

# DYSTONIA NEWS

SUMMER | 2- 2024



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DYSTONIA  
EUROPE



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Dear readers,

It's already back-to-school time! I hope you had a wonderful summer and a good vacation.

The Board had a pleasant and instructive General Assembly and Member Meeting in Timisoara, Romania, together with the representatives of our members' organisations.

We held a webinar on June 18th to present our structure and activities to the public. You can find the recording on YouTube, Dystonia Europe channel.

Monika participated in a meeting of Boston Scientific Foundation Europe and at the DBS Engineered to Adapt Event, and at other dates.

In this edition you will also read about research with Dr. Stavros Tsagkaris, located in the UK, winner of our 2024 David Marsden Award, and with Prof Juho Joutsa from Finland.

You will discover the story of Vidar from Norway and Sanne from Denmark.

We are in September, it's Dystonia Awareness Month, follow us on social media and participate in this communication campaign by liking, sharing, commenting... join us in raising awareness!

You will also read about our annual theme: #volunteerfordystonia. We need you to join the national organisations and become a volunteer.

Last but not least, meet us on Sept. 21 at 10:00h CET for our online 2024 Dystonia Day conference on Zoom, you will learn a lot about Dystonia, its forms and conditions.

On behalf of the Dystonia Europe team, I would like to wish you in advance a beautiful autumn, and I look forward to seeing you all online soon.

**Edwige Ponseel**  
President  
Dystonia Europe



## General Assembly and Member Meeting in Timisoara, Romania

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Sometime last year board member Catalina persuaded us to hold our annual General Assembly and Dystonia Day conference in her home town of Timișoara, Romania. After months of careful planning the day to travel finally arrived on Wednesday 29th May.

I left home at about 3:30am for the 6 o'clock flight to Schipol, Amsterdam. At Schipol I had the same problem I usually have there in that my transfer time was very tight and I had to join the huge queue at the Schengen border. It always makes me feel rather nervous that I will miss my flight, but I have to say I haven't missed a flight yet and made it time for my next flight to Bucharest. I had a bit more time in Bucharest airport but wished that I hadn't as it is rather boring just waiting around for a flight. I guess there must be a happy medium for time spent in an airport but I haven't found it yet.

Last flight of the day was to Timișoara, where Monika, Sissel and Jukka were waiting for me. It was so lovely to see them again! We shared a taxi to the hotel, Hotel Timișoara, which is lovely. We were soon checked in and met Merete who had arrived the day before and of course Catalina who lives in Timișoara. Unfortunately Edwige couldn't make it to this event but we will see her soon I am sure.

Our first evening was very relaxed and Catalina took us to a lovely restaurant in the town. We walked to the restaurant and discovered some of the beauty of Timișoara. It is a very pretty town with lots of important history. I must admit I was so taken with the story of Timișoara, that I am going to buy a book about it when I get home as I would love to know more.

Our waitress and Catalina suggested we try the sharing platter to give us a taste of a few different Romanian dishes. We all agreed but then we dithered about the drinks and the poor waitress ended up completely confused, she did well though and brought us exactly what we wanted.

The platter arrived and our eyes almost popped out of our heads, it was huge!! Even with five of us sharing we knew we wouldn't be able to finish it. There were all sorts of meat dishes, mostly chicken and pork but all cooked differently. It also came with a salad and the whole dish was delicious! We were right though we couldn't eat it all so Catalina got a take away box and took some for her husband Marius.

As we were too full for any dessert we took a slow walk back to the hotel with Catalina pointing out places and buildings of interest, including the building where the Romanian revolution started which of course resulted in the communist government being overthrown and a democratic government taking over. I can't imagine what it must have been like to live in a communist country and then to need a revolution to make conditions better. The Romanians who took part must have been very brave and sadly some of them lost their lives as did a number of children.





## LATEST NEWS

We got back to the hotel dodging between the raindrops and said our goodnights. The rooms are lovely and I slept quite well.

Breakfast was very nice, I wasn't hungry after our feast the night before but I managed a slice of toast and of course the all important cup of coffee!

We met for our planned board meeting at 09:30 ready and willing. As usual we had a great deal to discuss so we got on with it as soon as everyone arrived. The morning was really to finalise all arrangements for the General Assembly the following day and the Dystonia Day conference the day after that. Lunch time came as a welcome break and we had a lovely walk to another restaurant where we had a light lunch, most of us were still full from the feast! It was good to have a break and chat with all my friends from the board although we missed Edwige of course.

We didn't sit talking for long though and we made our way back to the hotel ready to continue our meeting.

There was a lot of discussion, planning, assigning tasks etc and we finished the meeting around 4:30, just time for a quick freshen up and then we met in the lobby at 5pm to go to Catalina and Marius gym, MC GYM Motion.

We were given a warm welcome there from Marius who explained how the gym had started and that they support dystonia patients along with MS and Parkinson's patients. The patients can go every Friday to use the gym with expert guidance from the team, free of charge! We all know that exercise is good for us but using a gym can be expensive. Marius and Catalina have given all their patients the ability to exercise no matter what it costs. Catalina also has an office there where she practises her psychology helping many patients to cope with their problems.

After the visit to the gym we went out for dinner to another lovely Romanian restaurant and another lovely meal. We were back at the hotel by around 9:30pm and we were all very tired after a long day so retired to bed as soon as we got back.

The following morning we had a 'morning off', this is unusual when we meet so it was lovely to be able to take advantage of that and explore the town a little.

After all the food I had eaten over the previous 2 days I didn't want any breakfast so I relaxed in my room with a coffee before I got ready.

Catalina had recommended an ice cream parlour so as soon as I was ready I went out for a lovely walk to take in some of the sights and ended up at the ice cream parlour where I enjoyed a small tub of my favourite ice cream.

Our members were beginning to arrive in Timișoara and it was lovely to see them all, it was a reunion of old friends and some new friends too.

The General Assembly started at around 12 noon with registration and a light lunch of sandwiches, fruit and drinks. Then we got straight down to business. The meeting was opened with a video of Edwige apologising for not being there and welcoming everyone to the meeting.



**Hotel Timisoara**

The business side of the meeting went very well and all our news etc was well received by our members. During the 'Any Other Business' section we got lots of really good comments and suggestions on how to raise funds etc.

The meeting closed around 3:30pm and once we had tidied the room we all went to freshen up for our evening activity.



We met in the foyer at 5pm and got on a coach to visit a winery and sample some wines.

