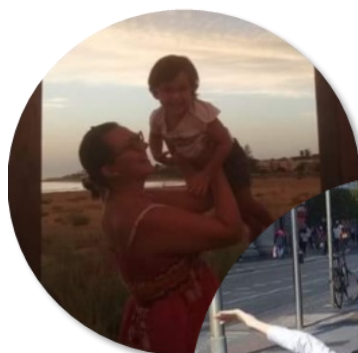


# DYSTONIA EUROPE

3 - 2020

WINTER  
NEWSLETTER



Read more on page 5

[www.dystonia-europe.org](http://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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*The best wishes to all of our readers for  
a peaceful and healthy Holidays.  
From Dystonia Europe*

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## President's Message



*Adam Kalinowski*  
*Photo: Stephan Röhl*

Dear all,

Welcome to the last issue of our newsletter in 2020.

Last September, during Dystonia Awareness Month, we re-launched our successful awareness campaign 'Jump for Dystonia' with a new twist. The first edition of Jump for Dystonia in 2015 focused on making dystonia better known and more heard of. People from all continents submitted all together more than 10 000 Jump photos!

This year we asked people what kind of jumper they are and encouraged everyone to celebrate the freedom of movement with a jump. Moreover, this year, in addition to the campaign, we ran a photo competition. The competition was held as part of #BrainLifeGoals initiative from EFNA (European Federation of Neurological Associations). You can find the summary of Jump for Dystonia 2020 and the winning photos in this newsletter.

You can also read articles about other projects such as our webinar series and our recently launched podcast, The Positive Twist. We are also happy to share with you information about the activities and research projects from our member organizations and partners as well as stories of people living with dystonia.

On behalf of the Dystonia Europe team I would like to take the opportunity to thank everybody for their work this year, which has been both strange and difficult.

Many thanks to the Dystonia Europe board members and staff, the medical professionals and researchers who work in the interest of people with dystonia. You all make a huge difference for those affected by this disorder.

A big thank you to our followers around the world who contribute to raising awareness of dystonia. Only by working together we can move forward! We are also very grateful to our partners and sponsors for their great support and collaboration.

2020 is different from any other year we have experienced and I think many of us have realised how to appreciate the little things in life. May your Christmas holidays and the coming year bring you gifts of health, love and happiness.

Merry Christmas and Happy New Year.

*Adam Kalinowski*  
*President*  
*Dystonia Europe*



### September is Dystonia Awareness Month

What a fantastic month of dystonia awareness in spite of the pandemic!

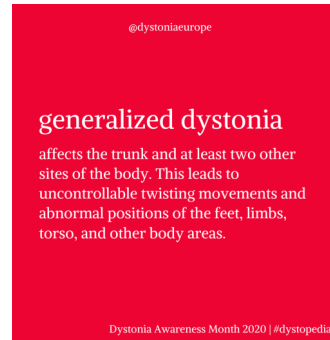
THANKS to all of you who took part in our on-line activities last September. The great success would not have been possible without your support and your help in sharing our content.

This was the fourth year that Dystonia Europe was taking part in the international Dystonia Awareness month. Every day of the month we had at least one post. They were dystonia facts, inspirational quotes, dystonia stories or promotion of our dystonia awareness campaign Jump for Dystonia. We were active on several social media channels such as Facebook, Instagram, Twitter and LinkedIn.

We had decided to re-launch the 5-year old campaign but this time with a twist, asking our followers what type of jumper they are. During the month you could submit your jump photo and by using the hashtag #jumpfordystonia2020 taking part in the special photo competition. See page 5 to find out who the lucky winners are and see their amazing jumps for dystonia.

Another project this year is our "Dystonia Facts", a series of 30 short videos with experts describing the different types of dystonias, their treatments, research etc. They can all be found on our YouTube channel: [https://www.youtube.com/playlist?list=PLFvCc6fYkjEu\\_33mOzHqpnOhXB2t-LeKj](https://www.youtube.com/playlist?list=PLFvCc6fYkjEu_33mOzHqpnOhXB2t-LeKj)

Some of these videos were launched during the awareness month.



We are very pleased with this year's awareness activities and we are already looking forward to September Awareness month 2021. 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](mailto:sec@dystonia-europe.org)

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

*Monika Benson*  
Executive Director  
Dystonia Europe





## Latest News

### #jumpfordystonia2020: the Winning Jumps

#### #jumpfordystonia2020: the Winning Jumps

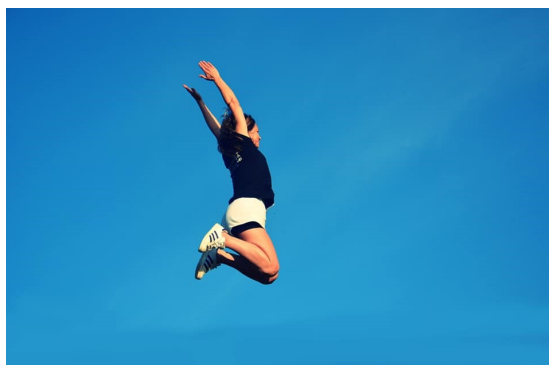
Last September, we relaunched our 5-year old campaign Jump For Dystonia, to celebrate the freedom of movement with a jump to raise awareness of dystonia. This time with a twist and with the possibility to win some cash prizes. We asked our followers what type of

jumper they are: splash, grounded, penguin, freestyle or star and to post and share and use the hashtag #jumpfordystonia2020. We received over 100 photos. We would like to thank all of you who took part, jumped in so many different ways, shared within your networks and helped to increase awareness of dystonia.

### CONGRATULATIONS to the jumping winners!



1st prize Pauliin Suvi, Finland



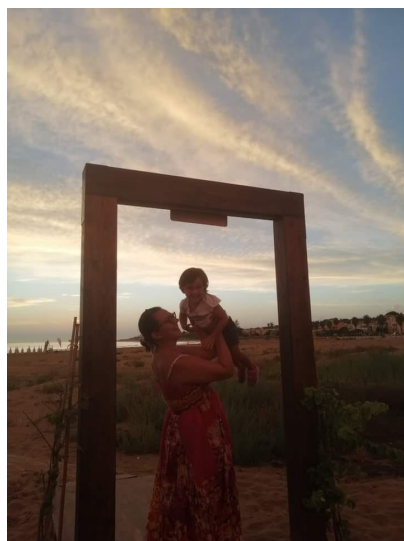
2nd prize Paulina Rembecka, Poland



3rd prize Mika Helkala, Finland



4th prize Simona Oriana, Ireland



5th prize Marika Lorefice, Italy

#### Extra prizes to:



Parkinsonliitto.  
Finland

Deborah  
Mahthttps://



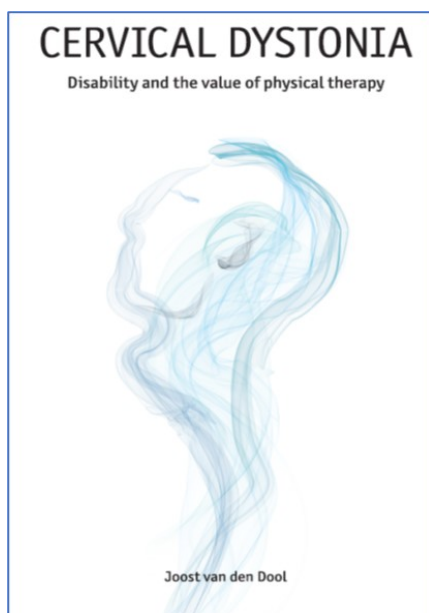
DDF Group, Denmark



The campaign is made possible with a grant from the European Federation of Neurological Associations as part of its #BrainLifeGoals campaign.

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

### Specialized Physical Therapy Reduces Disability and Pain in Cervical Dystonia



September the 21<sup>st</sup> was a memorable day for Joost van den Dool. On that day he successfully defended his PhD thesis at the University of Groningen in the Netherlands. His research focused on the effectiveness of a standardized physical therapy program for patients with cervical dystonia. Cervical dystonia is a type of dystonia characterized by involuntary movements and abnormal postures of the head and neck, causing pain and limitations in the ability to perform daily life tasks. It is usually treated with botulinum toxin injections in the affected muscles to decrease these movements and postures. Besides the treatment with injections, patients are often referred for physical therapy but evidence towards its effectiveness was lacking. Therefore Joost developed a specialized physical therapy program in cooperation with the Dutch DystoniaNet which he compared to regular physical therapy.

The specialized program aims to teach patients to handle their symptoms independently as much as possible since cervical dystonia is a chronic condition. From intensive therapy to strengthen the non-dystonic muscles to independent exercising and regular coaching by the therapist.

