

DYSTONIA

NEWS

SPRING | 1 - 2022

Program on page 4!

DYSTONIA DAY 2022

21 May 2022
Copenhagen

ANNUAL
CONFERENCE
LIVE!

IN THIS ISSUE

PG. 4

Dystonia Day 2022

Read more inside on how to
register and view the program

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Dystonia Research Update

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Meet Jan from England, My
Journey with Dystonia

dySTONIA
EUROPE

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Adam Kalinowski

Dystonia Europe
President

Dear readers,

Welcome to our first Dystonia News of 2022.

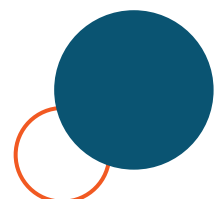
Our team has been busy the last few months preparing our much-awaited Dystonia Day conference and the 2022 General Assembly. We look forward to meeting our members' representatives, patients, their families, dystonia specialists and partners live after two years of online meetings. The event will be held in Copenhagen on May 20-21. More details and preliminary program are available in this release on page 4.

We are also preparing for the Dystonia awareness month. In September, in addition to educational materials and a campaign involving dystonia patients, we are delighted to share with you the highlights of the Patient Journey Map for people living with cervical dystonia (page 6).

In other news in this issue, we give you some updates on research, projects we are working on and activities of our members and partners. As always, you will also find an interesting Dystonia Story here.

Last but not least, Dystonia Europe stands in solidarity with Ukraine. Our thoughts are with the Ukrainian people and in particular with people living with dystonia. Together with our member organizations, we do our best to support people with dystonia seeking access to treatment in European countries. We stand in solidarity with the people of Ukraine, and we hope for a peaceful resolution as soon as possible.

Enjoy the read!



CALENDER

May 9	EFNA 20th Anniversary, Brussels, Belgium
May 10	EFNA General Assembly, Brussels, Belgium
May 19	Dystonia Europe Board Meeting, Copenhagen, Denmark
May 20	Dystonia Europe General Assembly, Copenhagen, Denmark
May 21	Dystonia Day 2022, Copenhagen, Denmark
June 23 - 24	EPF Congress, Brussels, Belgium
June 25 -28	EAN Congress, Vienna, Austria
June 25	David Marsden Award 2022, Basal Ganglia Session, EAN, Vienna
June 28	ECRD online Conference
July 22	World Brain Day
July 27 - 30	Toxins, New Orleans, USA
September 1 - 30	Dystonia Awareness Month
September 15 - 18	MDS Congress, Madrid, Spain
September 20	Dystonia Europe Board Meeting, Lund, Sweden
September 21	Dystonia Summer Think Tank 2022 Lund, Sweden
October 29 - 1	Dystonia ERN-RND Annual Meeting , Tübingen, Germany

Dystonia Europe Stands in Solidarity with Ukraine



Dystonia Europe is deeply concerned about the latest horrific developments in Ukraine, at the enormous human suffering and loss of life caused by the war. Our thoughts are with the Ukrainian people and in particular with people living with dystonia and their families, as well as our dystonia member association in Ukraine.

We are especially concerned about the situation of people living with movement disorders such as dystonia, who are vulnerable to disruptions in healthcare services, medical treatment and medicines caused by the war.

DE is in close contact with our Dystonia member association in Ukraine to assess the current needs of people with dystonia affected by this situation. We would like to assure them that in these difficult times they can count on the support of the dystonia community in Europe.

We are also in close contact with our member associations in the neighboring countries of Ukraine where refugee dystonia patients may be entering and might need assistance for medical treatment and care.

We encourage our partners who may be able to provide assistance to people with dystonia and those who care for them in Ukraine to get in touch and see how and if we can work together.

We stand in solidarity with the people of Ukraine and we hope for a peaceful resolution as soon as possible, to minimise the amount of pain and hardship for all people.

Adam Kalinowski
Dystonia Europe
President

Monika Benson
Dystonia Europe
Executive Director

Handwritten signatures of Adam Kalinowski and Monika Benson in blue ink.

Support_{for} Ukrainian dystonia patients

Thanks to the support of our member organizations, we are committed to supporting people with dystonia seeking access to treatment in different European countries.

We have created a special page on our website where people in need can find contact information to our members who provide support in specific countries.

<https://dystonia-europe.org/2022/03/support-for-ukrainian-dystonia-patients/>

LATEST NEWS

Welcome to the Dystonia Days 2022 at the Scandic Copenhagen Hotel in Copenhagen in Denmark 20-21 May. For information and registration: <https://dystonia-europe.org/projects-1/events/dystonia-days-2022-copenhagen/>

We are looking forward to finally meet face-to-face and to listen and learn from dystonia experts and to connect with old and new friends from across Europe.

DYSTONIA DAY 2022

AGENDA

21 May 2022, Copenhagen
VENUE: Scandic Copenhagen Hotel

09:00

Registration open

09:30

Welcome and Dystonia Europe introduction

DE President &
DDF Chairman

SESSION I: UNDERSTANDING DYSTONIA

09:45 - 09:50

Opening video: patient testimony

Tracey McCann, Ireland

09:50 - 10:35

What is dystonia & advantages of guided injection of botulinum toxin in dystonia

Prof. Tobias Bäumer, Lübeck

10:35 - 11:00

Dystonia - where does it come from? Genetics?

Prof. Lena Hjermand, Copenhagen

11:00 - 11:30

Q & A

11:30 - 12:00

Coffee

SESSION II: TREATING DYSTONIA

12:00 - 12:25

Understanding Plasticity

Prof. Espen Dietrichs, Oslo

12:25 - 12:50

Deep Brain Stimulation for dystonia

Prof. Annemette Løkkegaard
Copenhagen

12:50 - 13:15

Q & A

13:15 - 14:00

Lunch

SESSION III: TREATING & MANAGING DYSTONIA

14:00 - 14:25

Childrens' dystonia

Dr. Jean-Pierre Lin, London

14:25 - 14:55

**Physiotherapy for dystonia
& new exercise platform**

Physiotherapist
Johanna Blom, Malmö

14:55 - 15:15

Living well with dystonia

Prof. Marjan Jahanshahi, London

15:15 - 15:30

Q & A

15:30 - 16:00

Coffee

SESSION IV: AWARD PRESENTATION & DE ACTIVITIES

16:00 - 16:05

Presentation of David Marsden Award 2022 winner

Adam Kainowski, DE President

16:05 - 16:25

Award winner presentation

Award winner

16:25 - 16:45

Dystonia Europe activities:
Patient Journey
MyDystonia
Dystonia Survey

Monika Benson, DE Executive Director
Adam Kainowski, DE President
Dr. Katarzyna Śmiłowska, Poland
Sandra Theil Sørensen, Denmark
Adam Kainowski

16:45 - 17:00

Testimony - family member of dystonia patient

17:00 - 17:15

Evaluation & thank you

17:15

Jump for Dystonia photo

END OF CONFERENCE

DIET AND DYSTONIA

Take a survey for change!



