

DYSTONIA NEWS

WINTER | 3- 2024



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September 2024

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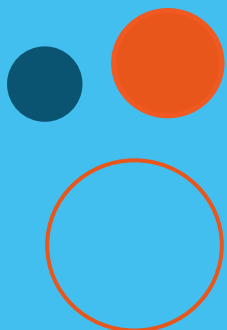
Luc Montigaud: a Tour of France for Dystonia, Research and Promoting Disability in the Workplace!

DYSTONIA
EUROPE



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SEASONS
GREETINGS!



Dear readers,

Welcome to the last issue of our newsletter in 2024.

You will discover a very rich edition; our team and our members are always very busy and it's good to reach our common objectives of dystonia awareness.

I'm convinced you will find some time during the Christmas break to learn more about it.

We organised our Dystonia Day conference in September online. The experts' contributions will be posted soon on our YouTube channel. Don't miss this wealth of information.

Our Think Tank meeting was held on Zoom in October, a constructive exchange with our sponsors on our projects.

We have also run a physiotherapy workshop in Newcastle, UK, thanks to the ADDER organisation donation, which was very successful. Other events will be held.

The Dystonia Europe team travelled around Europe and attended the DBS nurses annual meeting in Sheffield, UK, the Ipsen Global Patient Organisations Advisory Board in Paris, France, the ERN-RND network annual meeting in Ljubljana, Slovenia or the EPF webinar on personalised digital medication.

We provide you summaries to learn about these various activities and information.

Our members organisations are also very active on their national level, you will read about Romania who attended a workshop on neuromuscular disorders, about France where a young man did a Tour of France for dystonia, about Germany and their members enjoying walking with alpacas, about Italy who organized their national dystonia day or about Norway for their Autumn meeting.

We have the chance to share with you Jean-Pierre Bleton's analysis of CD Movement disorders through 3 medical studies, we thank him for providing readers a comprehensive summary.

For the long winter evenings, let me suggest you watch the video shot for the CD Patient Journey project with actress Carmel Stephens from Ireland, or check if your language translation is available, read Gill's testimony on travelling with dystonia, meet Mikko from Finland and Elizabeth from Ireland.

You can also listen to the new season 3 of our Positive Twist podcast.

On behalf of the Dystonia Europe team, I would like to take the opportunity to thank everybody for their work and commitment again this year: the Board members and staff, the medical professionals and researchers, our partners and sponsors, our advisors, our followers...

Our whole community contributes to our cause throughout the years and it's by working together that we can move forward and make a difference.

Now let us take a break to be full of energy for the new coming year.

I invite you to our next webinar on Children, Dystonia and DBS which will be held on Jan. 29 and to be prepared for the international annual Rare Disease Day on Feb. 28!

May your Christmas holidays and the new coming year bring you health and happiness,

Merry Christmas and Happy New Year.

Edwige Ponseel
President



Workshop about Physiotherapy and Cervical Dystonia in Newcastle upon Tyne

A one-day course about physiotherapy and cervical dystonia for physiotherapists was organised on Friday at the Silverlink Hotel outside of Newcastle upon Tyne in the UK.

22 physiotherapists, most of them from the local area but also from all over the UK, had come for the course.

Gill Ainsley, Secretary and Vice President of Dystonia Europe (DE) welcomed the participants. She explained that this inaugural course was funded by monies raised by the now closed charity ADDER who raised awareness and helped dystonia patients for more than twenty years and was based in the northeast of England. The money raised was donated to Dystonia Europe with the criteria that it is used to train physiotherapists in treating dystonia. As the money was raised and donated by people in the northeast of England it was appropriate to host the first course in the region.

Dystonia Europe Executive Director Monika Benson pointed out to the group that one of the main activities of DE is to support and add value to the work of the national member associations. "I hope this course will benefit dystonia patients in the local area as well around the UK" Monika said.

Dr David Ledingham from the University Hospital of Newcastle gave a comprehensive lecture on dystonia, what it is, causes, genetics, BTX treatment and how it works.

Physiotherapist Johanna Blom from Skåne University Hospital, in Malmö, Sweden, continued with her part which included a live assessment and analysis of 2 dystonia patients. After lunch focus was on treatment strategies and demonstration of exercises together with the patients who had joined.

