

Connecting people for dystonia

DYSTONIA EUROPE

NEWS

AUTUMN 2017

WELCOME TO DYSTONIA EUROPE 25th ANNIVERSARY IN BRUSSELS



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THE DATE**

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**D-DAYs
2018**

**AND 25TH
ANNIVERSARY
OF DYSTONIA
EUROPE**

Read about the upcoming Dystonia Europe 25th Anniversary & D-DAYS in Brussels on page 17

www.dystonia-europe.org

Connecting people for dystonia

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Dystonia Europe
connecting people to
spread information
raise awareness &
promote research

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*From Dystonia Europe to all of
you, a Happy Holiday Season
and all the best for the New Year!*



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President's Message



Dear all,

We are at the end of 2017 and a new year is waiting around the corner - 2018, a year that I am very much looking forward to since we will be celebrating the 25th Anniversary of Dystonia Europe. This event will take place in Brussels, Belgium where our organisation is registered.

It all started almost 25 years ago in Spoleto, Italy where our European Dystonia Federation was founded in 1993 by 11 member organisations. In 2011 we became Dystonia Europe and today we are 22 member organisations from 19 countries. We are very pleased to share with you in this newsletter activities and meetings organized by some of these members. There were Anniversary celebrations: AMADYS – the French Dystonia Association turned 30 years; DDF – the Danish Dystonia Association and the Italian Dystonia Association turned 25 years. In Finland, every autumn, they organise their annual Dystonia Days. In Italy the Italian Dystonia Association published a book with dystonia patient stories.

Dystonia Europe has throughout the years not only brought many of the national European dystonia associations together, but have also made strong connections with other dystonia organizations, like the DMRF (Dystonia Medical Research Foundation). One of the highlights of our collaborations was the 5th International Dystonia Congress held in Barcelona in 2011 and we are now discussing the possibilities of working together on such a project again.

My thoughts often go to those who founded Dystonia Europe 25 years ago and all the people who have contributed throughout the years to make Dystonia Europe to what it is today. The accomplishments would not have been possible without the dedication and continuous work of our founders, leaders, board members and staff during all these years. Many thanks also to all clinicians and researchers working in the field of dystonia and our Medical and Scientific Advisory Board who has given valuable support and advice over the years.

We are also very grateful for all the support from partners and sponsors who contribute to the development of our organization, projects and activities. The Think Tank meetings have created an excellent platform where we exchange ideas and work together with the best interest for dystonia patients in mind.

Our partnerships with EFNA – European Federation of Neurological Associations; EBC – European Brain Council and EPF – European Patients Forum are very valuable. By working together with other disease areas, especially within neurology, we are able to advocate on common topics of interests such as stigma, access to healthcare, and increased funding of brain research in Europe.

Finally I would like to thank you all for the important work you do for dystonia patients and their families across Europe.

Wishing you all a Happy Holiday Season and all the best for the New Year!

Merete Avery

President

Dystonia Europe Takes Part in Dystonia Awareness Month

At the last Dystonia Europe General Assembly, it was agreed to join the international Dystonia Community and work on dystonia awareness during the month of September. Since this was the first time DE joined the initiative there was no special campaign planned.

Instead the idea this year was to post on social media, once a day, some information about dystonia and ask people to share. We had posts with physicians talking about dystonia, patients telling how it is to live with dystonia, facts about dystonia and we also shared posts of our partner organizations to support their work.

During the month we launched the Dystonia Survey by Professor Maja Relja. Read more on page 5 .

The increased on-line activities contributed to more visits on our website as well as Facebook page compared to September of last year:

Website:

- 1 Sept to 30 Sept 2016 – 523 visits.
- 1 Sept – 30 Sept 2017 – 1558 visits.

Facebook Average reach/day:

- Sept 2016 – 174
- Sept 2017 – 2028

The three most popular posts were:

- A short video explaining DBS which reached 7007 viewers and was showed 10 599 times.
- Our Dystonia Survey launch reached 5452 viewers and was shared 51 times.
- A video with our Dystonia Europe President Merete Avery reached 2980 viewers and was shared 54 times.

For the September Awareness month in 2018 we hope to plan some special activities. If you have any special ideas of what to do on-line or in your country please send us an e-mail and let us know at sec@dystonia-europe.org

The more we are working together to raise awareness of dystonia the more will dystonia be heard of and known.



Dystonia Europe Delegates moving dystonia awareness forward.

Take a Survey for Change

In our Dystonia Europe spring newsletter we informed about the recently launched Dystonia Europe survey platform: <https://surveys.dystonia-europe.org>.

Dystonia Europe works to support researchers in moving forward research that could lead to future treatments and cures for dystonia. Help us by filling out our short surveys on treatment satisfaction, quality of life, access to treatment etc. Your personal dystonia experience and input can benefit the dystonia community today and in the future.

Our first survey on the platform is a European Dystonia Survey by Professor Maja Relja from University of Zagreb. If you are a dystonia patient and you have not yet filled out the survey please do so on: <https://surveys.dystonia-europe.org/survey/public/RAREORNOT>.

The use of questionnaires as a method of data collection in health-care research is widely accepted. Take 10 minutes of your time for this survey. With your help we could evaluate the accessibility of patients to treatment and dystonia specialists in Europe, the effectiveness of care and treatment as well as the influence of dystonia on quality of life. Results derived from this survey could help to improve dystonia care in Europe and prove that dystonia is not a rare disease.



Prof Maja Relja

This survey is anonymous, but we do want to register your country for the benefit of the survey. When the survey is done you have an option to register your name and email address if you want to receive a copy of the survey results.

The survey, which will run until 31 January 2018, has been translated to 21 languages and is being promoted by our member organisations across Europe. So far we have almost 1000 participants.

The first results of this survey will be presented by Prof Relja at a special lunch event to be held in the European Parliament on 12 April 2018, to kick off our 25th Anniversary weekend. Read more on page 41.



Dystonia Master Debate in Paris

Almost one hundred dystonia experts and Boston Scientific staff had gathered at the Fillerval Castle north of Paris for the two-day meeting: “Boston Scientific International Masters’ Debate: Reshaping the Future of DBS”. Presentations followed by debates engaged the participants who contributed to fruitful discussions. Boston Scientific also celebrated its 5th Anniversary since the launch of their first DBS (deep brain stimulation) device.

BS Vice President Milad Girgis opened the second day by stating the company’s mission: ‘Boston Scientific is dedicated to transforming lives through innovative medical solutions that improve the health of patients around the world.’ The company will keep developing technology to advance and move forward treatment.

Caroline Loveless EPDA (European Parkinson’s Disease Association) and Monika Benson from Dystonia Europe represented the patients. During coffee breaks a special fund raising initiative took place where participants were asked to throw darts to target the sweet spot! By the end of the meeting Dystonia Europe and EPDA were presented with a donation for each one of our organisations.

We thank Boston Scientific for their generous gift and valuable support and for organizing this very important master debate. We also thank all the experts for the work they do every day to move forward treatment for dystonia patients.



Busy Days for Dystonia in Brussels

• My Voice Matters

On 21 November the exhibition ***My Voice Matters – Integrating Patient’s Preference in the Healthcare Agenda***, was launched in the European Parliament, hosted by MEP Lieve Wierink from Belgium. The event was a collaboration between several organisations (Medicines for Europe, Value Added Medicines, Active Citizenship Network and EFNA – European Federation of Neurological Associations) and the exhibition featured information stands from the different organisations.

Each year 1 in 3 people are affected by a brain disorder and 1 in 5 by chronic pain. Brain disorders are the biggest economic challenge of European healthcare costing 800 billion euros a year. The WHO estimates that brain disorders cause 1/3 of the burden of all diseases. Across Europe 2/3 of people with brain disorders receive no treatment and 40% of people with chronic pain report that it is not adequately controlled. These diseases are the most complex and least understood in medicine. Drugs in the field take longer to develop and only 8% of candidates succeed and are often hugely costly.

The objective of the exhibition was to provide a platform for patient groups and representatives to raise awareness on their needs, the importance of a healthcare agenda, and how to integrate the patient preference within a range of therapeutic areas. EFNA used the opportunity to further their work on access to employment under the hashtag #makeworkwork.

The overarching message from all groups is “my voice matters” – the need for patient centricity in healthcare and EU policy.

*Monika Benson, DE,
Elizabeth Cunningham,
and Donna Walsh, EFNA*

• BMP – Brain, Mind & Pain Interest Group

The following day the BMP – Brain Mind and Pain – Interest Group Meeting was held in the Parliament. The theme of the meeting was: “**Ensuring equitable access to high-quality treatment in brain, mind and pain disorders**”. MEP Lieve Wierink welcomed the participants and said: “I believe that this kind of meetings provide an excellent opportunity to raise awareness on both challenges and successes regarding the treatments in brain, mind and pain disorders. This issue is one that requires substantial attention from the EU Institutions and stakeholders.”

The first session focused on **CASE-STUDIES from A Health Professional Perspective STROKE** - **Prof. Franz Fazekas** presented the results of a questionnaire conducted by the European Stroke Organisation which highlights disparities in access to stroke treatment across Europe. He also reported on an EAN study which gives an overview of the current practice of neurology across Europe; highlighting examples of good and poor practice – as well as briefly mentioning access to quality neurology education and training.

PARKINSON’S DISEASE - **Prof. Guenther Deuschl** reported that many treatment options are now available for PD patients but these are not accessible for all. He also mentioned a project EAN is preparing which will aim to assess availability of the necessary health care interventions for neurology patients across Europe.



CHRONIC PAIN - Prof. Christopher Eccleston reflected upon the book “European Pain Management”, the first comprehensive publication on the state of pain care and access to treatment across Europe. Prof. Bart Morlion gave a brief overview of the European Pain Federation’s activities and how they help to improve equitable access to high-quality treatment for patients in Europe.

