

# DYSTONIA

# NEWS

WINTER | 3 - 2021

Virtual Dystonia Day 2021



## IN THIS ISSUE

PG. 3

Dystonia Day 2021

PG. 6

Dystonia Awareness Month  
2021

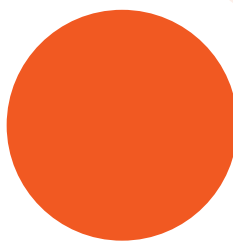
PG. 8

Dystonia Physio Exercise Hub

PG. 33

My Dystonia Story by Johan  
Arnfinn Warvik

DYSTONIA  
EUROPE



# CONTENT

|                                 |    |
|---------------------------------|----|
| President's Message             | 2  |
| Latest News                     | 3  |
| Research                        | 10 |
| Other News                      | 15 |
| EU Activities                   | 20 |
| My Dystonia                     | 23 |
| Around Europe and Beyond        | 24 |
| Hello There                     | 32 |
| My Dystonia Story               | 33 |
| Events                          | 35 |
| Board, Advisory Board and Staff | 36 |
| Get in Touch                    | 38 |
| Partners and Sponsors           | 39 |



**Adam Kalinowski**

Dystonia Europe  
President

Hello and welcome to our winter newsletter, the third this year, which we hope will help you keep updated on our latest news and provide you with information about our projects as well as the activities of our members and partners.

We hope you enjoyed the summer and autumn months, with plenty of sun and colours around to get us all up and active and enjoying the great outdoors.

The last few months have been very intense for Dystonia Europe. September, the dystonia awareness month, began with our annual Dystonia Day Conference, which was held online for the first time. During September we also encouraged people with dystonia to engage with us and let us know what they do to manage their symptoms and feel better through our #EscapeDystonia campaign.

We also worked on our two big projects. The new version of the MyDystonia application and the Dystonia Physio platform which was launched in November.

Many of our members have returned to the live meetings and we are happy to provide you with articles about these activities in our newsletter.

We, at Dystonia Europe, also hope to come back to face-to-face meetings in 2022 and the plan is to hold our General Assembly Meeting and annual conference in Denmark, and meet you all live.

In the meantime, we wish you all Happy Christmas filled with love, happiness and good health!



## Dystonia Day September 2021

---

Well what can I say, the Dystonia Day conference held online on Saturday 4th September 2021 was a huge success with many attendees watching and listening to various experts in the field of Dystonia.

Adam Kalinowski (DE President) started the day off by introducing us all to the conference and giving a brief outline of what was to come. He also gave us a brief history of Dystonia Europe and highlighted how much the organization had achieved since beginning in 1993. He also outlined the current projects that DE are working on along with their sponsors.

Adam especially highlighted the current Dystonia Awareness campaign, 'Spot Dystonia' and 'Escape Dystonia'.

The first invited speaker of the day was Professor Mark Edwards from St Georges Hospital in London, England answering the question 'What is Dystonia?'. He described all types of dystonia from Isolated Genetic Dystonia to Task Specific Hand Dystonia. I have had dystonia for many years and have volunteered with a UK charity (ADDER) and Dystonia Europe and there were some types of dystonia that I have never heard of, Functional Dystonia for example which was previously known as Psychogenic Dystonia.

I am sure all fellow dystonia patients would agree with Mark when he explained that dystonia is very difficult to diagnose as symptoms are different from patient to patient. He did advise us that to get the best diagnosis we should be seen by a neurologist who specializes in movement disorders.

Mark then went on to say that we can help our neurologist/medical professional by being totally honest with them and explain to them how dystonia affects our daily life, in fact he recommended that we all use the My-Dystonia app developed by Dystonia Europe. This app helps us to keep a regular record of our symptoms which we can then summarise into a report for our treating physician to read.

You can download the free app from the appropriate app store for your smartphone.



**Prof Mark Edwards**  
St George's Hospital in London

Mark finished by telling us that we can also help ourselves, we can take note of things that make our dystonia worse or better. I know I have various distraction techniques that I use all the time and I am sure you all do too. The DE awareness campaign 'Escape Dystonia' is all about that very thing and if you would like to send in your own thoughts on escaping dystonia or read about other peoples please look on our facebook page and take part in the campaign. One of my own techniques is to take notes, so while watching the conference I was taking notes on my lap top.

Our next speaker was Vera Issel from Italy who is a Cellist with musician's dystonia. She explained how she has worked to overcome the problems dystonia caused her while playing music. She is an inspiration to anyone who has any sort of problem to deal with, her patience and perseverance has allowed her to continue playing her cello to a very high standard and her dream is to bring music to us all. At the end of Vera's presentation we went into a welcome coffee break and Vera's music was played for us all to enjoy.



Vera Issel





**Dr Francesca Morgante**  
St George's Hospital in London

The third presentation was given by Dr Francesca Morgante on Treatments for dystonia. Francesca is a neurologist specializing in movement disorders and works in St George's Hospital in London.

Francesca explained that the aim of dystonia treatment is to reduce involuntary movement and tremor and also improve non-motor symptoms of dystonia, pain, anxiety, depression, poor sleep. All of which should improve quality of life for the patient.

She explained her own approach to deciding which treatment is best for each patient and she told us about the variety of drugs that are available for dystonia patients and how each of them help to reduce symptoms. However, sometimes they do produce side effects and this must be taken into consideration.

Francesca always considers the whole patient and not just his/her dystonia, she feels the psychological aspect of coping with dystonia should also be explored and treated where necessary. She also talked about the most used treatment, botulinum toxin injections and about Deep Brain Stimulation and why sometimes it is not successful.

Francesca is also keen that all dystonia patients have access to good physiotherapy and feels at the moment that is not the case.

Also, like Professor Edwards, Francesca stressed the importance of talking honestly with your neurologist.

A question and answer session was next on the agenda and viewers were encouraged to send in their questions for Professor Edwards and Dr Morgante. Monika Benson (DE Executive Director) and Rachel Jones (moderator for the event) collated the questions sent in and asked our two speakers to reply. The questions were wide ranging from dopamine responsive dystonia diagnosis to using cannabinoids to relieve symptoms.

There were also questions about covid and dystonia and how covid is likely to make dystonia symptoms worse but dystonia is not likely to make covid symptoms worse. All questions asked were given a full and informative reply.



**Prof Kailash Bhatia**

Professor of Clinical Neurology in the Institute of Neurology, Queen Sq, London

After a short break for lunch Prof Kailash Bhatia (Prof of Clinical Neurology in the Institute of Neurology, Queen Sq, London) talked to us about Prof David Marsden and how he enjoyed working with him until David passed away in 1998. The work and research carried out by Prof David Marsden and his team was vital to the diagnosis and treatment of dystonia today. Kailash gave us a brief history of research into the genetics of dystonia and explained that around 8 new genes have been identified in the last 4 -5 years and he is expecting at least a further 8 - 10 genes to be identified soon. Of course much more research is required.



Adam Kalinowski then introduced us to the David Marsden Award 2021 which is given in his name as recognition for all the research work he did and encouraged. Adam also thanked Ipsen who sponsored this award.

Adam was delighted to announce the winner to be Dr Martin Reich from Germany.



**Dr Martin Reich,**

Julius Maximilians University, Neurology Department,  
Würzburg, Germany

Dr Martin Reich from Julius Maximilians University, Neurology Department, Würzburg, Germany then went on to present the research paper with which he won the David Marsden Award.

Martin and his team have developed a complex computer programme which can predict how the brain will react to the levels of current emitted by their Deep Brain Stimulation device.

Currently a deep brain stimulation specialist will work with the patient to determine the best levels of output to give them the best result possible. There are millions of combinations possible and this process is time consuming and expensive, it can take months to find the best option for each patient.

Dr Reich and his team have developed mapping which shows various electrode placements and predicted outcome for each placement. He could then forecast how well the patient would respond to DBS with electrodes placed using this probabilistic mapping.

This process is quicker and more accurate than the experimental approach to determining the best levels for each patient. I'm sure you can all imagine how that would improve the outcome for all DBS patients, it is no wonder that he won this year's David Marsden award! Congratulations Martin, David would certainly have approved!

Another question and answer session came next and Professor Bhatia and Dr Reich had many questions to answer. Again Rachel and Monika collated the questions and asked our two speakers for their responses.

The questions were very varied and ranged from questions about current research to whether or not DBS patients can scuba dive. To my amusement Prof Bhatia answered all his questions from The Oval while he was watching India and England play cricket!

We enjoyed another coffee break and came back to Dr Kasia Smilowska talking to us about her two surveys. One has already been launched and is available on the DE website, that one is all about dystonia and how it may or may not affect sexuality. Her next survey will be launched later this year and is about diet and dystonia.

If you wish to take part in either or both surveys please look on the DE website. <https://dystonia-europe.org/projects-1/projects/dystonia-survey/>

The final presentation of the day was Adam showing us all the latest version of the MyDystonia app. As mentioned by at least two of our speakers today it is so important to keep a record of your symptoms so you can show your consultant how your symptoms have been since your last treatment. The MyDystonia app is the perfect way to do this, it can be downloaded from the appropriate app store for your smart phone.

What a great day! Approximately 100 people joined in using zoom. I know I learned a lot of new things and particularly found news about treatment options and Dr Reichs research very interesting and promising for the future of treatment for all dystonia patients.

