

Connecting people for dystonia

DYSTONIA EUROPE

NEWS
WINTER 2018



Thumbs up for Dystonia Europe!
Delegates at the Dystonia Europe 25th Anniversary in Brussels 2019

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Connecting people for dystonia

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

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President's Message



Dear all,

First of all I would like to thank you all for a great year.

A year when Dystonia Europe celebrated its 25th Anniversary. A milestone that many of our member associations also have reached.

This year we saw an increase in our on-line activities during dystonia awareness month and that is very much thanks to you, all our followers, who share and comment and take part in the discussions. We are

already looking forward to awareness month 2019 and how we can all work together again. In 2019 we will award the 9th David Marsden Award. Application deadline is 31 January 2019 and the award will be presented at our D-DAYS in London next July. This is our annual event and for the first time ever the theme will be more focused on young people living with dystonia. We hope to see many participants of all ages there.

We are very grateful for all the great work that is taking place around Europe for dystonia patients and their families. Together we are stronger and it is only by working together we can make a difference for dystonia.

Now I wish you all a wonderful and relaxing holiday season. Take good care of each other and hope to see you in 2019.

Merete Avery
President



www.dystonia-europe.org

MyBrainNet – a Digital Platform for Brain Diseases

We are very excited to present our new project: **mybrainnet**. All made possible by the first BMP grant which Dystonia Europe, together with two other projects, was awarded last June in Brussels.

The Brain, Mind, and Pain Patient-Centred Innovation Grant has been initiated by Pain Alliance Europe and supported by Grünenthal Group with the main aim of encouraging patient-centered innovation, resulting in better quality of life for patients suffering from pain, or neurological disorders. Learn more about the grant here: <http://bmp-grant.eu>

So what is mybrainnet and what is the story behind it?

For the last year we have been discussing the possibilities of upgrading MyDystonia, our digital diary, to My Dystonia Version 2.0. with an improved and more flexible platform where various functionalities can be added in the future.

From the start of the Ambassador program we have received much valued feedback with many good ideas and wishes from our users. Due to technical restrictions of the present platform and the costs included to make these changes we realised very soon that this was not possible. We have also received important feedback from the medical profession. Dr. Jean-Pierre Lin, Paediatric Neurologist at Evelina Children's Hospital London, and Hortensia Gimeno, Clinical Research Fellow at NIHR and Consultant Occupational Therapist have both expressed the benefits of a

MyDystonia app especially designed for children. Additionally, at some of the presentations of MyDystonia at various meetings, members of other patient organisations within the neurological field have expressed an interest in using a copy of MyDystonia for their own members.

With these wishes in mind: an update of MyDystonia, a version of MyDystonia for Children and for other patient organisations to use the MyDystonia diary as a template, we embarked on a journey that led to the creation of **mybrainnet**!

We created and designed a new platform that could not only handle the updated MyDystonia2.0 and the MyDystonia for Children, but also apps for other patient organisations.

MyBrainNet is a completely new platform with the aim of updating MyDystonia, including improvements based upon the feedback received over the last few years. There will be a redesign of the way questions are presented in the app, making the app suitable for treatments like DBS as well as differentiating the questions based on the type of dystonia you have. We also want to add the ability to add photos and perhaps even videos to the diary, so special conditions can be made available in a visual manner and not only using text.



Latest News

We are also looking into the possibility of sharing the reports with the GP or neurologist by giving them direct access to the reports, making it possible for them to create reports in such a way that it gives them the most valuable information to make informed decisions and to let them create it at the time that is convenient to them. This should increase the usefulness of the diary greatly.

One of our goals with this new platform is that we want to make use of the information users have entered into the diary. Although the diary is primarily used for the communication between patient and physician, the information can also be of great use for research projects. Of course all of the research information will be made anonymous, so no-one can ever track a piece of information back to a specific person. Before the use of the diary information for research projects the user has to agree of course.

MyBrainNet will be created on a modular basis and as mentioned earlier we will start with the creation of the diary function in order to replace the current MyDystonia.

In the future, with the support of additional funding, we will be able to develop new modules, creating

new functionalities for MyDystonia. Several ideas have been proposed, such as the ability to communicate directly with other patients or to find and access quality information about dystonia.

The most important aspect of MyBrainNet will be the option for other patient organisations to join the project and have an app of their own. We aim to share this platform with other patient organisations working in the field of brain diseases. We believe it's an interesting offer especially for the small patient organisations of other rare neurological diseases. Although we may all have a different neurological condition, we are faced with the same kind of challenges, wishes and hopes. MyBrainNet will be a project of collaboration and sharing, in order to create an awesome platform. By working together we can much better use available funding, use the time spent on the project more efficiently as well as benefiting from the same legal framework.

If you are interested in learning more about the project or how you can be involved let us hear from you: sec@dystonia-europe.org

Eelco Uytterhoeven
MyBrainNet IT Coordinator



BMP grant winners 2018

Dystonia Europe at the 23rd ESSFN Congress in Edinburgh

Last September Dystonia Europe took part as an exhibitor at the 23rd Congress of The European Society for Stereotactic and Functional Surgery, an organization which frontiers the progress of functional and stereotactic neurosurgery of the human nervous system. About 700 participants, including exhibitors, had come to Edinburgh for this special event which took place at the Royal College of Surgeons, a venue with over 500 years of rich surgical history.

The first Congress of the ESSFN was held in Edinburgh in 1972. This year's congress was the first one to be jointly organized by neurosurgeons (Ludvic Zrinzo and Marwan Hariz from The National Hospital Queen Square, London) and psychiatrists (Keith Matthews from University of Dundee) therefore many meeting topics included neurosurgical approaches for psychiatric disorders. Pain, epilepsy, Parkinson's and other movement disorders, such as dystonia, were also major topics with discussions of the latest advances in clinical management, technology and scientific research.

The special session on Movement Disorders and dystonia included Dystonia Experts such as: Dr. Laura Cif from Montpellier who presented "20 years' experience of DBS for paediatric dystonia" and Prof Joachim Krauss from Hannover who presented the work on "a registry of real-world outcomes using DBS – deep brain stimulation* for dystonia".

At the Dystonia Europe booth we informed about our organization, our activities and projects. In collaboration with Boston Scientific we encouraged participants to get behind the Dystogram to take a photo for #DE25years and the #YestoDBS campaign. It is very valuable for Dystonia Europe to be able to connect with the medical profession and the industry at these special congresses. It gives DE the opportunity to share our work and experiences which may lead to new partnerships as well as providing us with updates on the latest developments within the field.

Our platinum sponsors Boston Scientific and Medtronic took part with major exhibitions and specific symposiums. Boston Scientific had organized a special activity at their booth "give an autograph – change a life".





Prof Joakim Krauss and Alistair Newton

At the end of their symposium the two patient organizations EPDA (European Parkinson's Disease Association) and Dystonia Europe were surprised with a donation of € 5000 each as a result of this activity. We thank BS for this generous gift and their continued support.

We thank the organizers for offering the exhibition space for free and we look forward to the next congress, which will be held in Marseille in 2020.

** Deep brain stimulation (DBS) is a surgical procedure in which two thin, insulated electrodes are inserted into the brain. These electrodes are then connected by a wire under the skin to a battery usually implanted in the chest or in the abdomen. The battery operates similarly to a pacemaker delivering targeted electrical pulses that block the signals that cause the symptoms of dystonia. The battery is implanted below the skin on the chest wall (or sometimes the lower abdominal wall) so is barely visible but an outline of its shape and of the wires connecting it to the brain may be visible.*

Monika Benson
Executive Director
Dystonia Europe



Vincent Sourdain, Sr Director EMEA at Boston Scientific, with Monika Benson Dystonia Europe and Francesco De Renzis from EPDA.

September Dystonia Awareness Month 2018

First of all a great THANK YOU to all of you who took part in our Dystonia Awareness Month on-line activities last September. The success would not have been possible without your support and help in sharing our posts, videos, quotes etc.

This was the second time Dystonia Europe had taken part in the Dystonia Awareness month.

At our last conference D-DAYS 2018 in Brussels, all presentations were recorded and published on the Dystonia Europe Youtube channel. There were also interviews made with several of the speakers which were edited into short video quotes. Together with links to our Youtube channel, information graphics, inspirational quotes a diverse and interesting content was created and published throughout the month on all our social media channels: Facebook, Twitter and Instagram.