The Cramele Recas winery is lovely and in a beautiful location, our guide was very knowledgeable and also funny, she gave us a tour and then sat us down for the wine tasting. We tasted 4 or 5 different wines all of which were lovely but my favourite was one of the white wines. There was a huge glass in the middle of each table for people to pour away any wine they did not want once they had taken a sip to taste it. As I don't drink a lot I just tasted each one and poured the rest into the big glass, I then enjoyed a full glass of the white wine I favoured with my meal.

After yet another lovely meal we all boarded the bus to go back to the hotel. I don't know what everyone else did with their wine but there was no singing on the bus so I guess no-one had a lot to drink, ha ha.

Our Dystonia Day conference started promptly at 9:30am on Saturday 1st June, we had presentations from The European Research Network, Rare Neurological Diseases, this prompted a debate about how rare dystonia actually is, some forms of dystonia are the 3rd most common movement disorder but some like blepharospasm and myoclonic are rare.

We then enjoyed presentations from the European Federation of Neurological Associations and the Boston Scientific Foundation. After a short break we had an interesting presentation by Prof Simu, a neurologist from Romania who treats dystonia. It was interesting to hear how she does her treatments and looks after her patients, she is a very caring lady.

Next was a recording of a drama depicting the journey of a cervical dystonia patient from onset of symptoms, through diagnosis and treatment to living with the condition. It was based on the Cervical Dystonia Patient Journey project we completed in collaboration with Ipsen. The video was around 30 minutes long and I think everyone in the room could identify with it. The actress who wrote and performed the drama really understood the journey that most of us have been on. I have to admit I shed a tear or two, it was very emotional.

We then heard from Oleks Gorbenko from Ipsen on how they work with Dystonia Europe and how beneficial that work is to both Dystonia Europe and Ipsen. By this time we were feeling hungry so Oleks didn't get many questions! Of course any one of us could ask him questions during lunch if we wanted to. The hotel provided a very nice 3 course lunch which gave us all the energy we needed to continue into the afternoon.

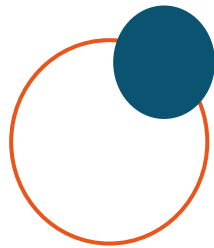
The afternoon session was mainly for us to hear from some of our member organisations and we had presentations from Catalina from the Association of Children's Joy in Romania, Vidar from the Norwegian Dystonia Association and Julia from Dystonie und du in Germany. It was very interesting to hear how the different organisations work, how they get funding, members, create newsletters etc. Needless to say there is a lot of hard work that goes into running a patient organisation and of course most of us are volunteers with other commitments to keep up too.



**From left:**

**Monika Benson, Executive Director and Gill Ainsley, Vice President and Secretary Dystonia Europe**











We then had a fun (but also informative) presentation by Laria from Timișoara who works alongside Catalina and Marius in their gym. She is an expert in mindfulness and uses Virtual Reality to help her patients. Those who wanted to tried out the Virtual Reality headset and found themselves in idyllic settings, some with bird song or the sound of waves on the shore. It was a lovely way to finish the meeting.

After another quick freshen up and we met again in the lobby ready for our walking history tour.

Our guide took us walking for around 1 hour and explained some of the history of Timișoara. As I said earlier the history of the town is so interesting and varied that I would like to learn much more about it.

Our tour finished at a lovely restaurant where we all enjoyed yet another tasty 3 course meal. After 3 days of lovely Romanian food I will need to go on a diet when I get home! I said goodbye to everyone at the end of the meal as my flight was early the next morning. I was sad to say goodbye to everyone but was looking forward to going home.

My journey home was very long with a 7 hour transfer time in Schipol so although I left the hotel at 6:30am it was almost midnight when I finally arrived home. As usual my lovely husband was waiting for me at the airport. It was so nice to see him after my long journey, usually when I get back from a Dystonia Europe trip I talk non-stop until I have told him all the things I have seen and done but this time I was just too tired. I did talk non-stop the following morning!

I hope you all enjoyed your time in Timișoara as much as I did and I hope you all enjoyed the General Assembly and the Conference day and maybe learned a few things too, I certainly did.

See you all next time!

**Gill Ainsley**  
Secretary and Vice President  
Dystonia Europe



## The General Assembly in Timișoara: How Dystonia Europe Unites Communities and Builds Connections

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Organising the Dystonia Europe General Assembly in Timișoara was an extraordinary experience, filled with enthusiasm and joy. It was wonderful to bring together members and experts from various corners of Europe in a setting that allowed not only for the exchange of ideas and strategies but also for cultural understanding, in an atmosphere where authentic connections were made.

The first day was dedicated to the administrative and strategic aspects of the organisation, while the second day featured a series of valuable presentations. Personally, I was very impressed by the collaboration and support provided by all participants, both speakers and delegates, and the positive feedback I received confirmed the success of the event.

It is important to highlight that the event was not just about the exchange of ideas and strategies but also about creating an environment where members felt understood. The organisation and presentations were carried out with attention to the needs of each participant, demonstrating a successful blend of empathy and a high level of professionalism.

This event once again underscored the importance of international collaboration and the close connections between our organisations, and I am grateful for the opportunity to have hosted such an important event.

**Catalina Crainic**  
Board Member  
Dystonia Europe



# Dr. Stavros Tsagkaris Receives the David Marsden Award 2024

Our congratulations to Dr. Stavros Tsagkaris, from the Evelina London Children's Hospital in London, UK and the David Marsden Award 2024 for his paper:

Metabolic Patterns in Brain 18F-fluorodeoxyglucose PET Relate to Aetiology in Paediatric Dystonia

<https://dystonia-europe.org/wp-content/uploads/2024/07/tsagkaris-et-al-brain-656e1e43a6c91253670147.pdf>

On Saturday 29 June Dr. Tsagkaris was presented with the award by Dystonia Europe Executive Director Monika Benson at the Basal Ganglia Session at the 10th EAN (European Academy of Neurology) Congress in Helsinki, Finland. Dr Tsagkaris expressed his thanks to Dystonia Europe for the award and then presented the work of his research.

Monika Benson, Executive Director of Dystonia Europe says:

*"We are delighted that this year's award goes to Dr. Tsagkaris for his important research on children with dystonia, since this is a field of research within dystonia that needs much more focus. We wish Dr. Tsagkaris good luck and look forward to follow his work".*

## About the winner:

Dr Tsagkaris is a senior Paediatrics trainee in London, UK. He is an aspiring Paediatric Neurologist, entering Neurology training.

Dr Tsagkaris completed his medical degree in National and Kapodistrian University of Athens, Greece. He completed a clinical research fellowship at Evelina London Children's Hospital Complex Motor Disorders Service under the supervision of Dr Jean-Pierre Lin, in collaboration with King's College London PET Imaging Centre, as a member of Professor Alexander Hammers' team.