Hope to see even more at the next conference in 2022, we may even be face to face for that one!

**Gill Ainsley**  
Secretary, Dystonia Europe

## Dystonia Awareness Month 2021

Another successful Dystonia Awareness Month has taken place. It is amazing to see all the dystonia awareness activities taking place across Europe and around the world. There were special dystonia days and fund raising activities organised by our member associations. Special social media content with information and education on dystonia was created and shared. In this issue you can read more about some of these activities of DE members.

We are so grateful to all of you who have helped to spread information, increase knowledge, raise funds for research – your support is important to the dystonia community.

Dystonia Europe focused this year on the campaign #escapedystonia where we asked people to share how they manage and cope with their dystonia. Can a passion for something or a special sport or hobby help you to forget the dystonia and better manage the symptoms?

Here are some of the people who shared what they do to escape dystonia:



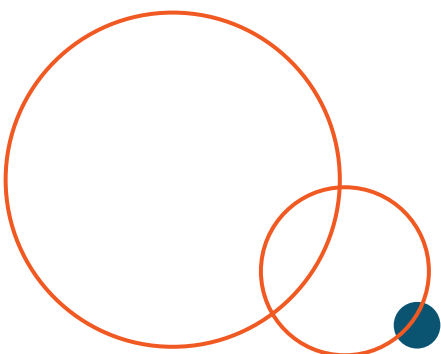
#ESCAPEDYSTONIA

*"My name is Tina and I have been diagnosed with oromandibular dystonia for over a year now. It has been life changing but I have gotten so far thanks to the support of my family, friends and your wonderful page. It has helped me a lot in the past months so thank you. Here is my #escapedystonia picture. Music and my cat make everything better."*

*"My name is Sabina and I enjoy riding a horse because I gain confidence in myself and it helps me to escape dystonia."*



#ESCAPEDYSTONIA





## LATEST NEWS

For more information and contributions see <https://dystonia-europe.org/projects-1/projects/escapedystonia-awareness-campaign/>

We had also created some infographics with the first results of the Dystonia Survey by Prof Maja Relja. These were posted throughout the month. Other content we shared on the Dystonia Europe channels was general information about dystonia, the different types and what treatment is available.

For next year we are planning a series of videos with a funny touch explaining and showing what it is like to live with dystonia. If you have any funny stories that you have experienced, please share with us and maybe it can be part of the content.

Please send to [sec@dystonia-europe.org](mailto:sec@dystonia-europe.org)

*"My name is Leonardo, I am 12 years old; when I was 8 I had first symptoms of dystonia, one year later the Gene KMT2b mutation was identified. Some months ago I had DBS and my life is now better! The activity that makes me feel good is sport climbing."*



**#ESCAPEDYSTONIA**



# Dystonia Physio Exercise HUB - A Digital Platform with Exercises for Cervical Dystonia

Research has shown that Botulinum toxin injections (BoNT-inj) combined with physiotherapy provide good benefit for most people with cervical dystonia (CD). Advanced treatment with Deep Brain Stimulation (DBS) also requires physiotherapy. Repetition of exercises is important to influence brain remodelling and achieve long-term improvements. Exercises should be individualised according to the pattern, nature and problem areas of dystonia. CD can manifest itself in a wide variety of individual patterns, switch in intensity depending on position, and respond negatively or positively to arm movements.

Therefore, the physiotherapist needs to have access to a large number of exercises, with the ability to make an appropriate selection for the individual patient, formatted into an exercise programme. With this as a basis and the pandemic's increased focus on digital solutions, I came up with the idea of a digital platform

containing a large exercise bank for cervical dystonia. The platform is being developed in close collaboration with Dystonia Europe (DE) and its IT expert Eelco Uytterhoeven. DE manages the platform and I am the project owner. The Boston Scientific Foundation Europe (BSFE) has endorsed our application for funding for this project, enabling us to move from idea to reality. All the exercises on the platform will be available via a login code to physiotherapists, who can use simple filter functions to select exercises for a home exercise programme for their patient with CD. The programme will be visible to each patient digitally on the public page through a personal code. For those who are not comfortable with the digital, there is also the possibility to print the programme.

The exercises are provided with 3D models, but in a later phase, animation will also be added. Initially, the platform is in Swedish for physiotherapists and patients in Sweden, and is expected to be available in the near future. In about a year, launch in Europe in several languages is planned. To this end, we have also involved Jean-Pierre Bleton, an internationally renowned French physiotherapist in the field of dystonia, who has laid the foundations for much of the physiotherapy that is currently practised for patients with CD. The platform is also being built with the possibility to extend it to other neurological diagnoses in the future.

**For patients**

Exercises are important for people with cervical dystonia to correct the position of the head, facilitate movement and reduce tension and pain. By seeking out and be assessed of a physiotherapist with knowledge of dystonia, you can receive an individually tailored home exercise programme on this platform. Your physiotherapist will give you a personal code, which you enter in the box below, and press the "My Exercises" button. This will open your home exercise programme, available on computer, tablet and smartphone. Each exercise consists of descriptive text and 1-2 models. For those who prefer to have the program in paper form, it can also be printed.

Enter your personal access code

**Demo**

The demo consists of a training programme with three more general exercises, and aims to give you as a patient, physiotherapist or for other reasons interested insight into what a training programme in the platform can look like. The exercises in the demo are not suitable for all types of dystonia, and cannot replace an individually tailored training programme, which is created and downloaded through the platform.

[Open demo](#)

**For physiotherapists**

This platform is designed to help you as a physiotherapist in your treatment of patients with cervical dystonia. As a physiotherapist you can create exercise programs for your patients in an easy way. For this you need to [register](#) and before registering, you can [view a demo](#) program. [Read more](#)

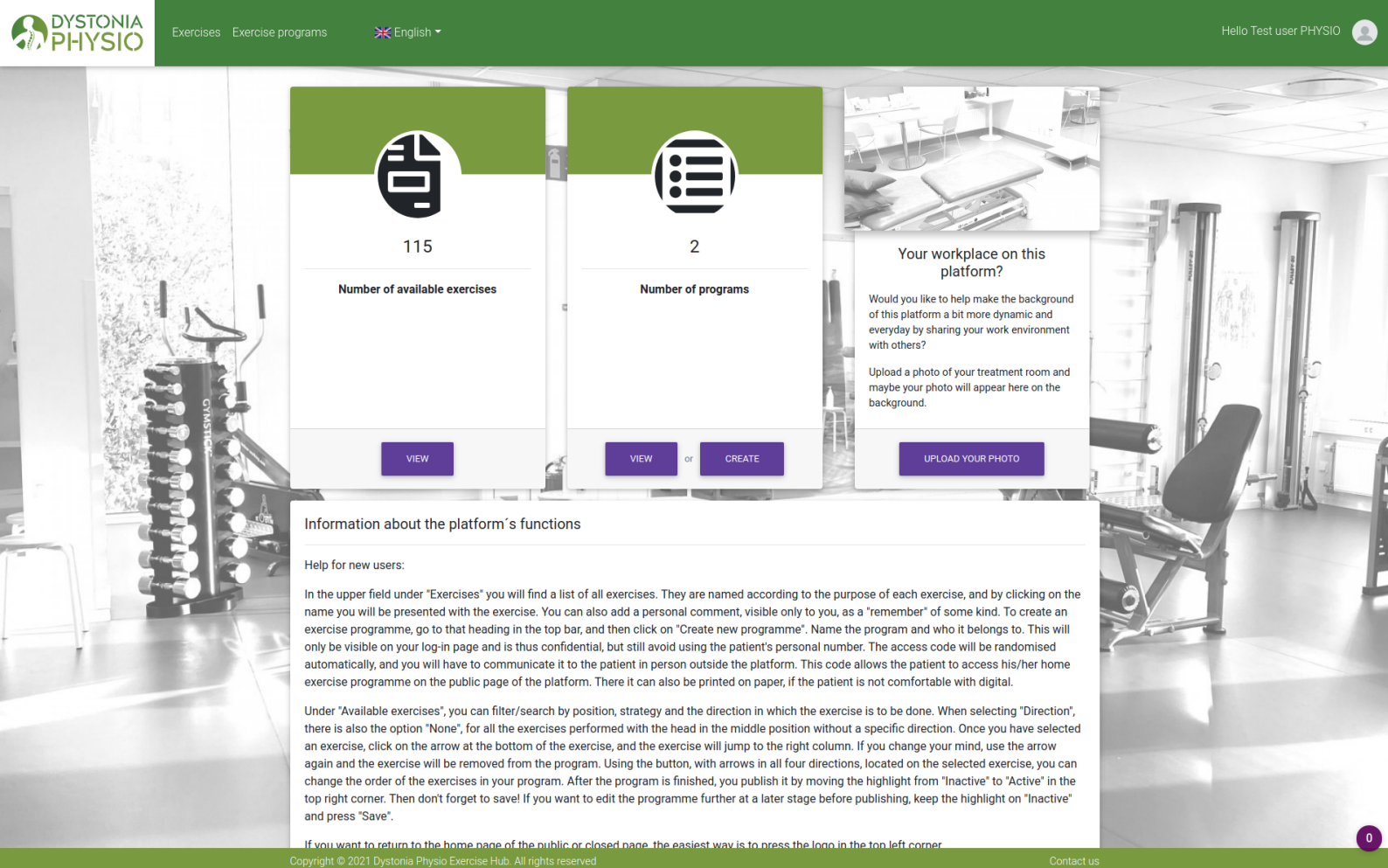
or [login](#)

**Latest news**

**Dystonia education for physiotherapists**

Here you can get some advance information about a dystonia education, step 1 and 2, planned for 2022 for physiotherapists/physiotherapists in Swede...

