

Connecting people for dystonia

DYSTONIA EUROPE

NEWS
SUMMER 2019



**Alistair Newton, one of the Founders and the first President of
Dystonia Europe receives honour at Buckingham Palace**

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Connecting people for dystonia

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

Contacts & Secretariat

President

Merete Avery

E-mail: merete.avery@dystonia-europe.org

Executive Director

Monika Benson

E-mail: monika.benson@dystonia-europe.org

Registered Office

Dystonia Europe

37 Square de Meeus, 4th Floor,

B-1000 Brussels, Belgium

E-mail: sec@dystonia-europe.org

Meet us @

Website: <http://dystonia-europe.org>

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

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

To all our readers, we wish you a
wonderful summer.

From all of us in Dystonia Europe



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President's Message



Dear all,

In the summer of 2013 I became a board member of Dystonia Europe. The last 6 years seems to have passed by very fast and my term as a Dystonia Europe Board Member, the last 4 years as President is coming to an end.

It has been very inspiring and I am thankful to have met so many people that use their free time to work for other people with dystonia and the people who have yet to be diagnosed. These people are within our member organisations, who themselves live with the challenges of dystonia.

Also medical professionals who devote year after year, fighting for dystonia patients to be better treated, better known, faster diagnosis and hopefully in the end a cure.

We are very grateful for all the great work that is taking place around Europe for dystonia patients and their families. Together we are stronger and it is only by working together we can make a difference for dystonia.

Again a great thank you to those who founded European Federation of Dystonia in 1993, which later became Dystonia Europe. It has been a pleasure to continue the work together with the DE board and our member organisations, our sponsors, our advisors and our outstanding medical team.

Even though I will leave the Board, I will continue to be involved in DE work in a different role.

We in Dystonia Europe hope that you will find it interesting and encouraging to read about the different things in this newsletter

I wish you all a pleasant and relaxing summer.

*Merete Avery
President*



*Memories with
dystonia friends*



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Dystonia Europe Founding President Receives Honour at Buckingham Palace

Founding President of Dystonia Europe was honoured by Queen Elizabeth II for his 30 years' work for dystonia and other neurological patients across Europe.

Our founding President, Alistair Newton, has received the honour of becoming a Member of the Ancient Order of the British Empire (MBE) for services to dystonia and other neurology patients across Europe. The Award was presented in February 2019 at a ceremony in Buckingham Palace, London, by Prince William, Duke of Cambridge, on behalf of Her Majesty the Queen.

Alistair's work for dystonia patients started in 1987, just a few years after his own diagnosis with cervical dystonia, and he was Vice-Chair of **The Dystonia Society** for many years, until he retired from that board in 2000. During his time at The Dystonia Society, in 1993, he brought national dystonia patient groups in Europe together, to create **European Dystonia Federation (EDF)** and was President until 2001. He then was Executive Director until 2013, and remained a Board Member of **Dystonia Europe** until he retired in 2015.

Alistair was also a founding committee member and a long-serving officer of both **European Federation of Neurological Associations (EFNA)** -2000-2011, and **European Brain Council (EBC)** – 2003-2014.

In 2016, he received the EFNA Neurology Patient Advocate Award.

During his years representing dystonia and other neurological patients, he served on a number of committees of patient and scientific organisations, and organised, chaired or made presentations at many meetings across Europe.



Alistair Newton



Alistair Newton with his family

Latest News

When we asked Alistair for his thoughts on the most important aspects of patient advocacy organisations generally, he said that there are three important aspects to bring success:

Bringing people together to work in partnership at all levels of activity and possible influence.

Professionalising the way patient advocacy works, to encourage clinicians, scientists and other partners to have the confidence to work with us.

Making sure that all reasonable possibilities for action are explored before making decisions.

We also invited Alistair to tell us what the highlights have been during his many years as a patient advocate. He answered that, at the personal level, he had met so many fine people, all of whom are trying to improve life for so many others. He greatly values the many strong friendships he has made over these years.

In practical terms of successful or potentially successful activity, he listed:

Formation of European Dystonia Federation in 1993
and its re-formation as Dystonia Europe in 2011.

Formation of European Federation of Neurological Associations in 2000

Formation of European Brain Council in 2003

Foundation of the David Marsden Award - 2003

EFNA Stem Cell Conference for European Commission - Brussels 2005

International dystonia medical conference 250 clinicians and researchers – **Hamburg, 2008**

5th International Dystonia Symposium 550 clinicians and researchers – **Barcelona, 2011**

European Dystonia Research Network - stimulating international dystonia research and funding training and experience for young dystonia specialists – **2011-2016**



*From left:
Executive Director
Dystonia Europe,
Monika Benson,
Alistair Newton and
Prof. Tom Warner*

In Memory of Paolo Corsi

Past President of the Associazione per la Ricerca sulla Dystonia in Italy

On April 25 Paolo Corsi passed away in Milan at the age of 78. He had been involved in the Italian Dystonia Association: A.R.D. since its beginning, first as a Board member, and between 2008 and 2014 he was the President.

He had laryngeal dystonia, which also affected his job as an engineer. He developed a strong cooperation with A.R.D. and after his retirement he devoted himself to work in the interest of dystonia patients. Thanks to him our Association expanded and got more visibility, as he established and strengthened contacts with many neurologists and hospitals across Italy. He organised many A.R.D. national meetings and in 2012 he decided to introduce the Award "Best Study about dystonia by young doctors" in order to encourage research on the disorder.

He took part in some Dystonia Europe meetings and promoted the translation into Italian of the MyDystonia APP.

He was a man who was eager to help, always loyal, dutiful and determined.

We are really grateful for all that he contributed for the success of A.R.D.

Thank you, Paolo <3

*Maria Carla Tarocchi
Vice President, ARD*

A Fine Patient Advocate

We were very sorry to learn the news of the passing of patient advocate, our colleague and dear friend Paolo Corsi.

Paolo was a very fine man and it was always a pleasure to meet him at the Dystonia Europe international meetings.

The last time we worked together was to plan for the D-DAYS 2017 in Rome. In spite of not feeling very well Paolo travelled to Rome to take part in the planning of the meetings. Unfortunately he was not well enough to attend.

Many, many thanks for all that you did for dystonia patients and their families in Italy.

*Monika Benson & Dystonia Europe Board
Dystonia Europe*



Paolo with Dystonia Europe delegates at the D-DAYS 2012 in Bol, Croatia.



Together with Paolo Corsi in Rome planning for D-DAYS 2017

4th International Congress on Treatment of Dystonia:

For All who Care for People with Dystonia

Under this motto almost 400 participants from 4 continents met from May 8th-11th in Hannover, Germany. Together with a faculty of more than 70 world-leading experts from the fields of neurology, neurosurgery, neuropaediatrics, neurogenetics, basic sciences and allied health sciences this was, again, the leading international dystonia congress.

The congress emphasised on novel treatments for all forms of dystonia, including botulinum toxin therapy, deep brain stimulation, various behavioural methods and new emerging strategies to improve or even prevent the development of dystonia. The scientific program was intense and lasted 3.5 days. Nine hands-on-workshops and focused lunch time satellite symposia supplemented the conference and contributed to the vivid exchange of ideas. Young scientists had the opportunity to present their work in the poster session and as free oral communications. Several patient organisations displayed their activities. The congress satellite symposium on dystonia in sports was well perceived. In the industry exhibition the latest technology in botulinum toxin drugs and deep brain stimulation could be discussed directly with their manufacturers.