His ongoing research work focuses on the field of movement disorders and particularly dystonia in children, focusing on neuroimaging, neurophysiology and neuromodulation. Dr Tsagkaris' special interest is functional neuroimaging in children with dystonia, aiming to deepen our understanding of the pathophysiology of the disease.



**Dr. Stavros Tsagkaris, Evelina London Children's Hospital in London, UK and David Marsden Award Winner 2024**

### About the research:

The exact mechanisms via which dystonia symptoms develop are not clearly understood. Brain imaging is a great way to unravel abnormalities that could be related to the disease. There has been extensive research on the structural brain abnormalities related to development of dystonia. However, there is a relative lack of imaging markers revealing the functional characteristics of different brain regions in dystonia, especially in the paediatric population. One way to assess the function of brain areas is Positron Emission Tomography (PET) scanning, where a glucose analogue is injected into the bloodstream and brain images are taken after absorption, to reflect the glucose uptake in the brain.

Dr Tsagkaris along with his colleagues examined the glucose uptake patterns in the brains of patients with different types of dystonia, including genetic as well as acquired dystonia cases. The researchers found that, on the one hand, most aetiologic subgroups shared some patterns of glucose metabolism, possibly reflecting innate characteristics of dystonia. On the other hand, the different groups also had “signature” characteristics, which distinguished them from the rest and therefore pointed towards distinct pathophysiological mechanisms.

The results offer further insights into the pathophysiology of dystonia, enhancing our understanding of the underlying biological mechanisms related to the disease. The various areas of altered brain metabolism revealed from this study relate to disease phenotype, suggesting their potential function on controlling movement and posture. They also introduce the possibility of PET scanning imaging patterns potentially being used as a biomarker for the various disease groups in the future.

Moreover, in combination with information obtained by structural neuroimaging as well as neurophysiology testing, this research work can help better inform decisions on management options, including deep brain stimulation, providing more individualized patient care.

### About the award:

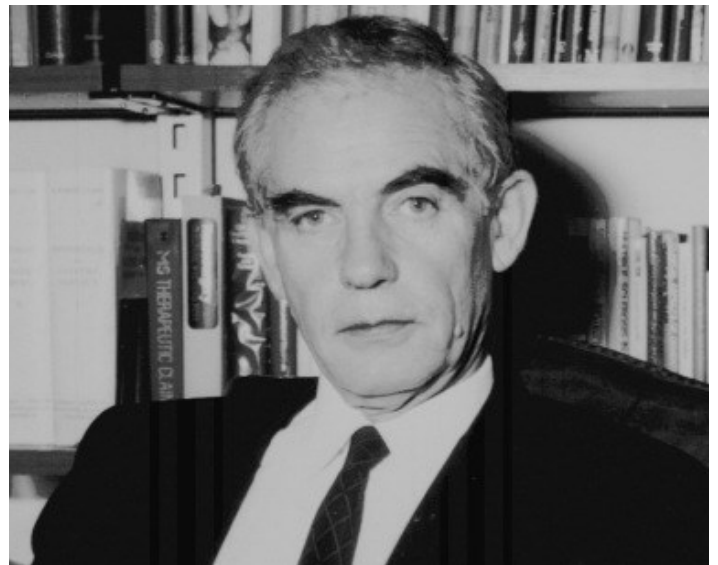
The Award was an idea of late former President of European Dystonia Federation Didi Jackson from Germany.

Late Professor David Marsden was the Dean of the Institute of Neurology in Queen Square in London and he was one of the founding members of the Movement disorder society. Many movement disorder experts across Europe and beyond first learned about dystonia from Professor Marsden. He especially encouraged young scientists to become involved in the field. When Dystonia Europe was founded in 1993 Professor Marsden gave us a lot of good advice, and took a genuine interest in the development of our organisation.

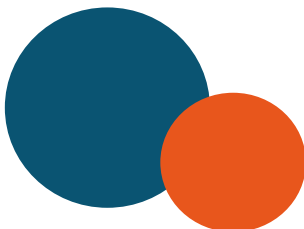
It was therefore entirely appropriate that David Marsden should be honoured by an Award given by patients in his name.

The David Marsden Award was first presented in 2003 to Professor Mark Edwards. Since then there has been a total of 12 awards. In the beginning the award was every other year but from 2020 it is an annual award. Next call for applications for the David Marsden Award of 2025 will start from 1 September.

**Monika Benson**  
Executive Director  
Dystonia Europe



**Prof C David Marsden (1938 – 1998) .**





# Discovering a Missing Piece of the Dystonia Jigsaw: An International Collaboration on Understanding Brain Glucose Activity Patterns in Children and Young People with Dystonia

By Dr Jean-Pierre Lin, Evelina London Children's Hospital, London, UK

The award of the Dystonia Europe David Marsden Prize to Dr Stavros Tsagkaris represents a significant recognition of the importance of our work in investigating brain activity patterns in childhood and adolescent dystonias task<sup>1, 2</sup> representing a 20-year project to carefully unravel the mechanisms of dystonia in children and young people.

## Setting up a children's dystonia diagnostic and management service:

In 2005 the embryonic Complex Motor Disorders Service (CMDS) at the Evelina London Children's Hospital set up a Multidisciplinary Team (MDT) to deliver a Deep Brain Stimulation (DBS) Service for children with dystonia and other movement disorders in collaboration with neurosurgical colleagues: Mr Richard Selway, Prof. Keyoumars Ashkan and latterly Mr Harutomo Hasegawa from the King's College Hospital Neurosurgery Department.

In 2008 Dr Jean-Pierre Lin was awarded a Guy's and St Thomas' Charity New Services and Innovation Grant G060708 for pump-priming support to build a dedicated CMDS MDT Team, leading to the current clinical-research structure.

## Dystonia Brain Function:

Given the relative rarity of individual causes of dystonia in childhood the CMDS MDT set out to gather the broadest possible information that could result in a better understanding of the impact of dystonia on function, comfort, growth and development and well-being in children and young people, by collecting very detailed clinical information on each child. Together with dedicated scales to measure function, dysfunction and dystonia alongside genetic, metabolic, imaging and neurophysiological parameters.

## Neurophysiology of dystonia:

Dr Verity McClelland spearheaded neurophysiological testing of the *central motor conduction time (CMCT)*<sup>4</sup> with transcranial magnetic stimulation (TMS) and evaluation of the sensory pathways from *somatosensory evoked potentials (SEP)*<sup>4</sup>. This was followed by simultaneous brain and muscle activity patterns during simple manual tasks<sup>5</sup>.

