

Connecting People for Dystonia

DYSTONIA EUROPE NEWS

Spring 2015

Dystonia Awareness in the European Parliament



The EU Commissioner on Health Vytenis Andriukaitis and UK MEP Glenis Willmott are JUMPING for Dystonia with DE President Robert Scholten and DE Executive Director Monika Benson

www.dystonia-europe.org

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

Contacts & Secretariat

President

Robert Scholten

E-mail: robert.scholten@dystonia-europe.org

Registered Office

Dystonia Europe

37 Square de Meeus, 4th Floor,

B-1000 Brussels, Belgium

E-mail: monika.benson@dystonia.europe.org

Executive Director

Monika Benson

E-mail: monika.benson@dystonia.europe.org

Communication

Newsletter

Sölvi E. G. Engeland, Norway

E-mail: g-engela@online.no

Photos from Paris:

Stephan Röhl

E-mail: info@stephan-roehl.de

Meet us @

Website: <http://dystonia-europe.org>

Facebook: <https://www.facebook.com/dystonia.europe>

Youtube: <http://www.youtube.com/user/DystoniaEurope>



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President's Message

Dystonia Europe: Connecting People for Dystonia



Robert Scholten.

Dear Friends,

The new theme of Dystonia Europe: “Connecting People for Dystonia”, is keeping us very busy. Our network is growing and more people and organisations are showing an interest in being connected to us. I am very pleased that Finland became a member of DE at last year’s General Assembly. For some time now, we also have a close collaboration with the Australian Dystonia Network. In the next few years we hope to get connected to more countries in the Eastern part of Europe.

MyDystonia.com was launched last March. The APP is a digital diary where dystonia patients can keep track of their symptoms, mood and daily activities. The collected data can be shared with the treating physician and support patient-physician communication when discussing symptoms, treatment options and goals. With the support of Merz, we are now developing the second phase of this project.

Dystoniacommunity.com (phase one) will soon be up and running. This is a website/social community for patients and their personal network. At the last D-days in Paris, the community was presented for the first time.

Our members gave valuable feedback for the development of the site. Thanks to the support of Ipsen and Medtronic, we can now work on phase two of the Community.

The ‘Jump for Dystonia’ campaign keeps spreading. It is my hope that our member countries will pick up this campaign and run it in their own country. The campaign is mostly spread through social media and has supporters from all over the world. The campaign has been picked up by patients, their family members and friends from Europe and beyond. It is great to see JUMP photos from China, Japan, USA and Australia. It is extremely important that all our stakeholders know about dystonia. We are grateful to Allergan for their support of this project which helps connecting people for dystonia.

On the 2, 3 and 4 of October, we will organise this year’s D-DAYS and Annual Conference in Rotterdam, The Netherlands. By June you will find programme and all the information about the event on the Dystonia Europe website. The event will be held alongside the 30th Anniversary of the Dutch Dystonia Association. On the Saturday the Dutch Dystonia Association will organize a family day. Almost 300 dystonia patients and their families have already shown an interest in attending the event, which could be the largest dystonia patient meeting ever held in The Netherlands. It is my pleasure to welcome you to the D-DAYS in Rotterdam. As you see there are many exciting projects going on, and I invite you to read more about each one of them in this newsletter.

Wishing all of you a wonderful spring and summer.

Best regards,
Robert Scholten
President.

D-DAYS and Dystonia Europe General Assembly 2014 in Paris

D (Dystonia) - DAYS

Last October 10 & 11, 2014, Dystonia Europe held its 21st Annual Conference, from now on also called the D-DAYS, in beautiful Paris. The conference had about 120 participants from 18 countries. There were researchers, neurologists, physiotherapists, dystonia nurses, industry representatives, delegates (representing national dystonia patient organizations), as well as AMADYS (the French Dystonia Association) board members and individual members.

President Robert Scholten of Dystonia Europe, and President Stéphanie Frehel of AMADYS opened the conference by greeting everyone with a warm welcome. AMADYS board members had been involved in both the planning and the execution of this successful international meeting. Some of the lectures were in French and a translation team translated the French lectures to English and vice versa. The participants could choose to follow the conference in either language using headphones.

Executive Director Monika Benson presented "Jump for dystonia" – a dystonia awareness campaign which was officially launched at the conference. The campaign invites anybody to participate in the contest where you submit a photo of a jump to a special JUMP for Dystonia Facebook page. The photo which receives the most votes will be the winner of a skydive. There will be four winners over the year. The program included presentations about Dystonia in Children, Oromandibular Dystonia, Pain and Dystonia, Writer's Cramp, Surgical Treatment, Coping with Dystonia and much more. You can read about some of the presentations on the Dystonia Europe website, where you also find a link to the abstract book. We thank Professor Marie Vidailhet for the organization of an excellent scientific programme.

After the conference, the Dystonia Europe Board, the national delegates and guests, joined a guided tour of Paris. The tour started by bus with a French guide who had a lot of interesting stories to tell about the history of Paris. The tour continued with an

unforgettable dinner cruise on the river Seine, from where we could see many of Paris most famous sights: The Notre Dame, The replica of the Statue of Liberty on the Île aux Cygnes, The Eiffel Tower and many more. The afternoon light turned into a beautiful sunset creating a stunning scenery while dinner was served.

General Assembly

The Dystonia Europe 21st General Assembly was held on 12 October. The Finnish dystonia patient organisation had applied for membership which was approved by the delegates. Finland is the 21st member of Dystonia Europe. After the General Assembly followed the session "Sharing Best Practice". Chairwoman of the Norwegian Dystonia Association Anniken Hansen Hagen presented "Physiotherapy for dystonia". This project is intended to educate physiotherapists from all over Norway on how to treat dystonia patients. Susanne Olenius from Finland presented the work of the "Finnish Dystonia Association". Barbara Pfäffl from the German Dystonia Association presented the work and ideas of the Segawa (dopamine-responsive dystonia) self-help group.

President Robert Scholten and Executive Director Monika Benson concluded by presenting the "Dystonia Europe Vision & Strategy 2020". The work of the next few years will focus on three projects: the DystoniaCommunity which is a Digital Platform for everybody with and interest in dystonia, the dystonia awareness campaign: Jump for Dystonia, and the annual dystonia conference, the D-DAYS. The long-term strategy plan together with the projects received great applause from the delegates.



*Merete Avery,
Secretary,
Dystonia Europe.*

Latest News

People & Moments from the D-DAYS in Paris



Dystonia Europe at Merz Meeting in Frankfurt

Last November the Merz Alumni meeting "Program for Expert Partnership" was held in Frankfurt, Germany. Professor Wolfgang Jost and Kristine Molt of Merz welcomed the 20 German neurologists taking part in the program. Monika Benson was invited to tell her Dystonia Story, which followed by a presentation of the work of Dystonia Europe and projects such as MyDystonia the patient app. There was a great interest of the patient app and the possibilities it could offer to physicians treating dystonia. The meeting ended with a joint JUMP for Dystonia.



Kristine Molt from Merz Germany welcoming the participants.