- ✓ Take the survey
- ✓ Support research
- ✓ Anonymous
- ✓ 16 languages

surveys.dystonia-europe.org

Dystonia survey

As many of you may remember, the 'Sexuality and Dystonia' survey was available on our dedicated platform for a few months. This poll was created by researchers with a special interest in movement disorders, including dystonia. The survey has been closed and its first results will be presented at the Dystonia Day 2022 conference in Copenhagen. We want to thank everyone who participated.

A new survey 'Diet and Dystonia' is now open on our platform. The main goal of this research is to examine how diet affects dystonia, and if so how dystonia specialists could address these problems. The survey is completely anonymous, which means that no personal information will be collected.

We will be very grateful if you decide to support research by completing this online questionnaire.

<https://surveys.dystonia-europe.org/>

Survey developed by:

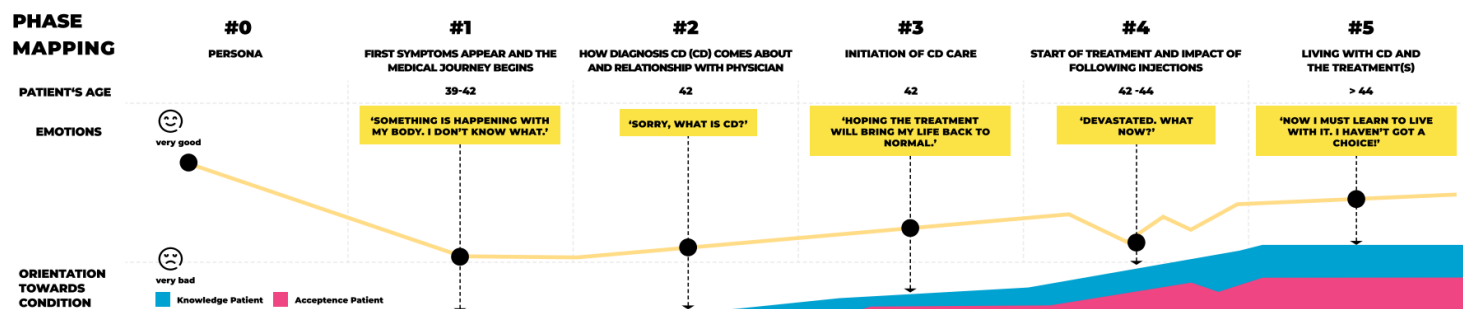
Dr Katarzyna Śmiłowska – Silesian Center of Neurology, Katowice, Poland

Dr Daniel J. van Wamelen – Institute of Psychiatry, Psychology & Neuroscience, Department of Basic & Clinical Neuroscience, King's College London, London, United Kingdom Parkinson's Foundation Centre of Excellence at King's College Hospital NHS Foundation Trust, London, United Kingdom

Supervisors:

Prof Kailash P. Bhatia – Department of Clinical and Movement Neurosciences, UCL Queen Square Institute of Neurology, University College London, London, United Kingdom

Prof K. Ray Chaudhuri – Institute of Psychiatry, Psychology & Neuroscience, Department of Basic & Clinical Neuroscience, King's College London, London, United Kingdom Parkinson's Foundation Centre of Excellence at King's College Hospital NHS Foundation Trust, London, United Kingdom.



First ever Patient Experience Map in Cervical Dystonia Reveals Multiple Barriers

The first cervical dystonia patient experience map was published in February in the peer-reviewed publication, the *Orphanet Journal of Rare Disease*.

The development of the new map was a collaboration between Dystonia Europe and Ipsen and was underpinned by research of people living with cervical dystonia in the UK, Italy and France to shine a light on the changing emotional and medical experiences present during different stages of this condition.

It revealed that the experience of living with this neurological movement disorder was often associated with multiple barriers to accessing holistic care, from pre-diagnosis to long-term management. Findings showed that patients were referred up to 10 different specialists for diagnosis and over half (53.3%) had received ≥ 1 misdiagnosis.

Even after a diagnosis and treatment plan are in place, people living with cervical dystonia have reported a "roller coaster" of relief associated with treatment of symptoms and the associated impact on daily life towards the end of a treatment cycle.

The need for movement disorder centers to develop and reinforce links with the allied services to enable a multidisciplinary management plan for cervical dystonia was also evident as the research indicated that patients were often left to seek complementary services such as physiotherapy and psychosocial support themselves.

As one of the most common forms of adult-onset dystonia, the impact of cervical dystonia has until now been widely underestimated, the new patient experience map highlights, that by listening to patients, gaps in service provisions can be seen through their eyes.

Dystonia Europe and Ipsen will continue to work together to ensure that new opportunities for improvement and innovation can be identified and we look forward to discussing the implications shown on the patient experience map at the forthcoming Dystonia-DAYS 2022 Annual Conference in Copenhagen.

You can read the full publication in the *Orphanet Journal of Rare Disease* [here](#).

The development of the Cervical Dystonia Patient Journey Map and editorial support for this article was funded by Ipsen.



**DYSTONIA
EUROPE**

IPSEN
Innovation for patient care

Dystonia Research Update

We are delighted to present this new page in our newsletter. Here we will share the most recent publications in the field of dystonia research together with a summary in lay language.

Ledda C, Artusi CA, Tribolo A et al. Time to onset and duration of botulinum toxin efficacy in movement disorders. J Neurol. 2022 Feb 3. doi: 10.1007/s00415-022-10995-2.

This study looked at factors that could influence botulinum toxin treatment benefit for people living with movement disorders.

The study found that the total dose of botulinum toxin injected may influence the time to start of treatment benefit and length of treatment benefit (a higher dose may reduce the time to start of benefit and increase the length of treatment benefit) experienced by patients. The length of treatment benefit also appeared to be related to the type of dystonia. For example, patients living with blepharospasm experienced a shorter length of treatment benefit than patients living with cervical dystonia and focal limb dystonia; Patients living with cervical dystonia experienced a treatment benefit that lasted longer than patients living with hemifacial spasm and sialorrhea; hemifacial spasm a shorter length of treatment benefit than focal limb dystonia; focal limb dystonia a longer length of treatment benefit than sialorrhea. Age was a strong predictor of an earlier start of treatment effect, with older patients showing an earlier effect.

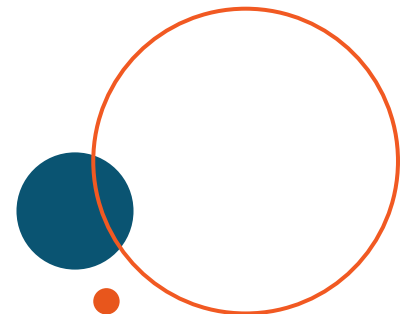
This study found new potential predictors of length of botulinum toxin treatment effectiveness worthy of being assessed in future studies and during clinical practice.

Hefter H, Ürer B, Brauns R et al. Significant Long-Lasting Improvement after Switch to Incobotulinum Toxin in Cervical Dystonia Patients with Secondary Treatment Failure. Toxins (Basel). 2022 Jan 6;14(1):44.

