

Connecting People for Dystonia

# DYSTONIA EUROPE NEWS

## AUTUMN 2015

**European Dystonia Research Network Conference in Milan**



*Participants gathered in front of Humanitas Research Hospital in Rozzano Milan, where the conference "Unmet Needs of Dystonia" took place. Read more on page 8 & 9.*

[www.dystonia-europe.org](http://www.dystonia-europe.org)

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**Dystonia Europe  
connecting people to  
spread information  
raise awareness &  
promote research.**

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## President's Message



Dear all,

After being the secretary of the Dystonia Europe board for two years and being nominated for re-election by the Norwegian Dystonia Association, I very carefully considered the board's proposal to appoint me as

President. It is an important and time-consuming role, and I look forward to working, along with the rest of the board, our partners and sponsors, for people with dystonia.

The Past President, Robert Scholten, decided not to seek re-election at our General Assembly in Rotterdam this year. On behalf of the DE board, I thank him for the time and effort he has contributed over the past two years, in support of DE's work to improve the lives of people living with dystonia.

The DE board membership is undergoing several changes, but we also have retained much experience and stability. Vice President Maja Relja has been involved with dystonia for her entire career, both as a Medical Professional and with patient group involvement. She represented Croatia at the founding meeting of European Dystonia Federation (now, Dystonia Europe) in 1993, and she has been on the DE board since 2011. Executive Director Monika Benson was President of DE for 6 years prior to becoming the Executive Director 2 years ago. Both continue on the board and possess a very high level of competence and experience which is invaluable. In addition I am grateful that several new people have agreed to become board members. Sorin Ionescu, from Romania, has been elected and Erhard Mätzener, from Switzerland, has been appointed as our new Treasurer.

The board of Dystonia Europe will do its best to continue the work of past years, to stimulate research for more effective treatment and, ultimately, to find a cure and improve the quality of life for people living with dystonia.

I was the Chairwoman of the Norwegian Dystonia board for 3 years from 2010. I believe that some of

my experience in that role will be beneficial in the work that lies ahead of us.

Also I am grateful for the excellent work and achievements of the people who founded and developed the organisation to what it is today. DE is an organisation with strong co-operation and collaboration with our partners, medical professionals and member organisations. I want to extend a thank you to all past board members and Officers. Especially I have to thank Alistair Newton, for his invaluable dedication and outstanding work for our organisation. Alistair was the founding President of DE in 1993 (then called EDF – European Dystonia Federation) and has been extremely active in our work for more than 20 years. He was also our Executive Director for many years and he has continued to deal with DE's responsibilities as Grantholder of the European Dystonia Research Network since his retirement in 2013. This responsibility comes to an end very soon, and we wish Alistair and his family a long, happy and very active retirement in the years ahead.

We are very pleased that one more dystonia association, Rodina spolu z.s., from the Czech Republic, was accepted as a member of DE at the General Assembly in Rotterdam. We are now 20 member organisations throughout Europe. The D-DAYS 2015 was held in Rotterdam, along with the Dutch Dystonia Association's 30th Anniversary, and was a great success. D-DAYS 2016 will be held 8 – 9 April in Oslo, Norway at Hotel Clarion Royal Christiania and we are working together with the Norwegian Dystonia Association to make it a memorable event that will benefit the patients, and strengthen the collaboration among our partners, sponsors, member organisations and medical professionals.

I have been greatly inspired by so many people I have met during my years in the Norwegian Dystonia Association, and in Dystonia Europe, and I look forward to the development of the foundations they have laid, to meet the challenges ahead.

The best wishes for the holidays and for the year 2016.

*Merete Avery*

### Dystonia Europe D-DAYS & General Assembly 2015 in Rotterdam

The 22nd Dystonia Europe Annual Conference took place on the SS Rotterdam 2-4 October. SS Rotterdam, also known as "The Grande Dame", is a former ocean liner and cruise ship, and has been a hotel ship in Rotterdam since 2010.

In addition to the D-DAYS, the 30th Anniversary of the Dutch Dystonia Association was held on the ship on Saturday 2 October. Over 300 patients from the Dutch Dystonia Association had come to the ship for the Family Day. They could choose to participate in several workshops and activities that were offered. The D-DAYS medical conference consisted of a very high level of medical presentations related to dystonia. Health professionals specializing in dystonia and movements disorders from all over Europe were present. Some of the topics at the conference covered Physical Therapy, Potential New Drugs for Dystonia, Rehabilitation, Diagnostic Strategies, Dystonia and Complex Regional Pain Syndrome, Non-Motor symptoms in Dystonia, Genetics and more. If you would like to read more about these topics, please visit the Dystonia Europe website where you will find the abstract book at <https://dystonia-europe.org/wp-content/uploads/2014/05/Abstract-Book-D-DAYS-2015.pdf>

At the conference the David Marsden award was presented to Cathérine C S Delnooz. Read more on page 7.

#### General Assembly

The DE General Assembly was held on Sunday 4 October. Delegates from 11 member associations were present. Robert Scholten welcomed everybody and then announced his withdrawal not to stand for re-election. Vice President Maja Relja continued to chair the meeting which included presentation of accounts, annual report, budget 2016, activities for next year and elections.

After the GA, there were sessions of "Best practices". Four member associations made the following presentations:

Capucine Devred and Edwige Ponseei from Amadys in France presented the "delegation force". The main goal is to motivate, and improve information and support to dystonia patients. They visit treatment centers, gather information and focus on

communication. Every delegate in the programme receives a backpack with leaflets and all the information needed to support patients. The delegates in the "delegation force" have a closed group on internet. The project is funded by Ipsen.

Susanne Olenius from the Finnish Dystonia Association presented how her association had worked with dystonia awareness using the Jump for Dystonia campaign. She had collected fun and creative Jump photos in a book that she presented and then handed over to Monika. Like Susanne said, it started with Monika and her idea to "Jump for Dystonia" when she was in Africa with her daughter, who agreed that this was a great idea. Finland is one of the winners in the Jump for Dystonia Skydive contest. This ultimate jump will take place some time in spring 2016.

Sabina Gall and Catalina Crainic from The Dystonia Association "Children's Joy", in Romania, presented "the road to treatment". Sabina started with thanking DE and Ipsen for their support and help. In Romania Dystonia is very underdiagnosed. The association signed a petition with the government, to receive free botulinum toxin treatment for dystonia patients. This year they received a positive answer from the Health Ministry and the National Health Insurance. The injections will from now on be free of charge for dystonia patients. Monika Benson paid a visit to Romania two years ago, which has helped this case move forward.

Sorin Ionescu from the other Romanian Dystonia Association, gave a presentation about dystonia and media. It is important to spread information about dystonia through media. In this way we can reach a lot of people. He also pointed out how to integrate this in everyday life. Sorin showed pictures that have been published in the Romanian press, and how he was successful in spreading information about dystonia. There has been information on the radio, in local and national newspapers, online newspapers and even in a TV campaign. Media means visibility and awareness. He encouraged the DE members to post pictures on Facebook, to share and like. In this way, more people will hear and learn about dystonia. Sorin was nominated from his organisation to the DE board and was elected at the GA as a board member.

## Latest News

### Moments from the D-DAYS in Rotterdam





*Dystonia Europe Board 2015*

Last November the new Dystonia Europe Board met in Oslo, Norway to plan for the work ahead, with special focus on the upcoming D-DAYS in Oslo.