Research results show that regardless of the kind of physical therapy, patients were less disabled to perform daily life activities and experienced less pain. Unfortunately, no significant differences were found between the specialized program and regular physical therapy. However, patients that received specialized care were better able to manage their symptoms independently and needed less treatment sessions for similar results.

As a newly graduated PhD, Joost recently started to treat dystonia patients himself to help them be more independent and have voluntary control over their symptoms. Together with DystoniaNet he also plans to organize training sessions for therapists so the specialized program becomes available for as many patients as possible. We wish him the best of luck!

*Monika Benson  
Executive Director  
Dystonia Europe*



*PhD Joost van den Dool*





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](http://www.davidmarsdenaward.org)**

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### New Artificial Intelligence Platform Diagnoses Focal Dystonia with High Accuracy in Less Than One Second

*This article was published in Dystonia Dialogue, Winter issue 2020 of DMRF (Dystonia Medical Research Foundation in the US), and we are happy to share it with our readers.*

*The article is about the recently published research using a new diagnostic tool diagnosing dystonia from MRI.*

Researchers at Massachusetts Eye and Ear in Boston have developed a unique diagnostic tool that detects dystonia from MRI scans, the first technology of its kind to provide an objective diagnosis of the disorder.

In a newly published study, researchers developed an AI-based deep learning platform called DystoniaNet to compare brain MRIs of 612 people, including 392 patients with three different forms of isolated focal dystonia and 220 healthy individuals. The platform diagnosed dystonia with an astonishing 98.8% accuracy. During the process, the researchers identified a microstructural neural network biomarker for dystonia. With further testing and validation, it may be possible for DystoniaNet to be implemented by movement disorder clinics to make high probability diagnosis of dystonia by MRI. In such cases a physician will be able to use this information to more confidently and quickly confirm the diagnosis and recommend treatment without delay.

“There is currently no biomarker of dystonia and no ‘gold standard’ test for its diagnosis. Because of this, many patients have to undergo unnecessary procedures and see different specialists until other diseases are ruled out and the diagnosis of dystonia is established,” said senior study author Kristina Simonyan, MD, PhD, Dr med, Director of Laryngology Research at Mass Eye and Ear, Associate Neuroscientist at Massachusetts General Hospital, and Associate Professor of Otolaryngology–Head and Neck Surgery at Harvard Medical School. “There is a critical need to develop, validate, and incorporate objective testing tools for the diagnosis of this neurological condition, and our results show that DystoniaNet may fill this gap.” Dr. Simonyan is a former member of the DMRF

Medical & Scientific Advisory Council.

The study included three of the most common types of focal dystonia: laryngeal dystonia, characterized by involuntary movements of the vocal cords that can cause difficulties with speech (also called spasmodic dysphonia); cervical dystonia, which causes the neck muscles to spasm and abnormal movements and postures in the neck; and blepharospasm, a focal dystonia of the eyelids that causes involuntary blinking and/or forceful eye closure.

Traditionally, a dystonia diagnosis is made based on tedious clinical observations. Previous studies have found that about 50% of cases go misdiagnosed or underdiagnosed at a first patient visit.

DystoniaNet utilizes deep learning, a particular type of AI algorithm, to analyze data from individual MRI and identify subtler differences in brain structure. The platform simultaneously detects clusters of abnormal structures in several regions of the brain that are known to control processing and motor commands. These small changes cannot be seen by a naked eye in MRI, and the patterns are only evident through the platform’s ability to take 3D brain images and zoom into their microstructural details.

DystoniaNet is a patent-pending proprietary platform trained using Amazon Web Services computational cloud platform. The technology interprets an MRI scan for microstructural biomarker in 0.36 seconds.

Future studies are needed to examine additional types of dystonia and will require trials at multiple clinics and hospitals to further validate the DystoniaNet platform in a larger number of patients.

*Valeriani D, Simonyan K. A microstructural neural network biomarker for dystonia diagnosis identified by a DystoniaNet deep learning platform. Proc Natl Acad Sci U S A. 2020 Oct 20;117(42):26398-26405.*

***The following article, page 9-14 , 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.***

### **DBS in Dystonia patients: An interview featuring Profs. Ferreira and Coelho from University Hospital of Santa Maria, in Lisbon.**

**D**ystonia is a heterogenous disease, which dramatically affects the lives of patients, their families, and caregivers. Stimulation (DBS) is among the different therapies available to help treat the symptoms of this debilitating condition.

Today, we have the pleasure to interview 2 world leading experts from the University Hospital of Santa Maria, in Lisbon: Professor Gonçalves Ferreira, the head of the functional neurosurgery unit and Professor Miguel Coelho, a movement disorders neurologist.

Professor Ferreira began working in functional neurosurgery and DBS 25 years ago, though he was with Professor Benabid, considered to be the Father of DBS, in 1987 and 1988 when he first performed the DBS implantation for Parkinson's Disease patients .



Professor Coelho has been working with dystonic patients for 20 years now, holding a botulinum toxin clinic for about 15 years. Professor Coelho coordinates the DBS program at University Hospital of Santa Maria, which began in 2006. Initially for Parkinson's disease, but has included dystonia patients since 2010. Professor Coelho is also the president of the Portuguese Society for Movement Disorders, allowing him to develop a unique perspective into dystonia.

### What do you like about your position, helping Dystonia patients?

*Both Profs Coelho and Ferreira:* Many dystonic patients go through a long process, seeking consultations in other specialities before they finally reach a neurologist. For us, it is really important to be able to identify which involuntary movement the patient has and understand the cause of it. There are many causes of dystonia; genetic, metabolic, pharmacological, or other neurological disorders that present with dystonia. Until

this point many patients have been told there is nothing wrong with them, or the problem was from the neck or spine. So, in that regard, it's really satisfying to be able to give the patient a diagnosis as it makes them feel more comfortable, because finally, they know what they have, and they have a name for their disorder.

### From your experience, what's the impact of dystonia on patients' daily lives?

*Prof Coelho:* Dystonia has a great impact in the daily lives of the patients, mainly affecting their quality of life. It is really disability in their everyday life, but also it causes social embarrassment for them because not a lot of general population are familiar with this disorder. In many cases, such as cervical dystonia, it is also associated with pain in many instances, and in that regard it's a constant cause of suffering.

*Prof Ferreira:* It is also important to take in consideration, that this disease will also affect the lives of others close to patients, that it is their family or caregivers, as many dystonia patients require a lot of different care measures.

### What are the different therapies available for patients with Dystonia?

*Prof Coelho:* Initial treatment with botulinum toxin provides very good outcome in patients with focal dystonia. If they don't improve significantly with botulinum toxin, they become resistant to it, or they

can't achieve a reasonable benefit, they should discuss the possibility of undergoing DBS with their physician or with their neurologist.

### How does DBS works and how can it help with the symptoms of dystonia?

*Prof Coelho:* DBS is very effective and very efficacious in treating dystonia. Many studies found an improvement of 50% to 75% increase in the quality of life for patients undergoing DBS, which is an excellent result.

*Prof Ferreira:* Therapy, as in other movement disorders, does not treat the cause of the disorder, but it interferes very well with the mechanisms that produce the major symptoms of the disorder. So, we interfere with high-frequency DBS, which means that usually it affects the structures where it is applied. It's essentially inhibitory.

We mainly induce this electrical inhibition in the Globus Pallidus pars Interna (GPI) because it's the best target. We manage to interfere and to diminish the dysfunction, essentially among the basal ganglia of the cerebral brain, and the symptoms are often improved.

In some patients we have a very good response to DBS, although dystonia is quite a different disorder to, Parkinson's disease, in which results are more homogenous and uniform, and therefore more reliable. However, dystonia is not a disease, it is a set of many different kind of disorders and so, we have rather different results with primary dystonia and secondary dystonia's, with the latter generally seeing poorer results.

Many patients appear in neurosurgery already at an advanced stage in the disorder and I think we should make an effort, all of us, to treat them earlier and earlier, because the results are usually better.



### Following DBS will patients resume some form of normal life or improve their quality of life?

*Prof Ferreira:* Their quality of life can change quite a lot. It does however depend on the clinical presentation of the specific disorder, which has led to their dystonia. When we inform the patients and their families about the prognosis for the future, we must be cautious because, in primary dystonia, we have a very good result in about a half to two thirds of patients. On the other hand, for the secondary dystonia's, it varies quite a lot. We can say that we can expect that about one half of the patients will improve, but that's not guaranteed at the beginning.