## Brain Activity Patterns in childhood dystonia:

Two imaging techniques were used to study the brain of children with dystonia: MRI brain imaging, led by Dr Daniel Lumsden, produces detailed structural brain images. *Fluorodeoxy-Glucose Positron Emission Tomography* brain scans fused with CT imaging (FDG-PET-CT), led by Dr Jean-Pierre Lin and Prof. Alexander Hammers, allow us to study brain activation patterns in dystonia.<sup>6,7</sup>

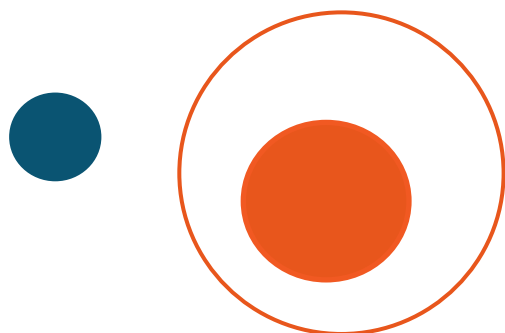
## How investigations and clinical evaluation are combined in assessing childhood dystonia:

Dr Stavros Tsagkaris studied the similarities and differences in regional brain glucose activity (i.e. glucose uptake and metabolism) in quietly awake children with dystonia which has shone a new light on the similarities and differences between different causes of dystonia when compared to healthy controls without dystonia.

This international multidisciplinary collaboration has enabled an understanding of direct brain activity assessment in childhood dystonias.

## Future directions:

The very large comprehensive dataset collected by the CMDS team over the last 20 years will allow careful unravelling of the many factors underpinning childhood-onset dystonias by describing and following up brain activity patterns (glucose consumption). With this data we can track the impact of age, timing and aetiology (i.e. causes) of dystonia.





**Dr. Stavros Tsagkaris and Dr. Jean-Pierre Lin,  
Evelina London Children's Hospital in London, UK**

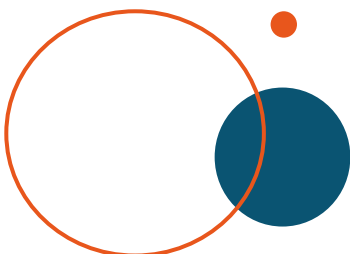
Future applications of FDG-PET-CT brain imaging will include 'before' and 'after' dystonia intervention imaging studies to evaluate the impact of advanced therapies such as deep brain stimulation or gene therapies on childhood brain activity patterns.

We intend to build on previous data<sup>7</sup> to characterise individual brain energy consumption patterns to fully explore the impact of the many variables, singly and in combination, underlying the similarities and differences in dystonia, expressed in all age groups, and relative responsiveness to DBS and other advanced therapies.

Our aim is to generate new hypotheses regarding causal mechanisms of dystonia leading to new management strategies.



**From left:  
Executive Director Dystonia Europe Monika Benson,  
DMA winner Dr. Stavros Tsagkaris and Dr. Jean-Pierre Lin**





## Acknowledgements:

Dr Jean-Pierre Lin supervised the clinical data collection; *Professor Alexander Hammers*, head of the King's College London PET Centre at St Thomas's Hospital, supervised the FDG-PET-CT analyses and *Dr Eric Guedj* of the Université of Aix Marseille, France, kindly provided the healthy adult control FDG-PET-CT brain scan data.

## Funding and support:

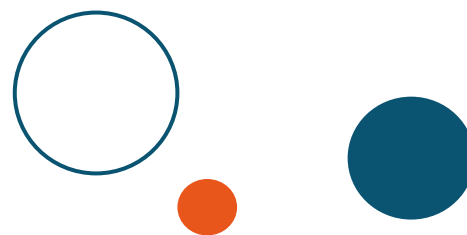
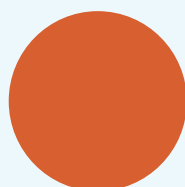
**J-P Lin:** Guy's and St Thomas' Charity New Services and Innovation Grant G060708; Dystonia Society UK Grants 01/2011 and 07/2013 and Action Medical Research GN2097; GSTT Charity Complex Motor Disorders Service Research and Education Fund A13.

**A Hammers:** Wellcome EPSRC Centre for Medical Engineering at King's College London (WT 203148/Z/16/Z) and also from the Department of Health via the National Institute for Health Research (NIHR) comprehensive Biomedical Research Centre award to Guy's & St Thomas' NHS Foundation Trust in partnership with King's College London and King's College Hospital NHS Foundation Trust.

**V. McClelland:** is currently supported by a Clinician Scientist Fellowship from the Medical Research Council UK (MRP0068681) and by a Continuation Funding grant from the Rosetrees Trust (CF-2021-2-112) and was previously supported by a postdoctoral clinical research training fellowship from the Medical Research Council UK (MRP0068681) and a project grant from the Rosetrees Trust (A1598).

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**Metabolic patterns in brain<sup>18</sup>**  
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[Role of 18F-FDG PET imaging in paediatric primary dystonia and dystonia arising from neurodegeneration with brain iron accumulation](#)

*Nuclear medicine communications*. 2015, 36 (5), 469-476

3. VM McClelland, A Valentin, HG Rey, DE Lumsden, MC Elze, R Selway, G Alarcon, JP Lin.

[Differences in globus pallidus neuronal firing rates and patterns relate to different disease biology in children with dystonia](#)

*Journal of Neurology, Neurosurgery & Psychiatry* 2016, 87 (9), 958-967

4. Verity M McClelland, Doreen Fialho, Denise Flexney-Briscoe, Graham E Holder, Markus C Elze, Hortensia Gimeno, Ata Siddiqui, Kerry Mills, Richard Selway, Jean-Pierre Lin.

[Somatosensory evoked potentials and central motor conduction times in children with dystonia and their correlation with outcomes from deep brain stimulation of the globus ... pallidus internus.](#)

*Clinical Neurophysiology* 2018, 129 (2), 473-486

5. VM McClelland, Z Cvetkovic, JP Lin, KR Mills, P Brown

[Abnormal patterns of corticomuscular and intermuscular coherence in childhood dystonia](#)

*Clinical Neurophysiology* 2020, 131 (4), 967-977

6. H Gimeno, JP Lin

[The International Classification of Functioning \(ICF\) to evaluate deep brain stimulation neuromodulation in childhood dystonia-hyperkinesia informs future clinical & research ... priorities in a multidisciplinary model of care.](#)

*European Journal of Paediatric Neurology* 2017, 21 (1), 147-167

7. SA Shah, P Brown, H Gimeno, JP Lin, VM McClelland

[Application of machine learning using decision trees for prognosis of deep brain stimulation of globus pallidus internus for children with dystonia](#)

*Frontiers in neurology* 2020, 11, 825



# Dystonia Research in Finland

## – Brain Lesions, Brain Networks and Brain Stimulation

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Turku Brainlab, a non-profit research laboratory at University of Turku in Finland, has recently ramped up dystonia research in Finland.

