# DYSTONIA NEWS

WINTER|3 - 2023

DYSTONIA EUROPE

## IN THIS ISSUE

## CONTENT

**Photo on front page:**

**Photographer Doreen Kennedy, Ireland.**
**She is also a dystonia patient.**

Dear Readers,

As we near the end of 2023, and already a year since our dear friend Adam left us, we pay tribute to him in this issue, still missing him dearly.

Following Dystonia Days with Dystonia Ireland in Dublin at the end of May and the 30th anniversary of Dystonia Europe, we were invited to follow the scientific presentations on the first day of the 6th Samuel Belzberg International Dystonia Symposium and the 25th anniversary of the Finnish Dystonia Association.

In September we also saw the 4th National Dystonia Day in Italy, and most recently the Spastic Dysphonia Day in Norway.

Monika attended the ESSFN Congress in Stockholm and I took part in The Move Europe in Paris in July, to meet the medical profession.

Dr. Dressler talks about stress in cervical dystonia and his research on page 8.

We bring you the inspiring stories of Julia, volunteer in Germany, and of Salvatore from Italy who suffers from myoclonic dystonia.

Don't forget to check out the 5 DystoniaLife videos on YouTube and share them and/or take part in the Dublin Research Group survey (page 5). Finally, the Dystonia Physio Exercise Hub is available to your professionals (page 6), so don't hesitate to tell them about it.

The Dystonia Europe Board, staff and advisors wish you a happy holiday season, see you in 2024 and take care of yourself!

**Edwige Ponseel**
President
Dystonia Europe

# Adam — Always Missed

It is now over a year that you have been missed and you will always be missed.

Your legacy and work live on in so many of our projects and activities. We are always so grateful for all you have done for the dystonia community. You brought energy, inspiration and a new vision to our organization and it was so hard to keep up the work in the same way after we lost you.

I think we can say that now a year later we have found a way to accept and cope with the situation and we do everything we can to take care of the good work you started and to develop it.

We miss you so much – our colleague and friend. Forever with us in our work for dystonia.

**Dystonia Europe Team**

**In memory of Adam Kalinowski**

# ESSFN Congress in Stockholm

The 15th ESSFN (European Society for Stereotactic and Functional Neurosurgery) Congress was held during the last week of September at the Waterfront Congress Center in Stockholm Sweden.

This congress takes place every other year and participants to this congress are neurosurgeons, neurologists and nurses. Executive Director Monika Benson participated and Dystonia Europe had a small booth in the exhibition hall. Unfortunately no other non-profit organisations were there. Many old friends and contacts came to visit the booth to find out about Dystonia Europe activities and got information on the PhysioExerciseHub, the David Marsden Award and the Cervical Dystonia Patient Journey.

The next ESSFN Congress will take place in Budapest, Hungary, end of September 2025.

**Monika Benson**
Executive Director
Dystonia Europe

*Monika Benson together with DBS nurse Russell Mills from Newcastle Hospital.*

*Monika Benson together with Professor Marwan Hariz from Umeå University Hospital.*

*Congress dinner was held at the Wasa Museum and here Monika is with Boston Scientific representatives Sophie Arajou and Yasmine Lafnoune*

# Dystonia Awareness Month 2023

Dystonia Awareness Month September 2023 was very successful. Thanks to everyone who followed us on our various channels and also for sharing our content further. It means a lot that the material we create is shared and spread to help raise awareness about dystonia.

This year focus was very much on the five DystoniaLife videos showing how normal daily life activities can be if you are affected by dystonia. These videos are available on our YouTube channel:
https://www.youtube.com/playlist?list=PLFvCc6fYkjEv6xOCqGpg_UALiLd8TbBYL

# Survey on the Use of Non-Traditional Therapies – take part!

Have you ever used acupuncture, herbal medicine or any other alternative treatment for your dystonia?

In this survey a research group from Dublin aim to investigate the use of non-traditional therapies (herbal medicines, acupuncture, CBD oil) in people with focal dystonias. The survey should take less than 10 minutes to complete and asks about the types of therapies that people are using and their effectiveness. These results will help healthcare providers better understand the use of these treatments and might help to formulate new treatment options.

This study is being conducted by the Dystonia Research Group, Dublin and University College Dublin. The Principal Investigators are Dr Conor Fearon and Dr Shameer Rafee.

The link to survey:

https://forms.gle/7c2PN1n3ageogvKJ6

For more information visit the research website: https://www.dystoniaresearch.ie/

**Irish Dystonia Research Group**

Dedicated to finding the cause of adult-onset dystonia

LATEST NEWS

# Dystonia Physio Exercise Hub

Dystonia Physio Exercise Hub is an online platform for physiotherapists where they can create individual training programmes for their cervical dystonia patients. The platform is an initiative by Swedish physiotherapist Johanna Blom and Dystonia Europe, and funded by Boston Scientific Foundation.

The digital tool was launched in Swedish first and very soon translated to five more languages: English, Spanish, German, Italian and Dutch. Over 200 physiotherapists from all over the world have already signed up and created training programs for their patients.