The amount of followers on our social media channels increased:

- Facebook from 3101 to 3198
- Instagram from 308 to 410
- Twitter from 312 to 386

Facebook average reach/day:

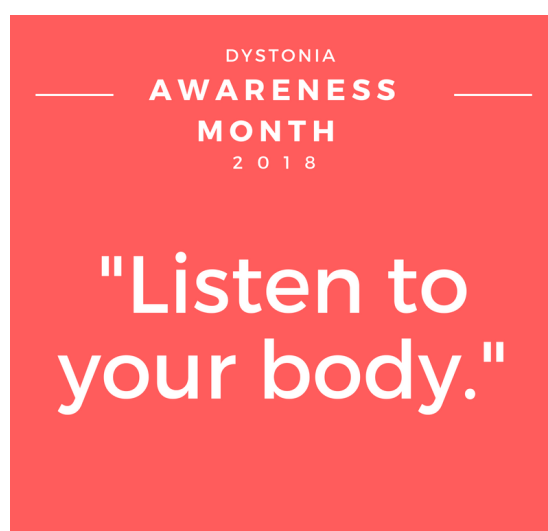
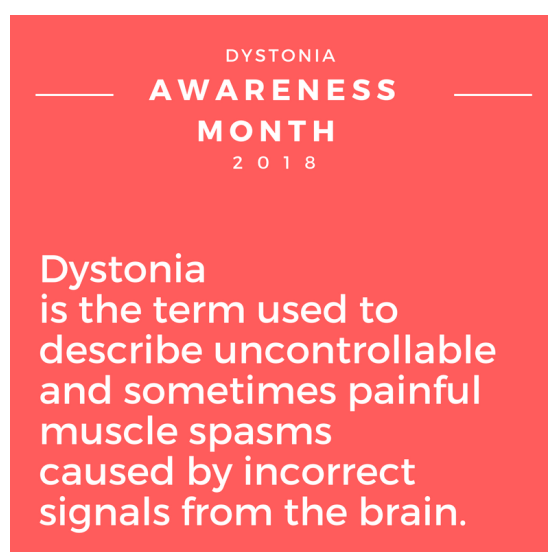
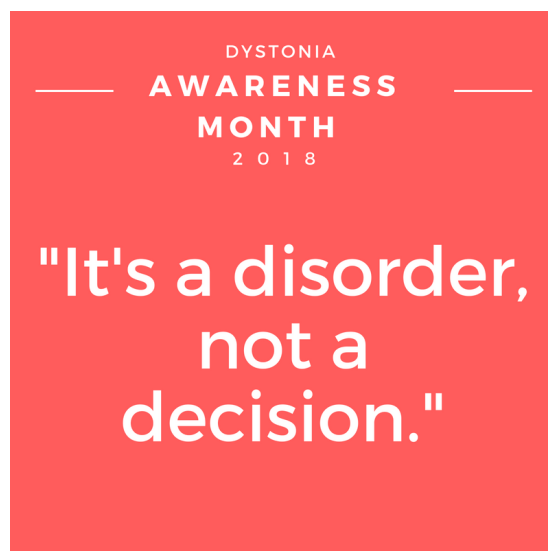
- Sept 2017 – 2028
- Sept 2018 - 2586

The most popular posts on Facebook were the posts in fact format containing inspirational quotes and various dystonia facts. They had the most viewers and shares.

We are very pleased with this year's awareness activities and we are already looking forward to September Awareness month 2019.

If you have any special ideas of what to do on-line or in your country please send us an e-mail and let us know at sec@dystonia-europe.org

The more we are working together to raise awareness of dystonia the more will dystonia be heard of and recognized.



Non-invasive brain stimulation in dystonia

There is a very interesting review by Erro et al. entitled “non-invasive brain stimulation for dystonia: therapeutic implication”[1] that I would like to draw to your attention.

Currently, there are two forms of non-invasive brain stimulation (NIBS). The first technique is called (1) transcranial magnetic stimulation (TMS) and the second one (2) transcranial current stimulation (tCS). The term “non-invasive” is used to underline the fact that magnetic stimulation is administered without the necessity of surgical intervention (in contrast to deep brain stimulation). The basic principle is that those methods are designed to modulate the function of brain systems, specifically cortical-subcortical network with magnetic pulses. Even though the treatment is non-invasive, some side effects were observed.

Repetitive transcranial magnetic stimulation (rTMS)

Repetitive TMS is a technique of electromagnetic induction of a small, cortical target in the brain. The magnetic field generator, so called “coil” (i.e figure-of-eight shaped), is held next to the scalp. The magnetic field passes the skin and skull inducing a weak current in the cerebral cortex, located below the area of application. Neuromodulatory effect depends on frequency and pattern of stimulation, namely length, form and intensity of magnetic pulses. The effect of rTMS is to change the function of targeted brain area and indirectly assess the brain neuroplasticity.

Theta burst stimulation (TBS) is an alternative method of TMS which is said to be more efficient. Two types of TBS are available: continuous TBS (cTBS), which incorporates an uninterrupted train of stimulation for short time (20s or 40s) and intermittent TBS (iTBS) with brief (2s) train delivered every 10 seconds.

It's worth noting that the response for the treatment may vary between the patients. One of the potential causes of this inter-individual variability may be the genetic polymorphisms.



Dr Roberto Erro

*Center for Neurodegenerative diseases (CEMAND) Department of Medicine, Neuroscience section
University of Salerno, Italy*



Katarzyna Smilowska MD, PhD

Transcranial current stimulation (tCS)

This technique uses low voltage currents delivered via a pair of surface electrodes on the scalp. The application of weak current modulates neuroplasticity and entrain brain network.

Again, there are two tCS techniques: transcranial direct-current stimulation (tDCS) and transcranial alternating current stimulation (tACS). The most commonly applied method is tDCS.

NIBS in research

There are only few studies exploring NIBS in dystonia. The major limitation of them is small sample size, study design and heterogenous groups of patients (different types of dystonia assessed together). Regarding adult patients, most of the participants were diagnosed with focal hand dystonia (writer's cramp, musician's dystonia). This reflects the need for novel therapeutic options as botulinum toxin injection are usually less effective in these types of dystonia. Additionally, there are some studies exploring the effect of NIBS on patients with cervical dystonia and blepharospasm.

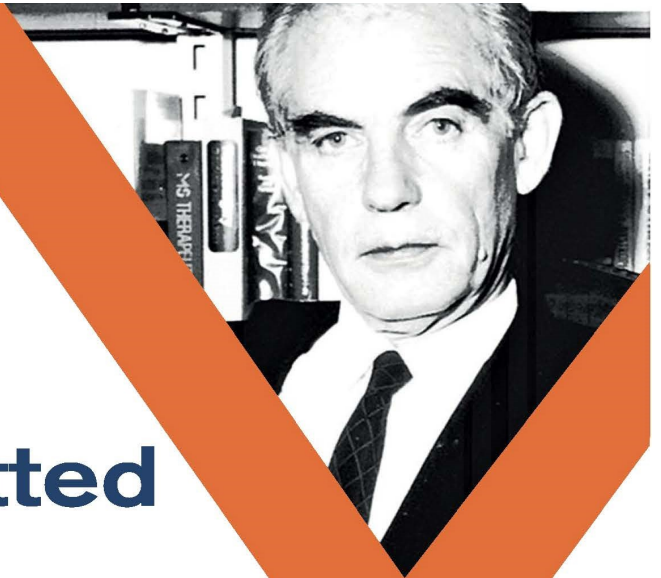
Data available from studies on children with dystonia suggested the reduction of muscle overflow but again, those studies have limitations as mentioned above. Furthermore, the intensity of stimulation was reduced in some cases as few children couldn't tolerate the full intensity.

Currently, there is limited evidences of NIBS effectiveness on dystonia. In this regard this method cannot be recommended as a therapeutic option. More, well designed studies are definitely needed. It is worth to note that some authors suggest that NIBS can be used as a add on therapy due to its potential to augment the botulin toxin effect.

[1] R. Erro, M. Tinazzi, F. Morgante, K.P. Bhatia, Non-invasive brain stimulation for dystonia: therapeutic implications, *European journal of neurology* 24(10) (2017) 1228-e64.

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DYSTONIA
EUROPE



Ipsen committed
to **patient** care
over the long term
supporting

The David Marsden Award 2019

10 000€

to stimulate research on dystonia

The award, introduced by Dystonia Europe in 2003 is presented every two years to stimulate developing knowledge of and interest in dystonia through publications on aetiology, pathogenesis, diagnosis or therapies in dystonia or on the psycho social effects.

The deadline for submissions is 31 January 2019

All information regarding the 2019 David Marsden Award are available at www.davidmarsdenaward.org

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Innovation for patient care

www.dystonia-europe.org

How to access innovative therapies?

Medical science has been rapidly advancing in recent decades and we can prove that with many examples: new therapies for diabetes, a vaccine for the prevention of cervical cancer, oral treatments for Hepatitis C curing more than 90% of the cases, the first Lupus drug in 50 years, personalized medicines to treat the most dangerous types of skin cancer, genome editing, immunotherapy eradicating cancer cells, and many many more. And we all remember AIDS and how it impacted millions of people worldwide. After the medical community became aware of the mysterious new plague, it took scientists just two years to identify it, understand how the virus spreads and suggest effective ways to slow down the epidemic. Within another ten years, new medicines turned AIDS from a death sentence into a chronic condition that no longer threatens one's life.

"Why ten years?" you can ask. Well, this is the approximate time needed so scientists can evaluate the safety and efficacy of a certain new molecule or medical device and this is possible only thanks to clinical trials.

