

Connecting people for dystonia

DYSTONIA EUROPE

2 - 2020

SUMMER
NEWSLETTER



Online General Assembly 2020

www.dystonia-europe.org

Connecting people for dystonia

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

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Wishing all our readers a good and healthy autumn.

From Dystonia Europe



President's Message



Adam Kalinowski
Photo: Stephan Röhl

Especially the relaunch of the Jump for Dystonia campaign. We are looking forward to a very busy month and we believe that with joint efforts we can increase dystonia awareness across the world and speed up diagnosis, access to treatment and better quality of life for people living with dystonia. Let's spread awareness, let's jump for it! Let's Shake the Earth for dystonia awareness!

Adam Kalinowski
President

Dear all,

I feel pleased to welcome you to the next issue of Dystonia Europe newsletter.

Despite the lack of face-to-face meetings, we have a lot of interesting news that we want to share with you.

Dystonia Europe has attended many meetings online, held webinars and attended other organisations webinars, such as European Patient Forum (EPF), European Federation of Neurological Associations (EFNA). We also have held Board Meetings and General Assembly online. This strange time gave us the opportunity to learn many new things. I believe that we will continue to use some of these online practices in the future.

In this newsletter you can find the latest news about research on dystonia, articles from our members and more. But I am most excited about presenting to you our plans for September - Dystonia Awareness Month.



Adam makes a «Jump for dystonia» in front of the Royal Castle in Norway in 2019, when attending the EAN (European Academy of Neurology) Conference in Oslo.

Dystonia Europe Virtual General Assembly 2020

Dystonia Europe held its 27th GA on 7 June. This was also the first time our General Assembly was held online. There was much planning ahead on how to hold the meeting online using the application Zoom. We still think face-to-face meetings are the best way to meet with our members. It is the time when we connect, share ideas and experiences, have a lot of fun and get to know each other better. Unfortunately due to the Covid-19 pandemic it was not possible this year.

Dystonia Europe President Adam Kalinowski welcomed all and then everyone present at the meeting introduced themselves. Dystonia Europe has 22 member organisations from 18 countries and at the GA 16 member organisations were represented.

Adam gave some practical information before he gave the word to Executive Director Monika Benson, who gave an update on Dystonia Europe Activities and Projects. This was done by sharing the screen with all participants showing slides from Dystonia Europe.

DE is a very active organisation and you can read more in the latest newsletter 1-2020 about the latest news, research updates and activities from around Europe and beyond. From 2020 we will have 3 newsletters every year instead of 2. If you would like to receive our newsletter by email, you can sign up here: https://my.sendinblue.com/users/subscribe/js_id/3lese/id/1.

There is increased activity on the various DE social media channels like Twitter, Instagram, Facebook, LinkedIn and YouTube. Especially during these times when many people may feel isolated it is great to be able to stay in touch online.

Formal documents such as Annual Report 2019, Final Accounts 2019 and Minutes from the GA 2019 were

sent out well ahead of the meeting according to the Statutes and were approved by the delegates. The Annual Report will be available this summer on our website.

DE IT Advisor Eelco Uytterhoeven gave a presentation on MyBrainNet and the development of the updated version MyDystonia 2.0.

MyDystonia Ambassador and Secretary of DE, Gill Ainsley spoke about the MyDystonia Ambassador meeting in Newcastle last October 2019.

Prof Maja Relja, University Hospital Zagreb, Croatia gave a short update on the status of the European Dystonia Survey and the VoT – Value of Treatment project together with EBC – European Brain Council. The results of the study may influence the management of dystonia in different countries throughout Europe. The data will be ready by the end of the year. Maja reported on the challenges following the recent earthquake that damaged the old city of Zagreb where the University Hospital is located.

Monika shared some of the plans for the September Awareness month and how we will work on sharing dystonia facts, inspirational quotes and dystonia testimonies throughout the month. There will also be an activity for all to take part in and more information will follow.

Adam thanked all the participants for a very good meeting and we all said goodbye wishing each other a happy summer!

*Merete Avery
Dystonia Europe*

Professor Dressler on Botulinum Toxin Therapy in the Times of Corona

We talked to Prof Dressler how the Corona crisis has affected dystonia patients in Germany but also in other countries.

Q: Professor Dressler, the Corona crisis has severely affected botulinum toxin therapy. What happened?

Dressler: During the Corona crisis the access to many routine medical services were restricted or even completely blocked. This also happened with botulinum toxin therapy. Numerous appointments for botulinum toxin therapy were cancelled and entire outpatient clinics were closed. Patients didn't know what to do and alternative medical care wasn't available. This situation was usually lasting for 6 to 8 weeks during the peak of the pandemic. Afterwards the affected institutions have not been fully operational for many months as they had to deal with a huge backlog of patients and as their capacities are still limited because of Corona prevention measures.

Q: Where did this happen?

Dressler: This happened in our medical centre at Hannover Medical School. Here the shutdown lasted 6 weeks. It also happened in most other university departments and hospital outpatient clinics in Germany. Private doctors usually managed to keep their services running. However, this treatment sector is very small in Germany. We believe that this situation was similar in all other European countries. The situation was even worse in countries where the medical system was stretched to or beyond its limits.

Q: What was the reason for the shutdown?

Dressler: The overall consideration was to focus the medical systems on the Corona threat. That was and still is reasonable. General governmental suggestions issued accordingly were balanced

as they explicitly allowed urgent treatments. The problem was how these general recommendations were interpreted: It makes perfect sense to have an aesthetic treatment postponed or for patients to choose for themselves to postpone their re-injections.

But to stop botulinum toxin therapy for patients with dystonia, spasticity and pain conditions indiscriminately was a gross misjudgement. It was also useless with respect to fighting Corona as none of us neurologists could help with treating Corona patients and none of our facilities could be used for this. Many of us neurologists were just sent home.

Q: You did a study on the effects of the Hannover shutdown on patients receiving botulinum toxin therapy?

Dressler: Yes, we used a standardised questionnaire design to study the effects of our 6 weeks shutdown on 45 patients receiving botulinum toxin therapy. 23 patients suffered cervical dystonia, 3 from blepharospasm, 9 from spasticity, 4 from pain conditions and 3 patients from hemifacial spasm.

Q: How did the shutdown affect the patients?

Dressler: The patients' quality of life was reduced by $40.2 \pm 19.5\%$. 93% of the patients noticed increased muscle cramps and 82% increased pain. 98% of the patients perceived the shutdown as inadequate, 98% felt their patient rights not respected.

Q: What did the shutdown teach us about botulinum toxin therapy?

Dressler: After the shutdown 66% of patients perceived BT therapy as more important than before, 32 % perceived it as unchanged. For all patients long-term availability of BT therapy was very important or important.

Q: Your summary?

Dressler: The Corona shutdown teaches us two things: 1) Our efforts to promote the public understanding of dystonia (and other movement disorders) were not successful.