Dystonia Europe at Boston Scientific Meeting in Paris

Dystonia Europe President was invited to speak at the Boston Scientific Staff Meeting "Everyone Makes an Impact" in Paris last November. Robert presented his dystonia story and the work of Dystonia Europe. DBS Marketing Manager Sophie Araujo said: "This was an important day for us to connect our employees to the work they do, the impact we make on patients' lives is the most rewarding part ... We received such a great feedback – very inspiring for the whole organization – my partners working on other therapies are willing to leverage your work, philosophy and the way you connect people @ Dystonia Europe ... As Robert said –

life is about having fun and overcoming challenges in a positive way ”



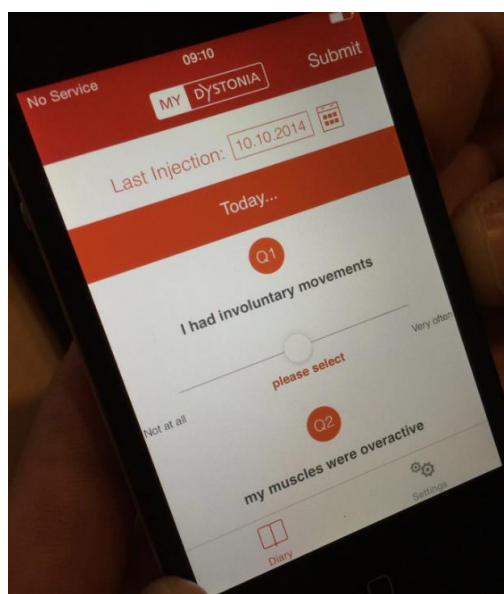
President Robert Scholten presented his dystonia story and the work of Dystonia Europe.



Sophie Araujo Boston Scientific Europe DBS Marketing Manager, Dystonia Europe President Robert Scholten, Cindy Mols, Boston Scientific Europe Quality Director, Michael Onuscheck, Boston Scientific Europe President.

MyDystonia – A disease Diary for Dystonia Patients

My Dystonia is an electronic diary created for people with dystonia. Here you can monitor your dystonia by documenting your symptoms in order to record and analyze the disease impact on everyday life. By answering predefined questions (e.g. symptoms like overactive muscles or pain; impact on daily living) the user is able to examine and to visualize his/her well-being according to the treatment schedule.



MyDystonia diary is designed to support and potentially improve patient-physician communication as the collected data can be presented and discussed with the treating physician or other patients to track treatment outcome and to define potential treatment goals. The user is able to communicate (instant messaging) and participate in the user community. Rewards are being earned for continuous use of the app and participation in the community. MyDystonia is available as a web-based service and from mid June it can be downloaded for free from the APP-store.

The App is designed and developed by patients for patients, with the support of Merz. A survey went out to 300 dystonia patients in the UK, France and Germany and they gave their feedback on what items/questions to include, features, name etc.

Dystonia Europe has the 100% ownership of the project, the database including the collected data of the users of the MyDystonia diary. Dystonia Europe owns the server hosting the MyDystonia database and is responsible for the maintenance, the availability, and backup.

The launch of the App took place during the Academy of Neurology Meeting in Dubrovnik last March.



Prof. Maja Relja and Dr. Stefan Wiemann of Merz.

Jump for Dystonia

The official launch of this exciting awareness campaign took place at the D-DAYS in Paris, last October. But already at the 20th Anniversary Conference in Edinburgh in 2013, the participants were encouraged to JUMP for Dystonia. Over the last year JUMP photos have been collected at congresses and meetings. Special JUMP for Dystonia events were also initiated by some of our partners such as Boston Scientific, Medtronic and Merz.

Dystonia involves uncontrolled movements just as a JUMP can be uncontrolled. So why not use a JUMP to spread awareness of dystonia? We invite everybody to join the campaign and if you cannot JUMP you can make a movement with your arms, eyes – use your imagination!

JUMP in front of a camera, upload the photo on the Jump for Dystonia Facebook page, and nominate your friends and family to JUMP as well! On the Facebook page you can choose if you want to be part of the Contest where you can win a Skydive, where the photo with the most votes wins. Four winners will be elected over the campaign year 2014-2015. If you don't want to be part of the contest you can just upload your Jump photo to the Jump for dystonia wall and thereby support the campaign.

The goal of the campaign is to collect as many jumps as possible. By people sharing their photos through social media we wish to spread the word dystonia to the general public together with some brief information: Dystonia – the little known brain disorder, causes involuntary muscle contractions, affects millions worldwide.

Dystonia Europe member countries are promoting the awareness campaign and due to

its presence on social media it has also spread to other continents and JUMP photos are coming in from the US, Australia, Africa and Japan.

People jump for dystonia all around the globe. If you are interested in learning more about the campaign and how you can participate please visit the Jump for dystonia Facebook page or the Dystonia Europe website: https://dystonia-europe.org/activities/projects/jump-dystonia/_or_contact_us_at_sec@dystonia-europe.org.

First Jump for Dystonia Skydive Winner from Romania

Ramona's jump rewarded her with the first Jump for Dystonia Skydive. She had received a total of 683 votes. On second and third place was Anniken Hagen from Norway with two different jump photos with 437 votes and 168 votes. The contest is now up and running again and there will be 3 more skydives to win! Don't miss this chance to experience the jump you ever dreamt about! Take a jump photo and upload it to https://www.facebook.com/jumpfordystonia/app_340493986057345 And good luck!



First winner of the Jump for Dystonia Skydive: Ramona Iona Pop from Romania.

Jump for Dystonia at the European Parliament in Strasbourg

EU Commissioner on Health Vytenis Andriukaitis (Lithuania) joined the dystonia awareness campaign last November at the EU Parliament in Strasbourg and made a jump for dystonia. Even though it was the first Strasbourg session for the newly appointed Commissioner he found the time to meet with Dystonia Europe, a health NGO (non-governmental organisation) to help raise awareness. Mr. Andriukaitis pointed out that people with a chronic illness are, above all, normal people, and that all stakeholders – including at national and European level – must work with NGOs and patients to deliver health for every citizen.

The event was hosted by MEP Glennis Willis who said: 'I am delighted to help raise awareness of this little known brain disorder if this can help to combat the stigma and isolation felt by people with dystonia. Raising awareness can also be the key to earlier diagnosis and treatment that is why I am supporting Dystonia Europe's call to Jump for Dystonia in Strasbourg on 25 & 26 November.'

'There is still a lot of misunderstanding about dystonia' said Robert Scholten, President of Dystonia Europe 'Dystonia is chronic but the majority of dystonias do not affect other brain functions. There is a lot going on and I invite all MEPs to join in this exciting journey to work for improved public awareness of dystonia, better treatments, increased research and one day, hopefully a cure. Together we can make a real difference for people affected by this devastating disease.'

MEPs from Belgium, Croatia, Finland, France, Germany, Italy, Ireland, Poland, Romania, Slovakia, Spain, Sweden, The UK,

The Netherlands participated and jumped for dystonia to help raise public awareness, combat stigma and isolation, improve treatments and increase research.

For the first time ever dystonia was featured in the Parliament Magazine:

<https://www.theparliamentmagazine.eu/articles/opinion/mep-calls-increased-awareness-dystonia-disorder>



UK MEP Glennis Willis with Monika Benson and Heather Clarke, Consultant EU Affairs.

In Strasbourg to network with MEPs and inform about dystonia, were Heather Clarke, Consultant in EU Affairs, who had been heavily involved in all of the preparations, as well as DE Executive Director Monika Benson, President Robert Scholten and DDG President Ute Kühn. The beautiful and energetic jump photos were taken by Margret Tielman, assisted by Marc Schellekens who made sure the photos were sent out immediately to the MEPs to use on Twitter and other social media. All MEPs jumping for dystonia are available on the Jump for dystonia facebook page in the special album "The EU MEP & Health Commissioner Jump for Dystonia Album". Thank you to everybody who participated and made this such a successful event.

Latest News

People and Moments from Jump for Dystonia Event in EU Parliament in Strasbourg



Jump for Dystonia at Merz Headquarters in Frankfurt

Merz headquarters in Frankfurt, organized a "JUMP for Dystonia" event for their staff end of November. The event took place in the canteen where Jennifer Fluck, Junior Global Brand Manager Xeomin, and her colleagues welcomed other staff members who wanted to jump. In the background was music of various songs with JUMP theme which created a happy and inspiring atmosphere. The photographers worked hard taking photos of everybody who wanted to JUMP to help spread awareness of dystonia. For each jump Merz donated € 5. After having jumped everybody was given a special "Jump for Dystonia" teacup, and a leaflet about dystonia and Dystonia Europe.



