DYSTONIA NEWS

WINTER|3 - 2022

In Memoriam - Adam Kalinowski

IN THIS ISSUE

DYSTONIA EUROPE

CONTENT

Dear readers,

At the end of November, we informed you about the death of Adam Kalinowski, Board Member of Dystonia Europe since 2017 and President since 2019.

Our team is very affected and in mourning.
We have lost a close friend, appreciated by all, smiling, cheerful, listening, caring, carrying ideas, full of resources and skills... We will miss Adam very much.

Also, the Christmas vacations will allow us this year in particular to take a break, welcome our sadness and to get back on track.

We are also a strong and united team, and despite our sorrow, we will put our hearts into our tasks and projects in progress in the new year. We will continue to represent the dystonia community, with your help and that of all the friends of Dystonia Europe.

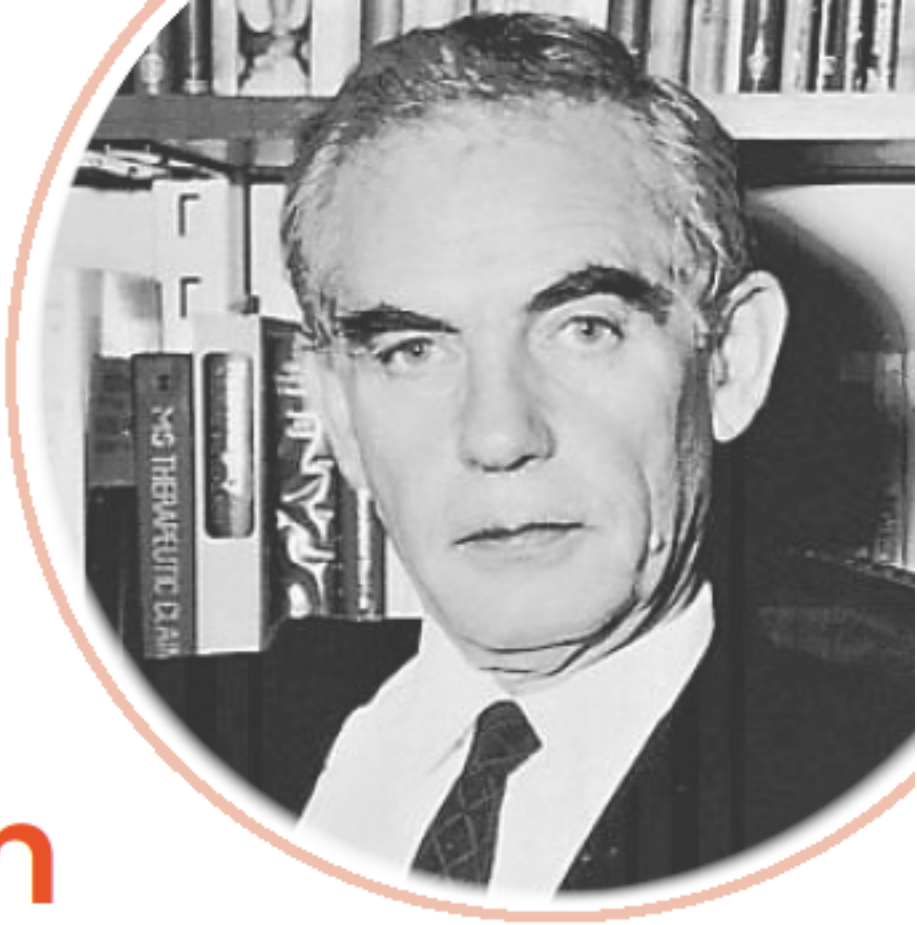
You can read about these projects in this edition, as well as a tribute to our friend, which we wanted to share with you.

We thank you for your understanding and support, for your messages of sympathy, also to Adam's family and friends, with whom we remain in contact.

We wish you a happy holiday season, hopefully with your loved ones, because they are precious. See you in 2023.

On behalf of the Dystonia Europe Board
Edwige Ponseel
President

DYSTONIA EUROPE



The David Marsden Award 2023

€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 2023

All information regarding the 2023 David Marsden award are available at

www.davidmarsdenaward.org

Adam Kalinowski – In Memoriam

It is with great sadness Dystonia Europe has announced the passing of our President, Adam Kalinowski, at the age of 37, following a tragic accident on 10 November 2022.

Adam is from Poland but has lived in Ireland for the last 16 years. In 2006 he was diagnosed with cervical dystonia. Very soon he founded an online support group for dystonia patients in Poland to "help myself", he has told us. Today this group has over 800 members and is still growing. It is a valuable source of information and support for dystonia patients in Poland. "In one weekend in your group I learnt more than in five years going from doctor to doctor", a member had told Adam. The support group marked the start of Adam's career as a patient advocate. His search for support and information led him to the App MyDystonia, developed by Dystonia Europe. Adam suggested to DE he would translate it to Polish, and so he did. In 2016 Adam joined the very first MyDystonia Ambassador meeting near Frankfurt, Germany. Adam has been a dedicated MyDystonia Ambassador since then.

Around the same time he became a member of the Polish Dystonia Association (Polskie Stowarzyszenie Osób Chorych na Dystonię) where he served as a Board Secretary.

Adam was elected a DE Board Member at the Dystonia Days in Rome in 2017. For the first few years on the board his main role was the coordination for the MyDystonia Ambassador program. In 2018 he organized a MyDystonia Ambassador meeting in Dublin, Ireland.
At the Dystonia Europe 25th Anniversary event in the EU Parliament in Brussels 2018 Adam spoke about his own dystonia journey, especially the difficulties it had caused him to have a work-life and career.

Adam was re-elected to the Dystonia Europe board in London 2019, and was until now the President of Dystonia Europe.

During the last few years the DE activities were very much affected by the Covid-19 pandemic and for over two years there were no face-to-face meetings. Adam's interest and skills in digital technology, helped us navigate during these circumstances and to find new and successful ways of working. Adam led our monthly Board Meetings on Zoom, and there were two Dystonia General Assemblies held on-line during this period.

He was also hosting the very popular Dystonia Webinar series with invited experts from across Europe on various dystonia topics.

Adam was enrolled on a Graphic Design course in Ireland. This had been a dream of his for many years. His creative talent spilled over to Dystonia Europe and he updated and improved the "look and feel" of the Dystonia Europe newsletter and the website. Any graphic material we needed he said: "Give it to me, I will do something".

Throughout the last year Adam also worked very hard on a very dear project to him: a series of five different dystonia awareness videos. His idea was from the beginning to create awareness around dystonia by producing funny videos. The board shared some funny stories that had occurred to them due to dystonia, and from these the work of creating the manuscripts started. Together with dystonia patients from Dystonia Ireland and a film producer in Ireland, Adam led this project until now. The videos were finalized in November and will be released in 2023 to raise awareness of dystonia and in memory of our dear friend and dystonia advocate Adam.

In his spare time Adam loved to go off camping and hiking in the Irish nature. His interest in photography has shown us many beautiful places in Ireland. One of the activities he truly enjoyed was surfing. He lived just 30 minutes from one of the best surf beaches in Ireland and for Adam surfing was a way of escaping dystonia.
For the last few years to kick off our Dystonia Awareness month in September Adam used to send a video greeting from the seaside and encourage everybody to take part in the awareness month activities.

Adam also had very close ties with his family. He often talked with us about his love for his sister's children in Poland.

The last time we met Adam was at our board meeting in Lund last September. We had a two-day meeting where we had great discussions and brainstormed around various ideas, and as usual we had fun together.

Adam was a very dedicated advocate and worked tirelessly to inform and increase awareness of dystonia. He leaves an enormous gap on our board, in our organization, and in the global dystonia community. His dedication, his ideas, his warmth, his smile, his voice - he is so missed.

May you rest in peace our dear friend.

Once again we send our deepest condolences to Adam's family and friends in this difficult time.