Treatment failures (where the treatment stops working) may occur in patients with long-term botulinum toxin treatment. Repetitive injections may activate the immune system with the risk of producing antibodies that reduce the effect of therapy. While the induction of such neutralizing antibodies is often related to reduced response to treatment, it does not prevent a clinical response.

This study evaluated the effectiveness of switching to a different botulinum toxin brand (in this case the name of the botulinum toxin was incobotulinumtoxinA) in patients experiencing treatment failure with their current treatment (abobotulinumtoxinA or onabotulinumtoxinA). Patients improved after the switch to the different brand of botulinum toxin but did not reach the improvement level obtained before the treatment failure developed.

In this study, a long-lasting improvement was shown in patients with treatment failure when switching to a different botulinum toxin brand.



Comella C, Hauser RA, Isaacson SH et al. Efficacy and safety of two incobotulinumtoxinA injection intervals in cervical dystonia patients with inadequate benefit from standard injection intervals of botulinum toxin: Phase 4, open-label, randomized, noninferiority study. Clin Park Relat Disord. 2022 Mar 14;6:100142.

Some patients with cervical dystonia who are responsive to treatment and receive botulinum toxin injections at standard treatment intervals (12 weeks) report a waning or reduction of clinical effect and reemergence of symptoms before their next injection.

The authors of this study aimed to evaluate whether patients experienced benefit from shorter injection intervals and whether there were any side effects caused by shorter re-injection intervals. Patients were divided into two groups; the first group were reinjected at intervals of <10 weeks (short intervals) and the second group were re-injected at the standard 12 week interval (long intervals). Patients were followed for 8 injection cycles. Improvements in dystonia severity, activities of daily life and pain were shown in both group of patients. Patient satisfaction with treatment improved over time in the short treatment interval. This was not shown in the long interval group. There were no new or unexpected safety findings with either treatment interval, and the number of participants with side effects was similar in both groups.

This study shows that patients living with cervical dystonia who experience early waning or “wearing off” of botulinum toxin effect can benefit from shorter injection cycles of incobotulinumtoxinA without increased risk and illustrates the advantages of adapting botulinum toxin treatment schedules to meet individual patient needs.

Chueluecha C and Moore AP. LIVECHART Patient-Reported Outcome Tool for Botulinum Toxin Treatment in Cervical Dystonia. Mov Disord Clin Pract. 2022 Jan 19;9(2):198-205.

The Liverpool botulinum toxin effects chart (LIVECHART) is a short questionnaire for patients which has been used for over 25 years in the botulinum toxin injection clinic at the Walton Centre in Liverpool. The LIVECHART allows patients to monitor how well their treatment is working between injections and to rate how well the treatment is working overall. This scale has not been formally tested so that it can be used in clinical trials. The aim of this study was to understand how well the LIVECHART captures the self reported effects of botulinum toxin treatment for patients with cervical dystonia.

The authors concluded that the LIVECHART adequately reflects the depth of treatment benefit, duration and overall benefit of botulinum toxin treatment, and is worth further formal evaluation to determine its validity and reliability.

On the following pages 9- 11, the articles 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.

INNOVATION IN DYSTONIA TREATMENT

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 **150,000 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 patients³

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 symptoms⁴



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:

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

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

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.

* 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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The new Boston Scientific Visualisation Software: Helping to Provide Personalised Deep Brain Stimulation Treatment for Dystonia Patients

For patients living with dystonia, deep brain stimulation (DBS) is an established, safe and effective treatment option.¹

DBS is a surgical procedure during which two thin electrodes are inserted into the brain and connected to a stimulator via an extension in the chest or abdomen.² The treatment works by delivering targeted electrical pulses to the brain, blocking the signals that cause involuntary muscle contractions in patients with dystonia and easing symptoms, such as tremor and pain.²

Over the 35 years since DBS was first developed, 3 considerable improvements have been made to enhance the technology. In the early days, clinicians did not have a lot of information to work with during the programming – relying on a ‘trial and error’ basis when placing the electrodes. In more recent years, as the progress of this treatment has continually improved, one ground-breaking development has been the introduction of visualisation software, such as the new Stimview-XT from Boston Scientific, which allows neurosurgeons to ‘see’ electrode placement in relation to a patient’s specific brain anatomy.

Armed with the knowledge of how certain lead placement and contact decisions will impact the patient’s symptoms, it is now possible to achieve a level of precision never experienced before, greatly factoring into the ongoing improvement of personalised treatments for each individual patient. Professor Volker A Coenen, University Medical Center Freiburg, who has been instrumental in the development of advanced imaging for more than 10 years, explains the significance of the software: “Visualisation software helps to join the dots in DBS. It is being utilised during the implant surgery to optimise placement and programming and help deliver the best outcomes for the patients.”



Bridging the communication gap with an image

With the visualisation tool available, diverse clinical teams – who don’t often have the chance to collaborate – can achieve better planning, programming and patient care because they are aligned – literally seeing the same results: something medical teams have long been striving for. “We’ve been wanting to go in this direction for over 20 years. It is a dream come true,” explains Prof Coenen. Creating the 3D reconstruction of the patient’s brain anatomy is a complex process, which is made simple and clear on a screen for every team member to access, enabling them to fine-tune and personalise DBS for dystonia patients.

Not only can this software potentially improve the accuracy and outcomes of DBS, it is also enabling a more streamlined workflow between these clinical teams. Prof Coenen adds: “Visualisation is starting to be much easier. The neurologist can come to me with a USB stick and then I can do the simulation.” As the software becomes more straightforward to use, it is hoped that even more patients may benefit.

While visualisation software is primarily used to place electrodes correctly, it can also be used for post-operative review of DBS, where teams can again use imagery to speak the same language as they explore potential improvements. Prof Coenen discusses: “We always look at the post-operative position of our electrodes, in every case. We have cases where we could improve the situation for the patient by utilising the possibilities that visualisation software presents.”

Seeing is believing

While one of the main benefits of the software is that it allows teams, such as Prof Coenen's, to offer a more personalised and accurate therapy, some patients can still feel daunted by the prospect of DBS. In Prof Coenen's experience however, the benefits significantly outweigh any initial doubts or concerns: "The feeling of being scared wears off when they realise the benefits to them. It is a question of accommodating to the situation, then there is no reservation."

For patients to best understand the process, "seeing is believing" says Prof Coenen, adding: "I can show the patient 'this is your head and these are the electrodes and this is how I can move them around.' They understand. Then I programme it and if it's better they say: 'oh wow, that's what the electrodes do.' We've always worked this way because patients appreciate being shown things on screen... some patients ask to see a photo of what is being done and this helps make it more real for them. They can comprehend what is happening," adds Prof Coenen.

DBS is not an experiment

Summarising his discussion on DBS and visualisation software, Prof Coenen believes that patients should be as informed as possible, so that they can benefit from DBS conducted using visualisation software. His advice to patients: "Don't feel that DBS is an experiment. It is going to help you; most patients are really helped by DBS. Go to an expert, have a consultation and ask questions so that you can understand if this might be the therapy you need. In dystonia, I have seen so many wonderful things happen for patients."