*Prof Coelho:* As dystonia is not a degenerative disorder, in contrast to Parkinson's disease, if you can improve the symptoms of dystonia, in most instances the disease will not progress. Patients will keep the benefit and

resume their normal or near-normal life. To give you an example of a successful DBS therapy, I remember particularly a young man of 20-year-old, who was suffering from tardive dystonia induced by medication. Due to his tardive dystonia, he had difficulty walking, and he was in pain every day. One week after his DBS surgery, he had minimal dystonia and he has now been functioning well for about five years, no dystonia, no medication, no botulinum toxin injections. He is leading a normal life and it was very pleasing to have had such an impact on his life. In this patient, I would say it's a permanent improvement. In other dystonia's, patients may get worse many years after the DBS, but most patients will maintain the maximum improvement they have reached.

### What is the main technological advancement of DBS that helps to treat dystonia?

*Prof Ferreira:* The directional electrodes have helped DBS to make good progress for the outcomes of the patient. It gives us the possibility to be more precise and therefore we can achieve more reliable results from the surgery.

When this new technology was first introduced (*in 2015*

*by Boston Scientific*), some neurologists feared that these electrodes, being more complex and with multiple contacts, would make programming more difficult. I think now those limitations have been overcome by most centres and in most cases, we are happy with the directional electrodes.

### What are the things patients should consider to decide to have DBS?

*Prof Ferreira:* It's necessary we guarantee the patient, and/or their relatives understand the DBS system. That's fundamental.

We must explain clearly that the patient will have for the rest of their life, an implant that consists of electrodes inside the brain, connectors, extensions, and the generator or generators. And so, it's very important that they accept this.

Afterwards, they must also be conscious that contrary to other movement disorders, we don't expect to have the best results immediately after surgery.

So, they may also need to accept that we might be making adjustments to the programming for months, until we have the best possible results. And, of course, another important thing is patients and relatives must be aware that DBS does not mean they can immediately stop the rest of the medication.

### **What are the most important characteristics from the patient perspective, when it comes to a DBS device?**

*Prof Coelho:* It's very important that they understand the procedure well, that they understand the benefits and the improvements and that it's not expected to be 100%. It is very important, because having unrealistic expectations will impact on how the patients perceive the benefits, they get from DBS.

They must ask the physicians to explain to them exactly what DBS is and where we are implanting the lead, so that they understand that the lead must be implanted

millimetrically in the right spot. The greatest benefit is achieved if we implant the lead in the right spot, and if it is implanted even one millimetre away from that place it may not lead to the expected improvement.

If this is correctly explained to the patient and the patient realises what the surgery involves, it's much easier to work with the patient if anything fails afterwards.

### **How long does a typical surgery take and what can patients expect from the surgery and afterwards?**

*Both Profs Coelho and Ferreira:* In the first visit, I (Prof C) observe the patient, I diagnose if they have dystonia and if that dystonia is indicated for DBS. If so, everything is explained to the patient. The probability of improvement, the probability of minimal improvement, how we do the surgery, the follow-up, how many days they will be in the hospital, what is the frequency of the follow-up visits, what to expect, and what side effects can arise from the surgery.

And then, patients are given time to go home and think about it. They will return a few weeks later or get in contact with us to ask additional questions and tell us whether they want to go ahead with DBS. Even during the selection process, we make patients aware that they always have the right to decline surgery.

The protocol may vary between centres. On the morning of the surgery, the patient is put under

general anaesthesia in our operating theatre. Then we make a CT and fuse it with the MRI to plan the procedure. Meanwhile, the patient is already asleep in the operating room. So, then it takes from about eight, 8:30 in the morning, until three to four in the afternoon for neurosurgeon to perform the DBS surgery. Patients are placed after into intensive care for one night. Then they go to the neurology ward, and they will be discharged after one week.

We start the programming while the patient is still in the ward. We take the opportunity during that week in the ward to adjust the parameters of the programming. And then, depending on the severity of the dystonia or on how far the patient is living from the hospital, we will make an appointment for some weeks after discharge.

### **After been discharged, how often patient will have to come back for programming?**

*Prof Ferreira:* In the case of dystonia, the patient might come back often for programming, if adjustments to the DBS parameters are necessary to improve the results. It can take six months to completely optimise the DBS parameters.

*Prof Coelho:* It is also very important that patients are made aware of this. However, in many cases, patients start getting better even while they are still in the hospital.

### How has COVID-19 affected your practice and DBS surgery?

*Prof Coelho:* So, COVID has affected many treatments for patients, whether it is Botulinum toxin injections or DBS. For patients who required Botulinum toxin they need a treatment to be done every three or four months otherwise it loses its effect.

*Prof Ferreira:* We had to stop every functional neurosurgery procedure. So, patients waiting to get their DBS surgeries have been affected too, as all surgeries have been cancelled from March to June 2020.

### Is there anything else that you would like to add for patients, families and caregivers?

*Prof Coelho:* It is really important for patients, families and caregivers to be affiliated in dystonia associations at a country level and at a European level. For all together to raise awareness of the disorder, so that patients reach the right diagnosis and the right treatment faster, and they get to the right centres to get

better and faster treatment. On our part, we will always be available to collaborate with dystonia associations, such as Dystonia UK whenever they want.

*Interviewer:* I would like to conclude this interview by thanking Professors Ferreira and Coelho for their time and insights, and to summarise our conversation: The surgery itself can be performed in a day, but the patient will have follow-up programming sessions with ~6 months required to achieve good outcomes. Whilst patients can see a 50-75% improvement in symptoms, this will depend on the underlying cause of their dystonia, therefore, it is important that patients speak with their DBS team about their expectations. Finally, it is important for patients and families to be affiliated to dystonia associations at a country and at a European level to ensure raise awareness of this indication, please find more information at

<https://dystonia-europe.org/about-us/members-organisations/>

and for patients living in Portugal on the Portuguese Dystonia association website

<http://distoniaportugal.blogspot.com>



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Scientific**  
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## INNOVATION IN DYSTONIA TREATMENT

More than **500,000 people**  
across Europe are living with dystonia<sup>1</sup>



### 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 **150,000 people** worldwide  
already treated with DBS<sup>2</sup>



### 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<sup>3</sup>

### DBS may reduce dystonia symptoms such as:



Tremor, cramps



Pain



Strained or whispering voice



Muscle spasms



Rapid eyelid blinking



Painful neck spasms

Improvements of 50-60% in general, some patients experiencing a 90 % reduction in symptoms<sup>4</sup>



Talk to your doctor about how DBS could help you and find out more here:  
<https://www.bostonscientific.com/en-EU/health-conditions/dystonia.html>

References:

<sup>1</sup> <http://www.braincouncil.eu/wp-content/uploads/2015/07/Dystonia-fact-sheet-August-2011.pdf>

<sup>2</sup> <https://www.neuromodulation.com/deep-brain-stimulation>

<sup>3</sup> DBS Masters Debate, November 2015.

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

\* A System that includes the Vercise™ PC, Vercise Gevia™, or Vercise Genus™ IPG and Vercise Cartesia™ Directional Lead(s) forms the Vercise Directional System.

\*\* The Vercise Genus or Vercise Gevia™ DBS System and Vercise DBS Lead-only system (before Stimulator is implanted) provide safe access to full-body MRI scans when used with specific components and the patient is exposed to the MRI environment under specific conditions defined in the supplemental manual ImageReady™ MRI Guidelines for Boston Scientific DBS Systems.

\*\*\* MRI Conditional when all conditions of use are met.



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### Botulinum Toxin Therapy: An Update



The therapeutic use of Botulinum Toxin (BT) was established some 40 years ago in ophthalmology by Dr Alan B Scott. Soon its use spread into the therapy of various dystonia indications. Ever since, it has been the backbone of dystonia treatment. Average subjective improvement is for most indications in the order of 70 to 80%. Its adverse effect profile is favourable and over decades of use in hundreds of thousands of patients it has demonstrated an excellent long-term safety record. In most cases BT therapy should be accompanied by additional therapeutic measures. BT therapy will then ideally become an integral part of a multifactorial and multidisciplinary treatment concept. In summary: BT therapy is an extremely powerful therapeutic tool with its efficacy and safety determined by the physician and his skills. In the following we will be exploring recent developments in BT therapy.

#### Treatment Algorithms

Treatment algorithms are describing the way BT therapy is applied. They include the treatment parameters and the way they are connected and modified to adapt BT therapy to the individual patient's need. Some of the most important progress in BT therapy has happened in the area of treatment algorithms.

