

DYSTONIA

NEWS

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DYSTONIA
EUROPE



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**Connecting people to
spread information
raise awareness
promote research**



Adam Kalinowski
Dystonia Europe
President



Dear all,
Welcome to the first issue of our newsletter in 2021. We are pleased to present you the brand new design of DE News! After many years of publishing, we decided to refresh the design and we hope you like this 'new look'. However, design is not the most important, but the content of our publications.

You can read here articles about the events and latest research projects from our member organizations and partners as well as inspiring stories of people living with dystonia.

As always, you can also find information about Dystonia Europe's activities and our new projects. We are especially proud to soon announce the launch of the new version of the application for patients and specialists MyDystonia, and the new project 'Dystonia Physio Exercise Hub'. But also other projects such as our webinar series, podcast and much more.

Such projects are a big undertaking and would not be possible without the support of our advisers, partners, members and sponsors. That's why we want to thank them all for their great support. Thanks to this cooperation and the hard work of the Dystonia Europe team we can realize great initiatives that can really help people with dystonia in Europe and beyond.

I have been working for DE for four years and I see a significant development of our organization over this time despite the difficulties for all of us. During this pandemic we have had to overcome future financial uncertainty and adapt to the new reality while still helping the dystonia community.

We think we did very well and learned a lot! But we also miss face-to-face interactions with our dystonia family. We believe that the worst is behind us and we will be able to gradually return to normal life. I wish you all this return to normality!

New Project: Dystonia Physio Exercise Hub

Behind this new project is physiotherapist Johanna Blom, at the Neurology Department of the University Hospital of Skåne in Malmö, Sweden.

For the last few years Johanna was involved in holding educational workshops for physiotherapists mainly across Scandinavia. But due to the pandemic she was not able to travel and all the workshops that had been planned were cancelled. However physiotherapists continued to contact her to get advice and support when creating exercise programs for their dystonia patients. To facilitate this process Johanna came up with the idea to create an on-line platform with a selection of about 100 exercises, especially developed for cervical dystonia patients.

Together with Eelco Uytterhoeven, Dystonia Europe IT expert, Johanna wrote a detailed project description and plan which was submitted to the Boston Scientific Foundation Europe.

On April 14 the Foundation approved the application and when Johanna was informed that the project will receive funding she said: "This is such great news, to see my idea become reality. I think this exercise hub will be a helpful tool for all the physiotherapists, but mainly and most importantly it will benefit dystonia patients."

The 2-year joint project between Johanna Blom and Dystonia Europe aims to create an international online platform with special physiotherapy exercises for cervical dystonia patients. The users of the platform will be physiotherapists and other medical professionals and dystonia patients.

On the platform the physiotherapist will be able to choose from 100 different exercises and can thereby customize a physiotherapy exercise program for each individual patient. The patient will receive log-in details for his/her specific exercise program on the platform.

In the first year, phase one, the work will focus on developing the platform, creating / adding the exercises, and launch the platform in Sweden.

During the second year, phase two, the aim is to launch the platform in five other European countries. In this phase the exercises will be animated and one of the aims is also to connect the exercise program to the MyDystonia digital diary.

Dystonia Europe President Adam Kalinowski says: "We are very grateful to Johanna who came up with this excellent idea and to Boston Scientific Foundation for believing in this project and for their generous support."

Commenting on the project, the President of the Boston Scientific Foundation Europe, Sandrine Bazile said, "We fully support this project because it mirrors perfectly the mission of the BSFE, to improve patient wellbeing using innovative solutions. We are excited about the potential the online physiotherapy platform has in benefiting the care of dystonia patients and are committed to supporting the first phase in Sweden as well as the second phase which brings it to patients across Europe."



Johanna Blom
Physiotherapist

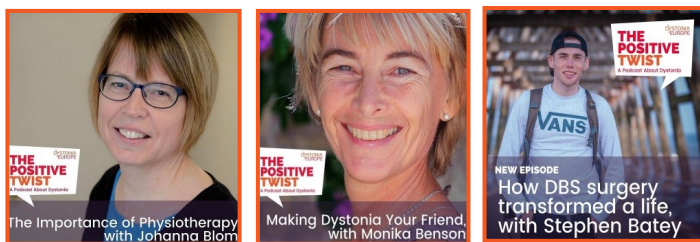
The Positive Twist a Podcast about Dystonia

In September last year Dystonia Europe launched the first season of its podcast: The Positive Twist. The activity was part of the **Digital Dystonia Days project 2020** and made possible with the generous support from Boston Scientific, Ipsen and Medtronic.

Together with Amanda Benson at The Rise Factory we developed a programme which included dystonia patients and medical experts. The first season has seven episodes and these are all available on various podcast channels or using this link:

https://feeds.buzzsprout.com/1337749.rss?fbclid=IwAR1bRLDnWAAvT_8N3QF_9HhxEvDjh5RgA2Po1qHFeGScQBkNwehTwJaAzDc

Until today (April 2021) the podcast episodes have been downloaded and listened to 900 times. The most popular episodes so far:



If you have not listened yet, take the time and hear and learn about dystonia from patients, various medical experts and researchers. Please share and spread within your networks and help to raise awareness of dystonia.

For the time being we are looking to develop season two in the beginning of 2022. We would appreciate to hear back from you what you think of the existing episodes and what you would like to hear in the future. For any feedback or ideas send an e-mail to

monika.benson@dystonia-europe.org.

Dystonia Webinar Series

Last month, on April 22nd, we hosted our 8th webinar out of the 10 planned until end of June this year.

The project was launched last year since we could not meet face-to-face for our annual conference due to the Covid-19 pandemic.

The webinars have created an excellent opportunity to invite dystonia experts in various fields and for people from across the world to attend, listen and ask questions. There have been participants not only from European countries but also from other continents such as Asia and South America. The number of participants following the webinar live on Zoom or on Facebook have been from 25 to 60.

All webinars were recorded and are available on the Dystonia Europe YouTube Channel: https://www.youtube.com/playlist?list=PLFvCc6fYkjEt_7GhGF9OwEEIXo2iBeVRk

The next step in our webinar series is to support our member associations to organize webinars on a national level in the local language. Speaker and moderator will need to be invited by the national dystonia association but Dystonia Europe can support with using the DE Zoom account as well as helping with promotional material. If your organization is interested in this please let us know and send an e-mail to

monika.benson@dystonia-europe.org.



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Boston Scientific
Advancing science for life™



Aasef Shaikh
MD, PhD
Co-Editor-in-Chief



Roy V. Sillitoe,
PhD
Co-Editor-in-Chief

DMRF Launches First Scientific Journal Dedicated to Dystonia

The Dystonia Medical Research Foundation (DMRF) has partnered with Frontiers to launch *Dystonia*, a Gold Open Access journal. The journal will bring visibility to the growing dystonia field and highlight advancements in science and clinical practice.

“The field is ready for a journal focused solely on *dystonia*,” said Co-Editor-in-Chief Aasef Shaikh, MD, PhD, Penni and Stephen Weinberg Chair in Brain Health and Vice Chair for Research in the Department of Neurology at University Hospitals, Cleveland, and Principal Investigator at Daroff-Dell’Osso Ocular Motility Laboratory at Louis Stokes Cleveland VA Medical Center. “There has been a steady increase of publications on dystonia in recent years. Now we have a designated platform to share discoveries and advancements.” Shaikh serves on the DMRF Medical & Scientific Advisory Council and is a past DMRF Clinical Fellow.

“Breakthroughs are being made in basic, clinical, and translational research,” said Co-Editor-in-Chief Roy V. Sillitoe, PhD, Associate Professor of Pathology and Immunology and Neuroscience at Baylor College of Medicine and Director of Neuropathology Core Laboratory, Jan and Dan Duncan Neurological Research Institute, at Texas Children’s Hospital. “It is an exciting time for the field, and the journal will support the momentum going forward.”

Sillitoe also serves on the DMRF Medical & Scientific Advisory Council.

DMRF Vice President of Science Richard Lewis, MD added: “DMRF is very proud to be spearheading this major development for the dystonia field. When there is a need in the dystonia community—whether from patients or researchers—DMRF consistently steps in to address those needs.”

The journal is partially supported by the Joan Miller Young Investigator Fund.

Dystonia is a chronic, often disabling, neurological disorder marked by excessive, involuntary muscle contractions that cause abnormal body motions and postures. Estimates suggest that dystonia affects 250,000 Americans and millions worldwide. Common signs include abnormal movements or positions of the head, neck pain, excessive blinking, a breathy or strangled-sounding voice, hand cramps, or a twisted foot. Although there is not yet a cure, treatment options are available including oral medications, botulinum neurotoxin injections, and deep brain stimulation.

This article is from DMRF website: <https://dystonia-foundation.org/journal-launch/>



New Consensus Guidelines for Botulinum Toxin Therapy of Dystonia and Spasticity



Prof Dirk Dressler

Botulinum toxin (BT) therapy is based on applying appropriate doses of BT into an appropriate selection of muscles. Both, the list of target muscles together with their BT doses, constitute the dosing scheme. Developing the dosing scheme for each patient individually requires considerable experience and makes BT therapy what some people might call a piece of art. To help in this process dosing tables give orientation about reasonable doses for each target muscle.