[Read more](#)



At the start-up, I alone have created all the exercises, but over time I may invite others with specific dystonia expertise, to have the opportunity to add new exercises. The platform is easy to use at all stages. The public part, where the patient downloads their program, works on computers, tablets and smartphones, while computers are recommended for working on the closed side. It should be emphasized that the platform does not replace a physiotherapist contact, but relies on the presence of a physiotherapist who makes an analysis of the dystonia and can thus also shape an individualised home exercise programme.

However, the platform makes it easier for the physiotherapist to select appropriate exercises, to communicate them and for the patient to take responsibility for his or her own training.

The platform is not a commercial activity and will be free of charge for both users and healthcare.

Together with DE, I sincerely hope that this platform, the Dystonia Physio Exercise Hub, will be of great benefit to every person with CD who wants to be involved in influencing their dystonia in the right direction.

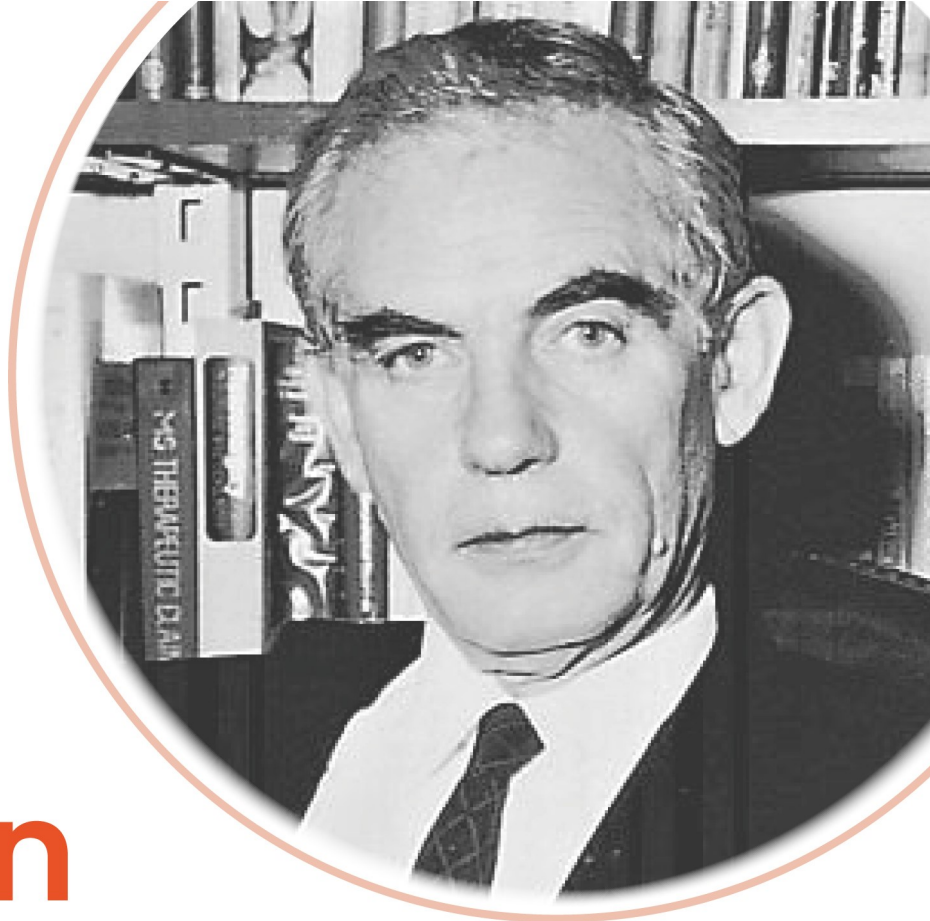
With hopeful greetings

**Johanna Blom**  
Physiotherapist, Neurology department,  
University Hospital of Skåne, Malmö, Sweden





**DYSTONIA  
EUROPE**



# **The David Marsden Award 2022**

**€10.000**  
**to stimulate research on dystonia**

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

**The deadline for submissions is 28 February 2022**

All information regarding the 2022 David Marsden award are available at  
**[www.davidmarsdenaward.org](http://www.davidmarsdenaward.org)**

This award is supported by a medical grant from





# EurDyscover

## Annual Meeting Update

On November 16 the annual meeting of the EurDyscover Consortium was held on-line. Professors Chi Wang Ip and Jens Volkmann welcomed the participants. Each working group then gave a presentation and update on the progress of the work. The Consortium includes specialists from dystonia expert centers in Germany, Czech Republic, France, Italy and Portugal.

By using multiple methods, translational approach and transnational collaboration the consortium aims to discover the pathophysiology of dystonia – role of gene-environment interaction and common pathophysiological pathways. The 3-year research project is funded by a grant of the [European Joint Programme for Rare Diseases](#).

Last July professors Chi Wang Ip and Jens Volkmann took part in a webinar for Dystonia Europe. Here they explain the work of the research project. The webinar is available on the DE YouTube channel:

[https://www.youtube.com/watch?v=PP6QK20\\_nNk&list=PLFvCc6fYkEt\\_7GhGF9OwEEIXo2iBeVRk&index=9](https://www.youtube.com/watch?v=PP6QK20_nNk&list=PLFvCc6fYkEt_7GhGF9OwEEIXo2iBeVRk&index=9)

**Monika Benson**  
Executive Director  
Dystonia Europe



# DBS study in Germany is still recruiting patients suffering from cervical dystonia

## A randomized, sham-controlled trial of pallidal neurostimulation versus botulinum toxin treatment for cervical dystonia (StimTox-CD)

Deep brain stimulation (DBS) of the internal globus pallidus is highly effective for various forms of primary dystonia, but is currently considered a last resort therapy for severe and medication-refractory segmental or generalized dystonia according to treatment guideline.

The first-line treatment for focal dystonia is selective peripheral denervation through repeated injections of botulinum toxin into dystonic muscles. Cervical dystonia, the most frequent focal dystonia, is a chronic condition with profound impact on quality of life.

A multicenter trial has demonstrated the efficacy and safety of pallidal neurostimulation in a large cohort of patients with cervical dystonia, who had failed on botulinum toxin therapy. The results encourage us to challenge the pole position of botulinum toxin in the treatment algorithm for cervical dystonia and to establish DBS as an early alternative by demonstrating:

- superior control of dystonia symptoms by DBS compared to botulinum toxin therapy;
- better health-related quality of life;
- acceptable safety of DBS.

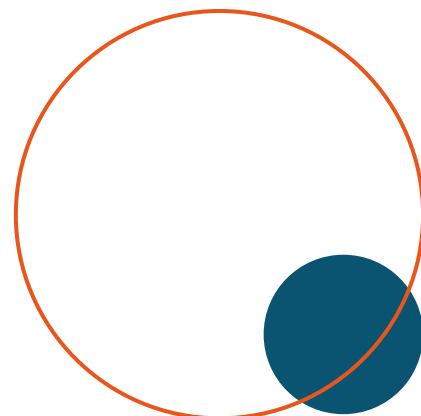
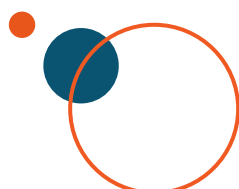
## Who is able to participate in the trial?

... patients suffering from cervical dystonia for more than 2 years aged 18-75 years;  
 ... partial but not satisfying therapeutic benefit from botulinum toxin injections;  
 ... willingness to undergo DBS surgery.

The study is currently recruiting in 12 DBS centres in Germany (Wuerzburg, Berlin, Tuebingen, Cologne, Düsseldorf, Kiel, Hamburg, Luebeck, Rostock, Hannover, Dresden and Magdeburg). Patients who are interested to participate in the trial can contact the clinicians in the next nearest hospital. Contact information and more details about the trial are provided on our homepage [www.dystract.de](http://www.dystract.de). Participation conditions for patients from abroad need to be checked individually. If you live outside of Germany and are interested in taking part please send an e-mail to [Odorfer\\_T@ukw.de](mailto:Odorfer_T@ukw.de)

Thanks for your support!

**Dr. Thorsten Odorfer**  
 Neurology Clinic  
 University Hospital  
 Würzburg



# Sexuality and Dystonia

**DYSTONIA**  
survey

## Take a survey for change!



### Register

If you want to take part in the survey register on [surveys.dystonia-europe.org](https://surveys.dystonia-europe.org)

### Answer

Answer questions on the effects of dystonia on relationships.

### Change

Your experience is valuable and can help specialists address the problems of patients with dystonia!

[surveys.dystonia-europe.org](https://surveys.dystonia-europe.org)

## Dystonia survey

The Sexuality and Dystonia survey is still open on our special platform. The survey is anonymous and available in 15 languages: Czech, Danish, Dutch, English, Finnish, French, German, Italian, Norwegian, Polish, Romanian, Russian, Spanish, Swedish, and Ukrainian.

Created by researchers with a special interest in movement disorders, including dystonia.

The main goal is to examine how dystonia influences sexual life and if so how specialists could address these problems.

Does dystonia affect relationship and sexuality? Take part and help to improve the knowledge of what it is like to live with dystonia.