On behalf of the Dystonia Europe Board written by :

Monika Benson
Executive Director
Dystonia Europe

Dystonia Awareness Month

Last September we celebrated another fantastic dystonia awareness month. Focus this year was the Patient Journey*. We had created a series of carousel posts describing a fictional cervical dystonia patient. Throughout the month we followed Lilly and her journey with dystonia from the first symptoms, through the various stages of diagnosis, treatment and living with dystonia. Her journey tells us not only about her medical experience but also about the emotional experience she is going through. These posts were liked and shared and engaged the community.

We also encouraged the dystonia patient community to do a short recording of how long it took to get diagnosed and send it to us.

We call this activity I am… It took.
https://dystonia-europe.org/i-am-it-took

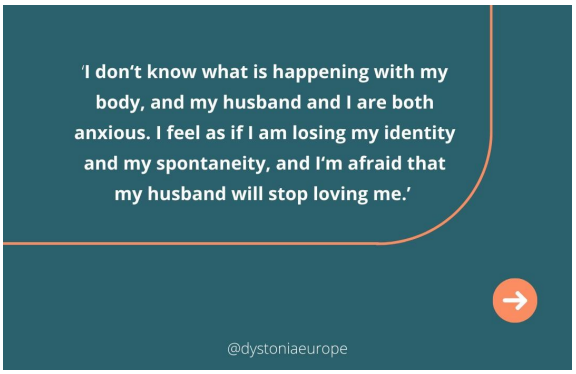
Additionally we posted the usual content of dystonia facts, inspirational quotes and patient stories.

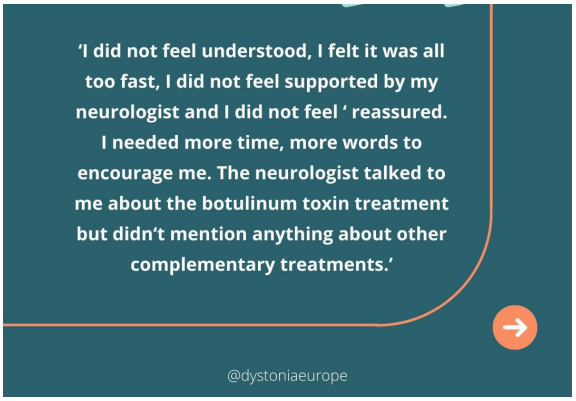
The post that engaged the most during the month was the infographic, inspired by a Dystonia UK infographic. Once again a great thank you to them for this excellent awareness idea!

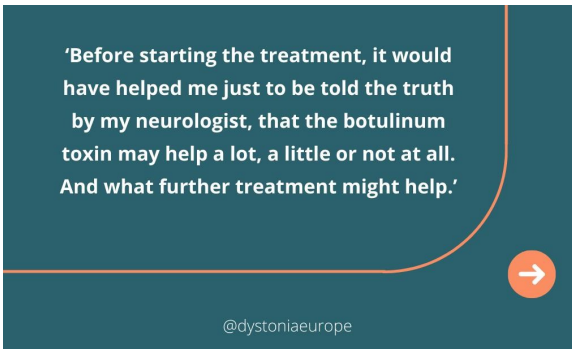
Overall there was a slight increase in followers on the various channels. Best growth was on Linked-In. This is exactly what we had hoped for since we want to reach out and better connect with HCPs and other partners.

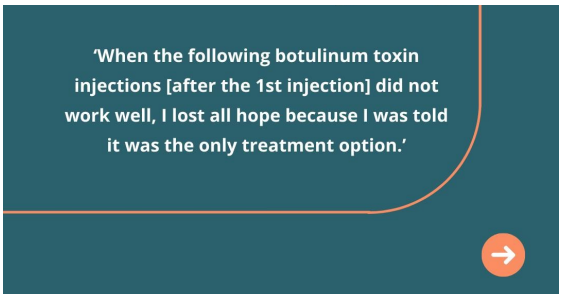
**For more information on the patient journey publication see: https://dystonia-europe.org/2022/05/first-ever-patient-experience-map-in-cervical-dystonia-reveals-multiple-barriers/*

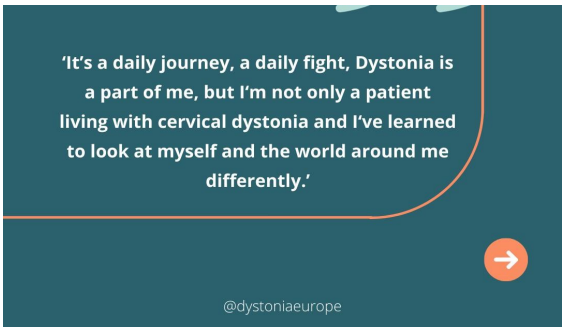
Dystonia Awareness Month—The Dystonia Journey











https://dystonia-europe.org/2022/05/first-ever-patient-experience-map-in-cervical-dystonia-reveals-multiple-barriers/

Launch in Europe: Dystonia Physio Exercise HUB - a Digital Platform with Exercises for Cervical Dystonia

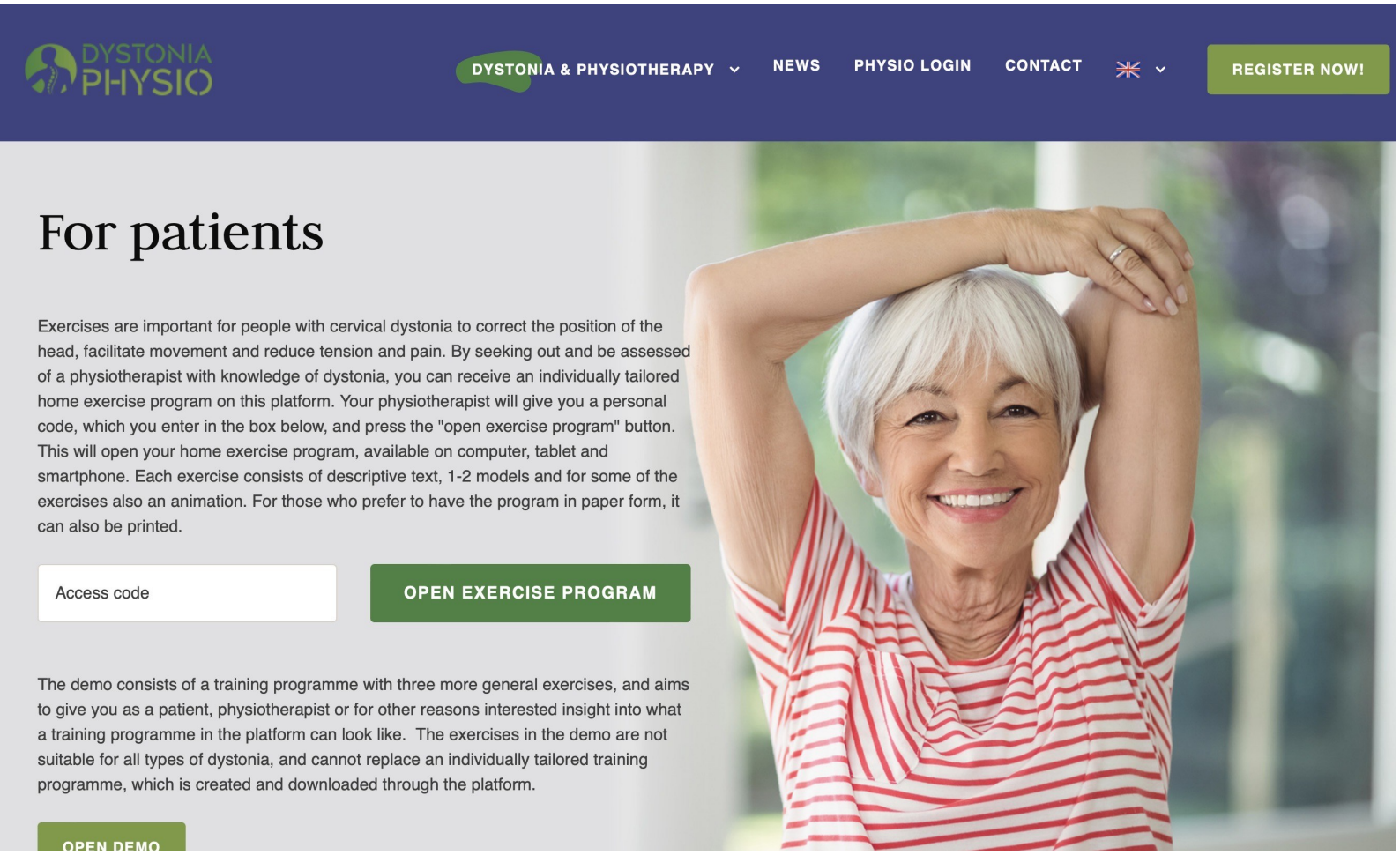
One year ago, a digital platform for cervical dystonia was launched in Sweden, and a few weeks ago, on 28 November it was time for the launch in Europe. Research has shown that Botulinum toxin injections (BoNT-inj) combined with physiotherapy provide good benefit for most people with cervical dystonia (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 patient in question, and create a personalised exercise programme. With this as a basis together with the pandemic's increased focus on digital solutions, I, Johanna Blom, physiotherapist in Sweden, came up with the idea of a digital platform.