Even physicians and neurologists seem to be unaware of the burden of disease associated with dystonia. This is frustrating. Patient advocacy groups still have a long way to go to establish dystonia as what it is: an often severe disorder associated with a considerable burden of disease. 2) Botulinum toxin therapy is a milestone therapy for dystonia. Some-times patients receiving it may get used to its stable and substantial benefit. Forced withdrawal reveals the full extent of this benefit.

Professor Dressler, many thanks for sharing this with us.



Prof Dirk Dressler

Photo: Stephan Röhl, www.stephan-roehl.de

Launch of Dystonia Europe Virtual D-DAYS 2020: the Dystonia Webinar Series & the Podcast the Positive Twist

As already shared in the last newsletter our most important event and activity every year, our annual meeting the D-DAYS Conference 2020 was cancelled due to the Covid-19 pandemic. Very early we realized this would greatly affect the work of Dystonia Europe. With no D-DAYS we would not:

- meet our members and connect with them and learn about their national activities
- meet dystonia patients and their families in the country where the conference is held
- meet the dystonia experts face-to-face
- learn about the latest information on dystonia treatment and research
- record and livestream all the presentations which are then made available on our Youtube channel throughout the year
- collect other material such as vlogs, patient testimonies, photos, video interviews
- raise awareness of dystonia through various campaigns
- add value to the work of our member organisations

Within the Dystonia Europe team we found it very frustrating that none of the above would happen this year and we had to rethink. What can we do instead to follow our objectives and goals and to stay connected with our members?

The place to meet this year is on-line. We have therefore decided to launch **the Dystonia Europe Virtual D-DAYS 2020** including a dystonia webinar series and a new dystonia podcast. The good thing with this is that it is not only for a few days but for the remaining months of this year and beginning of 2021. If this proves successful we might continue these activities also after the pandemic.

DYSTONIA EUROPE WEBINAR - DYSTONIA AND MENTAL HEALTH - living well with dystonia



Prof. Marjan Jahanshahi



With the participation of
Dr. Francesca Morgante

Neurologist Consultant, London

WEBINAR DYSTONIA EUROPE
Saturday May 9, 2020
17:00 CET

Cervical dystonia rehabilitation in these times of difficulty in having access to usual therapy - Practical self-training advices

Jean-Pierre BLETON
Rehabilitation specialist
A. de Rothschild Foundation - Paris

ROTHSCHILD FOUNDATION HOSPITAL

*Dr Jean-Pierre Bleton
and Neurologist
Dr Marie Helene Marion*

Latest News

We are grateful to Boston Scientific, Ipsen Pharma and Medtronic, who usually sponsor our face-to-face D-DAYS, for their generous support of these new and exciting on-line activities for Dystonia Europe.

The webinar series was launched already at the beginning of May with the first session on «Cervical Dystonia Rehabilitation in Times of Difficulty in Having Access to Usual Therapy», with Dr. Mari-Hélène Marion from London and Dr. Jean-Pierre Bleton from Paris. The webinar is available at: <https://www.youtube.com/user/DystoniaEurope>.

The second webinar was held at the end of June with Professor Marjan Jahanshahi and Dr. Francesca Morgante from London. This time it was about «Dystonia and Mental Health – Living Well with Dystonia». This is also available on our Youtube channel.

On 30 September at 17.30 CET our 3rd webinar will take place. This time on «DBS – treatment – all you want to know about deep brain stimulation» with Dr Francesca Morgante and moderated by Dr Fiorella Contarino.

For information on how to join check out our facebook page and website. If you already have questions you can send them to sec@dystonia-europe.org

Our other exciting activity is the launch of our podcast: **The Positive Twist**. This is a series of 6 30-minute episodes where we will invite patients, carers, experts and hear their stories and advice. The first episode is planned to be launched in September.

Very soon the final programme for the webinar series and the podcast series will be available on our webpage. Make sure to follow us on Facebook for the latest up-dates.

We are looking forward to an autumn filled with educational and inspirational sessions on-line and we hope you will join us wherever you are.

*Monika Benson
Dystonia Europe*

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Further, Together

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Launch of European Dystonia Research Consortium: EurDyscover

On Tuesday 7 July the kick-off meeting of the **EurDyscover** Consortium took place on Zoom. The coordinator is the University Hospital of Würzburg, Neurology department, and Jens Volkmann and Chi Wang Ip.

Other partners in the consortium are:

- Antonio Pisani, IRCCS Fondazione Santa Lucia, Laboratory of Neurophysiology and Plasticity, Rome, Italy
- Albino Oliveira-Maia, Fundação D. Anna Sommer Champalimaud e Dr. Carlos Montez Champalimaud, Champalimaud Research, Lisbon, Portugal

- Andrea Kühn, Charité, University Medicine Berlin, Dept. of Neurology, Movement Disorder and Neuromodulation Unit, Berlin, Germany
- Robert Jech, Department of Neurology, Charles University, 1st Faculty of Medicine, Prague, Czech Republic
- Marie Vidailhet, Department of Neurology, and ICM research Center, Hôpital Salpêtrière, Paris, France



Chi Wang Ip and Jens Volkmann

Research

By using multiple methods, translational approach and transnational collaboration the consortium aims to discover the pathophysiology of dystonia – role of gene-environment interaction and common pathophysiological pathways. Learn more about the 3-year-project [here](#).

The consortium is funded by a grant of the [European Joint Programme for Rare Diseases](#) and was one of 11 successful applications of a total of 217 applicants. The funding is €1,6 million over three years.

Dystonia Europe is very much looking forward to be part of the EurDyscover research network and will support the consortium with education and information of its work, recruitment of patients for trials etc.



Coordinators & Partners



www.dystonia-europe.org



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

The David Marsden Award 2021

€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 2021

All information regarding the 2021 David Marsden Award are available at
www.davidmarsdenaward.org

An award initiated by

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The following article, page 12-17, makes 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.

PERCEPT™ PC Neurostimulator: A breakthrough on the way to adaptive DBS

The Medtronic BrainSense™ Expert Meeting was originally planned as a face-to-face event in Barcelona. Due to COVID-19 limitations, the meeting was held virtually on May 11-12 2020, with an international faculty and chaired by Prof. Dr. Andrea Kühn, Head of Movement Disorders and Neuromodulation Section at Charité University Hospital of Berlin, and Priv.-Doz. Dr. med. Jan-Hinnerk Mehrkens, Head of Functional Neurosurgery of the University of Munich (LMU), Campus Grosshadern. Around 1,400 registered attendees followed the experts' discussion about the latest clinical evidence on sensing in Deep Brain Stimulation (DBS) and the potential role that the recently launched Percept PC neurostimulator with BrainSense technology will play in better understanding DBS and applying adaptive DBS (aDBS) in future.

Today, DBS is a well-established therapy option to alleviate symptoms in patients with movement disorders and with inadequate or adverse response to medication. To date, electrophysiological recordings can be performed during implantation of the DBS device in order to position electrodes and therapy programming. After implantation, the window for discovery of deep brain signals is closed until the next stimulator replacement. As consequence, most of today's evidence was obtained through brain recording by a complex experimental setup of externalized DBS electrodes without the possibility to collect long-term data. In 2013, Medtronic made an experimental sensing-enabled Activa™ PC+S neurostimulator available to study centers worldwide that allowed LFP recordings by the implanted pulse generator (IPG).



