

Connecting People for Dystonia

DYSTONIA EUROPE NEWS

SPRING 2016

Together Under the Umbrella at the D-DAYS 2016 in Oslo



Participants at the D-DAYS 2016 conference in Oslo taking part in the Under the Umbrella campaign by EFNA.

www.dystonia-europe.org

Contents

Contents	Page
Content	2
Contacts & Secretariat	2
President's Message	3
Latest News	4
Research	10
Other News	17
EU Activities	20
My Dystonia	23
Jump for Dystonia	24
Around Europe and Beyond	25
Events	29
Members, Donation & Support	30
Medical & Scientific Advisory Board	30
Management & Staff	31
Partners & Sponsor	32

**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

Photos from Oslo:

Photos: Stephan Röhl

E-mail: info@stephan-roehl.de

Website: www.stephan-roehl.de

Meet us @

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

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

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

Disclaimer

The views in Dystonia Europe News are not necessarily those of Dystonia Europe or any of its Officers, and are for information only. They do not represent an endorsement of any particular treatment, products, companies or organisation.

President's Message



Dear all,

Since being elected President last year in October, I have participated at congresses and meetings. I am truly happy and very impressed to see that there is such a vast interest in improving the quality of life for patients with dystonia and other movement disorders. All these research projects and activities, we believe will lead to better treatments and rehabilitation.

To move forward there is a need for more awareness and we are happy not only to work on Dystonia Europe's awareness campaign, but also in coalition with other patient organisations, through partners like EFNA. You can read more about some of the campaigns like "Jump for Dystonia" and "Under the Umbrella" in this newsletter.

Dystonia Europe held its annual conference D-DAYS 2016 in Oslo in cooperation with the Norwegian Dystonia Association. The board of NDF along with the board of DE worked together to make this another great D-DAYS. We had a lot of positive feedback after the conference and DE appreciates very much the assistance of the Norwegian Dystonia Association board. We thank NDF for the great collaboration at the event. Thank you also very much indeed to all the speakers and chairs that contributed at the D-DAYS.

We are planning for the D-DAYS in 2017 which will take place in Italy, in May 2017. DE has 21 member organisations in 18 countries. Delegates from 10 organisations were present at the GA in Oslo. We hope that representatives from the majority of our member groups will participate at the next D-DAYS.

You can read more about our activities, projects and events on the following pages.

I look very much forward to continue working for dystonia as a team with the rest of the DE board.

With some summer pictures from Norway I want to extend my best wishes to all for the summer of 2016.

Merete Avery
President



D-DAYS 2016 in Oslo

A joint project between Dystonia Europe and NDF - the Norwegian Dystonia Association.

It was a great honour for the Norwegian Dystonia Association (NDF) to be co-organizer of this year's D-DAYS conference in Oslo, the capital of Norway! Since Oslo is my childhood city, and has an important place in my heart, it was very special to me that the annual dystonia conference took place in my 'home-town'. I have participated at the D-DAYS conferences in Paris 2014, and in Rotterdam 2015. In my eyes these conferences were very well organized and with a high professional level. This year's conference was no exception!

When NDF was asked to be a co-organizer of this year's conference, we saw a unique opportunity to promote the work of our own association and to raise awareness of dystonia in Norway. During the conference, we highlighted some of our work. We had a separate stand with brochures, unfortunately only in Norwegian. We gave information about the projects we focus on. On the second day of the conference I presented a three-year physiotherapy project. Being a physiotherapist and also Chairwoman of NDF, it was a great honour to inform about the project that has been a major success!

Dystonia Europe (DE) has many years of experience in organizing quality conferences.

Since last November there has been close contact between DE and NDF. The DE Board held a board meeting in Oslo where I took part in the planning of the event. We discussed topics for the conference and suggested speakers. Together with DE and its large network, we were able to choose among top experts within the field of dystonia. The result was, in my point of view, a programme of very high quality. The programme was aimed at patients first of all but the medical profession was also invited to join. The first day of the conference focussed on "Faces of dystonia" and "Future of dystonia". On the second day there were presentations on "Managing dystonia", "Physiotherapy and Rehabilitation" and "Coping strategies for Dystonia". An abstract book, containing most presentations, can be found on the Dystonia Europe website: www.dystonia-europe.org.

The NDF Board participated actively during the D-Days conference. As Chairwoman of the association, I was proud to see this determination of our Board. Before the opening of the congress, we all helped with the packing of conference material and registration and welcoming participants. During the conference we made sure to be available to answer questions from participants, which contributed to a lot of good discussions, new connections with participants, speakers and partners as well as between our own members.

On Saturday afternoon, after the conference, Dystonia Europe delegates together with speakers and guests were invited to a sightseeing tour of Oslo. We were picked up by bus at the hotel. The first stop was at the Kontiki museum which is located at Bygdøy, a peninsula outside the city. The bus continued to the Vigeland sculpture park and to the ski jump arena at Holmenkollen. During the sightseeing several "Photo Shoots" under umbrellas in orange and blue, with logos of DE and NDF, were organized. The umbrella is the sign for the brain awareness campaign "Together under the umbrella" symbolizing that one in three people, is affected by a brain disease in his/her lifetime. On Sunday, April 10, this was celebrated with a "Together Under the Umbrella" event outside Østbanehallen in Oslo. Read more about the campaign on page 21.

The Saturday sightseeing tour ended at the spectacular Opera House, the pride of Oslo. Here we were served a three course dinner in the restaurant overlooking the Oslofjord while the sun was setting. For all of us Norwegians, it was very special to see the appreciation and enthusiasm of our guests. Thank you to the Board of DE who chose to organize this year's event in the capital of Norway. Thank you for giving us the confidence to be co-host. It was an informative and eventful weekend with many memorable moments. Together we increased the understanding and knowledge of dystonia.

*Anniken Hagen, Chairwoman,
NDF – the Norwegian Dystonia Association*



Latest News

Moments from the D-DAYS in Oslo



Dystonia Europe General Assembly 2016



The 23rd Dystonia Europe General Assembly was held on 10 April at the Clarion Hotel Royal Christiania in Oslo Norway.