Merz staff in a JUMP for Dystonia.

There was a short break in the middle of the afternoon and Yannick Grosskreutz, Executive Director & Head of Global Strategic Marketing & Medical XEOMIN, welcomed everybody and gave a short summary of the last few years of collaboration between Merz and Dystonia Europe. Hans-Eric Diede, Lead Medical Expert XEOMIN, explained what dystonia is and how it is treated. Then followed a presentation by Monika Benson of Dystonia Europe who shared her Dystonia Story and how the disease has affected her and her family. By the end of the day a total of 150 jumps were collected.

Merz has continued to organize "Jump for dystonia" events for staff and partners and a total of 438 Jumps have been collected. Dystonia Europe is very grateful to the team of Merz and their commitment to help raise awareness of dystonia.



Jennifer Fluck Jump for Dystonia.



Yannick Grosskreutz, Merz.

Jump for Dystonia in Finland

After the D-DAYS in Paris 2014, where Jump for Dystonia was launched, I was very excited when coming back to Finland. I started right away to contact the board members to get their approval for launching the campaign in Finland. As we didn't have any budget planned for it, we had to look for volunteers to arrange events, and to use social media. We have jumped at our board meeting. We have also been to our head association Parkinson Finland, and informed about the campaign. They have been very positive and promised some support for us.

I contacted a friend of mine, who works at a radio station, and I was able to come for an interview about my dystonia, as well as the campaign. It was very good publicity for us and dystonia.

Before Christmas I also sent the story of Monika Benson via STT News Agency; how the idea of the Jump campaign came up. A major commercial newspaper published it on their web-site.

We sent lots of e-mails to our MEPs in Strasbourg, according to the instructions given to us by Dystonia Europe. Two Finnish MEPs jumped: Merja Kyllönen and Henna Virkkunen. They both have promised to help us, if needed. We have translated the campaign to Finnish and many hours have been spent on giving information through Facebook, as well as sending out letters to all our dystonia clubs. We have printed info-cards telling how to raise awareness of dystonia and with instruction on how to upload your photo to the Jump for dystonia contest page etc.

We have approximately 20 clubs all over Finland. Some of them have jumped at their Christmas party and some of them have jumped only for fun, when having meetings. A major event was the "Rare Disease Day" on February 28, where Sari and friends from Kauhajoki, had planned the whole day around dystonia, and they were even interviewed by a local newspaper. You can find a photo of Sari and her friends on the Jump for dystonia contest page.

The Turku Club jumped at their last meeting. Now Asko from Turku already has over 130 votes. *We want Finland to win!* We try to share the photo on facebook to family and friends and we ask them to vote. Unfortunately not all use Facebook that is a pity!

Very soon, we will send a letter to all the clubs, informing them on how to arrange events and give ideas on what they can do to tell about jump for dystonia.

Finally I want to share this with you: this winter I was travelling in Spain for one month and we got an amazing photo of my stepson jumping for dystonia over the clouds in Tarifa Valley, and with Africa under his feet.



Susanne's stepson Ville Lahtinen jumping for dystonia above the clouds.

We have planned some new events in Finland, but I cannot reveal them yet, more will come in the next DE News.

**JUMP AND HAVE FUN,
WITH YOUR FRIEND'S AND YOUR MUM!!**

*Susanne Olenius
Finnish Dystonia Association
Finland*



Susanne Olenius and Taina Lehtinen from Finland jumping for dystonia.

Jump for Dystonia in Romania



In October last year, the Romanian Dystonia Association "Asociatia Dystonia" represented for the first time all Romanian dystonia patients at the annual conference of Dystonia Europe, D-DAYS 2014, which took place in the French capital of Paris. On this occasion, Dystonia Europe officially launched the European dystonia awareness campaign "Jump for Dystonia".

In Romania dystonia is little known and therefore dystonia patients are very often misunderstood. Our association decided to promote the campaign through various activities. The first one was held alongside the presentation of the dystonia association at an event organized at the university in Cluj-Napoca. On this occasion our President G. Sorin Ionescu of Asociatia Romania, participated in a TV-program: "Unprejudiced". This was broadcasted on the regional TV station (TVR Cluj), where he was interviewed and also talked about the dystonia awareness campaign "Jump for Dystonia".



Romanian dystonia participants Jump for Dystonia.

The second activity to promote the campaign, was held in Satu Mare, at a pre-university educational institute. The program included presentations on dystonia and the opportunity to jump for dystonia, have photos taken and share these on-line. Dozens of high school students and teachers and even educators from other institutions in the city, attended the successful meeting. Unfortunately, many students did not meet the required age of 21, and couldn't participate in the on-line "Jump for dystonia" contest. In spite of this, the students contributed in

the spreading and sharing of jump photos on all social media networks. In Satu Mare, President Sorin G. Ionescu, was the guest of another regional television, TV information Satu Mare, where he talked exclusively about the campaign and how to promote the project.

At the medical conference on movement disorders held in Bucharest last November, where also many Romanian dystonia patients participated, Sorin Ionescu presented the dystonia awareness campaign, together with the two other major projects of Dystonia Europe: dystoniacommunity.com and the APP; MyDystonia – a digital patient diary.

Last activity of 2014 was the cultural meeting held in Brasov. At this meeting, our Dystonia Association, was invited by the organizers to present the campaign and by the end of the meeting the group joined in a "Jump for Dystonia."

During the few months since the launch of JUMP for Dystonia in Paris, the campaign has already shown promising results. The first winner of the on-line contest and a Skydive went to a Romanian participant. Before the ending of this campaign, there will be Jump for dystonia events in at least three other large cities in Romania, as well as at several other events.

Asociatia Romania advocates and promotes the rights of patients with dystonia in Romania, under the motto "Together for the love of people!"



Sorin G. Ionescu, President, Romanian Dystonia Association.

Latest News

People jumping for dystonia around the world: Australia, China, Japan, Italy, Spain, The US and many more countries



The following articles, page 16 – 22, 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.

DBS Study

“Use your choices:

The earlier you start treating dystonia, the more effective it will be!”

Prof. Dr. Lars Timmermann on treating dystonia today, deep brain stimulation and latest clinical research in the field



Prof. Dr. Lars Timmermann.

About Prof. Dr. Lars Timmermann

Describe yourself in 140 characters:

I am an enthusiastic physician, who enjoys what I do. I am committed to improving the lives of people with movement disorders.

Years of experience:

I started my career in 1999 and have over 15 years of experience in treating movement disorders.

What do you like most about your job?

Seeing my patients get better. Receiving their feedback that I was able to help them and they can lead a better life, with my advice and successful treatment.

Your one piece of advice for dystonia patients:

Go and see a dystonia or movement disorder specialist! Don't put off making decisions and please don't wait too long. The earlier you see an expert and start your treatment, the more effective it will be.

Would you jump for dystonia?

Yes of course!



«Jump for dystonia: The gravity of knowledge.... »

Dr. Amande Pauls and Prof. Dr. Lars Timmermann, the Cologne dystonia experts are feeling the gravity of knowledge when they jump for their dystonia patients!

7 Questions for Prof. Timmermann

Prof. Timmermann, what's the best way of treating dystonia today?

How you best treat dystonia really depends on the type of dystonia. Botulinum toxin certainly is one of the cornerstones in treating most types of dystonia today. Conservative possibilities are rehabilitation and physiotherapy and for people with tremors, oral medications such as anticholinergics are good therapeutic considerations. Deep brain stimulation (DBS) is proven to be very effective as well, especially for patients with cervical dystonia and for people who are impacted by movement difficulties in the whole body.