Visualisation software is a long-awaited game changer for neurosurgeons performing DBS, helping them to achieve a level of precision that was once unattainable. It has created a common language amongst clinical teams, ensuring everyone is striving for the same result. As a patient with dystonia, you can feel confident that your clinical team is using first-class technology to fine-tune and personalise your DBS, with the ultimate aim of improving your quality of life. The software is designed to ensure that everyone is on the same journey, understanding the process together and treating with precision.



Prof Volker A Coenen

References

1. Ortiz, R.M., Scheperjans, F. & Pekkonen, E. Deep brain stimulation for dystonia in Finland during 2007–2016. BMC Neurol. 2019;19:137.
2. Dystonia UK. Deep brain stimulation. 2019. Accessed online on 24 March 2022. Accessed at: <https://www.dystonia.org.uk/deep-brain-stimulation>
3. Gardner J. A history of deep brain stimulation: Technological innovation and the role of clinical assessment tools. Soc Stud Sci. 2013;43(5):707-728.

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Dr Alan Scott – Death of the Inventor of Botulinum Toxin Therapy

A pioneer in medical science, whose invention helps millions of people every day, has died, at the age of 89. Dystonia Europe gratefully acknowledges the enormous benefit Dr Scott's work has given to many dystonia patients and to people living with other illnesses.



Dr Alan Scott with Monika Benson and Merete Avery 2019

Prof Dirk Dressler, in Hannover, has known Dr Scott for many years, and he has provided the following obituary:

Dr Alan Brown Scott †

On December 16th 2021, Dr Alan Brown Scott died in his 90th year of age. He is the inventor of the botulinumtoxin therapy, a novel therapy dramatically changing the fate of so many patients in various medical specialties and - besides - generating an industry with annual sales in excess of 6 billion US-Dollars. Scott was not frightened by the apparent absurdity of the idea to use the deadliest poison on earth to treat patients. With this, Scott became a shining example of creativity, encouragement, persistence and pragmatism at its best. In brief: Scott was one of those researching physicians who shaped our modern medicine in the 20th century, but who have become rare in times of governmental research programs with all their obvious shortcomings. Clearly a man of the scientific anti-establishment, he never received a Nobel Prize, although he had met its requirements like nobody else.

I first met Alan at the beginning of the 1990s through a mutual friend, Peter Roggenkämper who brought

botulinumtoxin therapy to German ophthalmology. We stayed in touch ever since. He closely followed the development of our botulinumtoxin centre in Hannover. Our new botulinumtoxin centre in Shanghai we will have to develop without him. His last major public appearance was at our International Congress on Treatment of Dystonia in Hannover in spring 2019 where he, together with Eric A Johnson, gave the keynote lecture on the development of botulinum toxin therapy: one as the inventor of the idea, the other as the tamer of the toxicity. Fortunately, this lecture was recorded by IAB - Interdisciplinary Working Group for Movement Disorders. It is now a historical document.

Dr Scott was born July 13th 1932 and finished medicine at the University of California San Francisco. After residencies in neurosurgery and ophthalmology, he joined the famous Smith-Kettlewell Eye Research Institute in San Francisco. During his affiliation from 1961 to 2013 he gained a worldwide reputation as a strabismus expert. In the early 1970s he pursued the idea to correct strabismus by chemical interventions in the external eye muscles to avoid operations in these mostly paediatric patients. Extensively searching suitable substances he came across Daniel B Drachman's previous observations on botulinumtoxin, which he tried with a preparation exclusively provided for him by Edward J Schantz and Eric A Johnson at the University of Wisconsin. It was soon clear, that botulinumtoxin produces a robust and lasting paresis without systemic adverse effects and without structural damage to the target tissue. By the end of the 1970s first strabismus patients were treated and in 1989 Scott's botulinumtoxin preparation was formally registered by the US Food and Drug Administration as a drug under the trade name of Oculinum®. In 1991 Scott's Oculinum Company, founded for this purpose, was acquired by Allergan, a large Californian manufacturer of eye care products and the product name was changed to Botox®, which now has become a pseudo-generic name for pharmaceutical botulinumtoxin.

Scott immediately realised, that botulinumtoxin may also be used in other conditions in which reduction of muscle activity is required. One of those conditions are dystonias occurring in ophthalmology as blepharospasm. Here, botulinumtoxin therapy was instrumental in the development of C David Marsden's and Stanley Fahn's then emerging dystonia concept. Without its potential to offer effective treatment for those patients, the real dimensions of this condition would never have been become apparent. Soon after, additional muscle hyperactivity disorders were treated including hemifacial spasm, spasticity, infantile cerebral palsy, tics and tremor, but also gastrointestinal and bladder disorders. Currently, this indication area includes at least 26 conditions in six medical specialties.

The use of botulinumtoxin in aesthetic medicine, now dominating its public perception, is also based on this muscle relaxing effect. Early on, when treating blepharospasm, we noticed, that muscular wrinkles in the forehead and around the eyes may disappear 'miraculously'. Using this effect in some of our associates only, we would never have dreamt that these 'beauty treatments' would become the most frequently applied procedure in aesthetic medicine.

Realising that botulinumtoxin can also modulate the innervation of exocrine glands, treatment of sweating and drooling became an option. A few years later, botulinumtoxin received a drug registration for treatment of migraine, thus opening up a totally new field of pain indications. Recently, even a use in depression has been explored. Theoretic research now aims at using fragments of the botulinumtoxin molecule with their specific functions to design hybrid drugs with novel effects.

With all of this, botulinumtoxin has become the drug with the largest number of indications in the largest number of medical specialties leading Time Magazine to portrait botulinum toxin as a kind of Swiss army knife. And the story carries on...

Reprint with kind permission from:

IAB - Interdisciplinary Working Group for Movement Disorders

<https://iabnetz.de/news/dr-alan-brown-scott-%e2%80%a0/>

See IAB video on this topic:

In Memoriam Dr. Alan B. Scott

https://youtu.be/advWbMGKa_0

Univ.-Prof. Prof.hon. Dr.med. Dr.h.c. Dirk Dressler

Leiter Bereich Bewegungsstörungen

Klinik für Neurologie

Medizinische Hochschule Hannover

Carl-Neuberg-Str. 1

D-30625 Hannover

Alan B Scott †, Eric A Johnson, Dirk Dressler (from left to right)



Winter Think Tank 2022

Dystonia Europe Winter Think Tank 2022 was held on Zoom last February. DE had a Board Meeting the day before. Members of the Think Tank are our Platinum sponsors: Boston Scientific, Ipsen, Medtronic and Merz.

President Adam Kalinowski welcomed all to the Think Tank meeting and Executive Director Monika Benson gave an update on the activities that DE has been involved during the last year.