#### Short Interval Therapy

One of the parameters of BT therapy is the interinjec-

tion interval, i.e. the interval between two subsequent BT injection series. Since the early 1990s with the first descriptions of BT antibody formation in patients receiving BT therapy, it was recommended to limit the interinjection intervals to at least 12 weeks in order to avoid BT antibody formation. In 2014 it became apparent that this minimum interinjection interval was limiting the potential of BT therapy, as 83% of patients with cervical dystonia have therapeutic effects starting to vanish before 12 weeks, thus leaving them with suboptimal treatment for prolonged periods of time (Dressler et al. 2014). To improve BT therapy, we challenged the 12-week recommendation (Dressler & Adib Saberi 2017) in a study evaluating 30 dystonia patients receiving incobotulinumtoxinA (Xeomin®) at interinjection intervals of less than 80 days. After an observation period of at least 2 years there was no indication of any BT anti-body formation. Instead the patients' annual time with sufficient therapeutic effect increased by 22%. Assuming an average of 4.3 injection series per year, this means 65 days of improved therapeutic effect each year for the patient.

This 'Short Interval Therapy' is able to increase the outcome of BT therapy and to improve the patients' quality of life considerably.

#### High Dose Therapy

Another parameter of BT therapy is the total BT dose applied at each injection series. Again, in order to avoid BT antibody formation, total BT doses were recommended not to exceed around 400MU per injection series. It was also felt that higher total BT doses might produce systemic adverse effects, i.e. systemic toxicity. In clinical practice, however, frequently higher total BT doses are necessary to treat more wide-spread and more severe forms of dystonia and spasticity. We also challenged this recommendation to improve BT therapy (Dressler et al. 2014). For this, we evaluated 100 patients with dystonia and spasticity receiving total doses of incobotulinumtoxinA of more than 400MU per injection series. After an observation period of at least 2 years none of these patients showed neither BT antibody formation nor any sign of systemic adverse effects. A subsequent company sponsored study confirmed our results (Wissel et al. 2017).

This 'High Dose Therapy' now allows treating patients suffering not only from focal dystonia, but also from non-focal dystonia, i.e. more wide-spread forms, and also from more severe dystonia forms. This also changes the dividing line between the use of BT therapy and Deep Brain Stimulation. Patients with more wide-spread and more severe dystonia have now the choice to try the much less invasive BT therapy before Deep Brain Stimulation has to be considered.

### **Multimodal, Multidisciplinary Treatment Approach**

Many dystonia patients receive BT therapy only. This may be sufficient in mild and uncomplicated cases. For the majority of patients, however, BT therapy needs to be combined with additional measures. In order to establish and to promote a multimodal, multidisciplinary treatment approach IAB - Interdisciplinary Working Group on Movement Disorders organised a consensus statement with 20 experts from all over the world (Dressler et al. 2015). This consensus statement describes how the severity and localisation of the patient's particular dystonia form influences the use of BT therapy, Deep Brain Stimulation, antidystonic drugs, adjuvant drugs and rehabilitation therapy with physiotherapy, re-training, occupational therapy, speech therapy, sociotherapy and psychotherapy. Patient groups play an important role in this concept.

### **BT Application**

BT therapy is a local therapy. This means, BT has to be injected directly into the target muscles, i.e. the muscles selected for treatment. BT therapy starts with the planning. Planning requires the selection of the appropriate target muscles and their appropriate BT doses. Both parameters will be recorded in the injection scheme, which is highly individualised for each patient and its particular symptomatology. If BT therapy doesn't produce the desired results, this is mostly caused by inappropriate injection schemes with usually too few target muscles selected and too low BT doses chosen. The next step is the BT application according to the injection scheme. This includes the localisation of the target muscles and the actual placement of the specified BT doses. One hypothesis suggests that exact localisation can reduce BT doses and adverse effects. Conventionally, BT placement is based on anatomical knowledge supported by topographical information, landmarks and palpation. Certain tricks can be of additional help. Alternatively,

ultrasound may be used to visualise target muscles and electromyography to give acoustic feedback about the localisation of the injection needle. Ultrasound requires expensive equipment not readily available everywhere. Electromyography also requires additional equipment. Special injection needles become necessary. They are thicker and produce more patient discomfort. Some studies, indeed, show that both methods can improve application precision. However, no study so far could demonstrate improved therapeutic results by application of these techniques. The additional application precision is obviously not necessary for the therapeutic efficacy. However, we feel that in special situations ultrasound or electromyography may be helpful. These include very localised forms of dystonia in forearm muscles as in writer's cramp or in musician's cramps or dystonia localised in deep limb muscles. Treatment of children with their particular anatomy may also seem to benefit from additional guidance techniques.

We conclude that ultrasound and electromyography may increase therapeutic efficacy in BT therapy of forearm muscles as in writer's cramp and musician's cramps and BT therapy of some deep limb muscles. Both techniques, however, are not a general requirement to perform BT therapy and their availability should not prevent making BT therapy available to patients.

### **BT Drug Development**

BT drugs are a global market with annual revenues in excess of 5 to 6 billion US\$. Half of this market covers therapeutic indications, the other half aesthetic ones. With international competition rapidly increasing, companies are in desperate search for unique selling points to distinguish their products from others. The most recent attempt to generate unique selling points are liquid BT drugs and BT drugs with prolonged duration of action.

### **Liquid BT preparations**

So far, rimabotulinumtoxinB (Neurobloc) is the only BT drug marketed as a liquid. Its advantage is that it is ready to use and physicians save the time for the drug reconstitution, which is a few minutes. Disadvantages of liquid BT drugs include that their maximal drug concentration is pre-set and cannot be increased if necessary.



If an existent BT drug should be changed into a liquid version a complex and costly re-registration in all countries involved would have to be initiated. Developing a liquid version of an existent BT drug with otherwise identical features is difficult, as the failure of the liquid Dysport® development project shows. Also, simultaneous marketing of conventional and liquid versions of the same BT drug seems to be challenging. We believe that liquid formulations are an option when new BT drugs are developed. Although actual advantages are limited for physicians, for patients they are non-existent. For aesthetic uses liquid BT drugs possibly in pre-filled syringes may be more interesting.

### **Long duration BT drugs**

Most recently, the duration of action of BT drugs became an issue, when a US company claimed that their substance increase patient compliance by reducing the number of their office visits. However, a prolonged duration of action would also unavoidably mean that adverse effects would also last longer and that the adaptation phase at initiation of BT therapy would be prolonged. Whether patients would really welcome reduced access to their physician and whether physicians would welcome this interference with their income basis is not clear. So far, there is no valid scientific concept as to how the duration of action of BT drugs can be markedly increased. The proposed concept of daxibotulinumtoxinA's manufacturer is unclear and data to support their claim of prolonged duration of action is lacking.

We believe that BT drugs with prolonged duration of action might actually only be welcome by a very small proportion of patients. Theoretical concepts to achieve a prolonged duration of action are unclear and no current drug development project has provided data that support such claims.

### **The Corona Challenge**

The Corona pandemic is directly challenging all health care systems world-wide. Countermeasures against it have and are still provoking massive interruptions of social, economic and medical interactions. Part of the interruptions of medical interactions are shutdowns of medical services. We wanted to study the consequences of a 6-week complete shutdown of the BT clinics at Hannover Medical School (Dressler & Adib Saberi

2020). For this, we interviewed 45 patients with various dystonia, spasticity and pain conditions with a standardised questionnaire. Not surprisingly, all patients experienced return of their original symptoms. Their subjective quality of life was reduced by 40%. Two thirds of patients perceived their BT therapy as more important than before. All patients stated that treatment availability was important or very important. 98% of patients felt that their patient rights were violated.

The corona pandemic is also producing numerous indirect challenges to health care systems. We already experience massively reduced national and international exchange at meetings and impairment of multicentre studies and projects. This damages competition and paralyses the scientific system. Cancellation of international meetings blocks revenues from registration fees and industry grants and destroys the funding basis of the scientific societies. We are pessimistic that this funding will ever return. Alternative funding sources are not likely, especially as the economic crisis is also eroding the funding basis of all general health care systems. As much as this is a problem in developed countries this is an even more catastrophic problem in developing countries. Interestingly, Asia does not seem to be part of this development. Especially China seems to have recovered more rapidly and will continue its expansion.

### **Summary**

Much progress has been achieved in further developing and refining the algorithms of BT therapy. Ultrasound imaging and electromyography offer valuable information for BT placement in special indications. Actual needs for further BT drug developments are unclear. Often such development projects are marketing-driven. It seems to be more important to expand the availability of BT therapy to all patients in need. This is a special challenge in underdeveloped countries. Corona shutdowns have dramatically underlined the importance of BT therapy for patients with dystonia as well as the considerable burden of disease generated by dystonia. The next months and years will be crucial to safeguard and protect our health care systems. Patient organisations will be playing a crucial role in this process.

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Prof Dirk Dressler

Photo: Stephan Röhl

### Dystonia UK Digital Conference

On 25 - 26th September, Dystonia UK held a digital Conference «Dystonia Matters Digital». There were morning and afternoon sessions on both days, with patient speakers and expert speakers from the medical field of dystonia.