What is deep brain stimulation (DBS) and how does it work?

Deep brain stimulation is used when the communication, or signaling, between different areas of the brain is somewhat disturbed. So in effect through DBS, we modulate the signaling of different areas that other areas in the brain may not be able to understand. We do this by using electrodes at the spots where there are most disturbances and we try to normalize the activity in these brain areas, so that the signaling is improved. For many patients, this has a tremendous effect on their symptoms.

How can DBS help people with dystonia?

Let's take the example of cervical dystonia. Using DBS, we are able to better treat the symptoms of patients considerably. In numbers, we have seen a 24-50 % improvement in most of the cases and more than 50% of patients see significant positive changes in involuntary muscle contractions of the neck, tremors and dystonic postures. For some patients, DBS can even help reduce severe pain, so that people can lower the dosage of their pain medications. What's most important though is that the improvement of these symptoms can have a great impact on people's lives. Activities of

daily living like eating, sleeping, socializing then become doable and normal again.

Who is eligible for DBS therapy?

Generally speaking people with tremors are eligible for DBS, so patients who experience shaking hands, limbs and other parts of the body, and especially tremors that cannot be improved well enough through medication. Who also benefits from DBS really well are people with 'ON' and 'OFF' states, meaning there are good days and bad days in terms of mobility, and where patients have reached a point where they cannot control their daily living activities anymore. Last but not least, children with dystonia between three and eight years of age are also good candidates for DBS.

What's the evidence behind using deep brain stimulation in children?

We are currently conducting a clinical trial in Germany with the Vercise DBS system called the STIM-CP trial. In this study, we are looking at cerebral palsy patients between 7 to 19 years of age. What's quite exciting is that we are seeing a very good response, which may indicate that it is actually necessary to treat patients when they are still young. It appears that the younger the patient is, the more flexible their nerve system is and it can also adapt more easily and faster to changes when we modulate specific areas of the brain through electrical impulses. So yes, kids can benefit well from DBS.

How easy or practical is it for patients to use a DBS device?

I can say from experience that the ease of use depends on the device. We know that dystonia patients, for example, generally need higher voltages to improve their symptoms compared to Parkinson's patients. So having a system with a long battery life and that can easily be recharged is important. In our clinic, we have had good experiences with the Vercise DBS System which has a battery life of up to 25 years and is very

easy to use for patients. Following surgery, they get an introduction into how to control the device and after a little practice, controlling and recharging usually works well. I often hear that patients find it convenient and really simple to handle.

What factors do you take into consideration when choosing the right DBS device for a patient?

First of all, we select a device that is suitable for the individual patient. For little patients or very

slim people it is preferable if the implantable device is smaller and has a rounded shape so it fits their anatomy better. Another factor we consider is how we can best shape the currents of the device. Novel devices like the Vercise DBS System offer many programming options to steer the currents effectively, which means that we can tailor the electrical impulses much better to the individual patient need. That's a plus – as a physician, I really like having different choices to achieve the best possible treatment and health outcomes of my patients!

***Prof. Dr. Lars Timmermann** is Professor of Neurological Movement Disorders, Senior Physician at the Department of Neurology, Head of Clinical Research Unit, Head Movement Disorders AG and Deep Brain Stimulation at University Hospital Cologne, and Spokesman of the Parkinson's Network in Cologne, Germany.*

Cervical dystonia and DBS

Editorial: Volkmann J, Mueller J, Kuhn AA, et al. Pallidal neurostimulation in people with medication-refractory cervical dystonia: a randomized, sham-controlled trial. *Lancet Neurol.* 2014;13:875-884, supported by Medtronic.

Cervical dystonia, also called spasmodic torticollis, is a type of focal dystonia characterized by tilting or twisting of the head and neck. Cervical dystonia can be a debilitating condition and severely impact the quality of life of people afflicted with this condition. Not only do people experience symptoms such as abnormal muscle movements and neck pain that interfere with daily activities, stigma created by these symptoms may affect participation in social activities.

Treatment of cervical dystonia may include oral medications, although botulinum toxin injections are typically utilized. Botulinum toxin works by blocking the nerve signal to the muscle in order

to relax the muscle preventing the involuntary muscle spasms. Botulinum toxin injections are effective in the treatment of cervical dystonia; however, some people may not be ideal candidates for botulinum toxin or have unsatisfactory outcomes with repeated injections. Deep brain stimulation, or DBS, works by delivering electrical energy to different parts of the brain through electrodes connected to a battery stimulator. DBS therapy is an option for people when other treatments do not work. For dystonia, the most common target of DBS therapy is the globus pallidus, a brain structure involved in motor movement.

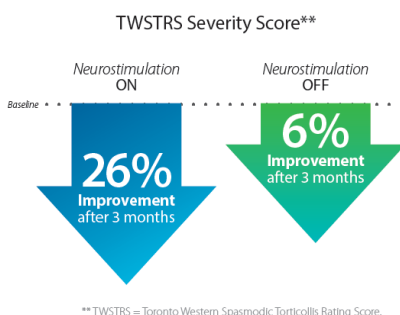
A number of clinical studies have shown that DBS therapy is useful for treatment of primary dystonia (such as DYT1) when other treatment options are not effective. A new study reports the results of DBS therapy in people with cervical dystonia.

Research

A new trial investigating DBS therapy in people with cervical dystonia was recently published in the journal *Lancet Neurology* (Volkman J, Mueller J, Kuhn AA, et al. Pallidal neurostimulation in people with medication-refractory cervical dystonia: a randomized, sham-controlled trial. *Lancet Neurol.* 2014;13:875-884).

This study was conducted across ten academic centers in Germany, Norway and Austria and France and included 62 cervical dystonia people between 18 and 75 years of age that failed previous medication and botulinum toxin therapy. All people in the study underwent surgery to receive the Medtronic RC DBS system and the investigators compared outcomes in one group of people that had their stimulator turned “on” (32 people) to another group that had their stimulator turned “off” (30 people). Comparing these two groups of people allows for a more accurate measurement of the effects of DBS therapy on outcomes in people with cervical dystonia. The investigators used the Toronto Western Spasmodic Torticollis Rating Scale, TWSTRS for short, to measure the effects of DBS therapy. The TWSTRS is a useful tool that measures cervical dystonia symptom severity, disability and pain.

When comparing the two patient groups after 3 months, the investigators found a significant decrease in dystonia symptom severity by 26% in the group receiving stimulation versus only a 6% decrease in the group without stimulation.



Disability also improved by 41% in the stimulation compared to only 11% in the group with stimulation turned off. These results showed that DBS stimulation improves cervical dystonia severity and disability and after 3 months all people had their DBS stimulators turned on. At 6 months, symptom improvements were maintained and when asked about their dystonia, people reported a 49% overall improvement in the severity of their symptoms with DBS therapy.

Clinical Global Impression Score*
Symptom Severity – Patient Rating



* Global rating of dystonia severity on a 10-point Likert scale (physician and patient rated).

Adverse events occurred in 32 people and were mostly known complications related to the DBS surgery or device. Serious adverse events related to surgery or device included infection, hemiparesis and seizure which resolved by 6 months.

One limitation of this study was the relatively short follow up period. It may take 6 to 12 months for dystonia people to experience the full beneficial effects of DBS therapy. However, since the investigators utilized a rigorous design and methodology, this study has greatly increased the understanding of DBS therapy in cervical dystonia and paves the way for additional research. Overall, this study provides evidence that DBS therapy improves cervical dystonia symptom severity and disability. The results of this study demonstrate that DBS therapy is an option for selected individuals with cervical dystonia that fail medical or botulinum toxin therapy.



