

Connecting people for dystonia

DYSTONIA EUROPE

NEWS
WINTER 2019



Dystonia Europe Delegates at Dystonia Days in London

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Connecting people for dystonia

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

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



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President's Message



Dear all,

When I started my work as dystonia patient advocate 3 years ago, I did not think that one day I would write this letter as the President of Dystonia Europe. At that time, I didn't even know that what I was doing was called 'Patient Advocacy'.

My mission began at the worst moment of my life with dystonia. At that time I felt lonely and misunderstood and I decided to set up a support group for people with dystonia in Poland in 2016. I am Polish, but I have lived in Ireland for 12 years. It turned out that my support group is much needed by people like me. In the same year I started to get involved in the work of the Polish Dystonia Association and Dystonia Europe [DE]. Now I am the secretary of the board in the Polish association and after two years on the board of DE I was elected president of this organization last summer.

While working for the organization, I met many interesting people - members of DE member organizations, medical professionals, people giving their time for work to improve the quality of life of people not only suffering from dystonia, but also from many other neurological diseases. I also participated in many conferences, meetings and workshops

of other organizations cooperating with DE. But above all I could meet hundreds of people who are struggling with the same thing in life as me - dystonia.

I want to thank our former President Merete Avery for her six years of great work for DE. I know that this role is very important and now I represent our membership organizations, people with dystonia in Europe, their families and carers. I will do my best not to disappoint you and I am sure that together with the entire DE board and our members we will work to have an increasingly stronger voice in the fight for a better life for those we represent!

In recent months, we've had many events like Dystonia Days 2019 in London and Dystonia Awareness Month 2019. Information about these events and much more can be found in this newsletter.

I wish you a Merry Christmas and a Happy New Year 2020!

Adam Kalinowski
President



The Dystonia Europe Board 2019

The 26th Annual General Assembly was held on 5 July at the at the Novotel London West in Hammersmith.

We are delighted to present to you the Dystonia Europe Board:

President Adam Kalinowski from Poland
Vice-President Edwige Ponseel from France
Treasurer Sissel Buskerud from Norway
Secretary Gill Ainsly from the UK
Board Member Catalina Cranic from Romania.
Appointed board member is Dystonia Europe Executive Director Monika Benson from Sweden.

The following Board members stepped down:
Merete Avery had been on the board since 2013, a total of six years which is the maximum period one can serve as a board member. First she was the Secretary and from 2015 she was the President.

Treasurer Erhard Mätzener from Switzerland and Board Member Sorin Ionescu were elected to the Board in 2015 and had both announced that they wished to leave the Board.

We thanked Merete, Erhard and Sorin for their time and many valuable contributions over the years and we wish them all the best.

Merete Avery will not be leaving us totally. She has agreed to take on the role as Operations Manager to support the Board and the Executive Director. We are extremely happy that Merete's knowledge and experience will remain in Dystonia Europe in order to continue to move forward the organization together with the Executive Director Monika Benson, under the leadership of the new President Adam Kalinowski.



From left:
Monika Benson, Sissel Buskerud, Adam Kalinowski, Gill Ainsly, Catalina Cranic and Edwige Ponseel

Dystonia Europe 26th Annual Conference in London 2019

The Dystonia Europe General Assembly was held on Friday 5th July, followed by a sightseeing trip and a dinner cruise on the river Thames in the afternoon. Delegates from the member countries, speakers and guests along with the The Dystonia Society board participated. DE received feedback that this was a great opportunity for the delegates in the member countries to network with other Delegates and medical professionals.

The actual Dystonia Day was held in collaboration with The Dystonia Society (TDS) on Saturday 6th July at Novotel Hotel Hammersmith, London. These D-DAYS we had the most participants so far, 178 patients, family members, medical and more, many of them members of TDS. The Dystonia Society had many volunteers, that along with the staff of TDS Andrea West and Dayna Ferdinandi, made sure that registration and welcoming all went very well.

Fiona Ross, Chairwoman of TDS and Merete Avery, President DE opened the conference, wishing everyone welcome, including those who followed us by live stream around the world. The Conference was divided into 4 main sections. Dystonia and Children, Dystonia from Adolescence to Young Adults, Dystonia in Adults, Research and Development.

In addition to the medical presentations by experts on dystonia and movement disorders, there were many patient stories at this conference. Sam is the parent of a child that is now 7 years old and they started to see that there was something different early on. The journey to find out what was wrong involved many visits to the physician. This was a very moving story of the struggle for a correct diagnosis which turned out to be generalized dystonia.

From feedback we received after the conference we understood that many participants appreciated the various dystonia stories presented as well as the medical presentations. To hear that you are not alone can be very helpful. Somebody else's story can give new insights and hope.

Next were presentations on aids for people with dystonia and movement disorders. A personally designed wheelchair that assists the child to participate in activities can make a huge difference. It can contribute to the child being able to participate socially with other children and to some extent take part in activities with other children.

Professor Tom Warner, UCL Queen Square Institute of Neurology in London, presented the latest on research and development of treatment of dystonia. The most common treatment is botulinum toxin. Few medications have good effects. He also mentioned medical cannabis, but that there is no science based research that proves or indicates that it has any effect on dystonia. Tom also stated that physical therapy in addition to medical treatment have proven to be very effective in many cases. It is important than that the physical therapist has good knowledge of dystonia. DBS surgery can be very effective for more severe cases or cases that have little effect of botulinum toxin treatment. He also believes there can be huge progress within treatment in the future.

All presentations were livestreamed and video recorded and are available on the Dystonia Europe Youtube Channel: <https://www.youtube.com/user/DystoniaEurope/videos>

Sunday morning was the last session for the D-DAYS 2020. There were Sharing Best Practices and a workshop on Strategy planning by Noemi Ambrus. After Noemi's presentation we were divided into groups to work on the different elements of Strategy planning. There were many good discussions and ideas.

*Merete Avery
Operations Manager
Dystonia Europe*

Latest News



Dystonia DAYs 2019 in London



The Dystonia Society UK and Dystonia Europe.



www.dystonia-europe.org

Latest News



www.dystonia-europe.org

Dr. Anne Weissbach Receives the David Marsden Award 2019

Every other year Dystonia Europe gives out the DMA (David Marsden Award) to a young Scientist that has published a paper on dystonia.

Our congratulations to Dr. Anne Weissbach, Institute of Neurogenetics in Lübeck, Germany, and the David Marsden Award 2019 for her paper: "[Alcohol improves cerebellar learning deficit in myoclonus-dystonia: A clinical and electrophysiological investigation](#)"

Dr. Weissbach was presented with the award by Dystonia Europe President Merete Avery at the Dystonia-Days 2019 held in London 5th July.

Dr Weissbach expressed her thanks to DE and Ipsen for the award and then presented the work of her research.

About the winner

Dr. Weissbach is a neurologist and clinician-scientist in Prof Christine Klein's team at the Institute of Neurogenetics in Lübeck. She studied Medicine at the University of Lübeck and finished her residency in Neurology at the Clinic of Neurology at the University Clinic Schleswig-Holstein. During her scientific education, she was trained in transcranial magnetic stimulation and blink reflex conditioning at the research laboratory of Prof. Robert Chen and Prof. Anthony Lang in Toronto, Canada and the Neuroscience Section of Prof. Münchau and Prof. Bäumer at the Institute of Neurogenetics in Lübeck, Germany.

Dr. Weissbach has a particular interest in the neurophysiological characteristics of monogenic forms of dystonia, that can serve as a model disease for currently genetically undefined (idiopathic) forms.

About the research

Currently, the pathophysiology of dystonia is still largely unknown, thereby impeding the development of causal treatment options. In recent years, growing evidence has emerged, pointing towards the concept of dystonia as a network disorder and emphasizing the specific importance of subcortical nodes, including the cerebellum in the pathogenesis of a subgroup of dystonias.

The lack of a clear understanding of the defective subcortical neural basis of dystonia and its possible modulation is, at least partly, explained by a paucity of neuropathologically delineated disease mechanisms. However, for myoclonus-dystonia (M-D) due to mutations in the *epsilon-sacoglycan*(SGCE) gene several important clues have emerged: At the molecular level, SGCE is highly expressed in gamma-aminobutyric acid (GABA)-ergic synapses of the cerebellum and additionally structural, functional and metabolic studies suggested cerebellar abnormalities in these patients.

Interestingly, the majority of patients report a remarkable decrease of motor symptoms after intake of alcohol, which acts as an indirect GABA agonist.



Prof David Marsden



Latest News

We therefore investigated 17 SGCE-positive M-D patients, who suffer from childhood-onset, often debilitating generalized myoclonic jerks and segmental dystonia and 21 matched healthy control subjects. We used classical eyeblink conditioning, a form of cerebellar-associative motor learning, that has been proven to involve the cerebellar interposed nucleus and cerebellar cortex and blink reflex recovery cycle, representing pontine/medulla oblongata-basal ganglia circuits. All measurements were carried out before and after alcohol intake, including extensive clinical video-based investigations with results being evaluated by three blinded movement disorder specialists.

In contrast to healthy controls, M-D patients showed significantly reduced eyeblink conditioning at baseline that was normalized by the intake of alcohol. Of note, alcohol also significantly reduced motor symptoms in these patients. Blink reflex recovery was normal at both time points.

Through our work we were able to establish an *in vivomodel* for a cerebellar deficit in dystonia, in which mutations in the *SGCE* gene cause a GABAergic deficit due to Purkinje cell dysfunction resulting in a disinhibition of classical eyeblink conditioning pathways that were temporarily compensated for by acute GABAergic substitution by alcohol intake. The combination of our findings suggests a crucial role of cerebellar networks in the generation of symptoms in these patients and will serve as a model opening up new avenues for the development of novel pathophysiological concepts and treatment strategies in dystonia.

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



DMA Winner Anne Weissbach

MyDystonia Receives a Prize for Patients' Empowerment

Active Citizenship Network held its prize ceremony of the 2nd Edition of the European Civic Prize on Chronic Pain at the Concert Noble in Brussels. The four categories were: Patients' Empowerment, Innovation, Professional Education, Clinical Practices.

Dystonia Europe had submitted an application for the Patients' Empowerment Prize for the project MyDystonia. And we were selected by the Jury!

It was a great honor to receive the prize from Ilaria Giannico (Secretary-General of European Union of Private Hospitals) and Liisa Jutila, Vice-President of PAE – Pain Alliance Europe, at the opening ceremony of the SIP 10th Anniversary Conference.

Dystonia Europe President Adam Kalinowski had made a video-recording explaining MyDystonia and how it works. This was shown to the audience before Monika Benson was asked up onto the stage to receive the prize.

Jury's motivation:

"Good sensible project with great organization to overcome identified obstacles. It is a superb opportunity for increased communication between patients and physicians and improved collaboration between patients with dystonia across Europe."

"Dystonia Europe introduces the patient to a diary with an interaction with the other patients and doctors reassuring them. The APP is very fast to complete, taking into account their condition. Moreover it is a global and evolving APP gathering information. It will include a very important population: kids!"

"Could become standard of documentation for dystonia and related pain features."



Dystonia Europe receives the MyDystonia prize.

From left Vice President Pain Alliance Europe Liisa Jutila, Finland, Monika Benson Dystonia Europe and Ilari Giannico, Secretary General of European Union of Private Hospitals.

Latest news



Director of Active Citizenship Network Mariano Votta

In Monika's thank you speech she included Active Citizenship Network and the Jury for selecting the Dystonia Europe project, the company Merz who believed in the idea and fully supported the project, the Dystonia Europe Board and Team and the MyDystonia Ambassadors for all their hard work to realize the project.

Last but not the least she thanked the MyDystonia users. "Their feedback has inspired us to continue our work and improve the APP and very soon the next version will be launched – MyDystonia2.0.", she said. The Dystonia Europe Board and Team are very proud of this prize and now looking forward to the next steps. Together with the prize Monika Benson was awarded an Honorary Membership of the Pain-Euro Mediterranean Coalition.

*Monika Benson
Executive Director
Dystonia Europe*



Prize Winners

Professor Pisani from Rome receives The Bachmann-Strauss Prize for Excellence in Dystonia Research 2019

Dystonia is a distinct movement disorder, a clinical entity determined by genetic and environmental factors. However, dystonia is commonly found as a disabling symptom of Parkinson's disease. Indeed, up to 30% of Parkinson's patients can exhibit dystonia as a presenting symptom, or even as a motor complication during the course of the disease.