Each year Dystonia Europe is involved in Dystonia Awareness Month in September. There was limited travels in 2021 as there was in 2020, but there was still much activity online, through various platforms as Zoom and Skype and others. You can read more about this and other activities during 2021 in our Newsletters, published 3 times a year, <https://dystonia-europe.org/media/newsletter/>.

An update was presented on how DE is moving forward on social media. The amount of people reached on Facebook, Instagram, YouTube and other channels keep growing each year. We are very pleased to see how engagements, shares and likes increase continuously. This helps spread information on dystonia.

Part of the TT meeting was dedicated to plan and discuss the upcoming Dystonia Awareness Month (DAM) in September 2022. For awareness this year, we plan to produce short video clips, that will focus on various forms of dystonia. Dystonia is often hard to recognize as it presents itself in many different ways. As an example of an older video clip showing Cervical Dystonia (Neck Dystonia) you can follow this link, <https://dystonia-europe.org/media/videos/seeing-is-believing/>

These short videos will be with minimal text if any. Without text the videos do not need translations and can be understood by all regardless of language.

We plan to hold the Summer Think Tank Meeting in September in Lund, Sweden.

Merete Avery
Operations Manager
Dystonia Europe

Dystonia Europe Digital Resources

In 2020 Dystonia Europe launched several new digital activities. The pandemic made it impossible to travel to any meetings for over 2 years. Therefore we had to look at new ways of working. All board meetings were held on Zoom and we had to change the way we work and move all our activities on-line.

Now we are very proud of all the valuable resources that were created.

• **The Positive Twist** – a Podcast about dystonia. There are so far seven episodes with dystonia patients and medical experts, and you find them here: <https://dystoniaeurope.buzzsprout.com/1337749>

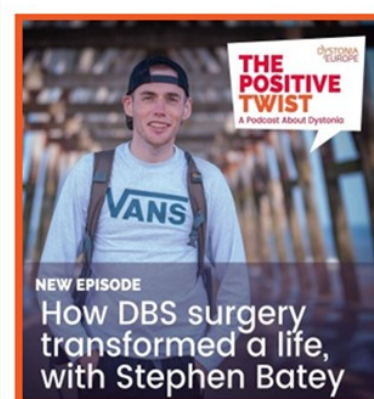
New episodes are being planned and launch is planned for early autumn 2022.

• **Dystonia Webinars** – ten webinars were produced in the last 18 months including dystonia experts and various topics. These are all available on the Dystonia Europe YouTube Channel:

https://www.youtube.com/playlist?list=PLFvCc6fYkjEt_7GhGF9OwEELXo2iBeVRk

Our social media channels continue to develop and grow and here you will always find the latest updates and news from us. Make sure to follow us!

Monika Benson
Executive Director
Dystonia Europe



A list of some of our webinars.

Follow the link in the article to view these and more.

Dystonia Physio Exercise Hub Project

The first team meeting for the international launch of the Dystonia Physio Exercise Hub took place at the end of March. Physiotherapist Johanna Blom from the University Hospital of Skåne in Malmö, Sweden is initiator and owner of the project. After a successful launch of the exercise platform in Sweden last November, it was time to proceed with the next step. The Boston Scientific Foundation granted funding for the second year of the two-year project including the international launch.

The following physiotherapists join Johanna in the international team meeting: Jean-Pierre Bleton from France, Heike Unger from Germany and Martine Pereira from the UK.

The platform was very well received in Sweden. About 50 physiotherapists in Sweden have registered on the platform and started to use it in order to create individual exercise programs for their cervical dystonia patients. Patients using the exercise tool are also very satisfied.

In this second year of the project the goal is for the exercises to be animated and for five new languages to be added to the platform.

More information: <https://dystonia-europe.org/2021/12/dystonia-physio-exercise-hub-a-digital-platform-with-exercises-for-cervical-dystonia/>

Monika Benson
Executive Director
Dystonia Europe



Project leader and platform creator is physiotherapist Johanna Blom at Malmö University Hospital in Malmö, Sweden, bottom right corner.

Members of this group are:

Physiotherapist Jean-Pierre Bleton from France (bottom row in the middle)

Heike Unger from Germany (top row left corner)

Martine Pereira from the UK (bottom row left corner)

Monika Benson, Dystonia Europe (top row in the middle)

IT expert Eelco Uyterhoeven (top row right corner)





AMADYS, France: Workshop on Focal Dystonia: Treatment and Rehabilitation

Since 2018, we have been organising training sessions on the rehabilitation of cervical dystonia and function (writer's cramp) given by Dr. Jean-Pierre Bleton, in the regions, in person, by communicating with local medical professionals and their federations or health care institutions.

We wanted to organise a session for the Paris area and Dr. Bleton had the idea of a new teaching formula, i.e., a live demonstration of a multidisciplinary consultation between neurologists and physiotherapists.

We decided on a giant training session, in person and by videoconference, both in French and English and reserved for medical professionals.



The technique, overview of the equipment

We used the services of Invivox, a medical e-learning company, which was responsible for the organisation, communication and management of registrations, Unik Production for the image and sound technology, and Global Interpreting for the instantaneous translation from French into English. These technical costs were covered by the sponsorship of Ipsen Pharma France. I congratulate the professionalism of these providers.

Medical professionals from all over France and Europe were able to follow the afternoon by videoconference and interact with the speakers. We had 180 registrations for the Visio and 30 lucky participants in the conference room, limited by the "white plan" in hospitals the day before, because of the 5th wave. Many more registered to access the recording later.

Indeed, a "replay" will be available for one year on the Invivox Internet platform, and permanently on the AMADYS Internet site, professional access. Thus, any specialist interested in perfecting the management of cervical dystonia and function, will be able to view this training without waiting for a future organisation.

The video in English will also be made available to Dystonia Europe for English speaking specialists.

This operation represents a precious support among our tools, which will be able to preserve the demonstration of the "Bleton method" and of a multidisciplinary consultation.

In the morning, we set up in the conference room of the Foundation Adolphe de Rothschild hospital, Paris, which I would like to thank for agreeing to host this training.

The equipment deployed by the technicians was impressive: numerous cases, a long table of consoles, screens, wires everywhere, cameras, projectors... connection tests, too, with the translators connected to the Visio in Zoom. On the spot, we set up the chairs, the position of the speakers, reviewed our script and our organisation.



Study of a cramp case by ultrasound

A quick lunch tray and the show was about to start. I jumped up to the lectern just before the countdown of the technicians (very intimidating, we are not actors) and 10/9/8.... 3/2/1, hand signal, go! The live session and recording were on!

The afternoon was divided into three successive groups: two on cervical dystonia with three patients each, one with two patients on writer's cramp, after an introduction by me for a presentation of AMADYS and Dystonia Europe, and then by Dr. Christophe Vial.

Questions from the professional audience were addressed at the end of each group.

The speakers exchanged on the different forms of cervical dystonia and their therapeutic proposals. They used the ultrasound to show the muscles involved and Jean-Pierre Bleton demonstrated after explanations and rehabilitation exercises.