Representatives from 10 of the 20 member organizations were present. They were from: Norway, Denmark, Sweden, Finland, Switzerland, the UK, France, Germany and Romania. President Merete Avery was delighted to welcome everybody to this meeting in her home country, and then she proceeded to the formal part.

The Final Accounts of 1 July 2014 until 31 December 2015 were approved. Erhard Mätzener had been nominated for election to the DE Board by the Swiss Dystonia Association and he was unanimously elected by the Assembly. The Dystonia Europe Board 2016 consists of President Merete Avery, Norway; Vice President Maja Relja, Croatia; Treasurer Erhard Mätzener, Switzerland; and board member Sorin Ionescu from Romania. Appointed board members are: Cristina Frosini from Italy and Monika Benson from Sweden.

There was one application for membership of Dystonia Europe from a newly founded German dystonia association: DFVD – Dystonie Förderverein Deutschland e.V. After its Chairwoman Martina Kühn had presented the association, the General Assembly approved the membership. The following members have finished their membership with Dystonia Europe: ALDEC one of the dystonia associations from Spain has had to close down; the Dutch Dystonia Association cancelled their membership last

November. At present Dystonia Europe has 21 member associations from 18 countries. We are looking to support the development of associations in Turkey, Hungary and Slovenia.

Merete and Monika presented the Dystonia Europe activities 2016-2017 to the delegates. This will focus around the theme: Connecting People for Dystonia: connecting with the public through the awareness campaign Jump for Dystonia; connecting with the patients through the roll-out of MyDystonia – the digital patient diary; connecting with the medical profession especially the young scientists through the upcoming David Marsden Award 2017, as well as connecting face-to-face at the major dystonia and movement disorder congresses.

Next year's D-DAYS and the 24th General Assembly will take place in the month of May in Italy, dates and venue still to be confirmed.

In the second part of the meeting we listened to Simona Biancu from EngagedIn in Italy who talked about fund-raising. The last session was Elizabeth Cunningham from EFNA, European Federation of Neurological Associations. She presented the awareness campaign Under the Umbrella to raise awareness of brain disorders. After the meeting we all headed to the Oslo center, where we had photos taken while we were all "Together Under the Umbrella"!

*Monika Benson
Dystonia Europe*

First Dystonia Europe Think-Tank in Lund, Sweden

Last January, representatives from our four Platinum sponsors, Boston Scientific, Ipsen, Medtronic and Merz, joined in the 1st Think Tank with the members of the Dystonia Europe Board in Lund, Sweden. Among the topics discussed were dystonia research and how to raise dystonia awareness. Constructive input and important feedback from all participants made it a very valuable day.

The next Think-Tank will meet beginning of July. The plan is to hold two think tanks per year with the purpose for DE and its partners to meet as one team and brainstorm and discuss various projects to benefit dystonia patients.

We thank all participants for a very fruitful day in Lund.



Sorin Ionescu, Merete Avery, Monika Benson, Jennifer Fluck, Cristina Frosini, Stefan Wiemann, Maja Relja, Erhard Mätzener, Nathalie Courtine, Sylvia Hanoune, Matteo Voleno, Sophie Araujo

Third International Congress on Treatment of Dystonia and Satellite Symposia attracted 500 participants from 37 countries

From May 4-7, the third triennial international conference on treatment of dystonia took place in Hannover, Germany. As in the previous conferences, again emphasis in this conference was laid on novel treatments of all kind of dystonias, including injection therapies with Botulinum toxin, deep brain stimulation, various behavioral methods and emerging means of influencing or even preventing the development of movement disorders.

About 80 world-leading peers from all continents gathered to share insights and new research data with overall nearly 500 attendants, including neurologists, neurosurgeons, neuropsychiatrists, geneticists, health-professionals and delegates of various patient groups. Furthermore about 70 PhD students and junior research fellows presented their work in the poster-area demonstrating impressively the attraction of movement disorders research to the future generation.

This time, the format of the conference was developed further by including as a new event a satellite symposium on Dystonia in Sports and for the second time a Symposium on Rehabilitation of Dystonia. Furthermore, an intensive course for industry professionals was offered in order to present a concise “state of the art” of the different options to treat dystonia. Nine hands-on-workshops and focussed satellite symposia on various treatments supplemented the conference and contributed to the vivid exchange of the attendants and the faculty.

Last, but not least, the beautiful spring weather and the carefully chosen social events, including a dinner in the legendary Celle Castle of the House of Hannover, – their descendants currently representing the ruling houses in the UK, Denmark, Spain and the Netherlands-, contributed to the success of the conference.

With respect to emerging new therapies it became clear, that pathophysiology of dystonia is far more complex than previously believed. In contrast to the traditionally predominating concept of dystonia as a disorder of the basal ganglia new data point towards a network disease, including basal ganglia, cerebellum and cortex. This has been impressively demonstrated with new brain-imaging studies, analysing resting state activity and coherences of distant brain regions. Furthermore, neurogenetics has revealed a plethora of new findings concerning different forms of dystonia and defining new entities of dystonias. Bottom line of this research is that many genes may be involved and that the phenotype of some genetic manifestations may be extremely heterogeneous, ranging from musician’s cramp to generalized dystonia. A new finding, put forward in sports and musician’s dystonia is the close link of task-specific focal dystonias to overuse and specific psychological conditions such as performance anxiety and fear of failure.

Botulinum-Toxin still is the therapy of choice for most of the focal dystonias. Here, development of new toxins and improvement of treatment algorithms were the most urgent topics on the agenda. However, the “old” anticholinergic drugs, such as trihexiphenidyl still prove to be useful when carefully dosed and closely monitored.

For deep-brain stimulation, hotly debated topics were the quest for new targets, such as the thalamus and subthalamic nucleus. Furthermore methodological improvements, new stimulation devices and more fine tuned frequency determination were discussed. Special emphasis was laid on treatment of severe dystonia in early infancy and childhood. Novel topics, such as treatment of dystonic storm, - a neurological emergency,- were for the first time included in the conference. Other unique features of the conference were the special lecture on dystonia in famous musicians, featuring amongst others Robert Schumann, Vladimir Horowitz, Glenn Gould and Keith Emerson.

Latest News

After four intensive days of presentations, scientific discussions, informal exchange and hands on training, participants and faculty returned home, full with precious memories and new ideas to further improve treatment of dystonia. The organisers are extremely grateful for the generous support of the industrial sponsors. Without their help this conference would

not have been possible. In the end, the aim of the conference was fully met: A conference for the benefit of those who suffer from dystonia!