Thanks to a new grant from BSFE the development of the platform will continue. There will be more languages and more exercises added. Some of the new features are: a Physiofinder and educational videos for physiotherapists. Inform your physiotherapist about the platform so he/she can start using it for more cervical dystonia patients.

https://physioexercise.org/en?locale=en

DYSTONIA PHYSIO

The first on-line platform with over 100 exercises for cervical dystonia patients

For physiotherapists so they can create individual exercise programs for CD patients

Available in: Dutch, English, French, German, Spanish, Swedish

physioexercise.org

A project by Dystonia Europe DYSTONIA EUROPE with the support of Boston Scientific Foundation Europe Boston Scientific Foundation Europe

# 6th International Dystonia Symposium in Dublin

After twelve (!) years of waiting and five (!) years of preparations we finally gathered in Dublin to convene the Samuel Belzberg 6th International Dystonia Symposium. After the Barcelona meeting in 2011, we heard that it was the best dystonia symposium people had ever attended; we hear now that the 6th one was even better!

Three days of meticulously planned sessions, carefully negotiated topics, and participation of essentially everyone deeply involved in dystonia research was a showcase of progress and advancement in all aspects of the dystonia field.

**Dystonia Europe Board arrived at the 6th Symposium on Dystonia in Dublin**

Talks ranged from fundamental summaries of clinical aspects of the dystonias to the very latest developments in fundamental understanding of it thanks to phenomenal progress in genetics, neurophysiology, animal modelling and other areas of dystonia neuroscience. Poster presentations, rapid five-minute talks and quick point of view debates added intensity and novelty to the symposium. The pace of presentations was impressive, the intensity of coffee-break discussions incredible and inspiring.

We hope that it will not take 12 years until the next meeting in this series.

**Doctors David Martino and Fransesca Morgante together with Dystonia Europe President Edwige Ponseel**

**DMRF Canada and DMRF USA**

**Executive Director Monika Benson, Treasurer Sissel Buskerud and Vice President and Secretary Gill Ainsley**

**Prof Maja Relja, Croatia and Prof Marie Vidailhet, France**

# Excessive Psychological Stress can trigger the Onset of Idiopathic Cervical  Dystonia

**Q:** Professor Dressler, you have just completed a study on excessive stress triggering the onset of idiopathic cervical dystonia. What is the background?

**Dressler:** Idiopathic cervical dystonia is by far the most common form of cervical dystonia. Idiopathic means that there is only cervical dystonia and that it occurs without any identifiable cause. Genetics appear to play a role, as a number of associated gene defects have been identified and the condition typically runs in families. However, when gene defects are identified, only a few percent of gene defect carriers actually develop the condition. This means that there must be additional factors that trigger the manifestation of the gene defects. These factors are known as epigenetic factors.

**Q:** What do we know about these epigenetic factors?

**Dressler:** Very little. Stress has been implicated in these speculations since cervical dystonia was first described. However, most of these reports are anecdotal. There is virtually no published evidence. This is what we wanted to change.

**Q:** What did you do?

**Dressler:** We collected 100 consecutive patients with idiopathic cervical dystonia from our clinics and described the natural course of their disease. In 13 of these patients, we found that excessive psychological stress preceded the onset of cervical dystonia.

**Q:** How was this excessive stress defined?

**Dressler:** It was defined as the worst stress the patients had ever experienced before and after the onset of their cervical dystonia.

**Q:** Can you give examples of these stressful situations?

**Dressler**: There were partner conflicts, including divorce, separation and domestic violence. There were special family burdens, legal disputes and migration. Some patients even had several of these factors combined.

**Q:** How was the onset of cervical dystonia related to stress?

**Dressler**: Cervical dystonia started 8.3±3.9 months (mean±standard deviation) after the onset of the stress.

**Q:** Was the cervical dystonia in these patients unique or special?

**Dressler**: The clinical presentation of their cervical dystonia was indistinguishable from idiopathic cervical dystonia without psychological stress. However, its course was very different: in 85% of our patients, the onset of cervical dystonia was very rapid. It took only 5.8±4.4 weeks for the cervical dystonia to reach maximum severity. This usually takes several years. 2.7±0.8 years after disease onset, remission began. Eventually, the disease severity decreased to 54.5±35.3% of the maximal severity. Again, this was very different from idiopathic cervical dystonia without psychological stress, where remissions are very rare and only mild. In short, cervical dystonia with psychological stress has a very rapid onset and an unusually good chance of remission.

**Q:** Why are your findings important?

**Dressler:** For the first time, we have described in detail a relatively large number of patients with idiopathic cervical dystonia in whom psychological stress seems to be the trigger for its manifestation. With this, we can now differentiate three main types of interactions between stress and dystonia: 1) Stress can be a trigger for the manifestation of dystonia. 2) Stress may modulate the severity of existing dystonia. 3) Stress may cause psychogenic dystonia.

**Q:** Any warnings?

**Dressler:** Everything we have said so far refers to idiopathic dystonia. Psychogenic or functional dystonia is a completely different condition. Although psychological stress can play an important role in the development of dystonia: Dystonia is not psychogenic in the vast majority of patients.

**Q:** What are the mechanisms linking stress and the development of idiopathic dystonia?

**Dressler:** This is largely unknown. Some potential mechanisms have been suggested in the literature, but they are very vague.

**Q:** Strictly speaking, your study was on cervical dystonia. Do you think that your findings apply to other forms of dystonia?

**Dressler:** You are absolutely right. Other forms of idiopathic dystonia would also need to be studied, before we could make definitive statements. However, it would be plausible that basic mechanisms such as those described here also apply to other forms of dystonia.

**Q:** So far, you have studied patients with massive psychological stress. Could the same mechanisms explain why milder stress modulates dystonia?

**Dressler:** It would not be surprising, if the same mechanisms were responsible for the dystonia-modulating effects of milder stress. This could have far-reaching implications for therapeutic considerations.

