

## Annual Report 2016

### Message from President and Executive Director

Dear all,

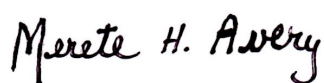
It is a great pleasure for us to present the Annual Report of 2016. We can look back at a year filled of many dystonia activities around Europe and beyond.

The highlight of the year was the 23rd Annual Conference and the 3rd D-DAYS which took place in Oslo. We collaborated with the Norwegian Dystonia Association and almost 100 participants attended the 2-day-meeting.

The work of **'connecting people for dystonia'** continued with several activities throughout Europe. In October we were invited to speak at the ENVI Committee Meeting at the EU Parliament in Brussels on "Living with a brain disorder – taking control of your life". The winning Skydive Jumps for Dystonia took place in Finland, Romania and Sweden. We continued our work on promoting the digital diary MyDystonia and the MyDystonia Ambassadors programme was launched. Each language has now a supporting Ambassador.

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.



Merete Avery  
President



Monika Benson  
Executive Director

## **Board, Staff & Volunteers**

### **Board**

President – Merete Avery, Norway  
Vice President – Maja Relja, Croatia  
Treasurer – Erhard Mätzener, Switzerland  
Board Member – Cristina Frosini, Italy  
Board Member – Sorin Ionescu, Romania  
Board Member – Monika Benson, Sweden

### **Advisors**

IT – Eelco Uytterhoeven, The Netherlands  
Research – Alistair Newton, UK  
Photographer D-DAYS – Stephan Röhl, Germany

**Executive Director** - Monika Benson, Sweden

## **Board Review**

Three board meetings were held during the year. The first one in January when the Board gathered in Lund, Sweden alongside the first Think Tank meeting. The next board meeting took place in April in Oslo alongside the D-DAYS 2016. The third board meeting of the year was once again held in Lund, after the Summer Think Tank meeting, beginning of July.

## **Communication Resources**

### **Website**

The Dystonia Europe website is the main channel for information and news to anybody interested in finding out about dystonia and Dystonia Europe. The news section is updated on a regular basis with reports on Dystonia Europe activities, members' activities and research news. The website has an average of 800 visits/month.

### **Newsletter**

DE News is issued twice a year, in autumn and spring. The two issues were sent by email to members and about 400 contacts in June and December. Printed copies were distributed at various meetings and conferences.

### **Printed Materials**

The Dystonia Europe information leaflet was revised and re-printed with the support of Medtronic. It was distributed at various meetings and congresses such as at: the MDS Congress in Berlin, the second EAN Congress in Copenhagen and at the Dystonia Europe 23rd Annual Conference, D-DAYS 2016, in Oslo.

### **Social Media**

There are three facebook pages. The Dystonia Europe Facebook page has increased its reach substantially since last year, and has now over 2600 followers. The goal has been weekly updates of DE activities as well as the latest news within the field of dystonia.

The Jump for Dystonia Facebook page has close to 3000 followers. This is the main page for the awareness campaign and even if activities have slowed down we keep the page for Jump photos that are still being submitted.

The third Facebook page is for MyDystonia, and has almost 400 followers and here updates on the APP are posted.

Other social media channels are: Twitter - 199 followers; Instagram - 239 followers; Youtube - 41 followers.

## **Activities**

### **The 23<sup>rd</sup> Annual Conference, 3<sup>rd</sup> D-DAYS & General Assembly 2016**

The Dystonia Europe 23rd Annual Conference and the 3rd D-DAYS was held in Oslo, Norway. About 100 participants, had gathered at the Clarion Royal Christiania Hotel. The large audience consisted of dystonia specialists, national dystonia patient group leaders from all over Europe and dystonia patients and family members from Norway.

The 2-day conference was a close collaboration with NDF – the Norwegian Dystonia Association and included sessions about the latest on research and treatment presented by both Norwegian and international dystonia experts.

The formal General Assembly was held on the Sunday morning. Erhard Mätzener was nominated by his organisation, the Swiss Dystonia Association, and elected to the DE Board. One application for membership of Dystonia Europe had been received from “Dystonie Förderverein Deutschland e.V.”. After the approval of the GA, DFDeV President Martina Kühn presented the association and its goals and activities. Dystonia Europe now consists of 21 member associations from 18 countries in Europe.

Then followed presentations on:

- Fund Raising strategies by Simona Biancu from Engaged-In.
- MyDystonia with Stefan Wiemann from Merz.
- EFNA & Under the Umbrella Campaign with Elizabeth Cunningham, Communication Coordinator, EFNA.

