

Connecting people for dystonia

# DYSTONIA EUROPE NEWS

## SPRING 2017

**Dystonia Europe Member Organisations and Partners  
Jump for Dystonia at D-DAYS 2017 in Rome**



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

Read more about the D-DAYS in Rome on page 4.

[www.dystonia-europe.org](http://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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### Meet us @

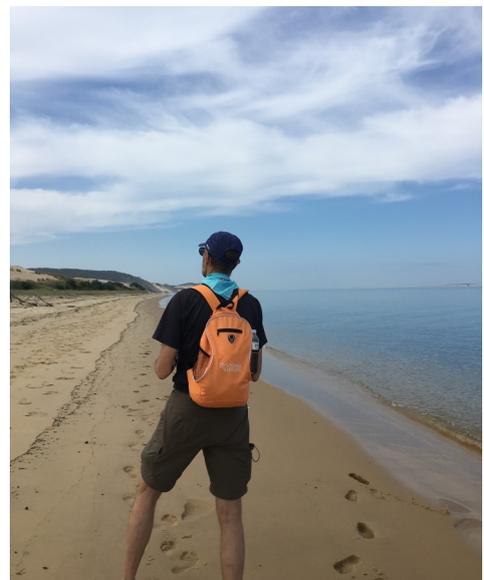
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From Dystonia Europe to all of you,

We wish you a wonderful summer !



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## President's Message



Dear all,

It is already summer and nearly two months have passed since we organised the D-DAYS 2017 and the 24<sup>th</sup> General Assembly in Rome.

Our Vice President Professor Maja Relja stepped down from the Board after serving the maximum period of six years according to the Dystonia Europe statutes. But she was involved long before that. In 1993 Professor Maja Relja and the Croatian Dystonia Patient Organisation together with ten other national dystonia associations founded the European Dystonia Federation, now Dystonia Europe, in Spoleto, Italy. Next year we will celebrate the 25<sup>th</sup> Anniversary of this occasion, in Brussels, Belgium where our organisation is registered.

We will continue to collaborate with Prof Relja on the Dystonia Patient Survey, which she developed together with her institution in Zagreb. The survey was launched at the D-DAYS in Rome and aims to reveal what are the gaps in the treatment of dystonia patients across Europe. Read more on page 8.

Board member Cristina Frosini from Italy served for two years on the Dystonia Europe Board and due to her own professional career she decided not to stand for re-election.

Many thanks to Maja and Cristina for their work for Dystonia Europe and for all dystonia patients.

We welcome our new board members, Adam Kalinowski from the Polish Dystonia Organisation and Edwige Ponseel from the French Dystonia Organisation. They had been nominated by their organisations and their elections were approved by the General Assembly in Rome.

It is also my pleasure to welcome the Ukraine Dystonia Association as a member of Dystonia Europe. Dystonia Europe now consists of 22 member associations from 19 countries. We hope to see new dystonia patient associations develop in countries where they still don't exist. And if we can assist let us know.

In June DE participated at the EAN 2017 (European Academy of Neurology) in Amsterdam. It is important for Dystonia Europe to take part in conferences, promote awareness of dystonia, to network and establish new contacts, and as the European umbrella organisation for dystonia, to be visible and do all we can to put dystonia on the neurology agenda.

Last, but not least, we would like to thank all our sponsors for their generous support making it possible for us to continue our work for dystonia patients across Europe. You'll find our Platinum sponsors on the last page of this newsletter.

On behalf of the Dystonia Europe Board I would like to wish everyone a wonderful and relaxing summer!

*Merete Avery*  
President

### D-DAYS in Rome

The Dystonia Europe D-DAYS 2017 and 24th Annual Conference and General Assembly were held on May 12,13 and 14th in Rome.

It was a joint event between Dystonia Europe and the Italian Association “Associazione per la Ricerca sulla Distonia ” A.R.D. which celebrated its 25th anniversary, as it was founded in Rome in March 1992 by Professor Alberto Albanese. Dystonia Europe (former European Dystonia Federation) was founded in Spoleto, Italy, 24 years ago, and next year will celebrate its 25th anniversary in Brussels in April.

The meeting in Rome took place at Hotel Ibis Styles, in Rome EUR business district. In the afternoon of Friday 12th, the Dystonia Europe Annual General Assembly was held and 28 members from 13 countries participated.

Later in the afternoon a guided tour of Rome showed many interesting areas of the most ancient and powerful city of the past. We stopped near the Colosseum and all together jumped with our orange t-shirts “Jump for Dystonia” in front of this impressive monument. Many tourists were there and took photos of us too! We stopped again at the Basilica of St.Peter.

On Saturday the conference began at 10 AM and there were around 100 participants, of which 50 A.R.D. members, coming mainly from Northern Italy, but also from the central part and Sardinia. Some Italian Professors spoke about Understanding Dystonia, Treatment of Dystonia, Research and development. Prof. Maja Relja from Zagreb spoke about “Non motor symptoms of dystonia”.

Occupational Therapist Hortensia Gimeno from London spoke about “Occupational therapy and dystonia” and Prof Buz Jinnah from Atlanta



*Maria Carla Tarocchi*

*Photo: Stephan Röhl*

spoke about “Dystonia research around the world”.

For more information on the presentations see: <https://dystonia-europe.org/activities/events/dystonia-europe-2017-rome/>

The David Marsden Award was attributed this year to Dr. Niccolò Mencacci, born in Milan but at present working in the Dept. of Neurology of the Northwestern University in Chicago. He received the Award for his study about “A missense mutation in KCDT17 causes autosomal dominant myoclonus-dystonia”.

We were proud that the award was given to an Italian doctor, even if he is now working in the USA.

In the afternoon a general discussion followed, during which the speakers answered many questions proposed by patients and participants; questions referred to general information about dystonia, while more specific or personal cases were dealt with personally.

## Latest News

Then the president of A.R.D. Flavia Cogliati (in charge from February) illustrated the past, present and future of our association, followed by Beatrice Pozzoli who presented the recently issued book “Distorie”.

This title is a mix between “dystonia” and “storie” (stories). It is a collection of short stories written by persons suffering from dystonia, in order to let people know what it means and how their life has been changed by dystonia. It is the first time that such a book is presented in Italy.

The conference ended at 6 pm. Later in the evening A.R.D. offered all the participants a dinner, which ended with a great cake decorated with “A.R.D. 25 anni” (ARD 25 years) We all toasted to D-DAYS, Dystonia Europe and A.R.D.

On Sunday morning a special session called “DE members capacity building “ was held, during which representatives of some of the member associations shared some of their work and projects during the Best Practice session.

Part of the morning was dedicated to a session by Simona Biancu (<http://www.engagedin.net>) on how to plan a campaign and how to raise awareness about dystonia.

In the afternoon a meeting about the MyDystonia APP was held with the MyDystonia Ambassadors who are in charge of diffusing and explaining this app in their own country.

This Conference has been really appreciated by Italian A.R.D. members and for many of them it has been the first one they attended.

It has been a unique opportunity to listen to both Italian and international speakers with important and interesting reports about our disease and also to meet other people with the same problems.

Even if nowadays it is easy to get in touch using social networks, a direct contact is more rewarding and involving.

We thank again Dystonia Europe for choosing our wonderful Rome as city of D-DAYS 2017.

*Maria Carla Tarocchi, Vice President, ARD*



*Members of the Italian Dystonia Association, ARD, with their 25th Anniversary cake.*

# Latest News

## Moments from D-DAYS in Rome



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

### DE General Assembly 2017 in Rome

The 24th Dystonia Europe General Assembly was held on 12 May at the IBIS Styles Roma Hotel in Rome, Italy. Representatives from 15 of the 21 member organisations were present. They were from: Croatia, Norway, Denmark, Sweden, Finland, the UK, France, Germany, Ireland, Italy, Poland, Switzerland and Romania.

President Merete Avery welcomed everybody to the meeting and wished all participants some interesting and inspiring days in Rome.

Executive Director Monika Benson gave an overview of the work of the past year including projects and activities. The final accounts of 2016 were presented by the Dystonia Europe Treasurer Erhard Mätzener and were unanimously approved by the delegates.

One application for membership had been submitted by the dystonia patient organisation in Ukraine and the Assembly unanimously approved their membership. Unfortunately its President Natalia Titova could not attend the meeting in Rome but we look forward to a presentation of the Ukraine dystonia organisation in due course.

At present Dystonia Europe has 22 member associations from 19 countries.

Then followed the election to the DE Board. Professor Maja Relja's term as Vice President had come to an end after serving the maximum period of 6 years. Board Member Cristina Frosini had announced that she wished to step down. We thank Maja and Cristina for their time and many valuable contributions to the work of the Dystonia Europe Board. New nominations were Adam Kalinowski from Poland and Edwige Ponseel from France and their elections were unanimously approved by the Assembly. Up for re-election were Board Member Sorin Ionescu and President Merete Avery and they were both re-elected by the Assembly.

The Dystonia Europe Board 2017 consists of President Merete Avery, Norway; Treasurer Erhard Mätzener, Switzerland; and board members Adam Kalinowski, Poland; Edwige Ponseel, France; Sorin Ionescu from Romania. Appointed board member: Monika Benson from Sweden.

Over the last few months a survey had been sent to DE members about the format of the D-DAYS and DE activities. Monika presented the result of the survey which included various ideas as well as members' top three activities for DE to focus on: **1. Raise awareness, 2. Information on treatment and research, 3. D-DAYS.**

It had been suggested already at the GA 2016 in Oslo to establish an awareness day/week/month for Dystonia in Europe. Suggestions had been made that we would follow the global dystonia community (US, Australia) and dedicate the month of September to Dystonia. The Assembly approved this suggestion. More information will follow on how we can work together on this effort.