Clinical trials are an integral part of the drug development process: without them, modern therapies would never reach the ones in need. It is a way for patients to have an innovative treatment for free years before it is in the pharmacies or hospitals. Being tested on animals, healthy volunteers and then patients with a particular condition, a compound is potentially turned into a promising medicine that can change or even save one's life. Even your smart-watch features tracking your daily activities have been proven in a clinical trial.

Ask scientists why they study the genome or try to connect the brain to a computer or try to create a mind inside a computer. Nine out of ten times you will get the same standard answer: we are doing it to cure diseases and save human lives.

Doctors don't just throw different chemicals into test tubes, hoping to chance upon some new medicine. With each passing year, doctors accumulate more and better knowledge, which they use in order to design more effective medicines and treatments. Currently, there are over 60 000 clinical trials worldwide exploring innovative approaches, procedures and drugs to prevent, treat, manage or cure a certain condition.

The bad news here is that these innovative treatments could never come into reality if there aren't enough people volunteering to take part in these research projects. What's worse, 85% of people don't know about clinical trials being a treatment option and how to access them.

And did you know that there are around [70 clinical trials](#) for Dystonia worldwide currently being conducted? Researchers are exploring innovative botulinum toxin injections, observing the efficacy of Deep Brain Stimulation in the treatment of patients with this condition, determining the relationship between brain changes and genetic risk factors, investigating how the brain and motor behaviour changes with exercise training and many many more. It is important to mention that these patients are not alone and medical science is thinking actively in new solutions and hopefully cures some day.

This is why at [FindMeCure Foundation](#) we are empowering patient communities to learn how to find, understand and join clinical trials worldwide with just a few clicks. Together with Dystonia Europe, we have partnered to inform people living with dystonia about the options they have to access innovative therapies for this condition.

Through a specially developed [widget](https://dystonia-europe.org/research/participate-in-research/) <https://dystonia-europe.org/research/participate-in-research/>, patients and caregivers have the option to directly get in touch with the medical teams running the study of interest and discuss whether this would be the right next step for them. The unique algorithm allows assessing trials on their safety and credibility and suggests trials relevant to patients' needs and personal criteria.

We should be aware that in the technological era we are now living, we have access to activities or technologies that break existing performance in a manner that expands the realm of the possible. When it comes to our own health, there are thousands of ways to live better and the first step is knowing all our options and making an informed decision after identifying their benefits and risks.

We can't avoid saying that the value of clinical trials participation is that we can help millions of people while helping ourselves. Medical science needs our input in order to keep advancing and creating miracles. This is why it is so important that patients are informed in the right way, at the right time. Information is everything but only if you know how to access it and how to benefit from all that!

Daniela Shikova
FindMeCure Foundation



The following articles, page 14–17, 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 and Dystonia: A Discussion with Dr Morgante

*Interview with Dr Francesca Morgante from
St George's University Hospital London, UK*

St George's Hospital in London is one of the UK's largest teaching hospitals and offers specialist care across the spectrum. The hospital is internationally renowned for neurology and offers comprehensive services for the diagnosis, treatment and care for all conditions affecting the brain, including Deep Brain Stimulation (DBS) for dystonia. Moreover, St George's is a major centre for research and education. Dr Francesca Morgante is a Consultant Neurologist at St George's and we spoke with her to find out more about dystonia, DBS and her work at the hospital.

How long have you been working in dystonia and what interested you in this field?

I've been working in this field since 2000. It was by chance in the beginning, because I was lucky to complete my training under the supervision of Dr Quartarone at the University of Messina, Italy. At the time, he was starting to study the mechanism of dystonia. This is how I met patients with dystonia and from this I became interested in firstly understanding this disease and secondly, treating this disease based on my understanding of the mechanism.

In 2005, I was given the opportunity to develop the large botulinum centre led by Prof Girlanda into a specialized dystonia clinic. Initially, people with dystonia were only very quickly assessed and treated so there was a need for a more established dystonia clinic that would take the time for a proper assess-

ment to really understand the impact of dystonia. Some people were labelled as doing very well but their quality of life is clearly affected.

What are the different types of dystonia?

Dystonia is a very heterogeneous disease. We can classify dystonia by etiology. Most of the people who are eligible for deep brain stimulation (DBS) have genetic or idiopathic dystonia (where the cause of is unknown). Genetic dystonia occurs through a genetic mutation: one of the most common mutations is DYT1 and usually becomes apparent in childhood. Regarding idiopathic dystonia, most adult onset cases relate to focal dystonia (where dystonia only affects the muscles in one part of the body).

We can also classify dystonia by body part – it can affect the whole body, which is called generalised dystonia. And as mentioned, there is also focal dystonia, which affects one part of the body. For example, dystonia in the neck muscle is called cervical dystonia. There is also segmental dystonia, which affects two connected parts of the body (e.g. the mouth and eyes). Most patients who are considered for DBS are those with focal and segmental dystonia.

How does DBS work for patients with dystonia?

The mechanism of action of DBS in dystonia is based on one main hypothesis: that the disease is due to impairment of firing in the basal ganglia circuit of the brain. This circuit includes a structure called globus pallidus internus (GPi) and the motor cortex.

In DBS, very small wires (leads) provide electrical stimulation to the GPi, which improves the impaired firing within that circuit in the brain, providing relief to a patient's symptoms. This hypothesis is supported by studies, but also by the fact that many people with dystonia show great improvement with this therapy. Relief in symptoms can appear as improvements in distorted movement, abnormal posture and tremor but also as non-motor symptoms such as pain.

Who is suitable for a DBS therapy?

The best candidates are those with generalised dystonia, whose dystonia is usually very severe. However, people who are suitable are those who have impaired quality of life (QoL), despite being treated with medical therapy – botulinum toxin is the first line treatment. This is a difficult criteria to measure because QoL can mean a number of things, including impaired social functioning and the psychological impact of dystonia on a person's life. For example, I recommend DBS to younger people with cervical or focal dystonia that may benefit, because their type of dystonia can really impact their work, social life and personal relationships. Dystonia does not just relate to the physical symptoms like having an abnormal posture. Of course there are many clinical factors but we should not ignore social and psychological factors too.

What are the benefits and risks of DBS?

Let's talk about the risks first. Being a neurological intervention there is a small risk of neurological damage, which includes bleeding in the brain, an infection of the system and infection of the brain. However, this only occurs in a very small proportion of patients – less than 2% – and can be treated. Also, these risks can be minimised when patients are accurately selected (through a brain scan) by an expert centre.

Regarding the benefits, there are improvements of abnormal movements, ranging from 30–60%. Most people see an improvement of 40–50% depending on the type of dystonia. There are also clear improvements in tremor reduction, QoL and symptoms associated with motor disability.

What is your vision on advanced programming options in DBS for people with dystonia?

Despite DBS therapy, some patients do not see a great improvement in symptoms. Now DBS technology has advanced, which allows for more sophisticated programming to minimise the side effects; these include fine tuning of the stimulation which may also be differently directed between segmented contacts of the DBS lead. With this technology we can now accurately control the stimulation of the part of the brain we want to stimulate and avoid stimulation in parts where a current would produce side effects.

Can you explain the link St. George's London have with dystonia patients?

There are two important factors that allowed us to specialize in the treatment of people with dystonia. The first factor is that St. George's is a very large clinic with many consultants who have developed expertise in this area. One neurologist I closely work with is Prof Mark Edwards. He has extensive experience and is doing a lot of clinical and research work for people with dystonia. The second factor is that St George's has developed a specific research group for people with dystonia. This group includes researchers such as Prof Edwards, Dr. Anna Sadnicka and myself, who have a specific interest in understanding the mechanisms of different types of dystonia.

What role does St. George's London play in this area of Dystonia and research?

We provide different treatment options for dystonia and we are specifically focused to treat disabling cervical dystonia using DBS technology. This was achieved thanks to the development of the DBS service led by our neurosurgeon, Erlick Pereira. We are also conducting research to understand the pathophysiology of dystonia, meaning the brain pathway of dystonia.

There have been few studies on this but we really do not yet understand dystonia, or why it can be so heterogeneous in different people – why it can affect the whole body or a single part, why it can be mild or severe or causing prominent pain or tremors. So that's what we are doing at St George's – trying to understand more about dystonia and the mechanism of disease behind it, using DBS.

What do you think people need to be more aware of when it comes to dystonia?

One very important thing I realised during my work with people who have dystonia – especially people in their 40s or 50s with cervical dystonia – is that there is a lot of stigma around this condition. Dystonia patients live their life hiding their symptoms. It's vital to communicate to the medical and patient communities, the importance of making time to talk about the impact of the condition on a patient's life. One of the major social disabilities is that pa-

tients are trying to hide their symptoms. What people may not realise is that constantly trying to hide these symptoms can lead to further problems, such as pain.

Part of the problem is that consultations are too short; a lot of patients will go to a normal clinic rather than a dystonia clinic. Patients need a multidisciplinary assessment at least once a year. Another problem is that patients don't realise how much their dystonia is affecting them until they have spoken with an expert who can ask them the right questions. Sometimes a consultation at a dystonia clinic can take one hour and together we learn what effect dystonia is having on their life. This is why it is very important that intervention happens as early as possible and is carried out thoroughly.