It started with pre-recorded sessions on the 25th of September, and after the sessions it was Q&A (Questions and Answers) via zoom. This was very interactive session and with great participation from the «audience».

After the Q&A, the participants were automatically assigned to a virtual breakout room to network with fellow attendees. The groups were divided into 5-6 persons and we had great opportunity to interact. On Friday morning the first session «Campaigning for Change» started with a presentation from Georgina Carr, Chief Executive of Neurological Alliance England, who shared her thoughts on neurology care and how we represent the community to continue pushing for more awareness and change at a governmental level.



**Professor Emeritus Marjan  
Jahanshahi**  
UCL Institute of Neurology

The afternoon session on Friday «Mental Health Matters» was focusing on the relationship between dystonia and mental health. Professor Emeritus Marjan Jahanshahi discussed in a pre-recorded

session, the need of balancing your mental wellbeing with dystonia, including tips for how to live well with the condition. It was very interesting and useful and after the session it was Q&A. The Q&A was with live panelists, Prof Janhanshahi, and two patient speakers Nick and Mandy.

Saturday morning session was about «The Future of Neurology» with leading clinicians from across the U.K. who discussed digital innovations and transformations such as tele-medicine, national frameworks, service studies and research, sharing their thoughts on the future of neurological care and services. Then again it was the live Q&A where all attendees could send in questions. The live Q&A panel consisted of Dr Peter Moore and Dr Richard Ellis from The Walton Centre, Dr Eoin Mulroy and Professor Tom Warner from UCL Institute of Neurology, Dr Jean-Pierre Lin from Evelina London Children's Hospital and Dr Kathryn Peall from University Hospital of Wales. The last session on Saturday was on «Know your Rights», and at the end of the session there were group discussions. This was a digital conference with pre-recorded sessions, packed with valuable information for dystonia patients.

Congratulations to the Dystonia UK for such a well organised and successful conference.

*Merete Avery*  
*Operations Manager*  
*Dystonia Europe*



## Other News

### Digital Activities:

#### Dystonia Webinar Series & the Positive Twist Podcast

As already shared in previous newsletters our most important event and activity every year, our annual meeting the D-DAYS Conference 2020 was cancelled due to the Covid-19 pandemic. Together with our partners (Boston Scientific, Ipsen and Medtronic) and the Dystonia Europe team we could rapidly change from the planned face-to-face activities to organizing on-line events suitable during the pandemic.

There have been four webinars organized and you can find them all on the Dystonia Europe YouTube Channel:

[https://www.youtube.com/playlist?](https://www.youtube.com/playlist?list=PLFvCc6fYkjEt_7GhGF9OwEElXo2iBeVRk)

[list=PLFvCc6fYkjEt\\_7GhGF9OwEElXo2iBeVRk](https://www.youtube.com/playlist?list=PLFvCc6fYkjEt_7GhGF9OwEElXo2iBeVRk)



We will continue the webinar series with about one webinar a month. Upcoming webinars will be on Writer's cramp and dystonia research. If you have any ideas of topic for a webinar please let us know and send an e-mail to [monika.benson@dystonia-europe.org](mailto:monika.benson@dystonia-europe.org). During the dystonia awareness month our new podcast series **The Positive Twist** was launched. Here we invite patients, experts and carers and talk about dystonia and different themes.



In the first episode you meet Stephen Batey from Newcastle, UK. He experienced his first symptoms of dystonia as a seven year old. It started in his right foot and eventually spread to his back, neck, and upper limbs.

Stephen was connected with a children's neurologist who gave him the diagnosis DYT1 positive primary torsion dystonia.

Stephen was started on oral medication along with regular botulinum injections. DBS surgery was presented as an option, but Stephen's parents decided to wait and let Stephen make the decision about having the procedure once he turned 18.

There was no hesitation on Stephen's end, as soon as he was of age to make his decision, he opted for the DBS treatment. Stephen's dystonia had progressively gotten worse and before his surgery it had gotten so bad that he was in a wheelchair.

The DBS surgery was performed on Stephen at 23 years old and he describes his quality of life changing drastically. During recovery he picked up photography, and that has developed into a business.

Listen to the episode to hear Stephen's story of living with dystonia and having the DBS surgery. He is a true inspiration when it comes to seeing life from the bright side.

[https://feeds.buzzsprout.com/1337749.rss?](https://feeds.buzzsprout.com/1337749.rss?fbclid=IwAR1bRLDnWAAvT_8N3QF_9HhxEvDjh5RgA2Po1qHFeGScQBkNwehTwJaAzDc)

[fbclid=IwAR1bRLDnWAAvT\\_8N3QF\\_9HhxEvDjh5RgA2Po1qHFeGScQBkNwehTwJaAzDc](https://feeds.buzzsprout.com/1337749.rss?fbclid=IwAR1bRLDnWAAvT_8N3QF_9HhxEvDjh5RgA2Po1qHFeGScQBkNwehTwJaAzDc)

The first season of the podcast will have 7 episodes. New episode is out the 4th Wednesday of the month.

Hope you will enjoy these two new activities: tune in and listen or watch!

*Monika Benson  
Executive Director  
Dystonia Europe*



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### Global Advocacy in Neurology by EFNA

Dystonia Europe is a member of EFNA, European Federation of Neurology Association and attended a virtual meeting about an ongoing project on Global Advocacy. The goal of the project is the development of a coordinated and inclusive strategy to ensure that neurology becomes a global public health priority. The aim is to have concrete policy actions that will bring hope and solutions for people across the world. The 1<sup>st</sup> phase of this project is in process while the 2<sup>nd</sup> phase is scheduled to take place in 2021 and 2022. Neurological disorders have the highest prevalence, biggest disability and greatest cost. The investment in care and research does not match the soaring burden.

EFNA along with their members call on decision-makers to change this and acknowledge that Neuro-

logical action plans are needed to future-proof the healthcare systems.

1 in 3 people will have a neurological disorder during their lifetime, examples are migraine, epilepsy, movement disorders like dystonia, Parkinson's and tremor, just to mention some.

Governments and public policy makers need to take urgent measures to reduce the risks and impact of neurological disorders.

With this project on global advocacy for neurology EFNA and stakeholders will create documents based on data to present for MEP's and other policy makers.

*Merete Avery  
Operations Manager  
Dystonia Europe*

## Update on Global Advocacy

### Making Neurology a Public Health Priority

September 24, 2020



### Results of EFNA's Survey on Stigma and Neurological Disorder

In celebration of World Brain Day 2020, the European Federation of Neurological Associations (EFNA) has published the results of its recent survey on stigma and neurological disorder.

According to the World Health Organisation, stigma is a major cause of discrimination and exclusion: it affects people's self-esteem, helps disrupt their family relationships and limits their ability to socialise and obtain housing and jobs. EFNA has chosen to examine the stigma suffered by those with neurological disorders by commissioning this survey into its causes and effects.

1373 responses to the survey were received from 37 countries. Responses came from a diverse range of neurological conditions, with the greatest numbers coming from the areas of Myalgic Encephalomyelitis (ME), dystonia, migraine or headache and chronic pain.

92% of respondents report feeling affected by stigma on account of the neurological disorder they live with. Lack of understanding is seen as the biggest cause of this, followed by myths/misconceptions about these disorders and their invisible nature.

The issue of stigma has proved most problematic during interactions with medical professionals. 74% felt that a medical professional did not believe the extent or severity of their symptoms and the same percentage feel they did not receive adequate or appropriate treatment because a medical professional did not take them seriously.

Stigma is also prevalent within families and in social situations. 49% say their families sometimes make them feel that they exaggerate their condition and, sadly, 32% of respondents with children have been made to feel that they are inadequate parents. Almost half of respondents who lived with a neurological disorder during childhood found it difficult to make friends or maintain friendships at school, and a similar number were excluded from school events on account of their condition.