The fourth conference is to come...

For the organizers:

Eckart Altenmüller, Dirk Dressler, Joachim Krauss



Professors Eckart Altenmüller, Joachim Krauss, Dirk Dressler

DYSTONIA
EUROPE

Ipsen committed
to **patient** care
over the long term
supporting

The David Marsden Award 2017


10 000€

to stimulate research on dystonia

The award, introduced by Dystonia Europe in 2003 is presented every two years to stimulate developing knowledge of and interest in dystonia through publications on aetiology, pathogenesis, diagnosis or therapies in dystonia or on the psycho social effects.

The deadline for submissions is 31 January 2017

All information regarding the 2017 David Marsden Award are available at www.dystonia-europe.org/activities/awards/

Supported by  **IPSEN**
Innovation for patient care

IPSEN Pharma - 65, quai Georges Gorse - 92 650 Boulogne Billancourt Cedex - France

April 2016

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.

“By making the surgery that enables DBS therapy shorter, more precise and more predictable for patients, we will facilitate an environment in which people with movement disorders will receive DBS systems in a comparable way to cardiac patients receiving heart pacemakers.”

Prof. Dr. Jan Vesper, Department of Functional Neurosurgery and Stereotaxy,
Heinrich Heine University Duesseldorf, Chair of the Center for Neuromodulation



First dystonia patients implanted with Vercise™ PC Deep Brain Stimulation System

Early this year, the first people living with dystonia were successfully treated with a new directional Deep Brain Stimulation (DBS) system that enables personalized therapy and reduces side effects. The implants were conducted by Prof. Jan Vesper and his team at the University Hospital Duesseldorf.

Precise targeting of the brain areas that are responsible for dystonia

“Compared to traditional DBS systems, the new directional system allows us to target specific areas of the brain that cause dystonia symptoms more precisely by directing and shaping the electrical field generated by the electrodes. This technique thus reduces the potential side effects induced by unwanted stimulation of neighboring areas,” explains Prof. Vesper. In general, DBS therapy involves mild electrical impulses generated by a stimulator around the chest, similar to a heart pacemaker. The current travels along thin wires to leads placed in specific areas of the brain mitigating the symptoms of abnormal brain activities that can cause dystonia.

Symptom relief for people with several forms of dystonia

There are several forms of dystonia that can be treated with DBS, mostly the forms that cannot be sufficiently treated with conventional medication. These are known as generalized dystonia, as symptoms are not limited to a certain part of the body, but affect it entirely, for example through muscle spasms or twisted or abnormal fixed postures. Usually these forms are also genetically derived and have an early onset. “There is no age-limit to dystonia. In fact there are severe forms of dystonia which already occur in early childhood. Here, DBS therapy can avoid later orthopedic disturbances and deviations of the spine”, explains Prof Vesper.

Learning to lose the fear of the surgery

“I am aware that patients tend to be afraid of DBS and the associated surgery. We therefore help them to overcome their fears in an incremental training process. First, we talk them through the procedure, explaining everything to them, showing them models of the brain and visual images.

Then, patients undergo surgery training together with the neurologist and they experience how it is to lie under the surgical drape.” Prof Vesper illustrates the patients’ psychological preparation prior to the surgery and adds: “The entire procedure is not really dangerous. It is kind of a routine procedure, very technical and mechanical. Hence, it is important for the patient to understand the entire process, so he or she learns that it is very predictable. Moreover, especially in dystonia cases, surgery is performed under general anesthesia and is not painful.”

Controlling symptoms and side effects

With the programming flexibility of the Vercise™ Cartesia™ segmented leads, the DBS system with Multiple Independent Current Control (MICC) technology enables physicians to adapt the therapy to the individual brain anatomy of their patients. These may vary from the textbook anatomies due to dystonia. “The electrodes in the segmented leads can be steered individually and be programmed with different intensities of electric current enabling us to work around certain areas or even stimulate two targets. Thus, we can ease symptoms such as abnormal movements and postures or dystonic tremor, while avoiding side effects including speech disorders or the paresthesia in arms and legs that we have encountered using traditional DBS systems with constant current and ring-shaped electrical fields.”

Future potential of Deep Brain Stimulation

There are two kinds of side effects associated with DBS: Those arising from the actual stimulation and those occurring due to complications during the surgery. “While side effects from overstimulation of neighboring brain areas can be drastically reduced by the new segmented leads, complications caused by the surgery are very rare. This is not because the surgeon is such a genius, but because the accurate pre-planning and mapping options that recently became available enable us to tailor the procedure to the individual patient and to proceed safely without affecting important brain structures.

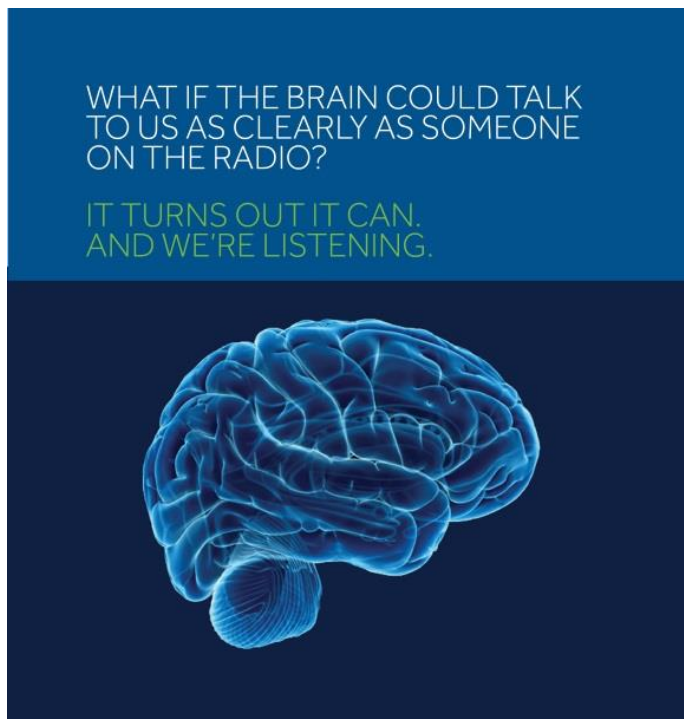
Moreover, with the new DBS systems, we can avoid mechanical problems of the stimulator and the electrodes. By making the surgery that enables DBS therapy more precise and more predictable for patients, we will facilitate an environment in which people with movement disorders will receive DBS systems in a comparable way to cardiac patients receiving heart pacemakers. That is the goal for the future, and I think we are well on the way to reaching this point with the new DBS technology,” Prof. Vesper concludes



The Vercise™ PC DBS System and the Vercise™ Cartesia™ Directional Lead combine to form the first and only directional system with current steering / Image courtesy of Boston Scientific Corporation

What if the brain could talk to us as clearly as someone on the radio?