Dr Francesca Morgante from St George's University Hospital London, UK



Dystonia Europe Summer Think Tank 2018

Last July the 5th Dystonia Europe Think Tank was held in Lund Sweden.

The Think Tank is held twice a year and members are the Dystonia Europe Board and two representatives from each one of our Platinum Sponsors: Merz, Medtronic, Ipsen and Boston Scientific. Together we discuss projects and activities, with the best interest of dystonia patients in mind. These meetings have developed to an important forum for exchange of ideas and experiences.

We thank all our Platinum sponsors for their generous support.



Participants at the DE Summer Think Tank 2018

Boston Scientific Foundation Launched

Boston Scientific, innovative medical solutions provider, announced last week the creation of its Boston Scientific Foundation for the EMEA region (Europe, Middle East and Africa) to contribute to society by supporting people in the communities. The mission of the Foundation is to support well-being through innovative solutions.

Its strategic focus is to address issues of public interest in disease prevention or management, using digital or innovative solutions by:

- improving the health of individuals and communities with unmet needs.
- facilitating access to prevention and awareness programs.
- supporting research programs aimed at improving prevention or disease management.
- using innovative solutions such as apps, e-platforms, social media, optimizing impact on well-being.

Should you be willing to know more visit <http://www.bostonscientific.com/en-EU/about-us/corporate>



INNOVATION IN DYSTONIA TREATMENT

**Boston
Scientific**
Advancing science for life™

More than **500,000 people**
across Europe are living with dystonia¹



Treatment options:



Injections

botulinum toxin temporarily weakens affected muscles and reduces spasms



Surgery

lesioning of nerves that control the muscles causing spasms



Medication

a number of medicines can help regulate neurotransmission



Deep Brain Stimulation (DBS)

brain stimulation can reduce symptoms of dystonia significantly



More than **120,000 people** worldwide
already treated with DBS²



What is DBS?

implantation of brain stimulator that helps regulate neural signaling

Vercise Directional System...

...powered with Current Steering technology is designed for

- Greater precision for improved patient outcomes
- Reduction of potential side effects
- Flexible programming to treat a greater range of patients



Boston Scientific in DBS



Contoured edges designed for patient comfort



Directional leads for less side effects



Leads compatible with MRI*



Full body MRI conditional**

89% of treating physicians think that a directional lead should be used for all their patients.³

DBS may reduce dystonia symptoms such as:



Tremor, cramps



Pain



Strangled or whispering voice



Muscle spasms



Rapid eyelid blinking



Painful neck spasms

improvements of 50-60 % in general, some patients experiencing a 90 % reduction in symptoms⁴



Talk to your doctor about how DBS could help you and find out more here:

<http://www.bostonscientific.com/en-EU/disclaimer-2.html?disclaim=en-EU/products/deep-brain-stimulation-systems/Vercise-PC-DBS/Patient-Resources.html&value>

References:

¹ Epidemiological Study of Dystonia in Europe (ESDE) Collaborative Group. J Neurol. 2000. 247(10):787-92.

² Fukaya C, Yamamoto T. Neurol Med Chir. 2015. 55(5):422-31.

³ DBS Masters Debate, November 2015.

⁴ <https://www.dystonia-foundation.org/living-with-dystonia/neurosurgery/brain-surgeries/deep-brain-stimulation> last access October 21, 2016.



* Vercise DBS Lead-only system (before Stimulator is implanted) is MR conditional. An MRI examination can be conducted safely when all instructions in the supplemental manual MRI Guidelines for Boston Scientific DBS Systems are followed.

** The Vercise Gevia DBS System is MRI conditional for full body scans.

A System that includes the Vercise PC or Vercise Gevia IPG and Vercise Cartesia Directional Lead(s) form the Vercise Directional System.

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The Dystonia Society and Dystonia Europe in Partnership for D-DAYS 2019 in London

Next year's D-DAYS will take place in London, UK on 5-7 July.

Beginning of November Dystonia Europe Executive Director Monika Benson met with representatives of The Dystonia Society, CEO Andrea West and Dayna Ferdinandi, Head of Fundraising and Communications, to discuss and plan next year's event. Occupational Therapist Hortensia Gimeno and Dr. Jean-Pierre Lin joined for the planning of the program.

The conference will take place at the Novotel West in Hammersmith, London. The venue is only a 20 minute underground ride from the airport and 15 minutes from central London.

The meeting starts on Friday July 5th with the Dystonia Europe Annual General Assembly.

On Saturday July 6th is the actual conference with a full -day programme.

The programme will soon be available on the Dystonia Europe website and information on how to register:

<http://dystonia-europe.org/activities/events/dystonia-europe-london-2019/>

We promise a different and special D-DAYS and hope to see you in London.

Welcome!



ED Dystonia Europe Monika Benson, Occupational Therapist Hortensia Gimeno and Dayna Ferdinandi, Head of Fundraising and Communications



Medtronic Training Programme for Young Neurologists

In May 2018 Dystonia Europe took part in the Young Neurologists Training Programme, held by Medtronic in Lausanne, Switzerland. President Merete Avery gave a presentation about Dystonia Europe and how we work as an umbrella organisation to promote dystonia for better quality of life for patients with dystonia. The presentation included information on the MyDystonia APP that can be a tool for communication between the patient and the neurologist. All participants received brochures on the MyDystonia APP.

European Parkinson's Disease Association was also at the training programme and held a presentation on their organisation, projects and treatment for parkinson's disease. There was a patient with parkinson's that talked about how life had changed and improved, with some challenges on the way, to a new and better life after DBS surgery.

The very enthusiastic young neurologists asked questions on what are the views of patients on treatment and all of us, representatives from the patient organisations Dystonia Europe and EPDA, as well as the patient with parkinson's, gave input from the patient's perspective.

We want to thank Medtronic for this opportunity to present our organisation and for arranging this training program on movement disorders for young neurologists.

*Merete Avery
President
Dystonia Europe*



Medtronic at our D-DAYS 2018 in Brussels

BMP - Brain, Mind and Pain

The next meeting of the MEP Interest Group on Brain, Mind and Pain will take place at the European Parliament in Brussels on November 21, from 8.00h to 10.00h. The event will be hosted by MEP Marian Harkin.

With the EU elections coming up in 2019, the MEP Interest Group on Brain, Mind and Pain is turning its attention to the next mandate. At this meeting, the scene will be set by reviewing the achievements of the Interest Group to-date and setting out our proposed policy focus areas from 2019. This will be followed by a series of short presentations from our members and partners on their policy priorities for the coming years; in the areas of Alzheimer's Disease, Stroke, Epilepsy and Chronic Pain.

An in-depth discussion with high level policy-makers and other experts on how we can align with their priorities for the coming years, will bring the event to an end and be used to inform the work of the group moving forward.



The Future of Healthcare in the EU – Towards more sustainable healthcare organisations

On 15-16th October, the EFNA Autumn Academy of the Training Initiatives for Neurology Advocates [TINA] took place. 30 participants from neurology patient groups from CEE countries gathered in Bucharest to discuss the future of health-care in the EU in the context of the up-coming EU elections, as well as how patient groups can achieve better financial sustainability.

The meeting also announced the launch of the Romanian Neurological Disorders Coalition, to ensure a better representation of those affected by these conditions. Patient groups involved include Multiple Sclerosis, Parkinson, Alzheimer, Epilepsy, Myasthenia Gravis, Stroke, Huntington, Dystonia and Spinal Muscular Atrophy.



Participants Bucharest



Prof Maja Relja at TINA meeting in Bucharest

EFNA Young People Survey

EFNA represents 20 European and International associations across a wide variety of neurological disease areas such as multiple sclerosis, epilepsy, migraine and ADHD. Consensus among our members is that young people are currently under-represented in their associations. It is also felt that the issues facing young people affected by brain and brain-related disorders are not getting the public or political attention they should.

Those living with chronic illness face a number of additional burdens as young people. Often they are unable to complete their education, unable to take a place in the workforce, fear they will not find a romantic partner or have to watch their peers participate in activities they cannot access. Comorbidity between neurological diseases and mental health disorders such as depression and anxiety is common. These comorbidities increase disease burden and stigma – issues acknowledged across our membership.

In 2018 EFNA conducted a survey to explore problems faced by this age group, as well as their feelings around levels of understanding of their disorder and their engagement in advocacy work or patient groups.