Survey ends on 28th February 2022.

We thank you in advance for your participation.

### 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



# INNOVATION IN DYSTONIA TREATMENT

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



## Treatment options:



### Injections

Botulinum toxin temporarily weakens affected muscles and reduces spasms



### Surgery

Lesioning of nerves that control the muscles causing spasms



### Medication

A number of medicines can help regulate neurotransmission



### Deep Brain Stimulation (DBS)

Brain stimulation can reduce symptoms of dystonia significantly



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



## What is DBS?

implantation of brain stimulator that helps regulate neural signaling



### Vercise Directional System\*

powered with Current Steering technology is designed for

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

## Boston Scientific in DBS



Contoured edges designed for patient comfort



Directional leads for less side effects



Leads compatible with MRI\*\*



Full body MRI conditional\*\*\*

**89%** of treating physicians think that a directional lead should be used for all their patients<sup>3</sup>

## DBS may reduce dystonia symptoms such as:



Tremor, cramps



Pain



Strained or whispering voice



Muscle spasms



Rapid eyelid blinking



Painful neck spasms

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



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

#### References:

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

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

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

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

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

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

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

All cited trademarks are the property of their respective owners. CAUTION: The law restricts these devices to sale by or on the order of a physician. Indications, contraindications, warnings and instructions for use can be found in the product labelling supplied with each device. Products shown for INFORMATION purposes only and may not be approved or for sale in certain countries. Product available in the European Economic Area (EEA) only. Please check availability with your local sales representative or customer service. This material not intended for use in France. NM-399107-AC\_AUG2020.

**Boston  
Scientific**  
Advancing science for life™

[www.bostonscientific.eu](http://www.bostonscientific.eu)

© 2020 Boston Scientific Corporation  
or its affiliates. All rights reserved.

## Prof Tom Warner is elected President of the Association of British Neurologists



Dystonia Europe is delighted to congratulate Prof Tom Warner, Institute of Neurology, Queen Square, London, on his recent election as President of the Association of British Neurologists.

This is a well-deserved honour for a very fine clinician and researcher, who is Director of the Reta Lila Weston Institute of Neurological Studies, and Director of the Queen Square Brain Bank for Neurological Disorders.

During his early years in the specialty of neurology, Prof Warner became interested in movement disorders, working in the teams led by Profs David Marsden and Anita Harding (two of the world leaders in the early work of understanding dystonia), at the Institute of Neurology in London. For almost 30 years since then, he has been a true friend and an invaluable scientific adviser for Dystonia Europe and a hugely beneficial influence for dystonia patients generally.

His generous support of Dystonia Europe's projects, with his time and expertise, has been an important part of our development since our foundation, and his clinical and research work on dystonia and related areas has contributed greatly to improvements for patients.

We are truly grateful to him for his continuing efforts for people living with dystonia and we wish him every success in his new role.

**MBE Alistair Newton**  
Advisor, Dystonia Europe





## Class for Contact Persons held by Norwegian Dystonia Association



**Dr Jeanette Koht**

To have Contact Persons is an important part of the work the Norwegian Dystonia Association (NDF). A contact person, in this context, means a person who is diagnosed with dystonia himself/herself and has had it for a while, and has been trained on how to respond to a person that contacts NDF.

On Wednesday 27 and Thursday 28 October 12 NDF members took part in a workshop at Scandic Lillestrøm Hotel, Norway, to get more knowledge on how to carry out the work of being a contact person. The training included sessions on how to meet people who either make contact through phone or email and want to learn and understand more about dystonia, how to live with dystonia, what treatments are available etc.

In the Norwegian Dystonia Association it is preferred that all board members undergo this and have the knowledge that is required to be a contact person.

As a contact person you are trained to talk with others about dystonia, from a patient to patient perspective. It is necessary to have a good understanding of the different types of dystonia and how they affect you. You need very good listening skills. It is also important to be able to answer questions from those who need someone to talk to about the strange and involuntary muscle contractions they may experience.

With the role of a contact person there is a set of rules one must follow and routines to adhere to, which was a theme in this class.

An experienced neurologist, Jeanette Koht from Oslo University Hospital, held a lecture on dystonia symptoms, diagnosis and treatment. Jeanette mentioned that about 30 of 100,000 persons are affected by dystonia. She also emphasized that many people are not being diagnosed, or it takes years for some to be diagnosed.

Jeanette explained the different kinds of dystonia for example cervical dystonia, blepharospasm, dysphonia (vocal cords) and others. She spoke about the various forms of treatment; medication, botulinum toxin, physiotherapy and surgery such as Deep Brain Stimulation (DBS)

On day two, NDF President Johan Arnfinn Warvik told us more on what it means to be a contact person. Most of all it is important to be a person with similar experience that has good listening skills and puts the other person in focus and to use their own experiences as a background to support the other person. Any medical questions, one must refer to those that have medical training and knowledge in the field.

Each contact person is responsible for ensuring confidentiality.

**Vidar Bjørkli**

Board Member Norwegian Dystonia Association  
translated by Merete Avery, Dystonia Europe



Participants and speakers at the class for Contact Person's

Left: President of the Norwegian Dystonia Association Johan Arnfinn Warvik



## Book about Musician's Dystonia, by Coralie Cousin: "The Day My Hand Stopped Playing: Treating musician's dystonia: Aurélien's story"



Dystonia Europe is pleased to present the new book by Coralie Cousin, a French therapist who has been close to our Medical and Scientific Advisory Board for many years. We are delighted to welcome this book, as musician's cramp is rarely documented or reported.

With a degree in physical therapy, Coralie Cousin has been specializing in the rehabilitation of the musician's hand dystonia for twenty years. Coralie Cousin has set up her medical practice: "Kiné des Musiciens" in Paris, France and has treated and advised more than 6000 musicians.

She is a consultant physiotherapist for renowned institutions: the "École Normale de Musique" (Music School) from Paris and the "Orchestre National d'Ile-de-France" (National Orchestra from Paris area). Through numerous articles, conferences, radio and television interviews, she tries to help musicians prevent musculoskeletal disorders (MSD).

### Presentation of the book by its author:

I am extremely pleased to announce the release of my book "The Day My Hand Stopped Playing", first published in June 2021 in French "De jouer, ma main s'est arrêtée".

For a long time, I have wanted to share my experience as a musician's physiotherapist on musician's dystonia, a tragedy that shakes the artist in his passion.

Musician's dystonia is a rare disease, which nobody wants to talk about, not even musicians among themselves because it is scary. And yet, it can be found among the prodigies of music, such as Robert Schumann and Leon Fleischer whose careers were prematurely interrupted.

Among the musicians I have treated for dystonia, one has agreed to testify. However, he always refused the format of a narrative.

Then one day, I came across "La guerre des tranchées" in comic book format. For the first time, thanks to the drawings, I saw the battle differently. I then realized that through illustrations, one could better understand the suffering of an artist affected by dystonia.

I then asked this musician to testify in order to write a true story, that of Aurélien, as a comic book with my illustrations. I wanted to demonstrate a slice of life of an artist suffering from dystonia from the patient's point of view. I didn't want to limit myself to the therapist's point of view. He immediately accepted, seduced by the project.

Professor Eckart Altenmüller\* found this idea very original and unique, and also agreed to participate in the project by writing the preface.

*"Based on a true story, the book explains the path to recovery from dystonia, its diagnosis, but also the ways out.*

*It tells the story of how multidisciplinary therapists treat, support, and restore the confidence of this artist so that he can play again and get back on stage."*

*\*(Prof E. Altenmüller is a German physician and musician and one of the leading researchers in the field of neurophysiology and neuropsychology of musicians.)*

*"The dystonia could have been avoided if I hadn't waited two years to get the right diagnosis. I probably wouldn't have fallen so far" says Aurélien in the story.*

Through this comic book, I wish to educate the world of music: professionals, amateurs, teachers, students in music schools and conservatories and therapists who meet musicians: "We had to break this wall of silence. The more we talk about it, the more we will inform and the less there will be victims" concluded this musician in his testimony at the beginning of the book.

Today the prevention of musician's function dystonia is an emergency.

