

Annual Report 2013-2014

Message from President and Executive Director

Dystonia Europe: Connecting People for Dystonia

At last year's General Assembly in Edinburgh a new Dystonia Europe Team was formed and I had the great honour of being elected new President of Dystonia Europe. Together with the Board and the new Dystonia Europe Executive Director Monika Benson we have had a very busy and exciting year.

The first step was to renew the **"Vision and Strategy Plan for Dystonia Europe until 2020"**. The main theme of the strategy is to connect people for dystonia. The Vision Plan was developed during the year and presented to various stakeholders which resulted in substantial support to initiate our plans.

When **'connecting people for dystonia'** we plan to focus particularly on the following areas:

A Digital Platform for Dystonia

In today's society we are increasingly sharing information and experiences through internet and social media. It is therefore important that all people with an interest in dystonia easily can be connected. We would like to facilitate these activities by creating a **digital platform for dystonia** over the next few years.

D-DAYS

The Dystonia Europe Annual Conference and General Assembly is an important occasion for interaction between member representatives. To increase these face-to-face contacts, one idea could be to combine the Dystonia Europe Annual Meeting with the meetings of national member associations. We call it the annual D-DAYS.

Awareness Campaign 2014: Jump for Dystonia

There is still a lot of misunderstanding about dystonia and it's crucial to continue the work of raising awareness and spreading information about the disease. Our next awareness campaign called 'Jump for dystonia' will be launched at the Annual Conference in Paris. It is our hope that this campaign will spread around not only Europe, but around the world.

We would like to take this opportunity 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. We look forward to our continued association with you all, and we invite you to join us in our mission to connect people for dystonia in the next year.



Robert Scholten
President



Monika Benson
Executive Director

Board & Staff

President – Robert Scholten, The Netherlands
Vice President – Maja Relja, Croatia
Secretary – Merete Avery, Norway
Treasurer – Heike Wolf, Germany
Board Member – Marina de Koning-Tijssen, The Netherlands
Board Member – Alistair Newton, United Kingdom
Board Member – Sölvi Engeland, Norway

Executive Director - Monika Benson, Sweden

Board Review

Four board meetings were held during the year, the first one in Edinburgh, the day after the 20th General Assembly. In January the Board gathered in Amsterdam, The Netherlands, and in June alongside the MDS congress in Stockholm, Sweden. The fourth board meeting took place in Paris before the 21st Annual Conference and General Assembly. In August the President and the Executive Director held a 2-day-meeting in the Netherlands on the development of various projects.

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 Dystonia Europe website went through further improvements and was re-launched before Christmas. It has an average of 700 visits/month.

Publications

The Dystonia Europe information leaflet was revised and re-printed. It was distributed at various meetings and congresses such as: the World Congress of Neurology in Vienna, the joint EFNS & ENS Congress of Neurology in Istanbul, the MDS Congress in Stockholm and at the Dystonia Europe 21st Annual Conference – the D-DAYS, in Paris in October.

Social Media

The Dystonia Europe Facebook page has increased its reach substantially since last year, and has now over 1400 followers. The goal has been weekly updates and posts regarding activities and news within the field of dystonia.

Dystonia Europe also launched accounts on Instagram and Linked-In.

Activities

The 20th Anniversary Conference and General Assembly 2013

Last September 6 & 7 Dystonia Europe celebrated its 20th Anniversary by holding the conference "Achievement & Hope" in Edinburgh, Scotland. About 85 participants from all over Europe had gathered at the King James Thistle Hotel in central Edinburgh. There were dystonia experts and national dystonia patient group leaders from all over Europe as well as dystonia patients from the UK.

During the conference, more than twenty internationally-respected dystonia experts from across Europe gave presentations spanning those twenty years. The conference extended over two days and, in the first session, it was about the history - the prevalence of the illness and the development of medications, surgery and botulinum toxin. In the second, presentations described the considerable advances of research into areas such as genetics, broader aspects - like rehabilitation - in managing the illness, paediatric dystonia and more effective use of botulinum toxin by better training of injectors.

A third session, covering more practical topics for patients, dealt with issues of pain, psychological factors, the benefits of teamwork in the clinical setting, patient advocacy, physiotherapy and the patients' expectations of the doctors who are treating them.

The Anniversary dinner was held at the Royal College of Surgeons in Edinburgh and the guests were given a real Scottish welcome, with bagpipes and Scottish country dancers at a reception, followed by a dinner. Alistair Newton was honoured with speeches and acknowledgments for his dedicated work for Dystonia Europe over the past 20 years, and by being made an Honorary Member of Dystonia Europe.

At the formal General Assembly President Monika Benson stepped down after serving the maximum period of six years. Robert Scholten from the Netherlands was elected the new Dystonia Europe President. Heike Wolf from Germany was elected the new Treasurer and Professor Maja Relja from Croatia was re-elected to the Board for another term of two years. Merete Avery and Professor Marina de Koning-Tijssen were appointed to the board for two years each.