A new consensus guideline from IAB – Interdisciplinary Working Group on Movement Disorders recently published in Journal of Neural Transmission provides these dosing tables (Dressler et al. 2021). For the first time the dosing tables are based on statistical evaluation of real-life data from the botulinum toxin clinics at the Movement Disorders Section of Hannover Medical School. For each target muscle its mean dose with standard deviation and its minimum and maximum doses are reported. The mean dose describes the typical dose, the standard deviation the dose variability and the minimum and maximum doses the limits of the target muscle dosing. 'So far dosing tables have only been reporting dose ranges coming out of group discussions. Usually they covered enormous ranges making them virtually useless for practical considerations,' said Dressler, first author of the publication.

'We give typical doses for each target muscle, we give variability and we give limits so that the user has all the information to decide the best target muscle dose.' The statistical analysis was based on treatment data from 1831 BT injections in 36 different target muscles in 420 dystonia patients and 1593 BT injections in 31 different target muscles in 240 spasticity patients. 'Also for the first time, we differentiated between dosing for dystonia and spasticity', said Dressler. For all main dystonia and spasticity indications the paper describes the typical number of target muscles and the frequency of their usage. In a general section the currently used treatment algorithms including the short interval therapy and the high dose therapy are reviewed. 'We are extremely grateful to our panel of 26 world class experts in BT therapy from all over the world. We are confident that this publication will be the key source for planning and dosing BT therapy in dystonia and spasticity for the years to come', said Dressler.

References: Journal of Neural Transmission

<https://doi.org/10.1007/s00702-021-02312-4>

NEUROLOGY AND PRECLINICAL NEUROLOGICAL STUDIES - ORIGINAL ARTICLE

Consensus guidelines for botulinum toxin therapy: general algorithms and dosing tables for dystonia and spasticity

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Abstract

Botulinum toxin (BT) therapy is a complex and highly individualised therapy defined by treatment algorithms and injection schemes describing its target muscles and their dosing. Various consensus guidelines have tried to standardise and to improve BT therapy. We wanted to update and improve consensus guidelines by: (1) Acknowledging recent advances of treatment algorithms. (2) Basing dosing tables on statistical analyses of real-life treatment data of 1831 BT injections in 36 different target muscles in 420 dystonia patients and 1593 BT injections in 31 different target muscles in 240 spasticity patients. (3) Providing more detailed dosing data including typical doses, dose variabilities, and dosing limits. (4) Including total doses and target muscle selections for typical clinical entities thus adapting dosing to different aetiologies and pathophysiologies. (5) In addition, providing a brief and concise review of the clinical entity treated together with general principles of its BT therapy. For this, we collaborated with IAB—Interdisciplinary Working Group for Movement Disorders which invited an international panel of experts for the support.

The following article, page 7-11, 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.

Press Release from Medtronic March 22, 2021

Medtronic Receives CE Mark Approval for SenSight™ Directional Lead System for DBS Therapy

This First-of-its-Kind Directional Lead Combines the Benefits of Directionality with the Power of Sensing

DUBLIN, March 22, 2021 /PRNewswire/ -- Medtronic plc (NYSE:MDT), the global leader in medical technology, today announced the CE (Conformité Européenne) Mark for the SenSight™ directional lead system for Deep Brain Stimulation (DBS) therapy as treatment of symptoms associated with movement disorders and epilepsy. DBS is a therapy in which a small pacemaker-like device sends electrical signals through very thin wires, known as "leads," to a targeted area in the brain related to symptoms. The SenSight directional DBS lead system works seamlessly with certain Medtronic neuro-stimulators, including the recently-approved Percept™ PC neurostimulator. This system will enhance detection of local field potentials (LFPs) and offers directional stimulation to provide individualized and patient-specific data plus additional programming features to tailor therapy for patients.

"This is the only directional lead with built-in sensing capabilities," said Jens Volkmann, M.D., Ph.D., FEAN, chairman and professor of neurology in the University Clinic of Würzburg. "The challenge of DBS is to provide stimulation to a very small brain region only at times, when fluctuating symptoms require treatment.

This new technology holds promise for a truly personalized therapy, which we can adapt using the objective data from each patient to inform programming in 'space and time.'"

With collaboration and insights from clinicians, Medtronic engineers have designed every component of the SenSight system to meet customer and patient needs and work seamlessly with the Percept PC neurostimulator to enhance detection of local field potentials (LFPs), which are 1 million times smaller than DBS stimulation pulses.¹

"The new lead system and supporting technology has been designed with the patient, neurosurgeon and programming neurologist in mind," said Professor Stéphan Chabardès, M.D., Ph.D., Grenoble Alpes University Hospital. "What may seem like small changes to materials, design and technology will actually result in meaningful improvements in things like precisely delivering stimulation to each individual patient, streamlining the surgical procedure, and capturing objective data for more efficient, informed programming."

SenSight directional lead systems were first implanted at the University Clinic of Würzburg and Grenoble Alpes University Hospital, by multi-disciplinary teams on March 17 and 18, and a full launch in Western Europe will immediately follow today's announcement. The product is currently under review by the U.S. Food and Drug Administration.

"Medtronic has been driving innovation in DBS therapy for more than 25 years and the approval of the SenSight directional lead system in the EU is our latest contribution to the quest for improved patient experiences and clinical outcomes," said Mike Daly, vice president and general manager of Brain Modulation within the Neuromodulation business, which is part of the Neuroscience Portfolio at Medtronic.

"Our commitment to evolving DBS therapy is unwavering and we look forward to introducing additional advancements in 2021 and beyond."

About Medtronic DBS Therapy

DBS therapy is currently approved in many locations around the world, including the United States and Europe, for the treatment of recent and longer-standing Parkinson's disease, essential tremor, primary dystonia, the disabling symptoms of epilepsy and treatment-resistant obsessive-compulsive disorder.

Medtronic was the first in the United States to offer full-body MR Conditional DBS systems for patients to have safe scans anywhere on the body under certain conditions. Since 1987, more than 175,000 Medtronic DBS devices have been implanted worldwide for movement disorders and other indications.

About Medtronic

Medtronic plc (www.medtronic.com), headquartered in Dublin, Ireland, is among the world's largest medical technology, services and solutions companies – alleviating pain, restoring health and extending life for millions of people around the world.

Medtronic employs more than 90,000 people worldwide, serving physicians, hospitals and patients in more than 150 countries. The company is focused on collaborating with stakeholders around the world to take healthcare Further, Together.

Any forward-looking statements are subject to risks and uncertainties such as those described in Medtronic's periodic reports on file with the Securities and Exchange Commission. Actual results may differ materially from anticipated results.

1. Neumann WJ, Staub F, Horn A, et al. Deep brain recordings using an implanted pulse generator in Parkinson's disease. *Neuromodulation*.

2016;19(1):20-24.

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View original content to download multimedia:<http://www.prnewswire.com/news-releases/medtronic-receives-ce-mark-approval-for-sensight-directional-lead-system-for-dbs-therapy-301252631.html>

SOURCE Medtronic plc



Medtronic

Entering a New Era of DBS Programming with Game-changing visualisation software

A variety of treatments are available for people living with dystonia; deep brain stimulation (DBS) can be a beneficial treatment option for improving their quality of life. The treatment involves the placement of two electrodes into the brain, connected by a wire under the skin to a stimulator, usually placed in the patient's chest or abdomen.¹ The DBS system delivers targeted electrical impulses to specific regions of the brain, to block signals, resulting in improvement of dystonia symptoms.²

Guide-XT, a new visualisation software developed by Boston Scientific, is being utilised by a team at the Würzburg University Hospital in order to optimise DBS programming and significantly reducing the time required to deliver the best results for patients. We discussed their work using visualisation software, such as Guide-XT, with Professor Jens Volkmann, Full Professor and Chairman; Dr Philip Capetian, Senior Consultant, Head of DBS Outpatient Clinic; and Dr Martin Reich, Junior Research Group Leader. Prof Volkmann believes: "DBS is the only therapy that is targeting the cause of dystonia," supported by