**Q:** What is the outlook?

**Dressler:** If we understand epigenetics and the mechanisms involved, we might be able to intervene. This could lead to preventive therapies for idiopathic dystonia in patients at risk. Even in patients where idiopathic dystonia has already manifested, modulating these mechanisms might allow us to reduce its severity. This would be the first causal therapy. Both would be major breakthroughs.

The original publication will appear as:

*Dressler D, Kopp B, Pan L, Adib Saberi F (in press)* Excessive Psychological Stress Preceding the Onset of Idiopathic Cervical Dystonia. J Neural Transm

https://de.wikipedia.org/wiki/Dirk_Dressler

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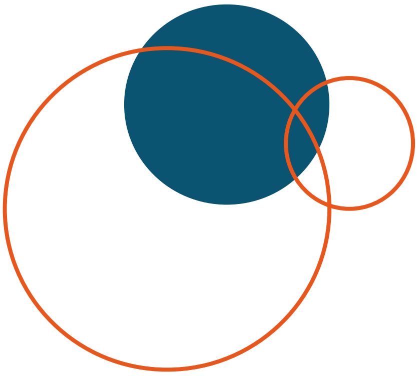

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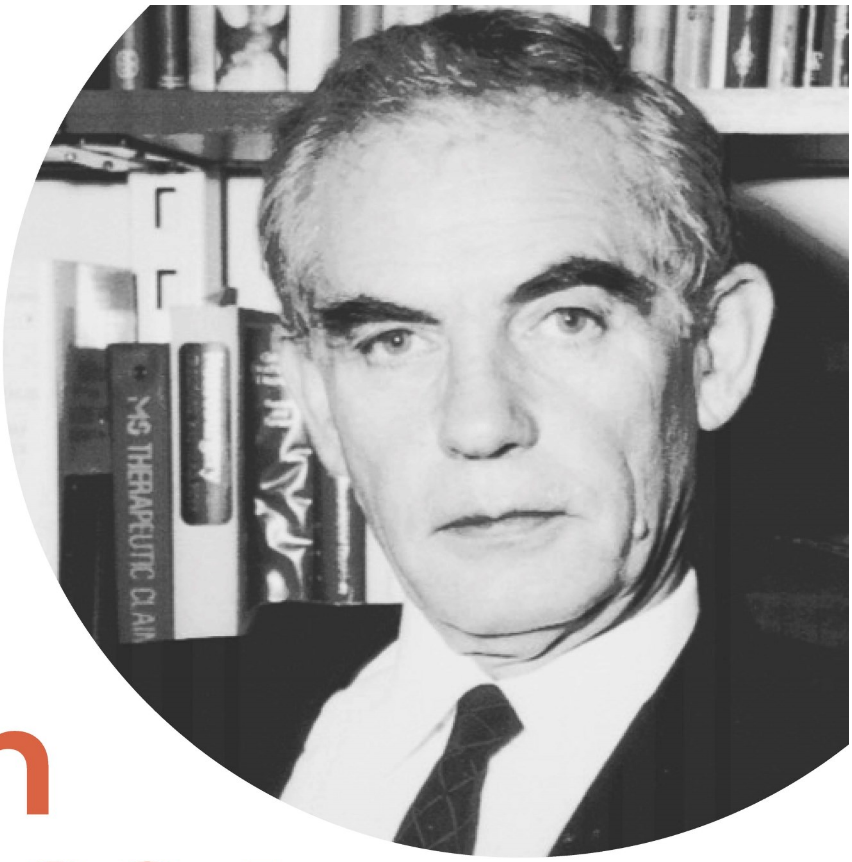


# The David Mardsen Award 2024

## €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 29 February 2024**

All information regarding the 2024 David Marsden award are available at

**www.davidmarsdenaward.org**

With the support from DYSTONIA EUROPE

*The following article, page 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 article are written by respected authors and are provided for the information of Dystonia Europe News readers.*

# Medtronic receives CE Mark for the Percept™ RC rechargeable DBS neurostimulator with BrainSense™ technology

**The next-generation DBS technology is now available in a rechargeable option**

Medtronic the world's leading medical technology company today announced it received CE (Conformité Européenne) Mark for its Percept™ RC neurostimulator for deep brain stimulation (DBS). The smallest and thinnest device on the market[1-4], Percept™ RC is the only rechargeable DBS system with BrainSense™ sensing technology[5] to be launched in the European Union (EU).

"This development represents a critical step in our journey to transform Brain Modulation through sensing-enabled DBS," said Amaza Reitmeier, Vice President and General Manager for Medtronic Brain Modulation. "We are excited about the potential of Percept™ RC to provide a comfortable, personalized DBS therapy to those living with Parkinson's Disease, Essential Tremor and Primary Dystonia. Percept™ RC is also the only rechargeable neurostimulator approved to serve patients with Epilepsy."

"In addition to being the smallest DBS device on the market, Percept™ RC combines proprietary battery technology with our brain-sensing technology. These innovations are the culmination of 30 years[6] of investment in clinical trials and R&D to improve the experience of DBS patients," said Domenico De Paolis, Vice President Neuromodulation International, which is part of the Neuroscience Portfolio at Medtronic.

Overdrive™ battery technology provides physicians with flexibility to adjust therapy without impacting battery capacity. With weekly charging, the device has greater than 99% battery capacity at 15 years. What's more, rapid recharging means that patients can charge under normal conditions (from 10% to 90% full) in less than an hour.

The Percept™ family of devices also features Medtronic's exclusive BrainSense™ technology, which enables physicians to track patient brain signals and correlate them with patient-recorded events, such as symptoms or side-effects associated with their disease, or the medications to treat it. Physicians can then tailor therapy to a patient's evolving needs based on that information, rather than on clinical assessments and patient-reported data alone.