Since 2014, the the Michael J. Fox Foundation for Parkinson's Research (MJFF) established a collaboration with the Bachmann-Strauss Dystonia and Parkinson Foundation, an US-based organization, whose co-founder, Bonnie Strauss helped fund several scientific activities over the past decades. Last November 16, 2019, in New York City, the MJFF awarded with the fifth annual Bachmann-Strauss Prize for Excellence in Dystonia Research two clinician scientists, Prof. Antonio Pisani, MD, PhD, professor of neurology at the University of Rome "Tor Vergata" in Italy, and Prof. David G. Standaert, MD, PhD, professor and chairman of neurology at the University of Alabama at Birmingham in the USA.



*Prof. Antonio Pisani, MD, PhD,
Professor of Neurology at the
University of Rome "Tor Vergata",
Italy*

*Photo: Filip Wolak / The Michael J. Fox
Foundation*

*Gathered on stage at the prize
ceremony (from left) MJFF CEO
Todd Sherer, PhD; prize winners
David G. Standaert, MD, PhD, and
Antonio Pisani, MD, PhD; Michael
J. Fox; Bonnie Strauss; and Tom
Strauss*

*Photo: Filip Wolak / The Michael J.
Fox Foundation*



Latest news

Pisani and Standaert have been working together for the past 15 years, publishing the first evidence of their scientific results in 2006. Since then, they have published about 10 articles on the pathophysiology of dystonia. Their work examined the role of different neurotransmitter activity in dystonia, in particular relationship between dopamine and acetylcholine, two major neurochemicals involved in synaptic transmission in the basal ganglia.

Both Pisani and Standaert are also practicing clinicians, therefore their research has a profound translational approach, trying to translate their findings from the bench to the bedside and vice versa.

The award will allow them to continue their productive collaboration, with the aim to further advance our understanding in the pathogenesis of dystonia, and therefore find a pharmacological therapy for all people suffering from dystonia.

The Bachmann-Strauss Prize for Excellence in Dystonia Research is awarded annually to recognize profound contributions to dystonia research.

About the prize:

"To broaden public awareness and recognize key scientific discoveries in dystonia"



Drs. David G. Standaert (second from left) and Antonio Pisani (middle) received the Bachmann-Strauss Prize for Excellence in Dystonia Research from leaders of The Michael J. Fox Foundation and the Bachmann-Strauss Dystonia and Parkinson Foundation at an event in New York City in November.

Photo: Filip Wolak / The Michael J. Fox Foundation

Dystonia Europe London 2019

This year London hosted an outstanding meeting of the Dystonia Europe (DE) family. People with dystonia, their loved ones, physicians, nurses, speech therapists, physiotherapists gathered to learn, teach and experience the magic of D-Days.

The conference in general, was divided into two parts: patient's experience and scientific update. Merete Avery, The President of Dystonia Europe, made an introduction on the vision of DE, which is to improve the quality of life for people with dystonia while supporting the search for cure. She also stressed the mission to promote education and research, raise awareness and spread information on dystonia.

The patients and their families shared personal experiences on their journey with dystonia. This was an incredibly meaningful and stirring part of the D-Days. Sam, whose daughter is affected by dystonia told about the process of getting the proper diagnosis and then adjusting the school to the little girl's needs. She was able to join school trips in her wheelchair, which gave her more independence and in this regard she started to be part of class. Her parents also organised school awareness week to familiarise the school community with dystonia and help others to understand the disease. Importantly, Sam would like to raise awareness that non-motor symptoms (e.g. depression, apathy) may also occur in dystonia and be equally as disabling as the motor symptoms.

We heard from Nick who started to drag his leg at the age of 7. The condition was not recognised in the very beginning. This under-recognition of dystonia symptoms is one of the most striking problems. Nick believes that the education in healthcare should be improved to prevent delays and harms caused by misdiagnosis. This should reduce patient's stress related to this unexpected life situation.

The third person who kindly shared her story was Tully, diagnosed with cerebral palsy. At the age of 13 she noticed foot dystonia. A year after she was wheelchair bound. She was diagnosed with generalised dystonia. Sport was always a major part of her

life and even though it was difficult to continue swimming, she challenged herself and won a golden medal in 2018.

During the scientific part the audience heard experts in the field of dystonia. The first speaker was Prof. Tim Adlam from University College of London with the very important topic of "Technology for capability: Enabling exploration". In the research, he focused on adaptive technology – how can the children with disabilities be able to move and explore? He designs an adaptive seating technology (KiTe) which provides support functions e.g. to help children to reach for toys, make a choice on what they are willing to do. In the future perspective, technology should bring the solution to help children to be able to play with other children. The beautiful underlying rationale is that it's a children's right to have freedom. A freedom to move.

Karen Esposito, an extremely enthusiastic speech and language therapist, encouraged all the audience to find their voice. In her lecture she presented different types of laryngeal dystonia and stressed how important it is to have the proper recognition and therapy provided by a multidisciplinary team.

Hortensia Gimeno, who is an occupational therapist, showed results of her study on Cognitive Orientation to daily Occupational Performance Approach (CO-OP). This is a very important study, where participants select their own goals, which again changes the approach to patient centered care. CO-OP was feasible and accepted by children and their families. At the end of therapy improvement of skills was observed.

Doctors Jean-Pierre Lin and Francesca Morgante spoke about advance treatment for dystonia. Dr. Lin elaborated on who is a perfect candidate for Deep Brain Stimulation (DBS). He argued that maybe the treatment should be offered when the brain still has a plasticity potential.

He referred to an analogy with children who underwent cochlear implantation. If it's done before the age of 5 children can still develop language, if later it's unlikely that children will develop speech. The age per se shouldn't be a limit for DBS.

Dr. Francesca Morgante showed the criteria for DBS in dystonia: (1) Poor quality of life and severe disability; (2) Factors impacting on quality of life in cervical Dystonia are many; (3) Abnormal head posture not corrected by BoNT; (4) Severe pain impacting on daily activities and/or sleep; (5) Severe head tremor (functional and social disabling). It's also important to know what are the potential adverse events related to DBS (1) bleeding (very rare in DBS for dystonia); (2) infections; (3) device related complications, which are more common in children than in adults. The most important message is that good selection of patients to DBS increases good outcome after DBS.

Dr. Marie Helen Marion presented the golden standard of treatment in dystonia, which is botulinum toxin injections. She stressed that the first injection will not be the best. Injections must be customised to make sure that the second injection will be better. It's important to understand that BoNT – “is not a quick fix” doctors and patients expectations may need to be adjusted and at least discussed before the start of the treatment.

Dr. Kathryn Peall and Prof. Marjan Jahanshahi focussed on non-motor symptoms of dystonia including depression, anxiety disorders, sleep impairment, pain and cognitive impairment. It is very important to recognise non-motor symptoms in dystonia because they can be as disabling as motor symptoms.

Prof. Mark Edwards presented a lecture on rehabilitation in dystonia. Dystonia is not a problem of muscle strength but mostly a problem of movement control. As such, the brain has mis-learned how to move. This gives an opportunity for relearning. The evidence from research on rehabilitation in dystonia is limited. However, there is evidence on the beneficial influence of physiotherapy on cervical dystonia (delivered 5 times per day). Prof. Tom Warner underlined that dystonia is diagnosed based on clinical judgment.

There is no test to diagnose dystonia. Genetics can only help to specify the dystonia. It is important to accurately characterise dystonia clinically (e.g. age of onset, distribution, temporal pattern, variability, isolated vs combined) and based on etiology (e.g. nervous system pathology, genetic or acquired).

Prof. Maja Relja presented the results from the international, online survey on the recognition of dystonia symptoms and accessibility to the treatment. The survey was translated into 24 languages and until now approximately 3000 people with dystonia shared their responses. This gives an important insight into the quality of care in Europe. Additionally, Prof. Relja showed that in Croatia tremendous progress was made, over the last 10 years, after she started an educational program on dystonia as a part of formal training for GPs. This shortened the time to diagnose dystonia and improved referral rates.

In conclusion, the take home message of this beautiful event is that education is the key step to improve awareness of dystonia.

*Katarzyna Smilowska MD, PhD
Silesian Center of Neurology
Katowice, Poland*



Dystonia Session at European Academy of Neurology in Oslo

Last June EAN 2019 - the European Academy of Neurology Conference was held in Oslo. Dystonia Europe organised one of the very first sessions with live streaming - <https://www.youtube.com/user/DystoniaEurope> .

Merete Avery, President of Dystonia Europe, opened the session and invited two outstanding speakers: Professor Maja Relja from Croatia and Professor Kailash Bhatia from the UK. Professor Maja Relja presented the preliminary results from her international online survey on the recognition of dystonia symptoms and accessibility to treatment. The survey was translated into 24 languages and closed last October. Until now more than 3000 people with dystonia shared their responses. This gives an important insight into the quality of care in Europe. Additionally, Prof. Relja showed that in Croatia tremendous progress was made over the last 10 years since she started an educational program on dystonia as a part of the formal training for GPs. This shortened the time to diagnose dystonia and improved referral rate. The education is the key step to improve awareness of dystonia.

Professor Bhatia gave a lecture on “Clinical evaluation of dystonia”. He started with a new classification of dystonia proposed by prof. Albanese et al. in 2013 (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3729880/>). The main aim of the new classification is to improve clinical characteristics of dystonia and organise current knowledge regarding the etiology of dystonia. Additionally, the term “primary” and “secondary” dystonia is no longer in use and has been replaced by isolated dystonia and combined dystonia. The category of isolated dystonia includes: blepharospasm, cervical dystonia, oro-mandibular dystonia, laryngeal dystonia, and task specific dystonia. It’s also worth mentioning that tremor is a common feature of dystonia and tends to affect the same body part. Combined dystonia is associated with other neurological or systemic signs (e.g. parkinsonism, ataxia, peripheral neuropathy). Professor Bhatia also presented patients videos to show peculiarity and complexity of the different

types of dystonia for example: sensory gesture (such as touching one's chin) or task specific dystonia. He also elaborated on the diagnostic test that should be performed such as MRI or ceruloplasmin to exclude Wilsons disease. However, clinical examination remains irreplaceable. In terms of treatment he recommended botulinum toxin injections, which are considered as a golden standard. Injections should be performed in experienced centres. It’s very likely that only the second or third treatment will be completely beneficial.

The dystonia session was a great success. The lectures were very interesting and educational. It was also a nice opportunity to meet the big dystonia family again.

*Dr. Kasia Smilowska, Silesian Center of Neurology
Katowice, Poland*



From Left, Monika Benson, Executive Director Dystonia Europe, Prof Kailash Bhatia and Prof Maja Relja

Tyler's Hope Think Tank

On November 12th, 2019, the 10th “Tyler’s Hope Think Tank” took place at the University of Florida, USA. This year around the topic of “DYT-TOR1A dystonia: *Finding a road map to cure dystonia*”. This meeting and the Tyler’s Hope Foundation are initiatives from the Staab family. The two eldest Staab children, Tyler and Samantha, developed generalized dystonia as young children. Tyler’s was so severe that he was (at the time) the youngest ever child to receive surgery for deep brain stimulation in the USA. The children are now at university, and the “Tyler’s Hope Foundation” continues to work with neurologists at the University of Florida to raise funds for dystonia research, and to optimize clinical care.

The meeting opened with a tour of the new Norman Fixel Institute for Neurological Diseases outpatient clinic at the University of Florida in Gainesville, the same town where the Staab family live. The building was architecturally designed for patients to attend clinic with their families. It integrates different specialties in one building: a patient can see a Neurologist, DBS specialist, physiotherapist, and mental health doctor all in one visit. This was made possible by fund raising, and the long-term commitment of the University of Florida, especially Dr. Michael Okun, Chair of Neurology.

The Think Tank is a meeting for dystonia researchers. Many attendees commented on how critical it is that they get together to share their newest findings with each other. This year it was also attended by representatives from the USA National Institutes of Health, and the Dystonia Medical Research Foundation.

DYT-TOR1A dystonia is a major topic for basic dystonia researchers, even though it is a rare type of dystonia. This is because researchers know the genetic mutation, and therefore can study how this disrupts cell and brain function. The Tyler’s Hope Foundation focus on DYT-TOR1A dystonia because this is the type of dystonia in their family. DYT-TOR1A dystonia is notable because it was the first

dystonia where a genetic cause was found. This discovery was made in 1999 by Dr. Laurie Ozelius (Harvard University). She attended the meeting as well, now 20 years after her seminal discovery. Its importance cannot be understated. It was the first absolute proof that genetic mutations can cause dystonia, in turn showing that dystonia has a real biological basis.