J. Volkman.

The Botulinum Toxin Therapy Research and Development Project at Hannover Medical School

Recently, DE News met Professor Dirk Dressler from the Movement Disorders Section of the Department of Neurology at the Hannover Medical School in Germany. Here is a report of their conversation about Prof Dressler's recent research program.

DE: What is the background of your Botulinum Toxin Therapy Research and Development Program in Hannover?

DD: In 2008 I was appointed by Hannover Medical School (MHH) as the first Professor for Movement Disorders in Germany. This was an exciting opportunity to start something new and something special. I was very keen to accept this offer, because Hannover is the most exciting place to do research in botulinum toxin (BT) therapy: With the MHH departments of toxicology and physiological chemistry, with Toxogen and world class basic scientists like Hans Bigalke, Thomas Binz and Andreas Rummel I had excellent partners. My job was to develop the clinical side. The patient base in Hannover basically covering the whole North of Germany was excellent. However, drawing talented people and getting the necessary funding was and still is a big challenge as it needs funding.

DE: Why did you come up with this R&D program?

DD: Over the years we have seen an enormous growth in the therapeutic use of BT. Many medical specialties are now using BT therapy. For dystonia, however, patients and young doctors keep asking: What is new? Where is the progress? All major indications including cervical dystonia, blepharospasm and spasmodic dysphonia have been introduced many years ago. So we sat together and tried to identify unmet medical needs in dystonia.

DE: And, did you find any unmet medical needs in dystonia?

DD: Yes, indeed, we did. First, we identified the problem of insufficient effect size. Often, we see a positive effect of BT therapy, but it is not strong enough. There may be dystonic muscles left untreated since the physician is afraid the total dose could become too big. Also, sometimes the effect in an injected muscle isn't strong enough, again, because the physician is afraid the total dose could become too big. So, we clearly have a problem: How big can the total BT dose be? How far can we go?

DE: How did you address this problem?

DD: Over the years we were the first to expand the number of target muscles in our patients. For example, treating cervical dystonia we introduced the deep neck muscles, the scalenii and the levator scapulae muscles as potential target muscles long before others were aware of the role these muscles play in dystonia. Another example: In dystonia of the shoulder region we pointed out the role of the teres major and latissimus dorsi muscles. This is why we had large numbers of patients and a long standing experience with high dose BT therapy. All we had to do was to examine these patients in detail, look at their long-term results and do some additional laboratory investigations. For this our digitalised BT therapy data bank in which we have stored all relevant treatment data became pivotal. To enlarge the data base for this study we also included patients with spasticity receiving BT high dose therapy.

DE: What were your results?

DD: We identified 100 patients receiving BT in doses of more than 400MU per visit and followed them up for at least 1 year. On average our dystonia patients received 570.1 ± 158.9 MU per visit and the observation period was 10.2 ± 7.0 (min 4, max 37) injection series. The maximum BT dose a patient received per visit was 1200MU. Altogether, this is a very large series of patients

and a very long observation period. The results were very straightforward: In none of our patients could we detect any sign of systemic toxicity, i.e. any 'intoxication'. This was true for side effects of the motor system and the autonomic nervous system. None of the patients developed therapy failure due to BT antibody formation either. Additional laboratory tests did not identify any abnormalities.

DE: You did your study on patients receiving Xeomin. Was there any reason for this? What does this mean for patients receiving other BT drugs?

DD: We did the study on patients receiving Xeomin since most of our patients receive that formation of BT. Additionally, we first studied patients receiving Xeomin since this BT drug has the lowest risk of BT antibody formation. We believe that the data on the lack of systemic toxicity can be transferred to other BT drugs as well. A large number of our patients had previously received Botox in identical doses, also, without signs of systemic toxicity. The safety with respect to antibody formation we cannot judge right now, as we do not have the long-term data on Botox yet.

DE: Why is this study so important?

DD: This study shows that we can use much larger BT doses than previously thought. We can therefore treat more target muscles or can use higher doses in those target muscles, if necessary. This means that we have to re-define the dividing line between the use of BT therapy and deep brain stimulation. Based on our data more patients with severe dystonia can be treated with BT therapy before they had to undergo much more invasive surgical procedures.

DE: What other projects did you pursue?

DD: Another project is our interval study. Conventionally, BT therapy is performed at intervals of at least 12 weeks. We know that many patients have a recurrence of their symptoms several weeks earlier than this. This inflexible minimum interval of 12 weeks would

mean that a number of patients would suffer from their dystonia before they get their next BT injections. In order to get hard data, we started a formal study on 59 patients with cervical dystonia. We collected 1289 treatment cycles. In 83% of our patients the therapeutic effect lasted for less than 12 weeks, in 36% of our patients it lasted for even less than 10 weeks. This means that our patients were sub-optimally treated for 23% of their time. Clearly, this is a finding that we, as physicians, have to address.

DE: How do you want to solve this problem?

DD: We want to collect data on patients who received BT therapy at shorter intervals, to see whether they have an increased risk for BT antibody formation. Our preliminary data show that, with Xeomin, shorter intervals are possible without producing BT antibody formation. These data will be published soon.

DE: What other projects did you cover?

DD: We developed a new ELISA test for detection of BT antibodies. This test is much cheaper than the conventional mouse tests and it does not require sacrificing large numbers of mice. This test will help us to better identify the risk factors for BT antibody formation. We also developed a new instrument to examine the BT effect over time. So far, everybody only looked at the peak BT effect after 4 or 6 weeks. This new instrument will allow us to see the temporal profile of the BT effect. This can be very helpful to determine when the best time would be to have re-injections.

DE: Anything more?

DD: Yes. What about compliance? BT has to be injected into the body. That is painful or at least unpleasant. Imagine as a patient, these injections could become less unpleasant. Would that be an advantage? I guess that most patients would agree. We have an R&D module that deals with injection site pain.

Research

DE: Any results yet?

DD: Yes, we are able to reduce injection site pain in our patients very easily and very elegantly.

DE: Can you tell us more about this?

DD: The data are currently under review and we do not want to interfere with the reviewing process.

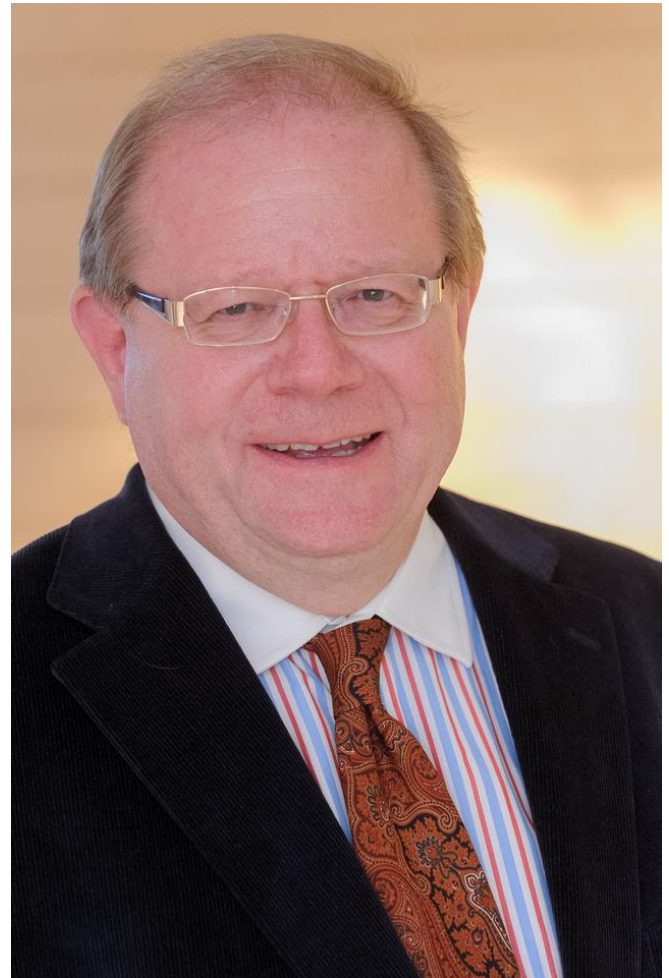
DE: Quite a lot of results within a short period of time. How can you sum up this R&D project?