Turku Brainlab hosts approximately 30 researchers from numerous countries and disciplines, including neurology, psychiatry, radiology, neuroscience and psychology. The unique strength of the lab is in its multimodal approach, leveraging several cutting-edge neuroimaging and brain stimulation techniques. Turku Brainlab is led by Prof. Juho Joutsa, chief neurologist at Turku University Hospital, who has studied movement disorders for the past 15 years.

Prof. Joutsa completed his postdoctoral training at Massachusetts General Hospital and Harvard Medical school, where he and his Australian colleague Dr. Daniel Corp, PhD, led a pioneering study localising the brain network of cervical dystonia based on causal brain lesions and a novel technique called lesion network mapping (Corp & Joutsa et al., *Brain* 2019). This study prompted a years-long collaboration between Joutsa and Corp with their common cause of finding solutions to dystonia. Dr. Corp is currently working at the Turku Brainlab alongside Prof. Joutsa. This breakthrough in cervical dystonia, together with a generous donation from an individual person (who prefers to stay anonymous) upon Prof. Joutsa's return to Finland in 2018, sparked a new era of dystonia research at University of Turku.

Currently, researchers in Turku leverage several approaches to study the neurobiological mechanisms of dystonia, with the aim of localising brain networks that can be targeted by therapeutic brain stimulation. The core of this work is lesion network mapping, which they also used in their cervical dystonia study published in 2019.

This technique leverages causal lesions (i.e. cases where a focal brain damage has led to development of dystonia) and combines the lesion locations with the brain connectome (wiring diagrams of the human brain). This approach circumvents one of the big challenges in neuroimaging research by using causal sources of information, instead of only analysing correlations and group differences in brain activity, as in traditional imaging approaches. By studying these lesions, the researchers extended upon their 2019 study in cervical dystonia to show that different types of dystonia are caused by damage to different brain structures, indicating that all dystonias are not the same neurobiologically (Corp...Joutsa, *Neurology* 2022). They are now using lesion network mapping to localise the causal networks across dystonia types.

The ultimate goal in Turku Brainlab is to translate their findings to therapies. Brain stimulation is increasingly used to treat brain disorders but is currently only available for a handful of neurological and psychiatric disorders. One of the main challenges is to know exactly where in the brain to stimulate. Without the correct target, the stimulation is futile. Luckily, we already know an efficacious target for deep brain stimulation in dystonia. However, we still don't fully understand its mechanisms of action. To address this, Turku Brainlab conducted the first study in Finland combining deep brain stimulation with positron emission tomography (PET), which measures glucose metabolism in the brain (Honkanen et al., *JNNP* 2024). The researchers showed that the effects of deep brain stimulation are in fact not mediated via changes in the DBS target activity but outside this region in brain areas that are connected to it, suggesting that the target is a network rather than a single anatomical region.

While this helps to define the mechanisms and neural substrates of DBS efficacy, because DBS is invasive it is only used in severe cases where other treatments are inadequate. In addition, although the treatment is highly efficacious on average, not all types of dystonia have good response to DBS, and there may also be side-effects.





Prof Juho Joutsa, MD, PhD

Therefore, the team is currently trying to translate their findings to novel brain stimulation treatment using transcranial magnetic stimulation, which is a non-invasive form of therapy. The preliminary results are encouraging, as they have already found out that transcranial magnetic stimulation to the cervical dystonia network results in changes in brain metabolism within the network, demonstrating engagement of this target network (Kokkonen et al. *Submitted*). In parallel, Dr. Corp is overseeing a pilot study at Deakin University in Australia, showing promising clinical benefits of stimulation to this exact site over 10 days (9 patients with cervical dystonia tested so far). If successful, this would set the stage for a larger-scale randomised controlled trial, which would be necessary to conduct before the new therapeutic approach could be brought to clinical care. Moving this line of research forward is mostly dependent on the available funding, which is unfortunately relatively limited for dystonia research.

This would also allow us to expand this approach to other types of dystonia. The road from initial discovery to new treatment is always long but we believe it can be achieved with persistence and teamwork between clinicians, scientists, funders, and most importantly, individuals with dystonia, as without their support none of this work would be possible.

**Juho Joutsa, MD, PhD**

Professor of Neurology, University of Turku  
Chief neurologist, Turku University Hospital  
Turku, Finland

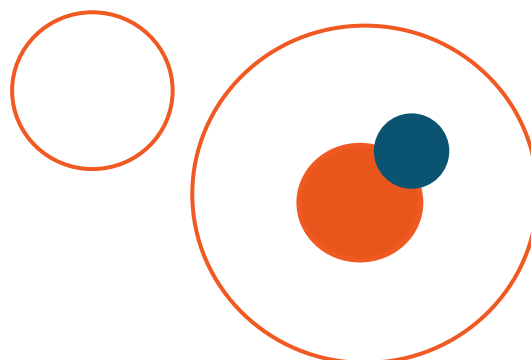
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## DMRF PRESS RELEASE

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### Available Now!

#### **Samuel Belzberg 6th International Dystonia Symposium**

#### **Summary for the Dystonia Community**

DMRF is thrilled to share this highly anticipated lay summary of the Samuel Belzberg 6th International Dystonia Symposium (IDS6), held in Dublin, Ireland last year. The symposium drew top dystonia researchers from 32 countries, including 68 faculty members and close to 350 attendees, pushing for a deeper understanding of the disorder and how to treat those who are affected.

This Summary Presents the Latest Dystonia Science in These Categories:

- Overview of where we are now
- New thinking and research findings
- Topics of debate
- Questions for future exploration

[Read the IDS6 Summary Here](#)

The DMRF is grateful to Ipsen Biopharmaceuticals and Merz Therapeutics for their support of the lay summary.



Frances Belzberg





## Annual Meeting of the Boston Scientific Foundation Europe

Mid May the annual meeting of the Boston Scientific Foundation Board took place at the Meridian Hotel in Paris. Dystonia Europe Executive Director Monika Benson is on the board as one of three external board members. Other board members are employees of Boston Scientific.



An external consultant engaged with the members of the board to focus on the strategy for the next 12 months and beyond, which inspired a great exchange of ideas and fruitful discussions.