The first session was on the “Cellular effects of the torsinA protein”, with talks from Dr. Ellen Hess (Emory University, USA), Dr. David Standaert (University of Alabama, USA) and Dr. William Dauer (Southwestern University, USA). These researchers all work with mice that have been genetically engineered to carry the DYT-TOR1A mutation, and their research teams investigate what happens in the brains of these mice. All three groups are working towards a better understanding of what goes wrong in neurons when the TOR1A gene is mutated, with the expectation that this will point to new targets for drugs to treat the problem. The groups each presented data showing that a brain area called the striatum is affected. The striatum is a complex brain area that contains different types of neurons that release different chemical signals, and communicate with different brain areas. The researchers want to understand which specific neurons are affected. Dr. Dauer also focuses on *when* the problems first occur, and presented evidence that things go wrong in early brain development.

The second session was on the topic of “Gene therapy possibilities”. This is still at early stages for dystonia. Dr. Matthew Farrer (University of Florida, USA) explained why researchers focus on genetic forms of dystonia.

Research

The genetic researchers also emphasized that some dystonia mutations cause different symptoms in different patients, and thus are not perfect predictors of what a patient can expect. They discussed the different ways that other genes and mechanisms interplay with a genetic mutation to determine symptom type and severity. Dr. Ozelius and Dr. Farrer also both share the view that most dystonia mutations remain undiscovered to date.

The final session was “DYT-TOR1A dystonia: Novel treatment approaches”. I presented my team’s work on signaling abnormalities that we have identified in cells of patients, as well as in dystonia mice. This gives us a new so-called “druggable target”. The next steps are to find a drug that removes the abnormal signals. Dr. Nicole Calakos (Duke University, USA) talked about a specific stress-related molecular pathway that can help reduce dystonia related phenotypes, and how she is screening for new drugs.

The final talk was from Dr. Takashi Tsuboi (University of Florida, USA) who had reviewed patient records to identify factors that correlated with good and poor responses to deep brain stimulation.

Altogether, this was a very productive meeting for dystonia researchers. From all across the globe, scientists shared their results, showing real progress in our understanding of the biological mechanisms underlying dystonia. Exchanging data and thoughts is key to further push forward the many different research efforts taking place in individual laboratories.

*Rose Goodchild, Ph.D.
Group Leader and Associate Professor
FDR Chair for Dystonia Research
VIB-KU Leuven Center for Brain and Disease Research,
Belgium*



Participants at the Tyler’s Hope Think Tank

7th Biennial Workshop on Dystonia and Parkinson's Disease in Rome

This workshop took place on September 18th and 19th; its planner was Prof Antonio Pisani (Tor Vergata University, Rome) who has organised this event since 2007.

Dystonia and Parkinson's disease have traditionally been viewed as distinct movement disorders. However, compelling clinical and experimental evidence suggest that these diseases can share, at least to some extent, common pathogenic features.

As for the past workshops, this biennial meeting has been focussed on clinical and scientific aspects bridging Dystonia and Parkinson's disease (PD). The primary aim of this meeting has been to provide a complete overview of these potential interactions. This year's title was "Cellular and molecular targets for novel therapeutics" and the sessions were focused on:

- Dystonia and PD: new genes, new therapeutics targets (are gene products leading to discoveries for novel therapeutic agents?)
- Novel cellular and molecular targets (do dystonia targets apply for PD?)
- Novel technologies for dystonia and PD research
- Molecular targets for dystonia and PD: clues from treatable inherited disorders.

More than 30 doctors from various countries (USA, Canada, France, Germany, United Kingdom, Belgium, Spain and Italy) spoke about and discussed the above topics with great interaction between speakers and chairs, aiming to fill the gap between basic and clinical neuroscience. One of the speakers was Dr. Niccolò Mencacci (Chicago Northwestern University) who in 2017 received the David Marsden Award during the D-DAYS in Rome.



Research

The workshop was addressed to neurologists, biologists, physiotherapists, neurophysiopathologists and geneticists; there were many of them and mostly young. The training objectives concerned: care and diagnostic pathways, rehabilitation and medical reports.

The workshop was supported by Dystonia Medical Research Foundation, International Parkinson and Movement Disorders Society, Parkinson Disease Foundation and by The Bachmann Strauss Dystonia and Parkinson Foundation, whose President Mrs. Bonnie Strauss attended the meeting and reminded us that she had her diagnosis of cervical dystonia 7 years after its first symptoms.

As usual the workshop was held in an outstanding place: the “Nobile Collegio Chimico Farmaceutico” which is a church of the 9th century built in a Roman temple facing the Forum.

In 141 AD Emperor Antonino built a temple in honour of his wife Faustina and after his death the temple was dedicated to him too, and it's still possible to read this on the lintel. In the 9th century the temple became a Catholic church dedicated to St. Lawrence and in 1429 Pope Martino granted it to the Roman Apothecaries University who still own it. The former temple door, which now is a window, provides an amazing view of the Roman Forum from an unusual and usually not accessible perspective.

*Maria Carla Tarrochi
Vice President ARD
Italy*



Participants at the Rome meeting.

New Research Ventures For Musician Dystonia

Musician Dystonia is a focal task-specific variety of the disorder which affects up to two percent of musicians, both professional and amateur. This is a far greater occurrence than afflicts any other fine motor skill occupation. These “Writer’s Cramp” dystonias can strike surgeons, chefs, dentists, tailors, writers, and even professional golfers when putting. As with most dystonias, there is no prevention or cure, and, to date, no completely successful therapies.

The Musicians With Dystonia Program of the Dystonia Medical Research Foundation (DMRF) was established in 1999 to provide information, support and medical referrals to this devastated population. In the last 20 years, we have contributed dozens of articles to neurological journals and music publications, and presented at countless symposia around the world. During our travels, a wonderful highlight has been meeting and visiting with the Dystonia Europe Presidents past and current, from the delightful Alistair Newton and Monika Benson to today’s Merete Avery, and the dear, late Didi Jackson.

The DMRF has been funding research protocols to treat, and ultimately cure, dystonia since 1976. The Dystonia-afflicted clarinetist James Kilik, a wonderful friend of the Musicians program, left an incredibly generous bequest to the Foundation to fund musician dystonia research when he sadly passed away in 2015. Late last year, the first important grants were chosen and funded. They are:

Modulating the Functional Connectivity of the Cerebellum in Musician’s Dystonia, Robert Chen, MA, MSc, MB BCh, MB BChir, University of Toronto
Dr. Chen is utilizing functional MRI to identify impaired connections between the cerebellum and parts of the brain that mediate movements, and will test whether these connections can be normalized by non-invasive brain stimulation. This is the first study to test the effects of cerebellar stimulation in musicians with hand dystonia.

A Study to Identify Kinematic and Force Measures Capturing Impairment in Musician’s Dystonia among String Players and Improvement with Retraining Therapy, Christine Kim, MD, Columbia University
Dr. Kim has studied retraining methods used with keyboard players, and hopes to better understand how dystonia affects timing, motion, and force of finger movements with string players. This research will then potentially develop successful retraining techniques for the very first time with violinists and other string performers.

We sincerely hope these exciting research initiatives prove beneficial to musicians afflicted with hand dystonia. There are also other important projects under DMRF medical review at this time. We will keep you apprised of the progress!

Glen Estrin
President, Musicians With Dystonia
Dystonia Medical Research Foundation
Musicians@dystonia-foundation.org

Glen Estrin with pianist Leon Fleisher (center) who is the most renowned musician with dystonia, and Steven Frucht, MD, the movement disorder neurologist, Head of Movement Disorders at New York University.



The following articles, page 21–25, 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.

Predicting Antidystonic Effects of Deep Brain Stimulation (DBS) Using Probabilistic Maps



Deep Brain Stimulation (DBS) is an established therapy for primary generalized and cervical dystonia, with an average dystonia score improvement of 50–60% as demonstrated in the literature^{1–5}.

The factors that contribute to the therapy outcome are: **patient selection criteria, variability in electrode placement and stimulation settings**. The search for optimal stimulation parameters is complicated by the fact that stimulation-induced effects onset with a significant delay⁶.

A recent multicenter study conducted by **Dr. Reich and colleagues** (Julius-Maximilians-University Würzburg, Germany, <https://visualdbslab.com>) presents a novel method for contact selection based on proba-

bilistic stimulation maps⁷. The outcome of DBS therapy in 87 dystonia patients was analyzed and the volume of stimulation was aggregated into 4 outcome groups. The average improvement of dystonia motor score was $50.5 \pm 30.9\%$ in cervical and $58.2 \pm 48.8\%$ in generalized dystonia, while 19.5% of patients did not respond to treatment (<25% benefit).

There was a significant correlation between the dystonia score improvement and the anatomical area of stimulation. The highest motor function improvement could be found in a small region covering the ventroposterior globus pallidus internus (GPI) and adjacent subpallidal white matter.

Research

Probabilistic stimulation maps were based on lead location and the volume of tissue activated with the help of SureTune™ software (Medtronic PLC). The stimulation volumes were subsequently normalized into common space followed by voxel-wise ranking for outcome distribution using a self-programmed MATLAB tool. The resulting probabilistic maps were used to predict individual outcomes in DBS dystonia patients showing robustness between the predicted and the observed clinical improvement. The predictions deviated on average by $16.9 \pm 11.6\%$ from the

observed clinical improvement.

As per the authors, these results emphasize the potential of applying probabilistic stimulation maps in the search for optimal therapeutic volume for pallidal neurostimulation. This technique is a topic of interest for computer-assisted planning and programming of deep brain stimulation.

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



See the device manual for detailed information regarding the instructions for use, the implant procedure, indications, contraindications, warnings, precautions, and potential adverse events, If using an MRI SureScan® device, see the MRI SureScan® technical manual before performing an MRI. For further information, contact your local Medtronic representative and/or consult the Medtronic website at medtronic.eu.

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- 2** Volkmann J, Wolters A, Kupsch A, Müller J, Kuhn AA, Schneider GH et al. . Pallidal deep brain stimulation in patients with primary generalised or segmental dystonia: 5-year follow-up of a randomised trial. *Lancet Neurol* 2012; 11: 1029–38.
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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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Other News

Inflammatory processes have recently been found to be involved in the etiopathology of most neurological diseases. This does not only account for the classical neuroimmunological diseases such as for example multiple sclerosis, but also to diseases like Alzheimers disease, ALS, epilepsy, movement disorders, stroke and migraine, conditions previously considered as “non-inflammatory”.

Dystonia Europe had a stand at EAN and many visitors from European countries and some from outside Europe stopped by the stand. DE focus on networking, distribute brochures, newsletters and spread awareness on dystonia and share the important work of patient organisations.

This year The Norwegian Dystonia Association assisted DE in this work. The President of NDF, Johan Arn-

finn Warvik, The Treasurer Sissel Buskerud and Board Member Rolf Villanger all joined DE in spreading information and networking to inform what the dystonia patient organisations do, in addition to strengthen the relationships with our partners.

*Merete Avery
Operations Manager
Dystonia Europe*

*Right:
Prof Maja Relja
and
Prof Marina de
Koning-Tijssen*



*Sissel Buskerud, Treasurer and Johan Arnfinn Warvik,
President Norwegian Dystonia Association*



*EFNA at EAN, Elizabeth Cunningham,
Cathalijne van Doorne and Joke
Jaarsma*

Other News

Summer Think Tank 2019

Dystonia Europe Summer Think Tank 2019 was held in Lund, Sweden last September, in the middle of Dystonia Awareness month. The board had met a day earlier for the first board meeting of the new board.

Think Tank members joined later in the day in time for dinner. Members of the Think Tank are our Platinum sponsors: Boston Scientific, Ipsen, Medtronic and Merz. Unfortunately the representatives of Merz and Medtronic could not attend this time.



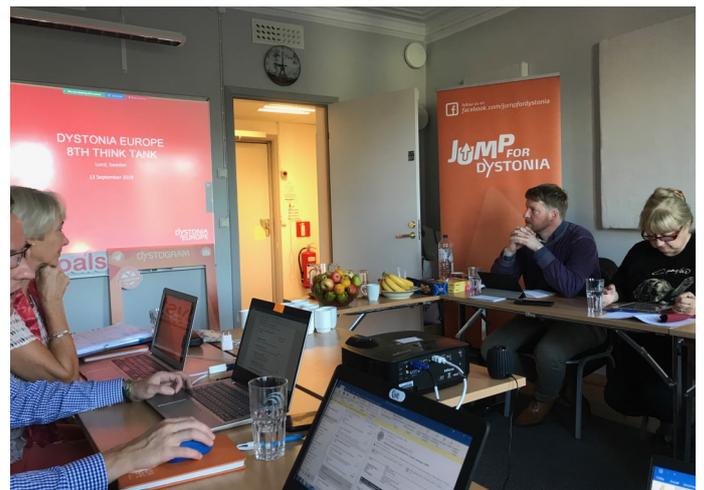
The Think Tank Participants make a «Jump for Dystonia»

It was a very fruitful meeting where focus was on what to do for next year's Dystonia Awareness month 2020. After lunch we put our orange t-shirts on and went outside in a sunny Lund and did some jump for dystonias together.