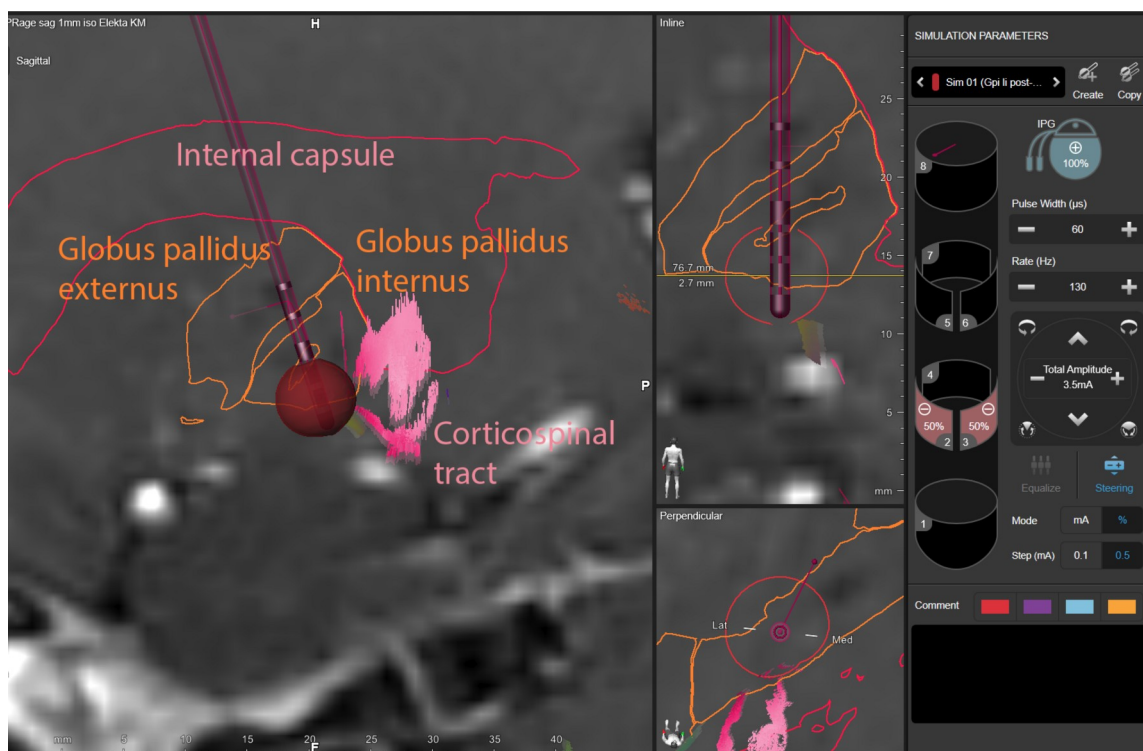
Dr Reich who emphasises that: "Visualisation software will change the way we programme patients in the future."

Visualisation software is the Google Maps for DBS

To understand how visualisation software, such as Guide-XT, works, Prof Volkmann explains: "The impact of DBS is all about location. You need to know exactly which few cubic millimetres of tissue in a certain area need to be stimulated to produce the best possible effects and to avoid adverse effects. In a way, it [visualisation software] is like GPS or Google Maps: it helps us to orient ourselves in 3D space."

The benefits of this are multifaceted, including confidence in placement to avoid adverse effects and to achieve optimal results: "Having an anatomical programming approach at our fingertips is really making things easier. It has already changed our approach, especially for dystonia patients... we gained a lot of confidence to programme," explains Dr Capetian.

Time can be a significant barrier when programming DBS, but with Guide-XT, this issue is irradiated, as Dr Capetian adds: "In the past, I needed to test the patients, and for dystonia it was a bit problematic because you wouldn't have immediate responses... now you really know where your electrodes are located, and you can simulate the field you can achieve with stimulation." Therefore, physicians can achieve optimal results from your initial visit.



Overview on the left Globus pallidus internus (GPI, orange) with stimulation electrode (red) in place. Surrounding structures, segmented for this patient's specific anatomy. The programming settings created by the physician are displayed on the right side of the screen and represented in red on the image on the left as the region that will be activated to provide the best outcomes for the patient.

Tapping into Big Data

Guide-XT has an impact that goes beyond individual patient cases. “We are in an era of digital revolution and we should learn from the approaches that come from totally different fields,” says Prof Volkmann. We are starting to see the impact of Big Data in other industries, and the potential in healthcare is seemingly infinite. With the Guide-XT system, we can pool data to improve diagnosis and treatment pathways.

This pool of data is already being captured and having a positive impact. Dr Capetian explains: “For many years, we have been collecting outcome data from our patients, so we have been collecting pre-operative data from all of our DBS patients and we have been collecting the clinical outcome data in a very broad sense and now we are starting to analyse the imaging data.” By harnessing the data of many patients, physicians can see the bigger picture and use this to more accurately treat a wider range of patients: “This can inform programming because you can create maps of multiple patients where you see certain responses or adverse effects,” adds Prof Volkmann.

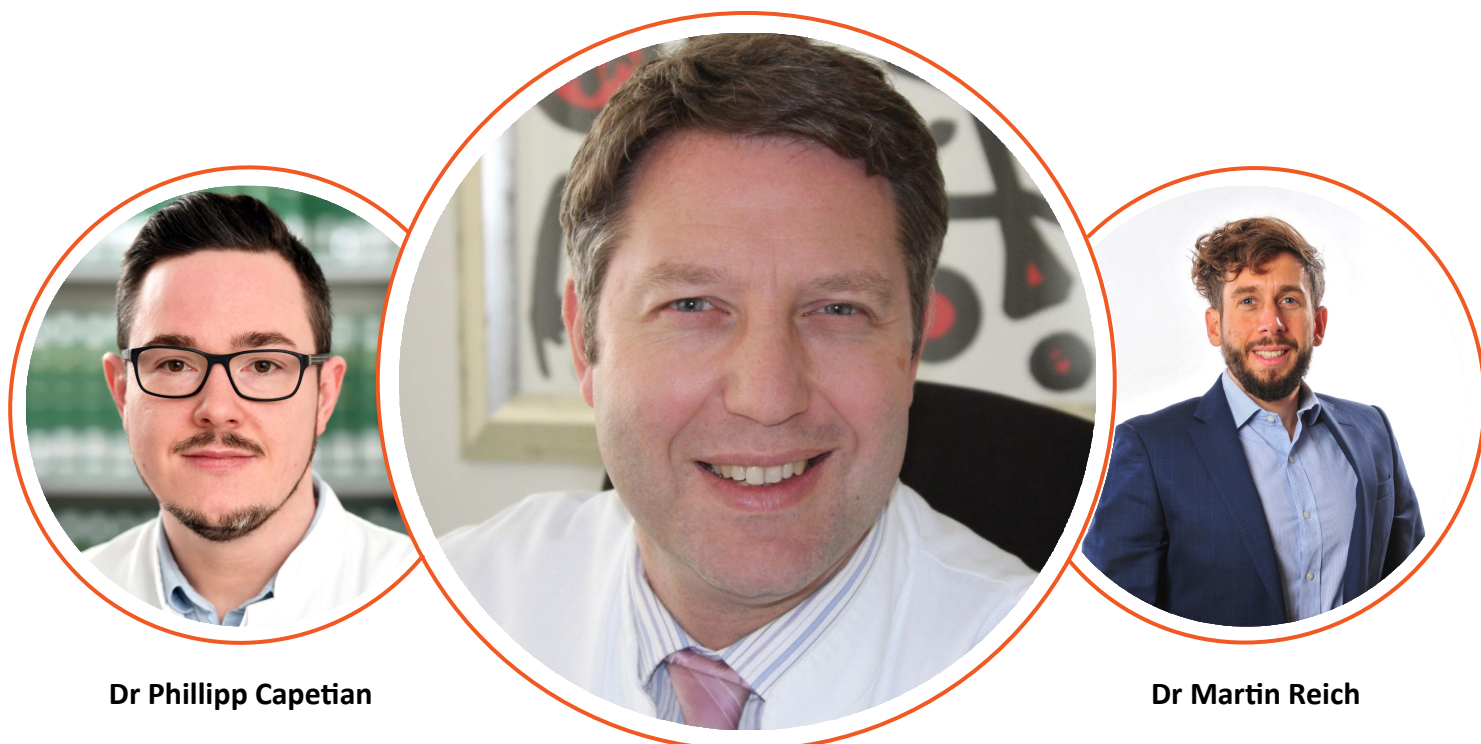
What are the benefits of this personalised treatment for people living with dystonia?

Prof Volkmann believes that patients are put off because “they are afraid of adverse effects.” These adverse side effects are caused if the electrodes are

not positioned in the optimal area of the brain or if they are inappropriately programmed – both of which are difficult to predict; however, visualisation software has changed the game for patients. “We can look at the images and verify the lead position and then make an educated choice. That is the big difference. This educated choice is much more likely to get a good clinical solution, in a much shorter time,” says Prof Volkmann.

This software is not just benefiting newly diagnosed dystonia patients, but also those who have established good outcomes, as Dr Reich recalls: “I remember a dystonia patient who had a really great response to DBS; she had 80% of symptom control, but at this time she had a little bit of cervical dystonia, which she suffered from and had a lot of neck pain. We went to the visualisation software and saw that the DBS electrode was nicely placed but we were stimulating too deep, so we changed it. This was a game-changer, for me, it wasn’t a troubleshooting case, but it was an efficacy case where she was already a good responder.”

Like most things within healthcare, this is not a ‘one size fits all’ treatment, and Dr Capetian reminds us that Guide-XT with DBS can provide targeted, individualised medicine: “We cannot make everything perfect by using our approaches and anatomy-based programmes, but most patients have some benefit...even patients out there who have been unhappy for years and years.”