As well as proprietary battery technology, the Percept™ RC DBS system features several other innovative features:

Engineered for patient comfort, it's the world's smallest and thinnest dual-channel DBS device. Low-profile design allows for a deeper implant depth and minimal visibility of the device.

The Percept™ family is the only DBS therapy with MR conditional labeling that allows for 3T and 1.5T full-body MRI scans (without having to turn off DBS therapy)10-13, providing patients access to cutting-edge medical imaging when they need it.

It's designed to facilitate expanded capabilities, allowing the Percept™ RC devices of today to benefit from software updates of the future.

Percept™ RC is approved in the EU for the treatment of symptoms associated with Parkinson's Disease (PD), Essential Tremor, Primary Dystonia, and Epilepsy.

The Percept™ RC neurostimulator will be available in Western Europe beginning mid-December, and will launch in additional regions based on local regulations.

Please read the full version here

https://news.medtronic.com/2023-12-05-Medtronic-receives-CE-Mark-for-the-Percept-RC-rechargeable-DBS-neurostimulator-with-BrainSense-technology

Medtronic
Engineering the extraordinary

# The Move Europe

On July 5 I was invited by Pr E. Flamand-Roze, neurologist at the Pitié-Salpêtrière Hospital, Paris, and co-creator of The Move program, to speak at the introduction of the competition.

The Move Europe is an annual international tournament between 2nd and 3rd year medical students, who mime neurological syndromes in 5-minute sketches to learn about and recognize the diseases involved.

This friendly tournament, the 4th, which takes place at the end of the university year, follows the principle of "The Voice" (in mime), with students competing in "battles", miming patients, in front of their coaches and a jury of professionals who judge them according to the neurological authenticity of their performance and the originality of the staging.

This makes learning about the major syndromes a joyful, modern experience. The students don't make fun of patients. This program enables them to reinforce their clinical skills, interpersonal skills, how to behave with a neurology patient, understanding the patient's perspective, and memorization through simulation. This teaching also combats neurophobia (fear of the neurology specialty and fear of coming face to face with patients suffering from neurological diseases).

This year, groups of students from France, Switzerland, Vietnam and Italy met.

Edwige Ponseel presents Adam's video to The Move with Prof Emmanual Flamand-Roze on stage.

After introducing myself I gave my testimony as a person living with dystonia, and talked about Dystonia Europe and projects.

Then I showed the video of this year's awareness campaign with Adam Kalinowski, previous President, of an anecdote with cervical dystonia at the airport, which fitted the subject, funny and poignant at the same time: "Welcome". Adam, a patient, plays his own role in the story. As patients, we also use humor to communicate about the disease.

I reminded that, even with a neurological disorder, we are all individuals, with our own lives and our own particularities, and that chronic illness cannot define us.

It was my pleasure to congratulate them all on their involvement, their interest, their motivation for neurology and their dynamism. I hoped they would become our future caregivers. I also invited them to come and challenge me during the breaks to see if they could mimic cervical dystonia as well as I could!

It was a great opportunity to meet some amazing, interested young people full of questions during the breaks. These committed, serious and studious young people are a source of joy and hope for the future. As they only came across serious hospital cases, they were also full of questions about moderately disabled or active patients. One of them was suffering from writer's cramp.

The organizers and coaches do an incredible job of supporting and organizing the event.

I laughed, talked and smiled a lot during this day that I'll remember for the rest of my life. What rich encounters, I left them at the end of the day with regrets.

I'd like to end this story with a special mention to the team from Angers, France, who were particularly inventive, fun, communicative and relevant.

Take care of yourselves, youngsters, as you'll be able to take care of us later on!

**Edwige Ponseel**
President
Dystonia Europe

Edwige Ponseel presents DE to THE MOVE EUROPE

# EPF holds Webinars on Label2Enable

EPF (European Patient Organisation) held 2 webinars this autumn on a project were EU works on a quality label for health and wellness apps.

This project is called Label2Enable made possible through funding from Horizon Europe.

**What will the project do?**
Label2Enable aims to promote the ISO/TS 82304-2 health app assessment framework and label to support the development and implementation of an EU quality label for health and wellness apps.

- Label2Enable will leverage the globally endorsed ISO/TS 82304-2, and will convert it into an EU assessment and EU mHealth label, which will be embedded within the approval and reimbursement processes of various EU countries.

The project also aims to foster cross-country alignment on these processes.

**What is the ISO/TS 82304-2?**
The ISO/TS 82304-2 is a framework drafted by the International Organization for Standardization, an organisation that develops and publishes international standards.

**What is EPFs' role?**

- EPF's primary contribution to Label2Enable is focused on engaging Patients, Citizens, and Carers.
- Within this focus, EPF leads the work on **enabling patients, citizens, and carers to make more use of trusted mHealth solutions** for **promoting their health and self-managing their health needs.**
- To achieve this, we will set up an inclusive pan-EU engagement strategy to make sure that the label is useful and impactful, and establish a patient,

**Why does this matter for patients?**

- Health applications (health apps) have a huge potential for health and care systems and patients.
- For example, apps embedded into a persons' care can help to promote a healthier lifestyle, provide more disease insight, lessen symptom burden, lessen hospital admissions, increase efficiency in care, and have been linked to longer lifetimes for users.
- Apps can also support patients in their own condition self-management, and even in prevention.
- However, those that use the apps or recommend them currently lack the information they need to determine the quality and reliability of these apps; at the same time, app creators face complex challenges to get their apps approved by national bodies.
- Label2Enable aims to provide a solution for both of these challenges – and in doing so, creating a trusted and recognisable system that reduces the burden on health systems, and hands back some of the control to patients.