*Wolf-Julian Neumann, Prof. Andrea A. Kühn
Charité, University Medicine Berlin; Movement
Disorder and Neuromodulation Unit; Dept. of
Neurology*



To accomplish the best possible symptom improvement for patients with dystonia, neurologists have to tailor the treatment for each patient to meet the individual needs and problems that she or he faces. Finding the right therapeutic strategy can be very challenging for both the patient and the physician, especially when the dystonic symptoms are widespread and complex and consequently difficult to treat with botulinum toxin. Furthermore, some patients develop neutralizing antibodies against botulinum neurotoxin that can lead to secondary therapy failure.

Deep brain stimulation (DBS) is a highly effective treatment alternative that can offer great clinical improvement for patients with general, segmental, cervical and other types of isolated dystonia that don't respond well to medication and botulinum toxin. Just like a pacemaker in the chest or abdomen for the heart, a small neurostimulator is surgically placed under the skin in the chest to deliver DBS therapy.

The device sends continuous electrical pulses in an area of the brain called globus pallidus internus – GPi that controls movement. These pulses disrupt brain rhythms that transmit messages that cause the symptoms associated with Movement disorders.

Stereotactic implantation of deep brain electrodes is the first part of the procedure that can be separated from the second surgery for implantation and connection of the neurostimulator in the chest or abdominal for a few days.

Researchers have used the time window, while the DBS electrodes are accessible to record brain activity directly from deep brain structures involved in the disease process. This has led to major advancements in the understanding of the mechanisms underlying dystonic muscle contractions. It could be shown that neuronal populations are synchronized in disease specific rhythmic patterns, so called theta oscillations, slow waves of brain activity that resonate at a frequency of 4 – 12 wave cycles per second (Silberstein et al., 2003).

The amplitude of theta oscillations could be shown to be correlated with the activity of muscle contraction that ultimately induce the dystonic movements (Chen et al., 2006). Furthermore, analysis of the temporal dynamics of theta oscillations and dystonic muscle activity revealed that theta activity precedes the muscle contractions, which suggests that theta oscillations may play a causal role in dystonic symptom generation (Sharott et al., 2008). Interestingly, it could be shown that DBS interferes with these pathogenic oscillations (Barow et al., 2014), which is one potential therapeutic mechanism of DBS in dystonia.

The concept of brain activity modulation through DBS has inspired an innovative new stimulation approach: the brain activity could be used as a feedback signal to monitor the dystonic symptoms and trigger the stimulation adaptively when needed.

In Parkinson's disease, another frequent DBS indication, the first clinical studies using the so called adaptive closed loop stimulation technique, have shown promising results (Little et al., 2013) with greater symptom alleviation and fewer side effects but reduced stimulation time. We are now aiming to translate this concept to improve and individualize the treatment of our patients with dystonia using a novel implantable device (Neumann et al., 2015) that can stimulate and record brain activity simultaneously (Brain Radio[®] technology, Medtronic).

Feedback-controlled stimulation systems will adapt to the patients individual needs and potentially lead to longer battery life time in the future.

However, it remains a long way to go until adaptive closed loop stimulation can be established as a routine treatment in the clinic. Further research requires the dedication of clinicians, technicians and most importantly dystonia patients that are willing to participate in the necessary clinical studies that can provide sufficient evidence for the beneficial effects of closed loop stimulation on dystonic symptoms and quality of life.

Medtronic provided the neurostimulators. The research was supported by the German Research Foundation.

Global Care Protocol for Cervical Dystonia Patients



By Anna Castagna and Marina Ramella

Current views on pathophysiology of dystonia are faulty sensorimotor integration, abnormal sensory processing and impaired motor planning. It was underlined that dystonia is a network disease between cerebellum, basal ganglia

and cortex. Efficacy of Botulinum Neurotoxin (BoNT) is clinically demonstrated and recent data show evidence that can change brain connectivity. Moreover there are several studies that rehabilitation can improve treatment outcome acting on sensory motor re-learning.

In our clinic in Don Gnocchi Foundation IRCCS Santa Maria Nascente, Milano we propose a Global Care Protocol for patients with cervical dystonia consisting in:

1. First access: clinical and family history collection and evaluation, discussion on shared goals and team management; eventual instrumental evaluation of cervical region in the Movement analysis Laboratory (Kinematic and EMG mapping).
2. EMG/US guided BoNT treatment
3. Sensory-motor Perceptive Rehabilitation INTEgrated (SPRINT) approach (50 min for 20 sessions, three times weekly)
4. Self-guided home rehabilitation
5. Follow up

The treatment goals of BONT associated to SPRINT approach are focused on improvement of:

1. Pain
2. Posture
3. Movement
4. Activity

The SPRINT approach is based on sensory-motor relearning techniques: guided motor exercises that

facilitate sensory-motor integration for reconstructing mental images, personal axis, body scheme and mental maps. The aim is to improve posturing and the ability to move interacting with the surrounding space. Movements become more effective and efficient consequently to a greater self-awareness; dependency on sensory tricks decreases because of learning to programme new motor strategies.

The acquired ability to restore motor control reduces anxiety also in social context and during high functioning request (ex. talking in public), improving quality of life.

The SPRINT approach exercises have temporal (contraction-rest-relaxation-rest) and spatial criteria. They can be done in different posture (lying, sitting, standing), with eyes closed or open and during activity (talking, walking, playing sports).