Dr Phillipp Capetian

Dr Martin Reich

Prof Jens Volkmann

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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Boston Scientific Foundation Europe



Spotlight on the Boston Scientific Foundation Europe (BSFE) – how Digital Health Initiatives are supporting patients across EMEA

In 2019, Dystonia Europe was awarded funding from the Boston Scientific Foundation Europe to create the Dystonia Talks awareness videos for that year's Dystonia Awareness Month. In this article, we hear from the BSFE President, Sandrine Bazile, as she reflects on the Foundation's successes and her hopes for the future.



Supporting Digital solutions that are tackling important health challenges across EMEA is a personal passion of mine. In 2018, we began the start of a new journey for Boston Scientific, with the launch of the BSFE, an exciting new direction for us to make a direct impact on people's health.

The mission of the Boston Scientific Foundation Europe (BSFE) is to support well-being through innovative solutions.

Eligibility criteria

To be eligible for funding, projects shall be in line with the Foundation's strategic focus, by:

- Improving the health of individuals and communities with unmet needs
- Facilitating access to prevention and awareness programs
- Supporting research programs aimed at improving prevention or disease management
- Using innovative solutions such as apps, e-platforms, social media optimising impact on well-being

Organisations must:

- Be non-profit organisations
- Have a track record of non-profit engagement
- Be based in Europe

For full details: bostonscientific.eu/foundation

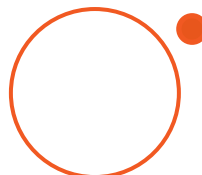


A year in a pandemic, COVID-19 has resulted in the accelerated adoption of digital healthcare solutions by healthcare providers and organisations around the world – taking health and social care online, so it is particularly gratifying to be a facilitator for this health evolution.

Looking back to the early beginnings, we found projects slowly. Now we have found our feet, learned and grown, and have supported nine incredible initiatives across the EMEA region that I am incredibly proud of, from e-training in paediatric cardiology to train young doctors from Africa for the Foundation Francine Leca, to an "Augmented Operating Room" Innovation Chair that modernises human and technological resources in the operating room, with the Assistance Publique-Hôpitaux de Paris (AP-HP), to creating online camps for children with chronic illnesses for the Bator Tabor Foundation to name a few.

Our [new webpage](#) includes the stories of some of the digital initiatives we have supported, including Dystonia Talks, which was an important project intended to help speed up diagnosis and access to treatment. My hopes for 2021 are to support more organisations in more countries embarking on digital solutions to reach and support their communities in the life of pandemic.

Please visit our website to discover how your organisation can apply. bostonscientific.eu/foundation



Dystonia Organisations Worldwide

Recently Dystonia Europe launched a new page on its website with the collection of dystonia organisations worldwide. At the moment you find organisations listed in Europe, North and South America and Australia.

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

We hope that this page can support and help dystonia patients and medical profession in finding the dystonia patient association they are looking for.

If you find incorrect information or know a dystonia organization that is not on our list please contact us:

sec@dystonia-europe.org



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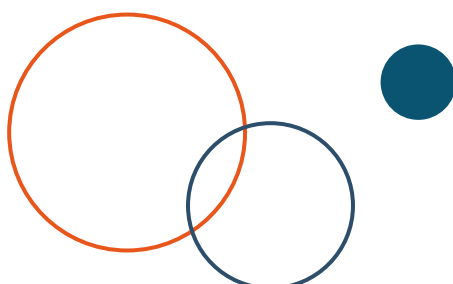


SOUTH AMERICA



OCEANIA

Note: If you find incorrect information or know a dystonia organization that is not on our list please contact us: sec@dystonia-europe.org



EPF AGM 2021

On 17th April 2021, EPF Members gathered online for the 18th Annual General Meeting (AGM). EPF-European Patient Forum is a strong and transparent pan-European organisation that Dystonia Europe is a member of. President Adam Kalinowski and Operations Manager Merete Avery participated in the meeting, representing Dystonia Europe.

EPF has a Board of 9 volunteers and a Secretariat of 20 people, with Marco Greco re-elected as President. The organisation promotes a Strong Patient's Voice to Drive Better Health in Europe. The EPF Secretariat executes the Annual Work Programme and works to support and inform the members. EPF's AGM plays a key role in the governing process of the organisation, approving the annual report and the financial report from the past year, as well as the budget and work plan for the coming year.

At the AGM the focus areas in 2020 were presented. Some of them are COVID 19, Focus on Access, Safety and Patients' Rights, the EU4Health Program.

Engagement with EU Health Strategy with focus on big data, artificial intelligence, will also be on the agenda of the EPF Congress in the autumn 2021.

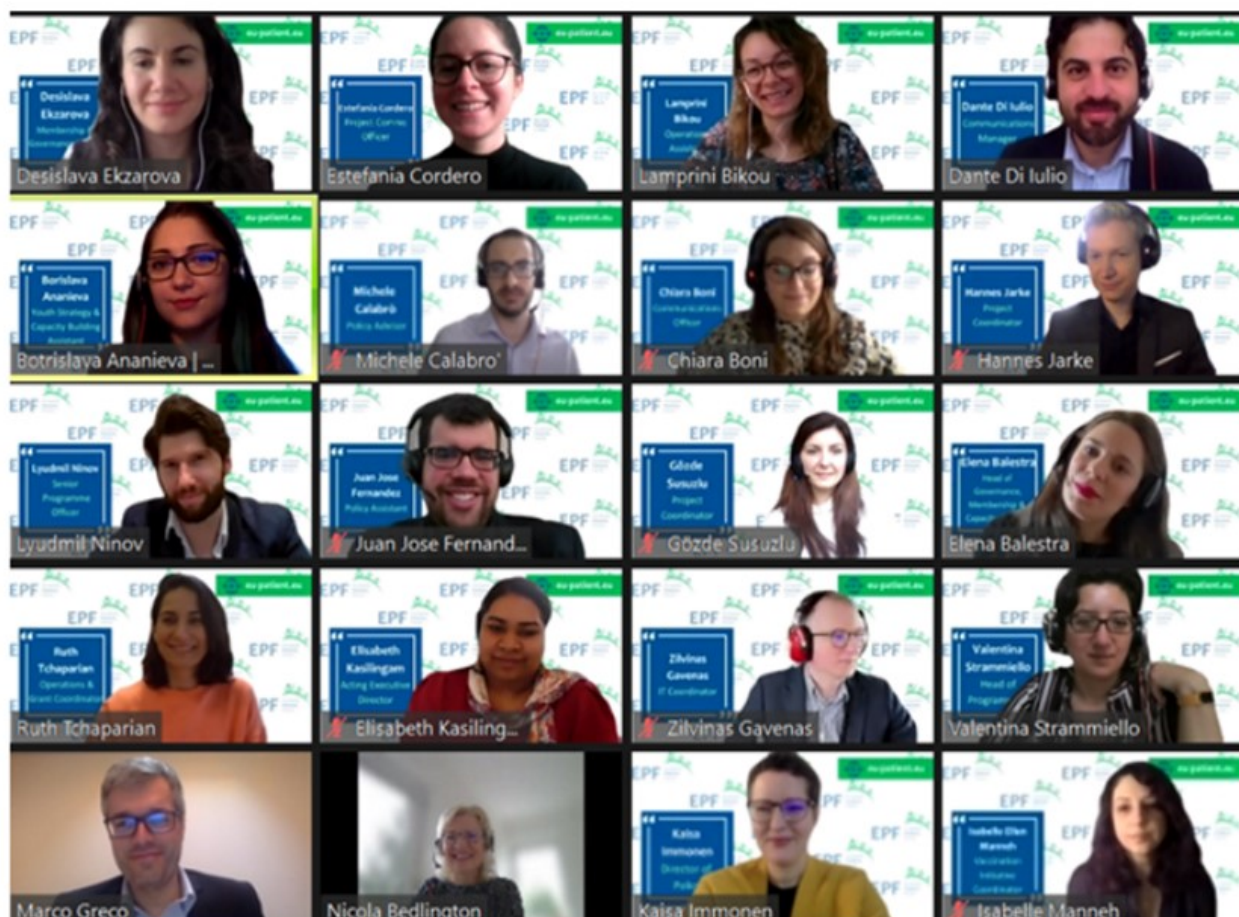
EPF's Director of Policy Kaisa Immonen gave an overview of the EU4Health Programme providing the most pressing objectives for patients. EPF continues to engage actively with the European Commission through workshops, webinars and task force meetings. The open dialogue will continue as EPF's patient advocacy work is at the forefront of their mission.

The updates on the Pharmaceutical Strategy were outlined, and a summary was given on the new EU Agency – Health Emergency Response Authority (HERA).

You can learn more about the projects that European Patient's Forum currently are participating in here <https://www.eu-patient.eu/Projects/ongoing-projects/>.

If you want to learn more about EPF, please follow this link <https://www.eu-patient.eu/>.