Johanna said: "The home training program is important to make the patient feel you can influence your situation - it is empowering." She stressed the importance of the team around the patient: neurologist, physiotherapist, occupational therapist, psychologist, counselor/social worker, nurse. She also demonstrated her platform <https://physioexercise.org/en?locale=en> with over 100 exercises that can be used by physiotherapists for free in order to create individualised exercise programs for their cervical dystonia patients.

She finished the day by showing a twisted tree on the shore of a beautiful lake in Sweden and said: "Just like this tree, you see the beauty even if it is twisted."



Physiotherapist Johanna Blom and Dr David Ledingham



Johanna demonstrating physio treatment for the participants

And tell your patients to see their beauty in spite of dystonia – they are a person with dystonia but they are not dystonia “.

There were lots of questions and discussions and it was great to see so many physiotherapists interested in dystonia gathered in the same room.

Feedback shows that we have sparked the interest and most participants wish for more physiotherapy training in the field.

We thank Graham for his contribution as a demonstration patient as well as Gill who was a demonstration patient and the local organiser of this workshop. Gill is already planning the next course!

Monika Benson
Executive Director
Dystonia Europe

Improvement Projects in the Field of Dystonia and Physiotherapy

As you were previously informed, in 2021, in collaboration with Dystonia Europe, I launched a digital platform, the Dystonia Physio Exercise Hub, with over 100 exercises for cervical dystonia. It has since become available in 12 different languages, and the exercises are accompanied by models or animations. Only physiotherapists can register on the platform to access the closed page with all the exercises and the possibility to create home exercise programmes. The patient is recommended to see a physiotherapist with knowledge of dystonia. The physiotherapist can then, after careful analysis of the individual dystonia pattern and the current problems, select exercises for the home exercise programme. This becomes visible to the patient through a personalised code, which is entered on the public side of the platform using mobile, tablet or computer. The building and updating of the platform is sponsored by the Boston Scientific Foundation Europe, which made it possible to offer it at no cost to users or healthcare providers.

Currently, there are over 500 physiotherapists registered on the platform, from 29 countries worldwide. Almost 130 of them are Swedish physiotherapists.

The platform is under constant development and now there is also a “physio finder”, where you can search for a physiotherapist active on the platform based on your home town. Those who are searchable are only those who have authorised it, and not all have done so for various reasons. On the public page, you can also see a

demo with examples of exercises, and a video where a patient with cervical dystonia talks about his experience of the platform. The platform will get a new, clearer design in the spring, and for physiotherapists some educational videos.

I (together with the patient associations) have organised regular workshops on dystonia for physiotherapists in Sweden, but also in Norway, Denmark and Finland for many years. With the platform, the knowledge gap is becoming more obvious, and more countries in Europe are starting to ask for this type of training. In October, I held a workshop in Newcastle upon Tyne, England, co-organised with the European dystonia association.

Doctors and physiotherapists from Sweden and the rest of Europe are increasingly getting in touch to establish collaborations to deepen and spread knowledge about dystonia, which increases the possibility of more radical changes and equal care.

I am also pleased to announce that my book ‘Muscles in Imbalance-Cervical Dystonia and Spasticity’ is being translated into English. The book is mainly aimed at physiotherapists, but also other health professionals. The translated updated version will be published by the end of the year.

The main part of the above-mentioned projects focuses on cervical dystonia on the basis that it is the most common form of dystonia and that there is the most scientific material and proven experience regarding this type of dystonia. I also believe that understanding cervical dystonia and its treatment strategies is the basis for analysing and treating other forms of dystonia as well. In Sweden, this spring we will organise for the second time a step 3 course, focusing on complicated cervical dystonia, but also other forms of dystonia.

Johanna Blom

Physiotherapist at the Neurology department
SUS Malmö



DYSTONIA PHYSIO

The first on-line platform with over 100 exercises for cervical dystonia patients

For physiotherapists so they can create individual exercise programs for CD patients

Available in 12 languages

New feature: Physiofinder

 physioexercise.org

A project by Dystonia Europe **DYSTONIA EUROPE** with the support of Boston Scientific Foundation Europe

Deep Brain Stimulation Nurses Association Annual Conference

Here I am off on my travels again. Not far from my home this time, just a short train ride from Newcastle to Sheffield in Yorkshire. Monika had much further to travel!