Merete and Monika presented the Dystonia Europe activities 2017 which will include the following projects: MyDystonia APP and the MyDystonia Ambassador Programme, Dystonia Survey 2017 (more information on page 8), development of DE website, and the upcoming Dystonia Europe 25th Anniversary and D-DAYS 2018. These will be held in Brussels on 12-14 April 2018. Information on venue will follow soon.



*The DE Board*

*From left:  
Monika Benson,  
Edwige Ponseel,  
Adam Kalinowski,  
Merete Avery,  
Erhard Mätzener,  
Sorin Ionescu*

*Photo: Stephan Röhl*

### Launch of a Dystonia Europe Survey Platform - Take a Survey for Change!

Dystonia Europe is very proud to launch our recently developed Survey Platform, <http://surveys.dystonia-europe.org>

Here we offer the possibility to researchers, health decision makers and other partners to submit surveys to the Dystonia Community. To take part in a survey regarding your dystonia could help form the future dystonia patient pathway. Contribute with your experience with the disease and information about your daily life for the development of better treatments and better quality of life for dystonia patients in the future. Take a survey for change!

We are very proud to announce our first survey on this platform by Dystonia Europe Special Advisor, Professor Maja Relja of Zagreb University, Croatia. Register now and take part.

#### Dystonia Survey 2017

Here we present our first *Dystonia Survey 2017*. The original work on the questionnaire was undertaken at Referral Center for Movement Disorders, Clinical Medical Center and Zagreb Medical School, University of Zagreb, Croatia in the mid-2009. The original questionnaire was part of the research conducted in Croatia to investigate the improvement of dystonia management by specific training of general neurologists (GNs) and family doctors (GP). The survey involved sending a three part questionnaire to dystonia patients in Croatia during 2010 and 2015 to compare the improvement of dystonia care five years after specific training of neurology residents, GNs and GP was introduced (postgraduate medical education as training schools, training courses, focused symposia).

Results of our research using this questionnaire were presented at AAN Boston 2017 and EAN Amsterdam 2017 showed that collaboration in specific training for residents, GNs and GP could represent the basis for improving all aspects of dystonia management especially diagnosis and therapy.

By definition, questionnaire is list of a research or survey asked to respondents, and designed to extract specific information. It serves four basis purposes: to collect the appropriate data, to make data comparable and amenable to analysis, to minimize bias in asking questions, and to make questions engaging and varied. The use of questionnaire as a method of data collection in health-care research is widely accepted. Advantages of questionnaires include increased speed of data collection, low cost requirements, and higher levels of objectivity compared to

many alternative methods of primary data collection. As a joint effort of all Research Network members (The European Network on the Study of Dystonia Syndromes (RN) is a coordinated effort of European Scientists specializing in movement disorders, in particular dystonias, funded, in part, under the COST action BM1101 2011-2015), a survey was conducted in European countries via the management committee (movements disorders specialists) to document managing strategies, facilities and expertise available in various EU countries in order to identify which measures should be implemented to improve the management of DS in EU (*Valadas A et al Eur J Neurol 2016;10:147*).

Using Dystonia Survey 2017 involving as many dystonia patients as possible accross Europe we would like to evaluate the accessibility of patients to diagnosis and treatment in Europe, the effectiveness of care and treatment as well as the influence of dystonia on quality of life. Although still an underdiagnosed condition, we hope to prove that dystonia is not a rare disease.

Dystonia Survey 2017 is composed of 3 major parts:

**Part 1. General questions** as name, age, etc.

**Part 2. Specific questions** as disease duration, type of DS, who made correct diagnosis, experience with first visit to GP, type of therapy etc.

**Part 3. Quality of life**

We hope that with the results of this survey we shall have additional proof that dystonia is not a rare disease and that it has a great impact on patients quality of life.

*Prof Maja Relja MD, PhD*

*Head Referral Center for Movement Disorders and Neurodegeneration, Clinical Medical Center, School of Medicine, Zagreb University, Zagreb, Croatia*

#### Welcome to Dystonia Survey 2017 - A Rare Disease or not?

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 our questionnaire could help to improve dystonia care in Europe and prove that dystonia is not a rare disease.

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.

<http://surveys.dystonia-europe.org/survey/public/DYSTONIA17>

### Dr. Niccolò Mencacci receives the David Marsden Award 2017

Our congratulations to Dr. Niccolò Mencacci and the David Marsden Award 2017 for his paper:

["A Missense Mutation in KCTD17 Causes Autosomal Dominant Myoclonus-Dystonia"](#)

Dr Mencacci was presented with the award by Dystonia Europe President Merete Avery at the D-DAYS 2017 held in Rome last May. Dr Mencacci expressed his thanks to DE and Ipsen for the award and then presented the work of his research.

#### About the winner

Dr. Mencacci is originally from Milan where he also received his medical degree. From 2011 until 2016 he was clinical research associate at the Institute of Neurology, Queens Square in London. Currently he is a Research Assistant Professor at the Department of Neurology, the Feinberg School of Medicine, Northwestern University in Chicago.

#### About the research

Studying genes causing inherited dystonia has yielded important clues about why the neurons do not function properly in dystonia.

Myoclonus-dystonia (M-D) is a rare familial movement disorder characterized by a combination of myoclonus (jerky contraction of groups of muscles) and dystonia. Mutations in a gene called epsilon-sarcoglycan are found in about 30-50% of familial M-D cases, suggesting that mutations in other genes responsible for this condition are yet to be discovered.

To identify a novel genetic cause of M-D, I studied a large British family with many individuals affected with M-D, but without mutations in epsilon-sarcoglycan. Through the combination of different genetic techniques, I identified a mutation in a gene called *KCTD17* as the only possibly disease-causing mutation.

A subsequent analysis of other familial M-D cases without a genetic diagnosis revealed the same mutation in a different family of German origin, confirming *KCTD17* as a novel dystonia gene.

The precise function of *KCTD17* is unknown, as is how the mutations actually cause dystonia.

*KCTD17* is very abundant in the brain and in particular in the putamen, a brain region which is known to be critical in the neuronal circuits that are dysfunctional in dystonia patients.

Preliminary work to understand the function of *KCTD17* showed that *KCTD17* contributes to regulate (1) the effect of dopamine (one of the neurotransmitters critical in the development of dystonia) and (2) intracellular turnover of calcium (one of the most important signaling molecule in neurons). Future studies are warranted to further characterize the molecular function and the interactors of *KCTD17* as a step towards identifying new pharmacological targets to effectively treat dystonia.

#### About the Award

The Award of € 10,000 is intended to encourage research into dystonia in all European countries, especially by young scientists. Dystonia Europe is grateful for this award so generously sponsored by Ipsen.



Monika Benson and Merete Avery from Dystonia Europe, David Marsden Award winner Dr. Niccolò Mencacci and Sylvia Hanoune, Ipsen.

Photo: Stephan Röhl

### Summary of the 6th Biennial Workshop on Dystonia: “Dystonia: the link between hypo- and hyperkinetic movement disorders?”

Rome, May 12-13, 2017

The sixth biennial workshop on dystonia, focused on clinical and scientific aspects of the relationship between dystonia and Parkinson’s disease (PD). Several clinical and experimental observations suggest that dystonia and PD may exhibit common clinical and pathogenic aspects.

Isolated dystonia may be linked to genetic mutations, whereas secondary forms of dystonia may be a clinical feature of different neurological diseases, such as Parkinson’s disease (PD), even as a result of side effects of PD pharmacological treatment. Filling the gap between basic and clinical neuroscience is our primary goal.

The aim of this edition of the biennial workshop was to provide a complete overview of the potential interactions, highlighting the role of the underlying mechanisms.

Cardinal clinical features, age of onset, neuroimaging and neurophysiological data were considered as potential risk factors, and confounders at the same time, such as in the case of Dopa-responsive dystonia. Similarly, focal dystonia may represent the early sign of a generalized form, but it may also remain focal forever. Dopaminergic abnormalities described both in imaging studies and in post-mortem samples have been often linked to generalized forms of dystonia. However, the discovery of the *GNAL* mutation, which is linked to dopamine signalling and has clinical features that not necessarily resemble a generalized form need to be taken into consideration.



*Participants at  
Nobile Collegio Chimico*

## Research

Indeed, the new genetic discoveries during the past few months generated interest and enthusiasm and promoted discussion on the potential functional roles of the gene products. Interpreting these novel mutations is challenging, although it was tempting to speculate that some similarities with monogenic forms of PD may be found. This consideration emerged by analyzing the link between PD-related genes (i.e. parkin, PINK1, DJ1) and the common appearance of dystonia as presenting symptom. It is definitely too early to attempt to link together the novel dystonia gene mutations, such as GNAL and ANO3, but interesting parallels were proposed and discussed.

To this respect, Dopa-responsive dystonia (DRD) which presents with clinical features that include both dystonia and parkinsonism represents a paradigmatic example of inherited dopaminergic dysfunction.

The contribution of neuroimaging and clinical neurophysiology was important, to discuss the potential circuit abnormalities observed in both focal and generalized dystonia.

Other sessions covered different aspects, i.e. the pathogenesis of levodopa-induced dyskinesias (LID) and dystonia, as well as cell biology and technological innovations.

Lastly, new potential therapeutic strategies were considered, involving both dopamine-mediated signaling as well as newly designed cholinergic medications, but also negative allosteric modulators of metabotropic glutamate receptors.