This can support patients to play bigger roles in their own care, empower them to manage their conditions via trustworthy tools, and encourage the use of trusted apps to encourage a healthier lifestyle and promote prevention.

*The text is a summary from EPF website*

**Merete Avery**
Operations Manager
Dystonia Europe

EPF European Patients Forum

# Finnish Dystonia Association 25th Anniversary

The Finnish Dystonia Association celebrated its 25th anniversary in September in Pori, Finland. As a nationwide organisation, we chose a new city as a venue. Approximately 50 members gathered to meet each other, to receive and provide peer support and to listen to interesting presentations by neurologists, physiotherapists, and rehabilitation psychologists.

A new president was elected in our annual autumn meeting to succeed Jukka Sillanpää (myself), who has been president for six years. The new president will be Mikko Juutinen, who has been the delegate of our association in Dystonia Europe's annual meetings in Copenhagen (2022) and in Dublin (2023).

**Jukka Sillanpää**
Board Member
Dystonia Europe

**The anniversary venue was located in the summery town of Pori**

**Vice President Paula Happonen and President Jukka Sillanpää ready for the anniversary.**

**There were active discussions with the speakers and among the audience**

# Spastic Dyphonia Days in Norway

Jens Øyvind Loven, Jannicke Devold and Jorid Løvbakk are specialists in spastic dysphonia also called laryngeal dystonia. On the 6th and 7th September 2023 they were happy to participate in a meeting held by the Norwegian Dystonia Association at Hotel Olavsgaard, Skjetten in Norway about the condition and the treatment opportunities. Altogether there were 15 participants, including the Norwegian Dystonia Association (NDF) board.

Spastic dysphonia is a neurological disorder that affect the vocal cords. In Norway it is estimated that there are approximately 250 people that are affected by this rare disease. The cause is most likely “faulty signals” in the brain which causes the vocal cord muscles to contract and become tight and not function normally.

The help one could give patients with spastic dysphonia has been very limited. The patients were often devastated, many unable to work due to this rare disorder. This led to a commitment for Dr. Jens Øyvind Loven, psychomotor physiotherapist Jannicke Devold and speech therapist Jorid Løvbakk to find a way to improve life quality for the patients. Through their different roles they cooperated to achieve the best possible form of treatment for the patients.

Dr. Loven said there was a breakthrough in the treatment of spastic dysphonia at the end of 1980’s when there was a report on the use of botulinum toxin (BTX) as a treatment.  Professor Andrew Blitzer at Columbia University in New York was a pioneer and the first in the world that started this treatment for spastic dysphonia. Jens Øyvind Loven travelled to Columbia University, New York in 1991 and learned about this treatment method from Prof Blitzer. Shortly after Loven started, together with Neurophysiologist Dr. Trond Ganes and Dr. Kjell Brøndbo, treatment with botulinum toxin (BTX) was started for spastic dysphonia in Norway. They were among the first in Europe to start BTX treatment for this rare disease.

According to Dr. Loven the treatment of spastic dysphonia with BTX was revolutionary. The treatment results have been especially successful for patients with primary (idiopathic) dystonia and with primary adductor spastic dysphonia.

Dr. Jens Øyvind Loven

“The larynx is a highly complex organ sensitive to emotional changes in the individual. It is affected by thoughts and feelings, our relationship with others and with our environment. In this way, the human voice acts rather like an emotional barometer”
(Butcher m.fl.,1993).

Speech Therapist Jorid Løvbakk

Psychomotor Physiotherapist Jannicke Devold

Treatment with BTX can help lessen the symptoms and improve the quality of the voice and therefore the quality of life for those who have spastic dysphonia. However it is often necessary with in depth interdisciplinary examination to find out more about the cause and why the body /muscles tighten and the breathing becomes limited and does not allow enough air for the voice. Psychomotor physical therapist Jannicke Devold spoke about this and said that stress has been mentioned as a triggering factor for spastic dysphonia. Stress can be many different things, but often it is about the feeling of incompetence. Psychomotor physical therapy treatment helps to become aware of the muscles being tense, to make a change in the body, and to provide increased familiarity and contact with one's own body. Its goal is to develop self-help. The treatment starts with a conversation and an examination. Inhaling often comes naturally, and we often say take a deep breath, however it is equally important to take the time to breathe out properly.

Speech therapist Jorid Løvbakk has a lot of professional experience on spastic dysphonia. Løvbakk explained the work of the speech therapist regarding spastic dysphonia. In the first appointment there is an examination and awareness of the use of the voice.
Spastic dysphonia is a rare neurological condition. Speech therapy will normally not lead to a cure but can help the person affected by this condition to cope better with spastic dysphonia.

In total there was very good feedback from the meeting and it was a success, says NDF President Johan Arnfinn Warvik. This also includes the presenters wholehearted effort.

**A summary of article by Vidar Bjørkli,**
**Norwegian Dystonia Association**

**Merete Avery**
Operations Manager
Dystonia Europe

**Photos: Vidar Bjørkli**

Photo: Participants Spasmodic Dysphonia Meeting

# 4th National Dystonia Day in Italy

On Sept. 30th Associazione per la Ricerca sulla Distonia (A.R.D.) organised the 4th National Dystonia Day. In order to increase visibility and attention towards dystonia, in 2020 we decided to create a National Day to be held on the last Saturday of September, preceded by articles or interviews published via various means of communication.