Monika and I were invited to attend the DBSNA annual meeting held in the Crowne Plaza Hotel, Sheffield.

We met at the train station in Sheffield and made our way to our hotel where we dropped off our overnight bags and then went to the Crowne Plaza for the meeting which started after lunch.

We were allocated a table where we displayed our mini banner stand and our various leaflets. We were in between Parkinsons UK and Dystonia UK and Tremor UK were also present.

Russell Mills, Deep Brain Stimulation (DBS) nurse and chair of the association opened the meeting by welcoming everyone and thanking them for coming.

Sadly we were told that Professor Tipu Aziz who was at the forefront of research into neurological conditions had passed away earlier this year. One of the nurses who worked with him spoke about him with respect and fondness.

We were also told that the association has a new patron, Prof Francesca Morgante, also a friend and advisor for Dystonia Europe.

The presentations then started with a description by a rep from Abbot who told us about the deep brain stimulator they have developed and produced. It uses some new technology and will be available soon.

Next up was someone from Boston Scientific who told us about Image Guided Programming. This utilises images and information that the neuro surgeon has used during the operation, for the nurses to program the stimulator.

After a coffee break we heard from Medtronic who told us about their vision for personalised therapy using Brain Sense for informed contact selection. This helps the nurse to program the stimulator for each patient. Currently they have good data showing how successful this is for Parkinsons' patients but not much data so far for Dystonia patients.

Professor P Limousin, consultant neurologist at Queens Sq London was next. He told us about the journey of deep brain stimulation and how both the technology and surgery have improved over the years. SubThalamic Nucleus (STN) DBS is still the most popular method but it is not the final solution and more research is needed.

Mr Harith Akram, also a consultant neurosurgeon at Queens Sq London was next up and he spoke about stimulator placement and that technology now allows the STN to be seen on Magnetic Resonance Imaging (MRI) scans aiding the placement of the contacts in the brain. A non metallic frame is fitted to the patients head to improve the quality of the MRI and he is working on speeding up the processing of MRI data such that the patient can be scanned and operated on in the same day.

The final presentation for the first day was by Yasmine Yazdani from Machine Medicine who have developed a digital platform for medical professionals to ask patients various questions about their condition, as soon as the patients complete the questionnaire the medical professional can see the reply and act upon any changes required. The patient can also contact the medical professional in the same way.

As this was the last one of the day, Monika and I went back to our hotel to freshen up and change for dinner that evening. We had a lovely three course dinner with wine and a good chance to network with the nurses, consultants and industry representatives who were there.

Day two started with Mr A Hussain consultant neurosurgeon at the Royal Victoria Infirmary in Newcastle spoke about wearable technology for Parkinsons' patients. This looks a little like a smart watch and measures brain activity by measuring Local Field Potentials (LFP). This can be used before and after treatment to confirm (or not) that the treatment is working for each patient. The patient wears the technology and when they visit their consultant/nurse etc the data is downloaded and analysed.

Next was Mr Jonathon Ellenbogen, consultant neurosurgeon at Alder Hey Children's hospital in Liverpool. He explained what dystonia is to children and how difficult it is to treat. He does DBS surgery on children but the stimulator is hard to program in children as they can't always say how they have been, what is better or worse etc. It can take months to get a good

response. Sometimes what is considered a success is simply that the child can now use a tablet. Mr Ellenbogen also used LFP to check the success of the DBS surgery.

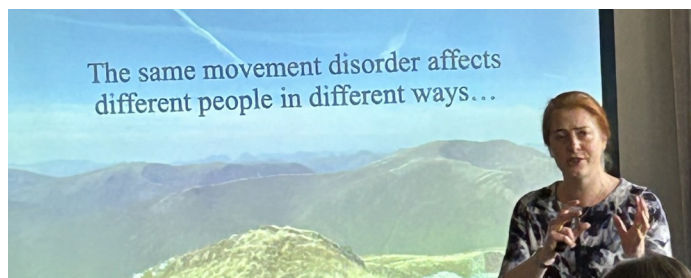
He concluded with a video of a child with generalised dystonia before and after DBS, as you can imagine the video was very emotional.