The platform is being developed in close collaboration with Dystonia Europe (DE) and its IT expert Eelco Uytterhoeven and Executive Director Monika Benson. For the European launch a group of physiotherapy specialists from England, France, Germany, the Netherlands and Spain have joined our team.



The Boston Scientific Foundation Europe (BSFE) has endorsed our application for funding for this project, enabling us to move from idea to reality.

The platform is not a commercial business and will be free of charge for both users and healthcare. For access to all the 115 exercises and possibilities to create training programs for patients with CD, the physiotherapist has to register on the public page and get approval.

Right now, there are about 80 Swedish physiotherapists registered on the platform. After an assessment of the patient, the physiotherapist can use the filter functions in the platform and create the training program for the patient. The program will be visible to each patient digitally on the public page through a personal code. For those who are not comfortable with the digital version, there is also the option to print the programme.

The public page is for everyone interested in CD, and there is information directed to the patients or physiotherapists, principles of physiotherapy, links to the dystonia associations in different European countries, a news section, information about the platform and a demo etc.

With the European launch there are some great and important updates. First of all, the platform is now available in a total of 6 languages including Swedish. New languages are: English, French, Spanish, German and Dutch.

The exercises are provided with 3D models, and with the recent update about half of the exercises are animated. The platform has a brand new design of both the public and the professional page, and better functions are in use.

The public page, where the patient can access his/her program, works on computers, tablets and smartphones, while computers are recommended for working on the physiotherapy page. It should be emphasised that the platform does not replace a physiotherapy contact, but relies on the presence of a physiotherapist who makes an analysis of the dystonia, and chooses the appropriate exercises. However, the platform makes it easier for the physiotherapists to find and select exercises, to communicate them and for the patients to take responsibility for training and to influence their situation.

Together with DE, I sincerely hope that this platform, the Dystonia Physio Exercise Hub, will be of great benefit for the patients, all over Europe, suffering from cervical dystonia!

With hopeful greetings
Johanna Blom
leg physiotherapist
Neurology department
University Hospital of Skåne, Malmö, Sweden

You can find the platform here:
https://physioexercise.org/en?locale=en

A randomised double-blind controlled study of Deep Brain Stimulation for dystonia in STN or GPi – A long term follow-up after up to 15 years A summary

Prof Annemette Lökkegaard

Deep Brain Stimulation (DBS) is a neurosurgical treatment, where electrodes implanted in deep nuclei in the brain, via stimulation, normalises output in motor networks affected by movement disorders. DBS in dystonia has proven a safe and effective treatment, but variable results have been presented depending on the types of dystonia and precise targeting in the network. The most common target is the internal pallidal nucleus (GPi), but effect has also been shown in the subthalamic nucleus (STN).

In 2003 a protocol was initiated in Copenhagen, where patients with medically refractory dystonia referred for DBS had electrodes implanted in both STN and GPi in an effort to improve target selection. The included patients were randomised to begin stimulation in either STN or GPi in a double blinded crossover design, where a shift to the other target was performed after 6 months.

We now wished to examine the effect of DBS in a long term follow up and to compare the effects of the two targets. We therefore included 21 patients (9 patients with generalised dystonia, 12 with cervical dystonia) who were part of the initial study and had since then received DBS in either GPi or STN, or both nuclei. In 14 patients we systematically tested for motor effect (BFMDRS) and quality of life (SF-36) using structured ratings. The mean follow-up time was 10.2 years (between 4.8 and 15.4 years). A statistically significant improvement on symptoms was demonstrated with stimulation in both STN and GPi. SF-36 improved for both targets. No significant difference was found between the two targets.

We concluded from this study that both targets were safe with regard to side effects and complications. We found an equal effect on motor symptoms and quality of life. An important finding was that a long-term effect was found for both stimulation in GPi and STN for up to 15 years.

Reference: Aske Nicolai Hock, Steen Rusborg Jensen, Katrine Wordenskjold Svaerke, Jannick Brennum, Bo Jespersen, Ove Bergdal, Merete Karlsborg, Lena Elisabeth Hjermind, Annemette Lokkegaard. A randomised double-blind controlled study of Deep Brain Stimulation for dystonia in STN or GPi - A long term follow-up after up to 15 years. Parkinsonism and Related Disorders 96 (2022) 74–79.

INNOVATION IN DYSTONIA TREATMENT

More than **500,000 people** across Europe are living with dystonia[1]

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**[2]

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 [3]

DBS may reduce dystonia symptoms such as:

- Tremor, cramps
- Pain
- Strangled 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[4]

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

References:
[1] http://www.braincouncil.eu/wp-content/uploads/2015/07/Dystonia-fact-sheet-August-2011.pdf
[2] https://www.neuromodulation.com/deep-brain-stimulation
[3] DBS Masters Debate, November 2015.
[4] https://www.dystonia-foundation.org/living-with-dystonia/neurosurgery/brain-surgeries/deep-brain-stimulation last access October 21, 2016.

* A System that includes the Vercise™ PC, Vercise Gevia™, or Vercise Genus™ IPG and Vercise Cartesia™ Directional Lead(s) forms the Vercise Directional System.
** The Vercise Genus or Vercise Gevia™ DBS System and Vercise DBS Lead-only system (before Stimulator is implanted) provide safe access to full-body MRI scans when used with specific components and the patient is exposed to the MRI environment under specific conditions defined in the supplemental manual ImageReady™ MRI Guidelines for Boston Scientific DBS Systems.
*** MRI Conditional when all conditions of use are met.

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Advancing science for life™

www.bostonscientific.eu

Diet and Dystonia Survey

'Diet and Dystonia' is now open on our platform.

The main goal of this research is to examine how diet affects dystonia, and if so how dystonia specialists could address these problems.

The survey is completely anonymous, which means that no personal information will be collected.

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

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

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

Publication on Dystonia: Dystonia Management across Europe within ERN-RND: Current State and Future Challenges

Liesanne M. Centen, [#1,2] David Pinter,[#3] Martje E. van Egmond,[1,2] Holm Graessner,[4] Norbert Kovacs,[3] Anne Koy,[5] Belen Perez-Dueñas,[6] Carola Reinhard,[4] Marina A. J. Tijssen,[1,2] and Sylvia Boesch[7]

Background

Since the first European-wide evaluation of dystonia management in 2016, several efforts have been made to improve dystonia-care. One of these was the development of the Dystonia Disease Group as a part of the European Reference Network for Rare Neurological Diseases (ERN-RND) that implemented several initiatives based on the recommendations made in 2016.

Aim

To evaluate the current state of dystonia management across Europe.

Methods

Twenty-four countries were surveyed via 62 dystonia experts from 44 ERN-RND related centers.