These intraoperative and postoperative studies in DBS patients have significantly contributed to today's understanding of the pathological neural activity related to movement disorders. And even more, they inspired a new paradigm called adaptive DBS or closed-loop adaptive DBS (aDBS) leading away from the chronic DBS stimulation towards an intermittent and patient-specific stimulation in future.

Percept PC neurostimulator:

First DBS device with chronic brain sensing

The launch of Percept PC neurostimulator in January 2020 is a crucial step on the way to an aDBS. It is the first DBS device with commercial brain sensing technology recording signals from the brain to understand the patient state inside and outside of the clinic.

Research

The dual channel recharge-free Percept PC neurostimulator is approved for Parkinson's disease, essential tremor, dystonia, epilepsy and obsessive-compulsive disorder.

Steve Goetz, Engineering Director, Technology, Strategy and Business Development at Medtronic PLC (USA) presented the details of this technological innovation. For decades Medtronic is committed to research and development in the field of DBS. As a result of this intensive development effort, the new Percept PC neurostimulator features a completely redesigned and ergonomic platform: First, it is a 3 Tesla MRI compatible system in addition to the 1.5 Tesla MRI safety Medtronic DBS devices already had previously. The 3 Tesla feature allows many more diagnostic and clinical scans as well as research activities. Moreover, the Percept PC neurostimulator is 20% smaller and thinner and it has a 15% longer service life for the average patient due to advances in battery technology.

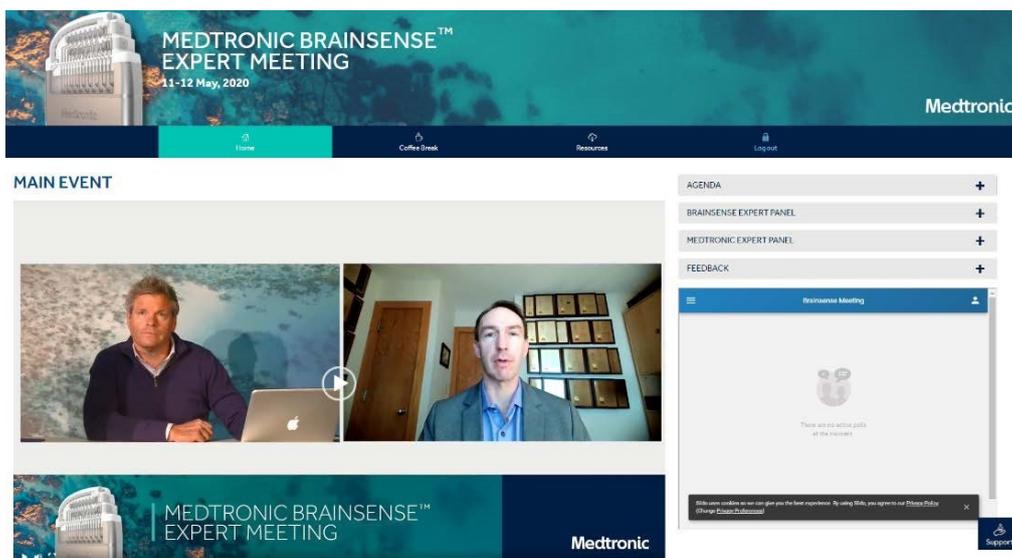
The innovation of Percept neurostimulator goes far beyond. It is the first device with BrainSense technology delivering a commercial sensing capability to record brain signals (local field potential, LFP) chronically using the implanted DBS leads. These signals can be recorded simultaneously while delivering therapeutic stimulation, inside and outside the clinic. Based on these data, the physician may adjust DBS stimulation settings, thereby personalizing therapy towards best possible treatment outcomes.

"The BrainSense technology has the potential to be disruptive", states Goetz. "It gives us unprecedented



insights into the patient's experience and the disease state. This window into the patient hasn't existed before." The Percept PC Neurostimulator uses embedded software for processing and analysis of brain signals in real time. These signals are stored on the device and can be viewed using the intuitive clinician programmer. They can also be exported in JSON, a machine-readable format, for offline data processing.

Several analysis tools are available for sensing. Outside the clinic, **BrainSense Timeline** can analyze the brain state during a long period of time. The tool captures previous 60 days of 24/7 real world data. "This is a powerful tool", explains Goetz. "You can identify changes of a signal over time, assess changes due to medication or check the impact of daily activities like sleep, wake and meals." In addition, the patient himself/herself can mark events of interest with **BrainSense Events** on his/her patient programmer. This tool helps to understand signals at a certain point of time. Events can be compared, and trends can be identified.



Inside the clinic, the BrainSense technology offers two more features: The **BrainSense Survey** allows the physician to understand the neuronal landscape. It shows which LFP signals are available across electrodes, type and location of signals. If there is a signal of interest that correlates with aspects of the patient state like rigid or kinetic symptoms, it can be clinically explored with **BrainSense streaming**. “This important element allows you to adjust stimulation and to understand how DBS stimulation is impacting the signal in the presence of stimulation”, explains Goetz, this is real time access to the brain state.

With these sensing tools, the physician can capture signals in the brain that correlate with the patient state, understand how stimulation impacts these signals over time and adapt the stimulation to patient specific brain state avoiding side-effects and/or saving battery energy. Besides the individual treatment of patients, Steve Goetz also points out the potential for aDBS: “Extending this idea of unprecedented insight, we really do believe that the idea of chronic brain monitoring is foundational. We can understand what is happening over long periods of time to signals of interest”, he says.

Clinical evidence of biomarkers in Parkinson’s Disease and Dystonia



Andrea Kühn showed which symptom-specific patterns of neuronal activity could be used as a feedback signal for adaptive stimulation based on the extensive research work in Berlin, but also by other international research groups. This study

was initially carried out using externalized leads and later with the Activa PC+S device which allowed for the first time a chronic recording from PD and Dystonia patients. In order to investigate the feasibility of subthalamic recordings via a chronical IPG, the Charité team obtained subthalamic LFPs from eight PD patients before and during DBS with Activa PC+S, ON and OFF stimulation conditions were also analyzed. The results showed that oscillatory beta band synchronization and its modulation by DBS is recordable with the system and may serve as a

biomarker for subthalamic closed-loop stimulation in PD patients. Even more, the group could show that beta activity is a stable long-term biomarker in PD and that beta activity correlates with improvement of motor impairment.

“In dystonia we know a little bit less”, said Kühn. “But even in dystonia we have a potential biomarker which needs to be explored further.” Kühn showed results from dystonia patients that underwent DBS at Charité Berlin. Irrespective of the type - generalized, segmental or cervical dystonia – similar patterns of low frequency activity could be found. In addition, symptom severity of motor deficits correlates with pallidal theta activity (4-12 Hz) while beta activity did not correlate with the motor symptoms.