The next speaker was another consultant from the RVI in my home town Newcastle. Miss Claire Nicholson consultant neurosurgeon. I know several dystonia patients who Miss Nicholson has operated on and they all sing her praises! She spoke very well about her main interest of DBS in Dystonia and explained that no 2 patients are the same and therefore there must be an individual approach to programming the stimulator. She explained that the average frequency used is 130 Hz but the pulse width of the signal is not defined. The amplitude of the signal is altered when programming the stimulator but the pulse width could also be altered, however no-one really knows which is best. If the pulse width is widened then lower current is required and vice versa. Miss Nicholson always aims for the lowest signal amplitude which gives the best results. I am a bit biased as I already knew of Miss Nicholsons work but she did give a really good presentation and she really knows dystonia and her patients.



After a coffee break we heard from Tom Payne, a clinical lecturer in neurology based in Sheffield Royal Hallamshire hospital. He spoke about Parkinsons in young people and took us through a case study of a young woman who had symptoms at 23 or 24. Her symptoms were quite mild at first but soon progressed to the point where she could no longer work. She also developed severe left sided dystonia. Her parkinson's symptoms responded well to Levodopa but her dystonia worsened.

At age 30 she had DBS which was successful but then a few years later her symptoms returned and worsened. She now uses a wheelchair to get around and despite her symptoms is enjoying life and recently got married.



Claire Nicholson consultant neurosurgeon

Caroline Robbins a nurse specialist from North Bristol NHS Trust spoke next. Caroline explained how remote programming works really well. She connected with a patient and we could all see her on the screen. Caroline and her were able to talk and Caroline could give advice, I'm sorry but I am not sure if the clinician can also alter the stimulator remotely or if they advise the patient how to alter their stimulator themselves. I think by this time my brain had reached saturation! However I am sure of the advantages of remote connections between patient and clinician, there is no travelling involved for the patient, especially good for those who live a long way from a treatment centre, it also reduces clinician time compared with an appointment in a clinic.

After lunch we heard from Russell Mills again, as well as being the Chair of the Nurses Association he is also a nurse specialist

in DBS in the RVI Newcastle. Russel spoke about the Get-Ready remote patient management by Medtronic. Russell is currently managing several patients using this system, similar to other remote patient access programmes, the patient and the clinician can send each other questions and answers. This system also reminds patients what they need to bring with them when they come to hospital for their DBS surgery and what to expect after surgery.

Mr B Miraz was next and he is a consultant neurosurgeon in the Royal Hallamshire Hospital Sheffield. He took us through a case study of a female in her 30s who has hemi-dystonia. The pain and twisting in her foot was so bad she considered amputation in 2018. She had DBS instead and had enough relief from that she didn't need to think about the drastic step of amputation!

LATEST NEWS

Kelly Storey is a Parkinson's specialist nurse and spoke about the use of Pro Duodopa to treat Parkinson's patients. This is a new drug available on the NHS (National Health Service in UK) which is showing good results but there are some side effects. The drug is very expensive, costs around £60 000 per patient per year so as you can imagine there are strict criteria that any patient has to meet before being prescribed Pro Duodopa. It has caused a skin reaction in some patients and 2 of the 8 patients she has prescribed Pro Duodopa for have stopped taking the drug. Clearly even at that price it doesn't suit every patient.

Monika and I had to leave at this point to get our transport home, my train to Newcastle and Monika's train to London where she was staying for a few days well earned break.

The conference was a huge success, well attended, great speakers and presentations and of course lovely meals and snacks. For Dystonia Europe it was successful in that lots of people came to talk to us and took leaflets away with

them and we connected with at least 2 consultants who agreed we can stay in touch, hopefully they will agree to do a webinar for us soon. Personally the highlight for me was understanding the technology! My background is in engineering although I haven't worked in engineering since dystonia started for me in my mid to late 40s, it was very reassuring for me when I realised I understood most of the technical side of the stimulators. Another highlight for me was using the simulator made by Boston Scientific and Brainsense, I put on the special headset and was instantly transported to inside someone's brain! I could walk through it and look around, it was amazing!