The new board consists of from left to right: Sorin Ionesco, Board Member, Monika Benson, Board Member and Executive Director, Merete Avery, President, Maja Relja, Vice President, Erhard Mätzener, Treasurer.

We would like to thank you for the support and interest you have shown for dystonia and Dystonia Europe in 2015.

It was a busy year with many activities such as: D-DAYS in Rotterdam, Jump for Dystonia events in many places around Europe, participation at several meetings and congresses, and the final conference of the Dystonia Research Network Project.

We now look forward to 2016 and to continue our work on various projects to raise awareness, promote research and connect people for dystonia!

**From all of us to all of you, Merry Christmas and Happy New Year!**

*Dystonia Europe Board*



### 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.

### Task-free functional MRI in cervical dystonia reveals multi-network changes that partially normalize with botulinum toxin

Cervical dystonia is characterized by involuntary, abnormal movements and postures of the head and neck. Current views on the pathophysiology of dystonia, such as faulty sensorimotor integration, abnormal sensory processing, and impaired motor planning, are largely based on studies of focal hand dystonia.

Using resting state functional MRI, we explored whether cervical dystonia patients (n=23) have altered intrinsic functional brain connectivity compared to healthy controls (n=22), by investigating 10 resting state networks. Scans were repeated immediately before and some weeks after botulinum toxin injections to see whether connectivity abnormalities, if any, were restored.

We showed that cervical dystonia patients have reduced connectivity in selected regions of the prefrontal cortex, premotor cortex and superior parietal lobule within a distributed network that comprises the premotor cortex, supplementary motor area, primary sensorimotor cortex, and secondary somatosensory cortex (i.e., the sensorimotor network).

With regard to a network originating from the occipital cortex (i.e., the primary visual network), selected regions in the prefrontal and premotor cortex, superior parietal lobule, and middle temporal gyrus areas have reduced connectivity. In contrast, increased connectivity in selected regions of the prefrontal, premotor, primary motor and early visual cortex was found within a network that comprises the prefrontal cortex including the anterior cingulate cortex and paracingulate cortex and parietal cortex (i.e., the executive control network).

Botulinum toxin treatment resulted in a partial restoration of connectivity abnormalities in the sensorimotor and primary visual network.

These findings demonstrate the involvement of multiple neural networks in cervical dystonia. The reduced connectivity, which is partly modifiable, within the sensorimotor and primary visual networks may provide the neural substrate to expect and explain defective motor planning and disturbed spatial cognition.

Increased connectivity within the executive control network suggests excessive attentional control and while this may also be a primary trait, perhaps contributing to abnormal motor programming and execution, this may alternatively serve a compensatory function in order to reduce the consequences of the motor planning defect inflicted by the other network abnormalities.



DMA winner Dr Cathérine C S Delnooz



**European Co-operation in Science and Technology**

## **European Dystonia Research Network:**

European Network for the Study of Dystonia Syndromes COST Action BM1101  
Research Network Report - autumn 2015  
Professor Alberto Albanese, the Research Network Chair, tried hard for many years to create such a network for dystonia research. After many applications to other funders, he finally found support from COST in 2011. Funding from the COST Association does not support research projects directly, but is focussed on developing networks of scientists to encourage international collaboration.

The money for the research projects needs to be found from other sources. Our COST grant arrangements cover the 4 year period to November 2015 and, at the time of writing this article, we are in the final phase of our relationship with COST. The main successes in our Network since its formation in 2011 have been in three main areas:

### **1. Training Schools**

Bol, Croatia, 2012 - Organiser - Prof Maja Relja

London 2013 - Organiser - Prof Kailash Bhatia

Groningen, 2015 - Organiser - Prof Marina de Koning-Tijssen

These Schools were 3-day events, covering clinical and research aspects, with grants to participants to support the cost of attending.

### **2. Short Term Scientific Missions (STSMs).**

Over the four years of the COST funding, the Network awarded 40 grants to young scientists, to allow them to study for short periods with dystonia experts in other countries.



The Training Schools and STSMs have provided facilities for more than 200 young scientists and clinicians to learn more about dystonia and its treatment and research. This was done in a practical way, by ensuring that the participants benefitted from the experience of many prominent dystonia experts. This is, clearly, an important factor in generating much more interest and more awareness for dystonia in Europe, especially among young medical professionals.

### **3. The formation of an online registry of clinical and genetic data**

The project has been funded from non-COST sources, and led by Prof Thomas Gasser and Dr Kathrin Grundmann, from Tuebingen, Germany.

The Registry and Biobank is managed in a secure online facility, and allows dystonia clinicians and scientists to share anonymised genetic data for collaborative research. The preparation work is ongoing and this extremely valuable facility will continue to be developed as a central function of the Network.

### **Events in 2015**

#### **Training School - April 2015**

This year's Training School was organised by Prof Marina de Koning-Tijssen in Groningen, The Netherlands, and was greatly enjoyed by over 50 young medical specialists, most of whom received funding support from the Network to attend.

Presentations by senior dystonia experts from across Europe were interspersed with teaching sessions with dystonia patients and plenty of opportunities for questions. The social and networking aspects of the event were also a great success and the excellent facilities of University Medical Clinic Groningen were much appreciated. The historic university city of Groningen provided a very interesting and lively setting for all participants.

### Final Conference

The Final Conference of the Network's partnership with COST was held on 16/17 October 2015, in the congress centre attached to the new Università Humanitas, near Milan, where Prof Albanese is now based. The title of the meeting was "Unmet Needs in Dystonia" and it was a great success, with around 100 participants from more than 20 countries, and plenty of discussion of what the 'unmet needs' are - to be considered for research in the future.

### Final Publication

The Network will produce a final publication, with support from COST, and authors have been invited to write chapters in various scientific areas surrounding dystonia. Further information on this publication will be available in future editions of DE News.

### The way forward for the Research Network

As the funding from COST comes to an end in November 2015, the Network has already begun to consider how to build on what has been achieved so far. The Network Management Committee and

Steering Committee meetings in Milan discussed various possibilities for larger-scale research projects, and how DE will continue to be involved in the

Network activities. In addition, Dystonia Europe's Vice President, Prof Maja Relja, has proposed that our organisation should continue the organising of Training Schools for young clinicians and researchers, and more news of this and other developments will be publicised in due course.

*Alistair Newton*



*Alistair Newton, Professors Alberto Albanese and Maja Relja*

### **The European Paediatric Neurology Society First International Symposium on Neuromodulation in Children, Vienna 25-26 May 2015**

The purpose of this two-day satellite symposium was to bring together the combined expertise of those involved in neuromodulation in children to enable us to learn from each other.

The full programme and speakers can be found on the EPNS symposium webpage.

<http://www.epns2015.org/cms/upload/bodytext/Flyer04May2015.pdf>

Readers may be surprised to learn that neuromodulation for movement disorders is fairly recent compared to other fields such as neuromodulation for deafness, long-standing incontinence or intractable epilepsy.

Do different conditions face similar decision-making to those of a child, young person or family considering the prospect of deep brain stimulation for dystonia?

We learned that this was very much the case and cochlear implantation for profound sensorineural deafness is a good example to begin with.