A specific combination of sensory strategies can be adopted using tactile, visual, acoustic, vibrational and verbal system in order to decrease need of correction (positive feedback) or to increase exercise complexity (negative feedback) such as contemporary head and trunk control while reaching a visual target. Kinesiotaping can be used to reduce pain.

These exercises help the patient to relearn both control and fluidity of previously limited movements, enhancing and probably prolonging the effectiveness of botulinum toxin treatment. At home the patient can continue to perform exercises integrated in real life and also practice recreative physical activities such as Tai Chi, dance or sport to improve proprioception, without obsessive repetition of already acquired exercises. Relaxing activities (meditation, acupuncture, yoga) can be associated. If necessary a short SPRINT summary can be organized (once a week for 4 weeks) after other successive BoNT injections.

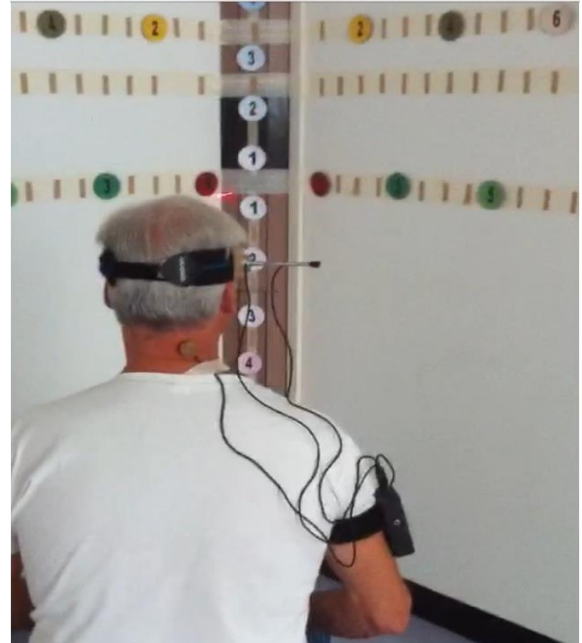


Biofeedback devices.

Research

Our preliminary study involving five patients who were studied with clinical scales and fMRI Resting State Network showed that BoNT associated to SPRINT approach is efficacious in restoring sensory-motor functional connectivity 4 weeks after treatment. Moreover we found a clinical prolonged effect at three months, as demonstrated by TWSTRS score, that can be due to the relearning techniques that could facilitate the functional connectivity between sensory motor and frontal parietal executive areas.

The SPRING approach has so far showed promising prolonged effects in reducing pain, abnormal movements and restore a better posture in patients with cervical dystonia by re-learning motor control in functional tasks and skills of daily life. It can help also in empowering and motivating the patients to find helpful strategies of self-managemet. Further investigations are necessary but it seems to be a useful complementary treatment to BoNT for patients affected by cervical dystonia



SPRINT session with inclinometer, laserpointer and buzzer.



*Multidisciplinary team:
Anna Castagna neurologist MD
Marina Ramella,
Luciana Sciumè PMR MD
Alessandro Crippa,
Chiara Corini,
Giulia Giacobbi – Physiotherapists*

Other News

Dystonia Europe at the 3rd International Congress on Treatment of Dystonia



Dr. Fereshte Adib Saberi and
Prof. Dr. Dirk Dressler

The first week of May Dystonia Europe President Merete Avery and Executive Director Monika Benson travelled to Hannover in Germany. The Congress started on Wednesday afternoon with the 2nd International Conference on Rehabilitation of Dystonia, followed by the 1st International Conference on Dystonia in Sports.

This 3rd International Congress on Treatment of Dystonia brought together more than 500 participants from several countries. Dystonia Europe had a stand in the exhibition hall and many visitors stopped to get the latest DE information leaflet and Newsletter, printed with the support of Medtronic. The MyDystonia APP was demonstrated and material was available in both English and German. There was also the opportunity to have photos taken for the two campaigns we are promoting: 'Jump for dystonia' and 'Under the Umbrella'.

It was some intense days of networking and we are very grateful to the organizers for letting us have a stand for free at this very important dystonia event. Read more about the congress on page 8.

DYSTONIA – The History Project

The famous article of Hermann Oppenheim

I. Originalmitteilungen.

1. Über eine eigenartige Krampfkrankheit
des kindlichen und jugendlichen Alters (Dysbasia lordotica
progressiva, Dystonia musculorum deformans).

Von H. Oppenheim.

In English:

About a peculiar cramping sickness in children and adolescents

DYSTONIA – The History Project

As most other movement disorders, dystonic conditions have a tremendously rich history and there is abundant material on it: Representations of cramps and spasms in artworks; first surgical alleviations dating back to the 17th century; drawings of patients from the vast resources of the outstanding French science in the 19th and early 20th centuries; a couple of noteworthy contributions from Great Britain and the US; the landmark studies of German neurologists and ultimately the history of a potentially fatal protein that is today's most promising treatment of dystonia. And whoever looks into this history will find fascinating, educating and enjoyable sources to dive into.

The history project DYSTONIA: THE HISTORY PROJECT, Milestones in research, diagnostics and therapy was inaugurated in 2014 as an interactive project to document historical aspects of dystonia including symptomatology, therapy and aetiology as well as the formation of the medical field of dystonia.

Project details:

DYSTONIA: THE HISTORY PROJECT

Milestones in research, diagnostics and therapy

Concept and idea: Christian Riederer, PhD

Scientific advisor: Dirk Dressler, MD, PhD

Supported by an unrestricted educational grant from Merz Pharmaceuticals

First presentation: Toxins 2015, Lissabon, Portugal

The goal is to collect relevant material and to disseminate it via historical exhibitions or printed works (brochures, booklets, etc.) on selected congresses and relevant events on dystonia, offering a broad spectrum of visibility for congress participants, visitors and readers.

As we continue to enlarge this exhibition and to work on new content, we welcome further contributions and comments that can be sent to criederer@email.de

We hope everyone will enjoy this project!

*Dr. Christian Riederer
Würzburg, Germany*

Project Manager:

Dr. Christian Riederer has been organizing medical historical exhibitions on neurological and psychiatric disorders since 2005. His collections include material on Parkinson's disease, Alzheimer's disease, Dystonia, MSA, ADHD and Alcohol addiction.