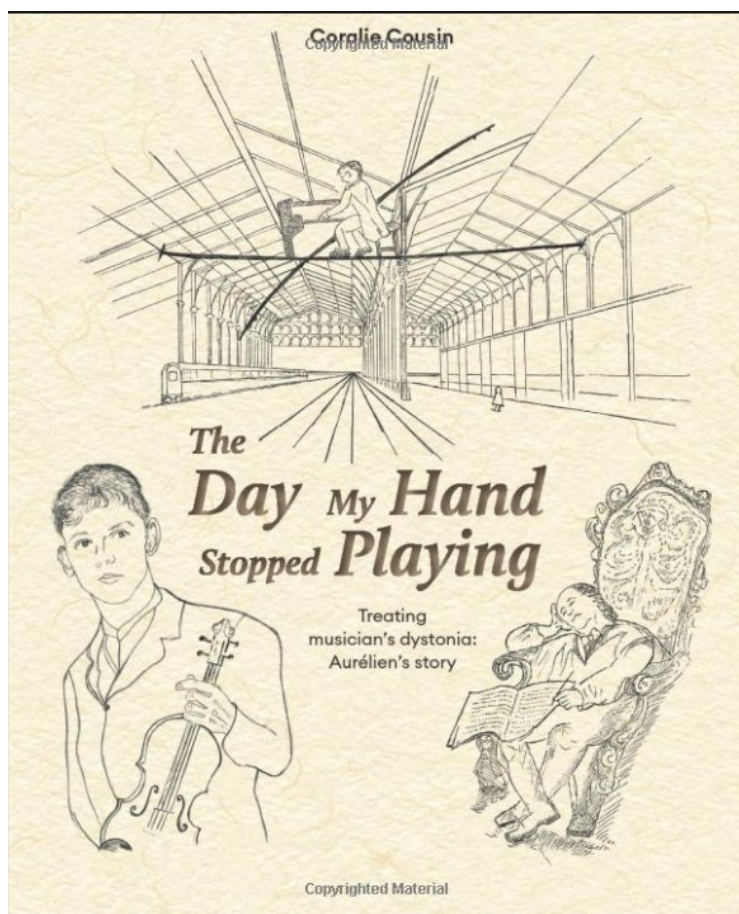
To order the book, visit: [https://www.amazon.com/dp/B09K1Z1F8R?ref=pe\\_3052080\\_397514860](https://www.amazon.com/dp/B09K1Z1F8R?ref=pe_3052080_397514860)

Amazon's user testimony: Addressing the theme of functional dystonia through the experience of a musician (and beyond, all the pathologies that affect musicians) is a brilliant idea. We musicians experience these problems very badly, we quickly sink into panic and despair. Lost, we consult all the opinions, all the medicines, expecting rapid results, even immediate. Thanks to Madame Cousin's book, we understand how to approach these problems, with more serenity, patience and hope. This perspective, that of the musician, allows us to identify ourselves, gives us hope, the hope of getting out of it, helps us to better understand what practitioners expect of us. It helps us find the calm essential to put into practice the advice we receive.

In addition, this book details a series of exercises very well described and well-drawn, very concrete, which allow each one to build his own protocol of \*cure. Thank you, Madame Cousin. When will there be a book for music teachers to help us guide our students?

\*Comment to Amazon's user testimony, there is no known cure of dystonia but many excercises relaxing techniques etc. can improve dystonia for many patients.

**Edwige Ponseel**  
Vice President, Dystonia Europe  
President AMADYS







## DE President at the celebration of the 30th Anniversary of the Spanish Dystonia Association

ALDE—Asociación de Lucha Contra la Distonía en España (the Spanish dystonia association), held a conference on November 20th in Madrid, to celebrate its 30th anniversary. Adam Kalinowski, took part in this event as a representative of Dystonia Europe.

It was a great opportunity for our president to meet representatives and partners of ALDE and to talk to dystonia patients in Spain.

This is an important anniversary, not only for the Spanish Association but also for Dystonia Europe. ALDE has been a member of DE since our organization was founded, and former ALDE President - Felisa Justo Alonso, was also one of the founders of Dystonia Europe in 1993.

Congratulations to ALDE and thank you for your work for the dystonia community in Spain and for 28 years working with Dystonia Europe.

More about this event in our next newsletter.

**Adam Kalinowski**  
President Dystonia Europe



**Adam Kalinowski**, Dystonia Europe president **Ana María Martínez**, president of ALDE



**Felisa Justo Alonso**, founder and former president of ALDE and Dystonia Europe



# EPF Congress – Digital Transformation of Health Care

---

EPF (European Patient Forum) held an online congress over 4 days, 26-29 October.

This was an extensive and excellent Congress given on a platform called Swapcard, with many possibilities to participate actively. Here we give a brief insight of some of the topics and discussions.

In the opening session, **"The digitalisation of health and care systems in light of COVID-19: what way forward and which role for patients"**, Dr Hans Kluge WHO Europe, warned of the risk of repeating the mistakes that led to past failure of digital transformation initiatives. He highlighted how the experience of Covid-19 could be seen as a wake-up call to put patients at the centre of innovation in development and use of digital technologies and also increase equitable access to the results.

Other sessions were

**"Patients' health data sharing: perspectives, risks and key concepts"**

with discussions on the current state of data protection, the implementation challenges around GDPR and the potential impact on patients' lives. It was emphasized that while the industry has a legal and policy framework in place, it lacks the supporting policies and practical guidance required to educate stakeholders about using health data effectively while protecting patient privacy.

**"Our health in our hands: the role of mobile health to improve patients' control of their healthcare"**

a discussion on the role of mobile health and digital therapeutics in improving patients' control of their own healthcare. It was highlighted that there are great Apps that can directly influence patient outcomes in areas such as cancer and that the planned standardization of apps using four key elements should help build patient confidence and use.

**"Patients and healthcare professionals: a partnership for and through digital health"**

Annabel Seebohm shared elements of the *Consensus Framework on the Digital Transformation of Healthcare*. She outlined the four key recommendations, focusing on upholding trust, patient confidentiality, protecting patients' rights and limiting commercial influence.

**"Improving medicine innovation through better use of health data: Big Data and real world evidence"** with discussions on how real-world data and big data can improve medicine innovation this data could lead to delivering better and safer treatments for patients, possibly at a faster rate and lower price, and in a more equitable way and it was highlighted how the regulatory challenges we see in randomised clinical trials provide the opportunities for real-world data, for example, in the identification of unmet needs, or increasing the quantity of available data on adverse events, as seen in the real-world example of vaccine safety with Covid-19

**"Artificial Intelligence in Healthcare"** This session was focused on the challenges and opportunities of AI in health, particularly in improving patient understanding and engagement and how it fits in the current regulatory framework.

**"The road to patient empowerment - Data and Digital Health Literacy"**

a discussion on the growing movement of digital health data literacy, highlighting that an increase in literacy can empower patients and bring improved healthcare services.

**"Safer digital health: how to ensure it at the European level"**

In a special session looking at the safety of commercialized products and the role regulatory bodies have, where among other points it was outlined the enormous growth of medical technology of the last few years, and how a circular process that covers different steps within the entire product lifecycle is needed to generate evidence in support of commercialization.

### "Patients as co-designers and co-innovators: between theory and practice"

In a panel discussion it was addressed the learnings from the EPF Congress 2019 and the development of the new Innovative Health Initiative which is helping to create an EU-wide health research and innovation ecosystem.

### Congress closing session

During the Congress closing session, co-hosts **Ivett Jakab** and **Tjasa Zajc** were joined by **Marco Greco**, the President of the European Patients' Forum. Before joining the co-hosts reflected on the last four days, highlighting that while ground-breaking progress is being made in data and digital health, it is essential to keep co-creating to bring answers to questions raised. On the topic of breathing life to the EPF Congress, Marco Greco underlined it was fundamental to get it off the ground due to the relevance to everyday life.

The world is generating data every moment and provides valuable information that can empower not only patients, but also other stakeholders. As per Marco's key takeaway, the congress was about education, co-creation, and opportunity. He concluded by announcing the follow-up event, EPF Congress 2022 taking place from 21-22 April in Brussels next year.

Summary from the Congress is partly from the EPF news of the Congress

**Merete Avery**  
Operations Manager

2021 **EPF**  
Congress

#EPFCongress2021

digital transformation of **healthcare**

# EPF Congress Closing Session



**Closing Address**

**Marco Greco**

*President, EPF*



**Tjasa Zajc**

*Congress Co-Host*



**Ivett Jakab**

*Congress Co-Host*



## Have you signed up for EFNA's eLearning content yet?

In late 2020, EFNA launched a pilot series of online e-learning modules on advocacy-related topics. These courses aimed to upskill participants on how they can effectively advocate in a virtual world by identifying and engaging key stakeholders and developing partnerships, hosting successful online events and developing and disseminating key advocacy messages.

The courses are video-based and divided into sections that can be watched independently at times that suit the viewer. Each module includes supporting notes and worksheets, as well as the option to take a quiz on the content and receive a personalised certificate of completion.

Following the successful launch of that pilot series, EFNA has developed two further e-learning series in 2021- one on the topic of personalised healthcare and one exploring EU Funding.

Personalised healthcare is a medical model that aims to provide tailor-made prevention and treatment strategies for defined groups of individuals. Over five modules, participants will learn more about the challenges and opportunities posed by personalised healthcare, and

what role patient representatives can play in making this approach a reality. Expert presenters explain the concept, discuss the role of patient empowerment, the future of research, the regulatory and reimbursement models of tomorrow, and the ethical implications of treatment based on genomics and supported by information technology.

The latest series, launched in November 2021, looks at EU Funding.

The EU provides funding for a broad range of projects and programmes covering almost all areas. Navigating all these programmes and applying for funding can be quite a daunting process. In this series of e-learning modules, you will be taken step by step through the relevant processes and provided with all the information you need about specific funding programmes.

EFNA's e-learning modules are free to access, though registration is required.

