.

Website

The new website was launched before Christmas 2012 and the work continues to improve this indispensable communication tool.

Publications

The Dystonia Europe information leaflet was revised and printed. It was distributed at various meetings: the Global Neuro Summit in Milan in March, the Second International Congress on Treatment of Dystonia in Hannover in May and at the Dystonia Europe 20th Anniversary Conference in Edinburgh, in September.

Social Media

The Dystonia Europe Facebook page has increased its followers substantially from last year, and now has over four hundred. The goal has been weekly updates and posts regarding activities and news within the field of dystonia.

A Dystonia Europe Youtube channel was launched for the publication of the Awareness Campaign: Dystonia Stories.

Activities

Annual Conference and 19th General Assembly 2012

The annual conference and the 19th General Assembly was held in Bol in Croatia alongside the first annual training school of the 'Action' supported by a grant from COST (www.cost.eu) to support the European Network for the Study of Dystonia Syndromes. On Friday and Saturday DE delegates were able to attend the teaching sessions. There were sessions on Genetics, Treatment with Botulinum toxin, DBS surgery, Physical Therapy and many more. One part of the programme was dedicated to the DE delegates and included presentations by: M Jean-Pierre Bleton and Professors Tom Warner, Marjan Jahanshahi and Maja Relja.

On the Sunday morning, the delegates from the various European member countries gathered for the General Assembly 2012. The member countries were invited in advance to share ideas about their recent work/projects to learn from each other, and we learned that there are many interesting projects on dystonia being carried out in Europe. Stéphanie Frehel, President of AMADYS talked about the CD/DVD on Physical therapy that they had developed together with Jean-Pierre Bleton from Paris. Maria Hickey from Dystonia Ireland presented a photo project, intended to raise awareness of dystonia – an Irish photographer,

herself affected by dystonia had portrayed dystonia patients and their interests through photographs. Merete Avery shared a 7-minute presentation on dystonia that the Norwegian Dystonia Association uses at meetings to explain dystonia easily to new audiences.

Sölvi Engeland from Norway was re-elected to the DE Board for a final term of two years, and she will continue her responsibilities of the DE website and the newsletter.

A professional photographer, Stephan Roehl from Germany joined us in Bol to document the conference and its participants, and he gave us his services free of charge. A special photo session with DE delegates took place in the beautiful surroundings, with all of them wearing the colourful new Dystonia Europe T-shirts for the occasion. The result is a collection of Dystonia Europe photos that has been made available to all member groups. These photos have been used during the year to further strengthen the 'brand' of Dystonia Europe.

In the evenings there were nice Dalmatians dinners for speakers and participants. DE's Vice-President, Professor Maja Relja, originally from Split and the main organiser of the successful scientific training school, also provided strong support in organising an excellent General Assembly meeting.

The European Network for the Study of Dystonia Syndromes

This scientific network was created with the support of a four-year grant awarded in 2011 by COST, a European intergovernmental organisation which pre-dates the European Union by many years. In 2011 Dystonia Europe was elected Grantholder of the Network and DE President Monika Benson is a member of the Management Committee. The project is intended to create better networking among dystonia experts around Europe, and to raise awareness of dystonia among the public. Nineteen countries are, so far, part of the project and the ten members of the steering committee lead the work of the four working groups: genetics, animal models, clinical studies, e-infrastructure. The responsibilities of Dystonia Europe, as the Grantholder, cover activities such as organisation of meetings and all aspects of the finances of the project.

In the year 2012/2013, the following activities have taken place:

- The first training school of the project was held in Bol, Croatia in September 2012. Thirty four of the young participants were awarded grants to support their costs in attending. The three-day programme included training sessions led by dystonia specialists from all over Europe, and the event was very much enjoyed by both trainers and trainees.
- Working group 2, Animal Models, held a meeting in Brussels in November 2012.
- The Steering Committee held a two-day-meeting in Brussels in July 2013.
- Five STSMs – short term scientific missions - were granted to young scientists who spent some weeks in the labs of other dystonia specialists in Belgium, Germany, France and Italy, in the first few months of 2013.
- The Action website was developed and launched at www.euro-dystonia.org. The website reports on the various activities of the Network, and lists the calls from various sources for grant applications in the area of dystonia.

COMPASS

The COMPASS project, which was granted funding by Medtronic Foundation in October 2011 and initiated at the beginning of 2012, had developed successfully, according to our plans. Therefore a new application was made for a grant to continue the project, and funding was agreed for another year. The main aim of the project has been to develop our partnerships with members, sponsors, and the medical profession, as well as to strengthen and broaden the communication channels. The project manager is Monika Benson.

The activities have resulted in:

- Stronger links to industry and partners through face-to-face meetings and joint activities.
- Visits to member groups to establish closer contact with DE. In the past year, Monika Benson spoke at the AMADYS annual conference in France and she also attended the DDG 20th Anniversary Conference in Germany.
- The establishing of contacts to develop new national patient groups in Czech Republic, Russia, Romania, Hungary, Estonia and Latvia. Meetings took place in Moscow in December 2012, and in Prague Czech Republic in May 2013.
- Increased sharing of DE information and activities through website and social media.
- Involvement in the COST funded research project The European Network for the Study of Dystonia Syndromes.