The first and second Dystonia Day in 2020 and 2021 were online events, due to Covid; last year and this year we were in a TV studio in Rome for a live broadcast on our social media. During the week before Saturday 30th some interviews concerning dystonia were transmitted, among which one was on the Vatican radio and one was by Prof. Alberto Albanese in a national newspaper.

This year we focused our Day on dysphonia, which is a rarer form of dystonia, but not less debilitating; the title of the Day was “When your voice changes your life” and our hashtags were #notloseyourvoice #neverwithoutwords.

In order to choose this topic, our starting point has been a book written by our member Anna Maria Puggioni; its title is “ Rare, you are not my defeat” addressed to her dysphonia. She wrote 18 poems “arising in her heart” and collected them in a booklet illustrated by drawings of some students of the local classical high school. She has dedicated this booklet to ARD and will give the proceeds to the Association.

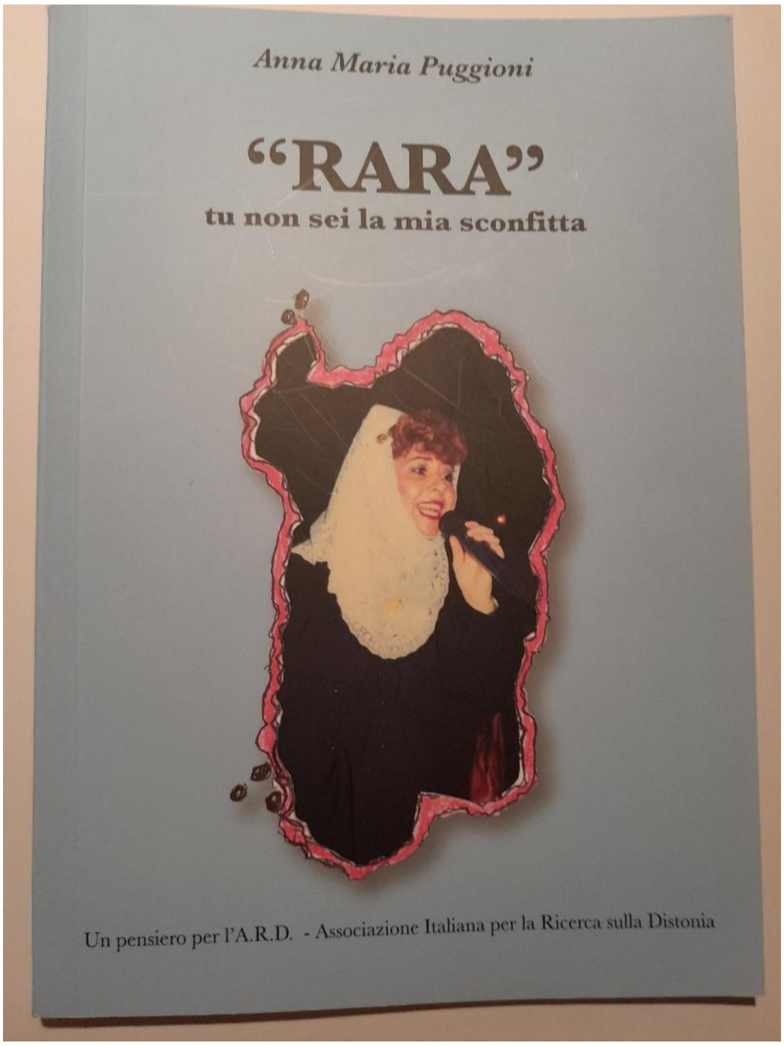
Anna Maria was born in Sardinia, an island where traditions are still deeply rooted as well as the Sardinian language, which is quite different from Italian even though it is also derived from Latin. She had a great vocal talent and for 25 years she has been a singer of popular Sardinian music, famous in Italy and abroad. Unfortunately 15 years ago her voice became feeble and hoarse: the “evil fairy” (so she names dysphonia) had stolen her voice.

Since then Anna Maria is speaking with her heart’s voice, as she wants to continue to transmit emotions; she feels useful in creating solidarity projects such as “Chida santa” (Holy week) a sacred representation of Christ’s passion,death and resurrection; it is a musical in sardinian with 80 actors and singers, conceived, realised and directed by Anna Maria, who donates all the profits to ARD.

Prof. Antonio Suppa (Department of Neuroscience and Mental Health, Policlinico Umberto I, Rome) was in the TV studio and explained that currently there is no certain data about the number of people with laryngeal dystonia. According to estimations, 4/6 persons out of 100 000 could be affected, therefore in Italy patients could be around 3 000 - 4 000, but far fewer patients are registered in neurological departments concerned with dysphonia. It can be adductor dysphonia when vocal cords get uncontrollably closer and the voice has spasms, or abductor dysphonia when vocal cords move away and a sudden aphonia occurs. The incidence of dysphonia is 4 females to 1 male, the reason is still unknown.

Prof.Alberto Albanese, who is the President of our Scientific Committee, took part from Milan and explained that dysphonia is probably the most difficult to diagnose as involuntary movements cannot be seen, conversely to what happens in all other forms of dystonia.