Prof Dirk Dressler

The highlight of the congress was the Keynote Lecture by Alan B Scott and Eric A Johnson on the 'Invention of the Botulinum Toxin Therapy'. It was the first time that the 'fathers of botulinum toxin therapy' appeared on one stage and shared their personal recollections of the early days of botulinum toxin therapy.

A video recording of this unique event will be soon made available through IAB - Interdisciplinary Working Group for Movement Disorders (www.iabnetz.de).



*From right:
Steven Frucht,
Eckart Altenmueller,
Monika Benson,
Merete Avery,
Joachim K. Krauss,
Dirk Dressler*

Research

In a Special Lecture Professor Dirk Dressler gave an insight into 'Translational Botulinum Toxin Research'. This lecture was marking the 10th anniversary of the founding of Hannover Medical School's Movement Disorders Section by Professor Dressler.

'This congress is now firmly established as the central international platform and meeting point for all who care for people with dystonia' said Professor Dressler on behalf of his co-organisers Professor Altenmüller and Professor Krauss. 'We are very pleased to see that there is a strong and growing interest in our congress, despite a more and more difficult environment.'

The field of dystonia needs to be developed further. We need to attract young people and we need new topics so that the field will be fit for the future. I personally see a lot of potential in Asia, both, in our field in general and for our congress' said Professor Dressler who is currently setting up a botulinum toxin research centre in Shanghai, China.

Last, but not least, Hannover's famous springtime and the congress's social events, including the congress dinner in the private moated Castle Hülsede, generated an atmosphere of openness and exchange contributing to the success of the congress.



Peter Roggenkaemper, Dirk Dressler, Eric A. Jonson, Alan B. Scott, Eckart Altenmueller, Joachim K. Krauss

David Marsden Award 2019 Update

The 9th edition of the David Marsden Award will be presented on 6 July at the D-DAYS in London. We have received several applications and the Selection Committee is now reviewing the submissions. We look forward to meet the winner in London and to present him/her in the next newsletter.

Dystonia Europe established the David Marsden Award in 2003, to acknowledge Prof Marsden's work on the dystonias, and to honour the immense part he played in improving the lives of so many people who live with the condition.

The aim of the award is to stimulate interest and developing knowledge of dystonia through publications of aetiology, pathogenesis, diagnosis in dystonia or on the psychosocial effects.

The Award is supported by a grant from Ipsen to Dystonia Europe. Ipsen has no control over the award, including evaluation of papers and selection of winner.

The last award presented in 2017 was given to Dr. Niccolò Mencacci for his paper:

["A Missense Mutation in KCTD17 Causes Autosomal Dominant Myoclonus-Dystonia"](#). The research was performed at the Institute of Neurology, Queens Square in London. Currently Dr. Mencacci is a Research Assistant Professor at the Department of Neurology, the Feinberg School of Medicine, Northwestern University in Chicago.

For more information on the Award and the past winners check out: <https://davidmarsdenaward.org>



Dr. Niccolò Mencacci receives the DMA in 2017, Rome.

Dystonia Rare or not?

Take a survey for change!

www.surveys.dystonia-europe.org

Survey by Prof Maja Relja MD, PhD associated with Zagreb University, Croatia

**DYSTONIA
EUROPE**

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How to search and apply for clinical trials through Dystonia Europe website?

There are over 70 000 ongoing clinical trials taking place in various countries worldwide. This means that innovative treatments are being investigated in order to prove they are better than the already existing ones. Researchers are actively exploring therapies with fewer side effects or such that will have a bigger potential to influence a certain condition in a positive way.

Now people have the option to search, understand and find the most suitable clinical trial for them online and thus access the drug, device or procedure years before it is publicly available. Thanks to [FindMeCure](#) people now can have an easier and faster access to all these treatments in development that otherwise would only be available in 10 to 15 years.

Together with Dystonia Europe patients living with dystonia can also use this searchable database through a specially developed [widget](#) on their own website. By only typing their condition, age and gender people can see what clinical trials are being conducted near them, read all the important information in a simple language and apply for participation (for free). Then, within a few days, they are connected with the doctor in charge of the trial who can answer all their questions and can determine whether they would be eligible to take part in the study. The unique algorithm allows assessing trials on their safety and credibility and suggests trials relevant to patients' needs and personal criteria.

Caregivers could also use the widget if they would like to search for a trial for their loved ones, even if they live miles away. They simply need to enter the location of interest, make sure to read the eligibility criteria and request more information.

A simple search on the platform shows that there are currently [74 open research studies](#) for Dystonia on a global level (including Europe). The number of these studies is growing which gives hope to all the patients out there looking for a better treatment for this condition. By further playing with the platform

and using the filters, you can see that 33 out of them investigate an actual treatment while the rest are observational studies, diagnostics or studies aiming to better understand the brain activity and the condition itself.

Even if you are not sure how to proceed with a certain trial, you always have the option to consult with your doctor and forward them the trial details only by clicking on a button. The other option is to ask your questions on the chat with the FindMeCure team who would be happy to assist you.

In many cases, available treatments are not your only option and you always have the right to learn about the other possibilities that medical science is giving you. Make sure you are fully informed so you can take the right decision about your health.

Daniel Shikova
General Manager
FindMeCure Foundation

The screenshot shows a web interface for finding clinical trials. At the top, an orange banner reads "Help advance research" and "Find and join a clinical trial near you". Below this, there are three input fields: "What's your condition?" with a heart icon and the text "Dystonia", "Age" with a person icon and the text "Age", and "Gender" with three buttons labeled "male", "female", and "any". At the bottom of the form is a large orange button labeled "SEARCH".

Powered by  FindMeCure

The following articles, page 11–14, 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.

Deep Brain Stimulation and Dystonia: The Vercise™ Dystonia Registry

Interview with Prof. Joachim Krauss, Director of the Department of Neurosurgery at the Medizinische Hochschule Hannover, Germany

Prof. Krauss, a pioneer in surgical dystonia treatment, has been involved in deep brain stimulation (DBS) therapy since its development in the early 1990s. Under his stewardship as the Director of the Department of Neurosurgery at the Medizinische Hochschule Hannover (MHH) in Germany for the past 15 years, the centre has become one of the leading DBS centres for dystonia-treatment and research in the world. Together with Prof. Alberto Albanese (Istituto Clinico Humanitas, Rozzano, Italy) he is currently the coordinating investigator for an ongoing registry to better understand the treatment of dystonia with DBS. We caught up with him to learn more about this registry.

What is your background in dystonia and DBS?

Actually, my interest to help people that are suffering from dystonia was triggered during my residency in the 1980s, many years before I started performing DBS. I got involved in deep brain stimulation in 1995 in Houston, Texas, where Rick Simpson and I introduced the therapy together for people with essential tremor and Parkinson's disease. Later, when I started working in Switzerland at the Inselspital (university hospital) in Bern, I introduced DBS for treatment of cervical dystonia. We demonstrated its remarkable therapeutic benefits for dystonia and published our first results in The Lancet in 1999.

Can you explain how DBS works?

DBS therapy is a very complex topic because it triggers a variety of effects. In dystonia, the mechanism of DBS is even more difficult than we initially thought. The clinical effect of DBS stimulation is delayed, especially for the tonic elements of dystonia, which are secondary to sustained muscle contractions. At the same time, when the therapy is maintained, other phenomena are observed like alterations in inhibition and long-term neuroplasticity, which is the ability of neuronal networks to change their functional capacity. We now understand that the delayed effect with DBS is not only secondary to the effect of the chronic stimulation of local neurons and nerve fibres but also to widespread changes in the basal ganglia network and the cortex. We can even record activity from the basal ganglia and demonstrate how the interaction within the network via oscillations in different frequency bands changes. As I said, it is a complex topic.