Two applications of membership from two Romanian dystonia associations: Children's Joy and Asociatia Romana, were approved by the General Assembly. Dystonia Europe now has 20 member associations in 17 countries.

Professional photographer, Stephan Roehl from Germany joined the annual Dystonia Europe meeting for the second time, to document the conference and its participants, giving his services free of charge.

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 took place at the Dystonia Europe 20th Anniversary Conference "Achievement & Hope", in Edinburgh, Scotland. After receiving the Award from Dystonia Europe President Monika Benson, Dr Lohmann presented her paper.

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 at its first meeting and DE Past President Monika Benson is a member of the Network Management Committee. The project is intended to create better networking among dystonia experts around Europe, and to raise awareness of dystonia among the public.

24 countries are, so far, part of the project and the ten members of a Steering Committee create the framework of activities for the four working groups: genetics, animal models, clinical studies, e-infrastructure. The responsibilities of Dystonia Europe, as the Grantholder, cover activities such as involvement in planning, organisation of meetings and all aspects of the finances of the project.

In the year 2013/2014, the following activities have taken place:

- The Second Training School of the project was held at the National Hospital for Neurology in London, UK in November 2013. Over 40 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.
- Alongside the Training School in London both Steering Committee and Management Committee meetings were held.
- Working group 3 Clinical Studies held a meeting in Amsterdam in February.
- Working group 1 Genetic Studies held a meeting in Frankfurt in March.
- Working group Neuroimaging & Neurophysiology held a meeting in Paris in May.
- The Steering Committee held a meeting alongside the MDS congress in Stockholm.
- 19 STSMs – short term scientific missions - were granted to young scientists from Italy, Germany, Romania, Croatia, Hungary, Israel, Czech Republic, Poland and UK, who spent some weeks in the labs of other dystonia specialists. The centres where they carried out their projects were in The Netherlands, France, UK, Belgium, Italy, Spain and Portugal.

Dystonia Europe Connecting with Dystonia Patients

After the successful activities of the COMPASS project to reach out to dystonia patients/groups in other countries, the DE Board had decided to continue with this work.

The first meeting took place in **Bucharest, Romania**. Dystonia patients and medical staff were invited to the event which was organized by Houston NPA for the Romanian Dystonia Association: Children's Joy, and was endorsed by the Romanian Neurology Society. There were medical presentations by Romanian dystonia specialists. The DE Executive Director Monika Benson presented the activities of Dystonia Europe and by using the Swedish Dystonia Association as an example the work and activities of a national dystonia patient association was described. The DE executive director also took part in a delegation which visited the Romanian Health Ministry in order to facilitate treatment access for dystonia patients in Romania.

Each autumn, NDF, the Norwegian Dystonia Association organizes a members' meeting and this year it took place in **Trondheim, Norway**. The DE executive director was invited to speak about Dystonia Europe and our aims and activities.

During the Christmas holidays our executive director, Monika Benson, was travelling on a personal trip in Australia and was asked to take part in a meeting for dystonia patients in **Melbourne**. About 50 dystonia patients and family members from all over Australia attended the meeting. Australia has not had a national dystonia association and one of the goals of the meeting was to get the various local support groups to come together and to strengthen the recently founded DNA – Dystonia Network of Australia. Monika gave a presentation on the work of Dystonia Europe.

Vision & Strategy Plan

Following the 20th Anniversary Conference the new DE President Robert Scholten outlined a Vision & Strategy Plan for the next six years. The theme is “Connecting People for Dystonia” which is also the new slogan. The plan was presented and agreed by the Dystonia Europe board and was introduced as the basis for discussion when meeting various partners/sponsors. Dystonia Europe aims to connect people by focusing on three activities: ***The Digital Platform Jump for Dystonia D-Days***
The Vision & Strategy Plan was very well received by several stakeholders, funding was secured and the three projects were initiated. The plan will be discussed with the member representatives at the General Assembly in Paris.

Projects

Digital Platform for Dystonia

In today’s society information and experiences are increasingly shared through internet and social media. It is therefore important that all people with dystonia can be connected. By developing a digital platform for dystonia we aim to facilitate these activities. The work was initiated after funding was received. First launch of a pilot version will take place in Paris 2014.

One of the features of the platform is a patient APP - a dystonia diary which will give patients the opportunity to record their dystonia symptoms and daily activities, in order to better manage their condition and to communicate this with their treating neurologist. The launch will take place in Paris.

Awareness Campaign 2014 - Jump for Dystonia

There is still a lot of misunderstanding about dystonia and it is crucial to continue the work of raising awareness and spreading information about the disease. The official launch of “Jump for dystonia” will take place in Paris. People will be asked to Jump for Dystonia and the photos will be uploaded to a special Jump for Dystonia Facebook Page.

During the year photos have been collected at various congresses and meetings of people jumping for dystonia. Some partners have already taken the campaign within their organization/company to raise awareness of dystonia among the employees and organized special Jump for Dystonia events.

D-Days – The first D-Days are being planned to take place in Paris October 10-12, 2014. AMADYS President Stéphanie Frehel and Professor Marie Vidailhet have been heavily involved in the preparations.