Merete Avery
Operations Manager



EPF Secretariat at AGM 2021

Virtual EFNA General Assembly 2021



Joke Jaarsma
President EFNA

On 19 April the Annual EFNA General Assembly was held on-line via Zoom. President Joke Jaarsma opened the meeting and welcomed the participants. After today's meeting there are now 19 member associations representing various neurological umbrella associations in Europe.

The morning session included the formal part. Executive Director Donna Walsh presented the EFNA Annual Report 2020, the 2020 accounts and the budget for 2021. In spite of the Covid-19 pandemic EFNA has managed very well. Face-to-face meetings were moved on-line and new digital projects were launched. One of them is the [e-Learning platform](#) including modules on various topics such as EU Advocacy and Social media. Additional modules will be created in 2021.

On-going EFNA projects are:

OneNeurology initiative launched in the EU Parliament in February 2020 aims to unite and strengthen neurology-related groups to stimulate collaborative advocacy, action and accountability for the prevention, treatment and management of neurological disorders worldwide. Find more information here: <http://oneneurology.net>

Elizabeth Cunningham, EFNA Communications Manager shared some interesting analytics of EFNA on-line:

- 50 000 impressions on Twitter monthly
- 3 700 followers on Twitter
- 2000 followers in Facebook
- 3000 visits/month on the EFNA website
- 900 subscribers to monthly newsletter

We recommend you follow EFNA on their various channels for the latest information on neurology advocacy and awareness in Europe.

Awareness raising initiatives

In 2019 the [Brainlifegoals campaign](#) was launched. The campaign has included a photo competition (2019-2020) where people submitted photos that represented their lives living with a brain disorder.

One of the winners was Susan Bagust, a dystonia patient from Australia. She says:

“I was diagnosed with a rare neurological movement disorder called Dystonia back in 2014 which over time has affected my ability to do everyday tasks. I am not just a drop in the ocean. I want to make a splash and let it be felt around the world. «



In the autumn of 2020 there was an art competition and 83 pieces of art were submitted. Winners have been announced on the

[EFNA website](#).

In 2020 EFNA launched a **grant scheme** and awarded €3000 to 10 organisations who had submitted applications for project within the theme of *Ensuring Equitable Access to Treatment, Services and Support for Neurology Patients and their Carers*.

One of the recipients was Dystonia Europe who received a grant for the

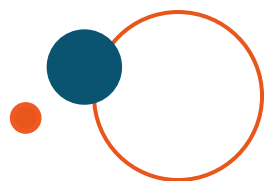
[Jump for Dystonia 2020 photo competition](#)

EFNA also ran a [survey on stigma and neurological disorder](#) and received about 1400 responses from across Europe.

Some of the key findings were:

- 92% of respondents report feeling affected by stigma on account of the neurological disorder they live with.
- 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.
- 49% say their families sometimes make them feel that they exaggerate their condition.
- 32% of respondents with children have been made to feel that they are inadequate parents.

The [EFNA Advocacy Awards](#) recognise the contribution of an individual or group to the development and promotion of advocacy for people with neurological disorders and is held biannually. This year its focus was "Action against Stigma" and winners were: Natalie Davidson, a British teacher living with Tourette's syndrome and the neurological umbrella organisation European Headache and Migraine Alliance.





EFNA 2021 marks the 20th Anniversary of the organisation.

On World Brain Day, 23 July the birthday celebration will take place on-line. Elizabeth encouraged the members to share video-clips wishing EFNA happy birthday and why it is important to work with them. Videos will be collected and shared for the celebration.

There will also be weekly focus on each member organisation.

The new **EFNA Board** was confirmed which now consists of 10 board members. DE Executive Director Monika Benson was elected for a third and last term on the Board.

President Joke Jaarsma said: "The work of EFNA is increasing. There is a lot of external representation and we hope the new board members will be able to support with this work. I am looking forward to working with the new board".

In the afternoon there followed a session on ***Covid-19 and its impact on neurology patients.***

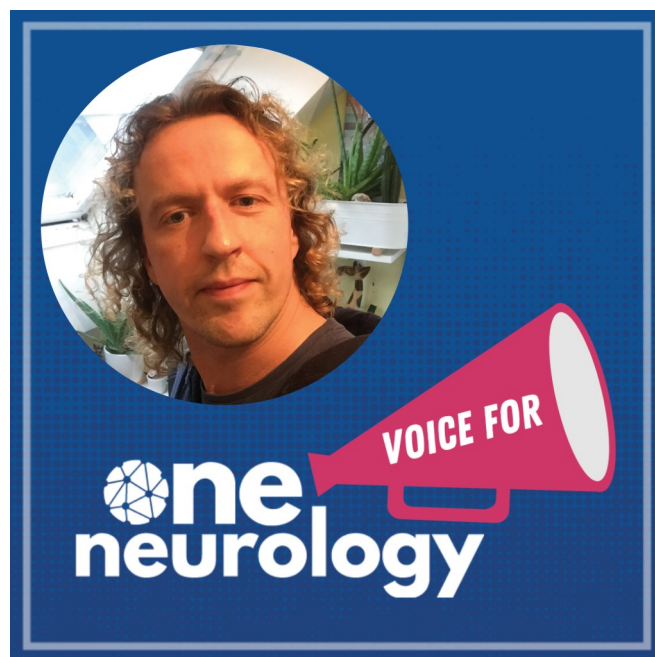
A consultant from Incisive Health presented the plans to create an advocacy report on Neurology and Covid-19. This will be based on the analysis of surveys/consultations carried out by EFNA and its members, combined with the scientific/medical data from the European Academy of Neurology.

The vision of the final report is to show what the pandemic has meant to neurology patients give key insights and common conclusions and provide clear recommendations for engagement and advocacy for the future.

Other sessions in the afternoon included a presentation from Simonetta Balbi from Boston Scientific who presented the work of the Boston Scientific Foundation, conditions and criteria for grant application. Read more about the foundation on page 12.

The last session focused on the EFNA Advocacy work and its activities MEP Interest Group Brain Mind and Pain and OneNeurology, mentioned above.

The OneNeurology initiative was very active during Brain Awareness Week with its launch of a special [podcast](#). Dystonia Europe President Adam Kalinowski gave his patient testimony in one of them.



President Joke Jaarsma concluded the meeting by saying: "From today's reports and presentations you have seen how active EFNA is. This is all made possible because of the excellent EFNA team, consisting of only 3 people doing a lot of work. They all deserve compliments for all we have achieved in the last year. We are now looking forward to this 20th Anniversary year of EFNA and to continue to be the voice of neurology patients in Europe and to add value to the work of our members. For our next GA Meetings in 2022 I really hope we can all meet in person."

Patient Engagement in EU-Funded Brain Research Projects

15-21 March was the international Brain Awareness Week in 2021, an educational initiative aiming to raise awareness of brain and research. During this week on 16 March, EBC, in partnership with EFNA & GAMIAN-Europe held a webinar on patient engagement in EU funded Brain Research Projects within research, health and policy making. Patient engagement in research involves meaningful and active collaboration with patients in the governance, priority setting, conducting and knowledge translation of research.

Paola Zaratin held a presentation on The EU-funded MULTI-ACT project, that aims to increase the impact of health research on people with brain diseases. The MULTI-ACT project will work with patients and patient organisations, academics, private and public stakeholders, to develop brand new tools to assess the value of research. To read more about MULTI-ACT you can visit their website <https://www.multiact.eu/>.

One of the main goals is to try to give many opportunities for patients to advocate and to make sure that the patient view and experience are taken into consideration in projects, and to develop guidelines for patient engagement. Patients should not become scientists, but enforce the patient's voice on what is important for them. A patient that is involved should be a full member in the project from the beginning and be included throughout the project.



Speakers from the organisers were

- Frédéric Destrebecq, Executive Director European Brain Council (EBC),
- Monica di Luca, President EBC
- Joke Jaarsma, President European Federation of Neurological Associations (EFNA)
- Hilka Kärkkäinen, President Global Alliance of Mental Illness Advocacy Networks (GAMIAN - Europe).

In addition speakers present were

- Pierre Meulien, Executive Director Innovative Medicines Initiative (IMI) Europe's Partnership for Health
- Irene Norstedt, Director who works at the European Commission responsible for the People Directorate within the DG for Research and Innovation



MY DYSTONIA

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



*Launch end of May 2021

NEW VERSION*

DYSTONIA
EUROPE



Jana Vičarová to the left and her cousin Eva Brown



Dystonia Seminar in
The Czech Republic

Meet Jana Vičarová The Czech Republic

What is your name?

Jana Vičarová

What are the benefits of working in a patient organisation?

In the beginning, I had a desire to find someone with the same disability. Once I succeeded, it changed my life.

It gave me a feeling of coexistence and the opportunity to discuss the social problems of dystonia patients. It also gave me the surprise of being able to see everything inside and out.

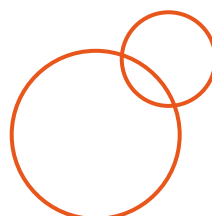
My social anxiety decreased and I no longer felt alone. I wanted to share these feelings with other dystonia patients. The complexity and closeness of people who bear the same burden is important and is human.