Results

Dystonia experts for adult patients were available in all surveyed countries. However, almost half of the countries evaluated accessibility as merely 'satisfactory'. Access to genetic and neurophysiological testing was challenging to varying degrees in over half of the countries. Main oral medications and botulinum toxin were available in all countries. Deep brain stimulation (DBS) was easily accessible in one-third of the countries. Dystonia research was conducted in 20/24 countries. Training on dystonia for general practitioners (GPs) was available in 11/24 countries. However, lack of training for other professionals was almost common. For paediatric dystonia, experts and specific training were available in over half of the countries.

Conclusions

In this overview, we present the current state of dystonia management within ERN-RND. Management has slightly improved since 2016 in several fields, including diagnostics, availability of DBS, and research. The results highlight that future challenges in dystonia management are accessibility of experts, diagnostic tools and treatments, education on adult and childhood dystonia, and optimization of referral pathways. These findings are important for improving dystonia care across Europe.

Full article available here:

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9540051/

Participation at the Reuters Event: Pharma Europe 2022

Last October the Reuters Event: Pharma Europe 2022 took place in Nice, France.

This meeting is for pharma pioneers and healthcare innovators and had more than 1000 attendees from across Commercial, Sales, Marketing/Digital, IT, Medical, Patient Engagement, Market Access, and RWE (Real World Evidence).

The 3-day meeting included a broad variety of interesting sessions. During the Patient Engagement track Dystonia Europe Executive Director Monika Benson had been invited to co-present with Dr. Oleks Gorbenko from Ipsen. Together they presented the work on the "Cervical Dystonia Patient Journey". For more information on the patient journey see:

https://dystonia-europe.org/2022/05/first-ever-patient-experience-map-in-cervical-dystonia-reveals-multiple-barriers/

Monika and Oleks pointed out the importance of working on projects like this together. All stakeholders contribute and benefit from such collaborations. The cervical dystonia patient journey will now serve as the reference for Dystonia Europe when defining strategy and activities for the next few years.

Monika Benson
Executive Director
Dystonia Europe

Monika Benson, Executive Director Dystonia Europe and Dr. Oleks Gorbenko from Ipsen.

MDS Congress 2022 in Madrid

Last September the MDS* congress took place for the first time after the pandemic. The 4-day meeting was held in Madrid, Spain and about 3000 participants joined from all over the world. Dystonia Europe Executive Director Monika Benson was there and had a stand in the room for non-profit organisations.

Lorraine Cuffe, IPSEN and Monika Benson, Dystonia Europe

* The International Parkinson and Movement Disorder Society (MDS) is a professional society of clinicians, scientists and other health professionals interested in some of the most difficult diseases to diagnose and treat: movement disorders, including Parkinson's disease, related neurodegenerative and neurodevelopmental disorders, hyperkinetic movement disorders, and abnormalities in muscle tone and motor control. MDS operates exclusively for scientific, academic and educational purposes.

The MDS provides a platform for more than 11,000 professionals around the world to channel their collective influence to improve movement disorder care, advance research and the dissemination of knowledge around the world.

It organises an annual international congress in a different major world city each year.

Monika Benson
Executive Director
Dystonia Europe

MDS Awards to Dystonia Europe Medical Experts

Professor Marie Vidahielt receives the Award

Honorary Membership Award 2022 to Professor Marie Vidailhet

The MDS Honorary Membership Award Program recognizes individuals who have made extraordinary contributions to the field of Movement Disorders or otherwise to the Society. Recipients of this prestigious award shall be entitled to lifetime MDS Membership.

Marie Vidailhet is Professor of Neurology at Salpêtrière Hospital, Sorbonne University, in Paris, France. She has a long-standing interest in Movement Disorders, Parkinson's disease, and dystonia in clinical practice. Her areas of research range from pathophysiology to experimental therapeutics. Within her research group at the ICM Brain & Spine Institute, she has contributed to the understanding of the pathophysiology of dystonia and other rare movement disorders and to the development of therapeutic approaches such as deep brain stimulation in dystonia and noninvasive stimulation in tremor.

Prof. Vidailhet is active in the International Parkinson and Movement Disorder Society (MDS) and has served as a member of its International Executive Committee, Bylaws Committee, and Congress Scientific Program Committee. She was a member of the Congress Local Organizing Committee for the 2019 International Congress in Nice, served as Secretary of the MDS European Section (MDS-ES), participated as faculty of several MDS International Congresses and core faculty of the MDS-ES Schools for Young Neurologists.

Presidential Lecture Award: Stanley Fahn Lecture Award to Professor Kailash Bhatia

The Stanley Fahn Lecture Award was created to recognize an outstanding scholar and role-model clinician in the field of Movement Disorders. The selected lecturer must show evidence of exceptional contributions which have resulted in better understanding of the cause, diagnosis, or treatment of Movement Disorders, which has translated into meaningful improvements in the standard of clinical practice.

Back to the future: Is the Clinical Phenomenologist Obsolete?

Learning Objective: Appreciate the challenges faced by clinicians in the era of genetic and other advances in the field and how to approach this in clinical practice.

Prof. Bhatia is a Professor of Clinical Neurology in the Department of Clinical and Movement Neuroscience at the Institute of Neurology, UCL, Queen Square, London and an Honorary Consultant Neurologist at the affiliated National Hospital for Neurology, Queen Square.

Prof. Bhatia obtained his medical degree and also neurology degree from Bombay University India and obtained further training in neurogenetics and movement disorders with the late Professors Anita Harding and David Marsden at Queen Square London. Prof. Bhatia is a Fellow of the Royal College of Physicians and corresponding Fellow of the American Academy of Neurology. His main research interest is in Movement Disorders, merging clinical, electrophysiological, and genetic methods to study the pathophysiology of movement disorder conditions like dystonia, Parkinson's disease and atypical parkinsonian syndromes.

Prof. Bhatia currently has over 620 peer reviewed publications, several book chapters and has edited four books including a large reference tome "Marsden's book of Movement Disorders" by Oxford University Press (OUP) which was the recipient of the Best Book in Neuroscience award at the BMA awards in 2013. Prof. Bhatia is the current and founding editor in chief of Movement Disorders Clinical Practice Journal (MDCP) and has previously been the Associate Editor of Movement Disorders Journal (MDJ). Prof. Bhatia is on the executive committee for movement disorders for the Association of British Neurology (ABN).

Prof. Bhatia has served on several international committees of MDS and the ENS, EFNS including the International Executive Committee (IEC) of International Parkinson and Movement Disorder Society and the Congress Scientific Program Committee (CSPC).
Prof. Bhatia has been an active member of the EAN as a delegate and full individual member and was the subcommittee chairman of movement disorders when the EAN was formed. Prof. Bhatia started a term in 2019 for two years as Secretary- Elect of the MDS- ES to continue the close collaboration in the education programmes with the EAN and other bodies.

Professors Bhatia and Vidailhet are both part of the Medical & Scientific Advisory Board of Dystonia Europe and we are very grateful for all the valuable advice and support they have and continue to give to our organisation.

Our warmest congratulations to Professors Vidailhet and Bhatia for these achievements.

Monika Benson
Executive Director
Dystonia Europe

Professor Kailash Bathia receives the Award

Ipsen Patient Advisory Board Meeting in Paris

At the beginning of November Ipsen organized a Patient Ad Board Meeting in Paris. The goal was to share insights and give input on the Ipsen Patient Centricity Roadmap.

The nine participants were patient leaders from both national, European and global associations.