Between March 12th and May 15th 2018, 1368 responses to the survey were received from 39 countries. Almost 80% of the respondents were female, with the majority of the responses coming from the below disease areas:

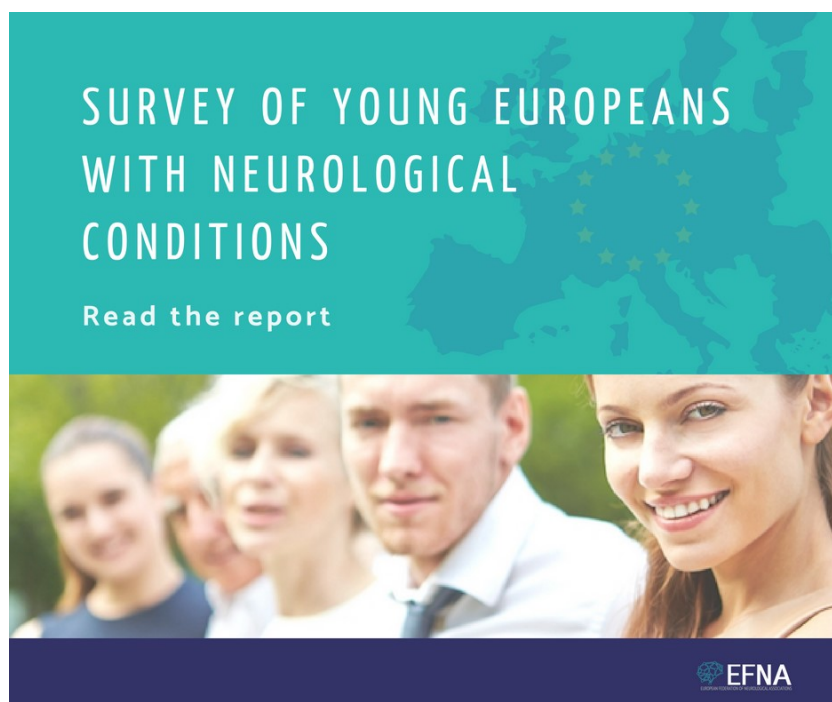
- Multiple Sclerosis
- Myalgic Encephalomyelitis
- Chronic Pain
- Migraine

The top concern cited by respondents was 'access to medication/treatment', followed closely by 'isolation' and 'stigma'. This isolation and stigma could be attributed to the lack of public understanding of brain disorders.

You can read the complete survey report here: www.efna.net/efnayoungpeoplesurvey/

Specific results from the survey from Dystonia patients are available here:

https://www.efna.net/wp-content/uploads/2018/07/Data_Dystonia_180704.pdf



The 2nd Value Added Medicines Conference in Brussels

The 2nd Value Added Medicines conference held end of November in Brussels gathered a wide range of experts in the healthcare community to raise awareness, inform and debate with the mutual intention of presenting solutions for maximizing the benefits and encouraging the development of continuous innovation. **Adjustments in the healthcare processes** – eg. adjustments on purchasing/procurement processes, acceptance of adequate evidence and, where needed, adjustment of pricing and reimbursement barriers –, as well as **seizing the benefits of digital technologies** and **increased stakeholder collaboration** should be maximized to bring value added medicines to patients.

EFNA Executive Director Donna Walsh gave the keynote address at the opening session, challenging the participants, and set the scene on value addition: 'how innovative are innovations and our attitude to innovation for patient relevancy and efficiency?'

Dystonia Europe Executive Director Monika Benson, presented the digital diary MyDystonia and how it can benefit dystonia patients when communicating with treating physician to optimize treatment outcome.



Marc-Alexander Mahl, Medicines for Europe President, highlighted that *"Today's event brought stakeholders who care about patient access to medicines together to reflect on the role of continuous innovation to deliver efficient and sustainable solutions to patient needs. Value added medicines deliver patient-centered gains from both the clinical and economic perspective. To capture this innovation, we have to integrate value added medicines in healthcare systems and seize opportunities in digital healthcare. Stakeholder collaboration will be key to fully ensure these benefits reach patients and the healthcare community and society"*.

The **Value Added Medicines Group**, a sector group of *Medicines for Europe*, aims to rethink, reinvent and optimize medicines based on known molecules by bringing untapped innovation to improve care delivery. The Value Added Medicines Group adopts a complementary perspective compared to the other *Medicines for Europe* sector groups by tackling the targeted portion of patient needs that remain unmet to this day, delivering additional improvements to the healthcare community as a whole.

Medicines for Europe represents the European generic, biosimilar and value added medicines industries, which provide high-quality cost-competitive medicines to millions of patients in Europe and around the world. The vision of *Medicines for Europe* is to provide sustainable access to high quality medicines for all patients, based on 5 important pillars: patients, quality, value, sustainability and partnership.

For more information: <https://www.medicinesforeurope.com>

Executive Director Monika Benson, presented the digital diary MyDystonia

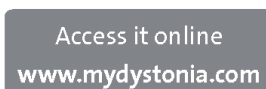


An electronic diary to improve your treatment outcome and your quality of life.

By patients. For patients.



Available in 10 languages



**DYSTONIA
EUROPE**

Developed with the support of



www.dystonia-europe.org

MyDystonia Ambassador Meeting – Dublin 2018

MyDystonia is an application created by Dystonia Europe for people with dystonia to monitor their health condition and daily routines. This electronic diary documents symptoms and disease impact according to medication. This tool can be used by patients for their own records and to improve communication with the doctor during medical appointments to get better treatment outcomes.

The application was launched in 2015. To achieve the goal of improving the quality of treatment, it is necessary to inform patients and specialists about the application and promotion. We're constantly working to improve the platform to make it as useful as possible. We create surveys and updates based on the opinion of users.

We also have the MyDystonia Ambassador program. An Ambassador is a person who works voluntarily with users of the application at the national level. Today, we cooperate with ambassadors from 9 European countries - Germany, Norway, Spain, Sweden, UK, Denmark, Poland, Finland and France. Since 2016, we have organized annual meetings of ambassadors to hear about problems and successes in their countries. The first inaugural meeting of ambassadors took place in Frankfurt in 2016. In 2017, the meeting took place in Rome after the D-Days conference.

This year, we met on October 20 in Ireland to work for MyDystonia. The event was attended by ambassadors from 7 countries, the Dystonia Europe board, our IT specialist and president of Dystonia Ireland - Maria Hickey.

Participants were welcomed by Merete Avery – DE president and Monika Benson – DE executive director. Monika presented updated information about the work of Dystonia Europe. Then our IT advisor Eelco Uytterhoeven, who is responsible for technical issues, talked about what has changed in the application since the last meeting. Adam Kalinowski - member of the DE board, who is responsible for coordinating the ambassadors, showed the results of the survey for app users. "MyDystonia Usage Activity Survey" was carried out in 2017 and was attended by over 150 users of the application. From the results we found out what users want to change in the application and what works well. The ambassadors had the opportunity to express their feelings about the results of the survey and compare results with their work experience. After this discussion, Eelco presented the next generation of the app, MyDystonia 2.0.

The second part of the meeting started with group work and the participants together answered the following questions:

- What features would you like to see in MyDystonia 2.0?
- What is your opinion about the current design of MyDystonia?
- Do you have suggestions on how to reach new users?
- What is the most difficult aspect of being an ambassador?



The MyDystonia Ambassadors at the meeting in Dublin

My Dystonia

The meeting ended with a summary of the report on the work of all groups.

In the evening, we met with participants to visit the capital of Ireland, have dinner together, get to know each other better and talk not only about work.

Thank you to all the participants of the meeting for the valuable contribution they make in the development of the project. Thanks to such meetings, we have a better picture of what needs to be done to make the MyDystonia application as useful as possible to improve the quality of life of people with dystonia.

We are also looking for new MyDystonia ambassadors from other countries, such as Spain, France, Ireland, Italy, Russia and more.

If you would like to cooperate with us, please contact us at poland@mydystonia.com.

MyDystonia is available in many languages and can be used on the website and smartphone. Find out more and register at www.dystonia.com

*Adam Kalinowski
MyDystonia Coordinator
Board Member Dystonia Europe*



The MyDystonia Ambassadors at the meeting in Dublin October 2018

Jump for Dystonia

Jump for Dystonia



Debbie from USA



From awareness campaign dystonia in Portugal



Czech Republic Dystonia Association



Jumps from the Czech Republic Dystonia Association



The Board members from the Norwegian Dystonia Association



Yvonne Maxwell, Dublin

www.dystonia-europe.org

Dystogram



www.dystonia-europe.org

Finland

New Way of Thinking

My name is Susanne I am 57 years old. I was diagnosed with cervical dystonia in 2011. After an accident my head began to turn to the right. I had earlier symptoms, but thought, it was due to working with a computer. My life changed totally!!! Had to stop working. Even with botulinum toxin treatment my neck got worse after a while.

Battle starts, as I want to find out more!!! I signed up with Finnish Dystonia-Association. Got some new friends with the same kind of issues. First it scared me. Some had very obvious symptoms. I wanted to know more so I started reading and learning about dystonia. After a while I was chosen to be the contact person for Dystonia Europe from Finland. There I got even more friends. DE is like a family and I have had lots of happy moments with them. I have been listening to doctors and physiotherapists in seminars since 2012. Biggest question still is that dystonia is an unknown disorder and there is no cure!!!

Then I heard about Dr Farias in Toronto. I signed up with his website and got a new perspective about curing dystonia. He had successfully treated patients with dystonia. I was not able to attend last year, as his seminars in Europe were fully booked.