A further study¹ with the Activa PC+S device could show that low-frequency activity is associated with dystonic motor sign severity, even months after chronic DBS. LFPs were recorded in 9 dystonia patients at 5 timepoints during an OFF-stimulation period of 5 to 7 hours in parallel with clinical assessment using Burke-Fahn-Marsden Dystonia Rating Scale. The results showed a significant association of increase in the Burke-Fahn-Marsden Dystonia Rating Scale scores with recurrence of low-frequency activity across timepoints after DBS was switched OFF. This underlines the potential utility of low frequency activity as a biomarker in dystonia for aDBS.

Percept PC neurostimulator: First experiences with the new device

Six centers across Europe shared their first experiences with the Percept PC neurostimulator during the Medtronic BrainSense Expert Meeting. The very first implantation of the Percept device was realized January 14th at Charité, Berlin. Andrea Kühn shared the first recordings after the pulse generator exchange in a female dystonia patient who had already benefitted from a pallidal stimulation for a few years. With these recordings, Kühn could confirm again the research work of her team regarding dystonia-specific biomarkers at low frequency. With the BrainSense Survey mode the team could record the neuronal landscape in a bipolar mode from different contacts. “In comparison to the Activa PC+S device, the data quality is much better now with the new device”, Kühn said. It even allowed the analysis of the interhemispheric coherence with the low frequency peaks.

With the second patient, a young man with generalized dystonia, the Berlin team did the recording with the BrainSense Streaming mode allowing analysis in the time frequency domain and titrating the stimulation therapy. Finally, Kühn shared the first pilot data using the BrainSense Timeline mode. Outside the clinic, the low frequency activity of the patient was recorded over 60 days at different time points. The findings are activity drops overnight and increased activity over the day. Over the complete time period of 60 days one could hypothesize that the low frequency activity is slightly diminished over time. “There could be some long-term effect, but of course we will need much more data”, said Kühn.

“We have beta activity and theta activity as a start, but we will learn much more with the chronic sensing device now, and we will hopefully be able to use this for aDBS in our patients”, Kühn closed her lecture.



The very first implant of Percept PC neuromodulator in Parkinson's disease in the STN took place at the University Hospital in Munich January, 15th (DBS electrodes) and January 17th (IPG).

Jan-Hinnerk Mehrkens presented the case of a 56-year old male PD patient with a disease duration of about 12 years. The patient developed severe on and off fluctuations in 2018 which was the indication for a DBS implantation (UPDRS III baseline score: On med 16, Off med 38). During surgery (bilateral STN, patient awake, MER incl LFPs), rigidity symptoms vanished completely on stimulation. First data recordings could be captured one hour postop on the ICU: “We saw nice readings in the left and right STN, great peaks in the beta range on both sides”, reported Mehrkens. Also, the first programming 4 days postop, showed instant effects on symptoms.

Being a neurosurgeon, Mehrkens mentioned the new Percept device to be well-shaped, allowing a robust data acquisition. He also judged the handling of BrainSense modes to be easy for physicians and patients.

Outlook: The promise of sensing

Mark Richardson, MD, PhD, Director Functional Neurosurgery at Massachusetts General Hospital and Member of the Neurosurgical Faculty at Harvard Medical School, USA, showed the enormous research effort that is being put into study activities on DBS globally. The Medtronic Engineering Group has played a large part in this, Richardson said, performing groundbreaking work that shows the future potential of DBS.

Although the main topic of discussion in the context of DBS is Parkinson's disease, there is potential for all different types of brain disorders because they can be understood as network disorders. “There is an immense potential for how we use the sensing information”, notes Richardson. The condition for this is the identification of reliable electrographic biomarkers of response to closed loop stimulation.

Following Richardson, there are still some open questions, which can now be partially clarified with the new clinical sensing experience. These questions include hardware issues such as the use of the same electrode for stimulation and sensing, as well as the idea of placing subcortical or cortical sensors outside the DBS target area. Another important question is how to involve the patient. “This question can be transformative”, said Richardson. “What obligations do we have to share this information with patients? How can patients use this information? Can these tools be used to help engage them overall in improving their quality of life?”

Finally, Richardson outlined the promise of sensing, showing the potential evolution of this technology in future. Currently, sensing-enabled DBS is going to provide a lot of useful data. However, the physician will need to manually adjust the device and the medication. In a not too far future, stated Richardson, a DBS device will provide relatively simple automated DBS adjustments. The vision ahead would be an intelligent adapted DBS using Artificial Intelligence. Such a device would have the ability to teach itself when the next maneuver should be done using brain information.



Research

Peter Brown, Professor of Experimental Neurology at the University of Oxford and Consultant Neurologist at Oxford's John Radcliffe Hospital, Oxford (UK), added why aDBS could be useful. The state of the art in Parkinson's disease today is continuous stimulation at constant frequency which is clearly beneficial. But it also has side-effects like gait and speech impairment, brittle dyskinesias or mood changes. The idea of aDBS is to modulate delivery of DBS according to feedback indicative of motor impairment. While the first motivation is the reduction of side effects this concept also aims for a better symptom control and saving of energy.

A crucial question, according to Brown, is what can be used as feedback for aDBS. On the one hand, brain signals must be robust enough, and they have to be registerable with a sufficient amplitude. On the other hand, they also need to correlate with aspects of movement impairment like finely tuned gamma activity does with dyskinesia and beta activity does with bradykinesia-rigidity.

A further question is how feedback is used. "How feedback modulates DBS is determined by something called the 'control policy'", explained Brown. The simplest control policy is threshold control, as used in air conditioning. When temperature rises above a certain threshold, this is detected by a thermostat and air conditioning reduces temperature.

"The choice of control policy for aDBS in PD will depend on our understanding of the nature of beta activity, or other biomarker activity, and on technical constraints. We are in a great need of a chronic trial of aDBS to show if it is chronically effective", stated Brown.

The Percept PC neurostimulator now offers a way to take this next step on the road to aDBS. **James Eubanks**, Director of Clinical Research for Brain Modulation at Medtronic plc (USA) announced the upcoming ADAPT-PD clinical trial for Parkinson's disease, which will start after commercial release of the Percept device in the US. Together with study sites in Europe, US and Canada, this pre-market IDE approval study will assess safety, tolerability and efficacy of different aDBS programs in comparison to conventional DBS baseline. The aDBS features for this trial are already enabled in Percept PC neurostimulator and will be unlocked for the study centers to deliver evidence.

1. Scheller U, Lofredi R, van Wijk BCM, et al. Pallidal low-frequency activity in dystonia after cessation of long-term deep brain stimulation. *Mov Disord.* 2019;34(11):1734-1739. doi:10.1002/mds.27838

MEDTRONIC BRAINSENSE™ EXPERT MEETING
11-12 May, 2020

Home Coffee Break Resources Log out

MAIN EVENT

AGENDA

Expert opinion on ANT-DBS therapy for patients with drug-resistant epilepsy (a Delphi consensus)

11.10 - 11.15
James Eubanks
Medtronic clinical evidence strategy

11.15 - 11.25
Thomas Brionne
Future directions

11.25 - 11.40
All faculty
Open discussion

www.dystonia-europe.org

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. *Neuro 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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EFNA #BrainLifeGoals Project Grant Winners 2020

The #BrainLifeGoals campaign is an initiative of the European Federation of Neurological Associations (EFNA) that aims to raise awareness of the impact of neurological disorders.