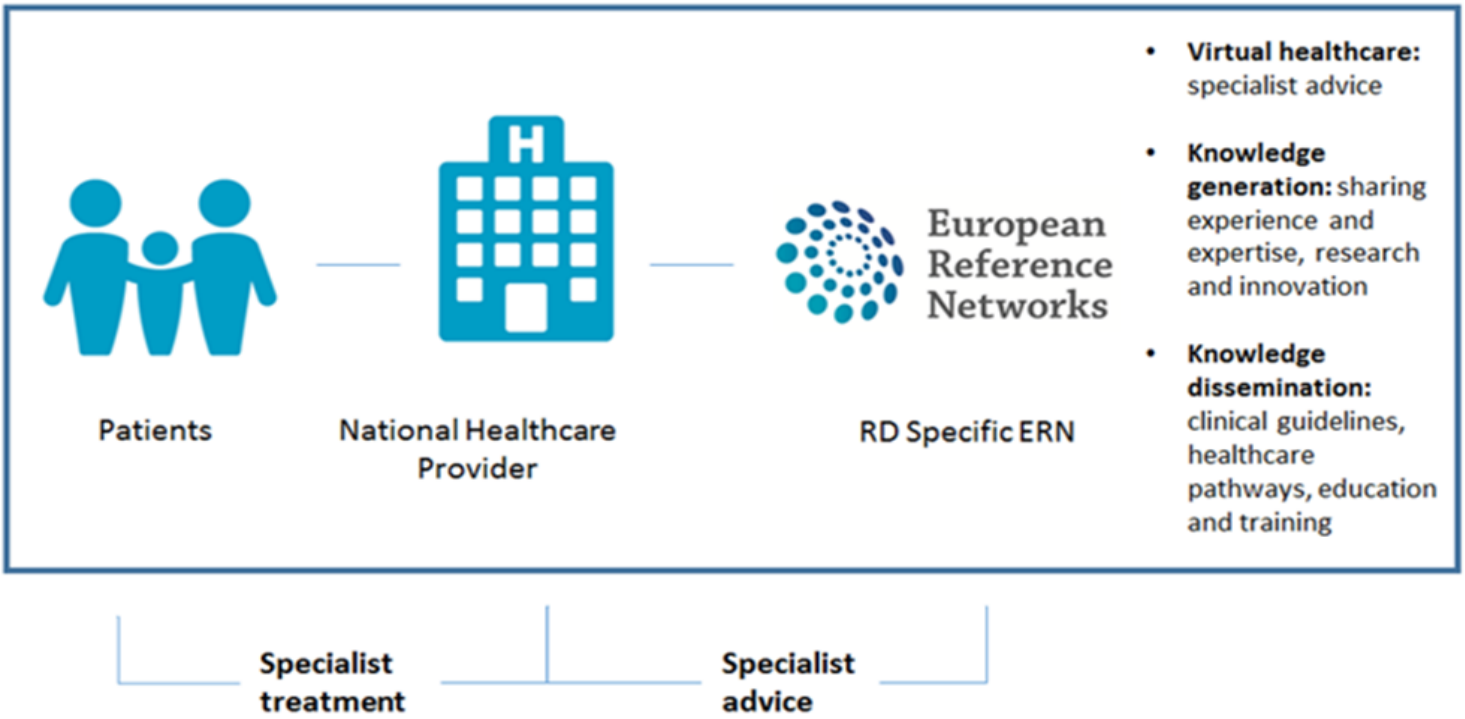
Facilitators from MediPaCe led the participants through various sessions on topics relevant to all stakeholders. The Advisory Board has met a few times already and follow-up meetings are planned for the future.

We thank Ipsen for the opportunity to take part in this valuable and important work.

Monika Benson
Executive Director
Dystonia Europe

Patient Advisory Board Participants

What is the ERN-RND Network?



The ERN-RND is a European Reference Network established by the EU to support patients and families affected by rare neurological diseases (RND) which requires very specialised knowledge, treatment and resources.

Some diseases are so rare that the necessary knowledge might not be available in the patient's nearest health centre or country. The patient doesn't travel but knowledge does. Specific information about the diseases ERN-RND covers can be found in the **Disease Knowledge** section.

European Reference Networks (ERNs) are virtual networks connecting healthcare professionals around Europe with expertise in rare diseases which allows them to discuss a patient's diagnosis and care, with their consent, via an online IT platform called the **Clinical Patient Management System (CPMS)**.

ERN-RND unites 64 of Europe's leading **expert centres** and 4 affiliated partners in 24 European countries and includes highly active patient organisations. Centres are located in Austria, Belgium, Bulgaria, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Hungary, Italy, Latvia, Lithuania, Luxembourg, Malta, Netherlands, Poland, Slovenia, Spain and the UK.

Monika Benson
Executive Director
Dystonia Europe

Meeting with the European Reference Network for Rare Neurological Diseases (ERN-RND)

"I have met many really hard working and dedicated people here in Tübingen and learned more about how they already work within the network and what their ambitions and wishes for future are", says an enthusiastic Astri Arnesen, EFNA Secretary General and ERN-RND patient representative.

The network partners met in Tübingen in Germany at the end of September for the annual meeting. Since the previous face-to-face meeting the network has gained many new partnering clinics. From the initial 31, there are now 68 clinics from 24 countries.

"In my opinion this network will be an important part of providing expertise and best practise treatment and support to RND patients all over Europe."

"It was very good to finally be able to meet people face-to-face again", says Astri. "I have been involved in the network since the start, and it is great to see that it's growing and evolving. In my opinion this network will be an important part of providing expertise and best practise treatment and support to RND patients all over Europe."

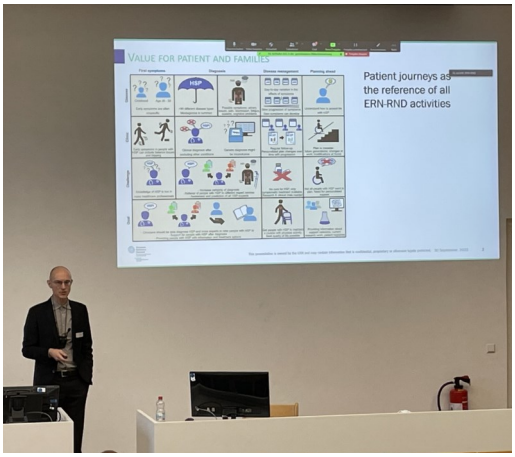
ERN-RND is coordinated from Tübingen by Dr Holm Grassner and his team. "I think I speak on behalf of all of us when I say that the network has a big potential to drive research, develop practices and really help patients affected by a rare neurological disease to live better lives", says Astri. "Together with my fellow patient representatives we work hard to make the network known in our disease communities and to have the ERN-RND partners committed to share their expertise both within the network but also in their respective countries."

"I learned a lot during the days in Tübingen and I look forward to working more with the network partners for the best of the patients and their families."

Elizabeth Cunningham
Senior Communications Manager
European Federation of Neurological Associations

Astri Arnesen, EFNA Secretary General and ERN-RND patient representative.

ERN-RND members



Prof Holm Graessner

Survey Results:
Assessing diagnosis and care pathways of people living with neurological disorders

Results have recently been published of the European Federation of Neurological Associations' (EFNA's) survey '**Assessing diagnosis and care pathways of people living with neurological disorders in Europe**', which was developed with the aim of identifying, reporting and beginning to address the varied challenges facing all affected by neurological conditions, either as patients or caregivers, from diagnosis to care pathway.

The survey reveals the shocking fact that only 1 in 5 have access to affordable therapeutic interventions that adequately manage their condition.

Other key findings include that females are less encouraged to visit a doctor, while being more aware of their symptoms and more engaged in research. Men are shown to be less aware of their symptoms, less engaged in research and believe they have fewer therapeutic opportunities. Furthermore, our data highlights that the majority of those engaged in providing care are female (85%).

Read the full report here:

https://www.efna.net/survey-results-2022/

Elizabeth Cunningham
Senior Communications Manager
European Federation of Neurological Associations

EPF COMPAR-EU
Final Conference Advocacy Event

In November EPF (European Patient Forum) held the final COMPAR-EU conference.

COMPAR-EU is a multimethod, interdisciplinary project that will contribute to bridging the gap between current knowledge and practice of self-management interventions.

The event was held in Brussels and lasted 2 days. In addition to the about 35 participants in Brussels there were EPF members following the meeting online.