*Drawing of torticollis
from the French doctor Cruchet*



*The exhibition at the 3rd
International Congress on
the Treatment of Dystonia in
Hannover*

Ipsen and Dystonia Europe met in Paris

Last March the Dystonia Europe management met with Ipsen representatives at their headquarters in Paris. Ipsen is one of the major companies manufacturing the botulinum toxin which is used to treat dystonia.

The collaboration between Ipsen and Dystonia Europe has developed over the years and we have worked successfully together in partnership on many projects such as:

- Several David Marsden Awards – a scientific award given to a young scientist within the field of dystonia every other year.
- Dystonia Awareness Videos – dystonia patients sharing their stories to raise awareness.
- International Cervical Dystonia Patient Survey where more than 1000 patients from 38 countries participated to give the patient perspective on disease impact, medical treatment and physician relationship.
- Support of the Jump for Dystonia awareness campaign.

It has always been a very fruitful partnership with Ipsen for the benefit of dystonia patients and their families. We would like to thank Ipsen for their commitment to support our important work and we look forward to our continued collaboration.



Dystonia Europe at Medtronic in Switzerland

The new Dystonia Europe President Merete Avery from Norway and the DE Executive Director Monika Benson were invited to the Medtronic European Headquarters in Switzerland beginning of March.

Specialists from the Medtronic DBS Team gave valuable insights of the company's work and mission. The programme also included a tour of the manufacturing site showing how various Medtronic medical devices are produced. Several ideas and projects were discussed and the day ended with a great team jump for dystonia.

We thank the Medtronic team for a very fruitful meeting and we look forward to our continued collaboration.



Dystonia Europe and Merz met in Frankfurt

In January the DE President and Executive Director were welcomed at the Merz headquarters in Frankfurt. The teams discussed various aspects of collaboration. Much focus was on the longterm project MyDystonia APP, the digital patient diary developed with an unrestricted grant from Merz. The plans are to translate the APP to several languages and to continue the roll-out in more countries. At present the APP is available in English, German, French and Danish. An android version is also being developed. We thank the Merz team for the great collaboration on this project and we look forward to continue this work over the next years.

Brain, Mind and Pain Group – a lively forum for debate in the European Parliament

Across Europe, millions of people with neurological and pain disorders struggle to get the diagnosis, treatment and support they need. The MEP Interest Group on Brain, Mind and Pain is committed to increasing political awareness of these disorders within the European Institutions and Member States.

The European Federation of Neurological Associations* (EFNA) are working in coalition with Pain Alliance Europe (PAE) in the European Parliament to push our concerns up the EU political agenda. In 2014 we commissioned a 'Book of Evidence' that outlines why brain disorders must be a political priority. The Book of Evidence included a testimony from a person with cervical Dystonia. The following year we formed the Brain, Mind and Pain Interest Group in the European Parliament. Our aim is to contribute to European policy by providing a forum to share and exchange best practice, encourage debate and discussion, that lead to tangible benefits to people with neurological and pain disorders.



We are calling on the European Institutions and Member States to:

- Support patient-led campaigns to raise awareness of neurological and pain disorders and reduce stigma
- To ensure appropriate support for people living with these disorders
- Improve regulation to better support medical research and drug development in Europe
- Strengthen patient involvement in research, policy-making and decision-making

We were delighted when MEPs Marian Harkin from Ireland, Jeroen Lenaers from the Netherlands and Daciana Sârbu from Romania, agreed to be our co-chairs and almost 50 MEPs signed our Register of Supporters. We meet three times a year and reports of our meetings on Stigma, Brain and pain disorders in the workplace and Health Promotion and Prevention can be found on the website.

Emily Benson speaking to the European Parliament on the way her mother's Dystonia impacted on her as a



child in our meeting on stigma. Our next meeting on 22 June will look at Patient Involvement in Research. We believe that involving patients at all stages of research produces higher quality, more relevant

research and ensures that the benefits are felt by the people who need it most.

For more information, including reports of past meetings you can access the Interest Group website at: www.brainmindpain.eu

Heather Clarke
EFNA

* EFNA brings together European umbrella organisations of neurological patient advocacy groups, to work with other associations in the field of neurology, in what has been termed a "Partnership for Progress". Our vision is a better quality of life for people in Europe living with a neurological disorder. We are delighted that Dystonia Europe is one of our members. For more information, checkout our website www.efna.net

Neurology Awareness: Together Under the Umbrella

Organised by the **European Federation of Neurological Associations* (EFNA)**, the Together Under the Umbrella campaign provides a platform for people with neurological disorders to share their experiences and stories and thereby build a greater understanding of these conditions among the wider public.

It reminds people that 1 in 3 Europeans may suffer with a brain disorder during their lifetime.

EFNA is delighted the campaign was so well supported by Dystonia Europe in Oslo in April. We would love you to build on that support and post more pictures under an umbrella on social media using the hashtag **#UnderTheUmbrella**.



Together Under the Umbrella was officially launched at the European Parliament during Brain Awareness Week with a cocktail event, hosted by Marek Plura MEP. Eight MEPs attended on the night – including Helga Stevens, Chair of the EP Disability intergroup and Bogdan Wenta, the best-ever Polish handball player!

EU Activities



Under the Umbrella in Oslo

The campaign came about in response to demands by EFNA members to 'brand the brain' by grouping brain disorders under a common symbol.

It is linked to the European Brain Council's Call for Action which asks:

- The European Commission to come forward with a European strategy to tackle brain disorders in a collaborative, integrated and comprehensive manner, as well as to further support European Union Member States and associated countries in their efforts to combat the impact of brain disorders.
- European Union member states and associated countries to implement public health programmes addressing brain health in a systematic way, making the best possible use of available resources in order to stimulate more and better co-ordinated brain research, and to foster strategies for prevention, early detection, diagnosis and adequate treatment.

To find out more about the Together Under the Umbrella campaign visit www.undertheumbrella.eu where you will find key messages, interesting facts, campaign resources and more details. And why not follow @UnderUmbrellaEU on Twitter.