My cousin, Eva Brown has her own health problems and is very close to us. She has been a real tonic to me and has helped me expand in another dimension. Eva also assists with the communication in English within the organisation.

How do you spend your free time?

I like to spend my free time with people who are close to me or with my fellow patients during a recreational stay in nature. Humor, music and tourism are very important in my life.

Jana Vičarová
Chairwoman
Czech Republic



Online meetings: A blessing in Disguise

COVID-19 has wreaked much havoc over the past year in Europe and beyond. For us at Dystonie.be, the Belgian association for dystonia patients, the biggest health crisis in living memory proved to be a cloud with a silver lining. Online meetings allow us to connect with members in all parts of the country.

You might even say the restrictions were a blessing in disguise for us. Before the pandemic, we organised all our activities separately in the westernmost and easternmost parts of the country.

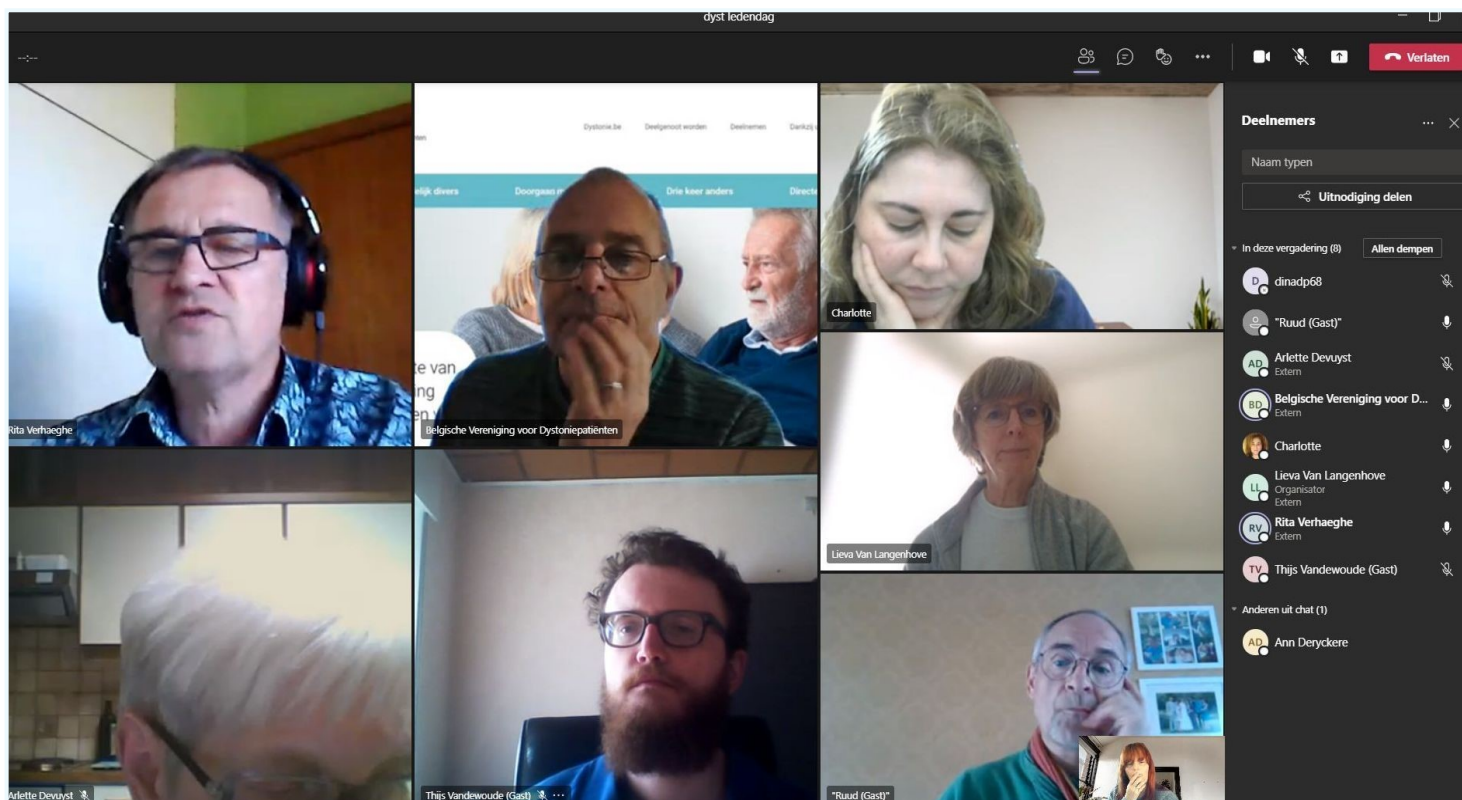
Long before facemasks, hand sanitizer and social distancing became part of our everyday lives, the year 2020 held a special significance for us at Dystonie.be, as it marked our 25th anniversary. We had planned a great celebration together with our members, sponsors and medical professionals,

but soon it became apparent that we would have to cancel all our plans. No silver jubilee and no other activities either, as meeting up physically at all was out of the question.

Our hearts sank: a whole year with an empty agenda and nothing to fill it, would our members put up with that? Was there nothing we could do to reach out to them?

It didn't take long for us as board members and volunteers to get acquainted with the finesses of online meetings – there really wasn't much of a choice! We still have to remind each other occasionally that someone's talking without turning on the mic first, only for the speaker to worry whether everyone can actually hear them. But practice makes perfect, and nowadays our board meetings run smoothly and swiftly. If that worked, could we perhaps conduct our member activities online as well, we wondered.

As it turns out, our doubts were unfounded: yes, we could! And more importantly: so could our members. We had feared that the hassle of preparing for an online meeting would put off many of our elderly members, but this could not have been further from the truth.



Board Members during an online meeting. Clockwise from top left:

Paul Durnez, Patrick Bauwens, Charlotte Delporte, Lieva Van Langenhove, Rudy Loos, Thijs Vandewoude, Arlette De Vuyst.

To our pleasant surprise, patients both young and old joined us for a *'dystoniebabbel'* ('dystonia chat') on 27 February and again for our members' meeting on 27 March.

Moderated by our board member Lieva, both meetings went as smoothly as we could have hoped.

Clear rules and etiquette were established from the start, and though there were some inevitable technical hiccups, we came away from this new experience with the feeling that our members appreciate our efforts to organise activities, in spite of the limitations imposed by COVID-19.

You might even say the restrictions were a blessing in disguise for us. Before the pandemic, we organised all our activities separately in the westernmost and easternmost parts of the country.

It spared many patients a long journey and still gave them a chance to attend. On the other hand, this had the distinct disadvantage that there were very few occasions where all our members could gather in one place. Moreover, for some people with severe forms of dystonia, even attending our meetings physically was out of the question. Online meetings have removed these barriers. No matter where they live, patients can log on, join the discussion and exchange experiences and health tips.

And so eventually we did get to celebrate the 26th anniversary of our association. It may not have the same ring to it as a 25th anniversary, but that didn't bother us in the least. Our treasurer Paul gave a brief overview of the history of our association from 1995 until the present, while Professor Patrick Santens (UZ Gent), member of our Medical Advisory Board, talked about dystonia throughout the ages. Many images, descriptions and other evidence show that our ancestors were aware of the symptoms of dystonia, even if they lacked the medical knowledge to formulate a correct diagnosis, let alone develop an efficient treatment.

That would take many years, until the end of the 20th century to be precise. 'It is no coincidence that the Belgian Dystonia Association was founded at a time when dystonia was identified as a neurological disorder rather than a mental illness', Professor Santens noted, crediting Dr David Marsden for this scientific breakthrough.

Finally, it was time to look towards the future, with the unveiling of our new logo. The colours red and blue symbolise tension and relaxation, the mirrored D's (for dystonia) refer to the two brain hemispheres. This new logo features prominently on our new website (www.dystonie.be). However, this website is more than just bells and whistles. With poignant testimonies, reliable information and useful links, we want to become a reference point for patients, caregivers and everyone in the Dutch-speaking part of Belgium who wants to know more about dystonia.

After more than a quarter of a century, Dystonie.be is going stronger than ever. Amidst the COVID crisis, we have embraced the opportunities created by new technologies to stay in touch with our members. Yet, no Zoom call or WhatsApp group can wholly replace the sensation of genuine, face-to-face human contact – or a real silver jubilee party, for that matter. But party we will, sooner or later.



Thijs Vandewoude
Belgium Dystonia
Association

Dystonie.be

Belgische Vereniging voor Dystoniepatiënten



DystOlympicGames - A.R.D.

Leonardo

During the month of March in our social media we have launched the project “ Le Distoniadi – anche il tuo passo conta” which means “ DystOlympic games – your step counts too”

We asked our followers to send us videos and photos of their sporting activities; we are well aware that sports require movement coordination and control, which are missing or difficult for us. We wanted to show and prove that even with dystonia it is possible to play sports, by adjusting them to one's own physical situation in order to enjoy a period of less severe symptoms.