To finish the 3-day meeting an UndertheUmbrella event was held in the centre of Oslo. Press releases had been sent out by the Norwegian dystonia association. About 30 participants gathered in the square outside of the central station wearing orange t-shirts, standing or jumping Under the Umbrellas. Norwegian Television interviewed NDF Chairwoman Anniken Hagen and it was all broadcast on the Sunday evening news.

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

Sponsors of the meeting were: Allergan, Boston Scientific, Desitin Norway, Ipsen, Medtronic and Merz. Some of them had stands with information material in the exhibition area. We are very grateful for their support.

### **The European Network for the Study of Dystonia Syndromes – COST “Action” BM1101**

This scientific research network, focused completely on dystonia, 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. [www.cost.eu](http://www.cost.eu)

Dystonia Europe was elected Grantholder of the Network at its first meeting and DE Past President Monika Benson was a member of the Network Management Committee, led by the project instigator, Prof Alberto Albanese from Milan. The project was intended to create better networking among dystonia experts around Europe, and to raise awareness of dystonia among the public.

Twenty four countries took part - each with the possibility of two scientific representatives on the Management Committee - and the ten members of a Steering Committee created 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 project finances.

The four-year period of COST funding has now completed and information has been provided to DE members on the activities of the Network, in past DE Annual Reports. Although the initial work of the Network has been completed, there are many more international research collaborations which continue, and it has encouraged much more networking in the world of dystonia science.

Discussions are under way among the Network leaders, to decide how to take the work forward after the current funding support ends.

In the year 2015/2016, the following activities took place:

#### ***October 2015 – Final Conference – Milan – “Unmet needs in Dystonia”***

This successful two-day conference attracted around 100 scientists from all over Europe, and was an appropriate format with which to complete the Action, with many interesting presentations and question/answer sessions.

#### ***2016 – Final Publication***

An additional grant was obtained from COST, to create a scientific publication which draws together many of the strands of research interest during the project, and at the Final Conference. This has taken some time to bring together, but the completed Ebook should be available freely online by summer 2017.

### **Dystonia Europe Connecting with Dystonia Patient Associations**

DE President Merete Avery and Executive Director Monika Benson were invited to attend the General Assembly of the Norwegian Dystonia Association (NDF) in the outskirts of Oslo in March. They gave a presentation on the work of Dystonia Europe and also informed about the upcoming D-DAYS in Oslo.

In August Monika attended the final workshop of the Norwegian physiotherapy project, held in Tromsø, Norway. She gave a short presentation on Dystonia Europe, activities and projects.

Mid September, Executive Director Monika Benson travelled to Czech Republic where the Czech Dystonia Patient Association held a Jump for Dystonia event in the centre of Prague followed by a dystonia afternoon at the University Hospital.

The Belgian Dystonia Association organised a meeting for their members in Bruges last November. Monika was invited to share her dystonia story and to present Dystonia Europe.

There were other occasions when dystonia patients attended the same meetings as Dystonia Europe such at the Treatment of Dystonia Congress in Hannover where the Austrian Dystonia Association and the German Dystonia Association also participated.

### **Dystonia Europe Think Tank**

This year the Dystonia Europe Think Tank meetings were launched, with the purpose to provide a platform for the DE Board and the Platinum sponsors to meet and discuss activities and projects that can benefit dystonia patients. Themes of this year's meetings were: communication and strategy. At these meetings representatives from Boston Scientific, Ipsen, Medtronic and Merz shared their ideas and gave valuable input which contributed to fruitful discussions.

These meetings are held twice a year: in January and July. Both meetings were held in Lund, Sweden where Executive Director Monika Benson can arrange for meeting rooms free of charge.

## **Projects**

### **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 awareness campaign "Jump for dystonia" was launched in Paris in 2014. It reached its peak during 2015 and all together more than 10 000 jump photos were submitted. 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 photos with the most likes won a Skydive There were four winners and they came from Australia, Romania, Finland and Sweden. The Skydives took place throughout the year and were all filmed. At some of these events the national dystonia associations promoted their activities.

The campaign has engaged and inspired dystonia patients all over the world. During the campaign there was an increase in visits to the DE website and facebook pages. We believe the campaign has helped to make dystonia a little more known.

### **MyDystonia**

MyDystonia (<http://www.mydystonia.com>) is the digital diary for dystonia patients where you can monitor symptoms, health and daily well-being by answering some 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 as well as in APP-Store and Google Play. It's now available in 10 languages (English, German, French, Spanish, Italian, Danish, Norwegian, Swedish, Finnish, Russian) and has a little more than 1000 users.