EFNA President, Joke Jaarsma, said:

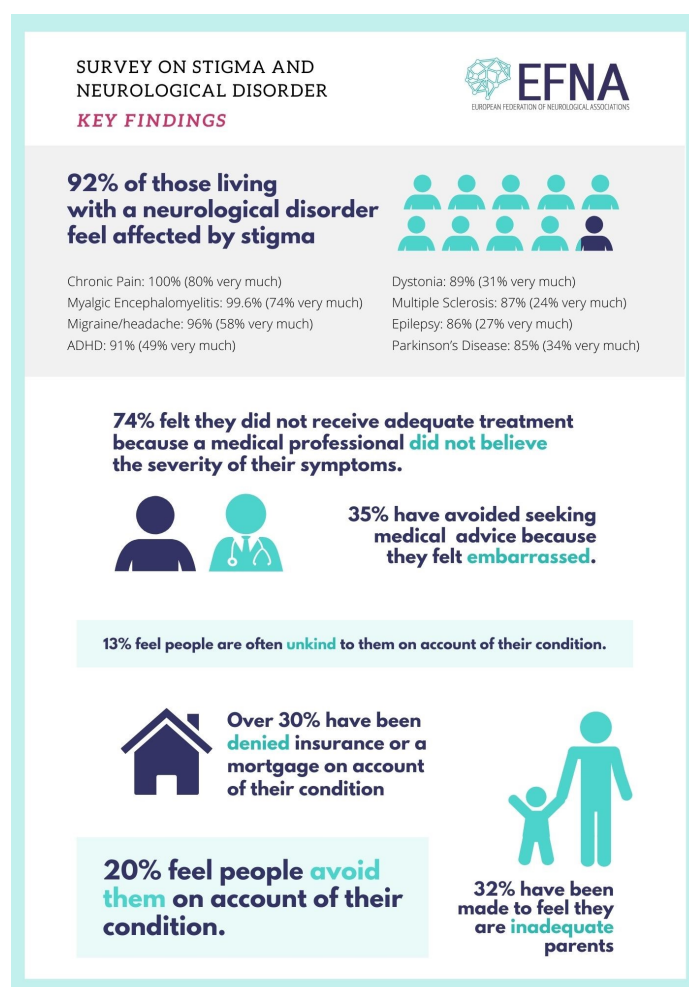
*"We hope that EFNA, together with our member organisations, can use these findings to work to*

*develop strategies that will combat stigma where it arises, thereby improving the quality of life of people living with neurological disorder".*

The report contains overall results, disease-specific results and a comparison of disease areas. The complete findings of the survey are available from EFNA's website at <https://www.efna.net/survey2020>

Elizabeth Cunningham

EFNA Communications Manager



### Webinar Series on Digital Health and Workshop by EPF

EPF (European Patient Forum) has held a series of webinars in 2020 on Digital Health. Dystonia Europe is a member of EPF ( a leading voice for patient organisations in Europe, working with EU stakeholder and expert groups). DE has attended all the webinars and workshops held by EPF in 2020.

Some of the topics in the webinar series were:

**“Data Saves Lives”**, which explains the role of governments in tracking their populations health and how the patient organisations can support and give input to keep in mind the best interest for the patients like quality of life, treatment etc.

**“E-health and Telemedicine”** which focused on a case study on telemedicine presented by Jessie Cunnett, Associate Director, Head of Health and Social at Traverse, a consultancy focusing on people development. Traverse partnered up with EPF UK member National Voices to design a research project on telemedicine and remote consultation in particular.

**"Artificial Intelligence in healthcare"**, this webinar was about the current status on knowledge and capacity of AI (Artificial Intelligence) and the plans for its future in healthcare.

#### Workshop

Last October EPF held a two-day online workshop on Digital Tools for Patient Empowerment and Person-Centred Care. The main objective of the workshop was on digital tools that have a potential to boost patient empowerment and person-centred care, and the aim is to foster collaboration between patients and healthcare professionals.

Some of the key topics were to bring together digital solutions by experts, developers, patient representatives, healthcare professionals, policy makers and industry representatives. The goal was to validate the in-depth-analyses developed by EPF and to further identify barriers and enablers of the digital solutions.

*Merete Avery  
Operations Manager  
Dystonia Europe*

A large graphic consisting of a dark blue circle on the right and a green curved shape on the left, resembling a stylized 'D' or a protective shield. The words 'Digital Health' are written in large, white, sans-serif capital letters across the blue circle.

# Digital Health



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**\* At Dystonia Europe, we're working on updating MyDystonia to version 2.0, which we plan to launch in the beginning of 2021.**

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# My Dystonia Story

## My Dystonia Patient Story

My name is Emilie and this is the story of my life with dystonia. I'm not quite sure when the first symptoms started to appear, but approximately around 9-10 years of age. I first had pain in my left arm and it felt a little weak. As a child, I remember that I just stopped using my arm. I visited several doctors and went for various examinations without anyone finding an answer. Eventually I became more and more tired and could not perform at school/leisure activities as expected. Around the age of 13, my neck started to become crooked and it became visible to people around me that something was physically wrong. Or could it be psychological? The road from there to diagnosis would still take an additional 4 years, with various medical examinations, X-rays, psychologist appointments and several physiotherapists. No one knew what this could be.

When I first started going for psychomotor treatment I was asked if I had been to a neurologist? I hadn't. Finally I entered the office of the neurologist. By then I was a tired girl at the age of 17, with a very crooked and spasmodic neck, and incipient scoliosis. As soon as we got into the neurologist's office he turned to me and said; "You have dystonia". I got the diagnosis spasmodic torticollis. I cried in relief that I finally received an answer. At the same moment I was informed that there is unfortunately not much treatment to offer.

I started with botulinum toxin injections every 3 months. Eventually the disease developed even further, my neck, back and arm got worse, and I also experienced spasms in my face and pain in my legs. I was around 19 years old when I was diagnosed with generalised dystonia. The botulinum toxin injections worked poorly and I was afraid of the future without any other treatment available.

At the same time as I got the new diagnosis, there was talk of a new revolutionary treatment. DBS (deep brain stimulation) surgery. And I was eventually asked if this is something I would want to consider?

I had (almost) no doubts, and my answer was yes! There was a waiting list and it was going to take a while. The following year I met my husband, the year I turned 21. It would be another year before the surgery was performed. In 2006, after I had turned 22, the day had finally come and I had DBS surgery at St. Olav's hospital in Trondheim. The operation took approximately 12

hours and I woke up to the message that everything went exactly according to plan. After this, we spent a whole year in and out of the hospital to find the right settings for me and my dystonia. Luckily there were two of us in this together, me and my husband, and he went with me to every hospital appointment. We finally found settings that make me have a very good everyday life despite the dystonia and to function as well as possible. I have been very lucky and had a very good result from the DBS surgery. We've been blessed with 3 healthy wonderful children, all 3 have been born after the DBS operation and have shared space in the womb with the battery. It has gone completely smoothly. In the beginning, I had to change the battery relatively often, about once a year for the first few years. But in 2014 I had a rechargeable battery inserted and I still have this. Today, in addition, I occasionally have physiotherapy treatment when I feel the need and this helps my sore and tight muscles to loosen up.

It's not a pain free life, but still, I have a good and happy life 😊 .

*Emilie Elnes, Norway*



*Emilie*

## Meet Pia, Chairwoman of the Danish Dystonia Association

### What is your name?

My name is Pia Vejle.



### Why do you like helping others?

I always had this thing about helping other people, making other people smile is the best gift. When I was around 15 years old (many years ago), it started out when some young children never got to the trips because they did not have the money for it, so I started a group where I lived, where they could come once a week, sometimes we made drawings, sometimes we went for a walk, the most important thing was, it did not cost anything and it was all about having a good day and not think about school or homework etc. Later it became groups about music, talking about music of specific artists and meeting them at the concerts. Some years ago I developed dystonia and I needed information, and it felt so

perfect to have it and give it by being a member of the Danish board.

### What are the benefits of working within a patient organisation?

I get a lot of knowledge and inspiration I would not find anywhere else, I have met a lot of fantastic people to know and share our ups and downs stories.

### How do you like spending your free time?

I participate in a concert likely every 3 days all year. Music has for me been the energy to move on through hard times and the energy in my all times.

I love forgetting everything else and just be there for the moment, I can go alone, I can go with friends or family, right there, it doesn't matter anything else but love the music, no worries.

### What keeps you motivated on the tough days?

The music, my family and the belief that tomorrow will be better.

### What makes you angry or frustrated?

People who judge other people, people that do not listen but only talk to hear themselves. If the "pay it forward" was a politician I would vote for that, if you help others they help you back.

## Around Europe and Beyond

### Denmark

#### Members Meeting Faroe Islands 2020



In September 2020 we had the members' meeting of the Faroe Islands. The meeting was held at Hafnia Hotel in the middle of Torshavn.

We ended up being a little group of members at the meeting, Covid-19 and the fear of participating in social groups had its impact. But it still was a very nice day and evening.

We started out with some information from the board of the Danish Dystonia Association about the time we are living in right now and about our treasurer having to be on long-term sickness leave. But we were also informed about the new board members and the future for our national association. We said goodbye to Simona who has been the contact for the Faroe Islands for many years, and now the time has come to find a new contact person.