Then followed a **PANEL DISCUSSION on the Patient Perspective** chaired by **Nicola Bedlington**, Director European Patients’ Forum. Panel participants were **Monika Benson** – Dystonia , **Neil Betteridge** – Rheumatic and Musculoskeletal Diseases , **Astri Arnesen** – Huntington’s Disease and **Joop van Griensven** – Chronic Pain.

The panel highlighted current disparities in access to treatment/services across Europe and the issues these create, from the patient perspective. Access to correct diagnosis and treatment are crucial for a good quality of life.

More educated patients and patient advocates would allow patients to advocate for access and be part of the solution in making healthcare systems more fit for purpose and in service of patients’ needs. The current EFNA project: TINA – training of Neurology advocates, is a good example of how patient organisations can support.



• Brain Health: The Digital Future is on its Way

The European Brain Council (EBC) organized together with xHealth this workshop in the European Parliament co-hosted by MEP Mr. Boni who is part of the ITRE (Industry, Technology, Research and Energy) Committee. He is very interested and has worked a lot in digitalization, information systems, and eHealth, to name a few. He opened the event with an introduction to eHealth as part of the EU Digital Single Market strategy, which aims to open up digital opportunities for people and business and enhance Europe's position as a world leader in the digital economy.

EBC President Prof. David Nutt chaired the event and the first speaker was Ms. Elen Ohov, providing a political update from the Estonian Presidency of the EU. She is the Counsellor for eServices (Health and Social Affairs) at the Permanent Representation of Estonia to the EU, and presented the views of the Estonian Presidency of the EU on eHealth & digitalization, based on the presidency’s agenda. Two of its priorities are ‘a digital Europe and the free movement of data’ and ‘an open and innovative European economy’.

Magda Chlebus, Director of Science Policy at the European Federation of Pharmaceutical Industries and Associations (EFPIA), gave a presentation on the Radar CNS project— a major new research programme which is developing new ways of monitoring major depressive disorder, epilepsy, and multiple sclerosis using wearable devices and smartphone technology— as well as the forthcoming EFPIA project on digital endpoints (mobility, mood, fatigue, sleep) as alternatives to today's not very reliable endpoints in clinical development.

Monika Benson, Executive Director of Dystonia Europe, gave the patient’s perspective on eHealth, the benefits of patient engagement in the digitalization of healthcare and an introduction to the MyDystonia app. This digital tool can help patients improve quality of life by continuously monitoring their health condition and daily routines.

Latest News

Prof. Giuseppe Carrà, Tenure track researcher in Psychiatry at the University of Milano Bicocca, covered the perspective of healthcare professionals on eHealth and digital tools.

Other speakers were: Kim Baden-Kristensen, Founder & CEO of Brain+, part of the Digital Therapeutics Partnership, who discussed the added value of multi-stakeholder collaboration and eHealth start-ups; Thomas Lethenborg of Monsenso, talking about Start-up showcase and Deepak Tawari, Founder & CEO of Privately. He gave a presentation of an AI (artificial intelligence) based tool/app, Oyoty, that supports online well-being in children.

The technology detects online threats and risks in real time and makes technical as well as educational interventions to help a young person to navigate their online lives.

The workshop brought together experts with many different views, covering data sharing, patient engagement, research & innovation, integration and examples of innovative solutions.

As demonstrated in the EBC study on the “Value of Treatment for Brain Disorders in Europe”, <http://www.braincouncil.eu/activities/projects/the-value-of-treatment> the future of healthcare and improved brain health lies in the hands of “information and communication technologies”.



Basic Research in Dystonia

A partnership between the VIB Research Institute (Belgium) and the Foundation for Dystonia Research (Ruelens – Van Gorp) supports basic research into dystonia. Their research group is located in Leuven, Belgium, and headed by Rose Goodchild, Ph.D. (UK, 1974) who was recruited after working on dystonia as a junior researcher in the USA. This team has been active since 2012 and last year published a paper describing a surprising connection between the DYT1 dystonia gene and synthesis of lipids (fats). Although it's still a long way from any new therapy, their finding brings new ideas on what goes wrong in the genetic DYT1 form of dystonia, and is attracting attention from other fields. Here they explain their strategy for basic research and the hoped for potential of their recent findings.

The terms “Basic” or “Fundamental” refer to research without patients and/ or research that begins without a specific outcome already in mind. Basic research teams are also often PhD scientists trained to work with cultured cells, genetic engineering, or the biochemistry of proteins, as examples. At first glance it is difficult to know how basic research can be useful for a disease like dystonia.

How is it possible to find out more on dystonia without looking at patients who suffer from the disease? While indeed not straightforward or fast, basic research is still the central route to therapies that act against the underlying causes of disease.

This is well accepted in fields like cancer or immunology where the basic research pipeline brings new ideas for new drugs, but has been slower to reach successful outcomes for most brain diseases.



Prof Rose Goodchild

Although dystonia looks like a muscle disease, it comes from misfiring neurons in the brain that activate the wrong muscles or too many muscles.

Basic researchers hope to find out how dystonia-causing insults change the molecular machinery inside a neuron to cause the misfiring. Once this is known, they predict that they can design new therapies that correct the defect. This would supplement or even replace the existing dystonia treatments that mostly act against the symptom of muscle contractions rather than the underlying cause.

Dystonia basic researchers use verified causes of dystonia to track the molecular cascade underlying neuronal misfiring. In most cases this means they start with a genetic mutation. Even though these mutations are rare and few humans with dystonia have them, they are vital “tools” for researchers to interrogate the earliest problems in cells exposed to an insult that causes dystonia.

The VIB/FDR research group mostly works with a dystonia gene called TOR1A that was found in 1997. TOR1A-dystonia is a 'dominant' dystonia, meaning that one mutant copy of TOR1A is enough to cause disease (patients still have one normal copy of TOR1A).

Finding out how TOR1A mutation causes dystonia has been a long-term topic for the researchers in Belgium. They take advantage of the fact that TOR1A is not just a human gene; there are TOR1A genes in all animals. Thus, they can ask about how and why TOR1A is important for cells using different organisms where different experiments are possible. This includes fruit flies that may seem like a strange choice for dystonia, but in fact are important research organisms for many diseases because of their rapid life span and a highly advanced genetic engineering tool kit. Flies are also animals. They have neurons and a nervous system that allows them to move, to sense their environment, to react to stimuli, etc. Indeed, it is clear that individual cells in a fruit fly have nearly all the same molecular machinery as a human cell.

In this case, the major breakthrough was finding that fruit flies lacking the fly version of TOR1A (*dTorsin*) die because they make too much of one kind of lipid, and not enough of another. This was completely unexpected, and the importance of the imbalance was proven via adding more mutations into the flies without *dTorsin*-, and seeing that flies start to live when a particular lipid enzyme is inactivated. The team published their findings in the prestigious *Developmental Cell* journal, where they also showed evidence that TOR1A affects lipid production in human cells like it does in fly cells.

Lipids are sometimes also called fat, but do much more than just energy-storing; they are building blocks for the membrane barrier of cells and provide electrical insulation in the brain. Thus, finding that TOR1A mutation causes imbalanced lipid production gives new ideas about the types of defects that cause dystonia.

The team is also excited because there are many "drug-able" targets in lipid synthesis – meaning that it may one-day become possible to correct abnormal lipid synthesis in dystonia.

Next up, however, is to find out if lipid synthesis can explain abnormal neuronal firing in mammalian brains, or that other things must go wrong too. In addition, the team want to know whether lipid synthesis is changed in other forms of dystonia? Nevertheless, even before we have these answers, the basic research finding is attracting attention from researchers who work on lipids, membranes or energy storage. These are researchers who had not heard before about dystonia, but will now also study the TOR1A dystonia gene. Thus, even though it will be many years before the new finding might translate to therapy, it is already a stimulus getting more researchers thinking and talking about dystonia.

Rose Goodchild, PhD.

Ruelens-Van Gorp Foundation for Dystonia Research – Chair for Primary Dystonia

VIB-KU Leuven Center for Brain & Disease Research

Leuven, BE

The following articles, page 12–15, make reference to certain companies and their products and any opinions expressed should not be taken to be the views of Dystonia Europe or its members.

The articles are written by respected authors and are provided for the information of Dystonia Europe News readers.

MAKE SURE YOUR DECISION TODAY PROTECTS YOUR PATIENT'S FUTURE

Your Deep Brain Stimulation (DBS) patients have now access to full-body MRI conditional scans¹ – with no interruption to their treatment – thanks to DBS systems approved by European regulators.

DBS therapy, an increasingly common treatment for neurological movement conditions like Dystonia, uses a surgically implanted medical device, similar to a pacemaker, to deliver mild electrical pulses to specific areas of the brain.

It's estimated that 7 out of 10 patients eligible for DBS therapy may need an MRI following their implant.² Until recently, such patients have had to turn their DBS systems off for scans – or forego MRI altogether due to the potential health risks and complications of using the two technologies together.

SAFE AND COMFORTABLE¹

Only Medtronic allows MRI scans with continuous therapy – this means that you don't need to interrupt the stimulation and your patients can remain as comfortable as possible during an MRI. This is especially important for people living with dystonia or tremors.

Furthermore, because the system remains ON during the MRI scan and movements are minimized, image quality may be improved, and you may acquire images faster as well.

INFORMATION TO CONSIDER WHEN SELECTING YOUR BATTERY REPLACEMENT

We know you care about the wellbeing of your DBS patients. That's why it is in our common interest to ensure the safety and reliability of the therapy we provide. It is recommended to only use DBS devices with components (e.g. leads and extensions) from the same manufacturer and to never mix a system with components by other manufacturers.

With a complete Medtronic DBS system, your patients have the confidence of knowing that they will receive the support they may need.

TESTED, PROVEN, ESTABLISHED



To ensure your patients get the most out of their therapy, Medtronic has carried out extensive testing on its DBS system in order to offer comprehensive expert support.

By having a complete Medtronic system, you and your patients will have access to our full expertise and system's warranty.