On day one Valeria Ramiconi from European Federation of Allergy and Airways Diseases Patients' Associations held a presentation on "Self-Management & Interventions & Patient Involvement." Health Literacy was addressed and how to engage patients more for self–management. This is meant as a supplement of medical care for best possible results and quality of life for the patient. Self-management helps to reduce hospitalization and health costs.

Self-management must not be misunderstood as less care or follow-up from the GP (General Practioner/Doctor) and other health care provider.

Carola Orrego (Avedis Donabedian Research Institute, FAD) presented the "Main Achievements of COMPAR-EU during 2018—2022" . You can read more on this here:

https://self-management.eu/compar-eu-project-2/

Ultimately, COMPAR-EU facilitates shared decision-making and supports implementation of best practices in different health care contexts through an interactive platform, featuring decision-making tools and other end products adapted to the needs of expected end users (member state policymakers, guideline developers and researchers, health care professionals, patients, and industry).

Merete Avery
Operations Manager
Dystonia Europe

EPF European Patients Forum

Bengt-Erik Calles

Meet Bengt-Erik Calles, Sweden

What is your name?

My name is Bengt-Erik Calles and I live in Sweden. I am President of Dystonia Sweden. I live 5 months of each year at my summerhouse in Hjortnäs, Leksand and the rest of the year in Falun. Both places are situated in Dalarna.

What are the benefits of working within a patient organisation?

I have always worked in different organisations. Politics, sports, Rotary and so on. Dystonia Sweden is my first patient organisation. I have been on the board since I retired from my work in 2011. I started in 2003 in our regional network, Dystonia Dalarna. I like to meet people and try to help them in different ways.

I myself have had Cervical Dystonia since 1980 and got my diagnosis in 1989 along with the correct treatment for people with Dystonia.

How do you like spending your free time?

I have a wife, who has had Alzheimer since 2010 and has lived in a specialist home since 2017. We have five children and thirteen grandchildren. I see my wife twice a week and visit and help my children with different things. I have four houses in Hjortnäs and a boathouse. And one in Falun, so there is always something to do on the buildings. I also like gardening and have a lot of flowers and berries in Hjortnäs and a lot of lawns to cut, 4000 m2. We play boules once a week and swim in the lake Siljan. We could also take a trip with my boat.

What keeps you motivated on the tough days?

On tough days I work a lot in the garden and walk in the forest. My brother and his dog are my neighbours in Hjortnäs. My children and grandchildren come to visit me and help me if I want something done.

So I never complain.

What makes you angry or frustrated?

I am seldom angry, but if someone is mean to someone, I will defend them like an animal!

Bengt-Erik Calles
President Swedish Dystonia Assocication
Sweden

The Dystonia Network of Australia Inc.

The Dystonia Network of Australia Inc. (DNA) arose from a support group in the Blue Mountains area west of Sydney. It was incorporated as a national organisation in 2014 and is the peak body for people with all forms of dystonia in Australia. It is a registered charity and run by a small committee of volunteers.

Our aims are centred on providing appropriate, researched information on dystonia, increasing community awareness, funding seminars and assisting research into dystonia.

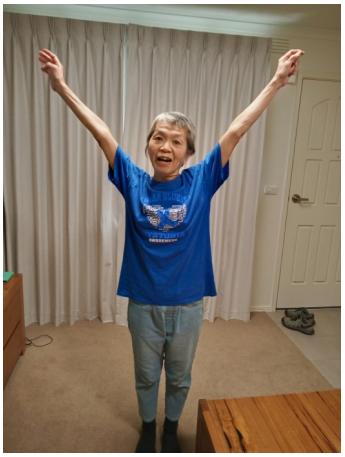
Every September we engage in activities to promote awareness of dystonia. Prior to Covid-19 we held seminars in person and had information booths at hospitals and botulinum toxin clinics and at health practitioner conferences. Now most of our work is online. We recently established our own YouTube channel and have posted a number of educational videos on it. The link can be found here - https://www.youtube.com/channel/UC4AmhY93x4a-5gQ4ZZlmg_A

This September we added three short videos by Australian health professionals and two videos by PhD students who are conducting research into dystonia. We were fortunate to be in the position, as a result of generous fundraising, to be able to contribute some funds towards the two PhD students' projects. It's very exciting for us as this is our first foray into helping to fund research.

We are aware that it is Dystonia Europe's 30th anniversary in 2023 and we would like to wish your organisation all the best for your celebrations and for the future. What a wonderful milestone and congratulations on all that you have achieved during that time!

Warm regards
Denise Duclos
President
Laraine McAnally
Secretary/Public Officer
Robyn McIlvar
Treasurer

Campbelltown RSL Jump



Lee Lim jump

Denise jump

Laraine Jump

Blue paintings

Finnish Dystonia Days 2022 in Oulu

The Finnish Dystonia Association, a nationwide patient organization, decided to arrange the Dystonia Days Conference in the largest city in Northern Finland, namely Oulu. Some 60 participants assembled to meet people from all over the country, get and give support and naturally, learn from expert speakers, a neurologist, and a neurosurgeon. After two years of COVID-19 pandemic we were able to arrange even patient discussion groups specializing in different forms of dystonia. It appears we should have allocated even more time for those discussions.

Neurologist Johanna Annunen described (in a simplified form) the way she makes dystonia diagnoses. The patients' age has a significant role in diagnosis. Typically, the younger the patient the more probable it is that the cause is genetics. Making a diagnosis is quite a holistic process starting from the moment a medical doctor first sees the patient sitting in a waiting room.

Johanna Annunen presented in an interesting way how she plans patient treatment consisting of botulinum toxin injections, medication, and DBS. Each method of treatment has positive and negative effects on patients. The doctor must evaluate which set of treatments have the biggest positive effect on the patient compared to potential disadvantages.

Neurosurgeon Maija Lahtinen concentrated on DBS treatment in her presentation. It was interesting to hear of the cooperation between neurologist and neurosurgeon when DBS treatment has been taken into consideration. Johanna Annunen and Maija Lahtinen are both employed by Oulu University Hospital. Therefore, they were able to describe the above mentioned cooperation.

The Finnish Dystonia Days Conference received great feed-back from the participants. The next Dystonia Days Conference in 2023 is planned to occur in Pori, South-western Finland.

Jukka Sillanpää
President Finnish Dystonia Association and Board Member Dystonia Europe

Annual Conference of "Dystonie-und-Du e.V."

Ulrike Halsch
Chairwoman Dystonie-und-Du e.V.

Annual conference of "Dystonie-und-Du e.V." sends out a signal of encouragement: Self-help association does not leave those affected and their relatives alone with their worries!

From September 9th to 11th 2022, the association "Dystonie-und-Du" met in Dresden. With this event, the self-help association was able to reach many of those affected, their relatives, top-class practitioners and politicians. The motto of the event was: "Make the best of it" - and it dealt with the topic of "twitches and spasms", among other things. It was a varied and lively gathering that encouraged visitors not only to learn more about the possibilities of treatment and therapy, but also to exchange ideas about possible solutions to the challenges of dystonia.

To be able to recognize the various symptoms of the disease and to actively alleviate the problems of everyday life together - this is the task the congress dedicated itself to. Political and medical representatives, but also scientists, manufacturing companies, therapists, psychologists and fellow campaigners from different regions were present.

At the general meeting, which took place on Friday, September 9th 2022, further steps to optimize the administration of the association were unanimously taken. Alexander Murawski is currently no longer able to act as treasurer due to a health problem. This situation was discussed and weighed up. In addition, the general meeting made important legal changes in the area of finance with the help of the legal advisor, Malte Uffeln.

The annual conference was opened on Saturday, September 10th 2022. Patron Michael Roth (Member of the Bundestag), Chairman of the Foreign Affairs Committee in the German Bundestag, and the Mayor for Social Affairs of the City of Dresden, Dr. Kaufmann, opened with a greeting and a speech. The video of Michael Roth's introductory sentences can be found on the association's website. The fact that dystonia is still largely unknown and places very high demands on the therapists and the employees in the social or political area - for example, the questions of professional integration, the choice of therapy in the diverse range of possible ones, complaints or public education about the disorder - was the focus of the event. The patron also pointed out how important it is to deal with crises for those affected with adequate and immediate help and to respond to the needs of such exceptional situations. Also, understanding for those affected must be raised and the human environment must be understood.