EFNA started an initiative #BrainLifeGoals Project Grant last year, to support work on one of the EFNA's advocacy themes. In 2019, in support of this campaign, EFNA awarded grants of €2,500 each, to projects that aimed to raise awareness and improve understanding of neurological disorders.

The focus for 2020 was on: *Ensuring Equitable Access to Treatment, Services and Support for Neurology Patients and their Carers*. Access to treatment is one of the central #BrainLifeGoals of many neurology patients. To help make that a reality across Europe, this year EFNA provided 10 grants of €3,000 each to selected organisations, working to address this theme. EFNA received 26 applications from across Europe and 10 projects received a #BrainLifeGoals Grant in 2020.

Dystonia Europe's project "Jump for Dystonia" was one of the 10 who won #BrainLifeGoals Project Grant in 2020.

Dystonia Europe first launched the "Jump for Dystonia" campaign in 2015. The successful dystonia awareness campaign that involved thousands of people worldwide is relaunched this year. The first edition of Jump for Dystonia focused on making dystonia better known and more heard of. People from all continents submitted all together more than 10 000 Jump photos.

For the 2020 edition, Jump for Dystonia will be taken to a new level. The messages on dystonia will be extended in order to increase the awareness of dystonia and therefore help to speed up diagnosis and access to treatment to reach a better quality of life for dystonia patients.

A recent dystonia survey in Europe, with over 3000 participants, shows that over 40 % of dystonia patients waited between 3-10 years before correct diagnosis. There is an urgent need to improve knowledge of dystonia among the public and the medical profession in order to improve access to treatment for dystonia patients across Europe. This can be done by talking about it and JUMPING for it!

The current situation in the world fosters digital projects and an online campaign can have much greater results. We therefore present Jump for dystonia with a new twist! There are many types of dystonias and that's why we will have several styles of jumpers.

Also, not everyone has the possibility of jumping. These types will allow the involvement of people with limited mobility.

You can read more about all the winners on EFNA's website <https://www.efna.net/winners-of-efnas-brainlifegoals-project-grants-announced/> -

We thank EFNA for the grant to support the relaunch the «Jump for Dystonia» Campaign.

*Merete Avery
Dystonia Europe*



EU Activities

EFNA Webinar - Where's Neurology? Influencing Covid Recovery Planning, Programmes

On the 30th June Dystonia Europe participated in «Where's Neurology?», a webinar held by EFNA (European Federation for Neurology Associations). The webinar is a part of a series to discuss how EFNA can ensure that our voices are heard and integrated in the post-pandemic recovery planning phase, including the development of policies and programmes.

EFNA gathered speakers from WHO (World Health Organisation), Non-Communicable Disease Alliance, European Commission and the Parliament along with patients within advocacy from around the world.



If you want to see this webinar it is available on EFNA's website, here <https://www.efna.net/webinar-wheres-neurology-influencing-covid-recovery-planning-programmes-and-policies/>

To read more about EFNA see www.efna.net

Webinar Series held by EPF on Digital Health

EPF (European Patient Forum) is an umbrella organisation that works with patients' groups in public health and health advocacy across Europe.

Dystonia Europe, who is a member of EPF, participates in a series of 5 webinars within Digital Health that is initiated and held by EPF. Health is an area which Europe can benefit from, during the digital data and Artificial Intelligence revolution.

As EPF states on their website "The road to fully exploit the potential benefits of data in health is only partially built, still extremely fragmented and not yet developed with patients' views at the centre".

The 1st webinar "Digital Health 101" was held in June and the 2nd webinar "The Role of Health Data in Medicines Regulation" in July. Dystonia Europe continues to follow these webinars, which will be a total of 5 this year. These webinars are for EPF members. The next webinar within Digital Health will be in September.

*Merete Avery
Dystonia Europe*



www.dystonia-europe.org



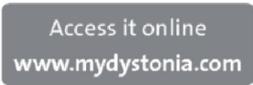
An electronic diary to improve your treatment outcome and your quality of life.

By patients. For patients.



Available in 10 languages

**NEW
COMING
NEW
VERSION
SOON***



**DYSTONIA
EUROPE**

Developed with the support of



*** At Dystonia Europe, we're working on updating MyDystonia to version 2.0, which we plan to launch in autumn 2020.**

Jump for Dystonia

From an Island Holiday Jump to a Jump for Dystonia Campaign

In 2015 Dystonia Europe rolled out its Jump for Dystonia Campaign for the first time with the possibility to win a skydive jump. The campaign circulated around the world and many thousands of jump photos were submitted and four skydive winners selected. For this year's Dystonia Awareness Month we are very excited to relaunch the campaign with a new twist.

How did it all start?

In 2013 Dystonia Europe Executive Director Monika Benson travelled to Africa to meet up with her youngest daughter who spent her second year of high school in Nairobi, Kenya. For the spring break they travelled to the little island of Pemba, outside of the Tanzanian coast. One day they were off to a sailing tour and stopped on a sand bank in the middle of the ocean. Surrounded by sand, sea and sky and the joy and beauty it created, they decided to do some holiday Jumps together. "It was a moment I never forget", Monika says. Later on when she was back home in Sweden, looking at the holiday pictures she discovered that they meant a lot more to her than the vacation memory itself. Monika has cervical dystonia since 2001 and struggled with the disease for many years before she could get out of her house, work and be more active again. "The jump photos showed me that I had come a long way in my dystonia journey, from having difficulties walking I could move around, travel and even jump again... I was very grateful", she says.

"So why not jump for dystonia? If you cannot do a real jump you can jump by raising the arms, waiving etc." she thought. The idea for the dystonia awareness campaign was born. Monika brought the idea to the Dystonia Europe Team and the awareness campaign was born.

The first Jump for Dystonia campaign

In the autumn of 2014, at the D-DAYS in Paris, the one-year campaign was launched. It took place on social media, above all on the special Facebook channel. We were so excited to see all continents taking part. In many countries there were self-nominated Jump Ambassadors, very often dystonia patients themselves, who worked very hard to organise events at schools and companies, contact

media and television in order to promote the campaign and raise awareness. Our partners and sponsors took part by organising special jump events and challenges for staff and colleagues. It was just amazing to see how we joined together around the world to spread dystonia awareness.

#jumpfordystonia2020

For the last few years the DE team has discussed how to relaunch the Jump for dystonia campaign. This year, with the support of our Think Tank members, we have taken the campaign to a new level with a new twist.

For this year's Dystonia Awareness Month we will ask our followers what type of Jumper they are? They can share their photo with us and be in with the chance to win up to € 500. If you do not know what type of jumper you are you can take the special quiz:

We hope to see a lot of activity and many jumps across our social media channels for the next few weeks. **For more information on the campaign see:**

<https://dystonia-europe.org/jump-for-dystonia-2020/>

The campaign has also been made possible with the support from EFNA BrainLifeGoals Grant Scheme.