The project has been very successful and will end in 2013, but much of the work will continue as part of our normal activities.

Dystonia Stories

The awareness campaign, generously sponsored by Merz Pharma, is running all through 2013, the year of the 20th anniversary of Dystonia Europe.

The meetings in Bol, Croatia were documented on photo and on film. Participants at the meetings, such as patient leaders from all over Europe, medical experts, students and representatives from the pharma and medical device industries were interviewed about their relationships with dystonia. The interviews were edited into 2-3 minute video clips which were subtitled to French, German, Spanish and Italian. The 20 clips were published from the beginning of March leading up to the Dystonia Europe 20th Anniversary in Edinburgh on September 6th.

The campaign is running on the Dystonia Europe website, and throughout the different social media channels such as Facebook and Youtube. Member organisations have been encouraged to use and share the information further to spread knowledge and raise awareness about dystonia.

The David Marsden Award 2013

The 2013 Award was generously sponsored by Ipsen Pharma and won by Dr Katja Lohmann of the Institute of Neurogenetics, University of Luebeck, Germany for her paper on: "Whispering Dysphonia (DYT4 Dystonia) is Caused by a Mutation in the TUBB4 Gene". This was selected by the adjudication committee of our Medical and Scientific Advisory Board, as the best paper submitted for this year's prize.

The formal presentation of the award will take place at the Dystonia Europe 20th Anniversary Conference "Achievement & Hope", in Edinburgh, Scotland, where Dr Lohmann will also present her paper.

International Cervical Dystonia Patient Survey

Little is known about patient perspectives on diagnosis and management of CD. For this reason a large-scale, international online survey was undertaken to assess patient views on the impact of CD with the aim of identifying unmet needs in patient care and highlighting where improvements in treatment protocols may be required.

The survey was developed in collaboration with Dystonia Medical Research Foundation (DMRF), supported by Ipsen Pharma and launched on-line in mid April 2012. It ran throughout the year and ended on December 31st. A total of 1071 patients from 38 countries worldwide participated. A poster of the results was presented at the Second International Congress for Treatment of Dystonia in May, in Hannover Germany. Results show that there is still a need to inform clinicians more effectively about the needs of dystonia patients and how this can be improved.

The final results will be published in appropriate journals later in 2013.

Participation at meetings & congresses

Congresses

Russian Patient Congress, Moscow, Russia

Dystonia Europe President, Monika Benson, participated at the Russian Patient Congress and made a presentation on European Patient Advocacy. There was also a video-conference that reached dystonia patients in twenty cities across Russia.

Global Neuro Summit, Milan, Italy

At the beginning of March 2013 Dystonia Europe, represented by President Monika Benson and Executive Director Alistair Newton, attended the Global Neuro Summit organised by the Istituto Carlo Besta, Milan and Merz Pharma. The programme of the two-day conference included speakers from the US and Europe. Five hundred participants attended a variety of interesting presentations and discussions on topical aspects of dystonia.

The First International Congress on Rehabilitation of Dystonia, Hannover, Germany

In May the very first congress on rehabilitation of dystonia was held. Dystonia Europe granted an award of € 500 for the best poster on rehabilitation, and this was presented by President Monika Benson to physiotherapist Jean-Pierre Bleton of Saint Anne Hospital in Paris, for his poster: *"Impaired force control in writer's cramp showing a bilateral deficit in sensorimotor integration"*.

The Second International Congress on Treatment of Dystonia, Hannover, Germany

Dystonia Europe was present with a stand at the three-day congress. Material was distributed such as: DE leaflets, DE News Winter 2013, DE Annual Report 2011-2012 and various flyers. Many congress participants and industry representatives dropped by the DE stand to get material and discuss collaboration.

Chamber of Deputies, National Parliament, Prague, Czech Republic

Executive Director, Alistair Newton, and President, Monika Benson participated and gave presentations at a meeting arranged by one of the industry partners in collaboration with the Association of Innovative Pharmaceutical Industry of the Czech Republic. The theme of the meeting was *"Living with Dystonia"* to which patients, physicians and the public had

been invited. The goal of the meeting was to raise awareness of dystonia and to inspire patients to form a national dystonia association.

4th Biennial Workshop on Dystonia, Rome, Italy

Dystonia Europe Executive Director, Alistair Newton, was invited by Professor Antonio Pisani to present the work of Dystonia Europe at the two-day international meeting “*Circuits and Pathways in Dystonia and Parkinsonism*”.

European partnerships

Activities with EFNA

European Federation of Neurological Associations (EFNA) organised a free two-day workshop on “Advocate for Neurology” in Brussels in February. Neurology patient group leaders from all over Europe had been invited to take part in an event aimed at preparing their organisations for the activities of May 2013 that had been designated by the European Commission as ‘European Month of the Brain’. DE President Monika Benson attended the meeting together with some members from national dystonia associations.