Is there a need for more research?

Yes, there is. Over the last decades, I have been part of many major studies on DBS and dystonia. Moreover, it has become one of my major points of interest for further research. When a new therapy is first introduced, very few believe the results immediately. However gradually, the DBS-treatment for people with dystonia is getting more widely accepted and about 10 to 15 years after it was introduced, new randomised studies confirmed the initial results.

Most of these studies however, have the limitation that they are only conducted for one or two years with no specific focus on long-term follow-up. There is a clear need for more data as we still do not know enough about what will happen after that initial study period.

In times where research is becoming more expensive and more demanding, registries provide a new window of opportunity; they allow clinicians to monitor patients for a longer time in a formal setting. When Boston Scientific proposed to collaborate on a long-term observational registry including endpoints specifically for people with dystonia, I was very pleased. With professional support, we are able to obtain this important data.

How does the Vercise™ Registry for Dystonia work?

Back in 2014, Prof. Alberto Albanese and I discussed how we could design such a registry. We agreed we needed to follow at least 200 patients from various hospitals across Europe for 3 years post implantation. In addition, there would be a need to have clear measurable endpoints in place. For this registry, we use a variety of scales to measure these endpoints, such as:

- Burke-Fahn-Marsden Dystonia Rating Scale (BFMDRS - for generalized dystonia)
- The Toronto Western Spasmodic Torticollis Rating Scale (TWSTRS - for cervical dystonia)
- The Clinical Global Impression of Change Scale
- Measurements on cognitive function
- Measurements on quality of life (QoL)

What makes this registry so important?

We really need this registry as it provides a structured approach to follow-up patients long-term from many medical centres across Europe. In other words, the Vercise™ DBS Dystonia Registry provides us with what is called real-world data, meaning that patients are being treated according to standard of care – personally, I don't like the term "real-world data", because it sounds as if clinical studies are not realistic – suggesting that data from these patients under special and controlled study conditions are less valuable.

With a solid basis for long-term observation and, very important, structured data of what happens to DBS implanted patients in real life, we can start mining the data to learn more on what worked well for different types of dystonia and what we can improve for patients, e.g. in terms of programming settings. In addition, we can discover more about the performance of the used Vercise™ DBS system, information which can be used for future developments.

How are patients chosen to be included in the registry?

Patients with any type of dystonia including idiopathic, inherited and acquired dystonia from the age of 7 years, who are scheduled to be implanted with a Vercise™ DBS system can take part in this registry. After the patient agrees to participate, they will be followed for 3 years to collect the data that will allow us to do our analysis.

How is the registry progressing so far?

We currently enrolled well over 60 patients in this registry, which is positive. However, we will still include up to 200 more patients. The registry will certainly help us to get new insights, which can be used to improve the treatment of people suffering from dystonia. We recently presented preliminary results of the data already available at the 4th International Congress on Treatment of Dystonia in Hannover.

Can you tell us a bit more about these results and the Hannover conference?

The results were made available in a poster session during the conference. The preliminary results suggest overall improvement at 6 months based on the general dystonia scale (BFMDRS) and the cervical scale (TWSTRS). Over 80% of patients and clinicians report clinical improvement, compared to the status before the device was implanted, with an acceptable safety profile. As more patient data becomes available the data will be analysed in more detail.

The International Congress on Treatment of Dystonia takes place in Hannover every 3 years. Together with Prof. Eckart Altenmüller and Prof. Dirk Dressler we want to bring “all who take care of people with

dystonia” together to share the newest developments and learn from each other. The leading experts, patient organisations, treatment industry, physicians, nurses and researchers from around the world come together to improve our knowledge on treatment of dystonia, as continued research remains a priority for this complex movement disorder.



**Medizinische Hochschule
Hannover**

*Prof. Joachim Krauss,
Director of the Department of Neurosurgery
at the Medizinische
Hochschule Hannover,
Germany*



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



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 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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Winter Think Tank 2019

Dystonia Europe Winter Think Tank 2019 was held in Lund, Sweden last February.

Members of the board and representatives of our Platinum sponsors: Merz, Ipsen, Medtronic and Boston Scientific took part! We thank everybody for their support, fruitful discussions and inspiring brainstorming sessions!

Together we work to raise awareness of dystonia, share information, support education and research & to improve the lives of people living with dystonia!



The participants of the Winter Think Tank

Toxins Conference in Copenhagen

The International Neurotoxin Association (INA), arranged the TOXINS 2019: Basic Science and Clinical Aspects of Botulinum and Other Neurotoxins, 16-19 January, 2019, in Copenhagen, Denmark. This was the 4th TOXIN Conference.

Dystonia Europe had a stand and participated at the conference with information of Dystonia Europe and its members. We also inform of ongoing projects, like the MyDystonia APP, David Marsden Award, The Survey and many more.

Some of the highlights of the conference were workshops on ultrasound guided treatment of botulinumtoxin. The overall goal of the workshops were to help attendees to understand the respective sonographic properties of bone, muscle, nerve, tendon,

and other soft tissues, to identify key muscles involved in upper and lower limb spasticity, dystonia, muscles involved in movement disorders of the head and neck, as well as salivary glands contributing to sialorrhea, based on pattern recognition using ultrasound.

The technical skills acquired during the workshop are designed to assist injectors with performing ultrasound-guided chemodenervation procedures in clinical practice.

You can read more about INA and the TOXINs Conference at www.neurotoxins.org.



Dystonia Europe at TOXINS 2019,

Left: President Merete Avery at the Dystonia Europe Stand



Dystonia Today – special session at the EAN Congress 2019!

Coinciding with the European Academy of Neurology's annual congress, Dystonia Europe – together with the European Federation of Neurological Associations [EFNA] – will organise a special session entitled: Dystonia Today.

When: Saturday, June 29th, 2019 from 9.00 am – 10.30 am.

Where: Arena Thon Hotel, Room Romerike – Nesgata 1, 2004 Lillestrøm, Norway

Recommended Audience: Health Professionals, Students/Residents/Trainees, Non-physician Health Professionals, Patients, industry representatives

Speakers and presentations will include:

Maja Relja: *Dystonia: under-diagnosed condition*

Kailash P.Bhatia: *Clinical evaluation of dystonia*

Marie Vidailhet: *Therapy of dystonia*

What will I learn?

Dystonia is a neurological disorder in which sustained and/or repetitive muscle contractions result in twisting and repetitive movements and/or abnormal posture. Dystonic movements are typically patterned, twisting and may be tremulous and painful.

Dystonia is difficult to recognize due to its large phenomenological complexity. Thus, the use of dystonia specialist is essential for better recognition and management of dystonia. Although an under-diagnosed condition, dystonia syndromes (DS) represent the third most common disorder in movement disorder centers.

We have shown lack of specific training in dystonia by general neurologist (GNs) general practitioners (GP) as well as other allied health professionals in the study performed by European network for the study of DS (A Valadas et al. J Eur Neurol 2015;0:1).

Although a treatable condition DS has a great impact on patients social life, functional and working capacity and Quality of Life (QoL). Recognizing dystonia is important for patient treatment and QoL.

Come along to hear how we can better recognize, evaluate and treat Dystonia Today!

With an opportunity to ask questions of the experts in this field.