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



Available on the
App Store

Available
Online

www.mydystonia.com

Jump for Dystonia

First Jump for Dystonia Skydive in Australia

Last December the first skydive of the Jump for Dystonia contest took place in Melbourne Australia. Andrew Elia was the lucky winner and this was the first time for him to do a skydive. He said: "Unbelievable, what a rush"

Many people in Australia have helped to promote the JUMP campaign and we would like to thank you all. Thank you to Micheline Elasmir for all your support and for joining Andrew on the big day of his skydive. This ultimate JUMP for Dystonia in St Kilda, Melbourne was performed together with Skydive the Beach & Beyond.

We encourage you to keep jumping for dystonia and send us your photos or post directly on the Facebook page:

<https://www.facebook.com/jumpfordystonia/>

Show us your Summer Jump for Dystonia!

JUMP for Dystonia in Figures:

Over 10 000 JUMPS from
More than 30 countries on
5 continents
4 Skydive Winners



Andrew Elia with his wife Elissa and Micheline Elasmir



*Andrew Elia
from Melbourne, Australia*

Austria: ÖDG 25th Anniversary Double Anniversary of the Austrian Dystonia Association

Last December in Vienna, Austria, ÖDG celebrated its 20th Anniversary as an association and its 25th Anniversary as a Dystonia self-help-group.

In 1995 Christa Hafenscher founded the Austrian Dystonia Association, five years after she had launched a Dystonia Support Group.

The Anniversary was celebrated at the Health Ministry in Vienna, with great participation of ÖDG members, physicians, representatives from health insurance companies as well as from Austrian health policy. The Federal Minister Dr. Magdalena Arrouas opened the event by congratulating the association. She underlined the excellent achievements of ÖDG through the tireless efforts of Christa Hafenscher and Richard Schierl.

International guests were Monika Benson from Sweden (Executive Director of Dystonia Europe), Ute Kühn (Chairwoman) and Hedwig Hagg (Deputy Chairwoman) of the German Dystonia Society (DDG). Prof. Dr. Eduard Auff, Head of the Department of Neurology Vienna, and since the founding of the association the medical advisor and mentor of ÖDG, spoke about 25 years of empowerment and health literacy. Prof. Auff as well as Prof. Dr. Peter Schnider from Landeskrankenhaus Hochegg, both agreed that in the past the patient very often had to wait many years for a correct diagnosis and access to treatment. This has improved. Today the dystonia sufferers will be referred more quickly to a neurologist, and thereby be diagnosed and also receive adequate therapy earlier.

Christa Hafenscher spoke about her time within ÖDG. She told the audience about her own experience of the difficulties as a dystonia patient and how this motivated her to help others in the same situation. No one should have to wait and fight for such a long time as she did before getting the correct diagnosis. She has since then been working hard to spread awareness to achieve early diagnosis and access to correct therapy.



*Christa Hafenscher
and Richard Schierl*

Mrs. Hafenscher highlighted two milestones achieved:

1. To educate all neurologists about dystonia.
2. To provide a uniform guideline for the treatment of dystonia in Austria, which is until now primarily treatment with Botulinumtoxin.

At the final roundtable discussion, Dr. Susanne Rabady, family doctor and member of the Austrian Society of General Medicine, stressed that more awareness is needed.

In order to make the correct diagnosis it is crucial to examine the patient well, get an overview of the symptoms and also to find out how much the symptoms affect the patient. It is important that young practitioners learn how to assess dystonia symptoms correctly. This should be taught in general medicine.

In his final words Mag Richard Schierl invited the Dystonia sufferers: "Come join a self-help group. You can leave your suffering to us! Shared problems are half problems."

Mag. Richard Schierl ended this wonderful and festive event by stressing the ÖDG motto **"You're not alone"**

Ute Kühn

President

DDG, the German Dystonia Association



Germany: Segawa meeting 2015

Last November 27-29 the third Segawa Group Meeting took place and this time in the 'Cardinal-Doepfner-House' in Freising, which is prominently located on the Cathedral Hill. The Segawa Meeting is a weekend event for people suffering from the Segawa-Syndrome (also known as dopa-responsive dystonia), which is one of the most rare types of dystonia. A fact shown by the small number of people diagnosed. For example in Germany there are only 60 persons known who suffer from this rare disease. This is the reason why it is so important for the 36 participants who came together, to talk to others in the same situation and to exchange experiences. It is almost impossible to find a person with the same disease in the proximity.

All participants arrived on Friday, November 27 around 4 PM at the 'Korbinian-Room' and the weekend started with the introduction of the participants. Each person introduced him-/herself with name and place of residence and described the first symptoms at the beginning of the disease as well as the long way he/she had until finally a physician made the diagnosis. Only a very small number of the people affected were diagnosed with Segawa-Dystonia straight away, due to the fact that this type of dystonia is often unknown to the physicians, and also because the symptoms vary from one person to another. Each participant also told the group what expectations he/she had on the meeting. It turned out that most participants prioritized the exchange of experiences and to meet others with the same diagnosis. It was astonishing that right from the start the meeting had a family atmosphere so that even new participants soon socialized and felt relaxed during the first evening. After a break for supper many topics were discussed: the daily dose of medicines, the various medications, preventive examinations due to medications, problems of everyday life, work, school and much more. While one part of the group went back to their rooms, the other part visited the Christmas Market in the courtyard of the Cathedral Hill. Here they found themselves surrounded by beautifully decorated stands and the air was heavy with the scent of waffles. In this pre-Christmas atmosphere one could treat oneself to a glass of mulled wine. Even here the conversations went on in an open and cheerful manner until one by

one everyone went back to their beds with cold feet, a head full of thoughts and a smile on the face. On Saturday at 7.30 AM everyone met in the dining room for breakfast. Everything which is required for a balanced breakfast, such as cereals, rolls, croissants could be found. The meeting resumed at 9 AM with new energy. Next on the agenda was a presentation from Ms. Wunderlich-Schmitt, the physiotherapist of a child, affected with the Segawa-Syndrome, and also attending the meeting. Ms. Wunderlich-Schmitt started her presentation by giving a general outline of the disease and proceeded to describing which problems or symptoms can be treated with physiotherapy. From the audience one could often hear „Ahh..“ and „Ohh..“ as expressions of astonishment, as many participants were not aware of the extent of various physiotherapeutic treatments. The participants asked questions, reported on their own physiotherapeutic experiences and could finally try out a training tool which had been brought along by Ms. Wunderlich-Schmitt. Afterwards, lunch was served and following this the participants could continue to try out the training tool. In the afternoon Ms. Esther Coerper, introduced the results of her master's thesis. This master's thesis broached the issue of integrative learning behaviour and went into details of the Segawa Syndrome. She had already sent out questionnaires to affected persons last May, in order to include these aspects in her master's thesis.