The Foundation has been working for six years and funded several projects in the field of digital innovation supporting patients' health and well-being. For more information on the projects funded see: <https://www.bostonscientific.com/en-EU/about-us/corporate-social-responsibility/people/foundation/projects.html>

**Monika Benson**  
Executive Director  
Dystonia Europe



Orso Chetochine, Eric Thépaut, Monika Benson, Elena Moya, Simonetta Balbi, Isabelle Wilbois, Karine Rolland-Roumegoux, Yannick Vogel, Jan Szemjonneck



## OTHER NEWS

# Dystonia Europe at Medtronic DBS Engineered to Adapt Event

Dystonia Europe together with Parkinson's Europe took part in the Medtronic DBS Engineered to Adapt event in Barcelona, Spain last May.

Both organisations had tables with information material in the networking area.

The opening session was with Amybel from the UK. She was interviewed by Professor Fasano from Canada. Amybel told her story of dystonia and how DBS changed her life.

A few years ago Amybel took part in our 25th Anniversary celebration in Brussels. Hear her story here: [https://www.youtube.com/watch?v=3oFA3Kw\\_bg&list=PLFvCc6fYkjEtsmzMs0ooetA2aPqqsECHh&index=12](https://www.youtube.com/watch?v=3oFA3Kw_bg&list=PLFvCc6fYkjEtsmzMs0ooetA2aPqqsECHh&index=12)

At Thursday night's dinner Monika Benson from Dystonia Europe and Francesco De Renzis from Parkinson's Europe presented the work of their organisations.

**Monika Benson**  
Executive Director  
Dystonia Europe



**Professor Fasano from Canada and Amybel Taylor**



**Above from left:  
Monika Benson, Amybel Taylor and  
Nathalie Courtine**

**Left:**

**In the middle DE Executive Director  
Monika Benson and Parkinson  
Europe representative Francesco  
De Renzis together with Medtronic  
staff**



## Dystonia Awareness Month 2024

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**#volunteerfordystonia**

Like every year, September is Dystonia Awareness Month. On our communication channels, you'll find videos, images, ideas and information about dystonia and its various forms. Share / like / comment on them to take part in this communication movement and raise awareness of dystonia and the condition of sufferers.

Don't hesitate to participate and make your contribution!

This year, we're putting the spotlight on volunteers with the hashtag: **#volunteerfordystonia**

Volunteers are the lifeblood of our community and our actions, and there aren't enough of them.

Let's understand the logic together.

If you're reading this newsletter, you're following Dystonia Europe news.

Dystonia Europe was created 31 years ago in 1993 on the initiative of 9 founding members, representing Sweden, Norway, Denmark, Germany, The Netherlands, Italy, Croatia, and the UK.

The members of Dystonia Europe are not individuals but legal entities, the national dystonia organizations.

Today, there are 22 national member associations in 20 European countries, representing some 20,000 members.

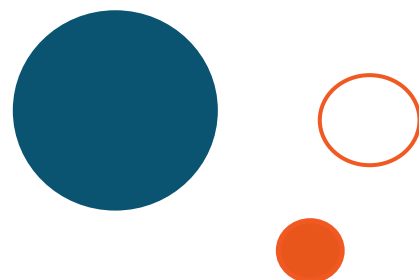
All have been in existence for an average of 20 to 30 years, if not more. or national associations to exist and function, they need members and volunteers.

**Membership** is the first essential act: supporting the existence and work of your national association, but above all giving it a voice, which will make it legitimate and give it weight in its ecosystem through its actions and advocacy.

Your national association needs **volunteers** to bring this work to life.

Over the past few years, we have observed that there are not enough of them, and that they are sometimes tired.

They need your help.





## OTHER NEWS

Who are these volunteers? Mostly people with dystonia, focal or generalized, young or not so young, working or retired, with families or other responsibilities, and coping with life's other chronic pathologies. There are also a few caregivers, family members of a person with dystonia.

They are all inspiring, willing and passionate!

We all have a little time, empathy, skill, know-how or simply a desire to learn to share.

Just 10 years ago, I contacted my national association with a vague idea of how such a structure would work, and no idea of the role I would play in it. Today, I'm writing this article!

Becoming a volunteer means breaking out of your isolation, joining a group, creating links and friendships, feeling useful, supporting others, learning, exchanging, discovering, sharing your experience (because we all become "expert patients" one day), making your contribution to raising awareness of our rare disease and seeing its treatment evolve, on the national territory and then across Europe.

I'd like to take this opportunity to thank all the stakeholders in our community: the scientists, researchers, pharmaceutical and medical equipment companies who support us, the foundations, donors, friendly associations in the USA, Canada, South America and elsewhere with whom we collaborate, the members in every country, and above all...

### THE VOLUNTEERS!

The volunteers in every country who give their time and energy despite the disease, who support sufferers daily, who organize events and meetings, who offer practical support tools, who keep the cause and care of dystonia alive and moving forward across Europe. Without them, the entire community and its organization would be nothing.

So, this year, dear readers, for the month of September, here's a triple mission for you: ☑

- Interact with our communication campaign,
- Join, subscribe, bring your voice to your national association if you haven't already done so,
- And become a volunteer! They need you; we need you!



**MEMBERS OF DYSTONIA EUROPE 2024**

- Austria
- Belgium
- Croatia
- Czech Republic
- Denmark
- Finland
- France
- Germany
- Ireland
- Italy
- Norway
- Poland
- Romania
- Slovenia
- Spain
- Sweden
- Switzerland
- The Netherlands
- Ukraine
- United Kingdom



Don't be shy. Make your voice heard through your actions and involvement. As individuals, we are all important, useful and indispensable to the smooth running of our movement.

To find your national association:

<https://dystonia-europe.org/about-us/the-organisation/>

Or the Dystonia Europe email address for information: [sec@dystonia-europe.org](mailto:sec@dystonia-europe.org)

**Edwige Ponseel**  
President  
Dystonia Europe



**Volunteers at the Dystonia Days Member Meeting in Timisoara 2024**

## Support EFNA's Call to Action for Rare Neurology!

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The European Federation of Neurological Associations (EFNA) recently led a multi-stakeholder group in developing the [Rare Neurology Charter](#). The Charter outlines high-impact policy solutions with the potential to transform the lives of patients.

Building multi-stakeholder support for the identified policy solutions creates a strong platform to address and engage European and national policymakers on an action plan to transform the lives of patients.

Please sign the [Call to Action for Rare Neurology](#) to show your support for the Charter and its recommendations. The Call to Action will be used to encourage engagement from policymakers ahead of Rare Disease Day 2025, through the [MEP Interest Group on Brain Health and Neurological Conditions](#).