How do I sign up?

If you are interested in attending this event, please sign-up by completing the online form available here: <https://goo.gl/AAE5T4>

Places are limited so please register **before June 13th, 2019**.

Note: You do not need to be registered for the Congress to attend this session as special badges will be provided to external attendees

Other information

All presentations will be delivered in English.

Tea/coffee and snacks will be served during registration from 8.30am outside the meeting room.



Other News



Prof. Maja Relja



Prof. Kailash P. Bhatia



Prof. Marie Vidailhet

DYSTONIA TODAY

DYSTONIA SESSION AT THE EAN CONGRESS 2019

VENUE

Arena Thon Hotel, Room "Romerike"
Nesgata 1, 2004 Lillestrøm, Norway

DATE

29th June 2019
9.00 - 10.30

DYSTONIA: UNDER-DIAGNOSED CONDITION

Prof. Maja Relja (Dept. of Neurology University of Zagreb)

CLINICAL EVALUATION OF DYSTONIA

Prof. Kailash P Bhatia (Dept. of Movement Neuroscience, UCL, London)

THERAPY OF DYSTONIA

Prof. Marie Vidailhet (Dept. of Neurology, Salpêtrière Hospital, Paris)



REGISTER HERE

Register at: <https://goo.gl/AAE5T4> or scan the QR code



PART OF THE 5TH CONGRESS OF THE EUROPEAN ACADEMY OF NEUROLOGY IN COLLABORATION WITH



www.dystonia-europe.org

EU Activities

Capacity building on Empowering Leadership and Positive Organisational Governance EPF (European Patient Forum) First Meeting 9-10 March

EPF have started the second EPF Capacity Building Programme: Enabling Leadership and Positive Governance

This is an ongoing training for about 6 months. Part of the training is “face to face”, the first meeting this summer in Brussels and the second meeting in Sofia, Bulgaria.

Between these two meetings there are homework and coach skype meetings every month.

The first meeting in Brussels was very different from any other organizational training I have participated in.

Instead of just listening and asking questions we were challenged in a different way. Through different exercises the goal was to learn to listen in different ways, and to see things from a different perspective.

I am only half way through this training, however I feel it has already given me some new interesting ideas and points of view.

Merete Avery



EPF have been limited to organisations in EU countries, but from 2019 any organisation within Europe may apply for membership regardless of if the country the patient organisation is registered in, is a member of EU or not, as long as it is in Europe.

Brain Awareness by Sharing #brainlifegoals

Brain Awareness Week (March 11 – 17) is the global campaign to increase public awareness of the progress and benefits of brain research. To mark the occasion, EFNA promoted the new **#BrainLifeGoals** campaign, and encouraged patient advocates to share their goals alongside the hashtag.



Sharing #LifeGoals has become a popular trend in social media. #LifeGoals are the often frivolous wishes people have – for example to own a designer handbag, meet a particular pop star or drive a Maserati. This campaign puts a new spin on the trend by instead sharing **#BrainLifeGoals**.

The campaign will improve public understanding of neurological conditions and reduce associated prejudice/stigma.

Brain Awareness Week is an ideal time to turn up the volume on the patient voice and ensure that decision-makers hear about the issues of most importance to us.

EFNA also shared a number of blog posts created by attendees of November's Young Advocates' Workshop. [Click here to read their stories.](#)

Brain Awareness Week 2019 may be over but the **#BrainLifeGoals** campaign continues! You can find out more about the campaign, and ways to get involved, by visiting the campaign page here: <https://www.efna.net/brainlifegoals/>. You can also keep up to date with the latest activities by following the **#BrainLifeGoals** hashtag on social media.

Recently EFNA announced that In support of this campaign, EFNA are offering grants, of €2,500 each, to 5 projects which best reflect the theme of the campaign, raise awareness and improve understanding of neurological disorders. Grants will be shared with registered non-profit EU/EEA-based organisations only. Therefore individual applicants should work on their project in association with an appropriately registered patient organisation at either National or European level.

Deadline for application is June 14th.

Further information and application guidelines are available at: www.efna.net/BLGgrants



DE Board Member Adam Kalinowski sharing his brain life goal

You can find out more about the campaign itself at www.efna.net/brainlifegoals and by following the



The Book of Evidence

Last April the **Brain, Mind and Pain (BMP)** initiative launched its updated **Book of Evidence** for the 2019-2024 EU mandate.

This Book of Evidence (BoE) sets a strategic vision on policy action to deliver better care for people with neurological and chronic pain disorders in the EU. It will be used as the core policy document of the MEP Interest Group on Brain, Mind & Pain – which will continue after the upcoming EU elections for the next 5 year mandate.

The Interest Group is coordinated by **European Federation of Neurological Associations (EFNA)** and **Pain Alliance Europe (PAE)**.

Donna Walsh, EFNA Executive Director, says, 'Following the successes of our MEP Interest Group over the past five years, we felt strongly that we needed to continue our work. However, for the coming years, we want to pursue more concrete policy recommendations within a narrower scope of action – reflecting the current policy opportunities at EU level but, most importantly, more centred on the priorities of the patient groups we represent.'



Therefore, this updated BoE outlines clear focus areas and proposes recommendations for policy actions, which, if implemented, would significantly improve quality of life for people with neurological and chronic pain disorders, as well as their families and carers.

The development of the document was led by EFNA and PAE and involved a wide range of key EU and national stakeholders from the patient, policy, industry and scientific communities.

This collaborative development process is reflected in wide ranging endorsements and support from organisations such as the **European Commission, European Brain Council, European Patients' Forum, European Academy of Neurology, European Pain Federation** and **European Alliance for Patient Access**.

Key areas for action

The BoE outlines the thematic areas of focus for the MEP Interest Group on Brain, Mind and Pain for the 2019-2024 mandate. These are:

- **Eradicate stigma, isolation and discrimination:** A lack of public awareness of BMP disorders feeds their stigma and the associated isolation and discrimination suffered by BMP patients, carers, and their families
- **Ensure equitable access to treatment, services, and support:** Access to treatment, services, and support is a topic of concern for patients in Europe due to high failure rates, delays in market access, relatively expensive treatments, and inequality in access across, but also within, EU Member States
- **Promote patient empowerment for increased involvement and engagement:** Patient empowerment is a means for more effective BMP patient engagement and meaningful involvement in the research, medical and policy conversations which affect them

These areas have been chosen in order to support the MEP Interest Group in leveraging current policy opportunities on the agenda whilst ensuring continuity with the past activities and successes of the BMP initiative.



EFNA President Joke Jaarsma

Driving policy change

The 2019-2024 mandate brings with it an active policy environment at EU level, with numerous opportunities for advocacy on behalf of people with brain, mind and pain disorders.

Ensuring that the Interest Group is capable of impacting policy discussions throughout the 2019-2024 mandate will be key in making progress in the three key thematic areas identified.

Additionally, with the global priority turning more and more towards NCDs (non-communicable disease), we need to ensure that brain, mind and pain disorders are part of global health policy agenda.

To this end, each chapter of the BoE contains a section on the policy opportunities and subsequent actions that can be leveraged to further progress in each thematic area and at EU and global level.

Looking ahead

It is now the responsibility of the Interest Group and the wider BMP initiative to leverage the policy opportunities and pursue the policy actions identified in this text throughout the 2019-2024 mandate.

EFNA President, Joke Jaarsma says: 'Progress is contingent on coordinated policy advocacy at EU and global level, taken forward by the BMP initiative as a whole and its partners.