Let's take flight and get this Dystonia Awareness Month off the ground!

Join me and jump for dystonia around the world again!

*Monika Benson
Dystonia Europe*



Win up
to €500!

JUMP FOR DYSTONIA

Jump, share, raise
awareness & win!



SEPTEMBER IS DYSTONIA AWARENESS MONTH

To raise awareness of dystonia we are asking everyone to celebrate the freedom of movement with a Jump For Dystonia..

Share a photo of your jump and style using **#JumpForDystonia2020** on Facebook, Twitter, Instagram or LinkedIn, between 1-30th September 2020, to showcase your support for people with dystonia, help raise awareness and be in with a chance of winning a cash prize.

Find the competition terms and conditions at dystonia-europe.org/jump-for-dystonia-2020/

Find us on Facebook
facebook.com/dystoniaeurope

DYSTONIA
EUROPE



JUMP FOR DYSTONIA

To raise awareness of dystonia we are asking everyone to celebrate the freedom of movement with a **#JumpForDystonia2020**.

A person's jump style can say a lot about them. What type of jumper are you?



PENGUIN

You're solid, reliable, practical and stoic – just how you like to jump.



SPLASH

You love experiencing the joy that comes from embracing your inner child – jumping into puddles, jumping into the air, and jumping for joy.



FREESTYLE

A true free spirit, you're laid back and easy going, taking life as it comes.



GROUNDING

You're well balanced and sensible – not one to over-exert yourself but you still find a way to join in all of the fun.



STAR

Confident and strong, you jump into the sky and express yourself freely.

Jump for Dystonia in September

Share a photo of your jump using **#JumpForDystonia2020** on Facebook, Twitter, Instagram or LinkedIn, by 30 September 2020, to showcase your support for people with dystonia, help raise awareness and be in with a chance of winning a cash prize.

Find the competition terms and conditions at dystonia-europe.org/jump-for-dystonia-2020



Win up to €500!

DYSTONIA EUROPE

Find us on Facebook
facebook.com/dystoniaeurope

Hello There!

Meet Thijs Vandewoude, Board Member and Contact Person Belgium



Thijs Vandewoude, Belgium

My name is?

Thijs Vandewoude. I'm 36 years old and I live in West-Flanders. I work as a court clerk within the Belgian Judiciary.

Why do you like helping others?

Because I experienced first-hand how important it can be to meet fellow patients and share experiences. I would like all dystonia patients to know that they are not alone. It is one of the goals that our association tries to achieve, and I like being a part of that in every way I can.

What are the benefits of working within a patient organisation?

The board of the Belgian Association for Dystonia Patients brings together people from all walks of life, but with one thing in common: our experience with dystonia, either as a patient or as a relative of a patient. Working within a patient organisation provides a pathway towards valuable contacts with both the scientific community and other patient

organisations. In the fight for a better quality of life for dystonia patients, I believe we are stronger together. The important role of Dystonia Europe in this regard cannot be overestimated.

How do you like spending your free time?

Reading history books and other works of non-fiction; taking walks in the beautiful countryside that surrounds the town where I live; volunteering with Davidsfonds, a local association that organises activities focused on culture and language; visiting museums and places of historical and cultural interest.

What keeps you motivated on the tough days?

Recognising that it is just that: a tough day, and that worrying about it will only make it tougher. Dystonia is only a part of me. It doesn't define completely who I am as a person, I won't let it control my life. For me, this goes a long way in helping me cope with my disorder, but it is something that I had to learn.

What makes you angry or frustrated?

Hearing stories of patients who often spend years living with their condition not knowing what it is, often facing disbelief and ridicule from other people. It is a story I know all too well myself. Then again, there are many positive stories that serve as an antidote to anger and frustration: people who eventually receive competent medical care, or have gotten in touch with a patient organisation and found the support they need.

*Thijs Vandewoude
Belgian Dystonia Association*

Around Europe and Beyond

Finland

Finnish Dystonia Days 2019

The Finnish Dystonia Association organizes annually nation-wide Dystonia Days calling members and people suffering from dystonia diseases to gather. Undoubtedly, the concept is quite similar to those held throughout Europe. The idea is to reach Finnish audience by arranging the event annually in different parts of the country and selecting venues with good public transport connections. Last year we met in Hämeenlinna which is between the three major urban areas Helsinki, Tampere and Turku.

The main goal for our annual D-DAYS, is to deliver relevant and possibly new information about dystonia, provide a forum for peer support and call the members to an annual fall meeting of the society. For many participants, the latest mentioned purpose is not the highlight of the Days. In Hämeenlinna, we had 80 participants, but only some 30 took part in the official meeting. Statues of the association require such a meeting, but it is not the reason for members to participate. Funnily, as the meeting was about to start, people just seemed to disappear somewhere. After the meeting we served some sparkling wine. A miracle occurred and the lobby in front of the meeting room was crowded with the members!

A need for information, maybe, is insatiable. Members are coming from all parts of Finland and do not often have as good an opportunity to learn from top neurologists as in Dystonia Days. Research is important, but a neurologist conducting medical practice is able to meet better the expectations of the audience. A very experienced neurologist Hanna Erjanti took the floor. Her experience of several decades sounded amazing. She made us understand there are no exact ways to provide the patients with botulinum toxin treatments. Pharmaceutical companies do create maps for physicians, but there's no substitute for practice and experience. Dystonia is such a capricious disease, that any neurologist must go through a trial and error method to get better and better with injections and treatment outcome. Hanna Erjanti remembered when she was a young and inexperienced neurologist. How little she really knew at the time – retrospectively viewed. How can the new physicians manage when they are in the early stages of their career? We really need mentoring and a shift of knowledge. If the treatment is not effective, it's rarely due to the medicine itself.



*Dystonia Days
Hämeenlinna,
Finland 2019*

*Photo:
Taina Lehtinen*

Around Europe and Beyond

Another issue, Hanna Erjanti raised, was the patients right to participate in the planning of his / her treatment. Physicians must listen to the patient. Feedback is crucially important, as the effects of the treatment appear with some delay. How could the treatment be carried out in a better way next time without the patients experience and emotions. Permanent treatment relationship between patient and neurologist is about encouraging the patient to give honest feedback for best treatment outcome.

Physiotherapists are customary speakers in Dystonia Days, as well. This time the representative of the profession was Silja Nasi. There are not too many physiotherapists specialized in dystonia. This time, there were both neurologists and physiotherapist in the conference room attending. The conclusion was that physiotherapist could accompany the patient at doctor's office. That way there could be an option to create a more comprehensive treatment plan.



In Hämeenlinna, we really devoted time to peer support discussions. Those discussions are important especially for those suffering from a rare type of dystonia. Spasmodic dysphonia, blepharospasm, dopa-responsive dystonia and other rare types had topics of their own. In local dystonia groups there may be only very few members suffering from a rare type of dystonia. Accordingly, there is not too much room for discussion in local groups back home.

The Jump for Dystonia theme offers time for group photos. It's a nice break in the middle of a sometimes tight schedule. Luckily, Dystonia Europe has occasionally sent some happy orange t-shirts. Active members have therefore a t-shirt of their own and the orange color spreads every year during our Dystonia Days.