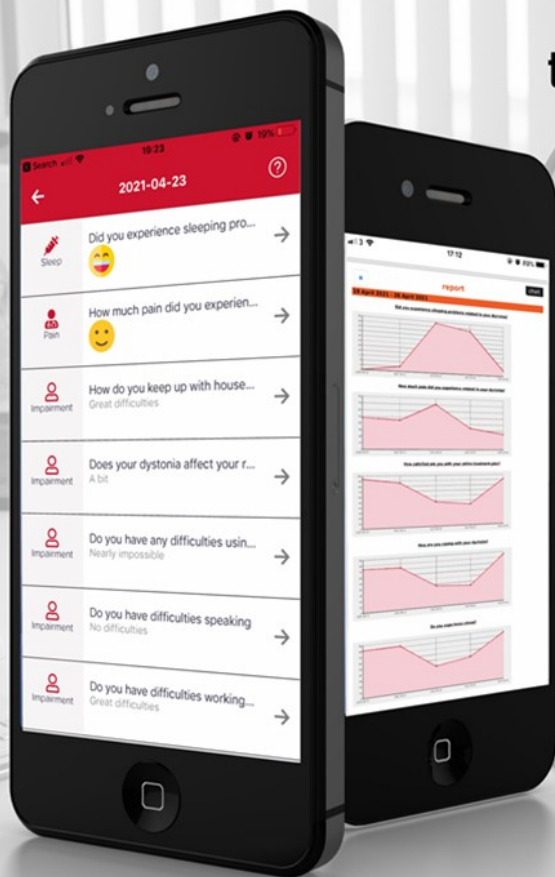
Learn more and register at: <https://www.efna.net/elearning>

**Elisabeth Cunningham**

EFNA



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 Days 2021 in Helsinki



During Dystonia Days the Finnish association had an annual meeting where Jukka Sillanpää was re-elected as a president for the period 2022-2023. Annually half of the board (and vice members) are to be elected. In the picture (from the left) Pekka Karimerto, Taina Lehtinen, Jukka Sillanpää, Sari Kuja-Kyyny, Paula Happonen, Leea Sihvo-Rajala and Martti Ketonen.

Photo:  
Tytti Svetloff, Finnish Parkinson Association

September was, once again, a great dystonia awareness month. Dystonia Europe's Dystonia-Days provided a good start for the month with a varied webinar. We arranged another dystonia webinar in collaboration with the Finnish Parkinson Association. The second webinar was conducted in Finnish as the local language is greatly preferred among our members.

The dystonia awareness month culminated in the Finnish Dystonia Days which took place in the capital of Finland, Helsinki. The venue was a new Pasila railway station with a great mall consisting of dozens of stores, restaurants and a hotel. Pasila has good accessibility by local and long-distance trains. The easy accessibility was highly appreciated by the participants. Sokos Hotel Tripla provided an excellent setting for the Dystonia Days as well.

Dystonia Days attracted approximately 60 participants to the scene to enjoy the program, meet other members and experts – and furthermore, get and receive support among the other people suffering from dystonia.

The program was constructed to cover issues from neurological aspects and dystonia research to physiotherapy, pain, and mental well-being. Having enough breaks was difficult to achieve as all presentations received a lot of questions and interest.

Dystonia research seems to progress at a slow pace. The first speaker, Rebekka Ortiz, finished her dissertation last year. The second speaker, Aleksi Kokkonen represented Turku PET Center, where they utilize magnetic resonance research methods to understand mechanisms causing dystonia. Both Ortiz and Kokkonen stated that mechanisms behind dystonia – especially cervical dystonia – can be more complex than previously assumed. The research is still going on. The Finnish Dystonia Association is supporting the research by conveying invitations to the members to participate in the experimental research.

Due to the current Covid-19 situation, the traditional Jump for Dystonia picture was decided to be taken in 2022, at the earliest.

**Text and pictures: Jukka Sillanpää**  
President Finnish Dystonia Association and Board Member DE





## Second Italian National Dystonia Day

On Sept.25th A.R.D. organized the Second Italian National Dystonia Day; it was an online event, shared by our social media, as it had been in 2020. Last year Prof. Albanese had launched an ambitious project concerning musicians: a survey in Italian Music Academies, Schools and Conservatories in order to know whether students are informed about dystonia and how many of them are now facing its symptoms. This survey is the first ever carried out in Italy about this topic and Dr. Anna Castagna presented the first results: 23% of the participants are singers, 15% play guitar and minor percentages play other instruments; 48% declared that they don't know what dystonia is, 20% maybe know and only the remaining 32% are informed about the disease. The aim of this survey is to have a picture of the connections between music and dystonia, in order to inform and take action before the artists are compelled to change their professional career. The survey is being carried out until December 31st. The hashtag of this day was "Ogni passo conta" which means "any step is valuable": this year we focused on 5 stories of patients who could fulfil their life and achieve their desires step by step, in spite of dystonia.

Our first story was from Vera Issel, a young musician with hand dystonia who took part in Dystonia Europe Dystonia Day on September 4th. As a young girl, she played bowed instruments (violin, viola, cello) but in 2010 she had to stop due to her hand problems which her teachers did not acknowledge, blaming her as "not a good player". Two years ago she began a new therapy and is now playing cello again, using 3 fingers of her left hand. She has realized that improvising music is better than reading it on the score: when free to play as she wants, her hand obeys and allows her to express her love for music. She played 3 short pieces for us on her cello. Now her aim is giving voice to people considered as 'outcasts' or 'different' through her music, being a spokesperson for those who could not speak or were not heard. That's why she plays in prisons, former mental hospitals and former concentration camps.

Then Giuseppe Grossi presented his story: he loves running and taking part in marathons, but some years ago he began to have problems in his right leg and did not have full control of it. After a very long period of therapies he has been able to walk and run again. Two years ago, in the A.R.D. team, he ran a relay race organized by Charity Program, a great solidarity project created and supported by Milano Marathon which allows people to run for a non-profit association, helping it to



Vera Issel

collect funds. Since then, he keeps running but now he prefers running on compact earth or grass paths, rather than on concrete roads as he feels that his leg works better on off-track paths.

A paralympic athlete (winner of 3 bronze medals in Tokyo this year) was our 3rd speaker: Monica Boggioni, aged 23. She cannot walk due to paralysis in her legs, and when a baby she began to swim as a therapy. Water gave her a sense of freedom and she was in her element. She decided that she wanted to participate in competitions but when 17 she developed an arm dystonia too. In spite of this, in 2017 she joined the Italian National team for international competitions: since then she has achieved 3 European records and 3 world records, winning many medals. In the Tokyo Paralympic Games she won 3 bronze medals, in 100m freestyle, 200m freestyle and 200m medley.



Giuseppe Grossi





Monica Boggioni

Monica is now attending Biotechnologies courses at the University of Pavia and wants to specialize in medical genetics, in order to find cures for scarcely examined pathologies.

Since 2018 A.R.D. has awarded 2 prizes *“Best study about dystonia by young doctors”* (each of €2000) on the occasion of the annual congress of the Movement Disorders Society (LIMPE-DISMOV).

We introduced Dr. Monfrini and Dr. Carbone who last year won the A.R.D. awards during the 6th Annual Congress of LIMPE DISMOV.

Dr. Edoardo Monfrini (aged 31) works in Fondazione Ca'Granda, Ospedale Maggiore Policlinico in Milan. He told us about his work: “A mutation in a novel lysosomal gene causes adult-onset generalized dystonia in an Italian patient” This study shows that the identified gene mutation causes some forms of hereditary dystonia.

Dr. Federico Carbone who works in the Neurological Department of the Medical University in Innsbruck, Austria, illustrated his work “Impaired inhibitory control of saccadic eye movements in cervical dystonia: an eye tracking study” A saccade is a rapid eye movement; this study shows that patients with cervical dystonia may

have a scarce or reduced control of saccades, probably due to a dysfunction of the corticobasal network. We think that it's very important to foster research and stimulate young doctors to develop knowledge and interest in our disease; these awards may be a good way of encouraging them.

Our 4th story was from Carlo Iacomucci, a painter and drawer with focal hand dystonia. He began to draw at the age of 13 years and to paint and engrave at 22, he has been a professor of painting disciplines for 36 years. In 2004 he began to feel a strong unbearable heat in his right hand, he could not hold his brush or chisel very well and eventually had the diagnosis of “task specific focal dystonia”. He began with botulinum toxin injections and was recommended by his doctors to exercise and re-educate his hand by writing and drawing in a notebook. He wrote many pages copying texts about the graphical techniques he used (xylographs, etchings with acid, aquatints, etc) adding his drawings on each page. His exercise pages were collected in a book issued in 2019 with a revealing title *“The rebel hand”*; it is composed of 40 drawings made with graphic pens, stamp punches and graphite shades. Mr. Iacomucci has developed a peculiar sensory trick, he touches his right middle finger with his left middle finger, so as to avoid involuntary movements and be able to grip his brush or pen.



Erika Alaimo

## AROUND EUROPE AND BEYOND - ITALY

Many books about dystonia have been published up to now, but usually they deal with stories of people with the disease. In Italy this is the first and only book with drawings by a dystonic hand and we thank Mr. Iacomucci who shows us how to take back possession of a "rebel hand".

Our last speaker was Erika Alaimo, a young lady who had many medical problems as a child (she had 2 cerebral hemorrhages with hemiparesis due to a cerebral angioma which was later burnt; when 16 she got a diagnosis of hand and arm dystonia). Her childhood and teens were very difficult at school and outside because she felt discriminated by other boys and girls, who made fun of her dystonia. A total change happened when she began University: using botulinum toxin and medicines her dystonia was less severe and she began to have friends. Now she is working as a teacher for students with disabilities, this satisfies her desire to help children who are now facing the problems she experienced herself. While telling us her story, her boyfriend was beside her, and she concluded that now she is really happy, smiling to her love.