'Using the BoE as a springboard for action, let's drive policy change and make a real difference to the daily lives of people living with BMP disorders across Europe!' she continued.

For any further information on the BoE or the activities of the BMP initiative – including its MEP Interest Group – please do not hesitate to contact EFNA at: advocacy@efna.net.



THE 2019-2020 EDITION OF THE BRAIN, MIND, AND PAIN GRANT IS LOOKING FOR PROJECTS WHICH TACKLE THE REDUCTION OF STIGMA

Pain Alliance Europe is happy to announce the **second edition of the Brain, Mind, and Pain Patient-Centred Innovation Grant** with the support of Grünenthal and [partner organisations](#).

The core of PAE's mission is to be the voice of patients, including chronic pain patients and patients living with a neurological condition. The new theme: *"Stop Stigma! Reducing stigma for the brain, mind, and pain patients"* expresses the need for transformation in the way pain is viewed and treated.

Pain is invisible. People who are lucky enough not to experience it on a regular basis, have no tangible reference, as usually for them pain comes and goes, so they have difficulties in relating to what chronic pain patients experience daily. This lack of understanding, when social connections are at the core of a meaningful life, make the situation difficult for patients. They have a right to be listened to and understood, and still they seem to be far from being able to exercise this right.

The fight against stigma, the BMP Grant theme for 2019-2020, is a step towards increasing awareness

and knowledge about these limits. The BMP Grant will reward good ideas on ways to end stigma. The BMP Grant team will be looking for innovative ideas designing new solutions to meet the need for a more understanding society. They expect the grant submissions to be based on knowledge, tolerance and empathy towards brain, mind and pain patients at all possible levels of interaction.

The ultimate aim of the initiators of this edition of the BMP Grant remains what was announced at its first edition's launch: improving the life of patients living with chronic pain or neurological conditions.

The 2019-2020 **Call for Proposals** will be available online for a period of 6 months starting **1st July 2019**. Visit the [website of BMP Grant](#) regularly for updates or join their [News Flash](#) mailing list to stay abreast of the next steps of this edition.



Boston Scientific Foundation Grant Opportunities

Last year Boston Scientific, innovative medical solutions provider, launched its Boston Scientific Foundation for the EMEA region (Europe, Middle East and Africa) to contribute to society by supporting people in the communities.

The mission of the Foundation is to support well-being through innovative solutions. Its strategic focus is to address issues of public interest in disease prevention or management, using digital or innovative solutions by:

- improving the health of individuals and communities with unmet needs.
- facilitating access to prevention and awareness programs.
- supporting research programs aimed at improving prevention or disease management.
- using innovative solutions such as apps, e-platforms, social media, optimizing impact on well-being.

Should you be willing to know more visit <http://www.bostonscientific.com/en-EU/about-us/corporate>



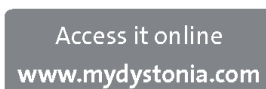


An electronic diary to improve your treatment outcome and your quality of life.

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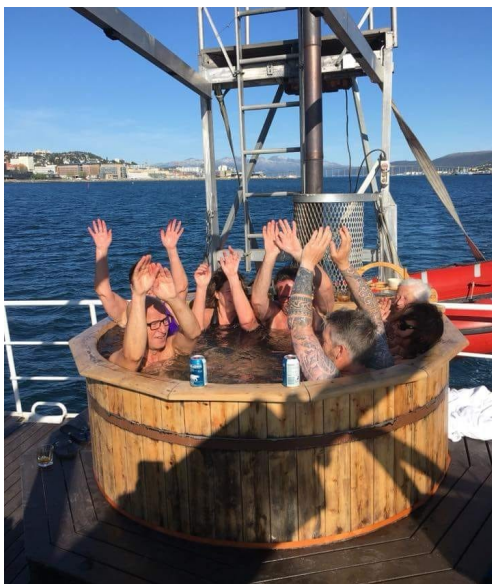
Jump for Dystonia

Haven't jumped for dystonia yet? Do as the people here and jump to raise dystonia awareness. Send your photo to us at sec@dystonia-europe.org or post on our facebook page and use the hashtag #jumpfordystonia

We cannot wait to see your jumps!



*In Hannover,
at the 4th International
Congress on Treatment of
Dystonia*



*Ambassadors for MyDystonia in Dublin at
the MyDystonia Ambassadors meeting*



www.dystonia-

Dystogram

Dystogram fun at the Treatment Congress in Hannover.

An activity to raise awareness of dystonia and its treatments. We thank everybody who took part in Hannover!



www.dystonia-europe.org

Meet MyDystonia Ambassador Gill from the UK

Can you introduce yourself briefly?

My name is Gill Ainsley and I am a 58 year old mother of two sons and grandmother of two granddaughters. I live in the north east of England with my husband of almost 40 years, John.

Tell me about your work experience and how it relates to your work as MyDystonia ambassador.

My profession is engineering and I worked for many years as an Electromagnetic Compatibility Test Engineer on military aircraft. These days I am retired from paid work but do voluntary work for a dystonia charity close to my home called Action for Dystonia, Diagnosis, Education and Research (A.D.D.E.R.). As an engineer I learned to question everything and accept nothing without evidence, I also learned how to work efficiently to time scales and tight budgets. Another skill learned was that of listening carefully to customer requirements and questions. Some of these skills are useful as Ambassador for the MyDystonia app particularly working to time scales and listening carefully. I find that answering users' questions as thoroughly and quickly as possible keeps the user engaged and encourages them to keep using the app.

Why do you like helping others?

When I was first diagnosed with dystonia approximately 14 years ago, I felt lost and alone. I couldn't find much information about dystonia and didn't know which web sites and/or organisations I could trust. By being an ambassador for the MyDystonia app I feel I am helping to provide a reliable resource for patients to use to communicate with their consultant. My volunteer work with A.D.D.E.R. enables me to provide reliable information and resources to dystonia patients and particularly to those newly diagnosed.

What are the benefits for yourself from working as an MyDystonia ambassador?

Working as an app ambassador I have met other dystonia patients who are trying their best to make a difference to all dystonia patients. Not only have I

made some lovely new friends but have been inspired by the work ethics of the other ambassadors. We also exchange views and advice which we can take back to our 'individual' charities to the benefit of our charities' members.

How do you like spend your free time?

Between doing my voluntary work, caring for my elderly mother and aunt, and helping to look after our two granddaughters I don't have a great deal of spare time. I do enjoy socialising with family and friends and I also enjoy doing several handicrafts such as knitting, sewing, making greetings cards and silversmithing where I make silver jewellery. All my handicraft hobbies help to keep my dystonia under control too!

What keeps you motivated on the tough days?

The times when my botulinum toxin injections have either worn off or not worked too well are difficult. The pain can be hard to cope with and the constant head shaking and jaw clenching can be embarrassing. I do have a wonderful support network in my family and friends but particularly my husband. He is the one to remind me that sometimes I need to rest and that it is ok to have a bad day and to treat each day as a new start.

What makes you angry?

Injustice makes me angry as does intolerance. In relation to my dystonia what angers me is people who show me pity. I do not want or need pity, just understanding and acceptance of the way I am.

*Gill Ainsley
United Kingdom*



Italy

Annual Meeting of the OF THE ASSOCIAZIONE PER LA RICERCA SULLA DISTONIA

On March 23rd, 2019 A.R.D. held its annual meeting in Hotel Adriatico in Florence; our last meeting in this charming town had been in 2007 and the first one was 20 years ago, in 1999.