Link: <https://www.efna.net/rnc-cta/>

**Elizabeth Cunningham**  
Senior Communications Manager  
European Federation of Neurological Associations



## SIGN THE CALL TO ACTION FOR RARE NEUROLOGY

Sign now and show your support for the development of rare neurology action plans at EU-level which will aid policy change.

[www.efna.net/RNC-CTA](https://www.efna.net/RNC-CTA)





## Patient Advocates of the ERN-RND Visit Expert Center in Innsbruck

The question our ePAG asked ourselves in January of 2024: What does good care look like? We thought it wise to visit an Expert Center to learn about the expertise and the standards that they provide to patients. We identified a centre that covered all of the representative diseases in the ERN-RND (European Reference Network on Rare Neurological Diseases). We then decided on the questions we would like to be answered.

On 24 May, the ePAG of the ERN-RND left their mark in Innsbruck, where they visited Dr. Sylvia Boesch and her team at the Center for Rare Movement Disorders Innsbruck (CRMDI) in the Medical University Innsbruck.

Dr. Matthias Amprosi, part of the neurology team at the CRMDI made a presentation, which covered the majority of the questions we sent them prior to our visit. We learned about the clinic and how many patients they see and help per year. We learned about studies that are currently in progress. We learned that there are also organisational, nursing and physiotherapy teams, as well as social workers, all of whom are exclusively assigned to the Department of Neurology. We then saw that in action.

Read full article here: <https://www.ern-rnd.eu/the-ern-rnd-epag-visits-the-medical-university-innsbruck/>



**“Getting coordinated care is not a pipe-dream. It is a reality in Innsbruck and can be a reality in other places” (Patient Advocate from ERN-RND)**

## ERN-RND Attending the EAN Congress in Helsinki

ERN-RND had a booth in the EAN (European Academy of Neurology) exhibition in the Neurohood section. Together with EFNA they organized the (N)euro-café. Coffee and biscuits were served and visitors could have a chat with the different disease representatives.



On the Monday afternoon there was an ERN-RND session in the Scientific Theatre with actress Carmel Stephens from Ireland who performed a short play about a conversation between a cervical dystonia patient and a member of a family affected by Huntington’s disease. They were sharing what they had in common being affected by neurological disorders. Carmel took part last year at the EAN congress in Budapest performing the patient journeys of a cervical dystonia patient and a patient affected by Huntington’s.

The Cervical Dystonia patient journey has been recorded and the video is available here.



<https://www.youtube.com/watch?v=PxJmQA1ewi0>

*Countless visits to doctors, the feeling of "something's wrong", being undiagnosed for years - many rare disease patients are familiar with that. The **patient journey movie** on Dystonia shows the different stages of the disease as it progresses - from first symptoms over diagnosis to treatment - and how it affects a patient's everyday life as well as ways of coping.*

**Monika Benson**  
Executive Director  
Dystonia Europe

# Meet Vidar from Norway

My name is Vidar Bjørkli, I am 64 years old and live in Finnsnes, Troms in Norway.

I am married to Berit and have two grown up sons. Before my retirement two years ago I worked most of my life (nearly 40 years) as a journalist in the local newspaper Troms Folkeblad in Finnsnes.

In 2013 I experienced the first symptoms of dystonia. The diagnosis came one year later. Immediately I became a member of the Norwegian Dystonia Association (NDF), and it has been an enriching community to be a part of. During autumn 2019 I was asked if I wanted to become a member of the board. This is now my 5th year as a board member after I said yes to another two years at the last annual meeting.

As a board member in NDF I am responsible for Facebook, our webpage and our newsletter Dystoni-Nytt.

The symptoms came suddenly and unexpected as for most of us. From one hour of being healthy to the next hour having a chronic, incurable disorder. It happened when I was on my way home from the evening shift at my job in the newspaper one day in 2013. Suddenly I noticed that I was walking with my head turned to the left walking along the street.

I was really wondering what is this? I assumed that it was something muscular, maybe due to stress at work. I decided to see if a chiropractor could help. The chiropractor tried manipulation and acupuncture. Since this did not help he started to think that it could be something neurological. Online he found out that the symptoms could be dystonia. But my General Practitioner doubted that dystonia was the correct diagnosis. At the neurological department at UNN I was even denied an appointment for an examination. Instead they referred me for an examination at the department for medical physical rehabilitation. Their conclusion was that it would take time for this to pass and I should do yoga and exercise.

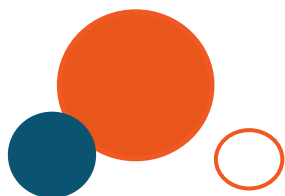


**Vidar Bjørkli with his motorcycle**

That was ok advice, but in the meantime the muscles continued to work overtime. It was also painful. Searching for answers on what could be wrong with me, I among other things wrote to the Norwegian Dystonia Association. They gave me valuable advice and tips.

I am a supporter of public healthcare, but a feeling of not being heard led me to contact a private hospital. Spring 2014 I had an appointment with a neurologist who worked at Volvat in Oslo. He did not need much time to determine I had cervical dystonia with torticollis towards the left.

After this it only took one month before I was referred for my first injections with botulinum toxin at UNN. I felt immediately that it relieved the stiff muscles and that it was easier to keep my head straight. Since then I have received treatments regularly every third month. Here I want to applaud UNN for continuity in the follow-up.





It was good to know that there is a patient organisation. At one meeting that NDF arranged in Tromsø I met with other members from Northern Norway.

As a new member I participated as a member with Berit at my side, the following years at Dystonia-days both in Oslo and Brüssel. We went privately and took it as a holiday.

It was liberating to join a group meeting where the participants shook their heads and to see that one is not alone. I was impressed to see the large number of experienced researchers, doctors and therapists that held presentations and continuously work to improve the treatment options for us who have this illness.

In the beginning I felt low because of having dystonia. I was somewhat embarrassed to be around people and thought now I am viewed as a weirdo.

After some time this passed. The dystonia does not affect me anymore in the way I had feared.

I could still work full time. Some of my dearest hobbies are to drive a motorcycle and to be in nature, go for fishing and mountain trips. I can still do this. Then I really relax and the dystonia is nearly absent.

Through the Norwegian Dystonia Association I have also had the chance to get acquainted with a lot of new nice people throughout Norway and abroad. So the diagnosis, no matter how bad it is, has also opened new exciting opportunities.