The meeting was successful in terms of scientific quality and participation (>100 attendees). Many of these were young medical students, PhD students, post-docs, all of them involved in neuroscience disciplines.



*Antonio Pisani, MD, PhD  
University of Rome Tor  
Vergata  
Neurophysiology and  
Plasticity Lab  
IRCCS Fondazione Santa  
Lucia, Rome*

*Photo: Stephan Röhl*



### SIXTH BIENNIAL WORKSHOP ON DYSTONIA

"Dystonia: the link between hypo- and hyperkinetic movement disorders?"

Università degli Studi di Roma Tor Vergata

[www.dystonia-europe.org](http://www.dystonia-europe.org)

### German study (STIMTOX-CD) compares botulinum toxin and deep brain stimulation for the treatment of cervical dystonia

By Hanna Drechsel and Jens Volkmann  
University Hospital of Würzburg, Germany

Cervical dystonia is one of the most common types of dystonia. People with cervical dystonia suffer from motor symptoms such as abnormal head postures, jerky and awkward neck movements or tremor, but non-motor symptoms such as pain, dizziness, depressed mood or anxiety are increasingly accepted as part of the disorder. Altogether, these symptoms can lead to significant restrictions in daily activities, professional life and social participation.

Research in recent years has made substantial progress in understanding dystonia as the result of abnormal neuronal activity within specific brain motor circuits. Although, there is still no cure for dystonia, there are now two treatment options for cervical dystonia, which have proven marked benefit in reducing the motor manifestations of dystonia and thereby restoring quality of life:

The first one, botulinum toxin, is known to most people with dystonia and addresses the cramping and muscular over activity, by repeated intramuscular injections, which lead to de-nervation and weakening of the muscles.

This chemo denervation is the first-line treatment for most people with cervical dystonia and has proven to be more effective than taking anticholinergic medication.

The second option, deep brain stimulation, acts by suppressing the abnormal brain activity which is transmitted to the affected muscles and causes the cramping.

It requires the implantation of two permanent electrodes into the internal globus pallidus on either side of the brain. The globus pallidus is a deep brain nucleus, which is responsible for important aspects in the regulation of movements.

The electrodes are connected to a pacemaker device, which is implanted into the chest or abdomen and transmits weak electrical currents to the brain tissue. These currents are interacting with the activity of nerve cells in the surrounding of the electrode and help to correct the abnormal crosstalk between brain motor circuits and muscles. Several studies have demonstrated a profound benefit of deep brain stimulation in severe and generalized forms of dystonia, but also in cervical dystonia<sup>1-5</sup>. Most patients with cervical dystonia, undergoing deep brain stimulation, had been treated with botulinum toxin initially, but failed to respond after months or years.

We have recently conducted a large, multicenter study in Germany evaluating a period of six months of effective neurostimulation against sham stimulation in patients no longer responding to botulinum toxin treatment and found a significant benefit of deep brain stimulation on dystonia symptoms severity, pain, depression and dystonia related quality of life<sup>6,7</sup>.

The surgery was well tolerated and did not result in any permanent adverse effects in the study population. The improvement from deep brain stimulation was profound and long-lasting for a follow-up of five to ten years, which most participants in this trial have reached by now.

It is a logical next step now to compare the efficacy and safety of botulinum toxin and deep brain stimulation treatment in patients, who do no longer satisfactorily respond to toxin injections, but still experience modest to moderate benefit from this therapy.

So far, these patients have carried on with botulinum toxin therapy, because there was no other alternative. A recent real-life clinical study<sup>8</sup> suggests that this group of patients is surprisingly large: The study evaluated clinical response and patient satisfaction with a single injection session of botulinum toxin A in people with cervical dystonia under chronic botulinum toxin treatment.

A satisfactory response was observed in only 60% of patients as defined by the improvement of physician-rated dystonia severity, self-perceived improvement on a global clinical rating scale and good tolerance. The proportion further dropped to 29% when adding sustained benefit throughout the standard 12-week treatment cycle to the response criteria.

We hypothesize, that deep brain stimulation will provide a better and more sustained improvement of dystonia in patients, who experience these problems with botulinum toxin therapy and are willing to undergo deep brain stimulation for their residual symptoms.

Our ultimate goal is to prove that quality of life is better with deep brain stimulation than with repeated botulinum toxin injections under these conditions.

Our study intends to give a choice to people with dystonia of opting for deep brain stimulation earlier in the course of disease and before a total failure of botulinum toxin causes severe handicap, professional impairment or socioeconomic decline.

Based on these thoughts, we have designed the first study comparing in a blinded fashion the efficacy and safety of botulinum toxin and neurostimulation therapy. This is important, because expectations, the so called placebo effect, can have a strong impact on symptom severity, that needs to be controlled in a clinical trial. Hence, we will operate all eligible patients, who volunteer for this study, with a deep brain stimulation device, but ask them for a period of six months after surgery, in which they will not know, if they are treated by deep brain stimulation or by continuing toxin injections. In other words, all participating patients will receive two injection cycles after the implantation, similar to their botulinum toxin treatment before surgery. In half of the participants, the injections will contain botulinum toxin, in the other half saline solution, a placebo.

In the group treated by saline injections the neurostimulation device will be turned on, while it remains off (no voltage) in patients receiving true toxin injections. Neither the patients nor the treating physician will know the treatment assignment, which is decided randomly.

This will reduce possible biases in the study results. During the six months, blinded study period, we will assess the severity of motor and non-motor symptoms of dystonia, impairment in daily life activities and quality of life at regular intervals. Thereafter, all patients will receive effective neurostimulation therapy adjusted to their individual needs and injections will be discontinued.

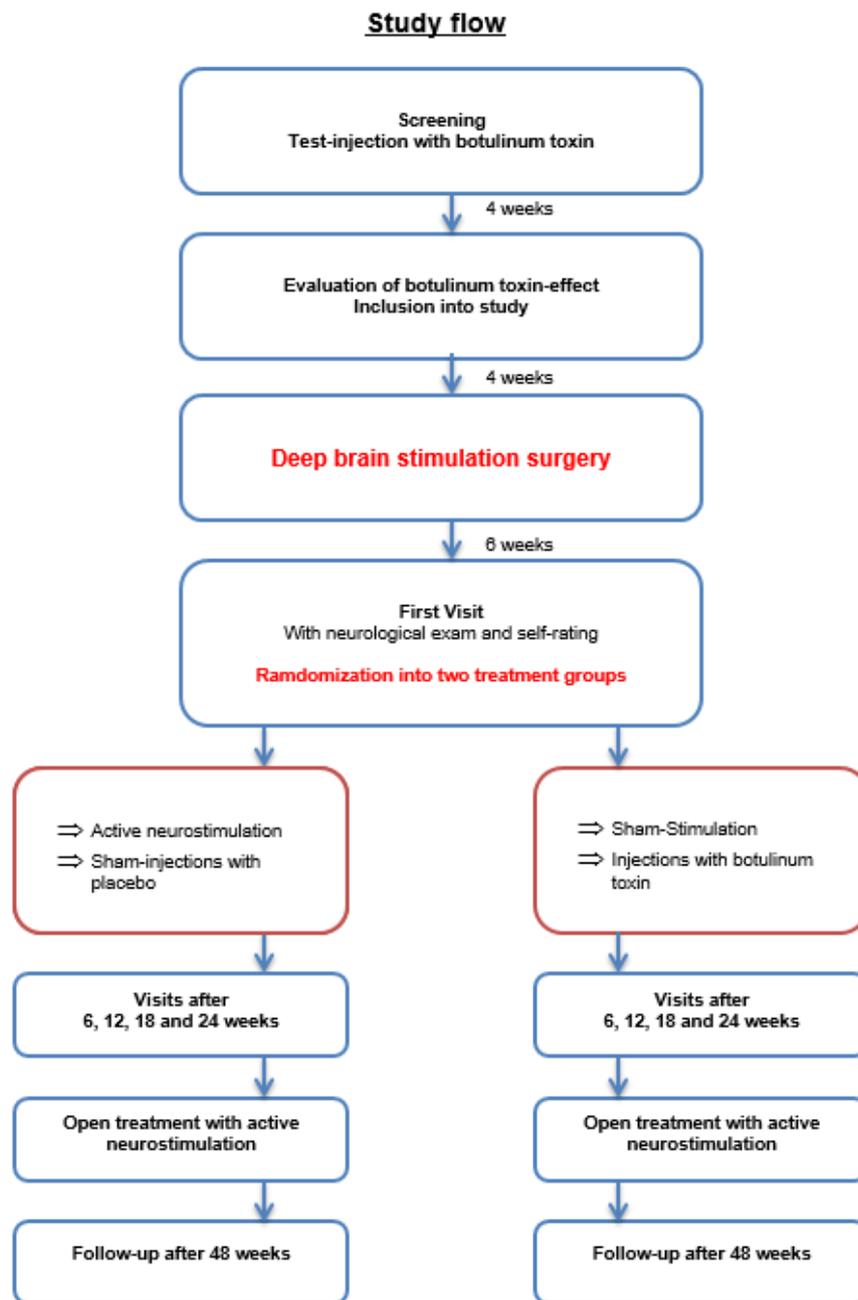


Fig. 1: Flow diagram of the StimTox-CD study. During the screening process eligible candidates will receive a test injection with botulinum toxin. The clinical response to this injection will be evaluated 4 weeks later and if there are no exclusion criteria the candidate will be included into the study. 4 weeks after inclusion the deep brain stimulation surgery will be performed. During the first visit 6 weeks after the surgery candidates will be randomized into two treatment groups: one group with active neurostimulation and sham-injections with saline solution (placebo); one group with sham-stimulation and botulinum toxin injections. During a six months period motor and non-motor symptoms will be assessed blindly, thereafter all patients will receive effective neurostimulation therapy.