The title for this year was ***“Looking to the future: research and experience in comparison”*** as we wanted to focus both on new studies and on acquired experience.

Since 2012 A.R.D. has awarded 2 prizes ***“Best study about dystonia by young doctors”*** (each of 1000 €) on the occasion of the annual congress of the Italian Neurological Society (SIN); in 2018,

2 more awards (each of 2000 €) were introduced on the occasion of the annual congress of the Movement Disorders Society (LIMPE-DISMOV), with the same title.

The 4 young doctors awarded in 2018 have been invited to our meeting to present their work but we also asked them to tell us their story: why did they choose to be involved in dystonia? Which disease feature do they face every day?

We think that research and young doctors are very important for our future, we must stimulate them to develop knowledge and interest in this often neglected disease.

Our meeting started with **Dr. Francesca Morgante**, a neurologist who has worked for many years on dystonia and is based in St. George's Hospital in London, UK. Dr. Morgante gave an update on novel research studies focusing on the disease. Specifically, she reported on novel research for the following topics: genetic causes, such as the KMT2B mutation; brain mechanisms determining different types of dystonias; non motor symptoms, and in particular pain and psychiatric symptoms; combined treatment of dystonia with physiotherapy and botulinum toxin; treatment with Deep Brain Stimulation. She also mentioned some studies on animal models, which have investigated the contribution of dopamine to the disease. The discussion was very interactive with many questions on current pharmacological and surgical treatments and reports of personal experiences on living with the disease. Some questions inquired about therapeutic use of cannabis for dystonia and Dr Morgante replied that,

so far, there are no scientific data available supporting the use of this medication.

Research involves many groups around the world and many enthusiastic young researchers, who are committed to understand its causes and mechanism, in order to define a personalized approach for people living with dystonia.

After Dr. Morgante, the 4 awarded doctors have presented their work.

Dr Enrico Saibene is a young physiotherapist (aged 23) and is working in Hospital Santa Maria Nascente in Milan. He approached dystonia by chance, as he was given a graduate thesis about this disorder, which is little known in physiotherapy too. As the topic was challenging and new, he decided to continue and now he is involved in the therapeutical treatment described in his work:

“Effectiveness of a combined treatment of cervical dystonia through a new rehabilitation approach with botulinum toxin”. He was awarded during the LIMPE-DISMOV Congress last May 2018.

This method is named SPRInt (Sensorimotor Perceptive Rehabilitation Integrated approach) and combines botulinum toxin therapy with biofeedback and spatial rehabilitation techniques. After the injection, patients begin the rehabilitation program 3 times a week, for 18 weeks.

The SPRInt approach seems to be a valid instrument for the cervical dystonia treatment, improving on disability, severity and cervical deviation.

Dr. Paola Imbriani is specialized in Neurology and is now at her second year of PhD in Neurosciences at Tor Vergata University in Rome. She began her career with clinical research about Parkinson, then she passed to basic research in laboratory: she carries out studies on animal models in order to find out the pathology mechanisms, investigating about neuronal cells.

Her work ***“Early structural and functional plasticity alterations in a susceptibility period in DYT1 dystonia striatum”*** received the ARD award during the SIN Congress in Rome last October 2018. It is work rather difficult for laypersons, as it deals with very specialist terms and concepts.

Around Europe and Beyond

Studies were carried out in young and adult mice, checking synaptic plasticity at a defined post natal time window in a DYT1 mouse model, in order to evaluate whether plasticity abnormalities occur early in life or later as adaptive changes.

Dr. Sabino D'Agostino is a neurologist aged 29 and works in Azienda Ospedaliera Monserrato in Cagliari. He began his speech remembering that in his books of neurology only a short paragraph concerned dystonia, and when at the beginning of his career he was asked to take care of blepharospasm he barely knew what kind of disease it was. But later he got interested and now he is following many patients with dystonic problems. His work ***"Sensory trick in task specific upper limb dystonia"*** was prized in the SIN Congress in Rome. The sensory trick is a specific feature of dystonia and is very common mainly in cervical dystonia and blepharospasm. In arm dystonia it is not so common, having a frequency around 20%. The results of his study are that performing the trick manoeuvre improves handwriting in 38% of patients, therefore it may be potentially more frequent than usually observed. Moreover, when sensory trick was effective, it was helpful when distinguishing dystonic and non dystonic tremor.

Dr. Elisa Andrenelli, after getting a PhD in Neurodegenerative diseases has specialized in Neurorehabilitation; she worked for 18 months in Messina and then in London with Dr. Morgante. Now she works in the Hospital of Ancona. She received the ARD award last May 2018 during the LIMPE-DISMOV Congress with her work ***"Kinesiotaping improves pain and modulates somatosensory processing in Cervical Dystonia"*** Kinesiotaping is a rehabilitative taping technique invented in 1993 by a Japanese chiropractor and consists in placing a tape on a target muscle, in order to reduce abnormal tension, providing support and stability to muscles. In her study, tapings were applied for 5 days to patients with idiopathic cervical dystonia and pain, 3 months after their botulinum toxin injections, demonstrating that KT can reduce pain and disability, especially with tremor, through enhancing the effect of botulinum toxin in the interval between consecutive injections.

The last speaker of the morning was **Dr. Silvia Brogelli**, an oculist working in Florence, who has been involved in A.R.D. since its beginning. She gave us a booklet published on the occasion of a meeting she organised in Florence ***"Update on Dystonia – therapeutic use of neurotoxins"*** dated April 10th 1999, exactly 20 years ago! In 1988 Dr. Brogelli wrote her first works about botulinum toxin use in human tissues, thanks to the cooperation between the Oculistic University Clinic of Florence and Mrs. Mattie Lou Koster, a Texan lady with blepharospasm who in 1981 had created BEBRF – Benign Essential Blepharospasm Research Foundation. These works received compliments by Dr. John Patrick Lee, the ophthalmologist who first introduced the use of botulinum toxin for blepharospasm in Great Britain. The title of Dr. Brogelli's speech was ***"What has changed in blepharospasm therapy after 20 years?"*** Some innovative therapies issued in the last 5 years are: cure of ocular surface with lacrimal substitutes (artificial tears, eye drops, collyrium, ophthalmic gel); proceedings on Meibomian glands (their dysfunctions occlude tear ducts; the glands secretion may be reactivate by physical treatments on eye lids); special filters on eyeglasses (excluding ultraviolet light); new surgical ophthalmoplastic treatments with laser, which don't leave scars; antidystonic medications like syrups made from cannabis, whose effectiveness is still controversial (therapeutic cannabis is produced by Military Pharmaceutical Institute in Florence since 2017).

After lunch our meeting scheduled 3 stories of persons with dystonia.



Maria Carla (second from left) and members from the Italian Dystonia Association

Around Europe and Beyond

Mrs. Cristina Frosini has been the first to tell us her story: she is a musician who began to study piano when very young, becoming a professional piano player and giving concerts around the world. In 2000 she realized that her middle finger had some problems, as it bended on her palm and did not allow her to press the piano keys. For 3 years she could keep on playing in concerts only using her thumb and index finger, as the other 3 were unusable, but in 2003 she had her career ended as she could not play the piano any more. In the meantime she had different diagnosis by neurologists, orthopedists and hand surgeons; eventually she had the middle finger tendon operated, but the problems increased. In 2005 by chance she went to a congress about musicians diseases in Milan, she saw a video with a piano player who had her same finger problem, so she discovered focal dystonia (she knew nothing about this disease, at first she supposed it was an oculistic problem!) She went to Hannover where Prof. Altenmueller confirmed this diagnosis, that was probably the same type of dystonia which Robert Schumann had.