We thank everybody for their support, great discussions and an inspiring brain-storming session! Together we work to raise awareness of dystonia, share information, support education and research & to improve the lives of people living with dystonia!

Next Think Tank of Winter 2020 will take place on 14 February in Lund, Sweden.

*Monika Benson
Executive Director
Dystonia Europe*



The participants of the Summer Think Tank in Lund, Sweden.

Other News

MDS Congress 2019 in Nice

The international congress of the “International Parkinson and Movement Disorder Society” has taken place this year in Nice, in the south of France.

Monika Benson and I decided to cover this event by holding a booth for Dystonia Europe and Amadys together.

This congress is one of the biggest for international neurologists and movement disorders, and has attracted this year some 6 000 neurology specialists from all over the world together.



Visitors at the stand collecting information and networking.



Executive Director Monika Benson and Vice President Edwige Ponsel, Dystonia Europe

It is a real opportunity to raise dystonia awareness to neurologists or other specialities (physiotherapists, nurses...) from Europe or from other continents, to talk about treatments, patients care, rehabilitation, patients' organizations if any, etc.



Dr Kasia Smilowska and with Boston Scientific representative from France.

Other News

We have been able to propose English and French documentation or flyers at the same dystonia meeting point (J.P. Bleton's rehabilitation guides for cervical dystonia, B. Girard's blepharospasm books, flyers for the International Dystonia Symposium in Dublin in June...).

We have had the opportunity to meet some well-known specialists such as Pr M. Relja, Pr M. de Koning-Tijssen, Pr M. Vidailhet, Pr E. Moro, Pr J.C. Corvol, Dr J.P. Bleton, Dr C. Vial, our David Marsden Award winner 2017 Dr N. Mencacci and many others. There were also visitors from across Europe and various countries such as Taiwan, Algeria, Israel, Guatemala,



Edwige Ponseel and Dr J.P. Bleton



Jump for dystonia at the charity walk along the Nice beach "Promenade des Anglais"

Iran, India, Brazil, USA...

The evening before the start of the congress there was a charity walk: The Movement Disorders Awareness 5K Charity Run/Walk along the famous Promenade des Anglais in Nice, to raise funds for the French Neurologist's Movement Disorder Society "SOFMA". The event was organized by Boston Scientific and DE had a stand with information material. Monika had performed the walk successfully! It was fun and great to see all these professionals, from every generation, running or walking together, despite the rain.

One of the next "must be" places will be again in France and Paris, in May next year, for the European Academy of Neurology (EAN) with some 8 000 expected specialists!

Edwige Ponseel

Dystonia Europe Vice President and Amadys President



Edwige Ponseel, Prof Elena Moro and Monika Benson at the charity walk "Promenade des Anglais"



Other News

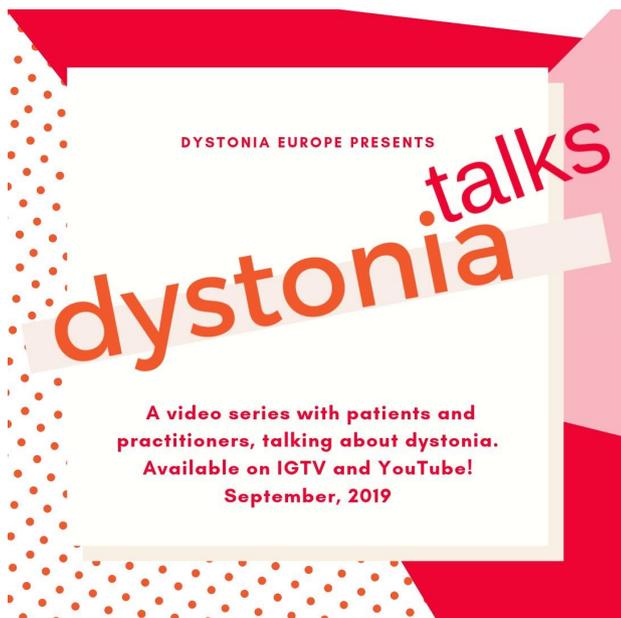
Dystonia Awareness Month 2019 & Dystonia Talks



First of all a great THANK YOU to all of you who took part in our Dystonia Awareness Month on-line activities last September. The success would not have been possible without your support and help in sharing our posts, videos, quotes etc.

For the third year Dystonia Europe was taking part in the Dystonia Awareness month.

At our last conference D-DAYS 2019 in London we launched **Dystonia Talks** – a digital project to raise awareness of dystonia and funded by a grant from Boston Scientific Foundation.



During the D-DAYS we invited patients, carers, dystonia patient leaders from across Europe, experts, researchers and industry to be interviewed and video-recorded. A total of approximately 20 videos are being developed. Eight of those were ready to be published during our Awareness Month. They can be found on our Youtube Channel:

The remaining videos will be published starting in December this year.

We are grateful to Boston Scientific Foundation for giving us the opportunity to work on such an important project in order to increase awareness and understanding of dystonia. We believe these videos can be re-posted, shared and used for the next few years.

**Boston
Scientific
Foundation Europe**

www.dystonia-europe.org

Other News

Other posts during Dystonia Awareness Month included inspirational quotes, facts, and articles from our Dystonia Europe newsletter. This very diverse and interesting content was published throughout the month on all our social media channels: Facebook, Twitter, Instagram and for the first time we were also more active on Linked-In.

During the month the amount of followers on our social media channels increased:

- Facebook from 3776 to 4046
- Instagram from 647 to 844
- Twitter from 575 to 673

Facebook average reach/day increased from 2018:

- Sept 2018 – 2586
- Sept 2019 - 4026

The most popular posts on Facebook were the posts in fact format containing inspirational quotes and various dystonia facts. They had the most viewers and shares.

We are very pleased with this year's awareness activities and we are already looking forward to September Awareness month 2020.

If you have any special ideas of what to do on-line or in your country please send us an e-mail and let us know at sec@dystonia-europe.org

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

*Monika Benson
Executive Director
Dystonia Europe*

@dystoniaeurope

cervical dystonia

(spasmodic torticollis)

causes involuntary movements of the head and neck. It is the most common form of dystonia and is typically treated with botulinum toxin injections.

Dystonia Awareness Month 2019 | #dystopedia

— DYSTONIA AWARENESS MONTH 2019 —

"Behind my smile
there's a story
you would never
understand."

– Unknown

@DYSTONIAEUROPE

www.dystonia-europe.org

Opening of DBS Educational Platform in Leuven

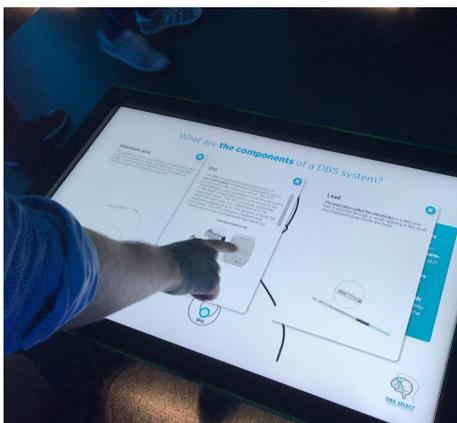
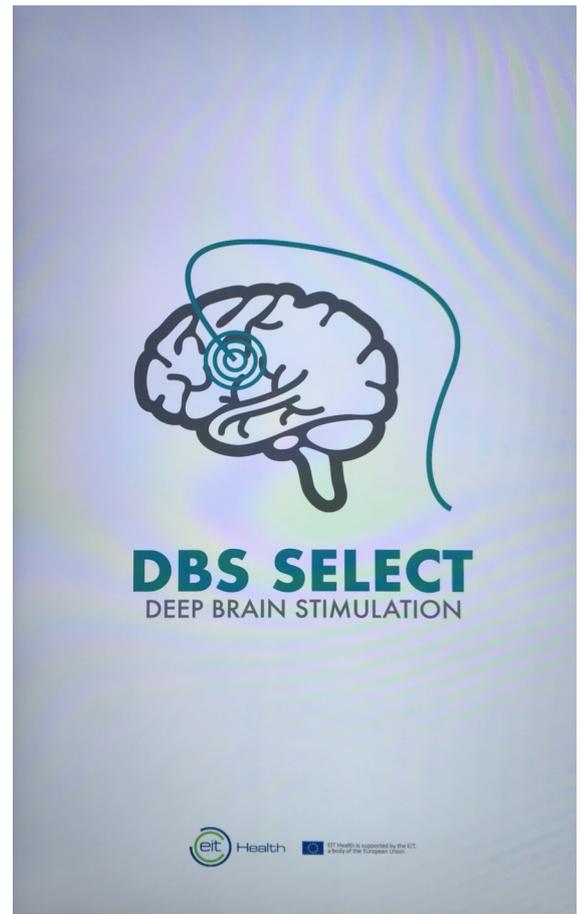
At the Health House in Leuven the first interactive patient education platform on Deep Brain Stimulation was launched – DBS Select.

The invited guests were divided into two groups and then taken on a tour to discover the DBS storyline following the patient journey from considering DBS, implant of DBS, and the outcome. Participants could learn about the most frequently asked questions on DBS; explore different brain anatomical structures, watch a movie about the DBS surgery; touch and feel the real devices and leads.

Health House has already now announced four different occasions for open visits at 17.00 on 17 December, 18 February, 21 April and 23 June. If you are a patient, health care professional near Leuven or in Belgium and The Netherlands take this opportunity to learn more about DBS treatment. You sign up at www.health-house.be/calendar

The next step of this project is to launch an on-line version and in other languages to make the educational platform reachable for patients from other countries as well.

Dystonia Europe will continue to follow the work of this project.



Boston Scientific Team from France and Belgium and Monika Benson, Dystonia Europe

Visit to a Dystonia Research Lab

Prof Rose Goodchild is one of the members of the Dystonia Europe Medical and Scientific Advisory Board and she had invited me to her LAB at the VIB KU Leuven, Center for Brain Research in Leuven, Belgium.

Since 2011 she has been leading a dystonia research group here. The 5-year project was funded by FDR (Foundation for Dystonia Research) together with Belgian public funding. The project was renewed in 2016 for another 5 year, until 2021.

Rose got involved in dystonia research at Columbia University in New York. Most dystonia research that takes place is done in the US. She thinks there should be more meetings organized for basic researchers so they can share their research with each other and discuss and network.

In Mid November Rose travels to Florida to take part in the Tyler's Hope Think Tank.

This is purely a research meeting with participating researchers sharing their findings in their latest research. What if we could organize a similar meeting in Leuven? Maybe every other year? To stimulate basic research in the field of dystonia, to inspire young researchers to join the exciting field of dystonia, to try and attract funding for dystonia research.

In this newsletter Rose is sharing the outcome of the Tyler's Hope meeting on page 17 and 18.

*Monika Benson
Executive Director
Dystonia Europe*



Prof Rose Goodchild

Other News

SIP 10th Anniversary Conference

The Societal Impact of Pain – SIP Platform was celebrating its 10th Anniversary last week in Brussels. SIP is a collaboration between: Pain Alliance Europe, European Pain Federation EFIC, Active Citizenship Network and Grünenthal.

The goal of SIP is to achieve improved care and pain management across the EU to reduce the societal impact of the disease, which touches upon all aspects of life. 1 in 5 people in Europe experience chronic pain. In Europe more than 150 million people suffer from chronic pain. Chronic pain costs the EU € 240 billion a year. For more information visit <https://www.sip-platform.eu/en>

About 100 participants had joined the one-day conference. Program included sessions on: Pain Research; Pain Education; Pain Employment; Pain as Health Quality Indicator.

Dystonia Europe attended this meeting for the first time and we think it can add value to our work since we already are working in partnership with EFNA (European Federation of Neurological Associations) and PAE (Pain Alliance Europe) for the BMP – Brain Mind Pain project.

*Monika Benson
Executive Director
Dystonia Europe*



EFNA President Joke Jaarsma



Monika discusses the EBRA project – European Brain Research Area - <https://www.ebra.eu> with Giovanni from EBC - European Brain Council.



SIP Participants

EU Activities

Capacity building on Empowering Leadership and Positive Organisational Governance EPF - Second Meeting Bulgaria

EPF held the second EPF Capacity Building Programme: Enabling Leadership and Positive Governance meeting in Sophia, Bulgaria in the beginning of September.