We all know that a child born with severe sensorineural deafness will not speak, though they may readily learn sign language and lip read. In fact deafness in children occurs in 1/1000 live births and has a range of varying causes from genetic, metabolic and acquired insults such as early meningoencephalitis or cytomegalovirus infections.

So in the 1980's when cochlear implantation became possible, only children who had suffered acquired deafness, for instance after meningitis and had previously already learned to talk, were offered a cochlear implant.

The reasoning was that the child already had learned language and all that the cochlear implant could do was to restore hearing. The policy was therefore to

offer a cochlear implant to children over the age of five years and to exclude deaf children with no previous language skills.

Over the next 15 years, from 1980-1995 this policy was radically overturned because evidence showed conclusively that the earlier the cochlear implant and the longer the child had been implanted, the better the results in terms of language and communication skills, particularly if the cochlear implant was offered under the age of 5 years and the child had more than four years experience of hearing with a cochlear implant.

The new data in fact showed that babies born deaf could learn to hear and speak if the cochlear implant occurred before the first year of life, that is, even before the child had learned to speak.

Now this is a very interesting discovery because it tells us that if you are born deaf or suffer deafness in the first year of life before you have learned to understand language or speak and you are offered a cochlear implant after the age of five years, the results are poor and restricted to possibly acquiring enough hearing to use to navigate using sounds indoors and outdoors, but you are very unlikely to understand the spoken word or to speak. But the earlier the cochlear implant the greater the chance of hearing the spoken word at normal voice level and of learning to speak.

Transcutaneous neuromodulation for bowel and bladder incontinence also depends on a critical 'window of opportunity' between 2-3 years of age: that is, the typical age at which we develop potty training.

Respective epilepsy surgery for intractable seizures in childhood is also more successful under the age of five, because it reduces the harmful effects of long-standing epileptic discharges on the developing brain.

Now we come to the important issue of the timing of deep brain stimulation for dystonia in children. The last 20 years' experience of DBS indicates that early surgery after the onset of dystonia symptoms produces the best results.

In young people, best results are obtained before skeletal maturity, that is therefore, before puberty. Indeed, some centres may advise against DBS if there is severe spinal deformity (scoliosis) or fixed joint deformities because the presence of these persists after DBS.

How can a child with early dystonia avoid or reduce the risk of deformities, maximise the possible benefits of DBS and at the same time increase the likelihood of a more normal development?

Well, the experience from other fields of neuromodulation for disabling problems such as deafness, epilepsy and incontinence is to offer neuromodulation as soon as possible, once the chronic nature of the condition has been established and it is clear that conventional medical and physical therapies are not going to help.

Of course, a child or young person with a typical (but rare) genetic dystonia caused by the DYT-1 gene will usually have acquired a normal set of motor, language, social and cognitive milestones before the onset of the dystonia and then usually be referred for DBS within one or two years of symptom-onset.

Cerebral palsy (CP) which occurs in 2/1000 live-births, commonly causes dystonia. Of course this usually presents within the first year of life. Those cases of CP offered DBS will almost certainly be over the age of 7 years in most centres, but more typically over the age of 10 years. So currently we are practising DBS implantation in the same way as the early cochlear implant pioneers practised in the early 1980's.

Milder forms of CP dystonic-choreoathetosis who can speak, use their hands and walk can still benefit from DBS implantations in their teens and early adulthood. But more severely affected children receiving DBS after the age of 5, 10 or 15 years will not benefit as much, because of a lack of underlying motor skills. Instead, they will feel a little more comfortable, sleep better, achieve longer periods of comfortable sitting, look better nourished and enjoy going to school and after school activities : still beneficial in the eyes of the child and carers.

### Conclusion

We need to learn from the history of other neuromodulation fields in children and also develop a strategy, through well-planned clinical research, to offer early DBS for dystonia while the brain still has the capacity to make developmental progress, to maximise the benefits of neuromodulation and reduce the burden of years of disability and dependency in children.

This will require an evaluation of the social and educational benefits of DBS for dystonia in children, not just measurements of dystonia reduction.

*Jean-Pierre Lin*

*Consultant Paediatric Neurologist*

*Complex Motor Disorders Service,*

*Evelina London Children's Hospital, London, UK*



*Dr. Jean-Pierre Lin*

*The following articles, page 12 –15, make reference to certain companies and their products and any opinions expressed should not be taken to be the views of Dystonia Europe or its members.*

*The articles are written by respected authors and are provided for the information of Dystonia Europe News readers.*

### EU approval for Medtronic DBS systems improves access to full-body MRI scans



Deep brain stimulation patients will for the first time have access to full-body MRI scans – with no interruption to their treatment – thanks to DBS systems approved in April this year by European regulators.

DBS therapy, an increasingly common treatment for neurological movement conditions like Parkinson's or Dystonia uses a surgically implanted medical device, similar to a pacemaker, to deliver mild electrical pulses to specific areas of the brain.

It's estimated that seven out of 10 patients eligible for DBS therapy may need an MRI following their implant.<sup>1</sup> But until now, such patients have had to turn their DBS systems off for scans – or forego MRI altogether due to the potential health risks and complications of using the two technologies together.

The extended approval applies to systems in Medtronic's Activa® portfolio of DBS therapy products – making these the first and only systems classified as 'MRI full-body conditional' in Europe.

People with movement disorders receiving deep brain stimulation (DBS) therapy finally have the option of full-body MRI scans<sup>2</sup> – without having to switch off their device.

#### About Medtronic

Medtronic plc, headquartered in Dublin, Ireland, is a global leader in medical technology – alleviating pain, restoring health, and extending life for millions of people around the world.

The development means an estimated 13,000 existing Medtronic DBS patients in Europe – as well as those receiving a new system – will now have improved access to MRI technology.<sup>2</sup> Dr John Thornton, medical physicist at the National Hospital for Neurology and Neurosurgery in London, said: "MRI is commonly the method of choice when diagnosing disease or monitoring existing conditions, but its use has often been limited in patients receiving DBS therapy.

Patients receiving DBS therapy can now receive more advantages of MRI.”

Ludvic Zrinzo, neurosurgeon at the National Hospital for Neurology and Neurosurgery, added: “Most conditions which may require MRI.

The ‘MR Conditional’ Activa® systems mean patients can receive DBS care, and may still have the option of MRI when needed to manage other conditions.”

To obtain approval for its ‘MR Conditional’ DBS systems, Medtronic developed proprietary test and measurement systems, together with advanced electromagnetic modelling tools. Existing Activa® DBS systems were rigorously tested and evaluated across millions of simulated patient scans spanning over 38,000 unique implant conditions to demonstrate patient safety<sup>3</sup>.

Lothar Krinke PhD, vice president and general manager of the Brain Modulation business at Medtronic, said: “We are proud to be the only company to offer DBS systems to patients across Europe allowing them access to full-body MRI technology. Continuous advancements such as these set Medtronic apart and reinforce our commitment to the field of brain modulation.

1. *Based on recommendations by European and national medical societies.*
2. *Under specific conditions of use. Before conducting an MRI examination on a patient with any implanted Medtronic DBS device, please refer to the MRI guidelines for Medtronic deep brain stimulation systems located in English at [www.medtronic.com/mri](http://www.medtronic.com/mri).*
3. *Medtronic testing data on file.*

“  
Patients  
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of MRI  
technology  
Dr John Thornton  
”



20<sup>th</sup> International Congress of Parkinson's Disease  
and Movement Disorders  
JUNE 19-23, 2016 • BERLIN, GERMANY  
[www.mdscongress2016.org](http://www.mdscongress2016.org)



“I am a neurologist in an academic environment. As a professor of Neurology at the University Department in Würzburg, I have a strong research and clinical interest in movement disorders.”