The 'crampers' were set up at the edge of a table to allow for writing tests. The cameramen took close-ups, while the speakers were equipped with tie mics behind their surgical masks.



The speakers' team from left to right: Dr Vial, E. Ponseel, Dr Karsenti, Dr Sangla, Dr Trocello, J.P. Bleton, Dr Goetz

During this interlude, a beautiful video was projected for the participants in Visio, representing a mix of the actions and colours of AMADYS and Dystonia Europe.

We ended the day outside the hospital, among speakers and supporters, for a welcome aperitif. We were joined by Dr Célia Rech, member of our Scientific Committee, and Vincent d'Hardemare, neurosurgeon, Breughel laureate (Amadys Research Award).

We were happy and satisfied with our work. The transfer of knowledge between specialists is essential for the good care of patients, and this action echoes the purpose of our organization's statutes.

AMADYS and the members or sympathizers of its Scientific Committee can be proud of this friendly collaboration and of such a production, in the interest of the patients.

We hope to be able to organise other actions of this type in the future for other forms of dystonia.

We would like to thank Ipsen Pharma for having made this event possible and for supporting the cause of dystonia, AMADYS and its actions.

It was interesting to understand, for example, that in the case of cervical dystonia, rehabilitation complements botulinum toxin injections, but for writer's cramp, it is rehabilitation that points out the abnormalities and injections that supplement them, to help better recovery through exercise. Sitting at a table, Dr. Vial took down the questions of the participants in Visio and passed the microphone around the room. While I kept an eye on the timer, we had planned for 20 minutes per patient, and I handed out countdown signs to the speakers so that they could adjust their speech.

We had a well-deserved 20-minute break between the cervical dystonia and writer's cramp groups. It was a long afternoon of recording for the speakers, staying focused on both the patients and the technique as everything went on.



Introduction by Edwige Ponseel, President AMADYS and Vice President Dystonia Europe

PS: for confidentiality and respect of the volunteers' patients, AMADYS and Dystonia Europe will not broadcast their image. The replay and the training will only be accessible to medical professionals.

Webinar Drugs and Dystonia



MD PhD. Inger Marie Skogseid

Senior Consultant Neurologist and Researcher
Oslo University Hospital

Photo by The Information Department at University Hospital

On February 22nd we hosted our 10th webinar in our webinar series. There were nearly 60 participants who followed the webinar on zoom, and sent live on Facebook.

Inger Marie gave us an introduction to dystonia as a symptom and to dystonic disorders (the dystonias). She also presented oral drugs that are used for treatment in dystonia and drugs that can cause dystonia.

Inger Marie stressed that «the dystonias» (the many disorders in which dystonia is an important clinical feature), is a diverse family of disorders with an enormous span of both the body distribution and severity.

Also we learned that the causes of dystonia are diverse and more than 100 causes are known. Still in most patients the cause is unknown.

At the end of the webinar, which lasted about an hour and half, many of the questions that participants asked through chat and Facebook were answered.

Merete Avery
Operations Manager
Dystonia Europe

Dystonia Videos

We are excited to announce that we are working on the new Dystonia Awareness Videos project.

Many years ago, Dystonia Europe published a short film "Seeing is Believing". This video shows the symptoms of dystonia with a bit of humour. We know that this video is liked by many. You can watch it on our website:

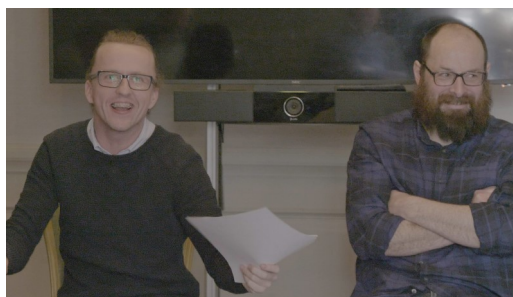
<https://dystonia-europe.org/media/videos/seeing-is-believing/>

We know that our body language is often misunderstood. The aim of this project is to show the symptoms of different types of dystonia for better understanding by people who have never heard of this disorder. We believe that by adding a 'funny twist' to the videos we make them more likely to be shared, and increase the spreading of awareness. There will be also no dialogues in the films, so the message will be understood regardless of the viewer's language.

We started by collecting the real stories from the dystonia community. In cooperation with a professional director, hours of consultations with Dystonia Europe, and a meeting with a group of patients, 5 film scripts were created. Professional film production began in May in Ireland and the main roles were played by real patients.

The films will premiere this summer on Dystonia Europe's channels. We believe this campaign will be very powerful for dystonia awareness.

We want to thank Dystonia Ireland for tremendous support on this project.

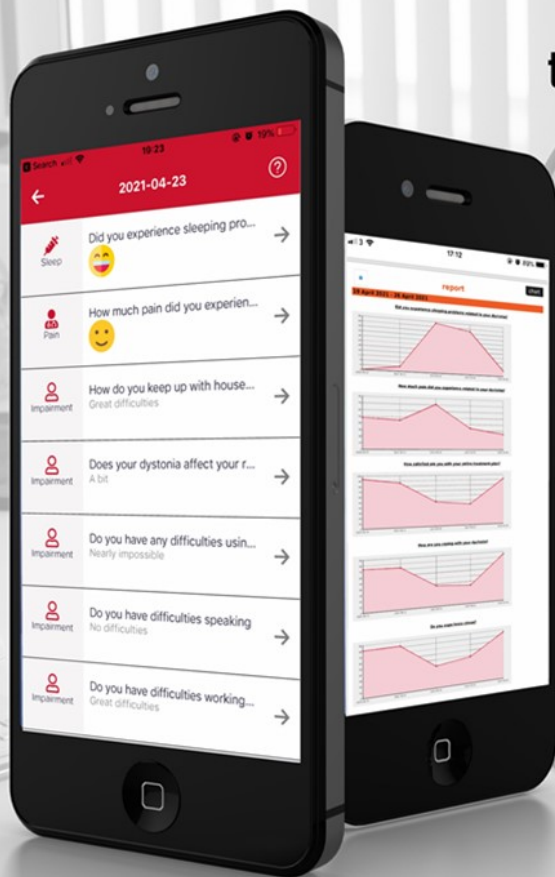


Adam Kalinowski
DE president
Andrew Keogh
Film director

Maria Hickey
Dystonia Ireland
Chairperson



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



NEW VERSION!

**DYSTONIA
EUROPE**

New, improved MyDystonia app!

We are happy to announce that the new version of the application for dystonia patients and physicians is now available!

After many years of experience, feedback from users and experts, we have created the new MyDystonia, which is very different from the previous one.

MyDystonia is an electronic diary created for people with dystonia. The App was developed with the collaboration of dystonia patients and a group of medical experts. This electronic diary enables patients to monitor their symptoms and how those symptoms affect daily life. You can monitor your dystonia by answering a series of predefined questions (e.g. core symptoms like overactive muscles or pain; impact on daily living) – wherever and whenever you like.