## Research

The STIMTOX-CD study is conducted within the framework of the Dystonia Translational Research and Therapy Consortium (DYSTRACT), a network of dystonia specialty centers in Germany, and funded by the German Ministry of Research and Education.

Additional funding for the study was obtained from Medtronic, a manufacturer of DBS devices.

It is a multicenter study coordinated by the University Hospital of Würzburg with 12 participating sites (University hospitals of Berlin, Kiel, Lübeck, München, Marburg, Magdeburg, Dresden, Köln, Tübingen, Düsseldorf, Rostock).

We plan to include 66 patients between June 2017 and December 2018. It is our hope, that STIMTOX-CD will expand the treatment options for people with cervical dystonia and convince health care providers to accept patient preference, if both therapies prove at least equally effective.



*Fig. 2: Prof. Jens Volkmann has designed the STIMTOX-CD study. He is a movement disorder specialist and chairman of the Neurology department at Würzburg university hospital. Dr. Hanna Drechsel is the scientific coordinator of the German dystonia research consortium, DYSTRACT, and of the STIMTOX-CD trial.*

If you are interested to learn more about the STIMTOX-CD study, please contact:

Dr. Hanna Drechsel, University Hospital Würzburg, Neurology Department, Josef-Schneider-Str. 1, 97080 Würzburg, Email: Drechsel\_H@ukw.de

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## The European Network for the Study of Dystonia Syndromes – COST “Action” BM1101

This scientific research network, focussed completely on dystonia, was created with the support of a four-year grant awarded in 2011 by COST, a European intergovernmental organisation which pre-dates the European Union by many years. [www.cost.eu](http://www.cost.eu)

Dystonia Europe has been closely involved in this successful project, acting as Grantholder and Administrator of the Network, which was chaired by Prof Alberto Albanese from Milan.



*COST Training School Groningen*

### 2017 – Final Publication

An additional grant was obtained from COST, to create a scientific publication which draws together many of the strands of research interest during the project, and at the Final Conference. This has now been completed and is freely available online, at <http://journal.frontiersin.org/researchtopic/4314/unmet-needs-in-dystonia>

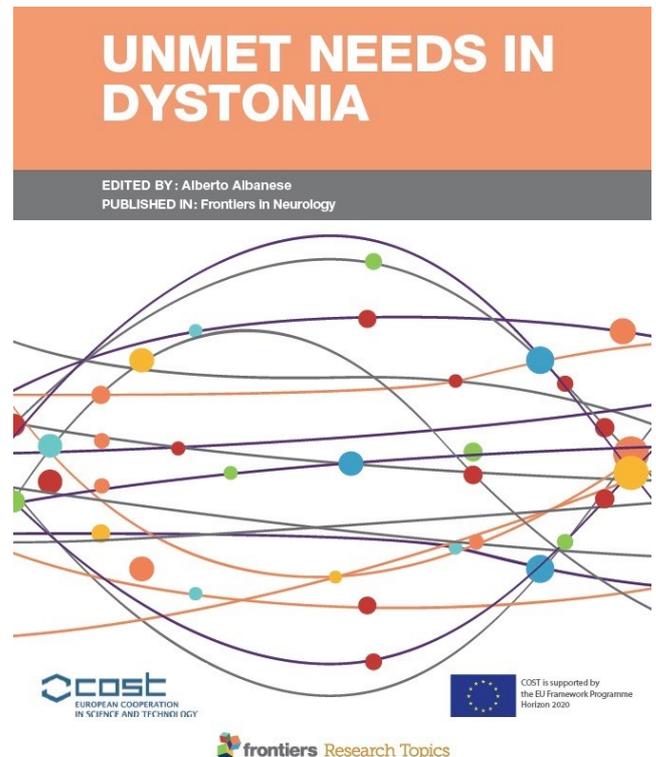
To obtain the publication when you reach the above webpage, click on the link "Download Ebook pdf"

*Alistair Newton*  
*Dystonia Europe*



*Professor Alberto Albanese*

*Photo: Stephan Röhl*



*The following articles, page 18–22, 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.*

### MAKING AN IMPACT

Before DBS, a 45-year-old man had suffered from constant pain and limited mobility, due to his Cervical Dystonia. Everyday tasks like driving, biking, & walking – even sitting upright – were becoming next to impossible. But all that changed when his device was successfully implanted in 2009, making him pain-free, with no visible symptoms of his dystonia.

*“I’m once again living an active life and I run 30–40 km a week (before DBS I couldn’t run at all). You could say that DBS saved my life!”*

### TROUBLE IN DUBAI

It was during his trip to Dubai for a race (he’s an avid runner) that he experienced an urgent situation. He had made sure to give his rechargeable device a full charge before leaving, but his plans hit a snag when he found himself missing the cord for his recharging unit. Without the cord, he couldn’t recharge his device, and risked having his therapy completely shut down – which would have caused him incredible discomfort.

### MEDTRONIC TO THE RESCUE

Despite this happening on a weekend, the patient’s hospital contact managed to reach a Medtronic representative in the patient’s native Sweden, who in turn called around the globe to locate a Medtronic representative in Abu Dhabi, and asked him to find – and send via courier – a charging cable suitable for the patient’s device.

*“I am unbelievably impressed and grateful for the professionalism, thoughtfulness and efficiency which Medtronic demonstrated when they helped me out of the pickle I had got myself into.”*



*“I am glad that I managed to support the patient before having his battery discharged, and the DBS therapy maintained. ...we never spare any effort to support Medtronic patients to keep their therapy on [an] optimum level” -- Daoud Udwan, Product Sales Supervisor – Abu Dhabi, UAE*

Safe at home in his native Sweden, the patient can rest assured that – wherever his world travel takes him – he’ll have the full support of Medtronic’s worldwide network behind him.

## Research

Medtronic helped pioneer DBS, and more than 150,000 patients worldwide have received Medtronic DBS Therapy TODAY

**Medtronic Activa Portfolio,  
tailored to each individual's need**

### *Brief Statement*

*See the instructions for use for detailed information regarding the implant procedure, indications, contraindications, warnings, precautions, MRI conditional labeling and potential adverse events.*

*Medtronic DBS Therapy is not for everyone.  
Not everyone will receive the same results.*

*Please consult your doctor for further information.*



Medtronic stand at D-DAYS in Rome

Photo: Stephan Röhl

### A call to action: DBS therapy deserves a central role in the treatment of dystonia, PD and essential tremor.

A report from the first-ever Expert Summit on the Future of Deep Brain Stimulation.

Magnificent baroque architecture, a splendid garden dotted with picturesque terraces and an imposing staircase once ascended by historic monarchs when visiting Würzburg's clerical rulers. Once an expression of the Church's power and influence, the Residence Würzburg is now an ideal site to showcase a new type of power: the power of possibility in world class neuroscience.

#### Experts united to enhance Deep Brain Stimulation (DBS) therapy

The first ever Expert Summit on the Future of Deep Brain Stimulation was held in November 2016 and brought together the world's leading neurologists and neurosurgeons to discuss the future of DBS therapy. Hosted by the University Hospital of Würzburg under Chairman Prof. Dr. Jens Volkmann and supported by Boston Scientific, the Summit had an ambitious agenda: to discuss solutions to current DBS therapy challenges, exchange best practices on technological advances, close knowledge gaps and develop a roadmap for future therapy milestones. Questions such as *How can we improve symptom control in dystonia, Parkinson's disease (PD) and essential tremor patients?* or *How can state-of-the-art technology such as directional DBS improve therapy outcomes for all patients?* took center stage at their presentations and talks.

#### DBS not yet standard of care in spite of new therapy options

"Despite the growing number of indication areas and patients that are benefitting from DBS therapy, it is often only implemented when other treatment options have already been exhausted.

We continue to see scientific evidence, however, that earlier and better access to DBS therapy can be truly life-changing for many patients who, prior to DBS, weren't able to live independent lives," says Prof. Dr. Jens Volkmann, Director and Chairman of the Department of Neurology at the University Hospital of Würzburg. It is this "last resort" mind-set that Boston Scientific intends to change: "We are committed and honored to support leading global experts in challenging this status quo and placing DBS at the heart of dystonia, PD and essential tremor therapy," says Maulik Nanavaty, President Neuromodulation at Boston Scientific. "By developing state-of-the-art technology solutions such as directional Deep Brain Stimulation and constantly enhancing programming options, we want to foster DBS as *the* standard of care."