To mark the European Month of the Brain EFNA was involved in various events in May where also Dystonia Europe was represented:

On May 7, EFNA opened a document in the European Parliament for signing by MEPs - ‘Putting Neurology Patients First: A pledge to support essential investment in neuroscience research and to protect the interests of neurology patients’. The following day EFNA Members held an Information Day in the Parliament to distribute leaflets on the various conditions and supports available to patients. Dystonia Europe information and leaflets were available.

On behalf of Dystonia Europe, Robert Scholten, of the Dutch Dystonia Association, attended the European Patients’ Forum 10th Anniversary Conference “Towards Active Patients’ Involvement in Healthcare”, held in Dublin under the Irish EU Presidency to mark European Month of the Brain. The Conference was organised jointly with EFNA and championed neurological disorders.

Activities with European Brain Council (EBC)

EBC is a co-ordinating council which brings together the large scientific ‘umbrella’ societies in brain illness, at the European level. It is a unique organisation because its founder members are neurological societies and psychiatric, with the clinical and basic neuroscience professions, and umbrella patient organisations from neurology and psychiatry. In addition, there is a separate board of representatives of the pharma, medical device and other industries which sends representatives to the main board. The EU decision makers have been greatly influenced by EBC’s extremely broad membership, which brings science together in partnership with society.

Dystonia Europe Executive Director, Alistair Newton, has served as Treasurer on the Board of EBC since its founding. During the past 12 months, he took part in many EBC Board and other meetings. Alongside scientists and speakers from the Commission and the Parliament, he made a presentation on the patient’s perspective at a meeting in the European Parliament to promote interest in brain research, during the Month of the Brain.

2013 & Beyond

The DE work and activities for 2013 and 2014 will involve the following:

The European Network for the Study of Dystonia Syndromes

The responsibility for DE continues, as Grantholder of the Action, and the network scientists, with the DE Board, have agreed a basis for a formal partnership in which both organisations will work even more closely together.

The 2013 Training School for young dystonia specialists will be held in London on 22-24 November. There are more than 30 grants available for young scientists and clinicians to allow them to attend the school. Alongside the TS there will be a Network Steering Committee meeting as well as the annual Network Management Committee meeting.

6 STSMs (short term scientific missions) are also planned for the beginning of 2014, which will allow young scientists to travel to dystonia specialist groups in other countries and learn and take part in their work.

Dystonia Outreach

After the successful activities of the COMPASS project to reach out to dystonia patients/groups in other countries, the DE Board has decided to continue with this work. Meetings are planned to take place in Bucharest, Romania, and in Trondheim, Norway. Other countries, where meetings are eventually planned to take place, are being considered in collaboration with the medical profession and industry partners, whose local support is important, especially in the initial stages.

Dystonia Awareness

The Dystonia Stories were developed as an awareness campaign leading up to the 20th Anniversary. All 20 clips are now available on the Youtube channel and website. Re-launches of these clips will happen over the next year.

Dystonia at Congresses

Dystonia Europe will continue to be present with a stand and representation at major neurological congresses. DE will attend:

The World Congress of Neurology in co-operation with EFNS, in Vienna, September 2013

The EFNS-ENS Joint Congress, in Istanbul, Turkey, May/June 2014

The 18th International Congress of Parkinson's Disease and Movement Disorders, in Stockholm, Sweden, June 2014

'Branding'

The new logo and colours have been greeted positively by members, medical and scientific partners and the industry. We therefore continue our efforts in promoting our "look" especially on the DE website and Facebook page but also with printed materials such as DE News, DE Annual Report, and a small collection of Dystonia Europe T-shirts, bags, and pins.

Board

Meetings are planned to be held in September 2013, January, April and September 2014.

Dystonia Europe 21st Annual Conference and General Assembly 2014

The next annual meeting will take place in September 2014 in Paris, France.

Members

Dystonia Europe consists of 18 national member groups from 16 European countries and they are:

Austria, Belgium, Croatia, Denmark, France, Germany, Ireland, Italy, Netherlands, Norway, Poland, Portugal, Spain, Sweden, Switzerland, United Kingdom.

Partners & Sponsors

In order to ensure its operations, Dystonia Europe relies on partnerships with external organisations. However, to ensure transparency and independence, we do not accept donations that are dependent on policies set by others. The DE Board is careful to ensure that any funds or other support received do not influence our organisation's ethical position or credibility.

There are 4 levels of core sponsorship: Platinum € 25 000 and more, Gold from € 15 000, Silver from € 10 000, Bronze from € 5000.

We thank the following partners for becoming Platinum sponsors for 2013/14:

Ipsen Pharma, Merz, Medtronic

Dystonia Europe also would like to thank all other partners and supporters for their continued interest and work in joint projects with DE. We look forward to working closely with them all in the future.

They are: DMRF – the Dystonia Medical Research Foundation, FDR – Foundation for Dystonia Research, Dystonia Coalition, EFNA – European Federation of Neurological Associations, EBC – European Brain Council.

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