Mayor Dr. Kaufmann later offered active help for individual sick people on site and also promised to improve conditions for those affected. In addition, she presented the conference venue and promoted Dresden as an inclusive city. The association and the specialists present agreed that the importance of involving family members should be emphasised, as well as high-quality treatment based on the latest standards. All measures, including surgical interventions, should aim to relieve symptoms. Self-help in all its facets also helps to meet this challenge - starting with advice, through networking to exchange.

The third day of the conference on Sunday, September 11th 2022, was dedicated to the particularly rare condition of Myoclonus dystonia with a look at the Europe-wide supply situation.

A group was set up specifically for this topic in 2019 by Ulrike Halsch with the support of Dr. Gruber, Senior Physician in Beelitz. The psychologist Feline Hamami and the scientist and doctor Dr. Anne Weißbach spoke about brand new research results. After their presentation, they answered a wide variety of questions from their fellow campaigners, with the scientific advisory board of the association, represented by the chairman Prof. Dirk Dressler, contributing important additions to an open discourse. The results will be published promptly on the association's website.

Following on from that, Mrs. Dr. Adib and Prof. Dressler served as substitutes for another lecture on social law and related issues for dystonia patients, which was already planned in the conference program.

This was followed by a lively debate with suggestions for active action and advocacy by those affected, but also for dealing with the clinical picture in the practical life process of the patients.

Uwe Athens from Bremen made a very important contribution. He gave a detailed account of his personal experiences and the course of his illness, speaking directly from the heart of many of those present. You find yourselves in his descriptions and thus experience a feeling of being understood and of solidarity.

With the help of the many inputs from the participants involved, the event succeeded in showing the difficulties in handling dystonia and at the same time working on perspectives to deal with hurdles realistically. In addition to the people mentioned, Chairwoman Ulrike Halsch also explicitly thanked Dr. Klingelhöfer from the University Hospital Dresden, Christine Bolte and Dr. Weißbach from the University Hospital Lübeck and the physiotherapist Gabriele Hupfeld from Bückeburg. Thanks also went to the hotel hosting the association, the association's internal working group for social affairs, represented by Gisela Murawski (Bad Oldesloe), with its members Dennis Riehle (Constance) and Uwe Ahten (Bremen), as well as Mirko Lorenz (Berlin) for the relaxation exercises and the companies "Abbott" with Mr. Voelz and "Boston Scientific" with Alexander Preuss.

Ulrike Halsch
President
Dystonie-und-Du e.V.
Berlin, September 30th 2022

Selbsthilfeorganisation
DYD
Dystonie-und-Du e.V.

30th Anniversary of Associazione per la Ricerca sulla Distonia – Italy

From left: Maurizio Persia, the A.R.D. Board and Daria Leuzingen

As A.R.D. was created in 1992, this year it reached 30 years and we wanted to celebrate the 30th anniversary in a special way; therefore we matched our Third National Dystonia Day to our anniversary, organising a concert followed by an online live broadcast, circulated by our social media.

Most recently, A.R.D. had been deeply involved in musician's dystonia, that's why for our anniversary we decided to host an event including a concert, but it seemed too difficult to achieve. By chance, last year we met Prof. Maurizio Persia who played trombone in Santa Cecilia Orchestra in Rome and contacted A.R.D. as he could no longer play due to a mouth dystonia. This summer, when he found out our wish for the anniversary, he was so generous as to offer his home for the concert and organise it, involving some of his musician friends.

On the afternoon of Friday September 23rd, we went to his villa not far from Rome, which is a building designed 50 years ago by a famous architect: the villa has a spiral base, with curving walls and without corners. Its name is Villa Ammonite as from above it looks like a fossil mollusc shell. In this amazing location Maurizio and his wife Daria Leuzingen who is a violinist had prepared a concert room where we could assist with the concert which was divided into 2 parts: first the String Quartet Henao (composed by William Chiquito from Colombia, first violin; So Yeon Kim from South Corea, violin; Stefano Trevisan from Italy, viola; Giacomo Menna from Italy, cello) played the "Quartet K387 in G Major" by Wolfgang Amadeus Mozart, followed by the tango "Por una cabeza" by Carlos Gardel. Later the pianist Monaldo Braconi played "Concert Fantasies on Tosca, Boheme and Gianni Schicchi" by Giacomo Puccini-Emile Tavan.

Around 40 people helped with the concert, most of them did not know about dystonia and with Maurizio we introduced A.R.D. and our activities.

Piano player

String Quartet

The event ended with a big cake dedicated to A.R.D.'s 30th anniversary. The President and the board blew out the candle and enjoyed this delicious cake with the guests. Once again we thank Maurizio and Daria for their exquisite hospitality.

The following morning, September 24th, the President Flavia Cogliati and vice President Maria Carla Tarocchi with a journalist, Francesca Romana Gigli, were in a TV studio in Rome for a live broadcast on our social media, FB, YouTube and Instagram. Prof. Alberto Albanese, who is the President of our Scientific Committee, took part from Milan.

This year our hashtag was #ilcoraggiodivivereatestaalta which means "the courage of living head on".

We began with 2 stories of life with dystonia.

Raquel is a member of our Board and told us about her pregnancy with dystonia: she has cervical dystonia and regularly has botulinum toxin injections with which she gets on well. She and her partner had decided to have a child, but the great problem was how to resist for many months without botulinum toxin, as usually it is not used during pregnancy to avoid any possible risk to the baby. At the end of 2021 Raquel realised that she was pregnant, she immediately took medical leave from work and spent her pregnancy without injections. She was helped with physiotherapy and acupuncture, until July 17th when Martina was born with an easy natural birth. At present she is breastfeeding her baby, which does not yet allow her to have injections. Raquel thinks that peculiar pregnancy hormones may have helped her to overcome this long critical period without botulinum toxin. This is the first time we have published a story of pregnancy with dystonia, which is unfortunately a little discussed topic in spite of its great relevance.

Our member Maria Gabriella had serious dystonia symptoms in her arm and could not use it any longer. Besides periodic botulinum toxin injections, she began to practise Tai Chi Chuan (the Chinese martial art) and gymnastics, which is also an active way of meditation. She felt she could improve her body control and now, after 7 years, she has totally recovered and is now a Tai Chi black belt and teacher herself. In a video she showed us some Tai Chi figures with harmonious movements and very high control of the whole body, which is a great success for somebody with dystonia. Gabriella said that Tai Chi allowed her to restore muscle tone, agility, breath control and balance.

Later we presented our annual A.R.D Awards: since 2012 every year A.R.D. awards young doctors under 35 years of age who propose the best study about dystonia in Neurological congresses. We give 2 prizes, each of €2000. Four doctors who have been awarded in recent years illustrated their study.

Prof. Alberto Albanese commented on the stories about Tai Chi, Pregnancy and the young doctors' studies, giving medical and behaviour information.

Prof. Albanese introduced a recently launched project "Botulinum versus DBS in cervical dystonia" which is supported by our Ministry for Health. It is research in order to evaluate in which cases botulinum is better or more appropriate than DBS in cervical dystonia. A.R.D. will cooperate to find volunteers for this project which for the first time compares the 2 treatment types.

The third part of our event concerned musician dystonia from a work perspective. At present, in Italy and in many European countries when a musician cannot play any more due to a focal dystonia, no specific State benefit is provided, as this is not considered an "occupational disease". Prof. Maurizio Persia is the first musician with dystonia to request this benefit. The legal consultant who is helping him illustrated the long bureaucratic procedures still in progress to get recognition of his dystonia as work related illness. We hope this goal will be soon achieved; it would be the first time in Italy. This certification could open the way to similar procedures for dystonia caused by other types of work.