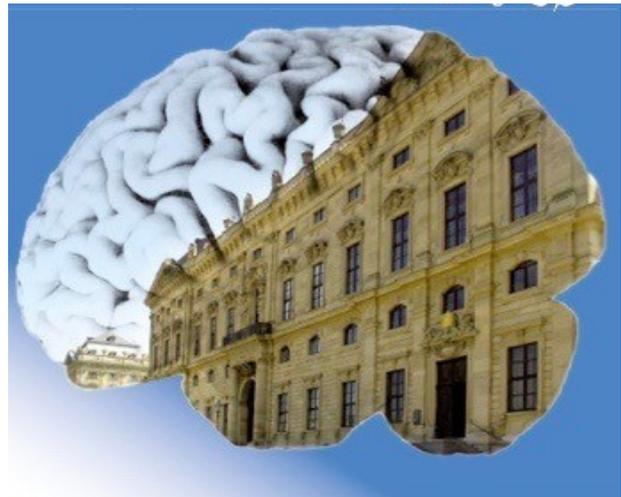


Monika Benson at the Expert Summit on the Future of Deep Brain Stimulation

### The road ahead: experts take to bikes to boost disease awareness

The Summit provided an important opportunity for Dystonia Europe and the European Parkinson's Disease Association to showcase their work as key advocates for increased awareness on dystonia and Parkinson's disease. This was not just about understanding patient perspectives but also about actively contributing to a good cause inspired by these same patients. By pedaling two bikes at an Alps-themed fundraising station, experts were able to experience for themselves a taste of Tony Seidl's inspiring tour, in which the 50 year old PD patient from Bavaria cycled across the Alps in eleven days last spring to raise awareness for PD and DBS therapy.

For every kilometer cycled on the two bikes out of the 650+ kilometer tour, Boston Scientific donated funds towards the work of Dystonia Europe and the European Parkinson's Disease Association. The result was impressive: Experts gave it their all and managed to secure 6,000 Euros for the cause.



1st Program Announcement:  
Expert Summit on the Future  
of Deep Brain Stimulation

The first ever Expert Summit on the Future of DBS was therefore a successful one for experts and patients alike, generating valuable discussions, funds and awareness as well as paving the way for more breakthroughs in the future. Further DBS awareness raising activities are already being planned for fall 2017.



*Dystonia Europe and EPDA receive a check of the funds raised by participants at the Würzburg meeting.*

# INNOVATION IN DYSTONIA TREATMENT

**Boston Scientific**  
Advancing science for life™

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



## Treatment options:



**Injections**  
botulinum toxin temporarily weakens affected muscles and reduces spasms



**Surgery**  
lesioning of nerves that control the muscles causing spasms



**Medication**  
a number of medicines can help regulate neurotransmission



**Deep Brain Stimulation (DBS)**  
brain stimulation can reduce symptoms of dystonia significantly



More than **120,000 people** worldwide already treated with DBS<sup>2</sup>



## What is DBS?

implantation of brain stimulator that helps regulate neural signaling

### Vercise PC 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



Directional leads for less side effects



Leads compatible with MRI\*



Contoured edges designed for patient comfort

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

## DBS may reduce dystonia symptoms such as:



Tremor, cramps



Pain



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<sup>4</sup>



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:

<sup>1</sup> Epidemiological Study of Dystonia in Europe (ESDE) Collaborative Group. *J Neurof.* 2000; 247(10):787-92.

<sup>2</sup> Fukaya C., Yamamoto T. *Neurof Med Chir.* 2016; 65(6):422-31.

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

<sup>4</sup> <https://www.dystonia-foundation.org/iving-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. All cited trademarks are the property of their respective owners. **CAUTION:** The law restricts these devices to sale by or on the order of a physician. Indications, contraindications, warnings and instructions for use can be found in the product labeling supplied with each device. Information is for the use only in countries with applicable health authority product registrations. Product available in the European Economic Area (EEA) only. Please check availability with your local sales representatives or customer service. Not for distribution in France. ANM-339107\_0C72016

# DystonieNET

## DystoniaNet:

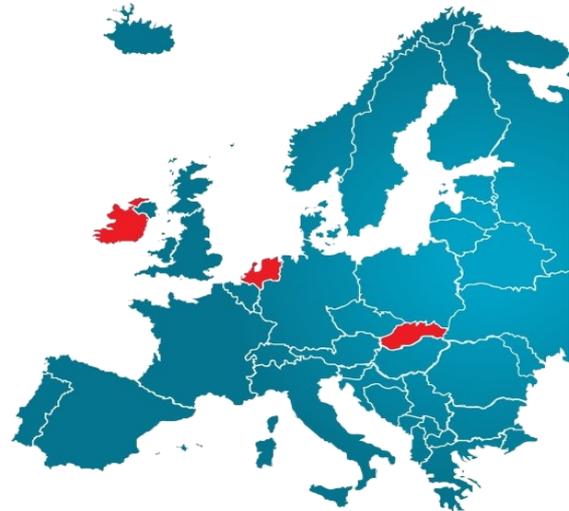
### The Dutch approach for optimizing the treatment of cervical dystonia goes European

After the success of the Dutch website DystonieNET, that was launched in the 2013 summer edition of the DE newsletter, we would now like to introduce the new European version of DystoniaNET (<http://dystonia.net>). DystoniaNET represents a network of dystonia specialists, including neurologists and physical therapists, in order to collaborate, both clinically as well as for research purposes. Furthermore, patients can use the website to search for a specialist in their own residential area.

The Dutch version of DystoniaNET was first initiated in 2011 by a group of Dutch academic movement disorder specialists. By now, many neurologists and physical therapists joined the network, which had led to sharing of knowledge. The Net also enabled the execution of larger national research projects.

Following this success, we are happy to launch the European version of DystoniaNET which will be online in about two weeks. Besides the Netherlands, Ireland and Slovakia joined the network, and other countries will soon follow.

The international collaboration shall further contribute to better treatment and hopefully will lower the threshold for international research studies. Moreover, the recently published European paper on evidence based clinical recommendations for botulinum toxin treatment (Contarino et al. 2017) and the successful outcome of Dutch DystoniaNET study towards the effects of physical therapy in cervical dystonia by Joost van den Dool (submitted for publication), will enable to organize training programs for neurologists and physical therapists to further improve the treatment of cervical dystonia.



Participating countries in the DystoniaNET

For more information on DystoniaNET, check the new website on <http://dystonia.net>

*Dr. Marenka Smit and Joost van den Dool,  
On behalf of Prof. dr. Marina AJ de Koning-Tijssen,  
University Medical Centre Groningen  
Chair Dutch DystoniaNet*

### Winter Think Tank 2017

#### 3rd Dystonia Europe Think Tank in Lund Sweden

Last week of January the 3rd Think Tank was held in Lund, Sweden.

The Dystonia Europe Board had come to Lund earlier in the week for the first board meeting of the year to plan and discuss this year's activities and projects.

Think Tank participants are the Board members and representatives from our Platinum sponsors. For 2017 they are the two medical device companies: Boston Scientific and Medtronic, and the two botulinum toxin manufacturers: Ipsen and Merz.

The theme of the meeting was communication and we discussed our different ways of communicating with you: on-line and face-to-face.

The main **on-line communication** channel and the hub of Dystonia Europe is our website with close to 1000 unique visitors per month. If you have not checked it out please take a look.

There you find information about our organisation: board members and statutes; sponsors and projects, activities and events and much more. On the Latest News section you always find the latest that has happened within the organisation. From the website you can connect with our social media channels: Twitter, Youtube, Instagram and Facebook. Here you can follow our day-to-day activities and easily connect with us.

From our website you can also connect with MyDystonia – our digital dystonia diary for dystonia patients. Here you can monitor symptoms, treatment and daily activities in order to create reports which can facilitate patient physician communication and treatment outcome. If you have not created your account yet do it today!

Soon to be launched is our David Marsden Award website which will specialize on the Award and David Marsden, the most recent Winner and past winners, together with our sponsor making it possible for us to continue to work and develop this distinguished Award.

The newsletter Dystonia Europe News is issued twice a year: in June and December. Here we try to collect interesting articles on research and activities taking place within Dystonia Europe and our member organisations across Europe.

Meeting our members and partners **face-to-face** is very important to us as well. At our annual D-DAYS we offer interesting presentations with top dystonia experts and the opportunity for networking and fruitful discussions, sharing best practise and development. We also take part in meetings and congresses around Europe such as EAN and MDS. When possible we also try and attend national dystonia meetings of our member associations.

The next, and also the 4th Think Tank, will take place in Lund, Sweden on 7 July.



*Think Tank members*

## EU Activities

### Governance Workshop & Dystonia Leaders Met in Dublin

A 2-day workshop on Governance was organised by the European Federation of Neurological Associations - EFNA, in Dublin, Ireland last March. It was held alongside the Extra General Assembly and members of the EFNA Board as well as representatives of member organisations from disease areas such as epilepsy, Huntington's, ADHD, ataxia, Brain tumor and more were present.

EFNA is the umbrella organisation for neurological patient organisations across Europe and has at the moment 20 members. Dystonia Europe is a member and Executive Director Monika Benson is on the EFNA Board.

EFNA's vision is "better quality of lives for people living with neurological disorders in Europe". By focusing on activities within the field of advocacy, awareness, empowerment, and engagement the purpose is to add capacity and value to the work of its member associations.

Noemi Ambrus, Senior Trainer at Civil Support in Budapest, Hungary, led the workshop which aimed to inspire our everyday organisational work as well as update the EFNA Constitution by providing information and opportunity for discussion on topics such as Governance, Transparency and Member Engagement.

**Governance** – Noemi compared the Board with the Control Tower, and the Pilot driving the plane and its passengers she compared with the Executive Director and the patients in the organisation. The role of the Board is to keep an eye on everything in order to follow the strategic plan of the organisation. The management wheel of a non-profit organisation includes: Administration, fund raising, finance, public relations & communication, human resources and marketing. It's not sustainable if the board is doing everything. It is important to have documents covering work descriptions for board members, code of conduct, conflict of interest, confidentiality agreement in place.

Recruitment of board members is done by getting to know the member organisations and their boards to identify people with the skills needed on the Board. It is recommended that most board members are patients and that they are elected at different times to sustain quality and experience.