This year however, I was lucky and he confirmed that I could attend his seminar in Porto in August. Each participant could bring a friend/family member who could assist by taking notes of the various exercises while I was involved in the training program itself. Hopes are high when you attend a seminar for the first time where someone says he has cured himself and other patients with dystonia. There were 9 patients from all over world. Mostly cervical dystonia patients. Firstly, we got lots of new ideas on how to think about our condition. The favorite saying still for me is "forget all about your neck" and "silly face". As you are trying to change your brain the exercises are done to strengthen weak points.

We got training methods in groups and also individually. I have now trained for several weeks.

I can already do tasks with my neck straight!! I am doing training each day. As doctor Farias said, nothing will happen if you don't do anything.

We learned a new way of thinking. I must say that he convinced me and we saw some amazing reactions where he could do some correction and the patient in question was "normal". It is recommended that you are active most of the day - 90% activity and only 10% rest. Meditation and relaxation are nice. Walking is even better. Breathing must be corrected etc.

It's long way or short way for getting a better life back. I will definitely speak for this and even though I am not brain doctor, I found it easy to understand what he meant. He explains everything in great detail that you can see in front of you about how your motions and emotions impact on your body. I am not going to even try to explain the medical side of this, as I am not capable of that. The only thing I can do is try to get my life back with this big opportunity to train my brain.

I will still have one botulinum injection in October even if I think I don't need it any more. Maybe later, when I am stronger, and I have proceeded with training.

I am not quite sure anymore, if botulin toxin is helping me or not?! I don't use any other regular medication for dystonia. I only use some painkillers, when my neck is causing headache.

Dr Farias is definitely a wise, warm and sensible guy, who knows what he's talking about. I will recommend his training and seminars to all, who are ready to work for their own wellbeing.



Never Give Up
♡ Don't stop trying!

*Susanne Olenius
Finland*

Germany

25th Anniversary of DDG – the German Dystonia Association

The Annual General Assembly of the Deutsche Dystonie Gesellschaft (DDG) was chaired by its president Hedwig Hagg and took place in the Hotel Strada in Kasel from 21st to 22nd July 2018. “Dystonia is moving – back then and today” (Dystonie bewegt – damals wie heute) was the motto of the event. Four people from Switzerland attended meeting: Claudia Schmid and Micheline Johnson from the board of the Swiss Dystonia Association SDG, Erhard Mätzener, auditor of SDG and treasurer of Dystonia Europe, and his partner Liselotte Illi.

The night before the meeting, on the occasion of the ‘silver wedding’, so to speak, the conversation went back to the birth of DDG in 1993. We strongly felt how close birth and death are by commemorating Didi Jackson, a person who set the pace for DDG and later for EDF - now Dystonia Europe: Member of the board, treasurer and later as chairwoman. As her son has fallen ill, an epitaph was presented by Christa Hafenscher, founder and honorary president of the Austrian Dystonia Association.

A speech was given then by Ms. Dr. E. Lohmann elaborating on the historical trail of Dystonia diagnostics. She spoke about the problems in description and separation of Dystonia from the 18th century on to today’s diagnostics. The term “Dystonia” for the first time occurred in 1911. It described a symptom. “Dys” stands for “bad” or “wrong” and “tonus” means “tension”. It was Hermann Oppenheim, who created the expression and described the different types of Dystonia. Jean-Marie Charcot, the founder of modern neurology, postulated a neurological cause of Dystonia 100 years ago. For some decades thereafter the psychoanalytical approach of Sigmund Freud and his ideas on unconscious conflicts causing organic problems was very popular.

Although there did not exist a term for this movement disorder, in 1614 cervical dystonia was described by Felix Platter as “disease of muscles and adjoining connective tissues”. In 1700 Bernardino Ramazzini called action-induced dystonia muscular diseases. Today the following aspects are important for a reliable diagnosis: Age when disease occurred, distribution/spreading

of symptoms, and beginning and progress as a dynamic approach. Furthermore, other diseases must be excluded. The diagnostics of dystonia is based on blood analysis, neuro-imaging, electrophysiology and genetic tests.

The next presentation with the headline “Reminiscence of the early days of botulinum therapy” was held by Prof Peter Roggenkämper, Ophthalmologist. He shortly described how the detection of the therapeutic benefit of botulinum toxin began. In 1822 the doctor and poet Justinus Kerner (also gourmet of wine – a vine is still called “Kerner”) thought about the sausage poison (Wurstgift) as a possible remedy for diseases with motor-driven hyper nervousness. Prof Roggenkämper’s vested interest started in 1979. It was at a conference in Bern, when he became aware of Alan B. Scott, who used botulinum toxin for a reversible weakening of the ocular muscles (chemodenervation) as alternative to surgery of strabismus. Since 1985 Prof Roggenkämper has been treating blepharospasm with botulinum toxin too. Up to the end of the 1980s Botox was delivered via Scott before Allergan took up the distribution and established a new price policy.

In London Prof Frank Erbguth, the next speaker, met David Marsden, who acquired huge merits as to research and treatment of neurological movement disorders and dystonia and still has personal mementos to him. He diagnosed dystonia a basal ganglia disease. Sadly, he died early, but his heritage is brought forward. Still today prizes are granted to researchers in his name, e.g. the David Marsden Award of € 10’000, which Dystonia Europe is granting in a biannual cycle. He was facing the inception of botulinum toxin and its triumphal performance from 1985 on. A great deal of diplomatic intervention with the customs authorities was necessary before the official approval, because botulinum toxin is classified a biological weapon in military circles. A great deal of progress has been achieved in the meantime to improve the application of botulinum toxin in sub forms of cervical dystonia by ultrasound or the collum caput concept. Electromyography e.g. helps to better identify the injection point.

Around Europe and Beyond

The morning session was concluded with a touching, but also positive review by Elke Schilling, a person concerned with dystonia for 25 years. Her statement once more confirmed the maxim: Together we are strong.

Prof Andreas Kupsch from Berlin referred to deep brain stimulation (DBS) – from history to the future. He started with the statement that (except for the Segawa syndrome) there is no satisfying pharmacological treatment besides botulinum toxin.

Neurostimulation (DBS) consists of implanting electrodes into different brain areas and activating a pace maker with a battery outside the brain. It is basically reversible, because the impulses to the electrodes can be switched off.

The breakthrough was achieved in 1987/88, when Alim Louis Benabid applied this procedure to a tremor patient and then published the outcome in renowned scientific 'Lancet'. DBS is allowed for essential tremor, Parkinson and also for dystonia. Interesting what the future might bring. In epilepsy and psychiatry (depressions) there already exists promising results

Complications cannot completely be excluded: The risk of dying through the operation is 0.5 percent. Infection risk lies at 2 percent. An operation costs as much as a small car. The main challenge of this technique is to better find and hit the optimal dystonia target point.

An important parameter for the success of a neurological therapy is measuring the quality of life. Prof Kupsch showed by means of 2 audio tests how the surgeon's team can listen into the brain during the operation. With a loudspeaker connected to the electrodes the frequency of the deep contact places in the brain can be measured. There is hope that already during the operation placement of the electrodes can be judged correctly. The muscle activity of dystonia patients is about 4 hertz on average.

Summary: Good results are achieved with cervical dystonia, DYT-1 dystonia, DYT-11 dystonia, tardive dystonia and partly with generalised forms of dystonia. Three to six months of continued stimulation may pass before an effect becomes perceptible. The outlook in the future is closely linked to the technical advances. At first Medtronic was the only supplier of DBS sys-

tems. With St. Jude and Boston Scientific the competition has grown. New types of electrodes have been developed. Similar to cardiac pacemakers, research is pushed towards "low weight devices". Not only 4 electrodes, but 8 are implanted nowadays in order to activate more tissue. Electric fields can thus better be adapted to the anatomic shape of the brain.

Finally Prof Kupsch presented the winner of the eleventh Oppenheim prize, Dr Michael Zech. He is active in the third main research focus of dystonia, the genetics. The prize of € 5000 is awarded biannually. Hedwig Hagg, Chairwoman of the Deutsche Dystonie Gesellschaft DDG handed the prize over to Dr Zech, who reported on the recent identification of a new genetic defect (KMT2B) triggering dystonia.



Micheline Johnson, Board Member Swiss Dystonia Association, Erhard and Lilo

Around Europe and Beyond

In the last presentation Dr Thorsten Odorfer talked about a study on torticollis carried out in Würzburg. It deals with the question whether botulinum toxin should be considered therapy of choice, as is the case to date, or deep brain stimulation.

The afternoon session was closed with compliments to the jubilee. On behalf of Dystonia Europe, Erhard Mätzener handed a beautiful bouquet of flowers to Chairwoman Hedwig Hagg. Many members of the DDG having supported the organisation during its 25 years of existence were honoured. Martina Kühn, treasurer for the last 9 years, received special applause.

The event closed with a dinner in a festive atmosphere with interesting conversations. A dance performance based on a song by Ute Kühn, former chairwoman of DDG, was touching. The title of the song, "Gutes Gift" (good poison), might perplex a little bit, but it is reality for many people affected by dystonia.