Our online event ended with the concert organised by Prof. Persia and recorded the day before. We are really pleased with the outcome of our celebration which was a mix of music, patients' stories, medical information and legal consultancy, marked by our big anniversary cake.

Maria Carla Tarocchi
Vice President A.R.D.

Dystonia Days in Bergen, Norway

In October the Norwegian Dystonia Association held their autumn meeting in beautiful Bergen, a city on the west coast of Norway. Almost 50 people attended the meeting.

The key lecture was Physiotherapy by Anette Holmelid Elvik. She had a very interesting presentation. There were lots of questions from the audience

We also heard a patient story by Atle Bogen talking about his journey with Dystonia. It was a story that really moved you.

From left: Sissel Buskerud, Anette Holmelid Elvik og President Norwegian Dystonia Association Johan Arnfinn Warvik.

In the evening we had a journey to Mount Fløyen. A funicular railway takes you up to one of Bergen's 7 mountains that surround the city. What a stroke of luck. The rainy weather disappeared, and we had sun when we arrived at the mountaintop.

Back at the hotel we sat down and talked about the challenges we all have to live a good life with dystonia. The meeting ended with a dinner at the hotel with good food and a quiz about Bergen after dinner.

Sissel Buskerud
Vice President Norwegian Dystonia Association
Treasurer Dystonia Europe

Special Workshop on Physiotherapy for Cervical Dystonia

End of October the first meeting of a 3-day workshop on Physiotherapy and Cervical Dystonia was held in Umeå in Northern Sweden.

Physiotherapist Johanna Blom from Skåne University Hospital in Malmö, Sweden, gave an introduction to what dystonia is and how it is treated. A demonstration patient was invited to take part in the session showing how to do the anamnesis. Johanna asked him several questions on his dystonia, when it started, how it affects him, his work and life in general.
"I tried to be normal but it didn't work very well", he said. Then followed a physical demonstration deciding what exact muscles are affected. Before lunch there was also time for Johanna to go through what types of exercises could be efficient for the patient to practice.

After lunch Dr. Ghad Loutfi from the Neurology Department of the University Hospital of Norrland in Umeå gave a presentation on dystonia, where it comes from, various types, different treatment approach.

In the afternoon followed another session with a new demonstration patient, identifying the muscles affected and what exercises to recommend.

15 physiotherapists had come to Umeå from all over Sweden, most of them from the Northern region. At the end of the day they all received the assignment to go home and practice the learnings on a dystonia patient and to document it all, preferably with video. When we meet again for the second part of the workshop in March 2023 everybody will show and report their work for the group.

The workshop is a made possible with a grant from Ipsen and Desitin in Scandinavia.

Monika Benson
Executive Director
Dystonia Europe

Theory with Johanna

Demonstration exercises

Dystonia UK

According to the European Brain Council, there are more than 500,000 people living with dystonia across Europe, 100,000 of whom are estimated to live in the UK. While much of our work is centred around the dystonia community here in the UK, Dystonia UK has plenty of resources easily accessible for those across Europe and beyond…

'Reach Out, Reach All' Webinars

Our webinars help you access advice and information at a time and place that works for you. We reach out to our medical advisors, network of medical professionals, and partner organisations to find the most relevant and experienced speakers to answer your questions about dystonia. You can catch up on a recording of a previous session wherever you are in the world.
www.dystonia.org.uk/pages/category/dystonia-matters-webinars

Dystonia Matters Podcast

We know how important it is to hear other people's stories and know you are not alone. Our Dystonia Matters Podcasts allow us to share the voices of our community, not only helping to raise awareness of the often-unknown condition but also giving you a chance to hear from others who may be on a similar journey. We've had a number of guests across the series including mums and dads, young professionals, and even a TikTok superstar!
https://www.dystonia.org.uk/pages/category/dystonia-matters-podcast

Dystonia Matters Magazine

Packed full of articles our Dystonia Matters magazine brings you personal stories, updates on research studies and all the latest dystonia news and events. 3 times a year, Dystonia UK members receive a printed copy for free. (Overseas members receive a digital copy.)
www.dystonia.org.uk/forms/join-or-renew-your-membership

Dystonia Animated

Have you watched 'Dystonia Animated', a short animation series designed for kids, carers & families to help support in all aspects of life living with dystonia? With 2 episodes so far, you can meet Dani in 'Dani Explains Dystonia' or follow Charlie as he visits his regional hospital in 'Charlie at the children's hospital'. Finally, 'Sam's Surgery Story' focussed on deep brain stimulation surgery will be coming to a screen near you soon!https://www.dystonia.org.uk/pages/category/dystonia-animated

We know that life with dystonia isn't always easy, and as we enter 2023, just like our sister charities, we will continue to be there for the community. To help make this happen we're asking everyone who can to donate £1 or €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.
Please donate £1 or €1 today to support the dystonia community, thank you.
https://bit.ly/JustOnePoundEurope #JustOnePound

Victoria Wareham
Director of Operations and Development
Dystonia UK


#JustOnePound

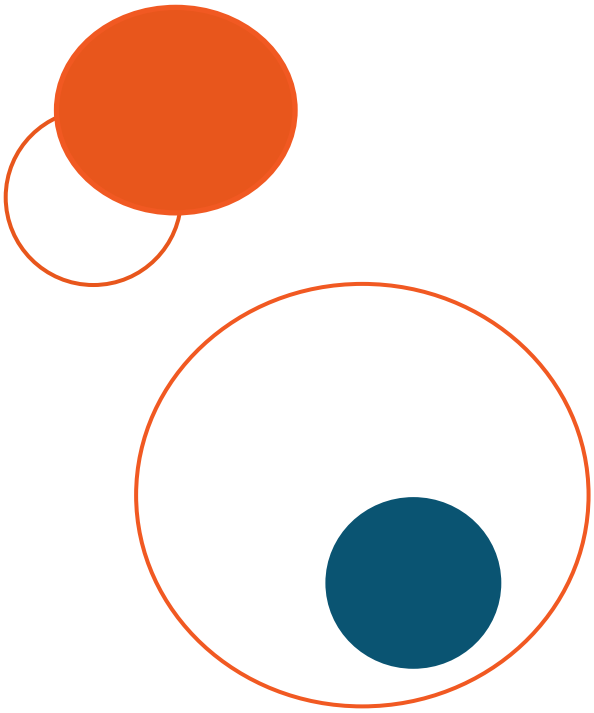
Dystonia Animated

Reach Out, Reach All webinars


Dystonia Matters Podcast

Dystonia Matters magazine

Calendar 2023



January

20 DE Board Meeting on-line

February

28 DE Board Meeting, Brussels, Belgium

28 Rare Disease Day

March

1 Think Tank Meeting, Brussels, Belgium

13-19 Brain Awareness Week

April

27 DE Board Meeting on-line

May

31 Dystonia Coalition Meeting, Dublin, Ireland

June

1-3 6th International Dystonia Symposium, Dublin, Ireland

3-4 Dystonia Europe 30th Anniversary Conference & Dystonia Days 2023, Dublin, Ireland
Presentation David Marsden Award 2023, Dublin, Ireland
Dystonia Europe 30th Anniversary Dinner
Dystonia Europe 30th Annual General Assembly

July

1-4 EAN Congress 2023, Budapest, Hungary

22 World Brain Day

August

27-31 International Congress of Parkinson's Disease & Movement Disorders, Copenhagen, Denmark

September

27-30 ESSFN Congress, Stockholm, Sweden

DYSTONIA EUROPE

Dystonia Ireland

Organized in parallel with the 6th International Dystonia Symposium

6TH

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DYSTONIA EUROPE

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National Tourism Development Authority

MEET IN IRELAND

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

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.

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 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. .

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

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

B-1000 Brussels, Belgium

E-mail: sec@dystonia-europe.org

Photos from Dystonia Days and portrait photos:

Stephan Röhl, www.stephan-roehl.de

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

We thank all our partners for their support and collaboration.

Donation and Support

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

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

Thank you for supporting Dystonia Europe!

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