Then we had the pleasure of having the Executive Director of Dystonia Europe, Monika Benson with us on-line talking about Dystonia Europe, what they

work for, what plans they have, background and development of the organization and a great deal of interesting information about Dystonia Europe.

At the end of the session Monika also gave us the news, that the Dystonia Days 2021 will be held in Copenhagen, Denmark (if possible considering the Covid-19 pandemic and its development).





## Around Europe and Beyond

We are very happy within the Board about this news and we are looking forward to helping in the planning and execution. Pia Vejle is the coordinator for the Danish board and will help Dystonia Europe as much as possible. \*

Then during the break we took time for some JUMP for Dystonia pictures. They are now on our Facebook page. In our next newsletter we will tell you more about the meeting and about Monika's great session. For the first time we gave our members the opportunity to hear some of the information the board members get from Dystonia Days. I hope that in the future we will be able to hold a similar session at members' meetings in the rest of Denmark.

After the meeting we had a delicious dinner with live music from Kasper Buch and Nigel Ray Beck

and around 21 o'clock the members' meeting 2020 ended.

*Pia Sørensen Vejle  
Chairwoman  
Danish Dystonia Association*

***\*At the last Board Meeting of Dystonia Europe on 26 November it was decided that the next D-DAYS 2021 will take place on-line, and therefore unfortunately not in Copenhagen, Denmark.***

***Due to the recent developments of the Covid-19 pandemic, the board agreed that it is not possible to organize any face-to-face meetings for the next few months. We are very sorry about this but the health and wellbeing of our team, members and partners are the most important.***



*JUMP for Dystonia*



## Around Europe and Beyond

### Italy

#### First Italian Dystonia Day

On September 26th A.R.D. (Associazione per la Ricerca sulla Dystonia) organized the first Italian Dystonia Day.

At the end of last year we had the idea of creating this day and began to draft some concepts. However, in March we realised that due to the Covid-19 pandemic we were compelled to change our plans.

Eventually, when it was clear that no event with an audience would be possible, we diverted our efforts into a live-streamed event on our Facebook page and YouTube channel. In such a way, we could reach much more people, who were glad to remain at home due to the unusually cloudy and cold weather all over the country.

The event began with an outstanding testimonial: Maestro Salvatore Accardo, a world famous violinist, performed a Mozart Sonata accompanied on the piano by his young daughter Irene. It was a ray of sunshine on this autumn day!

Later Maestro Accardo revealed for the first time that 40 years ago he began to have symptoms of dystonia, and he was afraid that his career was over. At the time it was Prof. Alberto Albanese who diagnosed him, and now 40 years later, during our live event, Prof Albanese reminded Maestro Accardo that when he played his violin in the hospital, during his dystonia tests, people stopped near the medical office creating congestion as they were enthralled by his music.

Maestro Accardo is now teaching in Conservatories, and said how important it is to have an early diagnosis of dystonia for musicians, so that they can begin to face the disease as soon as possible and accomplish their career in spite of the disease.

Prof Albanese launched the idea of a survey in Italian Music Conservatories in order to find out how many musicians with dystonia are now studying there. The goal is to have the survey completed by our second D-Day next year in 2021.



*Maestro Salvatore Accardo and his daughter Irene*

### **The central part of our first D-Day event involved four patients who told their stories:**

-A mother whose son began to show symptoms of dystonia in his arms, legs and tongue at the age of only 8. Eventually he was diagnosed with genetic dystonia caused by the Gene KMT2b mutation. Her son is now 13 and is scheduled to have Deep Brain Stimulation. Despite his movement problems he is now very fond of his hobby: Sport Climbing.

- A man whose dystonia began suddenly after some years of chronic autoimmune gastritis, which should not be involved in his dystonia. Now he is in a wheelchair and has to face these two diseases.

- A lady with generalised dystonia and some other rare symptoms which do not overwhelm her. She remains positive and considers herself a warrior.

- A man who was diagnosed with dystonia 13 yrs. ago and since then has tried various alternative methods and found that he got relief (although temporary) in dancing. He says that hope is the best medicine and suggests doing what one loves.

The audience greatly appreciated these life stories shared by the four patients. Everybody recognized his/her own grief, discouragement and resilience, ending with a message of hope.

### **Then it was the turn of the medical professionals:**

14 doctors took part during this D-Day; some of them just gave regards from the Neurological Academies and Societies who cooperate with A.R.D., whereas each of the 8 doctors of our Scientific Committee spoke about a specific topic (such as genetic dystonia, paediatric dystonia, diagnosis and taking charge, DBS, instrumental investigation techniques and confidence in treatment).

This section ended with a video made by Fondazione Don Gnocchi in Milan which featured Daniela, a lady with cervical dystonia who is treated there.

She was filmed while being examined with echo-grams and an electromyogram, injected with botulinum toxin and doing physiotherapy. She says that she feels totally confident with the doctors, which is so important for the patient.

Another idea for 2021 D-Day was suggested by Prof. Albanese: A survey of all the Italian neurological centres treating dystonia, in order to create a data-base for doctors and patients, indicating which types of dystonia are treated by each centre.

The final part was dedicated to our book “DiStorie” published in 2017. It is made up of 26 stories about people with dystonia told by themselves or by relatives. Their ages vary from 16 to 60, the types of dystonia are various, from cervical to blepharospasm to generalised dystonia, genetic or not. The title of the book is “DiStorie” as it is “DISTONIE” where the N is deleted and replaced by an R. In Italian it is an excellent mix of dystonia and stories, which is exactly the aim of the book.

Reading these stories is not easy, as in most cases there is no happy ending. All of them show a past with problems and pain, a present with at least a diagnosis and some medical treatment, a future with maybe an improvement or maybe a worsening of quality of life.

During our event four different stories were read by Pino Strabioli, a TV actor and director. They involved toughness, optimism, despair and love. Writing about a disease has a therapeutic effect in itself, when you put in writing your own pains and fears, this can help to accept and overcome them. Writing about your disease is a victory over it.

## Around Europe and Beyond

Our live event lasted for three and a half hours, without any interruption. It was really like a whole day dedicated to dystonia, as we had so many inputs and emotions and information that time seemed longer.

During the event we met many doctors and had from them reassuring news about research and new therapies. Many people asked questions in the chat, and everybody got an answer by Prof Morgante and Prof Nardocci.

We are glad that we could achieve this event in spite of all the problems of this period. A.R.D. has already scheduled the Second Italian Dystonia Day next year, on September 25th, hoping that we can meet without masks and smile at each other.

*Maria Carla Tarocchi*

*Vice President*

*ARD - Associazione per la Ricerca sulla Dystonia  
Italy*



A.R.D.

Associazione Italiana per la Ricerca sulla Dystonia



**Campagna di Sensibilizzazione sulla Dystonia**

*Raro non vuol dire trasparente*

**#INSIEMESIAMOPIUFORTI #GND2020**

## Around Europe and Beyond

### Norway

#### Contact Person Training in Bergen Norway by NDF

The Norwegian Dystonia Organisation (NDF) held a training class for contact persons last October in Bergen, Norway.

On the webpage NDF have listed contact persons from within the organisation who can be contacted about dystonia. It is important that all contact persons make it clear that they are not medically trained.

A contact person is a person who also has dystonia and has had the diagnosis for more than a year or two. They will have attended special training and have knowledge of dystonia in general. It is important to keep in mind that within the diagnosis of dystonia the symptoms can be very different from person to person. Therefore it is important for the contact persons to have some knowledge of the most common types of dystonia.

Dystonia is not very well known, despite being the third most common movement disorder, many who are newly diagnosed will have some questions. A contact person is there to listen and to give general answers. For example for newly diagnosed patients, treatment with botulinum toxin (BTX) may not be optimal in the beginning. This is because the Neurologists/ Movement disorder specialists, has to adjust the treatment individually. This might take time, maybe 2, 3 or more treatment occasions.

The key message is that there are people with the same diagnosis that can be contacted and most of all they can listen and give general advice on how to manage the challenges that dystonia might bring forth in daily life. They are not medical professionals. To talk to someone who knows exactly how it feels, how dystonia can affect you, what challenges and misunderstandings there can be, are very important issues for most people who are newly diagnosed with dystonia.

#### The main objectives of the Training Class:

- Introduce and create an interest for volunteer work within being a contact person.
- Point out important qualities of being a contact person
- How to set limits
- Confidentiality

#### The main qualities of a contact person:

- To be a person who can empathise and has had dystonia for some time.
- A person with the ability to listen and to focus on the person who contacts the organisation, keeping in mind that many things are different from one person with dystonia to another, but that there are also a lot of similarities
- A person who uses his/her own experiences as a background
- A person who sees possibilities
- A person who sets limits for themselves
- A person who gives non-professional guidance
- Someone that the organisation has appointed to have a role as a contact person.