With MyDystonia you create an accurate picture of your disease and treatment outcome over time. Now you can share insights with your doctor to discuss how to optimize your treatment approach. Reports created using MyDystonia can be printed or shared electronically.

Benefit immediately from MyDystonia and create your own account. Download for free from the Apple App Store or Google Play.

The new version is available in English only , but we will be working on adding more languages in the future.



Finnish Dystonia Association Spring Meeting in Wintery Joensuu

After two years with restrictions to assemble due to COVID-19 pandemic, The Finnish Dystonia Association decided to set a nation-wide presence as a theme. Normally, we arrange our association meetings in the densely populated areas in southern or south-western Finland. This time we chose to meet in Joensuu which is the capital of Karelian province close to the Russian border. The weather appeared to be rather wintery even if it was the last weekend of March. When one travels some 600 km, it is easy to notice how large a country Finland really is. The weather conditions in the southwestern part of the country appeared very much like spring at the time.

The northern and eastern parts of Finland are often regarded as rather distant and sparsely populated. However, The Finnish Dystonia Association have active peer support groups. It was an honor and a delight to meet our members in Eastern Finland. It's useful to learn the challenges confronted in areas where the demographic structure differs from the one you normally operate. Some creativity is often required, and the options are sometimes scarce. After all, the everyday life is quite similar all over the country.

How to get volunteers to organize peer groups? Is it possible to share the burden of running the peer group? Where are all the young people suffering from dystonia? Issues around the treatment of dystonia are a topic anywhere.

People from the left: Board members Martti Ketonen and Leea Sihvo-Rajala, local volunteers Paula Hiltunen and Tuula Hirvonen (in front), board member Paula Happonen, and president Jukka Sillanpää, secretary Taina Lehtinen, and local volunteers Jaana Vainio and Aarno Komu.

Photo: Tytti Svetloff, Finnish Parkinson's Association

The hotel in Joensuu provided us with good facilities to conduct the spring meeting of the association. It was possible to follow the meeting via remote connections, as well. After the meeting, we had an opportunity to learn about the subject: dance as a part of neurologic rehabilitation. The most observations were made in relation to Parkinson's disease but are applicable to other movement disorders as well. Dance has several positive effects on the body and mind.

Our autumn meeting and the Dystonia Days will take place in Oulu in northern Finland in September. We are really looking forward to meeting our members there. The program will be interesting and arrangements splendid, as always.

Jukka Sillanpää

Board Member Dystonia Europe
and President Finnish Dystonia Association



Winter at meeting in Finland

Children's Joy Rare Disease Day



Rare Diseases Day was observed in Timisoara, Romania during the art exhibition's 4th edition "Look at me from the inside" which is a continuation of the exhibition's 3rd edition "Captive in my body".

This art exhibition reflects rare diseases including some forms of dystonia.

The purpose of this exhibition is to draw attention to the public in an artistic, subtle way to the rare diseases that are estimated at between 6,000 and 8,000 variations. Over 95% of these rare diseases have no treatment anywhere in the world: 75% affect children and over 80% have a genetic background.

Viewed by society as a rather phenomenon, it is estimated that approximately one million of the population in Romania are living with a rare disease and strive to manage various diagnoses. Many patients and their families that are affected by rare disease live with feelings of insecurity and find it difficult to cope with

the stigma while at the same time strive to fight for treatments to improve quality of life on both physical, emotional, material, and social levels.

Ms. Catalina Crainic, organizer of the exhibition, President of the "Children's Joy" Association, and patient suffering from cervical dystonia, stated: «Through the art exhibition look at me from the inside», we want to convey that everything that we contain in our inner universe, we manifest in the outside world, as a look in the mirror, either constructively or destructively influencing human life, both ours and those around us. So, we want to fill this inner world with color, joy and positive feelings, peace, acceptance, gratitude, to generate and share from within to society what we must give, because only by giving can we receive in return.

During this campaign, talented 11th grade students from the High School of Fine Arts Timisoara made the joint work entitled "Free Spirit". Artists also donated to the association in the works of a past exhibition edition "Captive in my body". Students of the creative workshop "Childrens Joy" contributed through creative workshops that were held to help raise funds for the association under voluntary coordination by Ms. Catalina Crainic.

Although most rare diseases put the affected person in the position of being "a person with a disability", the "Childrens Joy" Association from Timisoara wants to convey that people facing a disability can maintain their moral values, can seek evolution and their own knowledge, development, add spiritual enrichment to keep these values, the society is a richer one.

The association of People with Dystonia "Children's Joy" based in Timisoara, regularly organizes creative workshops with healthy children to help support monthly expenses, and awareness campaigns for people in vulnerable categories. Fundraising through workshops helps patients with dystonia fight against discrimination and labeling, but also stand for patients' rights through approaches to the authorities and by connections with patients about equal opportunities.

The exhibition edition "Look at me from the inside" takes place at the Banat Museum, Therezia Bastion and is open for a 2-week period starting on February 28th when the Rare Diseases Day is being held. After completion, artwork will be available for sale and the funds will be directed to the association to organize workshops for patients with dystonia in Romania.

Catalina Crainic

President Asociatia Children's Joy
and Board Member Dystonia Europe





Meet Jan from England: My Journey with Dystonia

I first noticed a problem with my neck, seventeen years ago at the age of 43. The main difficulty was trying to turn my neck especially when crossing a road. The situation worsened very quickly in that my neck was turning to the right. At the time I was working as a financial adviser and I noticed that when talking to clients that my neck was turning and making it difficult to do my job on a daily basis.

My first thought was to make an appointment with my doctor. I did mention to her that my Mum and various other members of my family had what had been diagnosed as a 'Familial Tremor'. At first, she dismissed this and thought I had maybe pulled a muscle. Not having any luck with my own doctor, I then made an appointment with a local chiropractor, who asked me to make appointments with him twice a week until it was sorted out. After about a month he then said that he thought it might be a problem with my jaw, at which point I lost faith in him as I knew that was not the problem.

Realising that I had an ongoing problem and I was getting very frustrated, my father recommended that I made an appointment with a physiotherapist at the local Nuffield Hospital. At the appointment I again mentioned the problem that my Mum and various members of my family were having.

Well into the appointment, the physiotherapist recommended that I make another appointment with my GP and ask for a referral to the Royal Victoria Hospital, (RVI) Neurology department.

Eventually I received my referral to the RVI and the consultant immediately diagnosed me with Cervical Dystonia, also called Spasmodic Torticollis which is a painful condition in which neck muscles contract involuntarily, causing the neck to twist or turn to one side, which in turn causes involuntary movements and neck spasms. He said he would refer me to a neurologist at Hunters Moor Hospital (now Walkergate Park) and they would give me botulinumtoxin (Botox) in my neck which may help with the spasms and the twisting.

Whilst a bit of a "roller-coaster", with good days and bad days, Botox did help to a certain degree for a number of years. However, within the last three years the effectiveness of the Botox started to reduce and my symptoms worsened, I was also in a lot more pain. The doctor suggested that she did a test to see if my body was building up antibodies to the toxin which can happen when injections are given over a number of years and the results showed that this was the case. It was suggested that I should have a period without Botox injections and this went on for a very difficult year. The next stage was to try different toxins but although this did help symptoms slightly, there was no significant change and the spasms worsened and I was in a lot of pain.