1. For a listing of indications, contraindications, precautions, MRI compatibility of specific Activa™ devices, MRI conditional labelling, warnings and potential adverse events, please refer to the instructions for use.

2. Based on recommendations by European and national medical societies[†]

[†] Analyses based on PD comorbidities recommended for MRI in Europe, the % was calculated for a real-life PD population potentially eligible for DBS, from US commercial health insurance database (Conroy et al, conference presentation, ECR 2015, Vienna)

3. Medtronic data on file: Report; NDHF1443-128376 - DBS Expanded MRI Labeling RF Lead Heating Design Verification Test Report

Prof. Dr. Lars Timmermann, Chair of Neurology at the University Hospital Marburg, specialises in investigating the impact of movement disorders and selecting tailored treatment options to make a positive difference in individual patients' lives. Through a German study group on DBS treatment for dystonia as well as leading the German Registry on Pediatric Deep Brain Stimulation (GEPESTIM) and a multicentre trial on DBS treatment for dystonia patients with perinatal hypoxia, he is committed to driving forward new treatments capable of improving quality of life for patients with dystonia.



Overcoming challenges in dystonia therapy: When is deep brain stimulation suitable for which patients?

Prof. Dr. Lars Timmermann shares insights on challenges in today's dystonia treatment, explains deep brain stimulation (DBS) as an alternative therapy option and provides practical guidance for patients.

What are today's challenges in the treatment of dystonia?

"Dystonia is always a diagnostic challenge. Symptoms vary significantly depending on each patient and their lifestyle. Thus, we need to understand more clearly how the disorder manifests itself in individual patients' everyday lives and to use treatments that enable us to manage and respond to this accordingly. Today, most dystonia cases are treated with botulinum toxin or medications that relax the musculature. On the one hand botulinum toxin can only be injected into one, two or maximum ten muscles making it difficult to treat symptoms which spread beyond a specific region of the body. Medication on the other hand has such a broad mode of action that this can not only involve many side effects but also makes it difficult to know in advance which type of medication is best suited to which type of patient."

How can DBS therapy help to mitigate dystonia symptoms?

"In the case of dystonia the communication within the network of different, deeper and superficial brain areas is disturbed. Communication does not run smoothly anymore and movements that used to be almost automatic do not work the way they used to. One of the

communication hubs in the network of different brain areas is the globus pallidus. By placing fine electrical wires (electrodes) into this area of the brain and adjusting the current applied to the brain tissue, we can normalise the communication between the different brain areas mitigating dystonia symptoms. The outcomes are sometimes extremely impressive."

What results can patients expect from DBS therapy?

"Results of DBS therapy in patients with dystonia vary significantly. Sometimes the therapy has very little effect even if the surgery was performed perfectly. In other cases symptoms can be mitigated significantly. The burden of dystonia decreases, patients have less pain and do not need to be afraid of so much staring when they go out. In these cases, their quality of life really increases."

Which dystonia patients are eligible for DBS therapy?

"Several dystonia types such as early-onset isolated dystonia can be notably improved with DBS therapy. In general we can say that in idiopathic dystonia we're seeing improvements of roughly 50% and in genetic forms of dystonia this rises to as much as 90%, particularly in children. However, results vary. Patients with non-genetic forms of dystonia and those with symptoms closer to the core of the body as opposed to in the extremities currently often experience fewer improvements in symptoms. Patients should also know that the earlier DBS is performed, the better the outcome will be."

How can today's medical devices help improve therapy results?

"While we are currently researching how to identify more easily which patients should be treated with DBS, the technology behind DBS therapy also advanced notably during the last five years. For instance, nowadays, we have smaller rechargeable devices with improved battery life that make the therapy much more comfortable for patients. Since many dystonia patients are children the battery is of great importance. Also in dystonia we need a lot of current to stimulate the intended area of the brain since it is bigger compared to other DBS therapy fields. Hence, patients with older non-rechargeable systems needed to undergo battery replacements almost once per year which is now no longer the case. Last but not least another major advancement was the introduction of new electrodes that enable directional stimulation. By steering the stimulation precisely to a certain brain area, we can avoid side effects resulting from the unintended stimulation of neighbouring brain areas with older electrodes. Thus, both patient comfort and therapy results could be improved notably."

How do you prepare patients for the surgery that marks the beginning of DBS therapy?

"The most important thing about preparing patients for the surgery is addressing their fears upfront. Most patients that are about to receive DBS therapy are afraid of character changes, which is not the case with dystonia. Here, we can tell them that this might be the case with other diseases, but not with dystonia. Moreover, we try to familiarise them with the procedure by explaining the different steps and introducing the team of experts that will be involved in the surgery. This is particularly important as some of the patients will be awake during the surgery."

How does the programming of the devices after the surgery work?

"Usually, we test systematically which position with which amplitude brings which result and which side effects. However, since the successful treatment of dystonia also depends a great deal on the individual patient we need to work together as partners to tailor the therapy to the individual's needs. Since the effects of DBS are not immediately visible after surgery in dystonia patients, they need to tell us if they experience any changes, improvements or side effects. Based on their feedback we can adjust the stimulation accordingly. From my perspective, it is also important to empower patients to have an impact on their own therapy with the remote control of the devices. Particular younger patients handle complex electronic devices in their daily life. So why should they not handle their DBS devices just as confidently?"

Prof. Timmermann's advice to people living with dystonia

Reach out to specialists for alternative treatment as early as possible:

Patients who do not experience full relief of symptoms with botulinum toxin or medication should discuss DBS with a specialist sooner rather than later, before complications occur, particularly in the neck or spine. Timely treatment with DBS could bring significant improvements.

Take part in clinical studies: This contributes to research aimed at improving understanding of dystonia, how best to treat it, and which treatment is best for each individual patient.

Join patient networks: The international and German networks provide paediatric dystonia patients and their relatives with a good source of support and extra information.

INNOVATION IN DYSTONIA TREATMENT

**Boston
Scientific**
Advancing science for life™

More than **500,000 people**
across Europe are living with dystonia¹



Treatment options:



Injections

botulinum toxin temporarily weakens affected muscles and reduces spasms



Surgery

lesioning of nerves that control the muscles causing spasms



Medication

a number of medicines can help regulate neurotransmission



Deep Brain Stimulation (DBS)

brain stimulation can reduce symptoms of dystonia significantly



More than **120,000 people** worldwide
already treated with DBS²



What is DBS?

implantation of brain stimulator that helps regulate neural signaling

Vercise Directional System...

...powered with Current Steering technology is designed for

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



Boston Scientific in DBS



Contoured edges designed for patient comfort



Directional leads for less side effects



Leads compatible with MRI*



Full body MRI conditional**

89% of treating physicians think that a directional lead should be used for all their patients.³

DBS may reduce dystonia symptoms such as:



Tremor, cramps



Pain



Strained or whispering voice



Muscle spasms



Rapid eyelid blinking



Painful neck spasms

improvements of 50-60 % in general, some patients experiencing a 90 % reduction in symptoms⁴



Talk to your doctor about how DBS could help you and find out more here:

<http://www.bostonscientific.com/en-EU/disclaimer-2.html?disclaim=en-EU/products/deep-brain-stimulation-systems/Vercise-PC-DBS/Patient-Resources.html&value>

References:

¹ Epidemiological Study of Dystonia in Europe (ESDE) Collaborative Group. J Neurol. 2000. 247(10):787-92.

² Fukaya C.; Yamamoto T. Neurol Med Chir. 2015. 55(5):422-31.

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.

* Vercise DBS Lead-only system (before Stimulator is implanted) is MR conditional. An MRI examination can be conducted safely when all instructions in the supplemental manual MRI Guidelines for Boston Scientific DBS Systems are followed.

** The Vercise Gevia DBS System is MRI conditional for full body scans.

A System that includes the Vercise PC or Vercise Gevia IPG and Vercise Cartesia Directional Lead(s) form the Vercise Directional System.

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Dystonia Europe Summer Think Tank 2017

Last July the 3rd Dystonia Europe Think Tank was held in Lund Sweden.

The Think Tank is held twice a year and members are the Dystonia Europe Board and two representatives from each one of our Platinum Sponsors:

Merz, Medtronic, Ipsen and Boston Scientific.

Together we discuss projects and activities, with the best interest of dystonia patients in mind.

These meetings have developed to an important forum for exchange of ideas and experiences.

By the end of the day the group had time for a walk through the city center of Lund a Jump for Dystonia by the old cathedral.

We thank our Platinum sponsors for their valuable input and advice during these meetings.



Think Tank members in a Jump for Dystonia by the cathedral in Lund, Sweden

Belgian Dystonia Association and Dystonia Europe in Partnership for the 25th Anniversary Conference & D-DAYS 2018

Dystonia Europe met with representatives of the Belgian Dystonia Association to discuss and plan the next D-DAYS 2018 which is also the 25th Anniversary of Dystonia Europe.

The 2-day meeting will take place at the Novotel Brussels Center Tour Noir on 13 and 14 April 2018. But already on 12 April the Dystonia Europe 25th Anniversary will kick off with a lunch event in the European Parliament. Special guests and speakers have been invited as well as representatives from the Dystonia Europe membership. The lunch will be hosted by 3-4 MEPs (Members of the Parliament). The theme of the Event is: The challenges of Dystonia: a snapshot across Europe. Professor Maja Relja, University of Zagreb, will present the first results of a survey to assess the challenges dystonia patients face in accessing treatments as well as measuring satisfaction with the treatment. See more information on page 41.