DD: We were surprised that nobody asked these questions before. They were so obvious. You just have to listen to your patients. They can give you directions.

DE: How do you see the role of the pharmaceutical industry in this respect?

DD: The pharmaceutical industry spends about 20% of their revenues on R&D. In BT therapy all indications except for migraine and some special bladder disorders were developed by physicians on the front line. If we had had only 1% of the industry's R&D budgets we could have advanced things much faster and much better.

DE: Professor Dressler, thank you very much for this interview.



MD, PhD, Dirk Dressler.

E-mail: dressler.dirk@mh-hannover.de



**THIRD INTERNATIONAL CONGRESS
ON TREATMENT OF DYSTONIA**

2016

For all who take care of people with dystonia

May 4th - 7th, 2016 | Hannover Congress Centrum



DySTracT – a German Collaborative Consortium for Dystonia Research

*Prof. Christine Klein
University of Luebeck
Luebeck, Germany*

With a prevalence of about 20 in 100,000, dystonia is one of at least 6.000 to 7.000 distinct rare diseases. In the past years, it has been recognized that research on rare diseases needs specific support to provide knowledge for prevention, diagnosis and better care of patients. The characteristics of rare diseases include a limited number of patients at a single center, scarcity of relevant knowledge and expertise, and fragmentation of research. Rare diseases such as dystonia are therefore a prime example of a research area that can strongly benefit from collaboration/coordination on a national or even international scale. Patients' support groups such as Dystonia Europe have put enormous effort into political advocacy. This is particularly important as commercial interest in rare diseases is typically low and thus governmental support is needed. In keeping with this notion, the German Ministry of Education and Research recently launched a program to support translational research for rare diseases.

The Consortium

Within this framework, a German collaborative consortium named "Dystonia Translational Research and Therapy Consortium" (DysTract) was founded and successfully applied for funding for a period of three years. The coordinators are Professor Jens Volkmann, MD (University of Würzburg) and Professor Christine Klein, MD (University of Luebeck). The consortium will represent the first large-scale, multidisciplinary coordinated research effort worldwide aiming to uncover shared disease mechanisms in dystonia.

The ten subprojects within this consortium are headed by leading dystonia researchers and experienced clinicians within Germany located in Berlin, Hanover, Lübeck, Marburg, Tübingen, and Würzburg.

Focus of the Research

Specifically, they will investigate the phenotypic variability and frequency of mutations in known and novel dystonia genes in a large national cohort of dystonia patients, an effort led by Katja Lohmann, the 2013 recipient of the David Marsden Award, in conjunction with Thomas Gasser. This cohort will be built based on individual, relatively small local cohorts and a German Dystonia Registry will be established. Further, endophenotypes will be identified using multimodal neuroimaging and electrophysiology, which may allow categorizing divergent clinical phenotypes into pathogenetically homogenous groups. Another focus lies on the elucidation of the disease mechanisms of dystonia and the identification of biomarkers and drug targets.

The Research Mechanism

For this, the group will combine human clinical and experimental animal research including cutting-edge technologies such as induced pluripotent stem (iPS) cell characterization from dystonia patients. This multipronged approach will lead to novel insights into the entire disease pathway of dystonia from the molecular level to brain network abnormalities. Finally, a clinical trial will compare the efficacy of peripheral selective denervation (by botulinum toxin injection) and central network modulation (by deep brain stimulation) in controlling dystonia-related disability.

Research

Research Goals

The ultimate goal of the consortium is to not only improve our understanding of dystonia but to also open up new avenues for better treatment of persons with dystonia. Patients will immediately benefit from this consortium through a more standardized diagnosis and treatment regimen and through a reference database for all groups involved in dystonia care. The consortium is grateful for Dystonia Europe's support in obtaining the grant.



Dr. Katja Lohmann and Prof. Christine Klein.



Around Europe & Beyond

Spain

10th Annual Dystonia Day in Barcelona

Last November 15, ALDEC (the Spanish Dystonia Association in Catalonia) held its "10th Dystonia Day" in Barcelona. The conference was opened by the Director for Social Services (Department of Social Welfare), showing the support from the Catalan Government for a patient organization's initiative to help improve the lives of those affected by dystonia, as well as their families.

Chairs of the meeting were Dr. Pilar Sanz, neurologist at the "General Hospital of Mataró"

and member of the ALDEC Medical Advisory Board, and Ms. Rosa Candela, member of the ALDEC Board. After welcoming the participants to this 10th Dystonia Day they introduced the speakers.

The first presentation was "Dystonia & Musicians" by Dr. Jaume Rosset, Medical Director of "Institut de Fisiologia i Medicina de l'Art-Terrassa" in Barcelona, a pioneering centre in the medical treatment of artists (musicians, dancers, actors etc). Doctors and therapists work as a team to help artists with various symptoms to recover in the most effective way. The Institute specializes in the treatment of musician's dystonia.

Around Europe & Beyond

Then Dr. Pilar Sanz talked about a very special case of musician's dystonia: the dystonia of Glenn Gould, a musician famous for his dystonic posture when playing the piano. His way of playing the piano: the "Goldberg Variations" is world famous. In the second part of the 10th Dystonia Day, Dr. Ramiro Alvarez, neurologist at the "Hospital Germans Trias" in Pujol, spoke about dystonia and surgery, a delicate topic due to patients' fear of surgical interventions in such sensitive areas as the brain. He explained the different types of dystonia, and how serious forms of dystonia lead to a very poor quality of life for those affected. A surgical intervention could help and improve their dystonia.

Dr. Jorge Muñoz, a neurosurgeon at "the Hospital Germans Trias" in Pujol, spoke about surgery and from the neurosurgeon's perspective. This presentation was especially interesting since videos were presented showing the whole process of Deep Brain Stimulation (DBS).

Then followed the presentation of Dr. Ellen Gelpi, responsible for the "Neurological Tissue Bank" at the "Clinical Hospital" of Barcelona. She talked about the work of the Tissue Bank, privacy and security, as well as the process to become a donor. With the help of such important donations research on dystonia and other neurological disorders can move forward.

In the last presentation Physiotherapist Emma Ludeña, "Physio Centre Day Hospital Clinic" of Barcelona, spoke of the "Postsurgical Motor-rehabilitation in Cervical Dystonia". She stressed the importance of physiotherapy in patients before and after DBS (Deep Brain Stimulation) surgery, as well as for all dystonia patients. ALDEC strongly promotes physiotherapy as an additional treatment for dystonia patients. At the end of the "10th Dystonia Day", Ana Sanchez, Vice President of ALDEC, thanked all the

speakers who had contributed to a successful meeting as well as all the participants for attending, and concluded by inviting everybody to the "11th Dystonia Day" which will take place in November 2015.

Before the meeting ended there was a joint JUMP for dystonia to support the on-going dystonia awareness campaign initiated by Dystonia Europe.



Ana Sanchez, Vice President, ALDEC.