Within my Dystonia group a number of friends have had the Deep Brain Stimulation (DBS) operation. This is a neurosurgical procedure involving the placement of a medical device called a Neurostimulator which sends electrical impulses through electrodes placed to specific targets deep into the brain. Connected to a relatively small, long-life, rechargeable battery placed under the skin in the chest, the low-level electrical impulses interfere/block the random impulses caused by Dystonia and reduce/stop the involuntary movement disorders. I discussed this operation with the doctor at Walkergate Park and decided that I had nothing to lose in looking further into this operation and she referred me to the RVI to see if I would be a suitable candidate.

Unfortunately, my first appointment with the Neurosurgeon had to be a telephone appointment as we were in the throes of the first lockdown due to covid 19. As I described my symptoms and the impact they had on everyday activities she definitely thought the operation would help me.

My next appointment was a face-to-face meeting with a specialist nurse who was extremely thorough, he too thought that the operation would make a big difference. The operation does not cure the disease but should hopefully help with my tremor, turning of my neck and the spasms.

I decided to proceed with the operation and had a face-to-face appointment with the neurosurgeon around Christmas time 2020. Unfortunately, she told me that operations were being delayed due to Covid and the strain of the virus on the hospital as a whole, however she hoped I would be operated on before the end of Summer 2021.

Then the good news arrived, the specialist nurse rang me in May 2021 from the RVI to say that they were able to go ahead with my operation in 10 days' time, I was so grateful and the short period of time gave me very little time to think about it or get too anxious.

All went well with the operation – I went in at 7.30 am and was home by early afternoon the next day. In order to first recover from the operation, the device was not switched on for the first few weeks.

At my first post operation appointment with the specialist nurse, he switched the device on and set it up so that I could increase the stimulator myself to a certain degree. In the first few weeks I saw very little difference and then all of a sudden, I got to a point where the stimulator was set at a level where the difference was dramatic.

Suddenly I was able to turn my head from left to right, walk without holding my head and even the pain has disappeared. I really feel as though I have been reborn and given a second chance to enjoy life. In fact my husband would go as far as saying that the operation has been like a 'magic wand'. The relatively small cuts on my scalp healed remarkably quickly and the speed in which my hair grew back was amazing. The battery in my chest is not noticeable under my clothes and after seven months the scar is fading fast.

I am so grateful to the neurosurgeon and specialist nurse who have really performed a miracle.

Jan, Newcastle upon Tyne, England





Martina Kühn

Meet Martina Kühn, Chairwoman Dystonie Förderverein Deutschland e. V. Germany

What is your name?

My name is Martina Kühn

What are the benefits of working within a patient organisation?

My mother has blepharospasm among other issues. Even though I do not have dystonia myself, I've come to realize over time how difficult living with dystonia can be in certain situations. More than 14 years ago I started volunteering in dystonia self-help. Due to various inquiries that I received as part of my board work, some colleagues and I founded the Dystonie Förderverein Deutschland e. V. (DFVD) in 2014. In the DFVD we have special possibilities to help dystonia sufferers directly. In contrast to other organizations, we can for example offer financial help to provide treatments or individual aids. It is very satisfying to help other people and to experience that through our support, others are doing a little better making their lives a little easier.

How do you like spending your free time?

I enjoy spending time with my family and friends. In addition, my hobbies such as knitting, crocheting, and sewing relax me. Our dog Vicky is also very important. In the evenings, I like to read before going to bed.

What keeps you motivated on the tough days?

A butterfly, a daisy, a kiss from my dog or a ray of sunshine. A small smile when I could help someone is often enough to say thank you. Knowing that even the small things can help others. It's not just the big things that can help. It is irrelevant whether the help is provided on a voluntary basis or in everyday life.

What makes you angry or frustrated?

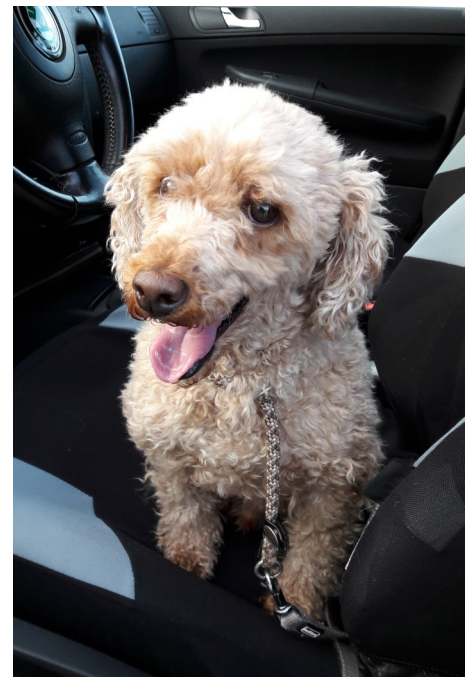
Carelessness, disrespect, egoism, intolerance, stupidity, ignorance, narcissism....

Martina Kühn

Chairwomen Dystonie Förderverein Deutschland e. V.
Germany



Martina's dog



Members

Dystonia Europe consists of 22 national member groups from 19 European countries and they are:

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

Medical & Scientific Advisory Board

Prof Alberto Albanese – Milan

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Prof Kailash Bhatia – London

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Prof Marina de Koning-Tijssen – Groningen

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Prof Maja Relja – Zagreb

Prof Marie Vidailhet – Paris

Prof Marjan Jahanshahi – London

**Connecting
People
for Dystonia**

Staff



Monika Benson

Board Member
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.



Adam Kalinowski
President

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 Polish but he lives in Ireland where he studies graphic design. Adam was re-elected to the Dystonia Europe board in 2019 and 2021. Now he is the President of Dystonia Europe.



Edwige Ponseel
Vice President

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 for a 3rd period in 2021, she is now the Vice President of Dystonia Europe.



Gill Ainsley
Secretary

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 re-elected in 2021. She is the Secretary of Dystonia Europe.



Catalina Crainic
Board Member

Catalina Mariana Crainic is the President of the Romanian Dystonia Organisation, Asociata 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 and re-elected in 2021.



Jukka Sillanpää
Board Member

Jukka has been the President of the Finnish Dystonia Association since 2018. The main targets of the association are to provide the members with support and to increase dystonia awareness among the healthcare professionals in Finland. Jukka has also been a Board Member of the Finnish Parkinson Association since 2020. Jukka has a university degree in accounting and finance. He has much experience in management and financial accounting as well as business planning in his working life. He has a lot of experience in different roles in many associations. Jukka has Cervical Dystonia. Jukka was elected to the Dystonia Europe board in 2021. .



Sissel Buskerud
Treasurer

Sissel is the Vice President 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.



**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.

**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**

IT 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.



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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.

Donation and 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.

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/>

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