This year there is a great uncertainty, do we have Dystonia Days in Jyväskylä in the mid-region of Finland? The amount of participants must be kept limited and special arrangements are required. Let's hope, the coronavirus situation is much better in fall 2021. WHO expects the coronavirus situation to settle in two years. After all, Dystonia Days will appear stronger than ever in the future!

*Jukka Sillanpää
Chairman
Finnish Dystonia Association*



*Jukka Sillanpää
Photo: Stephan Röhl*

*Photo to the left:
Jump for dystonia by Finnish Dystonia Members
Photo: Emmi Nuppula*

United Kingdom

A.D.D.E.R.

DRUGSTARS®

Giving by taking

We all know how difficult it is to raise funds for our charities/organisations, it's hard work and very often the results are disappointing.

I was introduced to an app called 'Drug Stars' when I was at the Dystonia Europe Ddays in London 2019. To be honest at first I thought this is just too good to be true!

You download the app onto your smartphone or tablet and record the medication you take regularly.

The app will then remind you to take your medication and award you one star for each single tablet you take.

Your stars quickly mount up and when you are ready you can make a donation to a charity of your choice!

Each star is worth 1p (GBP) so it does take a lot of stars to make a valuable donation but it is surprising just how quickly they build up! If you can get your members signed up to use the app the cumulative amount of donations will rise even quicker.

For your security your contact details are not passed on to anyone, Drug Stars use the collected data to give feedback and research data to various drugs companies but all data is anonymous. The app is free and you will not be bothered with lots of emails/text from Drug Stars, but they are very easy to contact if you have a problem with your app and I have found them to be very pleasant and always helpful.

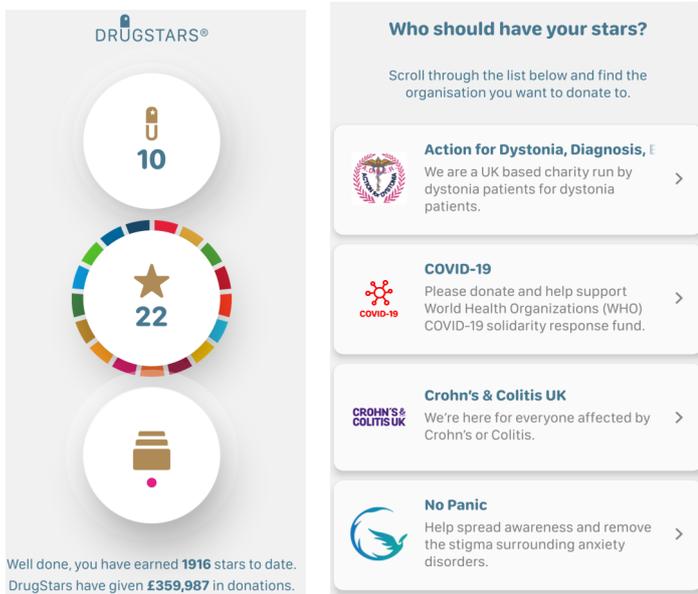
If you are interested in using Drug Stars you can get more information and download the app from www.drugstars.com.

If you would like to register your charity with Drug Stars simply send them an email and they will tell you what information etc they need, its very easy to do.

Simply download, enter your information then sit back and watch the pennies mount up!

Gill Ainsley
A.D.D.E.R UK and
Secretary Dystonia Europe

Photo: *Stephan Röhl*
www.stephan-roehl.de



Around Europe and Beyond

United Kingdom Dystonia UK

Dystonia Awareness in the UK

Dystonia UK is dedicated to helping people affected by dystonia in the UK and is spearheading the awareness raising activity this September. We are so excited to share our plans for a festival themed Dystonia Awareness Month and how you can get involved!

Dystonia Around The World

At the end of July, we launched Dystonia Around The World and invited 100 champions to join us in virtually travelling 25,000 miles from Dystonia UK's HQ around the world and back, and raising £25,000 to help raise global awareness of dystonia.

We wanted this campaign to be as inclusive as possible and so it is not just about how many miles you can run or walk, but also allows everyone to be involved with every 10 minutes of activity you

do being the equivalent of 1 mile.

One of our champions has taken on the challenge of writing for 1,000 minutes. Another is mixing it up with both walking and drawing to get her miles and minutes in.

"It's so nice to see that you can log activities other than fitness for a change. LOVE IT, WELL DONE Dystonia UK!!!" - quote from one of our Dystonia Champions taking part in the challenge

The challenge is due to finish around the end of September, and we would love to have you sign-up to become one of our champions. Whether you choose to walk, cycle, paint, draw, cook, bake, dance or craft get involved and together we will take dystonia awareness 25,000 miles around the world. To find out more, and sign up, head to [our dedicated website](#).



www.dystonia-europe.org

Around Europe and Beyond

Dystonia Matters Digital

We are rounding off our festival themed Dystonia Awareness Month with our Dystonia Matters Conference taking centerstage! Taking place on the 25th & 26th of September this year, we have gone fully digital with #DMDigital.

We were delighted to host some of you at our annual conference last year, held in London in partnership with Dystonia Europe, and are thrilled to be able to tell you about our plans for 2020.

Spread over 2 days, and 4 sessions, #DMDigital presentations will be a mix of practical advice and shared life experiences from patients as well as specialists with live Q&A's for each session, plus plenty of networking opportunities. You can read a short overview of the session summaries below and find more information on the [event website](#).

Campaigning for Change: How our work with Neurological Alliances from across the UK is used to **magnify the voice of dystonia patients** and to raise awareness.

Mental Health Matters: Specialists in the field will have an in-depth conversation about how you can **look after your mental health**.

The Future of Neurology: Leading clinicians share their thoughts on the future of neurology, including digital innovations.

Know Your Rights: In partnership with Disability Rights UK, we will be sharing **practical tools and tips** on rights for the dystonia community, including the PIP process.

While we all love getting together in person, the stress of travelling can weigh on people and there's much to be said for being able to take part from your own home, with your creature comforts around you.

The digital conference format has allowed us the flexibility to be able to host delegates from all across the world and for each delegate to be able to choose between a full conference ticket or if they prefer just to attend a session or two. Each session has a limited capacity so please do ensure you book early to avoid disappointment.

To find out more, and buy your tickets, head to the [event website](#).