It is with thankfulness we are looking back to exciting and informative days in Kassel and we are looking forward to building new contacts and reinforcing our good collaboration.

German Text: Claudia Schmid, member of the board, Swiss Dystonia Association

Translation: Erhard Mätzener, Treasurer, Dystonia Europe

While our friends of the DDG had to work again on Sunday (GA at 10 o'clock), sightseeing was scheduled for us, as the trip back to Switzerland for the four of us was scheduled for Monday. It was a hot and sunny day.

The city's main attraction is "Wilhelmshöhe" (Williams height). From the railway station "Wilhelmshöhe" we went along the straight and slightly rising avenue "Wilhelmshöher Allee" up to Bad Wilhelmshöhe, the neoclassical castle Wilhelmshöhe and finally to Hercules on the top. Water is fascinating, notably on hot days. Therefore we were excited to admire the gigantic water game in the Bergpark Wilhelmshöhe, a UNESCO world heritage site. Thousands of other people linked this idea to a Sunday afternoon promenade. The whole spectacle started at 14.30 sharp high up at the Hercules monument. The flood then flew down by 4 stages on its 2.3 km trip to the pool at a 200m lower level, where a huge fountain marked the climax and the end. The big cascades first, then the Steinhöfer waterfall, the devil's bridge. Finally an aqueduct led the flood into the fountain pool. The water gates are opened and the flood starts flowing to the next stage at the exact scheduled time. Thus the spectators can move downwards seeking the best places for the next attraction. The whole game lasts 75 minutes.

We finished the eventful day at an old beer garden, where we satisfied our hunger and thirst and had a lot to discuss, before we went back to our lodging pretty late.

Erhard Mätzener

Germany

Heavily disabled – slightly mad!

The original title in German is **“Schwer behindert, leicht bekloppt”** and it is a book about a special friendship.

Author Bernd Mann says: *“The fear of healthy people towards disabled persons is as large as the fear of handicapped against the healthy ones. It is the fear of not disabled people that disabled are different and the fear of the disabled of being excluded. The fears are different, but omnipresent.”*

Bernd Mann has been looking after his friend Christian Kenk for 25 years now. Christian suffers from severe generalised dystonia, unable to perform everyday tasks like holding a spoon still or taking a shower. He can move by lying on a special wheelchair, or if this is not possible, then by piggyback with Bernd. Bernd is Christian’s advisor, carer and friend.

Bernd fought massively against health insurances, social securities, and other institutions, even in court and in appeals procedures, where he was successful several times.

The purpose of the book is to encourage others to stick to their ideas until they become reality. There are plenty of obstacles to overcome and all too often we ourselves are the obstacles on this way. This book just wants to say: Hey - even the apparently impossible is possible!

<https://www.zdf.de/gesellschaft/menschen-das-magazin/menschen---das-magazin-vom-30-juni-2018-100.html>

www.leicht-bekloppt.de/unser-buch/



Germany

Dystonie und Du e.V. celebrating one year Anniversary

On 10. November Dystonie und Du celebrated one On 10 November 'Dystonie und Du e. V.' celebrated their first Anniversary and Dystonia Europe was invited to which took place at Karlsruhe Schlosshotel in Germany. About 55 members of the organisation were present.

The President of 'Dystonie und Du e. V.', Volker Kreiss opened the meeting and welcomed all. The non-Profit National Association for dystonia and their relatives in Germany was formed on November 11 in 2017 by Evelyn Kreiss, Elke and Horst Roth, Susanne and Edwin Kerschbaum, Daniela Jäger, Mrs. Dr. Anja Dell Mann. The aim of the organisation is to inform, together with a scientific advisory board, about the disease and treatment options. Then the Major of Karlsruhe, Klaus Stapf held a speech and stressed how important patient involvement is in society, both to improve treatment and awareness but also to meet others with the same disorder that meet similar challenges.

Next Prof Dr med Dirk Dressler, Hannover spoke about treatment on dystonia. It was a detailed and very interesting presentation with many aspects of various treatment methods. Then Prof Dr med h.c. Ptok held a presentation on Spasmodic Dysphonia, which is a type of dystonia that affects the muscles that control the

speech. This is a rarer form of dystonia. He stressed the importance to recognise this disorder to get the best possible treatment.

In the middle of the conference we had a delightful dinner and it was really nice to meet many of the members in the 'Dystonie und Du e. V.' organisation. I had some challenges with my German language, I understand well, but cannot find all the words since I have not spoken much German in many years, however with good help we had great conversations.

After dinner there was another presentation on dystonia with Dr med Henning Rickmann who spoke about what is so far known about dystonia, history and treatment. Prof Dr Heinen who has been appointed for the Scientific advisory board of 'Dystonie und Du e. V.' was also a part of the conference.

The meeting was scientific, interesting and informative. In the end it was coffee and cake, it was again time to socialize before the conference ended.

I am thankful for the invitation and the opportunity to join 'Dystonie und Du e. V.' at this event and look forward to our future collaboration and working together.

*Merete Avery
President*



Board members and members from Dystoni und Du e. V., Prof Dirk Dressler and Dr Fereshte Adib, and Merete Avery, Dystonia Europe with a Jump for Dystonia.

Around Europe and Beyond

Ireland

Do not be afraid of society - educate!

I have had dystonia for many years, I have been avoiding people and public events more and more during these years. Paradoxically, when my symptoms got worse, I started approaching people.

Over a year ago, my body developed antibodies to the botulinum toxin. I have a cervical dystonia and my head has turned permanently to the left. For 8 years the toxin worked on my muscle spasms and my symptoms were not as visible as they are now. People around did not really see anything wrong with me. But I was ashamed that I could not control my neck and that I looked different to my friends. I slowly stopped meeting people, going to concerts, tours and public events. Shopping in the supermarket caused me panic attacks. When my condition got worse and I stopped working, I understood that I was lonely and if I did not do something myself, nobody would help me. I could not let dystonia take away everything I like to do!

At that moment, I created my online support group and decided to do something crazy that would change me and break my fears. I asked my photographer friend to go to Galway - a city in Ireland where I live, to document my campaign. I stopped people on the streets of Galway and told them that I was suffering from dystonia. I explained what dystonia is and what problems I face in my life. After each conversation, we took a picture with these people and with the logo of my support group. Nobody said no! Nobody said that there is no time to talk! Nobody ran away from me! This campaign showed me that the biggest barriers are the ones we put into our own heads. Since that time, I've been approaching and speaking to people more and more often. It is not easy. Especially at a time when the image of beautiful people is being cultivated on television, magazines and on the internet. Remember, we only live once! Nobody will give us back the years that we now have. Let's live as best we can! Get out of the house and do not care what people in the street think of you, it's your own life!

It is important not to hide with our symptoms. We need to educate people about what's happening to us. Do not be afraid to go to the hairdresser, tell him what dystonia is and you will never be afraid to go again.



Do not be afraid of meetings, people show interest if you start telling them about the superpower you have - called dystonia. When people see your heart, they will stop seeing your neck.

Adam Kalinowski
Board Member Dystonia Europe &
Polish Dystonia Association

Around Europe and Beyond



Photos by: Katarzyna Dabrowska
www.facebook.com/KatarzynaFotograficzna/

www.dystonia-europe.org

Romania

Report from a Busy Dystonia Awareness Month

The Romanian Association for patients with dystonia: **Asociata Children's Joy** organized on the 8th of September, the 6th edition of the National Conference dedicated to patients who suffer from various types of dystonia, their families, and specialists who work in this field. The event took place during dystonia awareness month. The event included workshops on aquatic therapy and physical recuperation, as well as presentations on nutrition, lifestyle, psychology, and neurology.

The participants received diaries where they could keep track of their symptoms, and booklets that included excerpts from Tom Seaman's book 'Diagnosis Dystonia'. The diaries were developed together with Desitin. The participants could also learn about the recent events and activities organized by the Association and about its future plans.

The event was really important both for the patients and the specialists. The focus of the event was on therapies meant to improve the physical condition of the patients and increase their quality of life. An important element of the event was also the communication among the patients and between the patients and the specialists. The patients and their families could share their stories and learn news about the treatments and physical therapies used for dystonia.



On the 9th of September Children's Joy together with the Association Fight Team Iguana launched the campaign Fight for Dystonia. The campaign was meant to raise awareness about dystonia and included a series of kickboxing fights organized at the Sports Hall Radu Voina from Sighisoara.

This event was also supported by other sports clubs from Romanian cities such as Dragon Fight Academy Kickboxing Medias, SuperPro Team Sibiu, and Tamashyi Sport Centre Timisoara.

THE MAIN AIM OF THE EVENT WAS TO RAISE AWARENESS ABOUT DYSTONIA AND SUPPORT PATIENTS WITH DYSTONIA IN THEIR EFFORTS TO INTEGRATE INTO SOCIETY



Photos from the Romanian Dystonia Organisation, Asociata Children's Joy conference in September during Dystonia Awareness Month.