The first meeting was in Brussels in March 2019, and you can read more about the meeting in the DE Newsletter 1, 2019. The participants were leaders from countries throughout Europe, to mention some, Malta, Iceland, Spain, Bulgaria, Croatia, Serbia, Norway, Portugal, Poland.

At the first face-to-face meeting in Brussels we did both exercises in small groups and one on one. These exercises were geared to open up and see things from different perspectives than other training in leadership that I have attended.

After the first meeting in Brussels we had monthly one on one coaching sessions by Skype. These calls focused on areas that we as leaders felt were challenging or could be improved.

Then after the monthly coaching sessions it was time for the final face to face meeting in Sophia Bulgaria. Before the last coaching session each participant had prepared a presentation on the project they had worked on.

It was very obvious that despite different diseases we share many similar challenges with other patient organisations. For example in most organisations the work is carried out by volunteers: people who are either affected themselves or by a caregiver or a parent to somebody with an illness.

It is very important to come together at these kind of workshops to learn from one another.

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.



Teamwork and reflection



*Presenting the work with policies for external contacts
From left: Coach Lachezar Afrikanov and Merete Avery, DE*

*Merete Avery
Operations Manager
Dystonia
Europe*



Health is a Shared Global Value



Globalisation has created convergence of individual countries' health problems and, consequently, mutual dependence for generating solutions. This means that in today's world, we can no longer consider health of particular countries or regions, such as European Union (EU), in isolation.

Certainly, diseases know no borders and countries share many of the same health problems, though perhaps of different magnitudes. At the same time, the pool of resources for addressing these challenges is greater than ever before and opportunities for developing and sharing knowledge and research are unprecedented.

In light of this, it is no surprise that global health priorities are increasingly shaping the course of both EU policy and that of individual European countries. We see this especially in large policy portfolios focusing on:

1. *Non-Communicable Diseases* (NCDs) that are by far a leading cause of mortality and account for most healthcare expenses. Simply put, we live longer at a cost of developing (often more than one) chronic illnesses as we age;
2. *Sustainable Development Goals* (SDGs) – a collection of 17 global goals set by the United Nations in 2015 for the year 2030. Goal 3.4 aims to reduce premature mortality from NCDs by one third, and promote mental health and well-being;

Universal Health Coverage (UHC) meaning that all people have access to health services they need, a topic that has now become a key priority for World Health

Organization.

At EFNA we decided to look closer at these various international initiatives, and discovered that they have so far not prioritised neurology adequately. This means that the level of expected attention is not proportionate to the rich evidence that we have, demonstrating a huge burden of brain disorders.

Therefore, in 2018, while maintaining our main focus on Europe, we also began the strategic process of aligning our agenda with international priorities, dealing predominantly with the above mentioned global health movements.

This has coincided with a unique window of opportunity that brain health is now witnessing – in the 2018 UN Political Declaration on NCDs, mental health (including neurology) was added as the so called 5th NCD, along with cancer, CVD, diabetes and Chronic Respiratory Diseases- conditions that for nearly a decade had been constituting key global priorities.

However, the WHO approach regarding neurology is ambiguous. The terminology it uses is implicitly including neurological disorders within its internal and external texts on 'mental health' – with no explicit mention of 'neurology'- let alone the more encompassing term of 'brain health'.

Consequently, we realised that patients affected by neurological ill-health are still truly under-served and, more than ever, it is now important for the neurological community to demand that more clarity and visibility be given to neurological health.

5X5

DISEASES



Cardiovascular Disease



Chronic Respiratory Diseases



Cancer



Diabetes



Mental and Neurological Conditions

RISK FACTORS



Unhealthy Diet



Tobacco Use



Harmful Use of Alcohol



Physical Inactivity



Air Pollution

Without this it may fall out of the scope of global public health efforts.

With this in mind, in the course of 2019 we have been undertaking a number of actions to engage with WHO, its member states and EU leaders. EFNA met with WHO Europe representatives in Copenhagen and have had a number of visits to Geneva (where WHO global headquarters are), to engage with WHO and Geneva UN missions. We are also joining the [NCD Alliance](#) – an influential NGO operating at a global level, to represent the voice of neurological patients.

Last but not least, EFNA has [teamed up with the European Academy of Neurology, European Brain Council and World Federation of Neurology to issue a joint statement](#). This calls for more clarity, visibility and priority for brain health. It also points out a need to develop a more unified and comprehensive approach to promote brain health and curb the prevalence of brain disorders, with meaningful involvement of the patient community. We also asked to change wording that appeared in a draft text of the UN Political Declaration on the Universal Health Coverage, since adopted on 23rd September by Heads of States and Governments in New York. The early draft, in line with wording from 2018 NCD declaration, made references to mental health only. Upon our request this has been changed in the final version and now, in several places, the text includes a full reference to “mental disorders and other mental health conditions **as well as neurological disorders**”.

This encouraging achievement shows that together we can make a difference and EFNA will continue to push for more. We already have a number of exciting plans in the pipeline, including participation at the World Congress of Neurology in October, where a meeting of Global Neurology Alliance will take place. We are also planning more meetings in Geneva and will organise a policy meeting in the European Parliament in Brussels early next year. This will explore how EU policies can better align with a new international focus including neurology among other key disease areas.

As always, we count on your support to improve neurological health for everyone.



Tadeuz Hawrot, Policy Responsible EFNA

EFNA co-hosts World Brain Day events in 4 EU capitals

To celebrate World Brain Day (July 22nd), the European Federation of Neurological Associations [EFNA] co-hosted events in four European capitals – Brussels, Bucharest, Dublin and Warsaw!

The aim of these events was to hear what matters most to neurology patients in terms of their health outcomes – [#BrainLifeGoals](#) – and to discuss how this can be better integrated in the policy and decision-making at both the national and EU level.

The Belgian #WorldBrainDay event was hosted by the newly-formed Neurological Patients Alliance Belgium, together with EFNA, the [European Brain Council](#) (EBC), the [Belgian Brain Council](#).

The Neurological Alliance of Ireland (NAI), in collaboration with EFNA, held a half-day seminar in Buswells Hotel, Dublin.

The event in Poland was celebrated in Warsaw and marked the launch of the Polish Brain Plan prepared by Foundation Neuropozytywni, in collaboration with the Polish Brain Council, Polish Neurological Society, Lazarski University and DZP law firm.

The theme of World Brain Day 2019 was migraine. At the event held in Bucharest, the Association for Patients affected by Neurological Disorders in Romania (APAN), focussed on this theme.

Magdalen Rogers, NAI Executive Director, said

“We in the Neurological Alliance are delighted to be part of the #BrainLifeGoals campaign. The focus of our upcoming project is around how Irish people are mobilising the supports available to them in unique ways in order to realise their own brain life goals.”

We would like to take this opportunity to extend our sincere thanks to EFNA for partnering with us on World Brain Day and making our event a success. We look forward to working with them on the Brain Life Goals campaign and into the future.”

EFNA is extremely grateful to our colleagues at the Neurological Patients Alliance Belgium, the Neurological Association of Ireland, Foundation Neuropozytywni and APAN Romania for coordinating these highly successful World Brain Day events – a tremendous example of collaboration among neurology patient groups. EFNA looks forward to working with these groups on further advocacy projects in the future.

You can read a complete report on the day’s events here: <https://www.efna.net/efna-co-hosts-world-brain-day-events-in-4-eu-capitals/>

*Adam Kalinowski
President
Dystonia Europe*



#BrainLifeGoals World Brain Day event, Bucharest



#BrainLifeGoals World Brain Day event, Dublin

Advocating for Access to Neurology Treatment, Services and Supports

As part of Training Initiatives for Neurology Advocates [TINA], European Federation of Neurological Associations [EFNA] coordinated a meeting in Poland.

This workshop took place Monday 28th and Tuesday 29th October 2019 in Warsaw and gave participants the opportunity to discuss specific access challenges in their countries/disease areas and reach consensus on the main barriers to equitable access to neurology treatment in Europe. The event was attended by lecturers and patient representatives - 60 participants, 21 nationalities, 15 disease areas. The group included representatives of EFNA's stakeholders: EAN, EPF, ECB and many more, also industrial representatives.

Day 1 began with welcome from Joke Jaarsma, president of EFNA, who introduced the organization and its Brain Life Goals campaign. Donna Walsh, EFNA executive director explained the purpose of the workshop. Donna pointed out that EFNA is an organization of associations on European level and such events give the opportunity to see a perspective at the national level. This event is also intended to help prepare the future EFNA strategy.

The first lecturer, Brian Kennedy, Executive Director, Global Alliance for Patient Access, introduced the Alliance. GAFPA works internationally to educate, empower and mobilize physicians and patient advocates.

Interactive exercise



Introduction by Joke Jaarsma, President EFNA

Dr. David Charles, GAFPA's founder talked about the lack of awareness, barriers to: diagnosis, access to care providers, medications, clinical trials, neurologists and the entire care team. Dr. Charles emphasized that the role of patients and the patient's cooperation with the care team is very important in the treatment process.

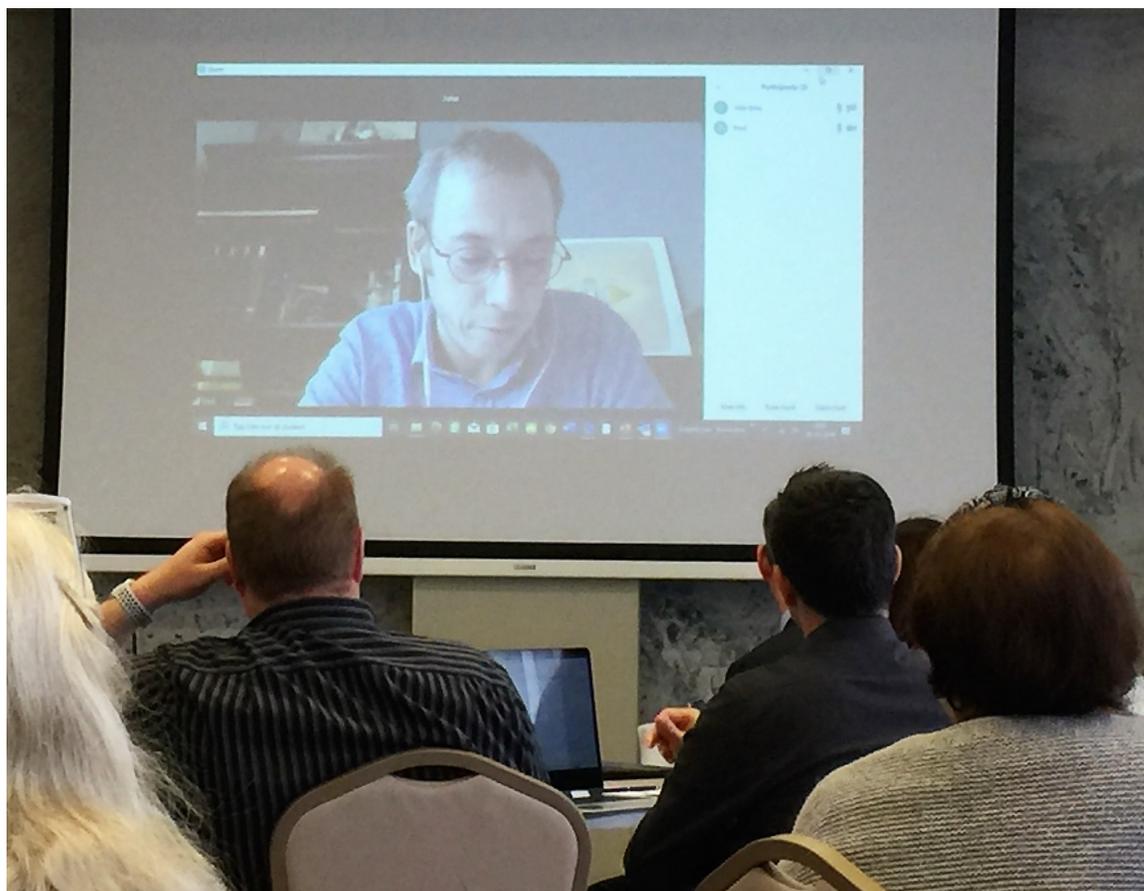
EU Activities

The next presentation took place via a teleconference connection. Frederic Destrebecq, Executive Director, EBC - European Brain Council presented the ECB's activities focussing on the organization's work on access to treatment. Frederic spoke about the high social costs of brain disorders on a European scale - 798 billion per year. EBC identified that the need for research is one of the biggest challenges. ECB initiated the Value of Treatment [VoT] project in January 2016. The VoT Research Project ultimately provide evidence-based and cost-effective policy recommendations for the adoption and implementation of a more patient-centred and sustainable coordinated care model for brain disorders. Like the EFNA, the ECB is a pan-European organization that needs to know the voice of associations working at national level. Creating Brain Plans for individual countries is a very important element in order to work effectively to improve the situation.