There should be time limits on how long you can be a board member. An Ex Officio Board member is the Executive Director who can vote and take part in all discussions except matters regarding his/her contract, salary etc.



*Noemi Ambrus  
and Donna Walsh*



The question was raised whether an election committee is used in international organisations. This is common for the Scandinavian organisations where an election committee is involved in getting to know members and suggesting them to the board. One participant shared that they had tried this in their international organisation with no success. Noemi pointed out that "member organisations have the possibility to submit nominations for board membership."

To facilitate for new board members it is recommended with a "Welcome package" containing all they need to know about the organisation – background, values, work description etc.

It is recommended to have routines for financial and internal control and to follow up the work of the Board by evaluations of both meetings, board members and staff in order to create good and efficient work atmosphere.

Regarding fund raising it is advisable to aim for four legs as income stream to secure the sustainability of the organisation.

When the participants shared their work and most successful projects and activities at the Wednesday evening dinner, it was very obvious that we have much in common despite our different disease areas. It was concluded that these kind of workshops are very valuable in order to grow our patient advocacy network, share best practice, and learn from each other to move forward with the work of our own organisations.

Many thanks to EFNA Executive Director Donna Walsh for initiating this workshop and to Noemi Ambrus for a very interesting workshop, and to all the participants for inspiring and fruitful discussions.

While in Dublin President Merete Avery and ED Monika Benson met with Dystonia Ireland Chairwoman Maria Hickey to discuss the on-going



*Monika Benson, Maria Hickey and Merete Avery*

work of our organisations and future collaboration. Maria shared that her organisation has about 750 members. They focus a lot of their work on partnerships with dystonia researchers. By organising fund raising events such as mini marathons, sale of Christmas cards etc. they have over the years funded research projects for more than € 300 000. We congratulate Maria and her team of Dystonia Ireland on this success.

### **Membership – why is it important to be a member of EFNA?**

The group discussed the topic and came up with the following benefits of being a member of EFNA:

- Forum for dialogue
- Knowhow can be shared
- Platform for rare diseases
- Contacts/memberships
- Network
- Perspective on other diseases
- Credibility
- Fund raising opportunities
- Training and capacity building

### Effective External Ambassadorship

On May 3<sup>rd</sup> and 4<sup>th</sup>, Communications Training for European Patient Associations in the field of Neurology was held in Brussels, organised by EFNA, the European Federation of Neurological Associations. This workshop brings together representatives from different European neurological associations and patients working to improve the perspectives and quality of life of people affected by the different conditions.

Dystonia Europe was represented during the event by Adam Kalinowski, Member of the new DE Board.

The training focused on boosting advocacy impact through effective communications with and via the media. Another key point on the agenda was the attempt at creating a powerful message addressed to policy makers. The organisers and the facilitator, Bettina Hausmann, took care to ensure opportunities for the participants to learn in practice how to optimize their communication and interactions for improved results. Bettina has trained hundreds of clients in how to handle media situations, including tricky interviews. Media training highlights include rehearsing with executives prior to BBC, HARDTalk and CNN interviews and coaching a national Minister prior to potentially hostile interviews.

On the first day, the trainer concentrated on creating hard-hitting messages during short presentations. Each participant was asked to prepare a 3-minute presentation making use of the techniques and instructions received earlier during the day. The presentations were delivered in 5 breakout groups. All speeches were recorded so that the participants could see by themselves how they did and what else could be improved. The homework for the next day was to make a drawing summing up all the learning acquired to date.



*Bettina  
Hausmann*

On the second day, the participants presented their drawings which was also great fun. Subsequently, we learned who the media are, how they work and how to prepare for an interview. Through simulation, each team member could act in turn as the journalist, the interviewee and the observer. The exercise helped us understand how to give an interview and convey our message, make sure it is well understood and effective. The last task of the participants was to record their video messages which was clearly the most stressful part of the project for many participants.

Tips, tools and examples of effective video messages helped the trainees carry out the task. The biggest advantage of the workshop was related to its interactive formula. Each participant took part in the hands-on challenges. When talking to other people, I learned that after the two days everyone was very tired which shows how hard we worked to upgrade our skills and become more effective in our daily work. It all would not have been possible without EFNA's excellent organisation and the professionalism demonstrated by Bettina Hausmann.

*Adam Kalinowski  
Board Member, Dystonia Europe*

### Brain, Mind and Pain Interest Group Meeting in the Parliament

'The Value of Early Intervention' is the topic of the next meeting of the MEP Interest Group on Brain, Mind and Pain.

Coordinated by the European Federation of Neurological Associations, it will take place in the European Parliament on Wednesday, July 12<sup>th</sup> between 12.30 and 14.45hrs.

The background to the meeting is a project entitled 'Value of Treatment: Bridging the Early Diagnosis and Treatment Gap for Brain Disorders'. This project is led by the European Brain Council, and aims to assess the socio-economic impact of interventions (clinical practice), or the lack thereof, in a number of neurological and mental health disorders.

It is hoped that the project will provide evidence and tools that can assist policy makers and healthcare actors in shaping effective policy responses to some of the most prevalent brain disorders in Europe.

#### The meeting will consist of two sessions:

1. Conclusions and recommendations from the 'Value of Treatment' project, focusing on the value of early intervention, and a discussion on how the EU can support the solutions identified.
  2. Possible next steps in the Value of Treatment project, exploring the application of the developed methodology to other disease areas. There are plans that rare diseases could be studied during Phase 2, and EFNA will be advocating for the inclusion of dystonia here.
- On the day, expert contributions will be made by health professionals, policy-makers, economists and patient advocates.



Donna Walsh

Interested in taking part?

Visit: [www.brainmindpain.eu](http://www.brainmindpain.eu) for more details – the agenda will be uploaded in late June. Or visit the website after the event to read the event report. You can also learn more about the Value of Treatment project by visiting: [www.braincouncil.eu](http://www.braincouncil.eu)

Donna Walsh,  
Executive Director EFNA



Member of the  
European Parliament  
INTEREST GROUP ON  
BRAIN, MIND AND PAIN

### TINA Workshop this July in Romania

The second edition of the TINA Romanian Workshop will take place on 21<sup>st</sup> of July at Hotel Cismigiu in Bucharest. Coordinated by the European Federation of Neurological Associations (EFNA) and organised together with the Association of Patients with Neurodegenerative Conditions in Romania (APAN), the workshop will take the opportunity to mark World Brain Day.

The theme of the workshop is Storytelling, Science and Social Affairs. The first part of the day will focus on better understanding the way the brain is affected in various neurological conditions and will present the current state of research. Participants will find out to what extent these conditions lead to disabilities and will learn about the rights of people with disabilities at international level and what can be applied in Romania.

As an example of good practice, it will discuss what other organisations at EU level (EFNA and EMSP) have achieved and will also launch the [Practical Toolkit for Employers](#) in Romania.

In the second part of the day the workshop will also address the issue of how patient organisations can communicate more effectively within the current health system.

It will focus on how patients can convey the message with more power through storytelling. It aims to find new opportunities to collaborate between neurological associations in Romania.

The organisers hope this workshop will be a milestone in the development of the representatives of patient associations in the field of neurology in Romania, for the benefit of the organisation and implicitly, of the patients they represent.

If your organisation is based in Romania and you would like to take part, please register [here](#).

For more details, please contact [andreea.antonovici@afectiuni-neurodegenerative.ro](mailto:andreea.antonovici@afectiuni-neurodegenerative.ro)

### Researchers and Patients Brought Together by a New Grant Offer

Pain Alliance Europe and Grünenthal are together introducing an initiative which will encourage patient-centric, patient driven, scientifically robust innovation and research projects, while creating better access to innovative treatments, promoting prevention and self-management approaches, decreasing stigma and finally, working together to improve quality of life for people living with these disabling conditions.

The Brain, Mind and Pain 'Patient-Centred Innovation Grant' aims to create an environment where patient centricity is the basis for future initiatives. This will contribute towards creating a sense of innovation, with direct impact on patients' needs, and at the same time increasing awareness of chronic pain conditions and neurological disorders.

**Pain: a challenge for individuals and healthcare systems** Pain causes a problem for individuals as well as a challenge for healthcare systems, economies and society: each year, approximately 1 in 5 Europeans or 20% of the adult population in Europe are affected by chronic pain (1). This includes 153 million people suffering migraine or other disabling headaches, 200 million people with musculoskeletal disorders and 100 million people experiencing other chronic pain (2).

Four of the top 12 global disabling conditions – low back and neck pain, migraine, arthritis and other musculoskeletal conditions – are persistent pain conditions (3). Pain related conditions result in more people having to retire too early. With more than 500 million sick days per year in Europe, musculoskeletal pain causes almost 50% of all absences from work lasting three or more days in the EU and 60% of permanent work incapacity (4).

The estimated direct and indirect healthcare costs for chronic pain disorders in European Member States vary from 2 % to 2.9 % of GDP across the EU (4). For 2016, this estimate results in €296 – €429 billions (5). Healthy citizens, on the other hand, reduce the strain on healthcare systems and boost economic growth by staying active for longer.

Pain has a huge personal impact, it is among the top causes of disability in every region of Europe and



*BMP task force group*

increases the risks of other health problems, social exclusion and poverty (6) (7). Stigma and lack of public knowledge worsen the burden on patients and families by preventing people from seeking treatment. Yet pain remains poorly managed and under-treated, affecting not only patients, but society at large (2). Large health inequalities persist in the EU as many patients do not have access to effective pain treatment.

