

Annual Report 2014-2015

Message from President and Executive Director

Dystonia Europe: Connecting People for Dystonia

Dear all,

It is a great pleasure for us to present the Annual Report of 2014-2015. We can look back at a year filled of many dystonia activities around Europe and beyond.

The successful launch of the annual conference with the new name D-DAYS took place in Paris in 2014, the largest annual conference ever organised by Dystonia Europe. Clinicians, healthcare specialists and patient advocates attended from across Europe and from USA.

The work of **'connecting people for dystonia'** continued throughout the year with several activities such as Jump for Dystonia events, the launch of the digital diary MyDystonia and with the participation of Dystonia Europe at several meetings and congresses.

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 the past year.

We look forward to our continued association with you all, and invite you to join us in our mission to connect people for dystonia in the year ahead.



Robert Scholten
President



Monika Benson
Executive Director

Board, Staff & Volunteers

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

Executive Director - Monika Benson, Sweden

DE News – Sölvi Engeland, Norway

Photographer D-DAYS – Stephan Röhl, Germany

Board Review

Four board meetings were held during the year. The first one in March when the Board gathered in Dubrovnik, Croatia alongside the DAN Congress. The second board meeting took place in Berlin alongside the EFNA General Assembly and the EAN Congress. An extra board meeting was held in Amsterdam on 19 September. The last board meeting of the year was held immediately before the 22nd Annual Conference and General Assembly, in Rotterdam. In June, Treasurer Heike Wolf announced that she will step down from the board. The book-keeping is now handled by DE's accountants in Belgium.

Communication Resources

Newsletter

DE News is issued twice a year, in autumn and spring. Dystonia Europe News Spring 2015 was 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 is updated on a regular basis and has now an average of 1000 visits/month.

Printed Materials

The Dystonia Europe information leaflet was revised and re-printed. It was distributed at various meetings and congresses such as: the MDS Congress in San Diego, the first EAN Congress in Berlin, and at the Dystonia Europe 22nd Annual Conference – the D-DAYS, in Rotterdam in October.

Flyers for D-DAYS in Rotterdam, Jump for Dystonia and MyDystonia were also distributed at congresses and meetings.

Social Media

There are now three facebook pages. The Dystonia Europe Facebook page has increased its reach substantially since last year, and has now over 1700 followers. The goal has been weekly updates regarding activities and news within the field of dystonia.

The Jump for Dystonia Facebook page has almost 2700 followers. This is the main page for the dystonia awareness campaign.

The third Facebook page is for MyDystonia, and has so far not much activity but is intended to handle communication with MyDystonia users.

Dystonia Europe has accounts on Instagram and Linked-In but due to lack of time and human resources, hardly any activities have taken place.

Activities

The 1st D-DAYS and the 21st Annual Conference, General Assembly 2014

Last October Dystonia Europe held its 21st Annual Conference and the 1st D-DAYS in Paris, France. About 120 participants, had gathered at Ibis Hotel in Northern Paris. The large audience consisted of dystonia specialists and national dystonia patient group leaders from all over Europe as well as dystonia patients from France and the US.

The conference extended over two days and simultaneous translation was offered in French and English. There were sessions on the latest research and treatment.

The formal General Assembly was held on the Sunday morning. There were no new nominations to the DE Board. One application for membership of Dystonia Europe had been received from the Finnish Dystonia Association. After the approval from the GA the Finnish delegate, Mari Susanne Olenius, presented the work of her association. During the session "Sharing Best Practice" delegates from Norway, Germany and France shared some successful projects of their national associations.

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

The David Marsden Award 2015

The 2015 Award of € 10,000 is generously sponsored by Ipsen Pharma and has been awarded to Dr Cathérine C S Delnooz for her paper on: "Task-free functional MRI in cervical dystonia reveals multi-network changes that partially normalize with botulinum toxin". The research was performed at the Radboudumc, Nijmegen, during Dr. Delnooz's neurology training. Currently she is a fellow at the movement disorders section, University Medical Centre in Groningen, The Netherlands.

This was selected by the adjudication committee of the DE Medical and Scientific Advisory Board, as the best paper submitted for this year's prize. A total of 16 papers had been submitted.

The formal presentation of the award took place at the 22nd Dystonia Europe Conference and 2nd D-DAYS, in Rotterdam, The Netherlands. After receiving the Award from Dystonia Europe President Robert Scholten, Dr Delnooz presented her paper.

The European Network for the Study of Dystonia Syndromes

This scientific research 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. 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 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 2014/2015, the following activities have taken place:

- The Third Training School of the project was held at the University Hospital in Groningen, The Netherlands in April 2015. Over 50 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 Groningen both Steering Committee and Management Committee meetings were held.
- Working group 3 Clinical Studies held a meeting in Groningen in April.
- 17 STSMs – short term scientific missions grants – were awarded 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

DE President Robert Scholten was invited to attend the General Assembly of the German Dystonia Association (DDG) last July. In March DE Executive Director Monika Benson took part in a dystonia meeting organised by the Finnish Dystonia Association.