#### Examples on advice a contact person can give:

- To look at the situation positively, but to not give false hope
- To encourage the patient to find new ways to do things that suits their particular condition.
- To advise the patient that it is ok to take more frequent breaks when needed.

*Merete Avery  
Operations Manager  
Dystonia Europe*



*The participants of the training class in Bergen, Norway*



# Around Europe and Beyond

## United Kingdom

### Dystonia Awareness Month September 2020

#### Action for Dystonia, Diagnosis, Education and Research (A.D.D.E.R.)

A.D.D.E.R. is a dystonia charity based in the North East of England and we have been supporting people with dystonia for 20 years. We are a small charity in that our committee is made up of only 7 volunteers, 6 of us have dystonia in various forms and all 7 of us give our time and dedication free of charge, A.D.D.E.R. has no paid employees.

In the UK Dystonia Awareness Month is a new and very welcome concept. One of our main aims as a charity is to raise awareness and in the past we have done this by hosting conferences, running workshops and meeting with our members and other dystonia patients.

In the early days of A.D.D.E.R. we had regular contact with medical professionals and students and held prize giving events for essays/research in Dystonia. These days we feel the majority of medical professionals are aware of dystonia so our efforts now are mainly in raising awareness amongst medical students and we do this by once or twice a year giving a presentation to the students at a local university, our aim being to persuade a few to go onto become neurologists of which there is currently a shortage in our area.

The September Dystonia awareness month has now become a big event in our annual calendar. It gives us some great opportunities to raise awareness and get our message out to as many people as possible. This year of course presented us with a few problems to overcome. We certainly couldn't host our usual meetings and/or conferences.

We decided the best and safest way to take part in Dystonia Awareness Month this year was to concentrate our efforts to our website and our facebook page.

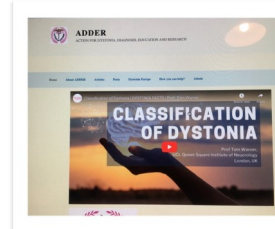
On Facebook we shared the following every day:

- Medical facts about dystonia.
- Information on types of dystonia.
- Positive messages on coping with dystonia.
- Dystonia Europe awareness posts.



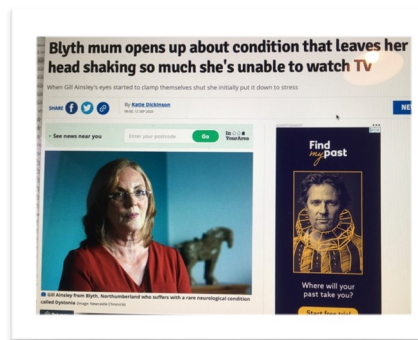
On our website we posted the following:

- Dystonia Talks videos shared from Dystonia Europe.
- Dystonia Europe videos of D Days 2019.



In the media:

- We were fortunate enough to get one story in our local online newspaper which is read by thousands of people every day.



Our posts on Facebook regularly attracted over 1,000 people each day and our website traffic was increased significantly.

On a personal note, as the newspaper article was about me, I got lots of lovely positive and supportive comments from my family and friends including friends I have not seen for many years.

The A.D.D.E.R. committee all share the same aim to raise awareness of Dystonia whether that is to thousands of people or one person, we consider our campaign to be a success.

*Gill Ainsley*

*A.D.D.E.R. Treasurer and Administrator  
Dystonia Europe Secretary*

*website: [www.actionfordystonia.co.uk](http://www.actionfordystonia.co.uk)*

*Facebook: ADDER\_Dystonia*

## Around Europe and Beyond

### United Kingdom

#### Dystonia UK Awareness Month 2020

2020 has been a year like no other, but throughout it all we have been inspired by the strength of the dystonia communities across the globe. As the year ends, we reflect on their importance.

Dystonia UK is a large community of children and adults with dystonia, carers, clinicians, fundraisers, families, friends, medical professionals and our amazing members and supporters, all working side by side. Despite the challenges of 2020, our community has undoubtedly strengthened.

While using digital technology to connect is nothing new, as the year encouraged these systems to become increasingly integrated into operations and more widely accepted, like many other organisations, we have embraced this opportunity to connect more digitally.

Shared learning continues with other dystonia communities across the globe on a much more regular basis, for example, with Dystonia Europe and the Dystonia Medical Research Foundation in the USA. Nationally, our relationships with Neurological Alliances in England, Wales, Scotland and

Northern Ireland and our connections with medical professionals across the UK have continued to grow. And through renewed partnering with other organisations such as National Voices and the Disability Benefits Consortium we have been able to magnify the voice of dystonia even more.

Our corporate medical partners have been more involved and connected than ever too, engaging on our awareness month campaigns and activities throughout the year. We have worked with them on mini-video series, webinars, campaigns and been able to use these relationships to ensure the patient voice is represented in the work they do.

This year we found innovative ways to connect and reach our patient community at the heart of our organisation. As part of our 'Reach Out, Reach All' campaign we launched our first webinars reaching over 10,000 people, we celebrated the launch of our new website and successfully held our first ever digital conference.

Our virtual support groups have grown, and it is heartening to see that despite the adversity faced by many people with dystonia, the community has rallied round to support one another and feels stronger than ever.

2020 also saw the dystonia community get behind our biggest dystonia awareness month campaign to date. Here in the UK we had two landmarks lit up in our iconic dystonia green, connected with our community through virtual 'Tea with the team' meetings, shared a whole host of personal stories, and our 'What is dystonia?' infographic reached over 60,000 people!

The launch of our first ever virtual awareness and fundraising campaign 'Dystonia Around the World' was a huge success. Our amazing champions ran, wrote, danced, and wheeled their way around the world collectively travelling an impressive 25,089 virtual miles (around the world and back again!) and raising an amazing £14,202.



## Around Europe and Beyond

### #DystoniaAwarenessMonth



We are so heartened to see that despite the challenges of 2020 the dystonia community remains strong, resilient, and supportive. We know that for many being a part of this community makes a real difference. If you would like to join our Dystonia UK community as a member or would like to find out more simply head to

<https://www.dystonia.org.uk/why-become-a-member>.

*Victoria Wareham  
Head of Operations and Development  
Dystonia UK*

## Events

### Calendar 2021

#### January

16-17 Toxins 2021 virtual conference

#### February

9 Dystonia Europe 11<sup>th</sup> Think-Tank, Zoom  
28 Rare Disease Day

#### April

19 EFNA General Assembly 2021

#### March

15-21 Brain Awareness Week

#### May

29-30 Dystonia Europe D-DAYS 2021, on-line via Zoom  
David Marsden Award 2021

#### June

1-5 EPNS Congress <https://www.epns.info/epns-congresses/epns-congress-2021/> Glasgow, UK  
19-22 EAN Virtual Congress 2021

#### July

30-2 ERN-RND Annual Meeting, Leuven, Belgium  
23 World Brain Day

#### September

1-30 Dystonia Awareness Month  
8-11 ESSFN, Marseille  
<http://essfncongress.org/en/>  
19-23 International Parkinson's and Movement Disorder Society Congress 2021, Copenhagen, Denmark

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



# VIRTUAL DYSTONIA DAYS 2021

SAVE  
THE  
DATE

Saturday, 29 May 2021  
Interactive Online  
Presentations

Sunday, 30 May 2021  
Online General Assembly  
(for members only)



DYSTONIA  
EUROPE



## TOXINS 2021

Basic Science and Clinical Aspects of Botulinum and Other Neurotoxins  
Virtual Meeting • January 16-17, 2021

New Virtual!

Abstracts and  
Registration Now Open!



Samuel Belzberg 6th International Dystonia Symposium  
1-3 June 2023  
Dublin, Ireland  
[www.internationaldystoniasymposium.org](http://www.internationaldystoniasymposium.org)

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



## 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](mailto: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  
Prof Alfredo Berardelli – Rome  
Prof Kailash Bhatia – London  
Prof Rose Goodchild – Leuven  
Prof Marina de Koning-Tijssen – Groningen  
Prof Joachim Krauss – Hannover  
Dr Francesca Morgante— London  
Prof Tom Warner – London  
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

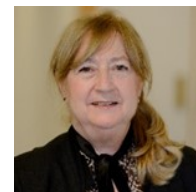
Childrens Joy and a Board Member of National Alliance of Rare Diseases, Romania. Catalina has broad training, within Art and Painting and also in Educator Recovery within the field of Social and Pedagogical for people with special needs. She also has training in Rare Diseases for Journalists and Effective 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 Dys-

tonia 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.



**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.

### PLATINUM level



## THERAPEUTICS

Better outcomes for more patients.

### SILVER level



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