**About the BMP grant** Several partner organisations are contributing to this project together with PAE and Grünenthal: the European Pain Federation (EFIC), the European Academy of Neurology (EAN), and the European Federation of Neurological Associations (EFNA).

The biennial grant provided by Grünenthal is for individual applicants as well as different organisations' initiatives and partnerships. They are invited to present their innovative projects or ideas with direct impact on brain, mind, and pain patients' quality of life.

The BMP grant's objectives focus on three working streams: access to innovative treatments, prevention and self-management approaches, and reduction of stigma and research into life quality improvements. A jury of patients' representatives supported by scientific experts will ensure that the nominated winner addresses the patients' challenges.

The first BMP Grant Awarding Ceremony will take place in Spring 2018. Interested applicants who meet the eligibility criteria will be able to apply online from 1st September 2017. More information will be available soon online, at [www.bmp-grant.eu](http://www.bmp-grant.eu) and [www.pae-eu.eu](http://www.pae-eu.eu).

## MyDystonia Ambassador Meeting in Rome

The second MyDystonia Ambassador meeting was held last May in Rome alongside the D-DAYS. The Ambassadors were Edwige Ponsel from AMADYS (the French Dystonia Association), Stefan Taubert from the Finnish Dystonia Association, Sissel Buskerud from the Norwegian Dystonia Association, Ulrike and Juliane Halsch from DDG (the German Dystonia Association), Yvonne Sörensen from the Danish Dystonia Association. Additional participants were Bengt-Erik Calles from the Swedish Dystonia Association and Maria Carla Tarocchi from ARD, the Italian Dystonia Association.

Eelco and Monika gave an update and overview of the development of the APP in the last few months. Today there are about 1200 users from 44 countries worldwide. The APP is available on Google Play and in the APP Store in 10 languages (English, German, Spanish, Italian, French, Swedish, Norwegian, Danish, Finnish and Russian).



*MyDystonia Ambassadors at Campo di Fiori in Rome.*

*Photo: Stephan Röhl*



*MyDystonia workshop in Rome*

*Photo: Stephan Röhl*

The Ambassadors then shared what they have done on a national level to promote the APP such as presenting it at members' meetings and with various communication activities through newsletters and social media.

In order to facilitate the work of the Ambassadors a special platform has been developed: MyDystonia Ambassador NET. During the second part of the workshop the participants had training on how to use the platform and how to resolve various issues encountered by MyDystonia users.

Once again we would like to thank our Ambassadors for their support and commitment to work with the MyDystonia project. Our vision is that all dystonia patients use MyDystonia in order to facilitate patient/physician communication, to optimize treatment outcome, and in the longer term, help form the future dystonia patient pathway.

"My dystonia data today can be important for tomorrow's dystonia research", says Merete Avery, Dystonia Europe President.

# My Dystonia



Monitor your dystonia and improve your life!  
**By patients. For patients.**

The smartphone screen displays the My Dystonia app interface. At the top, it says 'SUBMIT' and 'MY DYSTONIA'. Below that are tabs for '1W', '1M', and '3M'. The main content area shows a line graph titled 'Physical symptoms' with two data series: 'Q1 (Proximal muscles)' and 'Q2 (Distal muscles)'. The x-axis represents weeks from CW14 to CW17. The y-axis represents the level of symptoms. The graph shows that Q1 symptoms generally decrease over time, while Q2 symptoms fluctuate. Below the graph, there are icons for 'Physical symptoms', 'Q1', 'Q2', and 'Q3'. At the bottom of the screen, there are icons for 'CLAMP', 'REWARDS', 'REWARDS', 'NEWS', and 'SETTINGS'.

Week	Q1 (Proximal muscles)	Q2 (Distal muscles)
CW14	High	Low
CW15	Medium-High	Low
CW16	Medium	Low
CW17	Low	High

Available on the App Store

Available Online

[www.dystonia-europe.org](http://www.dystonia-europe.org)

# Jump for Dystonia

## Summer Jump for dystonia!

Make a special Summer Jump for Dystonia! Where are you this summer? Do you travel or stay home? Show us by taking a Jump photo, use the hashtag #summerjumpfordystonia as well as #jumpfordystonia and post it on our Facebook page or Instagram.



[www.dystonia-europe.org](http://www.dystonia-europe.org)

### Belgian Dystonia Association Meeting in Bruges

The Belgian Dystonia Association had invited its members to a meeting at the university hospital in Bruges, Belgium last November. After an introductory welcome from Frans Vanderstraeten the first speaker was introduced. Professor Santos from Bruges gave an interesting overview of dystonia in various areas such as genetics, non-motor symptoms and treatment. Following the coffee break Monika Benson spoke about "Dystonia – from a patient point of view". She shared her personal story and then moved on to talk about Dystonia Europe, its activities and projects. She also presented MyDystonia, the digital dystonia diary. At the end of the meeting all 40 participants gathered in a JUMP for Dystonia.

Many thanks to the Belgian Dystonia Association, and to Merz for organising this meeting.



*Frans Vanderstraeten from the Belgian Dystonia Association.*



*Belgian members jump for dystonia*

## Around Europe and Beyond

### Norwegian Dystonia Members Annual Meeting 2017 in Trondheim

Last March the Norwegian Dystonia Association held its Annual Meeting and General Assembly in Trondheim, Norway. Around 40 members (dystonia patients and family members) had come from all over Norway for the 2-day-meeting. President Anniken Hansen welcomed everybody and gave an update of the achievements of the Association over the past year. The 3-year Physiotherapy Project has now come to an end and has been a great success. 82 physiotherapists from all over Norway have been certified. The Association has six local support groups throughout Norway which organise meetings twice a year for members in their regions.

After lunch neurosurgeon Sasha Gulati from St. Olav Hospital in Trondheim gave an informative presentation on DBS (deep brain stimulation) for dystonia, showing videos on how it is done and how it works. DBS is performed at two University Hospitals in Norway: Trondheim and Oslo, and more and more dystonia patients are being treated with satisfying outcomes. His presentation was followed by NDF member, Cecilie Benterud, who shared her dystonia story and how she struggled until she finally, after three years, had a correct diagnosis. She had treatment with botulinum toxin but the results were not what she expected and in 2012 she was treated with DBS. "I had a new life" she said. Today she is doing well and is working. We thank Cecilie for sharing her story.

MyDystonia Ambassador and NDF Board Member Sissel Busekerud gave a short presentation of the APP MyDystonia. Together with Monika Benson they encouraged the participants to use the APP which can be a helpful tool to support and facilitate patient/physician communication and improve treatment outcome. And the more we are using the diary the more anonymous dystonia data is collected. Monika stressed that "your dystonia data today can help form the future dystonia patient pathway".

In the afternoon all guests joined in a guided boat tour of Trondheim. The weather was gorgeous and so is Trondheim, Nidelva, the fjord and the surrounding mountains. There was also time for a short stop at the small island of Munkholmen. Here we all joined for a JUMP for Dystonia Under the Umbrella to support Brain Awareness Week, 13-17 March.

On the Sunday morning the General Assembly was held. President Anniken Hansen stepped down after leading NDF for four years. New President is Johan Arnfinn Warvik. We thank Anniken for her dedication and great work for dystonia patients in Norway and we welcome Johan and wish him and his new team much success in their work.

Dystonia Europe had been invited to attend the meeting and was represented by Executive Director Monika Benson. It's very important for us to meet with members in our different member countries. By talking and listening to them we understand better the needs and we can plan and move forward in our work for dystonia.

Thanks for inviting us and giving us the opportunity to attend your meeting.



*New President Johan Arnfinn Warvik and past President Anniken Hansen*

### Amazing Glance into the Universe of Pacemaker Production

On May 5 I attended a visit to **Medtronic** in Tolochenaz, Switzerland, which was organised by Eric Huber, Board Member of the Swiss Dystonia Association (SDA) and President of its French speaking fraction.

I took the train to Morges, walked along the shore of the lake of Geneva through a wonderful old park, where the “fête de la tulipe” (Tulip festival) took place. The “sentier de la truite” (trout trail) guided me along a little runnel and after several trial and error operations I arrived at the site.

The Dublin domiciled company with its operational headquarter in Fridley/Minnesota operates in more than 140 countries and employs almost 100'000 persons. The Tolochenaz/Switzerland site is subdivided into three units:

**EMEA** (Europe, Middle-East and Africa) coordinates the activities in these regions.

**SMO** (Swiss Medtronic Operations) is the production plant of the most sophisticated implantable stimulators in the world.

**The Formation Centre** welcomes thousands of medical persons from all over Europe every year to provide introduction and support in order to ensure professional implementation and application of its devices.

At the beginning of the visit an interesting overview of the company's history and businesses was given by Mr Cyrille Le Terrien, Sales Representative Neurosurgery and DBS. It was pretty impressive to witness the permanent improvement and miniaturisation in the field of these tiny power machines supporting disordered hearts and brains activities.

Prof. Jocelyne Bloch, Neurosurgeon at Swiss Brain Stimulation Unit (Centre Hospitalier Universitaire Vaudois CHUV, University of Lausanne) provided us with an introduction into the different types of dystonia and its surgical treatments (deep brain and cortical) in stereotaxic and functional neurosurgery,



*Swiss Dystonia Association at Medtronic*

whose main objective is to improve the brain's poor ability for self-healing by means of neuromodulation (stem cells, brain plasticity mechanism). Her field of research includes new indications in deep brain stimulation. DBS is used for the treatment of Parkinson, Tremor and Dystonia.