Participation at meetings & congresses

Meetings

Throughout the year President Robert Scholten and Executive Director Monika Benson have participated at various medical meetings arranged by the industry (Boston Scientific, Ipsen, Medtronic, Merz) to present the work of Dystonia Europe.

Congresses

The World Congress of Neurology, Vienna, Austria

Dystonia Europe provided information from a stand in the exhibition hall at the World Congress of Neurology in Vienna. Many visitors from all over the world came by to get material and talk about dystonia and treatment with President Robert Scholten and Executive Director Monika Benson.

The EFNS-ENS Joint Congress, Istanbul, Turkey

Dystonia Europe was present at the EFNS/ENS joint congress for Neurology in Istanbul Turkey with a booth in the exhibition hall. Visitors from all over the world were given DE leaflets and flyers of the upcoming D-DAYS in Paris in October 2014 and in Rotterdam in 2015. At this congress, these two scientific organisations finally merged, to become the European Academy of Neurology (EAN).

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

Dystonia Europe was present with a booth in the exhibition hall to distribute material, to network and connect with partners from the medical profession and from the industry.

European partnerships

Activities with EFNA

EFNA held its General Assembly 2013 in Vienna alongside the World Congress of Neurology 2013. DE was represented by President Robert Scholten and Executive Director Monika Benson.

In May 2014, The EFNA General Assembly took place alongside the EFNS congress in Istanbul, Turkey, where the DE Executive Director participated.

Another activity organized by EFNA, where DE was present, was the Health Technology Assessment Course Part 2 – a 2-day-workshop on Pharmaceutical Pricing, Access and Reimbursement at the London School of Economics. The program gave insights on: (a) how pharmaceuticals fit within the overall health care system; (b) how different countries in Europe and beyond pay for pharmaceuticals in treatment of patients; (c) what are the most salient regulations addressing coverage/access and how these affect patient access; (d) how stakeholders – including patients – participate in the decision-making process.

The DE President was present at the 2-day workshop "Advocate for Brain, Mind and Pain" in Brussels. Here EFNA launched the project 'Stronger Connected' – a guide aiming to encourage the formation of National Neurological Alliances.

2015 & Beyond

The DE work and activities for 2014 and 2015 are planned around the Vision & Strategy Plan and the new title: **Connecting People for Dystonia**

This will be done by continuing the following projects:

1. ***A Digital Platform***
2. ***Jump for Dystonia***
3. ***D-DAYS***

The David Marsden Award 2015

The Award of € 10 000 will once again be supported by Ipsen Pharma, and it is intended to encourage research into dystonia in all European countries, especially young scientists under the age of 40.

The award will be presented at the Dystonia Europe 22nd Annual Conference in Rotterdam, the Netherlands, and during the Basal Ganglia Club session at the First Congress of EAN (European Academy of Neurology) in Berlin next June 2015.

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 2015 Training School for young dystonia specialists will be held in Groningen on 12-14 April. There are more than thirty five 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.

Sixteen STSMs (short term scientific missions) are also planned for the beginning of 2015, with grants which will allow young scientists to travel to dystonia specialist groups in other countries and learn and take part in their work.

Dystonia Network for Medical Care and Rehabilitation

Board member of Dystonia Europe, Professor Marina de Koning-Tijssen, developed a network for neurologists and physiotherapists in the Netherlands called dystonienet. The plan for 2015 – 2016 is to invite Croatia, France, United Kingdom and Czech Republic to join the network with their own national spot on the European network which in the future will be called: www.dystonia.net.

Dystonia Europe Connecting with Dystonia Patients

Dystonia Europe continues its work to reach out to dystonia patients/groups in other countries. 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. Suggestions for 2015 are Hungary, Portugal and Spain.

Dystonia Europe at Congresses

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

The Dystonia Coalition Annual meeting in St Louis, USA, November 2014

The EAN Congress in Berlin, June 2015.

Board Meetings

Meetings are planned to be held in October 2014, January, May and October 2015.

D-DAYS - Dystonia Europe 22nd Annual Conference and General Assembly 2015

The next annual meeting will take place on October 2-4 alongside the 30th Anniversary of the Dutch Dystonia Association in Rotterdam, the Netherlands.

Members

Dystonia Europe consists of 20 national member groups from 17 European countries and they are:

Austria, Belgium, Croatia, Denmark, France, Germany, Ireland, Italy, Netherlands, Norway, Poland, Portugal, Romania, 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, 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 € 17 500, Silver from € 10 000, Bronze from € 5000.

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

Platinum: Ipsen Pharma, Medtronic & Merz

Gold: Boston Scientific

We also would like to thank the following partners for their support of various projects:

Digital Platform – Ipsen Pharma, Medtronic

Jump for Dystonia – Allergan, Boston Scientific, Medtronic, Merz

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, EAN – European Academy of Neurology, EFNA – European Federation of Neurological Associations, EBC – European Brain Council, MDS – International Parkinson and Movement Disorder Society.

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