Erika Alaimo

We had invited Adam Kalinowski, President of Dystonia Europe, to take part in our day. He had registered a video in English, which had been subtitled in Italian; he greeted all the participants and illustrated the activities of DE; he reminded us that DE had been founded in Spoleto, Italy in 1993 as "European Dystonia Federation" and now includes 22 associations from 19 European Countries.

There is a strong cooperation between DE and A.R.D, which has been strengthened in recent years starting when the annual Dystonia Days meeting was held in Rome, in 2017 on the occasion of the 25th anniversary of our Association.

We had 2 sessions dedicated to Q&A as we had received a large quantity of questions; Dr. Francesca Morgante and Dr. Nardo Nardocci answered many of them but it was impossible to reply to them all. Dr. Morgante promised a specific webinar dedicated to the questions which could not be answered. As for the doubts about dystonia and the COVID vaccine, the doctors clarified that up to now a lot of patients have been vaccinated, without side effects; COVID may be much more dangerous in dystonia patients who are not vaccinated.

At 1,30 pm, after 3 and a half hours without breaks, we ended our live broadcast. We have received thanks and compliments for this successful event and we are already thinking of our next Dystonia Day next year, when A.R.D. will celebrate its 30th anniversary.

**Maria Carla Tarocchi**

Vice President

Associazione per la Ricerca sulla Dystonia A.R.D.  
Italian Dystonia Association





## A.D.D.E.R. Action for Dystonia, Diagnosis, Education and Research Dystonia Awareness Month 2021

Dystonia Awareness Month each September is one of the biggest things in our annual diary. It is a great opportunity to raise awareness around the world especially using social media.

This is the third year A.D.D.E.R. have designed and delivered our dystonia awareness campaign throughout the month of September.

The next slide explained dystonia correctly and hopefully educated a few people!

The main part of the campaign was to ask people to imagine they had dystonia and how they would cope.

I really wanted people to know just how it feels to have dystonia, far too many times people have told me to 'stop fighting it' as they seem to think we have the choice! I felt they may gain a better understanding if they could imagine how dystonia feels. These slides attracted a great deal of attention on our Facebook page and were shared many times.



**How can you help?**

A great deal more research is required to better understand dystonia and improve treatment.

**You can make a donation to the ADDER research fund on [justgiving.com](https://www.justgiving.com)**

**You can use the Drug Stars app and choose ADDER as the charity you would like to support. [drugstars.com](https://www.drugstars.com)**

**You can buy your utilities from Utility Warehouse and quote ref G71381.**

**You can help to raise awareness by sharing our posts.**

**You can register ADDER as your charity to support on Amazon Smile [smile.amazon.co.uk](https://smile.amazon.co.uk)**

After a great deal of thought I came up with the idea of asking people to imagine what it is like to have various types of dystonia. The campaign was aimed at people who know nothing about dystonia or who may have heard of it but aren't sure what it is.

I began by creating a slide called 'Do you know what dystonia is?'

As the slide says, these are all questions I have been asked when I've told people that I have dystonia.

Of course the people who use our Facebook page will already know about dystonia but each time someone shares one of our posts the message gets out to those who don't know about it.

I shared them myself to my own personal facebook page and my friends then shared them further afield which of course is what I hoped would happen, so far I felt the campaign was going really well.

## AROUND EUROPE AND BEYOND - UK

As well as sharing our own campaign I also shared Dystonia Europe's campaign which was much more extensive than the one I created. These posts were also looked at and shared many times.

My aim was to get dystonia talked about and it was looking like I had succeeded in that!

The last slides I shared were about treatment options and finally how people could help us to spread awareness and get more research done.

There were times throughout the month when I was disappointed with the number of interactions I got with my posts. When I looked at the figures for last year, there were many more interactions and I wasn't sure why. looked back at last year's



### Do you know what dystonia is?

Is it a country in Europe? No, that is Estonia.

Is it an unpleasant fictional society? No, that is dystopia.

Does it make reading and writing difficult? No, that is dyslexia.

Is it an unnatural desire to drink alcohol? No that is dipsomania.

Is it an upset stomach? No that is dyspepsia.

**These are genuine questions I have been asked when I have told people that I have dystonia.**



### Do you know what dystonia is?

**Blepharospasm:**  
Dystonia in one or both eyelids.  
Causes eyelids to clamp shut rendering the patient functionally blind.

**Imagine you have a foreign body in your eye/s and your eyelids refuse to stay open.**

**Now imagine that your eyes feel like that all day every day.**

**How would you cope?**

Keep watching to find out about treatment options.

campaign and realised each post contained a photograph, maybe that made them more interesting. This campaign had reached less people than last year so in future I will include photographs in my campaign to make the posts more interesting.

At the end of September I checked out the number of interactions and was very pleased to see that we had 2,738 people who had seen and/or interacted with our campaign. Even though it didn't attract as much attention as last year, at 2,738 people reached I can safely say our campaign was successful.

So, that is our campaign over for 2021 but as we all know dystonia doesn't only affect us for one month.

of the year, we will continue to work hard all year round to raise awareness and encourage research, improve treatment and continually search for a cure.

**Gill Ainsley**

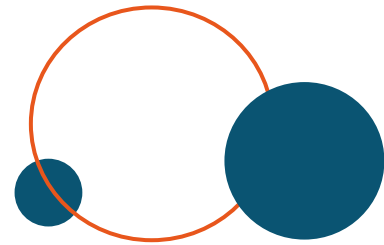
A.D.D.E.R. Treasurer and Administrator  
and Secretary Dystonia Europe





## Dystonia UK Activities 2021

---



As another unpredictable year draws to a close, Dystonia UK reflects on a busy year of activities, while eagerly looking forward to the potential opportunities of the New Year.

Virtual activities have continued with great strength. At the time of writing, we have provided 6 'Reach Out, Reach All' webinars, including one live from Scotland, the first series of our Dystonia Matters podcast, a digital conference for kids, carers & families, and many online support group meetings. They have been an invaluable opportunity to continue connecting the UK dystonia community and we hope to continue into 2022.

In a year while so much still had to take place online, it was a real highlight as part of Dystonia Awareness Month 2021 for the team to hit the road with their 'Team on Tour' across the UK. From Edinburgh (Scotland) to Kent (England), and from Wrexham (Wales) to Oxford (England) we certainly made the most of being able to travel again! We really appreciated being able to connect with our amazing community in person once again and are so grateful to all of those who came out to meet us on our travels.

As part of the tour, we were thrilled to launch the second episode of 'Dystonia Animated', a short animation series designed for kids, carers & families to help support in all aspects of life living with dystonia. Episode two, 'Charlie at the children's hospital' follows Charlie as he visits his regional hospital for the first time and takes a glimpse into his life at home and follows on from 'Dani explains dystonia' where we meet Dani & Charlie who both have dystonia. The 2 episodes have now reached an incredible 1,000,000 people and counting!

We were also lucky enough here in the UK to return to some normality and be invited back again to cheer on our fantastic fundraisers at challenge events in person! The buzz of the Great North Run in Newcastle, England, felt even more special after so long. We were equally

excited to bring back our very own virtual awareness and fundraising campaign 'Dystonia Around the World' following its hugely successful debut in 2020. This year, our amazing champions baked, cycled and learnt new languages all in a bid to collectively travel 25,000 miles, the distance around the world, to raise awareness of dystonia. They smashed their goal travelling 25,075 miles and raising an incredible £16,461!

On a theme of smashing goals, one member of our amazing community went above and beyond, bringing home a silver AND gold medal from the Paralympics. We are of course referring to our incredible patron, Tully Kearney, who not only came 2nd in the Women's 200m Freestyle S5 and 1st in the Women's 100m Freestyle S5 representing GB but also broke her own world record! Tully was very open about her dystonia in the media and used the platform to help raise vital awareness of how dystonia can severely impact life.

We know that life with dystonia isn't always easy, and as we enter 2022, just like our sister charities, we will continue to be there for the community. To help make this happen we're asking everyone in our community to donate £1 to support our work. We aim to raise £100,000, one pound for every person thought to be affected by dystonia in the UK. According to the European Brain Council though, there are more than 500,000 people living with dystonia across Europe, and if every one of them donated £1 we could do so much more including support of vital dystonia research.

Please donate £1 today to support the dystonia community, thank you. [www.DonateOnePound.org](http://www.DonateOnePound.org)  
#JustOnePound

**Victoria Wareham**  
Director of Operations and Development  
Dystonia UK









Ulrike Halsch

## Meet Ulrike Halsch, President Dystonie und Du e.V, Germany

---

### What is your name?

My name is Ulrike Halsch

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

The voluntary work in the patient organization is a lot of fun and is very diverse, but it requires a lot of responsibility. It is not guided by economic interests and has a social value because of its members. In the patient organization, you can work together towards goals for the patient. It is motivating to have so many other support points and encouraging to achieve something for the community as a whole. That's why it is also very important that the organizations are also supported by each individual to tackle problems and find solutions together. For me, it is also important to have good, neutral cooperation with other health associations,

doctors and health insurance companies. Networking between politics and associations is also indispensable in order to be able to demonstrate organizational expertise from different perspectives.

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

I like to spend my free time with my hobbies, glass art and gardening. My family, dog and nice friends are very important to me. If there is time left I love to travel.

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

In the basic work you experience a lot of suffering and tough stories from the patients. On the one hand it is an absolute highlight when you have made it and were able to help patients to achieve happiness and progress in life.