On Friday morning (13 April) the formal meeting, General Assembly of Dystonia Europe will take place. From 12.30 registration is open and at 13.30 the afternoon programme starts. The same evening the 25th Anniversary Dinner & Dance Celebration will take place to honour 25 years of dystonia patient work in Europe. On Saturday there will be presentations on dystonia between 9.30 and 16.00. The programme will soon be available on the Dystonia Europe website and from middle of January it will be possible to register for the congress. <https://dystonia-europe.org/activities/events/dystonia-europe-2018-brussels/>



*Monika Benson, Dystonia Europe,
Stefan Wojciechowski, Merz,
Rob van der Linden, Merz,
& Wim Smets, Frans & Martine Vanderstraeten,
Belgian Dystonia Association*

We hope to see many members from Belgium and the rest of Europe in Brussels.

Welcome!

Development Workshop for the Dystonia Europe Board

Beginning of November the DE Board met in Brussels for a Development Workshop led by Consultant Noémi Kiry Ambrus. She is an independent consultant, working for many years on improving efficiency of non-profit organisations by providing them innovative and integrated organisational development solutions. With her almost 20 years of experience in working with non-profit organisations in Hungary, Europe and beyond, she loves sharing her knowledge and inspiring others. Topics were Governance and Management; Strategic planning; Transparency and Ethics. The board had three days of inspiring and valuable work together.

The Board is now: President Merete Avery, Norway, Treasurer Erhard Mätzener, Switzerland, Board members Sorin Ionescu, Romania, Adam Kalinowski, Poland and Edwige Ponseel, France. Monika Benson, Sweden is an ex-officio board member.

The meeting was held at the Novotel in Brussels where we will hold our upcoming D-Days 2018 next April.



*The DE Board Members
and Consultant Noémi Kiry
Ambrus*

A New look for the European Federation of Neurological Associations (EFNA)

The European Federation of Neurological Associations (EFNA) is an umbrella group representing pan-European neurology patient groups.

Their slogan 'Empowering Patient Neurology Groups' encapsulates their goals as an association. EFNA strives to add capacity to their members – allowing them to be the most effective advocates possible in their own disease specific areas.

EFNA embraces the concept of Partnership for Progress – working at a high level with relevant stakeholders from the fields of policy, medical, scientific/research, industry, patient partners and other key opinion leaders.

During their Annual Partners Meeting in Brussels last July, EFNA launched their new branding, including a new logo and [redesigned website](#).

EFNA's Communications and Events Coordinator, Elizabeth Cunningham, explained the reasoning behind the new look:

"2016 was an exciting year for EFNA, with the launch of some of our biggest-ever independent projects. These included our [Training Initiatives for Neurology Advocates](#) and the [Together Under the Umbrella](#) awareness campaign. Existing central activities such as the [MEP Interest Group on Brain, Mind and Pain](#) have been further developed and so the EFNA programme of activities continues to grow. It felt an appropriate time to reflect the growth of the organisation through refreshed branding and materials."

Elizabeth goes on to describe the new logo. "EFNA is an umbrella organisation of neurology patient groups. It was important that our new logo had an obvious connection to neurology, but also the connection between our members which is so vital."



You can [download EFNA's logopack and brand guidelines](#) here and [learn more about the organisation](#) here.

People around the world get Together Under the Umbrella on World Brain Day 2017

World Brain Day takes place annually on July 22nd. The main objective of this day of the brain is to increase public awareness and promote advocacy related to brain health. The day is an initiative of The World Federation of Neurology, whose theme for this year's campaign was **"Stroke is a brain attack – prevent it and treat it"**. Stroke will affect one in six people in their lifetime. To learn more about stroke please visit our member Stroke Alliance for Europe (SAFE)'s website – www.safestroke.eu.

As part of EFNA's Together Under the Umbrella campaign, organisations and individuals were encouraged to take a photo under an umbrella and share it to social media to raise awareness, mentioning the neurological disease area they are either affected by or represent. The aim was to highlight to wider society, the range of disorders of the brain – their impact and prevalence.

Hundreds of photos were shared social media from across the world throughout the day.

In addition to these images, this year EFNA recorded a series of interviews with patients/patient advocates from seven different disease areas. You can watch the videos in full here: <http://undertheumbrella.eu/category/your-stories/>

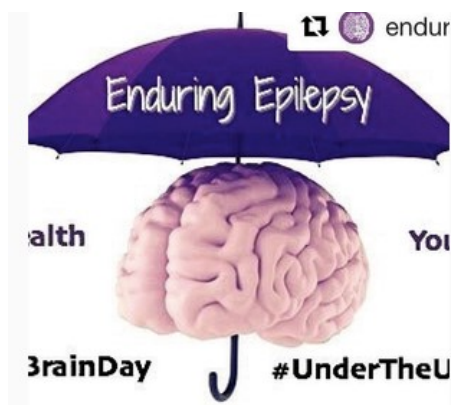
Speaking on the day, EFNA President, Ann Little said:

"By continuing to work together we can maximize the visibility of brain disorders as a whole and ensure we can access the resources required to tackle the enormous burden these diseases pose. We would like to thank everyone who got involved on the day – but also throughout the course of the campaign. And we hope to see more of you under your umbrellas in the months to come!"

If you are interested in learning more about the campaign, you can visit:

www.undertheumbrella.eu or search for **#undertheumbrella** on [Facebook](#), [Twitter](#) or [Instagram](#).

Pictures below shared on Instagram:



Pro-Step Final Conference in Brussels 23 and 24 October 2017.

This event was arranged by EPF (European Patients Forum). About 90 delegates attended the event where the projects' preliminary outcomes were presented. The PRO-STEP project - *Pilot project on Promoting Self-management for Chronic Diseases in the EU* - is a pilot project financed by the European Union that focuses on self-management in chronic conditions, its impact and added-value for the sustainability of healthcare systems including cost-benefits analysis, as well as enablers and barriers. At the conference different views and aspects were presented and discussed on the topic of self-management in chronic conditions, how it can be promoted, and how it can contribute to improved quality of life.

The event summarized conclusions on the trilogy of studies EMPATHiE/PiSCE/PRO-STEP and discussed steps forward.

Flashback from the PiSCE Final Conference 17/03/2017

- The future of healthcare is self-care and the future is now
- Technology will drive the development of self-care
- Improvement requires change, but change always generates new challenges

There were many speakers at this event. Ana Duarte from Patient Innovation Platform presented ideas by patients. Catolica Lisbon, University of Business and Economics, have an online platform where patients and caregivers can share and search solutions that others with the same condition had developed. Patient Innovation Community provides feedback to improve the solutions. There are 40 000 users on this platform and 650 solutions from more than 40 countries.

Breast cancer patient Lisa Crites, USA developed the first and only patented water resistant garment to protect chest surgery patients while showering. She developed this after initially using plastic trash bags herself to protect her surgical drain sites after breast cancer surgery.

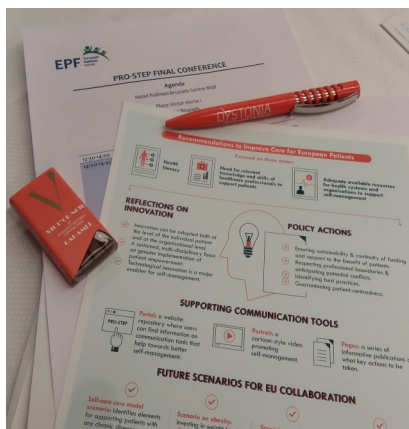
The 2 day event covered many areas of Self-Care and also thoughts on health care in the future and the role of the patient. Health Literacy was discussed, the conclusion is that the patients that have more information on their condition, can provide better self-care.

More information about the PRO-STEP pilot project can be found here:

<http://www.eu-patient.eu/whatwedo/Projects/prostep/>.



Merete Avery, Dystonia Europe and
Klara Zalatnai, Osteoporosis, Hungary



Right: Bert Vrijhoef,
Panaxea & PRO-STEP expert



Jump for Dystonia

During our Dystonia Awareness Month, last September, our Jump for Dystonia campaign kicked off again and jumps have kept coming in. From Mike in the US we received a very special photo where he is jumping with his grand-daughter, already a future dystonia advocate it seems like! We thank all of you who support our campaign to help raise awareness of dystonia. Keep jumping for dystonia awareness!



Mike says: "The last day of September I joined an event to post a pic doing a [#JumpForDystonia](#) which was started 3 years ago. I asked Syl (my grand-daughter) to do it with me and then I realized she has been bringing awareness before she ever came into this world. She kept saying more more. I may have found someone to take my place...!"



Jump for Dystonia



Debbie
from US



Jump for Dystonia in Ireland



Czech Dystonia Group



Emilia from Finland

www.dystonia-europe.org

Jump for Dystonia



Susanne from Finland



Yvonne and Carina from Ireland



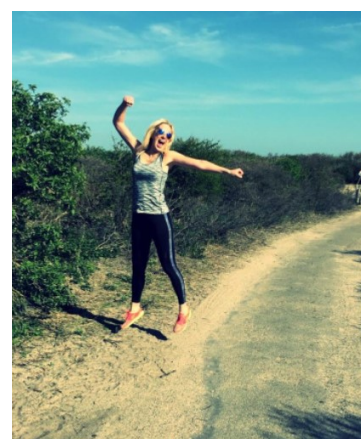
Sorin Ionescu from Romania



*Elenonora,
Svante and
Sixten from
Sweden*



Sabina from Romania

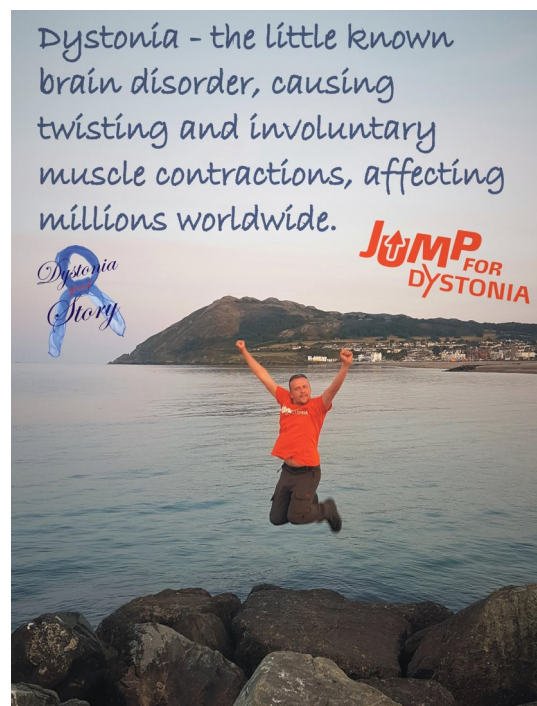


Minouche from The Netherlands

*Aino-Maja
and Liisa
from Finland*



*Adam
Kalinowski,
Ireland*



www.dystonia-europe.org

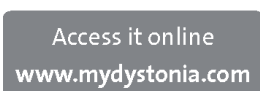


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EUROPE**

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Meet Dystonia Europe Board Member Edwige

Hello European readers!