There were other occasions when dystonia patients attended the same meetings as Dystonia Europe such as meeting members of the Swiss Dystonia Association at a Medical Meeting in Berne, American dystonia patients at the MDS in San Diego. At a medical congress in Slovenia discussions were held with a dystonia patient and neurologists about the possibility of starting a dystonia patient association in Slovenia.

The Dystonia Association of Czech Republic applied for membership of DE.

Projects

D-Days – The first D-DAYS took place in Paris on October 10-12, 2014. Programme and local organisation was handled by AMADYS President Stéphanie Frehel together with other members, as well as Professor Marie Vidailhet who was responsible for the scientific programme.

Jump for Dystonia

There is still a lot of misunderstanding about dystonia and it is crucial to increase awareness and spread information about the disease. The official launch of the awareness campaign "Jump for dystonia" took place in Paris, and has spread to all five continents.

People have been asked to Jump for Dystonia and the photos have been uploaded to a special Jump for Dystonia facebook page: <https://www.facebook.com/jumpfordystonia>.

The campaign has engaged and inspired dystonia patients all over the world who have created their own jump events at shopping malls, markets and schools, with friends and colleagues and sometimes with media coverage.

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

In November a special Jump for Dystonia event was organised in the EU Parliament in Strasbourg. About 40 MEPs from several of DE member countries received information about dystonia and jumped. The highlight of the event was when EU Commissioner Vytenis Andriukaitis joined and jumped for dystonia.

A total of about 5000 jumps have been received.

MyDystonia

MyDystonia (<http://www.mydystonia.com>) was launched last March and is a digital diary for dystonia patients where you can monitor symptoms, health and daily well-being by answering some simple and predefined questions. The data can be downloaded into a PDF-file which can be shared with the treating physician to optimize treatment and improve quality of life. The APP is available on-line and also in the APP-Store. French- and English-language versions of MyDystonia are now available as app and online. Versions in German, Italian, Norwegian, Swedish, and Russian are being prepared, and there are plans for versions in additional languages.

Dystonia Community

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. The project was introduced in Paris 2014. In 2015 the most important technical parts were developed. There are questions left we have to deal with, like questions of law and regulations and content management.

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, Medis) to present the work of Dystonia Europe.

Congresses

The 19th International Congress of Parkinson's Disease and Movement Disorders, San Diego, US

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.

The 1st EAN – European Academy of Neurology – Berlin, Germany

Dystonia Europe was present at the 1st EAN Congress in Berlin, Germany and had a booth together with the German Dystonia Associations.

European Partnerships

Activities with EFNA

EFNA held its General Assembly 2015 in Berlin, alongside the EAN. DE was represented by President Robert Scholten.

This year EFNA launched the interest group on "Brain Mind and Pain", an initiative together with Pain Alliance Europe (PAE), co-chaired by MEPs Marian Harkin, Jeroen Lenaers and Daciana Sârbu. The aim is to encourage research into and access to innovative treatments, promote prevention and self-management approaches, decrease stigma and work together to improve quality of life for people living with these disabling conditions. In June the first event was held in the Parliament under the theme "Preventing Neurological and Chronic Pain Disorders".

2016 & Beyond

The DE work and activities for 2015 and 2016 are planned around the Vision & Strategy Plan and the theme: **Connecting People for Dystonia**. This will be done by continuing the following projects:

1. **D-DAYS**
2. **Jump for Dystonia**
3. **MyDystonia/Dystonia Community**

The David Marsden Award 2017

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. Submission of papers for the award will be accepted from June 2016.

The award will be presented at the Dystonia Europe 24th Annual Conference and 4th D-DAYS event, in spring 2017, venue and date to be confirmed.

The European Network for the Study of Dystonia Syndromes

The project is coming to an end in its present form and the Final Conference “Unmet needs of dystonia” will be held in Milan, 16 and 17 October 2015. Discussions are under way among the Network leaders, to decide how to take the work forward after the current funding support ends.

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.

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 Washington USA, March 2016.

The 3rd Congress on Treatment of Dystonia, Hannover, Germany, May 2016.

The EAN Congress in Copenhagen May/June 2016.

The MDS Congress in Berlin, June 2016

Board Meetings

Meetings are planned to be held in January, April and October 2016.

The 3rd D-DAYS - Dystonia Europe 23rd Annual Conference and General Assembly 2016

The next annual meeting will take place on April 8-10 in Oslo, Norway.

Dystonia Training School

Dystonia Europe Vice President, Professor Maja Relja has suggested that DE takes the lead in organizing Dystonia Training School for young neurologists in Europe. The first one to possibly take place 2016/2017.

Members

Dystonia Europe consists of 21 national member groups from 18 European countries and they are:

Austria, Belgium, Croatia, Denmark, Finland, 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, Gold, Silver and Bronze.

We thank the following partners for becoming sponsors for 2014/15:

Platinum: Boston Scientific, Ipsen Pharma, Medtronic & Merz

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

Digital Platform/Dystonia Community – Ipsen Pharma, Medtronic, Boston Scientific

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

MyDystonia – Merz

D-DAYS 2015 – Allergan, Boston Scientific, Ipsen Pharma, Medtronic, Merz

Dystonia Europe is grateful to 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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