Simona is another patient with dysphonia, she sent us her story to be read by us during the transmission. She is a teacher of Mathematics and 2 years ago the symptoms of hoarseness, temporary aphonia, trembling voice began, leading to a diagnosis of dysphonia. Since then Simona is no longer teaching, her school is employing her in other activities and she feels she has lost her social identity along with her voice. She compares dysphonia to a landslide in a mountain road and botulinum toxin to a tractor which swipes away the landslide: at present the tractor has not yet completely removed the obstacle, as her injections of botulinum toxin have not yet given good results. This peculiar analogy (dystonia=landslide/ botulinum=removing lorry) shows that any patient has a personal relationship with the disease and a way to consider it.



Two more neurologists from Milan participated in our event: Dr. Giovanna Zorzi spoke about dysphonia in children, a topic rarely discussed; it does not exist as an isolated form but is part of generalised dystonic forms and its real incidence is still uncertain.

Dr. Anna Castagna focused on the importance of a multidisciplinary approach, based not only on botulinum toxin but also on speech therapies and psychological help.

Two specific professional roles concerned with phonatory apparatus are very important for taking care of dysphonia: they are phoniatrician and speech therapist. Prof. Lucia Longo (phoniatrician) illustrated the diagnostic tools necessary for an accurate diagnosis: laryngoscopy, stroboscopy, spectrographic exam . Dr.Valeria Crispiatico (speech therapist) spoke about relaxing techniques and exercises to increase voice control and manage collateral effects post botulinum toxin.

The last story of a patient with dysphonia concerned Paolo Corsi, who had been President of ARD until 2016 and unfortunately passed away in 2019. His son told us that he led a very active lifestyle, not diminished by dysphonia which appeared when he was 50 years old. He began to cooperate with ARD and soon became its key pillar, working to increase visibility of dystonia and spread awareness about it. Thanks to his efforts, for several years now in Italy, botulinum toxin has been provided in total charge of the National Health System for all types of dystonia. Moreover, through a solidarity association he could obtain a fund of €100 000 for DBS devices offered to 2 neurological children's hospitals in Milan and Rome.

Our live broadcast lasted around 3 hours, we had many questions from our social media and doctors answered; patients are always eager to get as much information as possible and this is the aim of our National Day.

The transmission is available on our Youtube channel.

**Maria Carla Tarocchi**
Vice President
Associazione per la Ricerca sulla Distonia (A.R.D.)
Italy

**Julia Kühne**

# Meet Julia, Germany

**What is your name?**
My Name is Julia Kühne. I live in northern Germany, in a city called Rostock.

**What are the benefits of working within a patient organisation?**
Working in a patient organization is a very special experience to me, as it is the first time since I was diagnosed with Dystonia, I don't feel alone with having this condition. There are people that can relate, that have gone or are going through the same experience as me. Furthermore, Dystonia is scarcely known around the world and to raise awareness for this condition, to exchange the latest knowledge about Dystonia and to maintain a community for others to feel not alone, is very important to me. It also is a great opportunity to learn how patient organisations are generally working and to network with other patients and scientists from around Europe.

**How do you like spending your free time?**
I really like to go outside, take a walk or travel to new places. With my Dystonia being clearly visible to others, it can be quite a struggle, but I don't want to hold back on life and I want to explore as much as I can. I live close to the sea and I love to take a walk along the shore, listen to the waves and breath the sea air. It makes me feel free in a sense. On days where there's not so much energy in me or I just don't feel like facing the world, I love to draw or paint. Creating art has been an important part of my life since my childhood. It takes my thoughts away from my condition, I get to express my emotions and do something with my hands.

**What keeps you motivated on the tough days?**
On tough days, it helps me to connect with my friends. I consider myself blessed to have them in my life. They don't have dystonia, but they are very empathetic and always take the time to listen to my fears and worries. Also, especially on these days I try to be mindful with myself. Yoga and meditation have been a key for me in order to be more friendly towards me and others, to calm down and to embrace myself the way I am.

**Julia Kûhne**
Dystonie und Du
Germany

# Meet Salvatore from Italy

**Introduction:**

Our life journey is marked by ups and downs, challenges that test us, and moments that inspire us. In my case, a neurological condition known as Myoclonus-Dystonia Syndrome led me down a path of difficulty and self-doubt. This article tells my story and how, through resilience and willpower, I found the strength to keep going despite the odds.

**Story and Resilience:**

Due to Myoclonus-Dystonia, my childhood and adolescence were marked by bullying, social isolation, and deep personal crises. The symptoms, which made it difficult for me to perform everyday tasks, made me feel different and isolated. In my youth, when the darkness of despair enveloped me, I even harboured suicidal thoughts. My inner strength gradually unfolded despite these challenges, comparable to the awakening of spring after a long, hard winter. Music became my faithful companion, helping me get through difficult times. It served as a refuge and created a space where I could express myself when words failed. Although the changes came gradually, two crucial turning points in my life stood out. The first was a conscious decision to respond to life when I was about 17 or 18 years old. I began to change my perspective and firmly believe in my inner strength. The second turning point was the DBS surgery in 2022, which changed my life and exceeded my hopes.

My disease had affected almost every aspect of my life, especially my social relationships. I felt lonely and as an outsider, which was especially challenging for a communicative person like me. Bullying in my childhood and teenage years inflicted additional pain on me. The DBS surgery in Milan ("Istituto Neurologico Carlo Besta") became a long-awaited turning point that changed my life. I hoped for improvement right after the surgery, but the actual results came gradually.

**Salvatore Curso**

Looking back, the improvement in my quality of life is truly amazing, and most importantly, my condition is getting better day by day due to Deep Brain Stimulation. Thus, the surgery has helped me to appreciate even the smallest moments of happiness in life. I notice this especially whenever I drink a glass of water or a cup of coffee without much hesitation. For a large part of my life, I was only able to drink with the help of a straw. The many new possibilities that opened up for me as a result of the surgery still seem like a miracle to me today. I have gained a completely new attitude towards life, and I am glad to have chosen Deep Brain Stimulation, even though the decision was not an easy one at the beginning.