I am Edwige, Ich bin Edwige, Me llamo Edwige, Je m'appelle Edwige.

I am 46 years old. I'm married and the happy mother of a 12 year-old girl.

I have a full-time job at the European headquarter of an international company, distributing electronic components, near Paris. I have a background as an international purchasing manager.

I work daily with my assigned sales offices in the UK, Germany, Austria, Switzerland, Belgium, Norway ...

I have been diagnosed with cervical dystonia 24 years ago, a myoclonic form with head tremor.

I think it has happened after a car crash.

At the age of 20 my condition was very disturbing since I was beginning my life, at a professional and social level, and the way people looked at me affected me. I have taken some medication which was helpful at the time.

Then, at age 35, when my daughter was born, I made the decision to stop all medication. If other people looked at me had become insignificant, and I am lucky that my cervical dystonia has neither progressed nor is it too painful.

Today, I am living many lives in one single! I have my family, my work, I have been the President of the French dystonia association AMADYS for 2 years now, and I had the luck to be elected to the Board of Dystonia Europe in May 2017 in Rome!



Prof Marie Vidailhet receiving an award from AMADYS President Edwige Ponseel during the 30th Anniversary



Edwige Ponseel

I am convinced that by working all together we will improve dystonia awareness and our future. Together we are stronger.

I'm not different, I'm like you, just trying to give some time and some of my knowledge and experiences for the Dystonia Community.

This voluntary experience is great and enriching because of the relationships, humanity, goodwill, travels, knowledge... I really enjoy it.

I would like to take this opportunity to thank all dystonia advocates for all the work done in the past, now and for the future. For my part, I will do my best to help to carry on with all Dystonia Europe projects and vision.

You will read in this newsletter about the AMADYS 30th anniversary. We are very proud of it and it was a demonstration of the longevity and strength of our French dystonia community, thanks to all our members and partners.

Most of all I hope to meet you in Brussels for the Dystonia Europe 25th anniversary in April 2018.

Connecting people!

Edwige Ponseel

Board Member, Dystonia Europe

Around Europe and Beyond

Denmark

25th Anniversary of the Danish Dystonia Association

End of October DDF – the Danish Dystonia Association – celebrated its 25th Anniversary. The organization was founded in 1992 and has today a little more than 600 members. The focus of their work is to raise awareness and inform about dystonia, treatment and research.

For this very special celebration about 100 dystonia patients and family members as well as representatives from the Scandinavian Dystonia Associations and Dystonia Europe had come to Scandic City Hotel in Århus, Denmark.

After lunch, Danish well-known actor Peter Mygind, held a very inspirational talk. How to overcome fears and become a stronger person. He stressed the importance of being physically active and said: “My wife and I have an agreement. If one of us suggests to go for a walk in nature the other person is not allowed to say no. And if you think about it, you never feel worse after a walk in the nature!” He encouraged the audience to enjoy life. “Tell the person you love that you love them”; “Get rid of the phone, be present”; “Look out, away from yourself, see and meet the world, rather than looking towards your inside. If you look inside, there is a stop, and it is tiring and not so much fun”. The audience had a good time and there was a lot of laughter. Chairwoman Pia Sørensen Vejle thanked Peter and then there was time to chat with him or have photos taken.

After a short break followed the General Assembly with approval of reports and election of board members. Pia Sørensen Vejle was re-elected President for the next two years.



The Danish Dystonia Association Board

The last session of the afternoon programme was an expert panel of five Danish Dystonia specialists.

The audience could ask questions on all they wanted to know about dystonia. It was very much appreciated and there were questions on treatment, research, physiotherapy, awareness etc.

In the evening there was a festive gala dinner organized and guests enjoyed a delicious dinner, entertainment and dancing to the live band “No Boundary” and singer Anja.

The Scandinavian dystonia representatives and Dystonia Europe congratulated Pia and her team with flowers and gifts. “Thank you for all the work that you do for dystonia patients and their families in Denmark. And for the next 25 years to come, we wish you much success”, said Monika on behalf of Dystonia Europe and its members.

Around Europe and Beyond

France

AMADYS 30th Anniversary

On the 30th September, the French Dystonia Association, AMADYS, celebrated its 30th Anniversary in Lyon, France. Over 200 participants had come from all over France to take part in the event.

President Edwige Ponseel welcomed everybody and wished them a fun and festive day. Professor Vial, member of the AMADYS Scientific Committee, was proud to welcome the participants to his home town.

After a special presentation by Dr. Jean-Pierre Bleton to honor late Professor Pierre Rondot (French movement disorder expert with special interest in dystonia), Michel D'Angelo took us on a historic journey of dystonia and AMADYS. From the beginning there were two dystonia associations in France and from 2007 they joined together in AMADYS. Today the organization has approximately 1600 members.

Dr. Marie-Hélène Marion's presentation focused on the history of botulinum toxin and how its discovery as therapy for dystonia contributed to greatly improve treatment results for many patients. Professor Brigitte Girard presented her book about blepharospasm for dystonia patients. With the support of Merz it had been printed and was distributed for free.



AMADYS blowing the candles



President Edwige and Prof Vial from Lyon

Other scientific presentations were given by Professor Vial who spoke about MyDystonia the APP and Professor Vidailhet spoke about dystonia and research. Professor Emmanuel Flamand Roze presented a research project Agent10.

In between presentations there were various workshops to attend and participants had to sign up in advance. The workshops were on: Writer's Cramp, Musical therapy, Feldenkreis therapy, Cervical Dystonia, Hypno therapy. Experts led these much appreciated workshops.

In the meeting room you could visit the exhibition of AMADYS 30th Anniversary art work. There were paintings, wooden sculptures, poems etc to honour the Anniversary. In another area of the meeting room were the main sponsors of the event with their information tables: Ipsen, Medtronic and Merz.

A three-course lunch was served accompanied by festive music. Special awards were given to certain members and advisors for their long-term and dedicated commitment to AMADYS. A young woman performed an Anniversary song especially written for the occasion, and got big applause. The Anniversary cake candles were blown out jointly by several members.

Around Europe and Beyond

In the afternoon followed presentations from the various partners of AMADYS: BrainTeam; AMR – Association for Rare Diseases; Aptes – Association for Essentiel Tremor; FRC – Association for brain research; ICM – Association for patients with chronic diseases.

Dystonia Europe presented the work of our organization and the advantages for a national dystonia association to be part of an international network. There can be an exchange of ideas and activities between countries. A successful project in France can be as successful in Finland and vice versa.

There is update on treatment and research between member countries. Dystonia is represented on a European level for all dystonia patients in Europe. And together we are stronger and can make our voices better heard in projects such as raising awareness and for example our successful Jump for Dystonia campaign.

After a very interesting and fun day Edwige brought on stage her 'Dream Team' – the 11 board members of AMADYS – and thanked them all for their hard work and support.



Prof Brigitte Girard



*Merete Avery and Monika Benson,
DE*

*Brigitte Girard and Edwige Ponseel
and her daughter Emilie*

Around Europe and Beyond

She also thanked the audience for coming to Lyon and taking part in this very special occasion for the association. Finally we all gathered for a group photo and of course a huge AMADYS Anniversary JUMP for Dystonia.

From Dystonia Europe we thank Edwige and her Board – the “Dream Team” for a beautiful and well organized event for their members and guests. We wish you much success in your future work.



AMADYS and Partners doing a Jump for Dystonia



Edwige with her board – the 'dream team'



The AMADYS Anniversary cake

Around Europe and Beyond

Italy

Under the Umbrella for World Brain Day 2017

In Italy this last summer it has been exceptionally hot and dry; most areas had temperatures up to 45° and no rainfalls between May and September. But at the end of July many people have looked for their useless umbrellas for a useful task: celebrating the World Brain Day on July 22nd .

This is the second year that this flashmob takes place. Everywhere in the world people take pictures under a coloured umbrella. A wide variety of disease areas were highlighted in these messages including Parkinsons, headache, mental health, chronic pain, myasthenia, rare diseases and of course dystonias.

In Italy more than 100 persons did so, alone or with others, at home or on holiday, early in the morning or late in the afternoon, and each of them wanted to show his/her wish of increasing and spreading knowledge of brain related diseases.

Most persons in the pictures have dystonia but many have not, and give nonetheless their support and their face for this important campaign.