At the end of the lecturers' part, the event participants could ask questions to the speakers. One of the questions was addressed to the Executive Director of the EBC. 'Why only selected neurological diseases were analysed for the VoT project.'

Frederic replied that in the first stages nine neurological diseases were selected but the ECB has the door open for future cooperation with organizations representing other areas.

After a coffee break, the participants returned for an interactive exercise. Participants were divided into 6 groups to discuss specific access challenges in their countries/disease areas and reach consensus on the main barriers to equitable access to neurology treatment in Europe – now and in the future. Long diagnosis period, lack of reimbursement for treatment, lack of awareness and specialists, lack of information for patients about trials, lack of research or incorrect location of funds in research, lack of support from care givers, lack of access to data for patient advocates, emigration of specialists from Eastern countries. This and many more barriers in access to treatment were found by workshop participants. Everyone agreed that the barriers are almost the same regardless of the area of neurological diseases.



*Frederic Destrebecq,
Executive Director,
European Brain
Council (EBC)*

The last part of the session was workshop feedback, followed by panel discussion with key stakeholders:

Prof. David Vodusek, European Academy of Neurology [EAN]; Stanimir Hasurdjiev, Patient Access Partnership; David Elvira, Europe Public Affairs Head and moderator; Dr. David Charles, GAfPA.

Prof. Vodusek said that it is very important to have one narrative for the whole group of neurological diseases. Simplicity in communication with policy makers is the path to success. He also highlighted the importance of awareness among medical professions, data collection and patient - physician communication.

Stanimir Hasurdjiev surprised the audience by telling frankly what the realities are. Today, we have not enough specialists and this situation will not improve in the future. To find solutions to our problems we have to start thinking 'outside the box', he said. How can we use technology, e.g. in communication with specialists? More specialists is also not a solution, maybe a system reorganization is needed?



Brian Kennedy, Executive Director, GAfPA

On the second day of the workshop focus moved more to Health Technology Assessment (HTA).

Health Technology Assessment (HTA) is "...a multidisciplinary process that summarises information about the medical, social, economic and ethical issues related to the use of a health technology in a systematic, transparent, unbiased, robust manner. Its aim is to inform the formulation of safe, effective health policies that are patient-focussed and seek to achieve best value." (EUnetHTA, 2007)

"Generally speaking, HTA aims to inform decisions made in health systems about which health technologies are of most value and should be invested in. This determination of value is complex and must take policy and social context into account." (European Patients' Academy, 2016)

The session started with a welcome back from Joke Jaarsma, President of EFNA.

Brian Kennedy, GAfPA, explains the importance of patient involvement in the HTA process on the example of an innovative neurotoxin treatment method described as "life changing" by some migraine patients, which has been rejected for The National Health Service in the United Kingdom.

Krystallia Pantiri, Pharmerit International, talked about how patient involvement in the decision-making process looks like on the example of Germany, France and the UK.

Valentina Strammiello, Senior Programme Manager, European Patients' Forum [EPF] presented why HTA matters to EPF and how they advocate in HTA.

Matteo Scarabelli, Patient Engagement Manager in HTA, EURORDIS, explained in a very simple and understandable way how patients can be practically involved in the HTA process.

Then Šarūnas Narbutas, President, Lithuanian Cancer Patient Coalition, presented the process of implementing the HTA reform in Lithuania. He emphasized that there is a lack of agencies specializing in HTA in some countries and that HTA training sessions dedicated to patient organizations are needed. Using the example of a cancer drug, he showed the importance of patient involvement in the drug implementation process.

EU Activities

Magdalena Władysiuk, Vice President, HTA Consulting – TBC, presented how the Polish healthcare system works. Based on her 20 years of experience, she said how little time in the entire HTA process is dedicated to patient involvement. There is a lack of legal regulations of patient's involvement in HTA in Poland, but the informal role of patients has increased over the past 5 years.

After listening to all presenters, participants divided into 5 groups and started an interactive exercise 'Creating a Map for Neurology Patient Engagement in the Medicines Lifecycle, along the road to Access.'

Donna Walsh, Executive Director, EFNA introduced topics for each group: Awareness, Policy, Health Workforce, Data evidence & research, Social care and support services.

After hearing feedback from groups and conclusions, Donna Walsh emphasized that all learnings from this workshop will be encapsulated in a report and subsequent advocacy tool, created by colleagues at the European Alliance for Patient Access with whom EFNA collaborate on this event.

The meeting was closed by the president of EFNA, who thanked Danuta Lis (President of the Huntington Dis-

ease Association) for her great support in organising this event in Poland.

A lot of attention in Europe is now focussed on the involvement of patient organizations in the HTA process. Dystonia patient organizations should be interested in how they can be involved in the process at the national level.

Adam Kalinowski
President
Dystonia Europe

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Interactive Exercise

My Dystonia

MY DYSTONIA

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

By patients. For patients.



DYSTONIA
EUROPE

Developed with the support of



***At Dystonia Europe, we're working on updating MyDystonia to version 2.0, which we plan to launch in early 2020.**

www.dystonia-europe.org

4th MyDystonia Ambassadors Meeting

A few months ago the Dystonia Europe Board asked me to organise the 4th Mydystonia Ambassadors meeting in my home town of Newcastle, England. I have never organised a meeting like this before and knew there was a lot to do and a lot to live up to as previous ambassador meetings had been very well organised and run.

In due course I chose a suitable hotel with good facilities for all our guests and of course for the meeting itself.

It is on the Gateshead side of the quayside, only a short walk across the bridge to Newcastle. I was not only pleased with the hotel but also the location as the quayside has been developed over recent years and there are lots of things to see and do.

Our guests arrived at Newcastle Airport on the Thursday and Friday ready for the welcome dinner on the Friday evening.

The weekend started at 7pm on the Friday when we all met in the hotel lobby for our pre-booked 3 course meal. We had a private room for the dinner (at no extra cost) so there was no worry about disturbing any other guests in the hotel while we did our formal welcome to the meeting.

Adam Kalinowski welcomed us all to the meeting and I welcomed everyone to Newcastle and gave them all a small gift of an Angel of the North badge. The Angel of the North is a large statue which looks over the main roads into Newcastle from the South and offers all of us protection and safety.

We were very pleased to be joined by one new ambassador, Raquel Vacas from Italy. The other ambassadors present had all met before as we have all been ambassadors since the program started.

The next day the meeting started promptly at 09:30am and we were all ready to hear all the news about the MyDystonia App. Eleven people attended the meeting and a further two joined us on Skype.

The meeting began with some updates from Adam and Monika and then moved onto an update from Eelco about the new version of the app currently being developed.

It very quickly became apparent that we all had lots of comments and questions about the new version as we are all committed to making it work really well for all of our users.



Eelco was, as usual, open to suggestions and proposed changes to what so far has been developed. We talked mainly about how it would look and of course the functionality too.

Everyone present was so engaged in the development of the app and had so many really useful comments and questions that we abandoned the rest of the meeting agenda and concentrated on the app development. That is of course our main objective, we are app ambassadors and we all had our users best interests in mind while we discussed the layout and functionality of the app.

Eelco will have lots of changes to make to the design, some will be easy changes to make and some will be more difficult, but he was confident that the changes could be made ready for the launch sometime next year.

After a long day of concentrating and listening to each others ideas we were ready for the meeting to close so some of us could have a short rest before our next event. No such rest for Monika, Adam and Eelco! They continued working while the rest of us returned to our rooms for a short break.

We met again in the hotel lobby at around 5:30pm for some relaxation and enjoyment. In previous years we have been lucky enough to visit the Guinness brewery in Dublin and a living museum near Frankfurt. I decided to show off my home town as the quayside is rich with history.

My Dystonia



I took everyone on a short guided walk around the quayside telling them some of the history along the way. We talked about old buildings and new, the great fire of Newcastle/Gateshead, the 7 bridges that cross the river Tyne and a lovely tale of a young girl called Bessee Surtees. She fell in love with a young man called John Scott and her wealthy parents disapproved of him. She climbed out of her bedroom window in 1772 (the house is still standing) and eloped with her young man. John Scott later became the Lord Chancellor of England, her parents then approved of him! We also talked about the general history of Newcastle and how it was first built in 213AD by the Romans. I also managed to squeeze in a nasty tale of how in 1649 27 women were found guilty of witchcraft and 14 of them were executed in the town.

The tour took just about 1 hour during which time it became dark and all the bridges lit up creating quite a spectacle, lots of photos were taken as it was so attractive.

The next part of our weekend was a meal in a restaurant on the top floor of a modern art gallery, The Baltic. We all enjoyed another lovely meal which was very welcome after the hard work we had done during the day.



It was lovely to have time to talk to each other about our lives and families, and to discover things we have in common apart from dystonia and our app. The next morning we were all leaving at various times from 6am (poor Adam!) through til 3pm. Those who were lucky enough to stay until 3pm had time to enjoy the artisan market which is on every Sunday morning and to explore Newcastle a little, I believe some even made it up to the football ground where Newcastle United play and had their photos taken with the Alan Shearer statue. Apologies if you are not interested in football but Alan Shearer is a local footballing hero! I left once I was sure everyone had their taxis booked to the airport and I was home in less than 30 minutes. I do really enjoy going to different towns and countries for our ambassador meetings but I must admit it was really nice to be able to just drive home.

We are not sure where next year will take us for our meeting but we would like it to be somewhere warm! The people of Newcastle are all friendly and welcome visitors with a warm heart, the temperature however did not match, it was very cold!

*Gill Ainsley
Secretary
Dystona Europe*



MyDystonia2.0

As you've probably read before, Dystonia Europe is currently working on the new MyDystonia. At the moment we are busy creating the new designs, so the new APP will have a brand new look and feel. We think this new design will be more appealing to use and also makes it easier to make new entries in the diary.

The new MyDystonia will have all the features you already know, but we will also be able to add new features in the future. This is one of the reasons we wanted to create a new MyDystonia, we want to add functionality to make the APP more interesting and make it more valuable for you.

Of course our Ambassadors are also involved in this project. During our last meeting in Newcastle in October this year we received some great feedback which is being processed by the design team. Our Ambassadors will be much easier to contact with the new MyDystonia. You will be able to find the Ambassadors directly inside the APP with their names and photos and send them personal messages directly from within the APP. You can always reach them with questions about the APP and if you have suggestions or new ideas for the APP, you can contact them directly.

Our Ambassadors are part of the larger User Focus Group, a group of people outside of Dystonia Europe, who have expressed an interest in testing the new APP before it gets launched. If you would like to be part of this User Focus Group and are willing to test the new app and provide us with feedback, please join our testing group. We are also looking for people who are willing to translate the new APP to your own language.

If you would like to translate the APP or join our User Focus Group, please send an email to Merete at merete.avery@mybrainnet.eu and she will put you on the list.

We aim to have the APP ready for testing in the beginning of 2020 and we should have all transla-

tions ready during spring. If you are part of our testing group, you will have a sneak preview in the beginning of 2020 and you will have the ability to influence the final result of the APP before the official launch. The official launch is during spring of 2020 and we will post messages about this on our website, social media and the mydystonia.com website. If you would like to receive an email when we launch the new MyDystonia, please send an email to Merete at merete.avery@mybrainnet.eu and she will send you an email when we launch.

Eelco Uytterhoeven
MyDystonia Project Manager



My Brain Net

MyBrainNet

Last year Dystonia Europe was one of the first recipient of the BMP (Brain, Mind and Pain) grant from Pain Alliance Europe and Grünenthal for our innovative project MyBrainNet.

This is a platform that allows us to create multiple apps and connect these to one platform, where all data is collected centrally. This central platform will allow us to publish new apps at a much lower cost than otherwise would be possible.

We want to share this platform with other neurological European patient organizations, so they can have their own diary for their members. This will bring together a lot of interesting information which can be used in research projects, providing unique data. Of course we value the privacy of our app users, so only data of people who have given their consent will be used for research.

If you are interested in developing an app – disease diary – let us know. Send an e-mail to
Eelco Uytterhoeven at
eelco.uytterhoeven@dystonia-europe.org

*Eelco Uytterhoeven
IT Advisor*



MY
BRAIN
NET

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!



www.dystonia-europe.org

Dystogram

Dystogram fun 2019

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



www.dystonia-europe.org

Meet Dystonia Europe Treasurer and MyDystonia Ambassador Sissel from Norway

My name is

Sissel Buskerud
Mother of two sons, 4 grandchildren and a dog.
Married to Oddbjørn for 49 years.
Living close to Oslo in Norway.