Other ways to get involved

We also have plenty of other activities planned, including sharing research updates and stories from people living with dystonia, so keep an eye on our social media channels as [@DystoniaUK](#) and sign-up to our mailing list [on our website](#) to make sure you don't miss out.

www.dystonia.org.uk

*Dayna Ferdinandi
Head of Fundraising and Communications
Dystonia UK*



25th & 26th September 2020

www.dystonia-europe.org

Events

Calendar 2020

September

- 29 Dystonia Europe 10th Think Tank Meeting
- 1-30 Dystonia Awareness Month
- 13-17 MDS International Parkinsons and Movement Disorder Society Virtual Congress 2020,
<https://www.mdscongress.org/Congress-2020.htm>
- 19-20 Dystonia Members' Meeting, Faero Islands, Denmark
- 23 Dystonia Europe Podcast launch: The Positive Twist
- 29 Dystonia Europe Virtual Think Tank
- 30 Dystonia Europe Webinar: All you want to know about DBS – deep brain stimulation for dystonia, Dr. Francesca Morgante and Dr. Fiorella Contarino

October

- 3-7 EFNA board meeting & workshop, Geneva

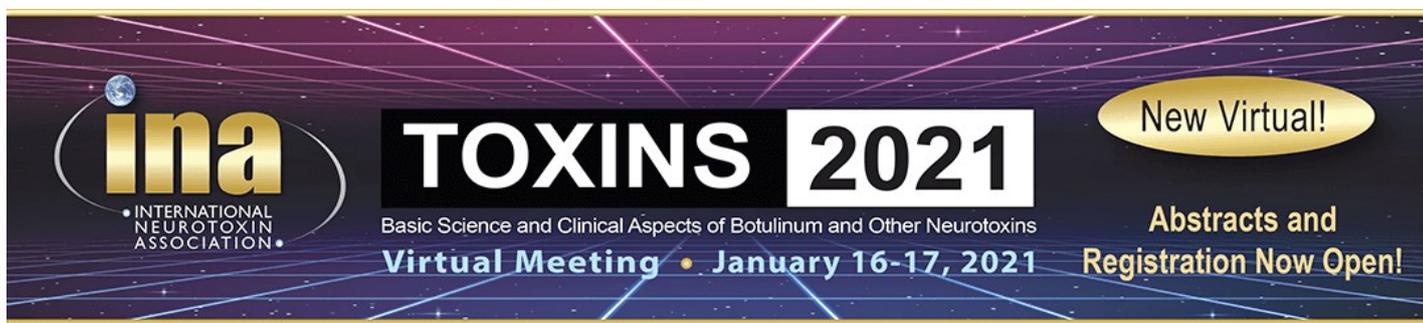
Calendar 2021

June

- 1-5 EPNS Congress <https://www.epns.info/epns-congresses/epns-congress-2021/>
Glasgow, UK

September

- 8-11 ESSFN, Marseille
<http://essfncongress.org/en/>



The banner features a dark blue background with a grid of glowing purple and white lines. On the left is the INA logo, which includes a globe icon and the text 'ina INTERNATIONAL NEUROTOXIN ASSOCIATION'. In the center, the word 'TOXINS' is written in large white letters, followed by '2021' in a white box. Below this, it says 'Basic Science and Clinical Aspects of Botulinum and Other Neurotoxins' and 'Virtual Meeting • January 16-17, 2021'. On the right, a yellow oval contains the text 'New Virtual!', and below it, 'Abstracts and Registration Now Open!' is written in white.

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 you can use the online button DONATE on our website.

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

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

Thank you for supporting Dystonia Europe!

Medical & Scientific Advisory Board

Prof Alberto Albanese – Milan
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Prof Rose Goodchild – Leuven
Prof Marina de Koning-Tijssen – Groningen
Prof Joachim Krauss – Hannover
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Dr Jean-Pierre Lin – London
Prof Maja Relja – Zagreb
Prof Eduardo Tolosa – Barcelona
Prof Marie Vidailhet – Paris
Prof Marjan Jahanshahi—London

Staff



Monika Benson,
Board Member and Executive
Director, Sweden

Monika was elected President of EDF, now Dystonia Europe, in 2007. She was re-elected for a second term in 2010. Monika stepped down as President in 2013 after serving the maximum period of 6 years. She took over as Executive Director after Alistair Newton's retirement. Monika has cervical dystonia and was a board member of the Swedish Dystonia Association for 10 years. Monika has been working as a coordinator of work-shops, courses and lectures at a school in Lund, Sweden.



Merete Avery,
Operations Manager, Norway

Merete was appointed to the board of Dystonia Europe in 2013 and was Secretary from 2013-2015. Merete was appointed President at the Board Meeting, following the GA, in Rotterdam 2015. She stepped down as President in 2019 after the maximum period of 6 years in the DE Board. She was diagnosed with cervical dystonia in 2006 and was Chairwoman of the Norwegian Dystonia Association between 2010-2013. Merete has been working with customer service, accounting and finance in Molde, Norway.

Management & Advisors

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



**Adam Kalinowski,
President, Poland**

Adam has had 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 Dystonia Association where he currently acts as a Board Secretary. In the same year he became Ambassador for the MyDystonia application.

Adam was elected to the DE Board in 2017. One of his roles is the coordination of the MyDystonia Ambassador program. Adam is a very dedicated advocate for dystonia patients and has spoken about dystonia in the EU Parliament in 2018. He is also an administrator of his own website called 'Dystonia Good Story'. He is Polish but he lives in Ireland where he studies graphic design. Adam was re-elected to the Dystonia Europe board in London 2019, and is now the President of Dystonia Europe.



**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. She was re-elected at the last GA in London and she is now the Vice President of Dystonia Europe.



**Gill Ainsley,
Secretary, UK**

Gill is Board Member of A.D.D.E.R. (Action for Dystonia, Diagnosis, Education and Research), United Kingdom. Gill is very

interested in raising awareness of dystonia and in research that would lead to a cure for dystonia. Gill's first language is English, she is also a skilled computer operator. Gill's profession is engineering and she worked for many years as an Electromagnetic Compatibility Test Engineer on aircrafts.

Gill was nominated and elected as Board Member to Dystonia Europe in 2019 and is the Secretary of Dystonia Europe.



**Sissel Buskerud,
Treasurer, Norway**

Sissel is the Treasurer/Accountant responsible and Board Member of the Norwegian Dystonia Association for the last 7 yrs. Sissel

has experience for more than 25 yrs. as an Accountant for a Norwegian Security Company. Sissel was elected to the DE Board at the GA in London in 2019 and is the Treasurer of Dystonia Europe.



**Catalina Crainic,
Board Member,
Romania**

Catalina Mariana Crainic is the President of the Romanian Dystonia Organisation, Associata

Childrens Joy and a Board Member of National Alliance of Rare Diseases, Romania. Catalina has broad training, within Art and Painting and also in Educator Recovery within the field of Social and Pedagogical for people with special needs. She also has training in Rare Diseases for Journalists and Effective Communication with the press, representing patients organisations. Catalina was elected to the DE Board in 2019.



**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. In 2019 Alistair received an MBE – Member of the British Empire for his work for neurology patients in Europe and especially for those affected by dystonia.

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**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, Between 2011 and 2017 Maja was the Vice President of DE. At present she is the project leader of the Value of Treatment project regarding dystonia. .



**Eelco Uytterhoeven,
Advisor, The Netherlands**

Eelco has been a professional IT-consultant and developer since 1999. For the last few years, since 2016 he has been working as a freelance developer on

several internet projects related to Dystonia Europe. Since the beginning of 2016 he is responsible for the maintenance and further development of the MyDystonia platform. 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.

We thank all our partners for their support and collaboration.

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