Maria Carla Tarocchi

ARD, Italian Dystonia Association, Rome, Italy



www.dystonia-europe.org

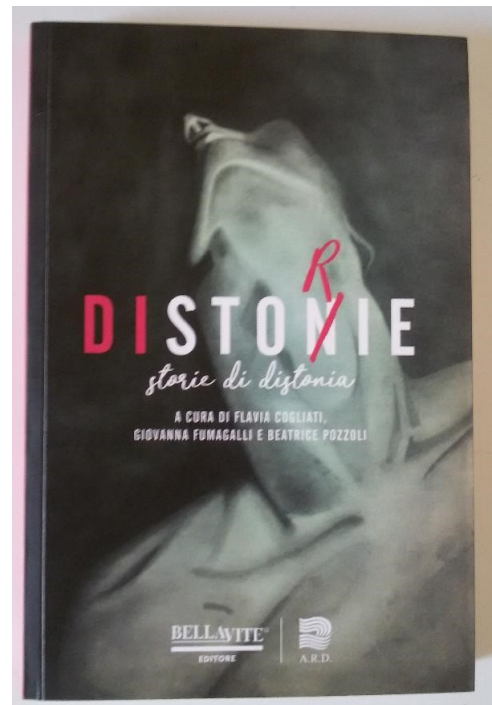
Italy - A book about Dystonia by Dystonia Patients

In 2015 a group of dystonia patients met on Facebook and decided to do something to raise awareness about dystonia in order to accelerate time of diagnosis, which is often too long. There were many possible ways but at last the idea was to write a book with some stories of ourselves and of our dystonia. A book of this kind had never been written or issued in Italy, therefore the experience was completely new. Flavia Cogliati and Beatrice Pozzoli, who had recently become members of A.R.D., decided to give it a try.

The first step was to collect the stories. Many people were asked to write down their personal experience with the disease, which had a therapeutical effect in itself. When you put in writing your own pains and fears it can help to accept and control them. Writing about your disease can be like a victory over it. Unfortunately, in some cases bringing back to mind difficult periods in life is too painful. Many patients are not strong enough to do it and usually when you feel better you want to forget the past.

Flavia and Beatrice found 22 persons who accepted to tell their dystonia stories. Additionally 4 relatives of dystonia patients (3 sons and 1 husband) also told their stories. Most persons are women (18 out of 22), and their ages vary from 16 to 60. They have different types of dystonias such as cervical dystonia, blepharospasm, generalized dystonia, genetic or not. Two neurologists specialized in dystonia (Dr. Roberto Erro from Salerno and Dr. Maria Antonietta Volontè from Milan) contributed with a scientific and medical chapter about the disease.

After collecting all the stories, proof reader Giovanna Fumagalli edited them and at the beginning of 2017 Flavia and Beatrice found a publishing house willing to issue the book, having A.R.D. as sponsor. A major problem was still ahead: the title of the book! We were all looking for a meaningful and short title which represented dystonia and all the connected stories. After many attempts, an ARD member proposed to take the Italian word for dystonia: "DISTONIE", delete the N and replace it with an R. You get: "DISTORIE" which you can see on the picture of the book cover. In Italian it's an excellent mix of dystonia and stories, which is exactly the aim of the book. In April 2017 the book was printed, just on time to be



presented at the D-Days and Dystonia Europe Congress in Rome on May 14th. Many of the persons who had contributed to the book attended the meeting. They were proud that their stories about dystonia could help to create greater visibility and knowledge of the disease.

The book has been given to many doctors and has been purchased by dystonia patients as well as others. It's possible to buy it online from the publishing house. The first edition of 300 copies is already sold out and 100 more copies will be reprinted.

Reading these stories is not easy, since in most cases there are no happy endings. All of them show a past with problems and pain, a present with at least a diagnosis and some medical treatments, and a future with either a possible improvement, or unfortunately a worsening in quality of life.

These 22 stories could be written in any other language by patients of any other country, since dystonia doesn't make geographical differences. Only more studies and research can make the difference in order to defeat dystonia.

Maria Carla Tarocchi
ARD, Italian Dystonia Association

Norway

Norwegian Dystonia Association Autumn Member's Meeting in Oslo

About 55 members participated from all over Norway at the national meeting in Oslo. President Johan Arnfinn Warvik welcomed all and informed of NDF's work and activities. Johan Arnfinn commented that the NDF board has been focusing on teamwork in 2017 with much success.

There have been many activities and meetings like the "contact person" meetings for those who have participated in training to become a contact person. A contact person has to know some guidelines on what is important when members and others call or write to ask about dystonia and how to live with dystonia, treatment and more. Often listening and acknowledging is the most important role for a contact person.

Johan mentioned the value of the member meetings, which is nationally held twice a year, one meeting in spring and another meeting in autumn. At these gatherings people with dystonia can meet and nobody thinks it is unusual to have involuntary movements and tremor. In addition to the national meetings, NDF have local meetings twice a year in 5 different locations of Norway. Since the population in some areas of Norway is dense, travel can be a real challenge.

NDF regularly meets with the Norwegian National Competence Services for Movement Disorders and other partners. There is also a Dystonia Network in Norway with professionals and they had a meeting 18 October.

In 2018 the Norwegian Dystonia Association will celebrate their 25th Anniversary on the 21 and 22 April. This event will take place near Oslo, Norway.

Sissel Buskerud, Treasurer in NDF and Ambassador for the MyDystonia App, informed about the app and the advantages of using the app as a tool of communication between the patient and health

care providers like neurologists, physicians, physical therapists and more. Sissel also presented the movie with «Dave» who describes how useful it is to have a digital diary for dystonia patients. Sissel specifically stressed that when registering, it is best to register first time on a computer instead of on your cell phone/mobile phone and informed that you can choose your own questions in addition to the questions that are in the app. If problems occur, contact the Ambassador in your country.

"The law of possibilities" by Anne-Mette Røsting, Norway

Røsting held a presentation at NDF's meeting on possibilities and how to live to fulfil the dreams in your life. . She has written a book that is called "Mulighetsloven" (The law of possibilities) and the book will be translated to English in 2018.



Anne-Mette Røsting

Around Europe and Beyond

Anne-Mette talked about self confidence and self esteem, which can be a challenge when your body language and your posture and/or movements change, due to dystonia, and you are not able to control your body like you used to.

We can change how we feel about ourselves. However, we are often afraid since we do not know all aspects of change, and what it will lead to and this can prevent us from fulfilling our life. Anne-Mette says we can “manipulate” ourselves to become happier, we can carry out our dreams if we focus and act, this can take time but we have to believe and trust it will happen. Maybe it will take 6 months, 2 years or 10 years but it will happen says Anne-Mette.

In the afternoon there was sightseeing in Oslo by bus. After the sightseeing the bus took us to Frognerseteren a beautiful and old restaurant with traditional food.

We enjoyed a nice dinner at Frognerseteren and the conversations were lively around the tables until the bus picked us up and took us back to the hotel in Oslo.

The following day there was a meeting for the leaders of the local NDF groups and they could share ideas for themes and activities for future



From Anne-Mette's presentation



The Norwegian Dystonia Association Board, except Tove Nilsen who was not present when the picture was taken.

Finland

Dystonia Days 2017

The annual Dystonia Days of the Finnish Dystonia Association were held in Seinäjoki on 23-24 September. The sunny weather welcomed the participants, about 40 enthusiasts who had gathered to enjoy the programme of the 19th Dystonia Days at Hotel Cumulus City Seinäjoki Hotel.

Stefan Taubert, Vice Chairman of the Association, and Pekka Karimerto, peer group leader of South Ostrobothnians, welcomed us.

Laura Suurla gave an emotional testimony of her dystonia. Together with her companion Eivor Hagmark, they presented three of her own songs "Let's Know We Love Them" on Rose's album (<https://www.youtube.com/watch?v=Il8NRv81WqE>).

As a final song they performed "The Last Spring". The songs were very beautiful and we all enjoyed them. Laura is well aware of the loss of dystonia symptoms when singing. After the show, she trained people in breathing exercises and to bite and smile, using body resonance. Working with sound is an interesting way of managing dystonia symptoms.

The representative of Medtronic introduced the DBS stimulator with the words "Thank you for being scared". Expert answers were given on many questions about the management of the device, the manuals and the surgery. There was a lot of people in the group who have had DBS surgery. When asked about the number of dystonia patients with DBS in Finland they estimated there are approximately about 60-70 people.

Then followed workshops in different groups of dystonia. It was very rewarding to hear the opinions of others. The groups discussed the specific features of the disease as well as the operating models of the peer support groups.



Laura Suurla and Eivor Hagmark

September is from this year the European Dystonia Awareness Month, a month of international Dystonia awareness, which is great for us in Finland since our Dystonia Days always take place in September.

At the Dystonia Days in Seinäjoki, participants received new information, met new friends and above all, had much peer support.

Mari Susanne Olenius. Finnish Dystonia Association



Members of the Finnish Dystonia Association

Around Europe and Beyond

Romania

A Small Study on Dystonia and Special Rehabilitation

Dystonia disables thousands of Romanians (around 3000 patients) and over half a million Europeans, making it the third most common movement disorder behind Essential Tremor and Parkinson's disease. It is a condition that does not disconsider anyone: it can affect children and adults, of all races and ethnicities.

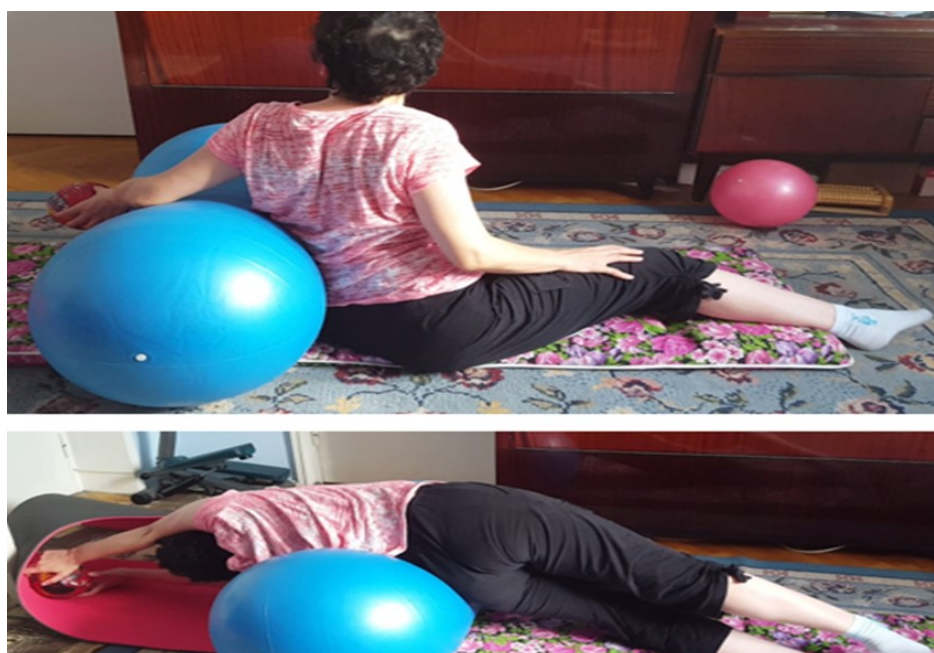
My study was performed on Sabina Gall, a patient with segmental dystonia which affects the neck and back, who had DBS (Deep Brain Stimulation) surgery in 2007 and repeated it in January 2017, without treatment of botulinum toxin injections. I investigated the effects of combined therapy: physiotherapy and massage between July 2016 and January 2017, respective hydrokinesiotherapy and massage between March and August 2017.