**Vidar Bjørkli**

Board Member

Norwegian Dystonia Association



Vidar hiking in the mountains of Norway





Sanne Rasmussen

## Meet Sanne, Denmark

### What is your name?

My name is Sanne Rasmussen. I live in Køge, which is 40 km south of Copenhagen. I am married and have 3 adult children who have long since moved away from home. Until I became ill, I worked in the financial sector, most recently 20 years as a branch manager.

My accident and later dystonia meant that I had to stop working and was awarded early retirement in 2010. I later became aware of the Danish Dystonia Association, which I joined. When I saw the great work that is being done to spread awareness of dystonia, I realized after consideration that, in terms of my previous job and experience, I had some skills and resources that the Danish Dystonia Association could use. I was later elected as deputy chairman of the Danish Dystonia Association.

### What are the benefits of working within a patient organisation?

To help make a difference. Being a volunteer brings joy and meeting like-minded people who also have the same challenges with a relatively rare and not widely known disease. To learn more about the disease and its consequences. Get an insight into doctors' progress regarding better treatment methods. To get involved in the public debate, with a focus on the relatively rare diseases and the importance that these diseases also come into focus.

### How do you like spending your free time?

I love to paint and I spend a lot of my time doing that. It gives me peace of mind and at the same time a great value. I usually say that art saved my life. Through my art, I also meet other artists at exhibitions in both Denmark and abroad. Most recently, I participated in a large international exhibition in Hamburg. I also love to travel and experience new cultures. I also love to read and knit. I am trying to have a meaningful life, while living with generalized dystonia and the challenges it brings.

### What makes you angry or frustrated?

It frustrates me that my body doesn't want to and fights with and against the fatigue that the disease brings. The challenges that everyday life brings. Ambitions and energy levels are not always in balance.

**Sanne Rasmussen**  
Danish Dystonia Association  
Denmark



Sanne

## Calendar Autumn 2024

### September

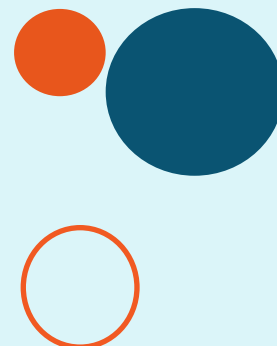
- 1-30 Dystonia Awareness Month
- 21 On-line Dystonia Day 2024
- 27-1 MDS Congress, Philadelphia, US

### October

- 10-11 ERN-RND Annual Meeting, Ljubljana, Slovenia
- 17-18 Dystonia Physio Workshop, Newcastle, UK
- 22 Dystonia Europe Board Meeting
- 28 Think Tank Meeting

### November

- 14 DBS Nurses Association 10<sup>th</sup> Annual Meeting, Sheffield, UK



Save the date

# Dystonia Day 2024

21 September, 2024  
10:00 - 13:30 CET  
on Zoom

Expert  
speakers

Patient  
testimony

Q & A



See the program here:

<https://dystonia-europe.org/wp-content/uploads/2024/09/Program-2024-final-.pdf>



## Members

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Dystonia Europe consists of 23 national member groups from 20 European countries and they are:

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

## Medical & Scientific Advisory Board

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Prof Alberto Albanese – Milan

Prof Alfredo Berardelli – Rome

Prof Kailash Bhatia – London

Prof Marina de Koning-Tijssen – Groningen

Prof Joachim Krauss – Hannover

Dr Francesca Morgante – London

Prof Tom Warner – London

Dr Jean-Pierre Lin – London

Prof Maja Relja – Zagreb

Prof Marie Vidailhet – Paris

Prof Marjan Jahanshahi – London

Shaping a Better  
Future for  
People  
Living with  
Dystonia

## Staff

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**Monika Benson**

Board Member  
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.



**Edwige Ponseel**  
President

Edwige is the President 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 full time in the purchasing and marketing department of an American company, in the European headquarter 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 reelected at the last GA in London and for a 3rd period in 2021. From December 2022 she is the President of Dystonia Europe.



**Catalina Crainic**  
Board Member

Catalina Mariana Crainic is the President of the Romanian Dystonia Organisation, Asociatia Childrens Joy and a Board Member of National Alliance of Rare Diseases, Romania. Catalina is a psychologist with right of free practice, working as psychologist for Asociatia Children's Joy and Mrd Clinical Psychology and Psychotherapy. 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 and re-elected in 2021.



**Gill Ainsley**  
Vice President and Secretary

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 re-elected in 2021.

Gill is the Vice President and Secretary of Dystonia Europe.



**Jukka Sillanpää**  
Board Member

Jukka has been the President of the Finnish Movement Disorder Diseases' Association since 2018. The main targets of the association are to provide the members with support and to increase dystonia awareness among the healthcare professionals in Finland. Jukka has also been a Board Member of the Finnish Parkinson Association since 2020. Jukka has a university degree in accounting and finance. He has much experience in management and financial accounting as well as business planning in his working life. He has a lot of experience in different roles in many associations. Jukka has Cervical Dystonia. Jukka was elected to the Dystonia Europe board in 2021.



**Sissel Buskerud**  
Treasurer

Sissel is the Vice President of the Norwegian Dystonia Association (NDF). She was also Treasurer for many yrs. in NDF until 2020. Sissel has a university degree in accounting and finance and she has experience for more than 25 yrs. as CFO—Chief Financial Officer for a Norwegian Security Company. Sissel was elected to the DE Board at the GA in London in 2019 and re-elected in 2021. She has Cervical Dystonia.

Sissel is the Treasurer of Dystonia Europe.







**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.



**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**

IT Advisor, The Netherlands

Eelco has been a professional IT-consultant and developer since 1999. For the last few years, since 2016 he has been working as a freelance developer on several internet projects related to Dystonia Europe. Since the 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.



## Contact

### President

Edwige Ponseel

### Executive Director

Monika Benson

### Operations Manager

Merete Avery

### Registered Office

Dystonia Europe, 37 Square de Meeus, 4th Floor,

B-1000 Brussels, Belgium

E-mail: [sec@dystonia-europe.org](mailto:sec@dystonia-europe.org)

### Photos from Dystonia Days and portrait photos:

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

## Meet us @



### Website:

<http://dystonia-europe.org>

### Facebook:

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

### YouTube:

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

### Twitter:

<https://twitter.com/dystoniaeurope>

### Instagram:

<https://www.instagram.com/dystoniaeurope/>

### LinkedIn:

<https://linkedin.com/company/dystonia-europe/>

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.

## Donation and Support

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

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!

## Disclaimer

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

## PLATINIUM



## Medtronic

Engineering the extraordinary



## THERAPEUTICS

Better outcomes for more patients.