**Prof Jens Volkmann**, Chairman of the Department of Neurology at the University Clinic Würzburg, Germany



### 3 Questions for Prof Jens Volkmann

#### **What is your experience with deep brain stimulation and movement disorders?**

“During my medical studies I focused on the area of movement disorders and since 1995 I have worked in the field of deep brain stimulation (DBS). At that time I was working together with Prof Sturm in one of the first centers to perform DBS in Cologne, Germany.”

#### **What do you like most about your job?**

“I like most about being a movement disorder specialist that we have many treatments available today that, like DBS, have a profound impact on improving patients’ lives.”

#### **What’s your one piece of advice for people with dystonia?**

“Consult a specialist early and look for an expert that can accompany you throughout the course of your disease.”

#### **The ‘Sweet Spot’ in Deep Brain Stimulation: How New Directional Systems May Advance Treatment of Dystonia**

“When I started working in neurology 25 years ago, the neurologist was basically the one physician, who knew everything about the

patient. He could come up with a perfect diagnosis but unfortunately there was nothing he could do to help the patient,” Prof Jens Volkmann, Director and Chairman of the Department of Neurology at the University Clinic Würzburg, recalls the beginning of his medical career. Today, there are a variety of therapy options available to treat movement disorders.

#### **Deep brain stimulation** – a universal treatment for movement disorders

Today, there are a variety of therapy options available to treat movement disorders. One of these therapies is deep brain stimulation (DBS). “DBS is a method to treat disorders caused by dysfunctions of brain circuits. This is particularly well established for movement disorders such as dystonia, Parkinson’s Disease or tremor, where the circuits are well researched and one knows where to intervene and to block the spread of abnormal activity.” DBS therapy involves mild electrical impulses generated by a stimulator, implanted around the chest, similar to a pacemaker. The electrical stimulation travels along thin wires, called leads, to specific areas of the brain. In Europe, DBS is approved for the treatment of Parkinson’s disease, essential tremor, parkinsonian tremor and primary and secondary dystonia and may help improve daily life for patients.

Fewer side effects and improved symptom control

The advanced technology of the new DBS systems not only supports physicians in providing personalized therapy, it also changes the risk-benefit relation of the procedure significantly. “Conventional systems were not able to deliver precise electrical signals. In addition, minimal deviations in the positioning of the electrodes that were inherent to this complicated procedure might have decreased potential treatment outcomes. With the new directional system, such uncertainties can be compensated through the programming after the surgery,” says Prof Volkmann, “You can think of the new directional system as a lighthouse. Similar to the light, electrical signals can be steered in certain directions by programming the electrodes, and thus avoiding side effects caused by unwanted stimulation of neighboring brain areas.”

### First successful implants in Germany

Three patients living with Parkinson’s Disease were implanted with the new directional DBS system by Prof Volkmann in cooperation with Prof Cordula Matthies, Head of Functional Neurosurgery at University Clinic Würzburg, in September 2015. “The first implants demonstrated the advantages of the new directional system. We hope results will be similar in the treatment of dystonia. This is currently evaluated in patients living with the disease. In the beginning we tried to simulate an old DBS system using a conventional way of programming but we did not achieve full symptom control and could not lower the side effects. Only when we started using the current steering technology were we able to optimize the therapy for our three patients. They are all doing well now.”



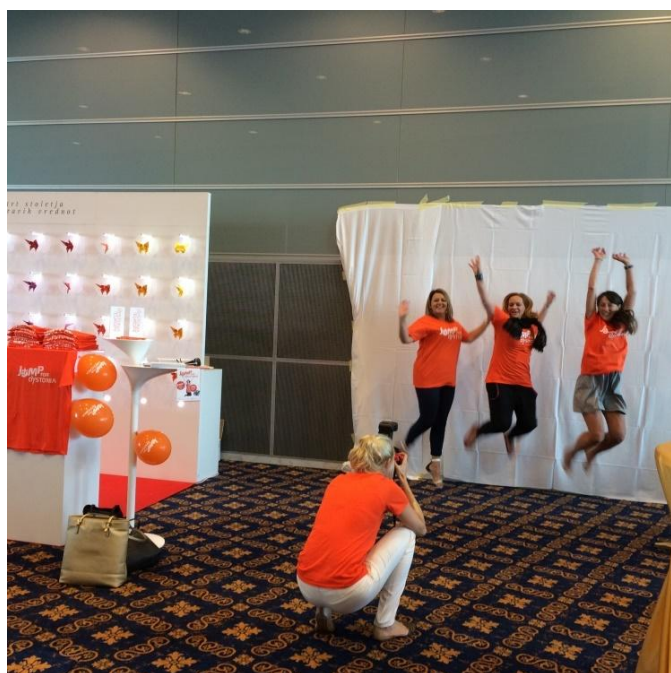
*Image courtesy of Boston Scientific Corporation.*

### Health Professionals in Slovenia learn about Dystonia

The Medical Congress "Heart & Soul" held in Portoroz, Slovenia, last September, attracted about 400 participants: family doctors, physiotherapists, nurses and many others from the medical field in Slovenia. Dystonia was one of the topics on the programme and after Neurologist Nina Zupancic, Ljubljana, had explained to the audience about dystonia: symptoms, diagnosis and treatment, Monika Benson told her dystonia story. A dystonia patient from Slovenia, Tedy, shared his story and how DBS treatment brought him back to life. We would like to thank Medis, distributor of botulinum toxin Xeomin in Slovenia, who helped to raise awareness by giving out Jump for Dystonia t-shirts and encourage people to JUMP for dystonia in the exhibition hall. The day before, Medis had organised a press conference at the Neurology Department of the University Hospital in Ljubljana. Together with Professor Zvezdan Pirtosek and Dr. Nina Zupancic, the possibility of founding a dystonia patient association in Slovenia was discussed.



*DE Executive Director, Prof Zvezdan Pirtosek and head nurse Lidija Ocepek.*



*Jump for Dystonia photo shoot in Slovenia.*



*Jelena Ivanović Repac, Medis*

### Dystonia Europe at MDS in San Diego

Last June the 19th International Congress of Parkinson's Disease and Movement Disorders took place in San Diego, USA. 3,700 people from 82 countries attended the four-day congress. Dystonia Europe and other non-profit organisations such as DMRF (Dystonia Medical Research Foundation), Michael J Fox Foundation had tables next to the exhibition hall. Many visitors came by to get information about DE and our projects such as MyDystonia, or to take part in the Jump for Dystonia campaign. Next year the MDS will take place in Berlin, end of June.



*DE Executive Director met DMRF San Diego Support Group leaders, Susi Pensel and Martha Murphy.*

### DE and DDG at EAN in Berlin



*DDG President Ute Kühn and Klaus Schweiger, leader of the regional groups in Germany.*

The first EAN Congress (the European Academy of Neurology) took place in Berlin, June 20-23, 2015, with 6400 participants from 106 countries attending.