The aim of this study was to analyse the benefits of physiotherapy, hydrokinesiotherapy and massage in improving the clinical aspects of segmental dystonia, and the quality of life for these patients.

There does not exist a cure for dystonia, it is more vital to build a multilateral treatment in order to obtain a good management of the symptoms which can range from a light morning stiffness to a chronic debilitating disease. The TWSTR (Toronto West Spasmodic Torticollis Rating Scale) was used in order to assess the area of pain, stiffness and physical function.

TWSTR Physical therapy + massage	Maximum	Before PT+ massage	After PT + massage
Severity Scale	35	29	22
Pain Scale	20	13,25	11
Disability Scale	30	18	13

TWSTR Hydrokinesiotherapy + massage	Maximum	Before PT+ massage	After PT + massage
Severity Scale	35	22	14
Pain Scale	20	11	8,5
Disability Scale	30	13	6



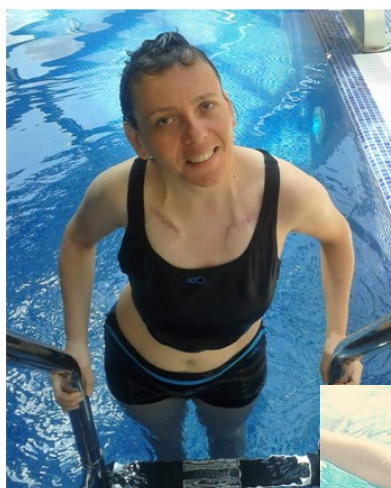
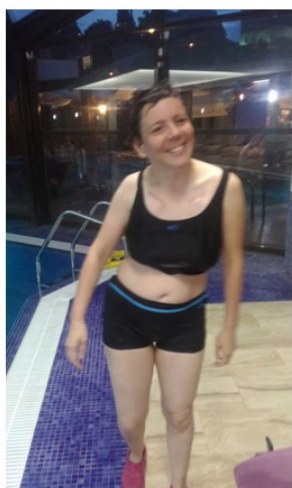
Around Europe and Beyond

My patient was investigated before starting the treatment and after finishing 66 sessions (in the first trial) and 60 sessions (in the second trial).



In this study I conclude that the best approach in the management of dystonia is a multilateral one, because it's quite difficult to set the proper treatment and to get great results, so we have to associate the drug treatment/surgery with other complementary treatment forms such as physiotherapy, hydrokinesiotherapy and massage. This combination of treatments will help to reduce pain and stiffness in the affected muscles/regions and increase the physical function of the person and of course improving the quality of life .

*Molnar Csilla Edit , Physical Therapist,
University of Medicine and Pharmacy of Târgu Mures
Masters Degree in Physical Therapy and Functional Recovery*



*Above: Sabina receiving treatment and
Sabina doing rehabilitation in the pool.*

*Sabina with Catalina and her daughter and Molnar
Csilla Edit , Physical Therapist*



Ukraine

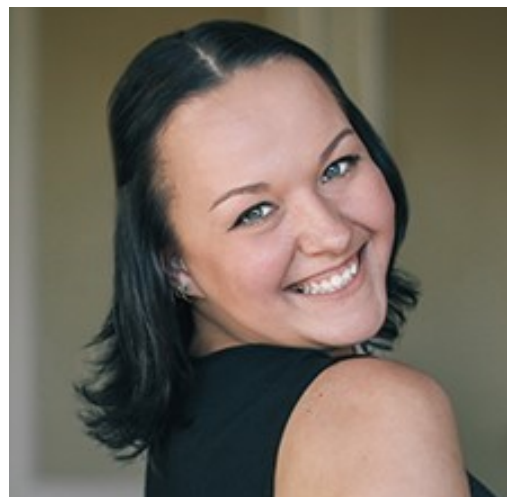
Meet Natalia Titova from Ukraine & Founder of The Association of Patients with Torsion Dystonia, 21st Member of Dystonia Europe

“At age four-and-a-half, I began to fall for no reason and experienced tremors in my hands. Many doctors offered diagnosis and prescribed medications, but I only felt worse. I could not walk for any period of time, and I started to experience speech problems. As my symptoms progressed, my mother had to feed me and every night my body was twisted by painful convulsions.”

“My mom and I continued to seek the right diagnosis and treatment. In 2010, at age 19, we finally found the right specialist who diagnosed me with torsion dystonia, a neurological movement disorder, and suggested deep brain stimulation (DBS) surgery. I wanted the surgery very much, but my family could not afford it and the Ukrainian government would not pay for any of it.”

“We sought help from charity foundations and through social media networks. In 2012, I became the first Ukrainian patient to receive DBS surgery. I cried with joy the first time, when at age 21, I could walk and not use a wheelchair. Finally, I realized I could have a full life. I entered the university, have friends, and, most important, am no longer a burden for my mother.”

“I want to inspire people with dystonia and tell them, ‘Even if you think you will spend your life in a wheelchair, you should never give up. There are people and technologies that can help you live a better life.’ I am using my extra life to fight for the rights of dystonia patients through the public organization I created, the Association of Patients with Torsion Dystonia. We work with doctors and the Ukrainian Ministry of Health to help people with dystonia receive a proper diagnosis and get reimbursed for treatment.”



Natalia Titova

The Association of Patients with Torsion Dystonia

is a nonprofit organization founded by Natalia Titova, who suffers from the disease. The organization works with doctors and the Ukrainian Ministry of Health to draw their attention to the challenges of people with dystonia, and to help patients receive proper diagnosis and treatment.

Last year Natalia was also one of the recipients of the BAKKEN Award from Medtronic Foundation which recognizes patients who, with the help of medical technology, give back through volunteerism and community service. In January 2017 Natalia together with other recipients travelled to Hawaii where she received the award of \$ 20 000. The grant will support a range of rehabilitation programs for patients after they go through treatment.

We wish Natalia and her Association very welcome to the Dystonia Europe Family and much success in their work for dystonia patients in Ukraine.

Around Europe and Beyond

United Kingdom

Spanning the Generations

In 2018 Dystonia Europe will be 25 years old. This made me think – this period is enough for a new generation to grow up to maturity and adulthood. When I was diagnosed in 2005 aged 48 I realised I had suffered from a form of dystonia since my childhood. The diagnosis had come after almost 50 years of confusion over neurological and physical symptoms that made schooling, starting a career and progressing in life difficult.

Going back another generation, my father had always had jerky muscular movements and difficulty with fine motor skills such as writing and holding an open cup without spilling its contents. He was a child of the 1930s and 40s and had protective loving parents who supported him but could get no diagnosis. I was told he had been born with his condition and was a sensitive and nervous man. This was perhaps as much as the GP had told his parents. Like many others of his generation he carried on his life undiagnosed through lack of knowledge and proper referral. This created stresses – on going for a medical as a young man he couldn't get life insurance as he was thought to have Parkinson's Disease, he tried to learn to drive but did not have the co-ordination to do so. Each stage of life was difficult with extra hurdles to deal with yet he faced them as best he could.

My mother was just as confused and after his parents died he broke down and began intermittent psychiatric care. He went down the psychiatric route so common then for many movement disorders. The view medically was very often that it was all psychological; 'Until the 1970s most patients with dystonia were referred to psychiatrists in the belief that these curious motor disorders were an expression of an unhappy mind' Electro-convulsive therapy, major tranquillisers – a variety of medications were used. My father's physical symptoms stayed the same, but he developed a bi-polar disorder and was described to the family by his GP and Psychiatrist 'as a very complex case'.

Then disability and particularly mental illness were seen by many as something that wasn't talked about and even shameful - as a family we lived in silence about my father's condition. It was something we couldn't decipher and there seemed no support or information we could turn to.



Andrew and his father John

No dystonia charity organisations existed and very few doctors or specialists knew enough about the condition to diagnose it. When I realised I was developing milder but similar physical symptoms I lived in a state of terror. Would I go mad too? I was prescribed tranquillisers which helped. Tremor and muscle discomfort were reduced yet when my mother found out she feared I was sinking into a state like my fathers. 'Come off these drugs' she pleaded 'or you will end up like your father'. I became more confused as from the 1980s tranquillisers were given a terrible press with newspaper reports saying, 'since they came on the market in the late Fifties, tens of thousands of people have become addicted to them and hundreds have died'. An unjustified reaction to a drug that has helped many with dystonia in a positive way when used and prescribed correctly.

My father was medically retired in 1984. This was the time when I was at a low myself, yet awareness of dystonia was growing. A modern definition of dystonia was worded in that same year. The Dystonia Society UK charity was registered in 1984, AMADYS, the French association for people with dystonia started in 1987, the Swedish Dystonia Association was founded in 1991.

Around Europe and Beyond

With the growth of these European organisations estimates of those who suffered from dystonia rose quickly, information and research increased and could be shared and disseminated more easily. Most importantly the time it took to diagnose many patients dropped significantly. The 'unknowing' generation of my father's time was passing.