### **MyDystonia Ambassador Programme**

In September the MyDystonia Ambassador Programme was launched to support the roll-out of the APP in Europe. The first meeting took place in Oberursel outside of Frankfurt with ambassadors from the UK, Germany, Ireland/Poland, Norway, Finland, Denmark and Spain. The main task of the Ambassadors is to support the users in their national language. For this purpose we developed the on-line tool MyDystonia Ambassador Net where the Ambassadors can share problems and have access to support materials, videos etc. The plan is to hold one MyDystonia Ambassador Meeting per year.

### **The David Marsden Award 2017**

Together with Ipsen the call for submission of applications for the DMA 2017 was launched at the MDS in Berlin. Flyers were distributed from the DE booth and special promotion was taking place at the Ipsen booth.

The 2017 Award of € 10,000 is for the fourth time generously sponsored by Ipsen Pharma.

## Participation at meetings & congresses

### Meetings

Throughout the year President Merete Avery and Executive Director Monika Benson have participated at various medical meetings arranged by the industry (Boston Scientific, Medtronic, Merz) to represent Dystonia Europe and sometimes present its work and activities.

### Congresses

#### ***The 3<sup>rd</sup> Congress on Treatment of Dystonia, Hannover, Germany***

Dystonia Europe took part in the Congress by having a booth in the exhibition hall.

#### ***The 20th International Congress of Parkinson's Disease and Movement Disorders, Berlin, Germany***

Due to a generous donation from Medtronic Dystonia Europe had a centrally located stand in the Exhibition hall which created an excellent opportunity to distribute material, connect and network with partners from the medical profession and from the industry. During the Medtronic Symposium the game "Who wants to become a DBS Expert?" put focus on DBS, Parkinson's and Dystonia. The winning prize was donated to the patient organisations.

#### ***The 2<sup>nd</sup> EAN – European Academy of Neurology – Copenhagen, Denmark***

Dystonia Europe was present at the 2nd EAN Congress in Copenhagen, Denmark.

#### ***DBS Expert Meeting, Würzburg, Germany***

Professor Volkmann organised together with Boston Scientific a DBS Expert meeting in Würzburg in December. DE was offered to have a stand in the exhibition hall. A special fund raising event of biking for dystonia and Parkinson's disease took place in order to raise funds for the patient associations.

## European Partnerships

### Activities with EFNA

EFNA held its **General Assembly 2016** in Copenhagen, alongside the 2nd EAN Congress. DE was represented by President Merete Avery and Executive Director Monika Benson. Monika was elected to the board of EFNA.

The meetings and the work of the interest group on "**Brain Mind and Pain**", an initiative between EFNA and Pain Alliance Europe (PAE), continued. 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. DE attended some of the workshops organised. For more information <http://www.brainmindpain.eu/events/>

### **EFNA European Patient Advocacy Award 2016**

EFNA held – once again – its Neurology Advocacy Awards. These awards recognise the contribution of an individual or group to the development and promotion of advocacy for people with neurological disorders in Europe.

This year's winners were presented with their awards at a Gala Dinner in Dublin on October 13<sup>th</sup>. Our Founder President and former Executive Director, Alistair Newton was presented with the European Patient Advocate Award.

<http://efna.net/efna-announce-winners-of-neurology-advocacy-awards-2016/>

EFNA launched its **Training Initiatives for Neurology Advocates [TINA]** in Dublin. These workshops are intended to increase knowledge and skills of patients advocates within themes such as: communication, campaigning, governance, research etc. Dystonia Europe President, Vice President and Executive Director took part.

### **ENVI Committee Workshop in the EU Parliament:**

#### **Living with a Neurological Brain Disorder – Taking Control of Your Life**

As part of the collaboration initiated in 2014 with MEP Glenis Wilmott DE was invited to take part in an ENVI workshop at the European Parliament. The aim of the workshop was to provide background information about the main characteristics of neurological brain disorders, as well as to identify new strategies and innovative tools to better support the prevention and treatment of these diseases. The MyDystonia APP was presented by Executive Director Monika Benson, illustrating how mHealth tools can better support treatment for patients affected by brain disorders.

Consultant Paediatric Neurologist Dr Jean-Pierre Lin gave a description of generalised dystonia that affects children for a lifetime, he believes that mobile health apps can assist a child transition into adulthood and help put the patient in control.