Later she began botulin toxin injections and rehabilitation; at last in May 2012 she could play again in public, in a concert organized by the German Dystonia Association. Since then, she has continued her rehabilitation, which is not yet complete (5% is still missing) but she is giving concerts again. In 2016 she was appointed Director of Conservatorio Giuseppe Verdi in Milan, an important job which also allows her to inform students about this pathology, its prevention and its cure. If immediately detected, musician dystonia may be easily faced and defeated. She has developed an innovative program of body awareness for students “Play music and feel good”.



Cristina Frosini



Mrs Laura Latini, representative of A.R.D., sharing her patient story of a long journey to receive the correct diagnosis.

Our second speaker with an autobiographical story was **Mrs Laura Latini**: in 1991 she began to have symptoms of spasmodic dysphonia and she could not receive any correct diagnosis in Italy. She went to Columbia University in New York where Prof Mitchell Brin, neurologist, and Prof. A. Blitzer, otolaryngologist, explained for her the disease, its unknown causes and the absence of a specific cure. Back to Italy, she went to Gemelli Hospital in Rome where she met Prof. Alberto Albanese, who in that period (spring 1992) had just created our Association. She became a representative of A.R.D; in June 1993, she took part in the meeting about Movement Disorders in Spoleto, with delegates from 10 European countries, where the European Dystonia Federation was founded. She remembers that it was really rewarding working with important persons involved in EDF like Didi Jackson, Feli Justo Alonso, Alistair Newton. By means of the work pursued by EDF, it was possible to establish a close and constructive relationship with the international medical community, who has learned to acknowledge the patient's organizations as necessary for spreading information about the disease and essential for making progress in research.

In the next Dystonia Europe Newsletter you can read the story of our third speaker **Mr. Carlo Iacomucci**.

About 80 persons took part in our meeting; many of them are longtime members, but every year at our conference we meet new members, who have recently had their diagnosis and rely upon us for help and support. We are 8 volunteer women who manage A.R.D. trying to do our best for spreading awareness about dystonia and supporting patients.

*Maria Carla Tarocchi
Vice President
ARD – Italian Dystonia Association*

Around Europe and Beyond

Norway

Norwegian Dystonia Association Spring meeting and General Assembly

In April the Norwegian Dystonia Association (NDF) held its national spring meeting at Hotel Olavsgaard, Skjetten nearby Oslo.

The President Johan Arnfinn Warvik opened the meeting and talked about activities and meetings they attend, like the Norwegian Dystonia Network (a network of medical professionals, where also NDF is invited to participate) and the National Competence Centre for Movement Disorders at Stavanger University Hospital, to mention some.

Then President of Dystonia Europe, Merete Avery held a presentation of the work of Dystonia Europe, activities, projects, meetings and conferences DE attend.

Board Member Heidi Tvetun Strand from Stavanger, shared her journey from the first dystonia symptoms, diagnosis and treatment. Heidi shared ideas on how to live with dystonia that has worked for her. She participated in health classes offered by the Hospital in Stavanger on how to better manage pain. She also participated in Wellness Centre training, which is a government led Centre for people with various diseases, where you get one on one training and help to take steps towards better quality of life.



Heidi Tvetun Strand, Board Member NDF



President Johan Arnfinn Warvik

The next morning NDF held its Annual General Assembly and all the board members were reelected and will continue the work in 2019 and until the next GA in 2020.

NDF holds 2 national meetings a year at different locations in Norway and in addition to that they have 5 local groups that have meetings twice a year or more. Dystonia Europe wishes NDF all the best on the work that lays ahead.



Hotel Olavsgaard

Around Europe and Beyond

Sweden Swedish Dystonia Association 25th Anniversary

Last February the SDF – the Swedish Dystonia Association celebrated its 25th Anniversary in Stockholm, Sweden.

The organization held its Annual General Assembly and about 35 members attended. Leaving President Bengt-Eric Calles welcomed everybody to the meeting.

After the formal part three physiotherapists gave a workshop on physiotherapy and dystonia. After a short introduction they held a session where participants were able to test various movements as well as dancing to music. It was well appreciated. In the evening there was a buffet dinner. Representatives of Dystonia Europe, NDF (Norwegian Dystonia Association) and DDF (the Danish Dystonia Association) joined the celebration and presented some gifts to the incoming President Johnny Rydow.

We thank the board members and all other volunteers of SDF for their work to support and help dystonia patients in Sweden and we wish them much success in their continued work.



Bengt-Eric Calles, former President of the Swedish Dystonia Association



New President Johnny Rydow

Poland

Drive for Dystonia

My story with Dystonia started in February last year. It came suddenly, without any signs of warning. My neck became stiff and my head started to turn to the side.

First there was disorientation - what's happening to me? Why can't I control myself? Why is my body not listening to me? Work and everyday life became difficult. The worst part though was not knowing. What is it? What caused it? And what solution do I have?

Each day my condition was getting worse and I had no idea where to look for help. Not knowing what was exactly wrong and I couldn't even explain it to anyone else.

Of course, I tried visiting my family doctor. I tried three times. Each time being sent away with a list of exercises for stiff neck. So I tried less conventional treatments too - chiropractic, acupuncture, all kinds of magic. None of them worked as I wished they would.

Eventually I found a clue on the internet. I went back to my family doctor and asked for a referral to a neurologist. It was not that easy though. I saw many specialists who had never heard of cervical dystonia. Finally, after trying various treatments I did try one which gave me some hope. Craniosacral therapy eased my stiff muscles and helped me relax.

I've found out about it, amongst many other things, thanks to Adam Kalinowski - founder of facebook Dystonia support group. I'm really thankful for all the help I received from him during those moments of crisis and hopelessness.

Then, after a couple of months of searching I finally met a neurologist who officially diagnosed me with Dystonia. What a relief, I said to myself. At last I've found the true name for it. And then a disappointment hit me - there is no cure for that.

I've been sent to a series of check-ups and treatment with botulinum toxin injections. Meanwhile I've also found out I'm pregnant. Those wonderful news brought also fear to me - how will this affect my illness and how will I manage to take care of a baby?

Luckily after a couple of weeks my symptoms got weaker and sometimes were even almost gone. All that without injections or any other medication. Just vitamins, sun and a bit of positive thinking.

Right now I'm a mum of a 3-month old baby boy and my Dystonia is weak enough to let me manage my everyday tasks and enjoy the time I spend with my family.

I think what also helps me fight the illness is my stubbornness. I can't imagine leaving all my dreams, plans or social life behind. For many years travelling the world has been one of the biggest goals in the life of me and my husband. Planning next trips, reading guidebooks - all of that now helps to keep my thoughts away from Dystonia.

This year for a change, my husband Kordian went on a solo motorcycle trip from UK to the most remote regions of Morocco. Together we packed all his gear and, again, with help from Adam Kalinowski who supplied the stickers and various merchandise, Kordian rode under the banner of Dystonia Europe to share awareness during the Brain Awareness Week.



Kordian

He first rode from Manchester to Portsmouth where he jumped on a ferry headed for the Spanish port of Santander. He travelled through Spain and after crossing the Strait of Gibraltar got to North Africa. He rode through mountains and deserts meeting people of different cultures, other bikers and lonely travelers who had one thing in common - none of them have ever heard of dystonia before.