### What makes you angry or frustrated?

Rarely anything makes me really angry, but what I don't like are falsehood and being deceitful. I always try to be calm and adjust to the situation, because you can't make other people change. What you can do is change yourself or at least your attitude to change something in the overall situation.

**Ulrike Halsch**

President of Dystonie und Du e.V  
Germany



### Meet Johan Arnfinn Warvik from Norway: My Life with and without Dystonia

After using some parts of my story as background for a presentation on “Living with Dystonia”, I was strongly encouraged to share my story in the Norwegian Dystonia Newsletter.

I was born on the west coast of Norway in 1954 and have had dystonia since 1985.

**Normal life:** Like most of us, my life started with an ordinary upbringing, childhood and teenage years filled with lots of play and fun. Early on I learned to take responsibilities and to work for what I wanted in life. After further education and service in the Army, I had a family of my own. I am married to Jorid and we have two children. I had a career, combined with much social activity and community engagement. Everything seemed normal.

**Unusual symptoms:** In March 1985, on an ordinary Sunday, my head started to make involuntary movements, it struck me like lightning from clear skies, my head was moving totally uncontrollably. I was partially stuck towards the left side. How could I stop this? What was happening to me? I felt a panic spreading throughout my body, and no one except for Jorid was informed. After one week I went to the general physician (doctor), as it did not pass like I hoped it would. *‘While I sat in a chair in front of my physician I was told that this is what happens when all the pieces do not fall into place’.* My Doctor told me it was psychological, that was the reason.

Ok, I just had to adjust to that. I took a long break from work and relaxed as much as possible. I went for long trips in the mountains and also carried on with other interests I have. But it just would not get any better! I studied others that I knew had psychological challenges, none of them had it like me.

How serious was my case, would I not make it? The questions were many, most of them I kept to myself. I just needed to start working again. I denied my illness for many years. There were lots of ups and downs, but somehow life continued. Every time I had to give in the message was the same, psychological, there is no other diagnosis for this. In the end it came to a stop. After a difficult conversation with my general practitioner, I demanded to be seen by someone that possibly had more answers. Then my general practitioner referred me to a neurologist. The waiting time for an appointment was long but I used it to move on and contacted a physiotherapist that was very clever and I felt I was seen and taken seriously.

The physiotherapist helped me relax and described what I should focus on. Thirteen months later it was time for my appointment with the neurologist. It took 10 minutes until she said, “I know what is wrong, you have dystonia. You have a type of dystonia called Torticollis (now mostly called Cervical Dystonia) and we can give you some treatment for this.

**The Diagnosis:** Now it is February 2009, 24 yrs. after the first symptoms and I finally have a name of what is wrong with me. There was no cure. It was like a heavy load was lifted off my shoulders, I did not know whether to laugh or cry. Was it better or worse than a psychological condition? I did not know, but at least with this there was hope for relief. I did not have to fall apart.

**The Fight:** A new and long fight started, the neurologist gave me brochures from the Norwegian Dystonia Association. and she also encouraged me to become a member of the Norwegian Dystonia Association. After I read through these brochures I became aware that maybe this was more serious than I first thought. And no, I did not want to join an organisation. I would handle this myself. However, the fight became hard. I had many thoughts and concerns, ‘How would this impact my family and what would my friends think?’ I did not want this illness, I just wanted to be like everyone else. Will I ever be able to work again? The doctor that diagnosed me with a psychological diagnosis was right in a way, I thought about the days ahead of me. Just going to the mailbox was almost impossible. What would the neighbours say? Solitude and nature became important, and most of all my nearest family and friends. They fully supported me.



A trip to town and a visit to a bookstore became my turning point.

**The Turning Point:** I was wandering around, hoping to find a book that could tell me more about what I should do now. Like a recipe, easy but of course totally unrealistic.

**The Law of Possibilities:** I found a book with this title and brought it home. Easy descriptions on what should be important and what you want. What you decide on you will achieve. Can this be correct? I read some chapters again and again, and ended up sitting down and giving myself concrete goals. They were not complicated, but for me in this situation they were very high goals.

I wanted to use as much energy, knowledge and effort to improve my health and my life; as I had done at work. I wanted to become so self confident that I could stand in front of a crowd of people and say whatever I wanted.

I wanted to become a good grandfather for my five grandchildren and to be a good husband. That was all. Nothing happened overnight, but step by step I got through the worst time. After my wife insisted, I also joined the Norwegian Dystonia Association. We travelled to Stavanger for our first meeting.

I discovered that I was not alone, more people were struggling with the same thing, some even had more challenges. I noticed a very special and friendly environment, nobody asked me about my work, my title or why my head moved. We enjoyed ourselves and decided that we wanted to join other meetings.

**Accept and Adapt:** After a while I realized that I would not recover totally. It is a chronic disease. To accept that life will never be the same is not easy. I needed to think through what values matter most. Could I create for me a new life where other values were put into focus instead of the values I had before? Returning to work was not possible.

I was so lucky that I had a small farm by the fjord, in addition to our main house. Here I could unfold myself. I nurtured the woods, the nature and my lovely place by the sea, created for both children and grownups. Maybe mostly for the children. I started to enjoy every project, the creativity was like a flooding river. I brought the little ones with me and we spent time together. Life had a new meaning. After a while I realized that my previous life was my previous life. The life that is now is being formed today and in the future.

After a while I was contacted by the election committee of the Norwegian Dystonia Association and asked if I would consider being on the board. I think I answered yes before giving it a second thought, one of my old weaknesses. But I thought that if such an association can function, someone must be willing to do the work. Maybe this could be a good combination, working for myself and getting out to socialise in between jobs.

**Support by people around me:** After visiting various neurologists, I now have a neurologist I fully trust. I get injections at regular intervals and a total evaluation each time. I have a physical therapist that is qualified in the treatment of patients with dystonia and knows me well. I have a family that has been there for me through all the ups and downs. Dystonia friends, well what can one say, it is the friendship that I have achieved here that has a huge meaning. Throughout my engagement I have met so many fantastic people. Not least those I have had the pleasure of working with in the Norwegian Dystonia Board. It has developed me as a person and given me friends for life.

**The new normal** There have been lots of hard challenges to overcome, but it has given me knowledge that I would not trade for anything else and I live today and do not plan in details 10-20 yrs. ahead.

At times I've even thought "Praise dystonia", though I would of course prefer not having dystonia, it forced me to think thoroughly about what is important in life.

I combine different types of activities, which I can feel triggers my dystonia, but I will not give up on those activities. It gives me more than it costs. If I just sit and think about what I cannot or should not do then I would lose so much. I would rather focus on what I can do despite dystonia. I enjoy the day and value my friends so much, some of them fell off when the battle was at its hardest, but I do not waste energy on them. Maybe they were not real friends after all. Life is so much more than dystonia. Laughter and happiness is definitely back!

**Johan Arnfinn Warvik**

President Norwegian Dystonia Association



# Calendar 2022

|                  |   |
|------------------|---|
| December 14      | EFNA 20 <sup>th</sup> Anniversary, Brussels, Belgium      |
| January 12 - 15  | Toxins 2022, New Orleans, USA                             |
| January 27       | Webinar 10: Dystonia and Drugs, Prof Inger-Marie Skogseid |
| February 10      | Dystonia Europe Board Meeting, Lund, Sweden               |
| February 11      | Dystonia Europe Think Tank Meeting, Lund, Sweden          |
| February 28      | Rare Disease Day  |
| March 14 -20     | Brain Awareness Week 2022                                 |
| May 19           | Dystonia Europe Board Meeting, Copenhagen, Denmark        |
| May 20           | Dystonia Europe General Assembly, Copenhagen, Denmark     |
| May 21           | Dystonia Day 2022, Copenhagen, Denmark                    |
| June 25 - 28     | EAN Congress, Vienna, Austria                             |
| July 22          | World Brain Day   |
| September 15 -18 | MDS Congress, Madrid, Spain                               |

# DYSTONIA DAY 2022

21 May 2022  
Copenhagen  
SAVE THE DATE

With the support of



**Medtronic**



By **DYSTONIA  
EUROPE**





## 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, 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

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.



## Contact

### President

Adam Kalinowski

### Executive Director

Monika Benson

### Operations Manager

Merete Avery

### Registered Office

Dystonia Europe, 37 Square de Meeus, 4th Floor,

B-1000 Brussels, Belgium

E-mail: [sec@dystonia-europe.org](mailto:sec@dystonia-europe.org)

### Photos from Dystonia Days and portrait photos:

Stephan Röhl, [www.stephan-roehl.de](http://www.stephan-roehl.de)

## Meet us @



### Website:

<http://dystonia-europe.org>

### Facebook:

<https://www.facebook.com/dystonia.europe>

### YouTube:

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

### Twitter:

<https://twitter.com/dystoniaeurope>

### Instagram:

<https://www.instagram.com/dystoniaeurope/>

### LinkedIn:

<https://linkedin.com/company/dystonia-europe/>

## 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](mailto: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/>

Thank you for supporting Dystonia Europe!

## Disclaimer

Disclaimer: The views in Dystonia Europe News are not necessarily those of Dystonia Europe or any of its Officers, and are for information only. They do not represent an endorsement of any particular treatment, products, companies or organisations.

## PLATINIUM

**Boston  
Scientific**



**Medtronic**  
Further, Together



**THERAPEUTICS**

Better outcomes for more patients.