The German Dystonia Association – DDG, had a booth in the exhibition hall with information about the work of their association. Dystonia Europe material was also available, and Chairwoman of DDG Ute Kühn, helped to promote the dystonia awareness campaign Jump for Dystonia, by encouraging people to JUMP. The EAN President Professor Günther Deuschl said: "The feedback was overwhelmingly positive. We take it as a message from this congress that our members want us to cover the whole spectrum of neurology. We are happy that the congress was a meeting point of all the subspecialties. Neurology is in the privileged position to have not only a unified voice for Neurology in Europe but also many specialty societies. They emphasize that at the EAN congress the neurological generalist meets the neurological specialist and the specialist can update his/her general neurology knowledge." The second EAN Congress will take place in Copenhagen, Denmark next May.

### Merz Leaders Connecting with Dystonia Patient

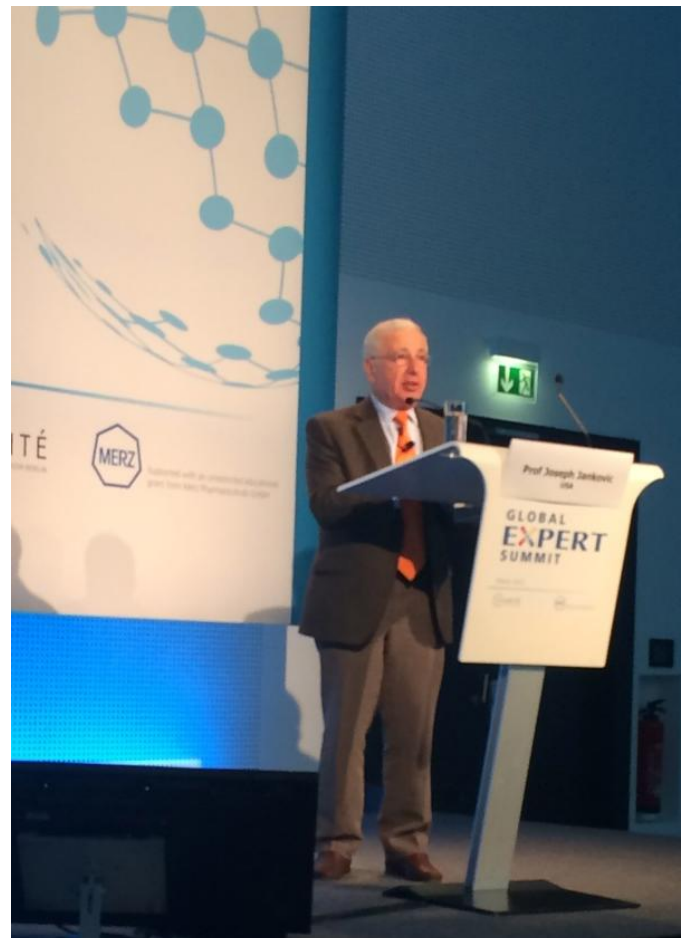
Over 100 Merz Leaders from 20 countries gathered in Mainz, Germany last spring, for the Second Merz Leadership Summit. The 2-day meeting opened with focus on customers & patients. Dystonia Europe Executive Director Monika Benson, a dystonia patient herself, shared her experiences and insights during a 45-minute interview on stage with Yannick Grosskreutz. Her key messages to the audience were: more awareness among the general public and the medical profession to combat stigma and speed up diagnosis and access to treatment; and more research is needed to improve treatment and ultimately to find a cure.



*Monika Benson and Yannick Grosskreutz.*

### Global Expert Summit in Berlin

The Global Expert Summit organized by Merz Pharmaceutical attracted about 400 physicians, physiotherapists, Merz representatives from all over the world last May in Berlin. On the programme were various sessions on "How to improve treatment outcomes and satisfaction of dystonia patients". Among the faculty were Professors Dirk Dressler from Germany and Joseph Jankovic from the US. At the networking session, by the end of the day, the participants could learn more about the Dystonia E-Diary at the special MyDystonia booth, or help promote awareness of dystonia by donating a Jump.



*Prof Joseph Jankovic from the U.S.*

### MyDystonia Booth at the Global Expert Summit in Berlin



*From left to right:*

*Maja Relja – Vice President, Dystonia Europe*

*Philip Buchard – CEO Merz*

*Debbie Marques – National Sales Manager Merz Australia*

*Stefan Wiemann - Senior Regional Marketing Manager XEOMIN*

*Jasmine Fokkens – Senior Medical Expert Merz*



### Dystonia Europe at Boston Scientific US

The Boston Scientific headquarters are in Valencia, California. Before the MDS in San Diego, Monika Benson was invited to the manufacturing site for a guided tour, followed by a "Lunch N Learn on dystonia" for the employees. Monika presented the work and mission of Dystonia Europe, as well as her own dystonia story.

At the end of the meeting there was a joint Jump for Dystonia.



*Boston Scientific Valencia Staff in a JUMP for Dystonia.*

### Dystonia Europe in Finland

The Finnish Dystonia Association, [Suomen Dystonia-yhdistys ry](http://SuomenDystonia-yhdistys ry), had invited their members to a meeting in Åbo/Turku Finland end of March. Neurologist Nina Collan-Suvanto gave a presentation explaining the various forms of dystonia and treatments available. Monika Benson was invited to share her Dystonia Story and talk about the work of Dystonia Europe. The meeting ended with some happy and fun JUMPs for dystonia.



*Jump for dystonia with Finnish Dystonia Members.*



*Before the MDS in San Diego, the DE Executive Director was invited to the manufacturing site.*

### Dystonia Europe in Germany

The annual meeting of DDG, the German Dystonia Association, was held in Kassel last July. Robert Scholten from Dystonia Europe took part in the meeting. After the medical presentations, there was the opportunity to take part in a Jump for Dystonia photo shoot. We would like to thank DDG in all their work to help increase dystonia awareness.



*Presidents Ute Kühn and Robert Scholten ,jumping with German professors.*

### EFNA – Empowering Patient Neurology Groups

Alongside the EAN Congress in Berlin last June, EFNA (European Federation of Neurological Associations) held its General Assembly. A new President, Ann Little (representing the International Bureau of Epilepsy) was elected. She takes over after Audrey Craven who stepped down after almost four years in the position, leading the work to implement EFNA's new strategic direction.

An awareness day on Headache and Sleep Disorders – organised jointly by EFNA and the EAN – was also held for German Patients.

The Corporate Partners Meeting with interactive sessions for the EFNA membership and sponsors capped five successful days of activity!

All of the above was made possible due to the respect the leadership of the EAN shows to the patient voice but also because of the support of the EAN's Liaison Officer Eveline Sipido – who has championed EFNA and its work for many years.

To recognise her outstanding contribution and dedication to the EFNA cause, Eveline was presented with the first "EFNA Lifetime Achievement Award" during the Congress.

Dystonia Europe was represented by Robert Scholten at the meetings.



EFNA President Ann Little



### EFNA First Advocacy Awards

Last October EFNA held its inaugural 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. With these awards EFNA wishes to recognise that many stakeholders are active in advocating on behalf of patients affected by neurological disorders. Nominations were accepted from EFNA Member Organisations and each Member Organisation could submit one nomination per category. The nominations were reviewed by a judging panel comprising: David Vodusek - Chair, Liaison Committee, European Academy of Neurology; Nicola Bedlington - Secretary General, European Patients Forum; Mary Harney - International Health Policy Advisor (former Health Minister); Nick Ross Broadcaster - Campaigner and Conference Moderator (former BBC journalist); Mary Lynne Van Poelgeest-Pomfret - Patient Advocate and Chair, European Platform for Patient Organisations, Science and Industry (EPPOSI).