Around Europe and Beyond

This event was aimed at raising awareness about dystonia, a neurological disease that has terrible consequences for patients and their families. It also intended to address prejudices and discrimination against patients with dystonia. The kickboxing fights were meant to send a message about the inner strength of people who fight the battle with the terrible symptoms of dystonia. The event included a fund raising campaign also. The funds raised will be used to organize future events.

“Patients with dystonia have an everyday fight with their symptoms, exactly the way we fight in the ring. In both cases there is need for perseverance, resilience, discipline, and hard work. Dystonia is a terrible disease which can even cause invalidity. With this event we want to show our strong support for dystonia patients. We hope people from Sighisoara and other places nearby will also come to show their support” declared Marius Crainic, the initiator of the campaign Fight for Dystonia, coach and president of the Sport Club Fight Team Iguana.

The Association Children’s Joy is located in Timisoara. The president of the Association is Catalina Crainic. The Association is a member in the Board of the National Alliance for Rare Diseases and a member of Dystonia Europe.

“Sport creates champions, dystonia creates fighters! Support us in this fight; we need the help of society for fighting and winning this battle” told Catalina Crainic.

Both events were dedicated to dystonia awareness month.

*Catalina Crainic
President
Childrens Joy Association
Romania*



Marius Crainic



Photos from the Romanian Dystonia Organisation, Asociata Children’s Joy conference in September during Dystonia Awareness Month.

Around Europe and Beyond

United Kingdom

Conference for Parents & Carers of Children and Young People with Dystonia

On 22nd September we were delighted to deliver our Conference for Parents and Carers of Children and Young People with Dystonia which was attended by over 100 adults and children.

Carol Huntley, whose husband has dystonia, was there with her family and we are grateful to Carol for taking the time to share her experience of the day with us below.



Photo: Carol Huntley

The conference was opened by our CEO Andrea West where she welcomed everyone before introducing us to our new Patron Miss Tully Kearney, Paralympian. Tully is an inspirational young lady who told us all the story of her journey from being diagnosed with cerebral palsy as a child and climbing the ranks of Paralympic swimming before being given the additional diagnosis of having generalised dystonia. The condi-

tion hit Tully hard but showing the strong and determined young lady she is she told the story of how she fought back and has been re-classified and swimming again winning medals this summer at the European championships – I personally was in awe of this strong and determined young lady – she truly is an inspiration with an amazing story to tell and a fantastic choice for our Patron.

The first of the speakers was Dr Jean-Pierre Lin from the Evelina Children's Hospital, London. He spoke about his years of research around the different forms of dystonia and how it affected many children in so many ways – his research is fascinating, and he has lots of experience in this field.

The next speaker stood in to speak at short notice as one of the planned speakers had unfortunately not been able to make it. This lady was a parent from the conference called Sam who has a 6 year old daughter who has dystonia. She bravely told the audience her story on how from an early age they knew something was wrong but it took a long time to get the formal diagnosis. Her story of the hurdles along the way was truly heart-breaking and I am sure they rang true with so many of those in attendance. Thankfully their tale wasn't all sadness as now they have the diagnosis they are able to handle the road ahead of them together as a family. She was so brave and honest in telling her story.

The afternoon speakers consisted of Dr Charlie Fairhurst, Hortensia Gimeno and Dr Alison Blencowe – all from the Evelina Children's Hospital in London. They all gave talks about the research they have carried out in and around the mysteries of dystonia. They discussed some of the outcomes of the research and Hortensia talked about her work with the charity Designability who are working on the prototypes of specialised wheelchairs.

Around Europe and Beyond

Each speaker throughout the day was very open to questions and open about the areas they work in and had lots of useful insights whilst all acknowledged there is still a lot of research to be done before the progress in areas to help those who suffer from this condition.

Throughout the day the children of those who attended were very kindly looked after in a room just across from the conference room – and what a day they had. The children were entertained all day with various activities they could take part in from drawing and face paints to videos and a visit from the fire service. The kind volunteers and staff of the Dystonia Society cared for all children and did a great job with them all – what a kind and caring team they all were on the day – superstars.

The day was very informative whilst relaxed– well organised by all involved – well done to all and I look forward to futures events.

Thanks again for all your hard work.

Carol Huntley

The Dystonia Society



Photos: Carol Huntley



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Events

Calendar 2019-2020

January

16-19 Toxins 2019, Copenhagen, Denmark

February

7-9 Dystonia Europe Board Meeting & Winter Think Tank, Lund, Sweden

16 25th Anniversary Swedish Dystonia Association, Stockholm, Sweden

March

11-17 Brain Awareness Week

April

11 World Parkinson's Day

13-14 EPF Annual General Assembly, Brussels

May

8-11 4th International Congress on Treatment of Dystonia, Hannover, Germany

June

29-2 EAN 2019, Oslo, Norway

30-1 EFNA Annual Meeting & General Assembly 2019

July

4-7 D-DAYS 2019, London, United Kingdom & David Marsden Award 2019

21 World Brain Day

September

TBC Dystonia Europe Board Meeting & Summer Think Tank

1-30 Dystonia Awareness Month

22-26 MDS – International Parkinsons and Movement Disorder Society Congress 2019 Nice, France

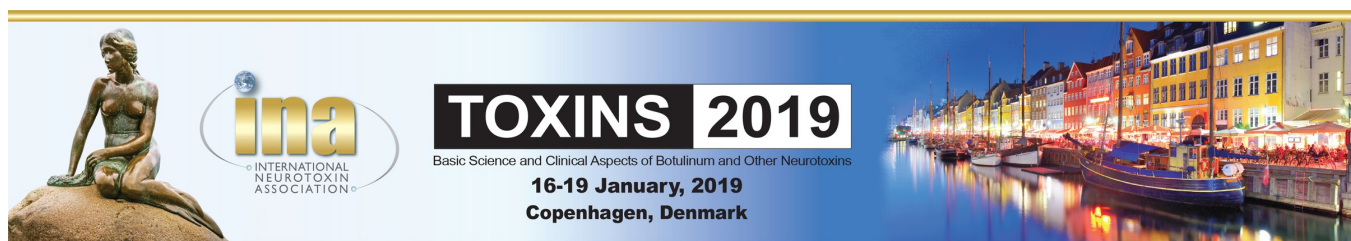
2020

May

23-26 EAN, Paris

June

3-6 International Dystonia Symposium, Dublin & D-Days 2020, Dublin



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Members

Dystonia Europe consists of 22 national member groups from 18 European countries and they are:

Austria, Belgium, Croatia, Czech Republic, Denmark, Finland, France, Germany, Ireland, Italy, Norway, Poland, Romania, Spain, Sweden, Switzerland, Ukraine 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.

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!

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Management & Staff

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 and re-elected at the GA in 2017. She was diagnosed with cervical dystonia in 2006 and was Chairwoman of the Norwegian Dystonia Association between 2010-2013. Merete is working with customer service, accounting and finance in Molde, Norway.



**Monika Benson,
Board Member and
Executive Director, Swe-
den**

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.



**Sorin Ionescu,
Board Member,
Romania**

Sorin is the founder and President of the Romanian Dystonia Association, Asociatia Dystonia.

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.



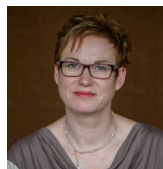
**Adam Kalinowski,
Board Member,
Poland**

Adam has suffered from dystonia since 2006. He founded an online support group for patients from Poland, which marked the start of his career as a patient advocate. In 2016, he became a member of the Polish association where he currently acts as a Board Member and public relation expert. In the same year he became ambassador for the MyDystonia application. In 2017, at the Rome meeting, Adam was elected a DE Board Member. He is also an administrator of his own website called 'Dystonia Good Story'. He is Polish but he lives permanently in Ireland where he is trying to develop his own Social Media Marketing business.



**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.



**Edwige Ponseel,
Board Member,
France**

Edwige is the Chairwoman of the French Dystonia Association, Amadys. The objectives of the association are to provide support to dystonia patients, to raise public awareness, to promote research and to organize meetings and events. Edwige works in the purchasing and marketing department of a company near Paris. She was diagnosed in 1994 with cervical dystonia. She was elected to the DE Board at the General Assembly in Rome in 2017.



**Alistair Newton,
Advisor, UK**

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 years.



**Maja Relja,
Advisor,
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, Vice President in 2012. She has now served the maximum period on the board, but remain as an advisor to the DE board. She also serves on the DE Medical and Scientific Advisory Board and is heavily involved in the COST-funded Dystonia Research Network.



**Eelco Uytterhoeven,
Advisor,
The Netherlands**

Eelco has been a professional IT-consultant and developer since 1999. For the last 2 years he has been working as a freelance developer on several internet projects related to Dystonia Europe. Since beginning of 2016 he is responsible for the maintenance and further development of the MyDystonia platform. Eelco was asked to become a special IT advisor to the Dystonia Europe board at the D-Days 2016 in Oslo. Together with the board Eelco wants to raise the professional level of the IT projects of Dystonia Europe and assist in creating new possibilities for the future.

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.



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