The project has been introduced by Dr. Anna Castagna, Neurologist in Hospital Don Gnocchi in Milan, who spoke about dystonia and physical activity. She said that many studies prove the benefit of aerobic physical exercises on the brain in

Giorgio

Parkinson disease, but no similar study has been carried out for dystonia. In a sample survey with 1000 persons with dystonia, 30% of them reported an improvement with activities like yoga, taichi, pilates, dance; 30% reported no advantage by sports and 40 % reported that staying at rest is better.

There is no therapeutic sport which will suit all kinds of dystonia patients; in some cases sport may worsen some symptoms, like head movements while running with cervical dystonia.

Agonistic sport is a different matter: it is much more challenging and must be carefully calibrated with the help of a trainer and a physiotherapist, in order to implement compensatory strategies in relation to the dystonic movement.

In conclusion, Dr.Castagna points out that physical aerobic activities are recommended, provided that they are adjusted to one's own situation; it's advisable to proceed in small steps, to set an achievable goal and to accept one's own limitations.

The cycling paralympic champion Giorgio Farroni sent a video with his story. His dystonia concerns the right part of his body and originates from a lack of oxygen at birth.

He began to ride a bicycle in his childhood; at the age of 22 he joined the Paralympic cycling team, taking part to the Paralympic Games in Sidney (2000) Peking (2008) London (2012) Rio de Janeiro (2016) and winning many medals. He hopes to go to the Tokyo Games next summer. He is an amazing example of determination and with a passion for sport, showing how much you can do in spite of physical difficulties.



Caterina



Benedetta

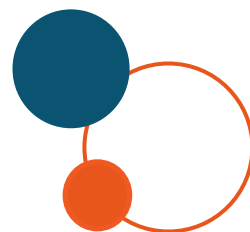
For our Distoniadi we have received many videos and photos of people with dystonia during some sporting activities or just walking along the seaside, as "any step counts". We would like to mention in particular some videos: Silvia who is roller skating, Federico while rowing on the river Po in Turin, Leonardo (a 13 years boy who had DBS last November) who is walking on a rope, playing football and climbing a rock.

We mention some photos too: Gabriella who practises Tai chi, Benedetta while skiing and paragliding, Massimo is winning medals with his Kayak team , Mirella is trekking on the Alps, Raquel and Sandra are riding their bicycles and Caterina with her katana who practises Ai-jutsu, a Japanese martial art meaning "Way of harmony".

Even if our Distoniadi are over, we invite you all to continue your favourite sporting activities, as results can only be positive.



Maria Carla Tarocchi
Italy



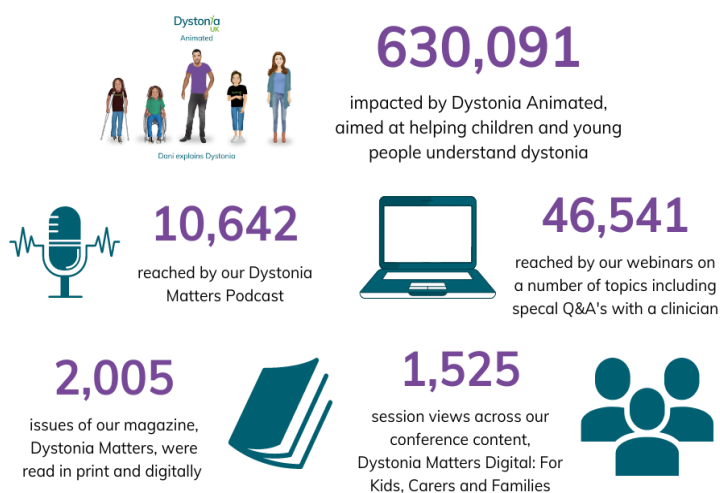
Reach Out, Reach All

In October 2020, we were awarded a grant by the Coronavirus Community Support Fund, distributed by The National Lottery Community Fund.

Thanks to this funding, we have been able to further grow our 'Reach Out, Reach All' campaign and bring the dystonia community closer together, despite the challenges of the pandemic.

We brought you a series of webinars, unveiled our patient led podcast, created the first episode in a brand new animated series, held another successful children's conference and are currently updating our most popular leaflets. It has been a whirlwind of activity and so far we have **reached over 707,000 people** across the world, with numbers still rising! We are thrilled to share the highlights of these

So far, we have reached over **707,000** people with content produced thanks to funding from the National Lottery Community Fund



And the numbers continue to grow!

Partnership with THE NATIONAL LOTTERY COMMUNITY FUND

Dystonia UK

Dystonia UK is the operating name of The Dystonia Society. The Dystonia Society is registered as a charity in England and Wales (1062595) and in Scotland (SC042127).

So, what does the future hold for 'Reach Out, Reach All'?

Visit our website to find out more and to tune into our previously recorded webinars and podcasts:

www.dystonia.org.uk/reach-out-reach-all

One of the highlights of this part of the Reach Out, Reach All campaign was the launch of the 'Dystonia Animated' series at the end of March. We focussed on young people with the condition and how we can help them and their families. The first episode, 'Dani Explains Dystonia', introduces viewers to Dani, Charlie, and some of their super supportive family members, as they share what their lives are like with dystonia.

"Dystonia affects a close family member, so I am particularly pleased to see this terrifically warm animation aimed at young ones with this challenging condition."

Stephen Fry, Honorary Friend of Dystonia UK

The animation has so far reached over 630,000 people worldwide and has been viewed, in its entirety or in parts, over 68,000 times through our website and social media. We have had amazing feedback from viewers in America, Canada, and Australia as well as plenty of European countries sharing their love for the accessible and easy to understand content. Although primarily aimed at children, and much loved by the ones who have seen it, we have had plenty of positive feedback from our adult supporters too! Many have been sharing the animation with family and friends.

One has shared this comment with us via social media: "Such a great simple way to explain what dystonia is and some of the ways it can affect people and their family_#DystoniaAnimated". Others have described it as "at the right level for children to understand, and to help those around them understand" and yet another viewer said that "This animation powerfully illustrates a range of the complicated issues that accompanies dystonia".

If you haven't yet seen the animation, please follow the link to our website so you can see for yourself what everyone has been talking about!

Dayna Ferdinandi

Director of Fundraising and Communications

Dystonia UK Animated



Dani explains Dystonia

Watch here: dystonia.org.uk/dystonia-animated

Highlights from some of the amazing feedback we received

“ This animation is fab. Dystonia UK are brilliant. This animation powerfully illustrates a range of the complicated issues that accompanies dystonia. ”

“ I've just watched the animation and it is fab. It is at the right level for children to understand, and to help those around them understand. ”

Dystonia Animated

“ Dystonia affects a close family member so I am particularly pleased to see this terrifically warm animation aimed at young ones with this challenging condition. ”

Stephen Fry,
Honorary Friend of Dystonia UK

“ This is a great explanation of what dystonia is to our friends and family. Our daughter is one that does not like to talk about how this has affected her. ”

“ I love how the young people were included and I hope they feel less alone. ”

Podcast

“ Just finished listening to this podcast. It was filled with great advice and inspiration. ”

“ Thank you for inviting me. It was lovely to talk to other parents going through the same things. It helps to remind us we are not alone. ”

Julie, Dystonia Matters Podcast contributor

“ Amazing stories that make me feel more at ease with the experience of dystonia seen through my eldest son. Thank you ☺ ”

Webinars

“ Thank you very much for a very informative session. In the month of accessing Dystonia UK I have learnt a lot. ”

“ Thank you so much for this evening's questions and answers with Mark.. Most of the answers were very helpful to me personally and I look forward to future events. ”

“ Thank you all for the very informative webinar. Janet explained things well. Well done Dystonia UK! ”

Conference

“ Well done to everyone involved in creating such a successful, informative digital conference. ”

“ Following my speech just wanted to echo again thanks to all of you Consultants, Doctors, and Patients and organisers for putting this all together. I have learned so much over the 2 days. I have taken away so much and feel a bit better, the road ahead is going to be hard but I will have the support of Dystonia UK and will learn to adapt with life. A big thank you x ”

Dystonia Matters Digital attendee



Constructive Activities During a Pandemic

Catalina Crainic, President 'Asociatia Childrens Joy', Romania

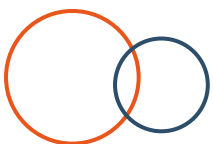
A fundraiser for genetic testing of 12 people with dystonia by The Children's Joy Association (adults and children).

Diagnosis and classification of dystonia is of great importance for the proper management of prognostic information and genetic counselling of patients. The cost of a test is \$250. Genetic testing must be done in the USA because in Romania the only tests available are those that identify dystonia in general, in the USA individual genes can be identified.

For the first phase of our program we would like to help 12 people with dystonia to be able to undertake complex genetic testing.

We organised our fundraising including Facebook with the title "Help dystonia patients get tested". For this reason several volunteers of the association were involved in order to work together to raise the amount needed.