At a gala dinner and ceremony held in Brussels on 13 October, the awards in the following categories were presented to:

1. Policy-Maker: Gay Mitchell, former MEP from Ireland.
2. Health Professional: Professor Cristina Tassorelli from Italy.
3. Media: Jeroen de Schepper from Belgium.
4. Patient Advocate: Shana Pezaro from Ireland.

Read more about the event on the EFNA website:

<http://efna.net/inaugural-efna-advocacy-awards/>.

Congratulations to all winners for their dedication and important work.

### Neurology Awareness: Together Under the Umbrella

During the "Brain Awareness Week" in March next year, EFNA is planning to launch the awareness campaign "Together Under the Umbrella". The aim of this campaign, agreed by the EFNA membership and sponsors, will be to educate society on the range of disorders which are 'neurological' and to provide the members with a platform to promote and profile their individual disease areas – through fundraising, advocacy and communication activities.

The campaign begins by asking the patient community, general public, and high profile figures to take a picture of themselves 'under an umbrella' using #UnderTheUmbrella and with a link to the campaign's website

<http://www.undertheumbrella.eu> where key messages, interesting facts/statistics, campaign details, etc. will be displayed – alongside a list of supporting neurology patient organisations and further information on the disease areas they represent.

Dystonia Europe will support the campaign and we encourage our readers and members, all our stakeholders, to take part in this activity to promote brain and dystonia awareness.



### Brain, Mind and Pain Interest Group

The interest group is an initiative of the European Federation of Neurological Associations (EFNA) and 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.

The group has organised two meetings in the Parliament this year. On 24 June the theme was 'Preventing Neurological and Chronic Pain Disorders'. The event was hosted by Romanian MEP Damian Draghici. The agenda included presentations on the importance of health promotion in raising awareness of common risk factors (e.g. obesity, poor nutrition, smoking, sedentary lifestyles, etc.). It also covered how EU legislation can be applied to help prevent these disorders, and enable self-management. For more information about the meeting see:

<http://www.brainmindpain.eu/health-prevention-and-promotion-event/>



*Some DE Delegates already under the umbrella at the D-DAYS 2014 in Paris: Bengt-Erik Calles and Monika Benson, Sweden, Merete Avery, Norway, Göran Olsson and his wife Britt-Mary, Sweden and Lottie Holm, Sweden*

## Daughter of Dystonia Patient Speaking at the European Parliament

This year's last meeting of the BMP Interest group took place October 14, with the theme 'Tackling the Stigma of Neurological and Chronic Pain Disorders'. Keynote Address was held by Mr. Michael Hübel, Head of Unit 'Programme Management and Diseases', DG-Santé, European Commission. On the programme were some powerful testimonies from a patient with chronic pain, a mother of ADHD children, and a daughter of a dystonia patient.

Emily Benson shared what it was like for her and her sisters, growing up with a mother diagnosed with cervical dystonia, and their experience of stigma surrounding the disorder. She emphasized the importance of brain disorders as a topic in biology class for increased awareness and better understanding, and concluded: "I hope that one day a stranger will tell me the latest news about dystonia. I want to hear people say: Have YOU heard of dystonia?"

We thank Emily for her participation at this event to help increase awareness of dystonia.

The next meeting of the Interest Group will take place 24 February 2016 in the EU Parliament and the theme will focus on the Workplace.



*Emily Benson speaking at the European Parliament*



*MEP Marion Harkin in the middle (in red) hosting the meeting*

## European Brain Council Call to Action 2015

Last November The European Brain Council launched a call to action, calling for developing national brain plans as well as a EU wide strategy addressing the brain health.

Dystonia Europe supports this call together with many other organisations.

- We call upon EU Member States to implement public health programmes addressing brain health in a systematic way, making the best possible use of available resources in order to stimulate more and better coordinated brain research, and to foster strategies for prevention, early detection, diagnosis and adequate treatment.
- We call upon the European Commission to come forward with a European strategy to tackle brain disorders in a collaborative, integrated and comprehensive manner, as well as to further support EU Member States in their efforts to combat the impact of brain disorders.





## Launch of Dystonia E-Diary: MyDystonia The APP

MyDystonia was already pre-launched at the D-DAYS in Paris last year. Last March the official launch took place at Royal College of Physicians in London, UK, where DE Executive Director presented the app to about 100 UK physicians.

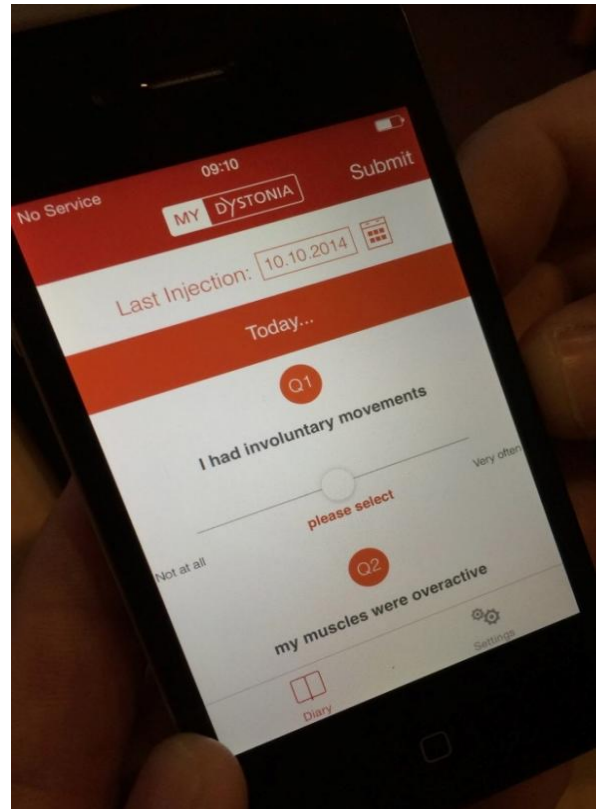
MyDystonia, which can be downloaded free of charge from the Apple App Store and online at [www.mydystonia.com](http://www.mydystonia.com), is basically an electronic diary that enables patients to monitor their symptoms and how those symptoms affect daily life and the quality of life by answering a series of simple predefined questions. This makes it easy for them to document and visualize the progression of their disease, so that the neurologists treating them can discuss the matter with them and thereby arrive at more appropriate treatment intervals and dosage regimes.

The APP has since the launch been presented at various congresses such as DAN (Dubrovnik Academy of Neurology) in Dubrovnik, Xeoforum in Minsk, the MDS in San Diego and the D-DAYS 2015 in Rotterdam, as well as at other medical meetings in Mainz, Berlin and Portoroz (Slovenia).