In the last twenty-five years Dystonia Europe has existed new treatments have become established; botulinum toxin injections for cervical and other dystonia's, a greater more enlightened understanding and development of drugs to control the condition and of course deep brain stimulation for more severe cases which has grown in effectiveness as many thousands of operations are performed for dystonia and Parkinson's Disease. My diagnosis was a revelation and as I described my father's symptoms the neurologist felt convinced my father had suffered from dystonia all his life. Perhaps because of him I have pro-actively accessed the treatment and help I need, worked for the Dystonia UK London group finding speakers and writing articles, even attending a dystonia Symposium in New York and in the process making up for my father's 'silent voice' and fearful suffering.

The voices of a new generation can now clearly be heard. Dystonia Stories was launched by Dystonia Europe four years ago. It consists of short video clips featuring interviews with dystonia patients, neurologists and researchers and their different views on dystonia.



John holding his son Andrew in 1958

ⁱ Regular Review: The dystonias: neurological disorders affecting 20,000 people in Britain. British Medical Journal p.139 Vol. 300 20 Jan.1990

ⁱⁱ McVeigh, T. Tranquilisers 'more lethal than heroin' p.15 *The Observer* 5 November 2000

ⁱⁱⁱ Fahn S, Marsden CD, Calne DB. (1987) Classification and investigation of dystonia. In: Marsden CD, Fahn S, editors. *Movement disorders* 2 ed. By Marsden CD, Fahn S. p.332-58. London: Butterworths.

^{iv} Parker, J. (2009) My story: sticking the pieces together. In *Dystoniamatters!* Issue 66 pp.19-20

Go to the [Dystonia Europe Youtube Channel](#) and you will also find them subtitled in French, German, Italian and Spanish. People talking about their condition alongside medical professionals and researchers talking about their work. Dystonia emerges as a complex condition which is many faceted and more recently the emotional elements – the anxiety, depression and mental distress that come with it have been more fully recognised and documented.

Recently I got in touch with a family who have a son who is now a teenager at college. He has the same condition as I and I'm sure my father had - myoclonic dystonia. I first read about him in an article in the UK Dystonia Society's newsletter and that he was diagnosed at the age of three and they made me clearly see how things have moved on. But life challenges still exist for all people with dystonia. Not only has awareness got to continue to grow but society's attitude must change to give all of us a better, more equal chance in life. Dystonia Europe is central in all this and will play a bigger role in the future. Here's to the next twenty-five years of this wonderful organisation of many parts in many countries working to give dystonia sufferers and medical staff Europe-wide more awareness and enabling and highlighting significant research to fight this condition. As a result all those with dystonia will continue to more informed, better treated and most importantly have a better life.

Andrew Russell, UK



John Russell ready for work in 1963

Events

2018 Calender

February

8-9 Dystonia Europe Board Meeting and Think Tank, Lund, Sweden

March

12-18 Brain Awareness Week

22- 25 CONy 2018- The 12th World Congress on Controversies in Neurology, Warsaw, Poland

April

11 Dystonia Europe Board Meeting, Brussels, Belgium

12 Dystonis Europe Lunch Event, EU Parliament, Brussels, Belgium

13-14 Dystonia Europe 25th Anniversary & D-DAYs 2018, Brussels, Belgium

16-17 EPF – European Patients Forum General Assembly, Brussels, Belgium

June

16-19 4th Congress of the European Academy of Neurology, Lisbon, Portugal

TBC EFNA General Assembly, Lisbon, Portugal

July

TBC Dystonia Europe Board Meeting & Summer Think Tank, Lund, Sweden

21 World Brain Day

September

1-30 Dystonia Awareness Month

25-29 22nd International Congress of Parkinson's Disease and Movement Disorders, Seoul, Korea



<https://dystonia-europe.org/activities/events/dystonia-europe-2018-brussels/>



www.dystonia-europe.org

Events

Welcome to a Special Lunch for D-DAYS 2018



Getting together every year, sharing experiences, meeting experts and most of all having fun is always part of our D-Days. Next year will be extra special because it is Dystonia Europe's 25th anniversary. It seems appropriate that we return to our beginnings, in Brussels, for the celebrations. And we have booked the prestigious salon of the [European Parliament](#) to mark the occasion.

Professor Maja Relja, from the University of Zagreb, will be presenting the first results of our survey to assess the challenges patients face in accessing treatments as well as measuring satisfaction with the treatments. It is an important snapshot of Dystonia treatment across Europe.

This survey - which more than 1000 of you fantastic people completed – will help Dystonia Europe and our members talk to the Members of the European Parliament (MEPs) and other policymakers to bring about the changes we need.



Professor Maja Relja

Our hosts will include the Polish MEP Bogdan Wenta and the Irish MEP Nessa Childers who both have a special interest in neurological diseases. We also have the Finnish MEP Merja Kyllönen who you may remember boldly jumped for Dystonia out of an aircraft.

Is there an MEP from your country you would like to invite to the lunch? Heather Clarke, our EU advisor can assist, do drop her a line heather.clarke23@outlook.com She will be delighted to help you. It could make a real difference to the number of MEPs who turn up.

The lunch will be followed by a tour of the European Parliament and of course a JUMP for Dystonia! We will be inviting 2 people from each of our member organisations to come to the European Parliament lunch and guided tour on 12 April. Electronic forms will be available for you to complete.

Heather Clarke, EU Affairs Consultant



*Finnish MEP
Merja Kyllönen*



*Polish MEP
Bogdan Wenta*



*Irish MEP
Nessa Childers*

www.dystonia-europe.org

Members

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

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

Donation & Support

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

To donate directly please use the following on-line banking details:

Accountholder: Dystonia Europe

BANK:	KBC Bank, 16a Tervurenlaan, 1040 Brussels
IBAN number:	BE83 7350 0508 5515
SWIFT/BIC	KREDBEBB

When making a payment please include a reference to allow us to identify the donor.

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

Thank you for supporting Dystonia Europe!

Medical & Scientific Advisory Board

Prof Alberto Albanese – Milan
Prof Alfredo Berardelli – Rome
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Prof Rose Goodchild – Leuven
Prof Marina de Koning-Tijssen – Groningen
Prof Joachim Krauss – Hannover
Prof Tom Warner – London
Dr Jean-Pierre Lin – London
Prof Maja Relja – Zagreb
Prof Eduardo Tolosa – Barcelona
Prof Marie Vidailhet – Paris



Management & Staff

Board of Directors - Dystonia Europe is governed by a volunteer Board of Directors.



**Merete Avery,
President,
Norway**

Merete was appointed to the board of Dystonia Europe in 2013 and has held the position as Secretary from 2013-2015. Merete was appointed President at the Board Meeting, following the GA, in Rotterdam 2015 and re-elected at the GA in 2017. She was diagnosed with cervical dystonia in 2006 and was Chairwoman of the Norwegian Dystonia Association between 2010-2013. Merete is working with customer service, accounting and finance in Molde, Norway.



**Monika Benson,
Board Member and
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 is also a board member of the Swedish Dystonia Association. Monika has been working as a coordinator of work-shops, courses and lectures at a school in Lund, Sweden.



**Sorin Ionescu,
Board Member,
Romania**

Sorin is the founder and President of the Romanian Dystonia Association, Asociatia Distonia. The objectives of the association are to raise public awareness, provide support and advice to dystonia patients and their families and to promote research. Sorin has a degree in social science and is a writer, painter and has been involved in social activities since 2010. He was diagnosed with Generalised Dystonia in 2012.



**Adam Kalinowski,
Board Member,
Poland**

Adam has suffered from dystonia since 2006. He founded an online support group for patients from Poland, which marked the start of his career as a patient advocate. In 2016, he became a member of the Polish association where he currently acts as a Board Member and public relation expert. In the same year he became ambassador for the MyDystonia application. In 2017, at the Rome meeting, Adam was elected a DE Board Member. He is also an administrator of his own website called 'Dystonia Good Story'. He is Polish but he lives permanently in Ireland where he is trying to develop his own Social Media Marketing business.



**Erhard Mätzener,
Treasurer,
Switzerland**

Erhard was appointed Treasurer by the Dystonia Europe Board in November 2015. He is a member of the Swiss Dystonia Association SDG since 2008, and from 2010 he is their auditor/controller. In 2012 he was appointed the SDG delegate to Dystonia Europe. Erhard is an economist and was working as an investment advisor for a Swiss Private Bank for more than 20 years until he retired in 2002. Erhard suffers from blepharospasm.



**Edwige Ponseel,
Board Member,
France**

Edwige is the Chairwoman of the French Dystonia Association, Amadys. The objectives of the association are to provide support to dystonia patients, to raise public awareness, to promote research and to organize meetings and events. Edwige works in the purchasing and marketing department of a company near Paris. She was diagnosed in 1994 with cervical dystonia. She was elected to the DE Board at the General Assembly in Rome in 2017.



**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. Alistair has had cervical dystonia for 30 years.



**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, Vice President in 2012. She has now served the maximum period on the board, but remains as an advisor to the DE board. She also serves on the DE Medical and Scientific Advisory Board and is heavily involved in the COST-funded Dystonia Research Network.



**Eelco Uytterhoeven,
Advisor,
The Netherlands**

Eelco has been a professional IT-consultant and developer since 1999. For the last 2 years he has been working as a freelance developer on several internet projects related to Dystonia Europe. Since beginning of 2016 he is responsible for the maintenance and further development of the MyDystonia platform. Eelco was asked to become a special IT advisor to the Dystonia Europe board at the D-Days 2016 in Oslo. 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.

Partners & Sponsors

We have good working relations on a variety of topics with:

DMRF – Dystonia Medical Research Foundation, FDR – Foundation for Dystonia Research, Dystonia Coalition, EFNA – European Federation of Neurological Associations, EBC – the European Brain Council, EAN – European Academy of Neurology, MDS – International Parkinson and Movement Disorder Society.



Live better. Feel better. Look better.



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