**Advice and Conclusion:**

The journey through Myoclonus-Dystonia has been one of resilience and willpower. Overcoming bullying, social isolation, and personal crises required strength and belief in one's potential. Today, after all the hurdles, I would like to pass on some advice to those struggling with similar situations:

- Believe in yourself and your inner strength, because it will carry you through the darkest days.

- Find your refuge - be it in music, art or other passions that give you comfort.

- Don't be discouraged by setbacks, for they are part of life. Your resilience will always get you back up.

- Remember that life is precious and worth enjoying to the fullest.

Also, always be willing to help reduce the suffering around you - only then will your own suffering diminish over time.

From my experience, it not only helps oneself to cultivate inner resilience, but it also makes the world a better place, step by step. Living among algorithms and information overload is causing society to become more and more divided.

Rather, we should now find our commonalities and celebrate them. Inner strength, courage, self-knowledge and keeping a cool head help us to deal with the complexity of life and to meet each other at eye level again. Of this, I am now firmly convinced.

**Salvatore Caruso**
Contact at: caruso.salvatore@outlook.com
Follow me on IG (Instagram): sulv.93

## Calendar Winter 2024

### 2024

**January**

| | |
|---|---|
| 17-20 | Toxins Congress, Berlin, Germany |
| 31 | DE Board Meeting |

**February**

| | |
|---|---|
| 27 | DE Board Meeting, Paris, France |
| 28 | DE Winter Think Tank, Paris, France |
| 29 | Rare Disease Day |

**May**

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|---|---|
| 30 | DE Board Meeting, Timisoara, Romania |
| 31 | DE General Assembly 2024, Timisoara, Romania |

**June**

| | |
|---|---|
| 1 | DE Members' Meeting 2024, Timisoara, Romania |
| 29-30 | EAN Congress, Helsinki, Finland |

**July**

| | |
|---|---|
| 1-2 | EAN Congress, Helsinki, Finland |

## Dystonia Europe Members' Meeting 2024 in Timisoara in Romania

For 2024 the Dystonia Europe Board has decided to organize a Dystonia Europe Members' Meeting in Timisoara in Romania. This meeting will be only for delegates of Dystonia Europe.

The meeting will take place at the Hotel Timisoara on 31 May and 1 June. On the agenda we will have the Annual General Assembly and presentations and there will also be the opportunity for members for a session on sharing best practice.

We wish our members welcome to Timisoara in springtime.

Hotel Timisoara, Romania

## Dystonia Days 2024

This year our Dystonia Days will be an on-line event. Save the date Saturday 21 September in your calendars. We are still working on the program but we can already promise that there will be expert presentations as well as dystonia patients sharing their stories.  Look out for more information on our website and social channels when we get closer to the event.

## Members

Dystonia Europe consists of 23 national member groups from 20 European countries and they are:

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

## Medical & Scientific Advisory Board

Prof Alberto Albanese – Milan
Prof Alfredo Berardelli – Rome
Prof Kailash Bhatia – London
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

**Shaping a Better Future for People Living with 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.

# MANAGEMENT

### Edwige Ponseel

President

Edwige is the President 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 full time in the purchasing and marketing department of an American company, in the European headquarter 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 reelected at the last GA in London and for a 3rd period in 2021. From December 2022 she is the President of Dystonia Europe.

### Gill Ainsley

Vice President and 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.

Gill is the Vice President and Secretary of Dystonia Europe.

### Sissel Buskerud

Treasurer

Sissel is the Vice President of the Norwegian Dystonia Association (NDF). She was also Treasurer for many yrs. in NDF until 2020. Sissel has a university degree in accounting and finance and she has experience for more than 25 yrs. as CFO—Chief Financial Officer for a Norwegian Security Company. Sissel was elected to the DE Board at the GA in London in 2019 and re-elected in 2021. She has Cervical Dystonia.

Sissel is the Treasurer of Dystonia Europe.

### Catalina Crainic

Board Member

Catalina Mariana Crainic is the President of the Romanian Dystonia Organisation, Asociatia Childrens Joy and a Board Member of National Alliance of Rare Diseases, Romania. Catalina is a psychologist with right of free practice, working as psychologist for Asociatia Children's Joy and Mrd Clinical Psychology and Psychotherapy. 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 Movement Disorder Diseases' 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.

# ADVISORS AND CONTACT

### 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**

Edwige Ponseel

**Executive Director**

Monika Benson

**Operations Manager**

Merete Avery

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**Photos from Dystonia Days and portrait photos:**

Stephan Röhl, 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/

We have good working relations on a variety of topics with: DMRF – Dystonia Medical Research Foundation, FDR – Foundation for Dystonia Research, Dystonia Coalition, EFNA – European Federation of Neurological Associations, EBC – the European Brain Council, EAN – European Academy of Neurology, MDS – International Parkinson and Movement Disorder Society.

We thank all our partners for their support and collaboration.

## Donation and Support

Dystonia Europe welcomes and greatly appreciates any donations/support from organisations and individuals to further develop all the work for dystonia in Europe by funding research, awareness and education. If you would like to support the work of Dystonia Europe please contact us at sec@dystonia-europe.org to discuss the possibilities.

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

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

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Innovation for patient care

Medtronic
Engineering the extraordinary

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