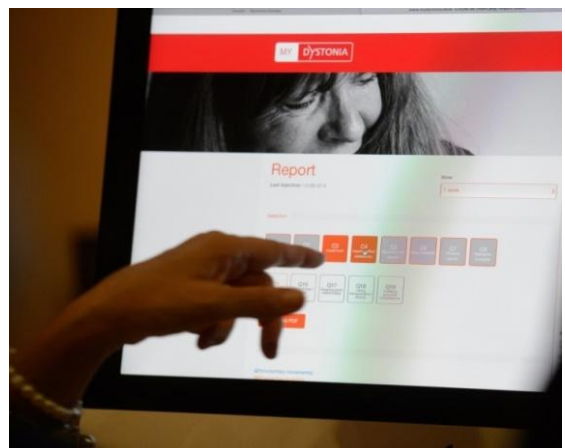
The APP is so far available in French and English and versions in German, Italian, Swedish and Russian are being prepared, and there are plans for additional languages.

There is now a special MyDystonia Facebook page where you can follow the latest updates or contact us if you have any questions or need any help.

<https://www.facebook.com/MyDystonia>



*The App on an iPhone device*



# Jump for Dystonia

## Success for Dystonia Awareness

There is still a lot of misunderstanding about dystonia and it is crucial to increase awareness and spread information about the disease. Therefore the awareness campaign "Jump for dystonia" was launched in Paris last year and has since then spread to all five continents.

People have been asked to Jump for Dystonia, take photos and then upload them 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 also receiving media coverage in press, radio or TV. Throughout the year photos of people jumping for dystonia have been collected at various congresses and meetings. Some partners and sponsors have also taken the campaign within their organization/ company to raise awareness of dystonia among their staff by organizing special Jump for Dystonia events. Last November a special Jump for Dystonia event was organised in the EU Parliament in Strasbourg. About 40 MEPs from several of the 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 special contest where you could win the ultimate jump – a skydive – was taking place on the JUMP facebook page this last year and there are now four winners coming from Romania, Australia, Finland and Sweden. These jumps will take place within the next eighth months and promote dystonia awareness again.

**Congratulations to the winners!**

### JUMP for Dystonia in Figures:

Over 10 000 JUMPS from  
More than 30 countries on  
5 continents  
4 Skydive Winners



*Rehab Group from Finland*



*Ramona from Romania*



*Sony from Australia*



*Michelle from Sweden*

### Dystonia Support in Australia

Support for dystonia in Australia received a boost on 29 May 2015, when the Parkinson's Australia National Conference held a day of dystonia sessions in Adelaide, South Australia, sponsored by Allergan Australia.

Keynote speaker, physiotherapist Jean-Pierre Bleton, gave a fascinating talk demonstrating a range of presentations of cervical dystonia and how these could be treated. Many people with dystonia in the audience came away feeling motivated to be their own therapist and practise exercises at home after an individualised consultation with a physiotherapist. Three Australian physiotherapists specialised in neurological conditions, James McLoughlin, Ann Buchan and Melani Boyce, gave live demonstrations on people with cervical dystonia. Allied health professionals and people with dystonia gathered around each demonstration and took notes, watching intently and asking questions as each patient was examined and exercises were suggested.

Dr Florence Chang, a neurologist at Westmead Hospital Sydney, gave a comprehensive overview of the latest knowledge in relation to the treatment of many forms of dystonia. We heard about the new botulinum toxin A (Xeomin) coming to Australia soon; results of studies on deep brain stimulation; new genetic discoveries; and current research trials. The Chair of the dystonia sessions, Professor Lynley Bradnam from University of Technology Sydney, presented her latest positive research results. She showed that transcranial direct current stimulation to the cerebellum and motor cortex over a twelve week period can significantly improve quality of life and TWSTRS scores in cervical dystonia.

Our patient presentation was given by Suzanne Bayliss, a long-time social worker and guest university speaker, with input from patient Maureen Slocum, a community welfare worker. Suzanne has had deep brain stimulation and has a significant family history of dystonia. She encouraged practitioners to really listen to their patients and not let them fall through the cracks, even when they have communication difficulties. A dystonia booth ran on both days of the full conference, attracting many people with dystonia as a secondary condition in Parkinson's disease, as well as those with primary dystonia.

The booth included contributions from the Australian Dystonia Support Group, Dystonia Network of

Australia (our new peak body), Brain Foundation Australia, Suzanne Bayliss's book *Heart and Soul*, Peter Chiverton's film script in development 'Life without Music', and Jump for Dystonia materials from Dystonia Europe.

Of course the day couldn't go by without a huge Jump for Dystonia to start off proceedings! The day left everyone buzzing with excitement and eager for more similar events in Australia in the future.

*Margot Chiverton*

Web links for further information:  
Conference website

<http://www.aomevents.com/ParkinsonsAustraliaNationalConference>

Speaker slide presentations

<http://www.parkinsonssa.org.au/whats-on/2015-national-parkinson-s-conference.aspx>

Dystonia Network of Australia

<http://www.dystonia.org.au/>

Australian Dystonia Support Group

<https://australiandystoniasupportgroup.wordpress.com/events/>



*Margot Chiverton, Chris Gavenlock, Suzanne Bayliss, Kerrie Jackson at the Dystonia Booth.*

## Around Europe & Beyond

**Physiotherapists Jean-Pierre Bleton from France and Lynley Bradnam from Australia jumping for dystonia together with conference participants in Adelaide.**



### FOR SALE!

Now you can buy the Jump for Dystonia t-shirt! They are in 100% cotton, bright orange color and in sizes S, M, L, XL, XXL, with the Jump for Dystonia logo on the front. The cost of € 20.- covers production, package and shipping. We deliver as soon as we can.

Order here:

<https://dystonia-europe.org/2015/03/jump-for-dystonia-t-shirts-in-stock/>

## Events

### 2016

**29 January**, Dystonia Europe Think-Tank, Lund, Sweden

**30 January**, Dystonia Europe Board Meeting, Lund, Sweden

**24 February**, BMP Interest Group Breakfast Meeting - Focus on the Workplace, European Parliament, Brussels

**3-4 March**, Dystonia Coalition, Rockeville, Washington, US

**15-16 March**, Launch Campaign 'Under the Umbrella' during Brain Awareness Week , European Parliament, Brussels

**8-10 April**, D-DAYS 2016 - Dystonia Europe 23<sup>rd</sup> Annual Conference and General Assembly, Oslo, Norway

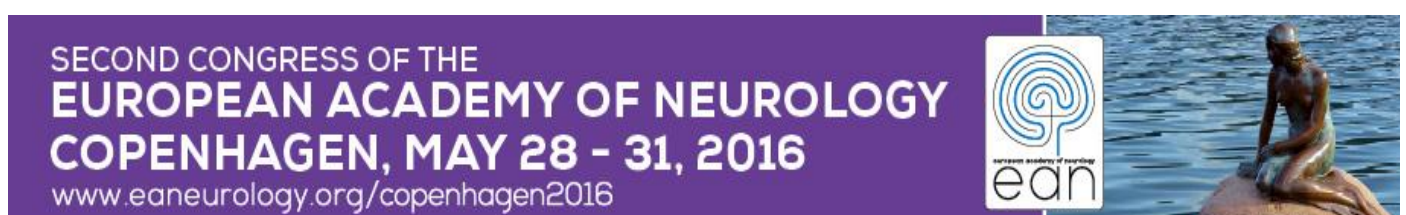
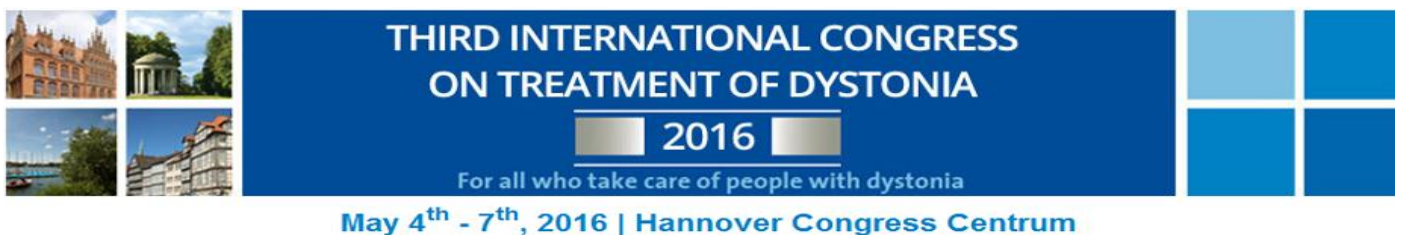
**4-7 May**, 3rd International Congress on Treatment of Dystonia, Hannover, Germany