*Sissel Buskerud
Norway*

Work experience and how it relates to my work as Dystonia Ambassador

I studied accounting and business at school, and have been working for many years as CFO (Chief financial officer) in a company. I am retired now and take care of the figures for The Norwegian Dystonia association. I am used to taking responsibility and deal with people. I think this is useful when I try to get people to use the Mydystonia app. I am used to speaking in public.

Why do you like helping others?

For me it is important to spread awareness of Dystonia. It is a good feeling when you can help people when they are diagnosed, and also later on when we have meetings.

We share our stories and learn from each other how to cope living with dystonia.

What are the benefits working as a MyDystonia ambassador?

I get to know the app very well. I can help people in my country to download the app and support them if they have questions. I meet other ambassadors so we can exchange views and questions.

How do you like spend your free time?

I love to be at home, or spend time in my cottage. Always lots of things to take care of. I like gardening, skiing, reading, knitting and walking with my dog and my son's two dogs. In summer time I enjoy riding my electric bicycle. I enjoy spending time with my children and grandchildren.

What keeps you motivated on the tough days?

I try to listen to my body and if I need to rest, I do that. I try to be positive and keep smiling. It is better than being depressed. I am very fond of Professor Marjan Jahanshahi and her rules for living with dystonia.

What makes you angry?

Injustice makes me angry. If people or animals are not treated well. If patients have to wait a long time to get treatment or get wrong treatment for their Dystonia.

*Sissel Buskerud
Treasurer Dystonia Europe*

Around Europe and Beyond

Italy

The Rebel Hand

A book presented at the A.R.D meeting in Florence, Italy.

Carlo Iacomucci is an artist, born in Urbino, the birthplace of Raphael.

He began to draw at the age of 13 years and to paint and engrave at 22, he has been a professor of painting disciplines for 36 years.

There is no doubt that he used his right hand very much, in 2004 he began to feel a strong unbearable heat in it, he could not hold his brush or chisel very well and eventually was diagnosed with "task specific focal dystonia".

He remembers that when he was teaching at school he felt uneasy, as his hand did not obey and his students did not understand what was going on. He had to accept that he could not rely on his hand, but thanks to his willpower and mental toughness he never fell into depression.

In order to make the best use of his right hand, Mr. Iacomucci has developed a peculiar sensory trick as you may see in the photo, he touches his right middle finger with his left middle finger, so as to avoid involuntary movements and be able to grip his brush or the pen.



The dose of his first injection of botulinum toxin was too high and for 2 months his hand was paralysed.

Afterwards he changed hospital, having correct dosage of injections. It was suggested by his doctors to exercise and re-educate his hand, writing and drawing in a notebook. He wrote many pages copying texts about the graphical techniques he used (xylographs, etchings with acid, aquatints, etc) adding his drawings on each page.



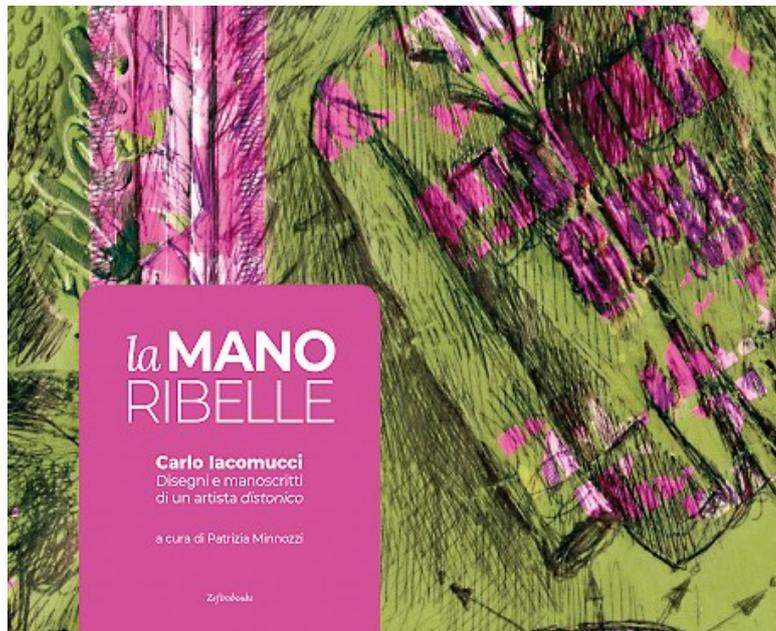
Carlo Iacomucci

Around Europe and Beyond



After 10 years of “exercises” his notebook had become part of his life, and he was encouraged by his friends and his neurologist to transform his notebook into an art book, which he presented for the first time at our A.R.D meeting in Florence, as it had just been printed.

The book has a revealing title “The Rebel Hand” and is composed of 40 drawings made with graphic pens, stamp punches and graphite shades. Each page has its date, showing that he created the book between 2008 and 2018; he has some recurring drawing themes: drops or traces (often 7, like 7 colours of light), tailor’s dummies and the kite.



Under the pretext of making writing and drawing exercises for re-educating his hand, he recorded in black and white his poetry and his art.

Many books about dystonia have been published up to now, but usually they deal with stories of people with the disease. In Italy this is the first and only book with drawings by a dystonic hand and we thank Mr. Iacomucci who shows us how to take back possession of a “rebel hand”.

Maria Carla Tarocchi
Vice President, ARD
Italy

Norway

Norwegian Dystonia Association, October Meeting in Ålesund.

12 October the Norwegian Dystonia Association (NDF) held its meeting in Ålesund, a charming small city on the west coast of Norway.

The leader of NDF Johan Arnfinn Warvik welcomed all and informed about the work of the organisation.

NDF has a focus on many areas, like networking with the National Health providers, Neurologists, Physiotherapists and Member activities both National and local. The organisation has 5 local groups around the country, that have meetings twice a year. Then there are National meetings twice a year with approximately 50-60 participants from all around Norway. It is estimated that about maybe 2500 - 3500 or more people have dystonia in Norway, but as in many other countries, the numbers are probably underestimated, due to that many wait many years to get the proper diagnosis and treatment.

In Norway there are about 600 members which is about 25 percent of people affected by dystonia, which might sound little, but compared to other patient organisations are very good. The population in Norway is close to 5 million people.



President Norwegian Dystonia Association Johan Arnfinn Warvik and Author, Broadcaster Oddgeir Bruaset



Johan Arnfinn Warvik introduced Oddgeir Bruaset, a Author and Broadcaster, who also was the host of a Norwegian TV Production, about how some people have lived and still live in very remote places in Norway.

Bruaset received the Helbergs price this year for a spectacular way of contributing to keep memories of culture in the mountain areas and how he with a sincere enthusiasm share how much the people cared and depended on each other to thrive and to survive.

There is a connection here between the caring for others in the same situation, like people within the dystonia communities work for awareness and support, and share ideas of coping and so much more. Many volunteers devote their time to do this.

Today we have Social Media which these people did not have, yet they stayed in touch by signals like lighting a fire and then «neighbors» would travel by boat or walk, which could take more than a day, to see if they could help and support. The forces of nature, sometimes lots of snow and cold weather, would not stop them.

The stories of Oddgeir Bruaset left the audience very moved and thoughtful. Oddgeir also said that many of the elders he had interviewed, that grew up in these remote areas, expressed that they were happier back then, they did not have much, but they had a strong community. «Together we are stronger» .

Around Europe and Beyond

Then we were divided into groups, depending on type of dystonia, like Blepharospasm, Cervical Dystonia, Generalized dystonia, DBS Treatment and more.

Since Dystonia is a very little known and understood disorder, then it is very important to meet, share and learn coping strategies from others with the same challenges. In addition maybe the most important thing is to meet someone who knows what challenges you face as affected by dystonia.

Then after a break, we went on a bus sightseeing tour. The Norwegian Dystonia Association had arranged a sightseeing tour in the area partly in Ålesund, but more so around the city of Ålesund. Ålesund is partly built on islands, and we visited 3 or 4 of these islands. The guide had a lot of interesting history stories to tell about the area. We also had a stop where we got out and enjoyed the beautiful view from Aksla.

After the bus trip we enjoyed dinner together at Scandic hotel Ålesund.

*Merete Avery
Operations Manager
Dystonia Europe*



*The President of The Norwegian Dystonia Association
Johan Arnfinn Warvik and Jorid Warvik*



Ålesund



*The Norwegian Dystonia Association meeting in
Ålesund*

Poland

Poland, the second country in Europe with the Brain Plan

A strategic Brain Plan report for Poland was announced on World Brain Day, July 22, 2019 after several years of work lead by NeuroPozytywni Foundation. The document was prepared by the foundation in cooperation with many experts. The event was organized with the support of the Patients' Ombudsman office in Warsaw. "Brain Plan for Poland" is the first attempt to analyse the Polish model of health care for patients with brain diseases in social, legal and economic terms.

The first national brain plan in Europe was launched in Norway in December 2017 however, the Polish brain plan was initiated as the first in Europe.

The Polish plan was drafted in collaboration with the Polish Brain Council, Polish Neurological Society, Lazarski University and DZP law firm.

No support was received from the Polish Government up to that point.

NeuroPozytywni is a foundation whose mission is to support people with widely misunderstood brain diseases (multiple sclerosis, cerebral palsy, epilepsy, depression, schizophrenia, Parkinson's disease, Alzheimer's disease, migraine, stroke and many others) and their relatives. The Foundation cooperates with the European Brain Council [EBC].

The speakers at the conference were representatives of the medical, legal and patient organizations. Among the invited guests were professors of medical sciences, representatives of international and national NGOs and patient organizations.



Tadeusz Hawrot, EFNA Introduction

Around Europe and Beyond



Adam Kalinowski, President Dystonia Europe and Iza Czarnecka-Walicka, President of the NeuroPozytywni

Panelists included prof. Piotr Gałecki - national consultant in the field of psychiatry, prof. Jarosław Sławek - chairman of the Polish Neurological Society, Iza Czarnecka-Walicka - president of the NeuroPozytywni foundation and Agnieszka Wernik - director of the Department of Strategy and Systemic Activities of the Patient Rights Ombudsman.

The event was also attended by representatives of international organizations - Marijn Scholte, European Brain Council and Tadeusz Hawrot, European Federation of Neurological Associations. After listening to the presentation, the conference ended with a panel discussion on 'Brain diseases, patient priorities and health policy priorities at national and European level'.

The conference was organized by the European Federation of Neurological Associations [EFNA] as one of four that day in various European countries. The event was linked to the EFNA campaign. The #BrainLifeGoals campaign raise awareness of the impact of neurological diseases by exploring the dreams and aspirations of those living with a brain disorder.

The event was attended by the president of Dystonia Europe, as a representative of the Polish Dystonia Association.

*Adam Kalinowski
President
Dystonia Europe*

Below: Panelists



Around Europe and Beyond

Romania

7th Edition of the Childrens Joy Association Event: Dystonia Rehabilitation for Adults and Children

People with dystonia have participated, as well as their families or but also specialists in the field of rehabilitation. From three cities in Romania - Timisoara, Zalau and Baia Mare.

Before the workshop, the patients had a social meeting, in the Dr I.Trifon Medical Clinic, where they could visit the cabinet where physiotherapy is practiced. During the social meeting they benefited from salinotherapy this being a very relaxing and useful social environment for participants.



The next day September 21st, at the request of patients who over the time wanted to find out how acupuncture can help in their rehabilitation, the event was opened with the acupuncture workshop coordinated and presented by Dr. Ioan Ometa.

This part of the workshop proved to be quite useful by giving many positive answers for patients.

Also in this framework it was discussed moreover about the social integration and the introduction on the labor market of people with disabilities, the presentation being supported by a vocational counselor who guides people with disabilities towards autonomy and a good integration on the labor market.



Rehabilitation for dystonia patients, adults and children in Romania

Around Europe and Beyond

This was followed by physiotherapy rehabilitation workshops coordinated by two physiotherapists representatives of the Medical Clinic, Dr Cioata Ionel Trifon-from Timisoara

The second part of the physiotherapy workshop was coordinated by the physiotherapist accompanied by a general medical assistant, both representatives of the Noro Center from Romania who have experience in working with patients with rare diseases but also with groups of patients with dystonia.

The event ended with the presentation of a physical rehabilitation program through sports adapted to the patients with dystonia whose condition allows them to do such activity, coordinated and designed by trainer Crainic Marius, who says that *"Rehabilitation programs are essential for the relief of dystonia symptoms. Physiotherapy teaches people with dystonia to recognize certain compensatory movements, the supervision of the specialist doctor is necessary. Physical and psychological rehabilitation are slow, the results appear in time, but improvements can be made through several aspects, movement awareness and control. Sport has a great importance in the life of every human being as far as he can practice it and together with the other therapies can significantly improve the quality of life of people with dystonia"*.