[http://www.europarl.europa.eu/RegData/etudes/STUD/2016/595331/IPOL\\_STU\(2016\)595331\\_EN.pdf](http://www.europarl.europa.eu/RegData/etudes/STUD/2016/595331/IPOL_STU(2016)595331_EN.pdf)

### **Member of European Patients Forum - EPF**

At the EPF General Assembly in March Dystonia Europe became a member of European Patients Forum. EPF has over 70 members who represent specific chronic disease groups at EU level or are national coalitions of patients. The EPF vision is that all patients with chronic and/or lifelong conditions in the EU have access to high quality, patient-centred equitable health and social care.

There are many benefits for DE being a member of EPF. Dystonia Europe is included in a large European Patient Advocate network and opportunities for partnership and collaboration increase. EPF also offer various training initiatives and workshops for patients advocates.

### **Biopontis Alliance**

BioPontis Alliance partners with patients' organizations and academic researchers to bridge the gap from promising science to medicines, ready for uptake by the biopharmaceutical industry. Dystonia Europe joined together with representatives of other patient organisations in a workshop held in Leuven last June.



## 2017 & Beyond

### Vision & Mission

**The Dystonia Europe Vision is better quality of lives for people living with Dystonia in Europe, while supporting the search for a cure.**

We will achieve our vision through the following core activities:

- **Raise awareness** and be the leading voice in Europe on the impact of Dystonia.
- **Share the knowledge** – provide the latest information and resources for our members and also be the source of information for the other stakeholders.
- **Connect people** with Dystonia, member organizations, healthcare professionals, European policymakers and the treatment industry to close the gaps of today's dystonia treatments.
- **Foster training and education** and educate multidisciplinary teams and stakeholders along the dystonia journey to optimize care and improve quality of life.

### Activities and projects in 2017

#### Board Meetings

Meetings are planned to be held in January, May and July. Eventually there will be an extra board meeting in the autumn due to new members on the board.

#### Think Tank Meetings

Two meetings are planned for 2017 in January and July, in Lund, Sweden. The themes of this year's meetings are: Communication and Fund Raising.

#### Connecting with Dystonia Patients

Dystonia Europe continues its work to reach out to dystonia patients/groups in other countries. Regions/cities 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.

#### Communication

To stay in touch with our members and all stakeholders we continue our work to develop newsletters and social media channels. Due to a recent grant from Google for non-profits we will focus much work on the information available on the Dystonia Europe webpages and how to increase the awareness and visits to website via Google Ad Words.

#### Dystonia Europe at Congresses

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

In 2017 DE will attend The EAN Congress Amsterdam in The Netherlands.

#### Dystonia Europe 24<sup>th</sup> Annual Conference, D-DAYS 2017 & General Assembly

The event will take place in Rome 12-14 May at the IBIS Styles Roma Hotel in collaboration with ARD, the Italian Dystonia Association who are also celebrating their 25<sup>th</sup> Anniversary.

## **Dystonia Europe 25<sup>th</sup> Anniversary Conference and General Assembly 2018 & the 5th D-DAYS**

Venue and dates will be announced shortly.

### **The David Marsden Award 2017 & 2019**

The 2017 award will be distributed at the D-DAYS in Rome.

A special website is being developed for the David Marsden Award with the purpose to promote the current winner as well as all past winners. From 2018 it will be possible to submit the application for the DMA 2019 directly via the new website where the Adjudication Panel will be able to log in to make evaluations on-line.

### **MyDystonia & MyDystonia Ambassador Programme**

The roll-out of the APP will continue and we will work in close partnership with our MyDystonia Ambassadors. The annual Ambassador meeting will take place alongside the D-DAYS in Rome.

### **Dystonia Europe Patient Survey**

Professor Maja Relja and the Medical School of Zagreb, Croatia, has developed the Dystonia Survey where patients are asked questions on time of diagnosis, access to treatment and quality of life. The Survey has been translated to several languages and can be accessed via a special Dystonia Europe Survey platform. The Survey will be launched at the D-DAYS in Rome and we ask the support from our members to promote it. Professor Relja will analyse the answers by the end of this year.

For the purpose of this survey a special Dystonia Europe Survey platform has been developed which will be used for all future surveys.

## Members

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

Austria, Belgium, Croatia, Czech Republic, Denmark, Finland, France, Germany, Ireland, Italy, 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 Platinum sponsors for 2017:

Boston Scientific, Ipsen Pharma, Medtronic & Merz

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

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

MyDystonia & MyDystonia Ambassadors Programme – Merz

D-DAYS 2017 – Boston Scientific, Ipsen Pharma, Medtronic, Merz

David Marsden Award 2017 – Ipsen Pharma

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, EPF – European Patients Forum, EBC – European Brain Council, MDS – International Parkinson and Movement Disorder Society.

## Contact

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