**28-31 May**, 2nd Congress of the European Academy of Neurology, Copenhagen, Denmark

**19-23 June**, 20th International Congress of Parkinson's Disease and Movement Disorders, Berlin, Germany

**22 June**, BMP Interest Group - Patient Involvement in Research- European Parliament, Brussels

**28-1 September**, Congress for ESSFN, Istanbul, Turkey



# D-DAYS

**23 RD ANNUAL CONFERENCE**  
**8 & 9 APRIL, 2016 OSLO,**  
**NORWAY**

**SAVE THE DATES**

**DYSTONIA**  
**EUROPE**



**Norsk**  
**Dystoniforening**



Visit the Hotel Clarion Royal Christiania at their website  
<https://www.nordicchoicehotels.no/clarion/clarion-hotel-royal-christiania/om-hotellet/>



You can already now book your room directly with the hotel and get a special room rate by using the D-DAYS conference code 602844. Book before 5 February to get the special conference rate.

## **PROGRAMME**

Programme and more information about the event will soon be available on the Dystonia Europe website, where you can also register for the congress. <http://dystonia-europe.org/activities/events/dystonia-europe-2016-oslo/>

Main topics on the programme will include: Overview of Dystonia, Dystonia Research, Treatment of Dystonia, Rehabilitation and Physiotherapy, and Coping Strategies.

We welcome patient leaders, dystonia patients and their families, physiotherapists, nurses, junior doctors and everybody else with an interest in dystonia.

**Hope to see you in Oslo!**

## Members

Dystonia Europe consists of 20 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 and United Kingdom.

## Donation & Support

Dystonia Europe welcomes and greatly appreciates any donations/support from organisations and individuals to further develop all the work for dystonia in Europe by funding research, awareness and education. If you would like to support the work of Dystonia Europe please contact us at [sec@dystonia-europe.org](mailto:sec@dystonia-europe.org) to discuss the possibilities.

To donate directly please use the following on-line banking details:  
Accountholder: Dystonia Europe

BANK:	KBC Bank, 16a Tervurenlaan, 1040 Brussels
IBAN number:	BE83 7350 0508 5515
SWIFT/BIC	KREDBEBB

When making a payment please include a reference to allow us to identify the donor.

You can also use the donate button on the Dystonia Europe website, which will take you to the following page:  
<https://dystonia-europe.org/donate/>

Thank you for supporting Dystonia Europe!

## Medical & Scientific Advisory Board

Prof Alberto Albanese – Milan  
Prof Alfredo Berardelli – Rome  
Prof Kailash Bhatia – London  
Prof Rose Goodchild – Leuven  
Prof Marina de Koning-Tijssen – Groningen  
Prof Joachim Krauss – Hannover  
Prof Tom Warner – London  
Dr Jean-Pierre Lin – London  
Prof Maja Relja – Zagreb  
Prof Eduardo Tolosa – Barcelona  
Prof Marie Vidailhet – Paris



### Board of Directors

**Dystonia Europe is governed by a volunteer Board of Directors.**



**Merete Avery, President, Norway**

Merete was appointed to the board of Dystonia Europe in 2013 and has held the position as Secretary from 2013-2015. Merete was appointed President at the Board Meeting, following the GA, in Rotterdam 2015. She is from Norway. She was diagnosed with cervical dystonia in 2006 and she was Chairwoman of the Norwegian Dystonia Association between 2010-2013. Merete is working with customer service and administration for a company in Molde, Norway.



**Maja Relja, Vice President, Croatia**

Maja is a professor of neurology, in charge of the movement disorders section at Zagreb University Hospital. She founded the Croatian Dystonia Association and has served as its president for over 20 years. In 2011, she was elected to the board of Dystonia Europe, and appointed Vice President in 2012. She also serves on the DE Medical and Scientific Advisory Board and is heavily involved in the COST-funded Dystonia Research Network.



**Sorin Ionescu, Board Member, Romania**

Sorin is the founder and President of the Romanian Dystonia Association, Asociatia Distonia. The objectives of the association are to raise public awareness, provide support and advice to dystonia patients and their families and to promote research. Sorin has a degree in social science and is a writer, painter and has been involved in social activities since 2010. He was diagnosed with Generalised Dystonia in 2012.



**Monika Benson, Dystonia Europe, Board Member and Executive Director, Sweden**

Monika was elected president of EDF, now Dystonia Europe, in 2007. She was re-elected for a second term in 2010. Monika stepped down as President in 2013 after serving the maximum period of 6 years. She took over as Executive Director after Alistair Newton's retirement. Monika has cervical dystonia and is also a board member of the Swedish Dystonia Association. Monika has been working as a coordinator of work-shops, courses and lectures at a school in Lund, Sweden



**Erhard Mätzener, Treasurer, Switzerland**

Erhard was appointed Treasurer by the Dystonia Europe Board in November 2015. He is a member of the Swiss Dystonia Association SDG since 2008, and from 2010 he is their auditor/controller. In 2012 he was appointed the SDG delegate to Dystonia Europe. Erhard is an economist and was working as an investment advisor for a Swiss Private Bank for more than 20 years until he retired in 2002. Erhard suffers from blepharospasm.



**Alistair Newton, Advisor, Scotland**

After several years as Vice Chair of the Dystonia Society in the UK, Alistair founded European Dystonia Federation, now Dystonia Europe, in 1993. He served 8 years as President and was the Executive Director between 2001 and 2013. He was appointed to the Dystonia Europe Board with special responsibility of the Dystonia Research Network. Alistair also co-founded EFNA – the European Federation of Neurological Associations – in 2000, where he acted as Treasurer and Secretary-General until 2011. In 2003, he was involved in the founding of the EBC – the European Brain Council, where he was a board member and a treasurer for many years. He is now an advisor to DE on special projects. Alistair has had cervical dystonia for 30 yrs.

## Partners & Sponsors

We have good working relations on a variety of topics with:

DMRF – Dystonia Medical Research Foundation, FDR – Foundation for Dystonia Research, Dystonia Coalition, EFNA – European Federation of Neurological Associations, EBC – the European Brain Council, EAN – European Academy of Neurology, MDS – International Parkinson and Movement Disorder Society.



Live better. Feel better. Look better.



[www.dystonia-europe.org](http://www.dystonia-europe.org)