Because it takes power, strength and courage, this campaign also involves the performance athletes of the Iguana Fight Team Sports Association led by Marius Crainic. As well as being the coach and President of the sports club Marius is a promoter of the Fight for Dystonia campaign, a member/volunteer of the Children's Joy Association and also Sasa Marcov performance athlete and volunteer.





Sabina Gall
Romania

Also the founder of the association Sabina Gall (DBS Patient) and Catalina Crainic, President of the association and a cervical dystonia patient, make decorative objects using various techniques and sell them for a donation to the cause. Catalina and Sabina created a Facebook page called 'One Thing' which is a platform for selling the decorative objects.

So far during February and March 2021 we have raised €2000!

Fundraising will continue until it can complete what we set out to do, to achieve our goal.

Patients need to be informed and given a correct diagnosis, as it is normal to want to know more about the disease they are struggling with. At the end of the fundraising we will launch an information and awareness campaign which will emphasize the importance of genetic testing. Patients will be better informed and educated in this regard with the help of specialists in the field who will be involved.

We are considering a good start to raise awareness and help both patients and specialists know as much as possible about dystonia. A small step which we hope will give new perspectives and opportunities to look at dystonia.

Catalina Crainic

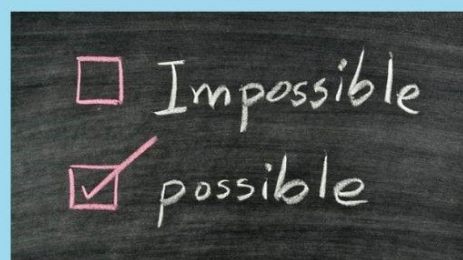
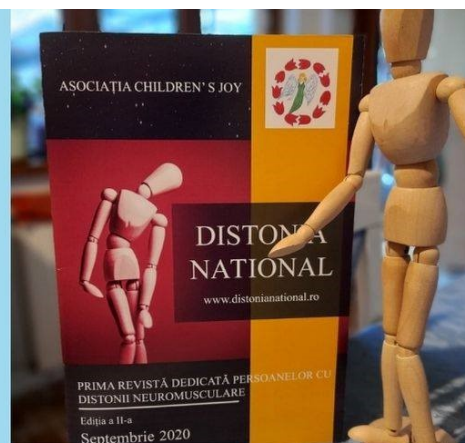
President Asociatia Childrens Joy, Romania
and Board Member Dystonia Europe



DOWN WITH DYSTONIA



HELP DISTONIA PATIENTS GET TESTED



www.dystonianational.ro

Digital Dystonia Activities



PhD Jeanette Koht
Norway

About Jeanette Koht

Working with Dystonia and treatment since 2001.

Adviser for Norwegian Dystonia Association (NDF) for many years

Last Project together with NDF: Dystonia and physiotherapy

Trained neurologist in 2006

PhD Hereditary cerebellar diseases

Head of Department of Neurology Oslo University Hospital.

The Norwegian Dystonia Association

arranged a webinar with Jeanette Koht 7th April 2021. The topics covered were as follows:

1. Corona virus and vaccine

- the situation in Norway and around the world.
- Norway is using the BioNTech Pfizer and Moderna (RNA technology) vaccines.

Best advice: When you are offered the vaccine take it. There are no known risks for dystonia patients. Botulinum injections can be taken the day after, or the day before. Jeanette asked people to follow this link from Dystonia Europe:

Care for dystonia in times of Covid-19 , professor Marie Vidalet (<https://www.youtube.com/watch?v=L6Lm-ULtW88>).

2 Botulinum toxin and guided injection

You can get better result by using EMG (electromyography) and ultrasound. All the younger neurologists are now trained to use that.

3. Second opinion

What to do if we feel we do not get sufficient treatment? You are free to change to another hospital or neurologist to get a second opinion, in Norway you have free choice of hospital for your treatment.

4. Questions, summary

Medication: No new medication, only the old ones that can relieve pain.

Muscles: Do they get thinner when you get injections? Yes, because they are used less.

Can dystonia spread to other parts?: Yes that can happen.

Summary by Sissel Buskerud

Vice President Norwegian Dystonia Association
and Treasurer Dystonia Europe



Photo: Jeanette Koht
(a pine with generalized dystonia in beautiful Norway)



Photo:
Instagram: @bypirazyoko

Emilia's Story

My dystonia story began at the age of 17. I am currently 39 years old. At the beginning, I was taking medications and had botulinum toxin injections, which helped. Except for maybe for 4 years I had peace, then my disease was in remission. In fact, I think my attitude towards illness helped more. While ill, I finished my studies. I started practicing various kinds of dancing zumba, belly dance, twerk, dancehall, hip hop, jazz, salsa). It was very relaxing. Writing poems was a way to respond. Everything changed completely when I got pregnant. Then my general health deteriorated too, that was over 11 years ago. Then I made the decision to stop taking drugs and botulinum toxin. Despite the terrible torment, I worked until the 6th month of pregnancy. At the time I was still studying and completed all the subjects. However, I did not have time to produce my master thesis. I did it after childbirth. Since giving birth to a child who will be 11 in August this year, everything has changed. I started to feel better. I don't know if this is the result of love or responsibilities?

The more obligations I imposed on myself, the better I felt and I passed my driving license which was quite stressful.

Of course, there are days when my muscles and spine hurt. Usually it happens when the weather changes, I'm stressed, have too many responsibilities, or when my period is approaching. Sometimes I have involuntary movements. People who don't know what's wrong with me think I'm cold or look at me strangely. However, I don't care. It's been a long time since I stopped worrying about what people think about me. I work 8 hours a day, sometimes longer, or even on Saturdays. I live a normal life.

Emilia Gaj-Parchowicz
Poland



MY DYSTONIA STORY

Currently, I have been working remotely for a year. It is better for me because I do not waste my time commuting and sometimes I also have time for overtime work. Although I try not to overdo it. Remote work also causes greater peace of mind, which in my case is very important. Without wasting time commuting, I can spend it, for example, on exercises.

Dystonia gave me the courage to try new things. I started ice skating, roller skating, scooter skating, I tried snowboarding. Unfortunately I could not continue due to the coronavirus. Once, I also tried horse riding, which had a very positive effect on me. Unfortunately, I don't have time for everything. I have been training pole dance for about five years. Maybe I do not have the same results as a healthy person, but that is not the most important thing. I think I have achieved a lot anyway. Currently, I have my own pole at home, I practice more thanks to this. I also have an aerial yoga hammock and I practice that sometimes. Stretching and Yoga is also great for relaxing. I also often use Autogenic Schultz techniques before I fall asleep, which is very helpful. At first I didn't even know it was called that. I made the effort loosen individual muscle groups in my mind.

My husband's massage is also good for my muscles and good for me.

I have Indiba treatments (non-invasive heat treatment) from time to time, which is also helpful for various kinds of pain.

For a year now I have had another passion - crocheting. It is very calming and relaxing. I forget that I am sick. I like to make mascots the most. I think I am good at it. By accident I discovered that I am good in painting, especially with watercolors. So maybe it's time for another passion. I cannot allow myself to be bored.

Emilia Gaj-Parchowicz
Poland



“Dystonia gave me the courage to try new things.”



Calendar 2021

May	
30	Dystonia Europe General Assembly 2021, on-line via Zoom
June	
8	EBC VOT Synthesis Meeting, virtual
19 - 22	EAN Congress, virtual
19	David Marsden Award winner presentation, Basal Ganglia Club session, EAN Congress
July	
2	ERN-RND Annual Meeting, Leuven, Belgium
23	World Brain Day
September	
1 - 30	Dystonia Awareness Month
4	Dystonia Day, on-line via Zoom
8 - 11	ESSFN, Marseille http://essfncongress.org/en/
17 - 22	International Parkinson's and Movement Disorder Society Congress 2021, virtual https://www.mdscongress.org/Congress-2021.htm

VIRTUAL DYSTONIA DAY 2021

SAVE
THE
DATE

Interactive Online
Presentations

4 September 2021
10:30–15:00 (CET)



DYSTONIA
EUROPE

Members

Dystonia Europe consists of 21 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.

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 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, 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 Ponsel

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 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

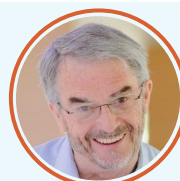
Sissel is the Treasurer/ Accountant responsible and Board Member of the Norwegian Dystonia Association for the last 7 yrs. Sissel has experience for more than 25 yrs. as an Accountant for a Norwegian Security Company. Sissel was elected to the DE Board at the GA in London in 2019 and is the Treasurer of Dystonia Europe.



Catalina Crainic

Board Member, Romania

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



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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Photos from Dystonia Days and portrait photos:

Stephan Röhl, www.stephan-roehl.de

Meet us @



Website:

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Facebook:

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

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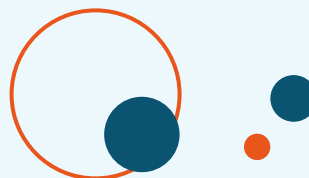
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PARTNERS & SPONSORS

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.

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.

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!

Disclaimer

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