"We want to inform patients about the rights they have, about the treatments that are good practice so that they can choose from what is available in order to have a good quality of life".

Also being the dystonia awareness month we will have the opportunity to popularize this diagnosis and the therapies that come into the benefit of patients" says Crainic Catalina, president of the Childrens Joy Association

Childrens Joy Association is the only active association in Romania for dystonia in the city of Timisoara, being a member of the board of directors of the National Alliance for Rare Diseases through the president Crainic Catalina, who is also a board member of the Dystonia Europe.

Catalina Crainic, Board Member Dystonia Europe and President The Childrens Joy Association, Romania



Participants at the events dedicated to rehabilitation dystonia for adults and children

Dystonia Patient Leaders Discuss Importance of Research and the Samuel Belzberg 6th International Dystonia Symposium



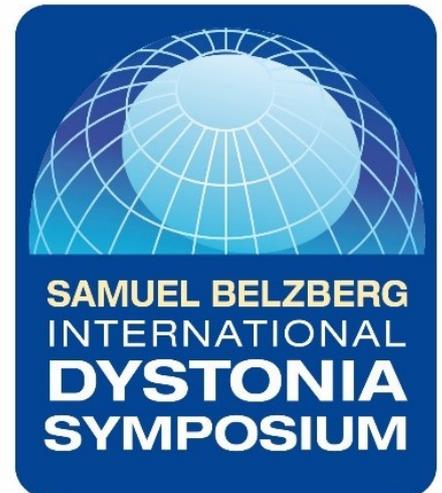
Merete Avery
Dystonia Europe



Art Kessler
DMRF

On June 4-6, 2020 the Samuel Belzberg 6th International Dystonia Symposium (IDS6) will take place in Dublin, Ireland. This Symposium represents the latest chapter in a definitive series of international dystonia meetings held since 1975 to bring together experts to present and discuss the latest information on dystonia. The Symposium is being organized by the Dystonia Medical Foundation and Dystonia Europe, the leading groups in the United States and Europe dedicated to funding dystonia research and improving the lives of those affected.

The Symposium is named in honor of Sam Belzberg, co-Founder of the Dystonia Medical Research Foundation (DMRF), who passed away in 2018. Sam founded the DMRF in 1976 with his wife Frances, shortly after their daughter was diagnosed with dystonia and he was relentless in his drive to find a cure and to provide services for families, like his, whose lives were upended by the disorder.



The Samuel Belzberg 6th International Dystonia Symposium is meaningful to different groups of people for variety of reasons. For researchers and clinicians it is a venue to network, share data and exchange ideas, engage in discussion and keep research momentum moving forward. For patients and their loved ones whose lives are touched by dystonia, the outcomes create a hopeful path forward to better understanding and improved treatments, and, someday a cure.

Below is an interview with Merete Avery, former President of Dystonia Europe, and Art Kessler, President of the Dystonia Medical Research Foundation. They provide important perspectives as patients and leaders on how advances in research have improved their daily lives and why the 6th International Dystonia Symposium is important for the dystonia community.

How long have you been with Dystonia Europe/DMRF and why did you get involved?

Merete: I have been with Dystonia Europe for almost 6 years. Before that I was the Chairwoman of the National Norwegian Dystonia Association,

a member organisation of Dystonia Europe.

I had been to a few Dystonia Europe yearly conferences and I was very impressed by their work as an umbrella organisation for the national dystonia groups in Europe. I believe that the importance of working together across borders is invaluable to achieve our goals for more research, better quality of life for people with dystonia, access to treatment and early diagnosis, and eventually a cure.

Art: The DMRF has been an integral part of my family since I was about 12 years old. That was when my parents became involved, shortly after my diagnosis of early-onset DYT1 dystonia. We became involved with the DMRF because it was the best way to learn about and support the cutting edge in Dystonia research. When I was first diagnosed with Dystonia in my early teens, my parents also wanted to meet and talk to others who were living with this disease. The DMRF became our support network. When I was in my 20's I joined the DMRF Board of Directors as head of the Junior Board and then later became VP of Science, and am currently the President.

As a dystonia patient, how has research impacted your life?

Merete: Research is very important. When I was diagnosed with Cervical Dystonia, I read a lot on dystonia and research of dystonia, other movement disorder and research of the brain in general. The research, from before I was diagnosed, led to treatments like botulinum toxin, oral medication, DBS and more. I have received botulinum toxin every 4 months for the last 12 years, which has improved my quality of life tremendously. It enables me to continue to work, although less than before I had dystonia.

Now I can again enjoy most of the things that I used to do before. I always loved mountain hiking. Since I was very young, my sister and I went on wonderful hiking trips, walking or skiing with our parents. I can no longer go for very long walks, but I can still mountain hike and go for short ski trips. Some people must wait many years for the right diagnosis, seeing many doctors. This means late treatment, and for many not being able to work or participate in social life, and stigma just to name a few of the consequences. Dystonia, especially untreated, is often very painful, can diminish quality of life severely, and is often very misunderstood.

Art: Dystonia research has impacted my life in profound ways. The breakthrough discovery of the DYT1 gene paved the way for genetic testing to screen for carriers of the mutation. Pre-implantation genetic diagnosis allowed my wife and I to conceive our two children to be free from the DYT1 mutation. Not passing Dystonia on to my children was very important to me. I have also benefited greatly from the development of Deep Brain Stimulation. I had DBS in 2007 and today I live virtually symptom free.

How is a meeting like IDS6 important to you and other patients in the community?

Merete: The IDS6 meeting is important for patients, for scientists, medical professionals, and others in order to meet and share knowledge, and to build connections for future collaboration. Instead of scientists and researchers working separately in each country or continent, we need arenas where they

can meet and share ideas. This is such an arena to network, learn and share and I believe that the outcome of this conference will lead to further achievements and increased knowledge of dystonia that will benefit patients.

Art: The IDS6 brings together the best and the brightest minds in Dystonia research. Whenever we get so many brilliant investigators in one place, progress always happens. Collaboration, exchange of knowledge, and future planning is what moves Dystonia research forward and that is what this meeting is all about. I am so excited to hear about what is new in Dystonia research from investigators all over the world and we at DMRF will look forward to sharing the highlights with the rest of the patient community.

If you could tell potential IDS6 attendees one thing, what would it be?

Merete: Many experts believe that dystonia is highly underdiagnosed, patients often see many doctors before they get the correct diagnosis and treatment. It is very important with more awareness and knowledge of the different types of dystonia and more knowledge of treatment. With awareness, and the right treatment the patient most often has great benefits. To researchers, medical professionals and patients, please attend if you have the opportunity.

Art: The Dystonia community appreciates your dedication to Dystonia research and all of your hard work. We believe in the power of knowledge and are counting on you to learn from each other and continue to move the Dystonia field forward.

For more information about the Samuel Belzberg 6th International Dystonia Symposium, please visit www.internationaldystoniasymposium.org

Events

Calendar 2020

February

- 13-14 Dystonia Europe Board Meeting & Winter Think Tank, Lund, Sweden
28 Rare Disease Day

March

- 16-22 Brain Awareness Week

April

- 25-26 EPF Annual General Assembly, Brussels

May

- 23-26 EAN Congress, Paris
EFNA Annual Meeting & General Assembly 2020

June

- 4-6 International Dystonia Symposium, Dublin, Ireland
Launch application for the 10th David Marsden Award 2021
6 D-DAY 2020, Dublin, Ireland
7 DE General Assembly 2020, Dublin, Ireland

July

- TBC Summer Think Tank 2020
22 World Brain Day

September

- 1-30 Dystonia Awareness Month
13-17 MDS – International Parkinsons and Movement Disorder Society Congress 2020, Philadelphia USA
23-26 ESSFN, Marseille



27TH ANNUAL DYSTONIA EUROPE CONFERENCE

D-DAYs 2020

DUBLIN, IRELAND



SAVE THE DATE
Saturday 6th June 2020



Organized in parallel with the 6th International Dystonia Symposium



INTERNATIONAL DYSTONIA SYMPOSIUM 2020

Croke Park, Dublin, Ireland
4-6 June 2020

ORGANIZED BY:



SUPPORTED BY:



Registration and abstract submission will open this fall

For more information, and to sign up for the conference newsletter, please visit:

www.internationaldystoniasymposium.org



www.dystonia-europe.org

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 you can use the online button DONATE on our website.

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!

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Staff



Monika Benson,
Board Member and Executive
Director, Sweden

Monika was elected President of EDF, now Dystonia Europe, in 2007. She was re-elected for a second term in 2010. Monika stepped down as President in 2013 after serving the maximum period of 6 years. She took over as Executive Director after Alistair Newton's retirement. Monika has cervical dystonia and was a board member of the Swedish Dystonia Association for 10 years. Monika has been working as a coordinator of work-shops, courses and lectures at a school in Lund, Sweden.



Merete Avery,
Operations Manager, Norway

Merete was appointed to the board of Dystonia Europe in 2013 and was Secretary from 2013-2015. Merete was appointed President at the Board Meeting, following the GA, in Rotterdam 2015. She stepped down as President in 2019 after the maximum period of 6 years in the DE Board. She was diagnosed with cervical dystonia in 2006 and was Chairwoman of the Norwegian Dystonia Association between 2010-2013. Merete has been working with customer service, accounting and finance in Molde, Norway.

Management & Advisors

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



**Adam Kalinowski,
President, Poland**

Adam suffers 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 Dystonia Association where he currently acts as a Board Secretary. In the same year he became Ambassador for the MyDystonia application.

Adam was elected to the DE Board in 2017. One of his roles is the coordination of the MyDystonia Ambassador program. Adam is a very dedicated advocate for dystonia patients and has spoken about dystonia in the EU Parliament in 2018. He is also an administrator of his own website called 'Dystonia Good Story'. He is Polish but he lives in Ireland where he studies graphic design. Adam was re-elected to the Dystonia Europe board in London 2019, and is now the President of Dystonia Europe.



**Edwige Ponsel,
Board Member,
France**

Edwige is the Chairwoman of the French Dystonia Association, Amadys. The

objectives of the association are to provide support to dystonia patients, to raise public awareness, to promote research and to organize meetings and events. Edwige works in the purchasing and marketing department of a company near Paris. She was diagnosed in 1994 with cervical dystonia.

She was elected to the DE Board at the General Assembly in Rome in 2017. She was re-elected at the last GA in London and she is now the Vice President of Dystonia Europe.



**Gill Ainsley,
Secretary, UK**

Gill is Board Member of A.D.D.E.R. (Action for Dystonia, Diagnosis, Education and Research), United Kingdom. Gill is very

interested in raising awareness of dystonia and in research that would lead to a cure for dystonia. Gill's first language is English, she is also a skilled computer operator. Gill's profession is engineering and she worked for many years as an Electromagnetic Compatibility Test Engineer on aircrafts.

Gill was nominated and elected as Board Member to Dystonia Europe in 2019 and is the Secretary of Dystonia Europe.



**Sissel Buskerud,
Treasurer, Norway**

Sissel is the Treasurer/Accountant responsible and Board Member of the Norwegian Dystonia Association for the last 7 yrs. Sissel

has experience for more than 25 yrs. as an Accountant for a Norwegian Security Company. Sissel was elected to the DE Board at the GA in London in 2019 and is the Treasurer of Dystonia Europe.



**Catalina Crainic,
Board Member,
Romania**

Catalina Mariana Crainic is the President of the Romanian Dystonia Organisation, Associata

Childrens Joy and a Board Member of National Alliance of Rare Diseases, Romania. Catalina has broad training, within Art and Painting and also in Educator Recovery within the field of Social and Pedagogical for people with special needs. She also has training in Rare Diseases for Journalists and Effective Communication with the press, representing patients organisations. Catalina was elected to the DE Board in 2019



**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. In 2019 Alistair received an MBE – Member of the British Empire for his work for neurology patients in Europe and especially for those affected by dystonia.



**Maja Relja,
Advisor, Croatia**

Maja is a professor of neurology, in charge of the movement disorders section at Zagreb University Hospital. She founded the

Croatian Dystonia Association and has served as its President for over 20 years. In 2011, she was elected to the board of Dystonia Europe, Between 2011 and 2017 Maja was the Vice President of DE. At present she is the project leader of the Value of Treatment project regarding dystonia. .



**Eelco Uytterhoeven,
Advisor, The Netherlands**

Eelco has been a professional IT-consultant and developer since 1999. For the last years, since 2016 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. 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.

We thank all our partners for their support and collaboration.

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www.dystonia-europe.org