After a group photo had been taken, Ms. Barbara Pfaeffl proceeded to the last item on the agenda: she reported on the tasks and work of the Segawa support group. In the evening the participants were given the chance to attend a guided city tour which the majority decided to take. At 7.30 PM the tour started with some historical tales on the Cathedral Hill and continued towards the historic district of Freising. In the course of this tour it was not only explained why the street signs in Freising are red but also why the conference room was given the name 'Korbinian-Room'.

On the day of departure the group met after breakfast in the meeting room to recall the weekend, make suggestions for improvements and to say goodbye.

Around Europe & Beyond

At about 11 AM the meeting came to its end and all participants agreed that they were already looking forward to meeting again next year. In conclusion, the participants' prevailing opinion was that they feel better with the medication and that they are glad that this disease is highly treatable. Furthermore, it is just

good to know that they are not alone with this, and this is exactly the reason why this meeting is a ray of hope for each and every person concerned.

Nicole Blos

Member of Segawa Group

Translated to English by Ursula Hahn



Participants at the Segawa meeting



FOR SALE!

Now you can buy the Jump for Dystonia t-shirt!

They are in 100% cotton, bright orange color and in sizes S, M, L, XL, XXL, with the Jump for Dystonia logo on the front. The cost of € 20.- covers production, package and shipping. We deliver as soon as we can.

Order here:

<https://dystonia-europe.org/2015/03/jump-for-dystonia-t-shirts-in-stock/>

Norway: Dystonia Europe at the Annual Meeting of Norwegian Dystonia Association

The Norwegian Dystonia Association, NDF, held its Annual Meeting and General Assembly at Hotel Olavsgaard, outside of Oslo beginning of March. About 50 members had gathered for the 2-day event. Chairwoman Anniken Hagen welcomed everybody and then informed about the past and upcoming activities and projects.

The very successful 3-year physiotherapy project is soon coming to an end. After the last workshop that will take place in Tromsø in August, 82 Norwegian physiotherapists will have received special training in physiotherapy and cervical dystonia. Other than Tromsø the course has been held in Oslo, Arendal, Bergen and Molde. It consisted of two workshops over two days each with both theory and hands-on training on dystonia patients.

The following presentation was made by Kjersti Bøe, who spoke about coping strategies in general when facing life's challenges and ups and downs. She stressed the importance of mindfulness, breathing techniques and mental training.

After lunch Merete Avery and Monika Benson from Dystonia Europe informed about the work and activities of the organisation. Focus was of course on the upcoming D-DAYS in Oslo on 8 & 9 April. The programme and the various speakers were presented more in depth.

On Sunday morning the General Assembly for the Norwegian members was held.

We would like to thank NDF for inviting us to this occasion with the opportunity to share what Dystonia Europe is all about to your members.

We also would like to complement you on all the good work you do for dystonia patients and their families in Norway. We wish you much success in the year to come.



Anniken Hagen



Merete Avery and Monika Benson

*Monika Benson, Executive Director
Dystonia Europe*

Events

2016

June

- 13-15 BioPontis Alliance Workshop, Leuven, Belgium
19-23 20th International Congress of Parkinson's Disease and Movement Disorders, Berlin, Germany
22 BMP Interest Group – Patient Involvement in Research, European Parliament, Brussels, Belgium

July

- 7 2nd Dystonia Europe Think Tank, Lund, Sweden
8 Dystonia Europe Board Meeting, Lund, Sweden

August

- 29-30 NDF Physiotherapy Project final work-shop, Tromsø, Norway

September

- 28-1 Congress for ESSFN, Istanbul, Turkey

October

- 13-14 EFNA workshop: Patient-Based Evidence, Dublin, Ireland

November

- 29 BMP Interest group - European Parliament, Brussels, Belgium

2017

January

- 11-13 2017 BPNA Annual Conference, Cambridge, UK
18-21 Toxins 2017, Madrid, Spain

February

- 2-3 World Paediatric Movement Disorders Congress, Barcelona, Spain

May

- 11-14 AOCCN 2017, 14th Asian and Oceanian Congress of Child Neurology, Fukuoka, Japan
Dystonia Europe D-DAYS 2017 & the 24th Annual Conference & General Assembly, Italy
Specific date in May and venue in Italy for the D-DAYS to be announced later.

June

- 4-8 21st International Congress of Parkinson's Disease and Movement Disorders, Vancouver, Canada
20-24 12th EPNS Congress, European Paediatric Neurology Society, Lyon, France
24-27 3rd Congress of the European Academy of Neurology, Amsterdam, The Netherlands



20th International Congress of Parkinson's Disease
and Movement Disorders
JUNE 19-23, 2016 • BERLIN, GERMANY
www.mdscongress2016.org



Members

Dystonia Europe consists of 21 national member groups from 18 European countries and they are: Austria, Belgium, Croatia, Czech Republic, Denmark, Finland, France, Germany, Ireland, Italy, Norway, Poland, Portugal, Romania, Spain, Sweden, Switzerland and United Kingdom.

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.

Donation & Support

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. She is from Norway. She was diagnosed with cervical dystonia in 2006 and she was Chairwoman of the Norwegian Dystonia Association between 2010-2013. Merete is working with customer service and administration for a company in Molde, Norway.



**Monika Benson,
Dystonia Europe,
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.



**Maja Relja, Vice
President,
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, and appointed Vice President in 2012. She also serves on the DE Medical and Scientific Advisory Board and is heavily involved in the COST-funded Dystonia Research Network.



**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.



**Cristina Frosini,
Board Member, Italy**

Cristina was appointed to the Board of Dystonia Europe in 2016. She is a pianist and

deputy Director of the Milan Conservatory. She has won many international competitions and played hundreds of concerts including orchestral recitals radio and television recordings. Since 2005 Cristina has been suffering from focal dystonia which forced her to stop her concert activities. After being treated in Hannover, Germany, she is now almost completely recovered. She therefore is devoting her focus on pianophysiology.



**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.



**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