Germany

“Musicians with Dystonia” - a Support Group of the German Dystonia Association

This support group was founded in 2003 during the 10th annual conference of the German Dystonia Association in Potsdam. At this event Chinese pianist Ya-ou Xie, who has dystonia, gave a concert. Because of intensive training with concert pianist and piano teacher Laurent Boulet she had been able to reobtain her full ability to perform and to return to the international concert stage. The participants of the conference were very impressed with her performance which proved that musician's dystonia is not necessarily a given fate but can be treated and even overcome. During this conference the attending musicians with dystonia had the idea to form a national support group providing exchange of information, support and further education to the members as well as spreading awareness and knowledge among therapists, interested musicians, doctors and the general public. Neurologists and medical specialists for musicians are contributing with medical and other scientific presentations. Famous musicians, among them Maestro Daniel Barenboim, are supporting the group as patrons.

In 2004 American pianist Leon Fleisher, who also suffers from dystonia, played one of a series of concerts from the worldwide campaign „Freedom to Play“ at the Berliner Philharmonie in order to raise awareness for the problems of musicians with dystonia. Prof. Dr. med. Eckart Altenmüller, world-renowned specialist for the treatment of musician's dystonia, spoke about the causes and treatments, especially the use of botulinum toxin. During this symposium Alexander Müller, who leads the German support group, was able to meet with his American colleague Glen Estrin. At that time the German group of musicians with dystonia consisted of just 10 members who

stayed in contact via phone and internet. Soon they wanted to meet each other in person and the first meeting took place in a recording studio of a pianist in the vicinity of Darmstadt.

In the following years the group kept growing and every year a specialist was invited to the meeting who would add valuable information as well as therapeutic help. In the years 2007 and 2011 the group was invited to the Institute for musician's physiology and medicine in Hannover by Prof. Altenmüller who introduced the work of this institute and informed the group about new findings and methods.



Members of the German Musicians' Dystonia Support Group.

In 2008 and 2013 the group met in Berlin with pianist and therapist Laurent Boulet, who informed the musicians about the possibilities and successes of his retraining program. In 2009 the yearly meeting took place in Bamberg, where the group was introduced to Feldenkrais therapy by violinist and violin teacher Hildegard Wind. In 2010 the main focus of the meeting was on embouchure dystonia with Prof. Angerstein and logopedist Barbara Amberge as specialists.

The 2012 meeting took place at the University for Music „Carl Maria von Weber“ in Dresden hosted by Prof. Hans-Christian Jabusch. Finally, in 2014 the focus was again on embouchure dystonia, and this time took place in Munich. The Alexander technique was introduced as a valuable additional therapy.

Around Europe & Beyond

Today the group „Musicians with Dystonia“ has about 50 members, and most of them have focal hand dystonia. About 15 % suffer from embouchure dystonia. An annual meeting has proved to be ideal for maintaining personal

relationships and a lively exchange of experiences and news about this still somewhat mysterious disorder.

*Alexander Müller
Leader of the German Musicians & Dystonia
Support Group.*

Romania Children's Joy Association Activities in 2014

Over the last year the two Romanian Dystonia Associations "Children's Joy Association" and "Dystonia Romania" were involved in several activities to support dystonia patients and their families, to advocate for access to treatment and to raise awareness. Read more about the Jump for Dystonia Activities in Romania on page 13.

The first event in 2014 was held in Timisoara, where we discussed:

- The treatment options available at a national and global level
- Access to treatment in Romania
- The need for implementation of a national program for dystonia treatment
- Under-Diagnostic problems at the national level
- Dystonia-Stigma-Disability

On May 16 dystonia patients participated in a manifestation in front of the Romanian Government. An open letter was put forward to the Government and the ministers concerned, appealing for dystonia patients' rights to access to treatment.

In the autumn we were pleased to participate in the EFNA workshop in Brussels where we could discuss the issues of Romanian dystonia patients and how to try and face these problems.



Around Europe & Beyond



The last Dystonia Patients workshop and meeting of the year was held in Bucharest. Topics were stigma regarding dystonia, access to treatment, DBS-treatment.

In summary it was a year with many activities and we made several appeals to the Ministry of Health in order to facilitate access to treatment and to advocate for the rights of all of those who suffer from dystonia in Romania.

Catalina Crainic.



Catalina Crainic and Sabina Gall of Children's Joy Association.

Other News

Ipsen Toxins Nordic in Copenhagen

For the first time Ipsen Scandinavia organized the meeting Toxins Nordic last October. About 100 participants, neurologists, physio-therapists, nurses from the Scandinavian countries had come to Dokken in Copenhagen to hear presentations on treatment of dystonia and spasticity and to take part in the various workshops. Monika Benson from Dystonia Europe was invited to talk about dystonia from the patient's perspective. After presenting her own personal Dystonia Story, Monika talked about the importance of a national patient

organisation and how we can work together with the medical profession. In the last part of the presentation she talked about Dystonia Europe and its three main projects: the Annual Conference D-DAYS, the digital platform – DystoniaCommunity with MyDystonia the APP, and the dystonia awareness campaign Jump for Dystonia.

In Copenhagen were also the Dystonia Associations of Sweden and Denmark present with Göran Olsson, Mette Spangsberg and Jens R. Tyle Petersen who distributed information material and made many new contacts.

Launch for Interest Group on Brain, Mind and Pain in the European Parliament



The official launch of the MEP Interest Group on Brain, Mind and Pain took place in Brussels on February 24th, 2015.

The group – a joint initiative of the European Federation of Neurological Associations and Pain Alliance Europe – was 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.

exploring possible solutions. This include testimonies from dystonia patients about stigma.

This document was presented and distributed at the launch with contributions from representatives of the aforementioned groups – including the President of the European Academy of Neurology, Prof. Gunther Deuschl.



President of Pain Alliance Europe, Joop van Griensven, MEP co-chair Marian Harkin and EFNA Executive Director Donna Walsh.



Heather Clarke, EFNA Senior EU Policy Officer, Donna Walsh, EFNA Executive Director, Joop van Griensven, President of Pain Alliance Europe, Maria Soledad Garcia Penalta, Board Member of Pain Alliance Europe, Cristina Fernandez, Secretariat at Pain Alliance Europe, Ann Little, EFNA Board Member and Executive Director of the International Bureau for Epilepsy.

In advance of the launch EFNA and PAE had been preparing a Book of Evidence which outline why brain and pain disorders should be a political priority; highlighting the current challenges/barriers but also

There has already been widespread support for the group with over 40 Members of the European Parliament [MEPs] signing a Register of Supporters during a two-day promotional event in Strasbourg on January 13th and 14th.

A list of the MEP signatories can be found on the EFNA website or on Twitter @EUneurology #brainmindpain.

A dedicated website www.brainmindpain.eu will be launched in the Spring.



*Donna Walsh
EFNA, Executive Director.*



Heike Wolf.

Meet Dystonia Europe Treasurer, Heike Wolf from Germany

Born in Wilhelmshaven on the North Sea coast of Germany, I grew up in the rural district of Friesland. I cannot remember a time without movement disorder, so I cannot tell you how it changed my life or how it would be without it. But there is little doubt in my mind that it would be somewhat better. As you might notice I don't use the word Dystonia but movement disorder for now.

When I started school teachers gave me bad marks for my handwriting. Once in a while they would bother enough to contact my parents who would try to get professional help. But nothing was found wrong with me, and since I was doing well enough in school (except in sports) it was generally agreed that I was just a bit nervous and the subject was kept under the carpet.

My favourite subject in school was English, and I spent a year going to high school in Medford, Oregon, staying with family. Multiple choice tests gave me a nice break from fighting to write with my trembling hands. However, it was during that

time that I noticed a new dimension of "being nervous": My neck started trembling and jerking to one side.

I went on to university to study languages, however, the still undiagnosed movement disorder took me to a breaking point, and I gave up my studies. I cannot thank my parents enough to give me back enough security and self-esteem to learn a trade that would allow me to support myself. After three years I had earned my certificate as a tax consultant's assistant.