Spending each night in a different place Dystonia Europe and dystonia awareness in the shape of stickers and leaflets reached out and found their new home in some of the least visited parts of Morocco.

Around Europe and Beyond

After making a huge loop through the country he crossed the sea again and went back home safely through Spain and France.

Altogether – he travelled for 23 days, through 4 countries all together 6500 kilometers on just a small, British Herald 125cc.

I believe that deep inside every one of us there is enough strength to fight dystonia. It's not an easy fight and we may never win it, but we simply can't give up. It's important to slow down and take proper care of your body, clear your mind and focus more on things that make us happy rather than ones that scare us. With the right mindset I believe this fight can eventually be won.

Paulina Handzlik

Dystonia Europe: On behalf of the dystonia patient community in Europe and elsewhere we would like to thank Kordian and his bike for this fantastic initiative. We are extremely grateful for your efforts to raise awareness of dystonia to the public in several countries .



Paulina and Kordian



www.dystonia-europe.org

Skiing from Border to Border- Rajalta Rajalle Hiihto 8-17 March

Springtime had already announced its arrival with snowdrops and crocuses around our home, when Lilo and I, together with 13 colleagues of ours started on a trip northward on March 8, eager to participate in a special skiing event, called **'Rajalta Rajalle Hiihto'**: Crossing middle Finland from the Russian to the Swedish border by ski in 7 days. A stopover in Helsinki enabled us to visit the market hall at the port and also the Dome. It was a rainy day. When we arrived at the Oivanki Outdoor Education Centre in Kuusamo shortly before midnight, it was snowing.

On Saturday we test and prepare our material. Wax or no wax? That's the question. It is still snowing and the weather forecast for the next day is alike. As it is pretty cold, most of us opt for waxed skis. At lunch we enjoy lohikeitto (salmon soup) and before dinner, sauna at the shore, just a few steps off the ice. Dinner and information at 8 p.m.

Next morning transfer by bus to Suorajärvi. Along its shore in wide turns at first, then through open fields with scarce pines. It is a sunny day. First stop at Uttusuo (km 21), where we enjoy soup and coffee.

The last service point is a school in Nissinvaara (km 35), where a retired teacher offers mehu (juice). Pictures of all the Finnish Presidents since the independence (6 December 1917) hanging on the walls. All except the only woman - a social democrat.

During our daily trips of several hours we are served with juice, pickled gherkin, raisins, chocolate, coffee and sometimes Makkara (sausages) from the open fire. On the second day we move for almost 25 km on a narrow-gauge railway embankment, built by war prisoners of the Deutsche Wehrmacht during World War II, not in use anymore – but still dead straight.

I arrive at the service station Pirinlampi Laavu (little open wooden hut) in the afternoon sunshine. It is a wonderful place. I sit down and I really enjoy sandwich, juice and cocoa. There is Finnish music. I know the sound because I was a member of the Finnish Choir Zürich some time ago.



*Erhard and friends
at their Finnish ski
adventure*

Living well with Dystonia

Climbing up in the afternoon sun for quite a while, up and up again, I am just about to reconcile myself with the never ending rise and to inhale the spheric afternoon mood, when a snowmobile approached from behind and as I move aside in order to let it pass, the driver does not agree. He just collects the signs of our route. So am I at the end of the trail? No, there is somebody behind me.

A ski lift takes me up to Pikku-Syöte, where I arrive completely frozen but admiring the twilight, which picturesquely lowers itself in cold pink to the seemingly endless expanse of this sublime view.

Sports journalists would call the 4th day's stage of 88 km "queen stage". But tonight I will not be crowned, because I took a short cut and I skied only 36 km.

So I missed the reserve Ahmatupa (wolverine hut). But I passed it twice 20 years ago. I like the expression "ahma", since it means glutton in German. And as Skiing requires a lot of energy, I feel a certain affinity with this animal in my habit of eating.

Next day the 46 km track leads through wide plains. A brisk wind, from behind and from the side, spoils the already not very stable track. In diffuse light, the track is often difficult to recognize, especially when no trees throw any shadows. Pines are all around, hardly man-high. Could be wetlands? I usually decline when Lilo asks if she should walk with me. Today I don't. I gladly accept the offer to be with her and I am grateful for that.

Short review on some keywords after stage 6 from Hosio to Honkama (60 km) at dinner:

Conditions difficult due to growing snowfall and relative warm temperature.

Kaspar puts the question of meaning

Kurt faces calf problems.

Hansjakob had to abandon today's stage

Marianne forgot her professionally prepared skis at the place where we slept.

The list is arbitrary and incomplete.

At the beginning of the last stage (55 km from Kallinkangas to Karunki) the track is in good condition and I move quite fast. At Lautama (km 23) it is very loud, music and dance. I prefer coffee and Munkki (sort of donut). Weak snowfall sets in and the journey is getting longer and longer.

From behind, excited Finnish Palaver approaches. This is not to be misinterpreted, I love the Finnish language: the unvoiced, sharp "S", the rolling tongue "R", the "L" far back in the mouth and the sonorous bass voices. Nevertheless, I speed up my step and try to escape the feminine dialogue. It's useless. The two cross-country skiers stick to my heels. I step out of the lane and want to let them pass. But they do not. They are wearing official jackets in blue and white. If they were not *allowed* to overtake, I ask. They affirm. Aha, these are the "broomwomen" - and I am at the end of the skiers' chain. With a little bit more distance they keep my pace. At the Maali (goal) I thank them for taking care of me. With a charming smile on their faces, they say that it was their job.

A bus brings us to Tornio. It's a long way and the time schedule of the day is getting tighter and tighter.

It is part of the tradition that the individual country groups introduce themselves the last evening, performing with all sorts of different productions like sketch, quiz, song, dancing performance.

Before returning to Zurich via Helsinki we spend a few hours in Oulu. It is raining, but we are all happy for having finished the Rajalta Rajalle Hiihto 2019.

I am happy having been able to participate in this adventure again. For hours and hours my blepharospasm disappeared from the focus of my thoughts and feelings – due to other 'pain' in my body J

Erhard Mätzener

Treasurer, Dystonia Europe



Loneliness of the long distance skier (Foto: Lilo Illi)

Events

Calendar 2019-2020

2019

June

- 29 Dystonia Today, special session EAN, Oslo, Norway
- 29-2 EAN 2019, Oslo, Norway
- 30-1 EFNA Annual Meeting & General Assembly 2019, Oslo, Norway

July

- 4-7 D-DAYS 2019, London, United Kingdom
- David Marsden Award 2019
- 22 World Brain Day

September

- 12-13 Dystonia Europe Board Meeting & Summer Think Tank, Lund, Sweden
- 18-19 7th Biennial Workshop on Dystonia, Rome, Italy
- 1-30 Dystonia Awareness Month
- 22-26 MDS – International Parkinsons and Movement Disorder Society Congress 2019, Nice, France

October

- 25-27 MyDystonia Ambassador Meeting, Newcastle, UK

2020

February

- TBC Dystonia Europe Board Meeting & Winter Think Tank

March

- 16-22 Brain Awareness Week

May

- 23-26 EAN, Paris

June

- 3-6 International Dystonia Symposium, Dublin. D-DAYS 2020, Dublin. Launch application for the 10th David Marsden Award 2021.



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Members

Dystonia Europe consists of 22 national member groups from 18 European countries and they are:

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

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:

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Thank you for supporting Dystonia Europe!

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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, Swe-
den**

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.



**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 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.



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