Then the 22 participants started for a plant visit, guided by Ms Isabel Hollstein, Marketing and Sales Assistant, and we could glance through large windows at the antiseptic production facilities of the medical device company, not only a pioneer for cardiac pace makers but also the world's largest standalone medical technology development company. At several places short video flashes provided more information for a deeper understanding of the production processes.

The impressive event was completed by a delicious dinner in the in-house VIP restaurant. And not to forget the building's modern architecture and its ground-plan: It symbolises the two ventricles of a heart!

I thank Eric and all the people from Medtronic involved in the organisation of this impressive event.

*Erhard Mätzener*

*Treasurer*

*Swiss Dystonia Association and Dystonia Europe*

## Meet DE Board Member: Erhard Mätzener

I do not remember exactly when and how I heard of the Swiss Dystonia Association (Schweizerische Dystonie-Gesellschaft, SDG) for the first time. It must have been around 2008. As a guest I attended a luncheon event of SDG and there Barbara Gygli, then delegate of SDG and board member (Secretary) of the European Dystonia Federation EDF 2004-2006 as well as the daughter of Dr Brigitte Gygli, co-founder of SDG in 1994 and first President, gave me more information on SDG. I became a member, and in 2009 I attended my first SDG AGM. One year later I was elected co-auditor of SDG, and in 2012 assigned main delegate to SDG at Dystonia Europe.

When I attended my first Dystonia Europe congress and AGM in wonderful Bol on the island of Brač (Croatia) in 2012, Monika Benson, President of DE at the time, asked me whether I could imagine to become active as a member of the DE board. I thanked Monika for the confidence but added that first I would like to grow more familiar with my new job as SDG delegate.



*Erhard in the Swizz Alps*

It was a wonderful morning at the impressive venue of the MS Rotterdam in October 2015 at the D-Days, when Alistair Newton, one of the 'spiritus rectores' of our organisation, approached me at breakfast and asked me if I could imagine to become a successor of Heike Wolf as the Treasurer of Dystonia Europe. I answered that I needed some time to think it over, and by November 2015 I was appointed Treasurer of Dystonia Europe.



*Lilo and Erhard*

A lot has happened since then, and during that period I have learned how much work got completed over all those years, and I very much appreciate the atmosphere of reliability and open-mindedness that is characteristic of the DE board. It is my strong will and bounden duty to serve the board of Dystonia Europe for the benefit of a huge number of Dystonia patients all over Europe.

## Hello there!

Besides the facts and figures I have been dealing with for decades, I like to practise sports. And when comparing my rather moderate degree of Blepharospasm to other forms of Dystonia I feel privileged being able to do physical exercise.

I was more than 30 years old when I started running, and I finished several Marathon races since. In wintertime, I am keen on cross-country skiing. I visited Finnish Lapland many times and participated in competitions like Pirkkan Hiihto, Finlandia Hiihto, Lapponia Hiihto, Rajalta Rajalle (7 days across the middle of Finland from the Russian to the Swedish border in Tornio) Vasa-Loppet and Birkebeiner Rennet. A tremendous experience was the Hiihtäen halki Suomen from Virolahti to Jäämeri, i.e. from the Baltic Sea to the Arctic Ocean (1800 km in 32 days). Also unforgettable is the Arctic Circle Race at the eastern coast of Greenland (Sisimiut).

I have been taking singing lessons for more than 10 years now, and have been active in several choir projects, including the Finnish choir of Zürich and the Russian choir "White Nights" of Zürich, which encompassed a trip to Siberia and a one-week cruise on Lake Baikal.

Born 24.08.1942 in Meiringen BE/Switzerland, in wonderful Bernese Oberland. Basic education in Unterbach and Meiringen. Apprenticeship at the District administration in Meiringen.

Economics studies at Zürich University. Working with a Swiss Private Bank as an investment advisor for more than 20 years until my retirement in 2002. My partner Lilo (Liselotte) and I have lived together for more than 35 years.

I suffer from blepharospasm. Many years ago, I was afflicted with writer's cramp, which has vanished in the meantime.

*Erhard Mätzener  
Switzerland*



*Lilo and Erhard  
in Rome during  
D-DAYS*

## Living well with dystonia

### The Joyful Rage - a Record about Love and Gratitude

My first symptoms of cervical dystonia I noticed when I was 16 years old. My head was shaking a little bit. Not much but enough to frighten me. At 21 the symptoms had become worse and after seeing a neurologist I got my diagnosis: cervical dystonia with my head twisting to the left. My symptoms are tremors and spastic muscles in the neck. But my greatest battles have been the shame I have felt. I've been more or less ashamed of myself these last 15 years. In 2012 I decided to start study singing, and at the same time face the one thing I feared the most: being in front of people and let them see my head shaking. To me it feels like being naked in front of the people.

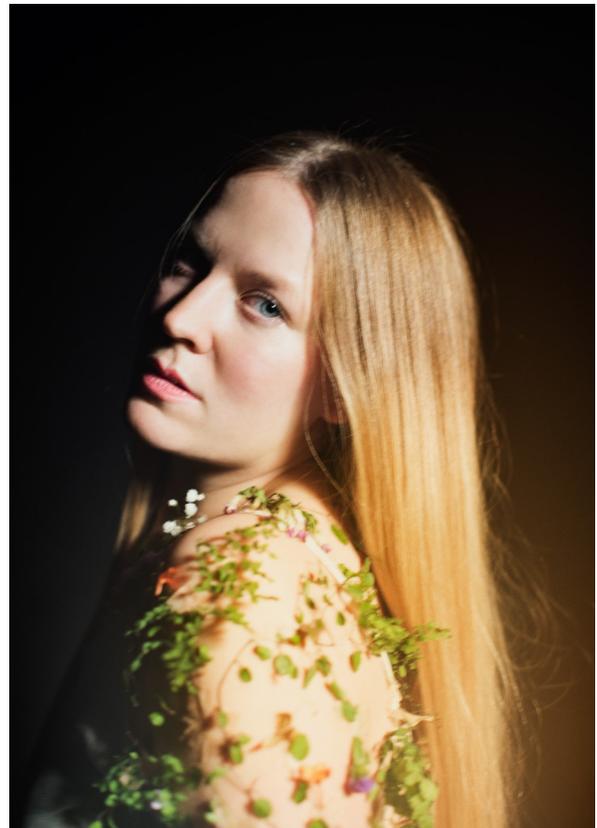
A little more than a year ago, at the age of 30, I decided to make my first CD. I had never made music before but here I had the chance to learn and make a recording. I study singing at the folk music department at the Central Ostrobothnian Conservatory in Western Finland, and they offer us a possibility to make a record as a form of degree work. So during winter and spring of 2015-2016 I made my first songs that ended up on my first CD.

The theme of the record is Love. This is maybe no surprise but my starting point is not the relationship love but the love for oneself and for life itself.

This originates from my own personal development in learning to love myself, learning to forgive and to let go, and from the huge gratitude and love for the world around us. I have been inspired by the Peace and Love movement of the 60's and I gave it my personal, modern approach. Musically I have been inspired by the 90's pop/rock music, when music arose from making music together as a band, as well as the medieval and Irish folk music.

The first song on the record is called \_dystonia\_ and it describes my feelings living with this disease. The musical and lyrical development on the record goes from dark to light ending in a song about just living your life in this moment and feeling free. These songs are some kind of mantras for the the difficult moments in life in order to find hope and light in each moment. The name of the record "The Joyful Rage", describes these contradictions of the dark and light, fear and faith. You can find my music on Spotify under my artist name Roses (right spelling is Rose's). You can find more information on [www.roses2.bandcamp.com](http://www.roses2.bandcamp.com) and on [www.weloveroses.com](http://www.weloveroses.com) Rose's is also on Facebook.

*Laura Suurla  
Kokkola, Finland*



*Laura Suurla  
Photographer: Kerttu Malinen*

## Events

### 2017

#### July

6 Dystonia Europe Board Meeting, Lund, Sweden

7 DE Summer Think Tank, Lund, Sweden

#### September

30 30<sup>th</sup> Anniversary of AMADYS, Lyon, France

### 2018

#### January

TBC Dystonia Europe Board Meeting and Think Tank, Lund, Sweden

#### March

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

#### April

11 Dystonia Europe Board Meeting, Brussels, Belgium

12-14 Dystonia Europe 25<sup>th</sup> Anniversary & D-DAYS 2018, Brussels, Belgium

#### June

16-19 4<sup>th</sup> Congress of the European Academy of Neurology, Lisbon, Portugal

#### September

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



[www.dystonia-europe.org](http://www.dystonia-europe.org)

**SAVE THE DATES!**

**D-DAYS 2018 &  
DYSTONIA EUROPE  
25TH ANNIVERSARY  
CONFERENCE**

**12 - 14 APRIL, 2018  
BRUSSELS, BELGIUM**

**VENUE AND PROGRAMME SOON  
ON OUR WEBSITE**



We welcome patient leaders, dystonia patients and their families, physiotherapists, nurses, junior doctors and everybody else with an interest in dystonia.

**Hope to see you in Brussels!**



## 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](mailto: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  
Prof Kailash Bhatia – London  
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 Dystonia.

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. **Sorin was elected to the DE board in 2015 and re-elected in 2017.**



**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. He is a Board Member of the Polish Dystonia Association and a Public Relation Expert. 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 and elected in 2016. 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 Ponsel,  
Board Member,  
France**

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



**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 served as its President for over 20 years. In 2011, she was elected to the board of Dystonia Europe, and Vice President from 2012. She has now served the maximum period on the board, but remain 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.



[www.dystonia-europe.org](http://www.dystonia-europe.org)