I found a job in the freshly reunified city of Berlin which has remained my home of choice ever since. It seemed to me like my city and I were both licking our wounds and enjoying a freshly found freedom. But I was soon about to lose my job because I was too slow and shying away from client contacts. A neurologist referred me to the movement disorder specialists at the Charité Hospital, and I finally received a diagnosis – well, actually two of them: Essential Tremor and Cervical Dystonia – at the age of - 40!

Receiving a diagnosis was like an awakening or empowerment. I was no longer a victim – I was in charge. I had words to explain and options to try. And I was no longer alone but soon found other patients and ultimately friends with similar problems in a local dystonia patient group I joined. Oral medication and botulinum toxin injections alleviated my symptoms.

During a charity concert in Berlin organized by the German Dystonia Society I met Monika Benson who drew me into the work of Dystonia Europe, ever so cleverly breaking my resistance. First serving as a delegate for the German Dystonia Society I was nominated and elected as Dystonia Europe Treasurer in Edinburgh in 2013. Serving on the board of Dystonia Europe is an honour and a great joy.

Hello there!

When I am not juggling files and numbers I like to go out into Berlin's beautiful parks and zoos to take pictures. For me, photography is a bit like meditation - being in that one moment I want to capture; being one with the light and the beauty surrounding me. And then I can relive that moment when I look at the picture at home and even share it with others.



Photo: Heike Wolf.

I think that finding something that fills your heart is a much underestimated puzzle piece of self-therapy. I feel that dystonias, or movement disorders in general, don't just affect our bodies but also our souls. Some say that dystonia attacks what we love the most. While we are still trying to find a cure for dystonia we must not allow it to eat away on our hearts and kill the joy of living. So while spreading awareness and searching for a cure are important aspects of the work of dystonia patient organizations, the third and maybe most important leaf of clover must be adding joy and happiness to patients' lives.

*Heike Wolf, Board Member,
Dystonia Europe.*

Meet Photographer Stephan Röhl



Stephan Röhl.

DE has the last few years undergone a major change of looks & appearance: new logo and colours, the launch of a new website, Facebook pages and an updated newsletter. These are all illustrated with beautiful photos of people and activities we take part in.

But who is behind these many bright and lively photos?

We met with freelance photographer, Stephan Röhl, to hear about his work, his passion for photography and how he got connected to dystonia.

Hello there!

Dystonia Europe - DE: Where are you from?

Stephan Röhl – SR: I am based in Berlin in Germany where I work as a freelance photographer

DE: What does photography mean to you:

SR: I love to capture the "right moment". I always aim at translating the atmosphere of a place and mood of a situation into my photos.

DE: What is your favourite object to photograph?

SR: I am very fond of taking photos of musicians, and it is actually at a musical event I first made contact with dystonia.

DE: Can you tell us more about that?

SR: It was a beneficial classical concert for Musicians' Dystonia in Berlin, a couple of years ago. This was organised by the German Dystonia Association (DDG), and to support this good cause I offered to take photos of the event. At this occasion I also met Monika Benson from Dystonia Europe.

DE: What is your connection with Dystonia Europe today?

SR: Dystonia being a little known brain disorder I support the efforts to raise awareness, and if my

photos can help in this important work I am very happy to contribute. I have done photo documentations of the Dystonia Europe Annual Conferences and so far I have participated in Bol, Croatia, Edinburgh, Scotland and Paris in France.

DE: What is it that you like when being at these meetings?

SR: It's not only that I am taking the photos for a good cause but it is also fun to work with Monika, Robert, Alistair and all the Dystonia Europe folks

😊

DE: If anybody is interested in getting in touch with you for work etc where can they reach you?

SR: Please visit my website at www.stephan-roehl.de and there you can see samples of my work. I am very interested in working at conferences and events all around Europe. Just send me an e-mail and we can discuss further.

DE: We are very happy with your work and we will continue to recommend you for further assignments. Thank you for taking the time to talk to us.

SR: Thank you.



Events

2015

27-30 May, European Paediatric Neurology Society Congress, Vienna, Austria.

29-30 May, 5th Biennial Workshop on Dystonia. "Controversies in Dystonia & Parkinsonism", Rome, Italy.

14-18 June, MDS Congress, San Diego, USA.

20-23 June, 1st Congress of European Academy of Neurology, Berlin, Germany.

2-4 October, Dystonia Europe D-DAYS - 22nd Annual Conference and General Assembly, Rotterdam, The Netherlands.

31 October-5 November, 22nd World Congress of Neurology, Santiago, Chile

2016

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.



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.

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22ND ANNUAL CONFERENCE

D-DAYS

OCTOBER 2, 3 & 4, 2015
ROTTERDAM, THE NETHERLANDS

ANNUAL EUROPEAN
DYSTONIA DAYS



Organized by Dystonia Europe and the Dutch Dystonia Association



PRELIMINARY PROGRAMME

Dystonia Europe 22nd Annual Conference
&
Dutch Dystonia Association 30th
Anniversary

Rotterdam, the Netherlands

- **FRIDAY, 2 OCTOBER**
Lectures about dystonia
- **SATURDAY, 3 OCTOBER**
Family day (expecting 500 members of the Dutch Dystonia Association). In the morning free activities for families, and in the afternoon workshops and lectures about dystonia. There will also be an information corner.

SATURDAY EVENING

30th Anniversary *Gala Dinner*
Dutch Dystonia Association

- **SUNDAY 4 OCTOBER**
Dystonia Europe 22nd General Assembly
For members only



Information & Registration: www.dystonia-europe.org

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 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 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.

Thank you for supporting Dystonia Europe!

Medical & Scientific Advisory Board

Prof Alberto Albanese – Milan
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Board of Directors

Dystonia Europe is governed by a volunteer Board of Directors.



Robert Scholten, President, Netherlands

Robert was elected President of Dystonia Europe at the General Assembly in Edinburgh in 2013. He is from the Netherlands and he is also the President of the Dutch Dystonia Association. Robert is working in the field of communication, marketing and public affairs. He has had cervical dystonia since 2000.



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.



Marina de Koning-Tijssen, Board Member, Netherlands

Marina is a professor in charge of the movement disorders department at Groningen University Hospital and has been committed to supporting the Netherlands dystonia patient organisation for a number of years as a member (and chair) of its Scientific Advisory Board. She was elected to the board of Dystonia Europe in 2011, is a member of our Medical and Scientific Advisory Board and heavily involved in the COST-funded Dystonia Research Network.



Heike Wolf, Board Member, Germany

Heike is a member of the German Dystonia Association and a delegate to Dystonia Europe since 2012. She was elected to the board of Dystonia Europe in 2013. After three years of professional training as a tax consultant assistant Heike has been working within this field in Berlin since 1997. Heike has cervical dystonia.



Merete Avery, Board member, Norway

Merete was appointed to the board of Dystonia Europe in 2013. She was diagnosed with cervical dystonia in 2006 and she was Chairwoman of the Norwegian Dystonia Association from 2010-2013. In 2013 she was elected Secretary to the Board of the Norwegian Dystonia Association. Merete works with administration work and customer service for a company in Molde, Norway.



Alistair Newton, Board Member, 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 has been appointed to the Dystonia Europe Board with special responsibility of the Dystonia Research Network. Alistair also co-funded 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, and has been a board member and Treasurer ever since. Alistair has had cervical dystonia for 30 yrs.



Sölvi Engeland, Dystonia Europe, Newsletter & Annual report, Norway

After serving her maximum period on the DE Board, Sölvi stepped down from her position at the last GA in 2014. Sölvi continues to be responsible for layout and design for Newsletter and Annual Report. Sölvi was diagnosed with cervical dystonia and blepharospasm in 1989. Sölvi's professional training is within management, strategy, sales and marketing.



Monika Benson, Dystonia Europe, 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.

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.