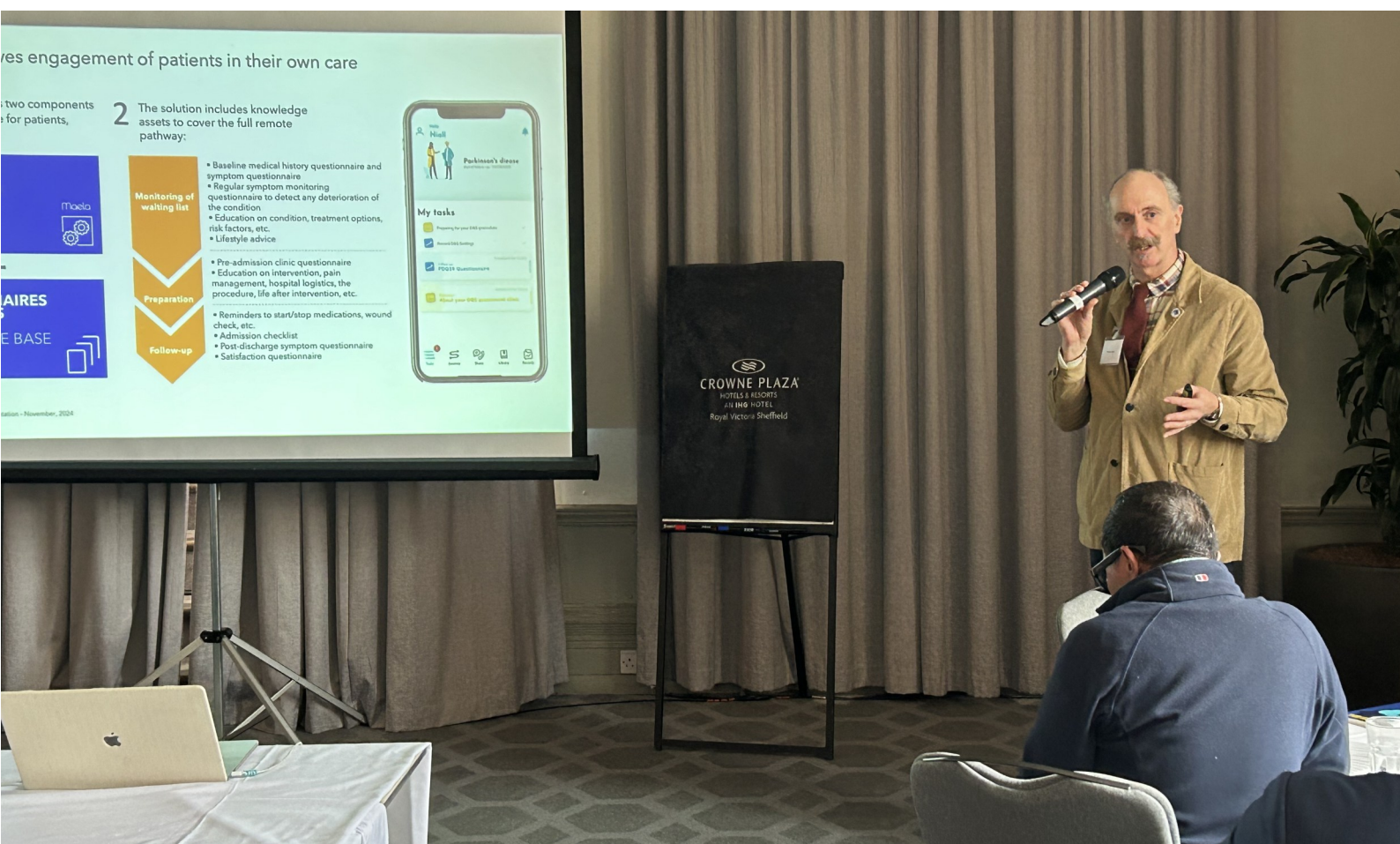
I wonder what the technology will be like the next time we attend this conference in 2025?

Gill Ainsley

Vice President and Secretary
Dystonia Europe



Photo below: Russell Mills, Deep Brain Stimulation (DBS) Nurse



Online Dystonia Day Conference September 2024

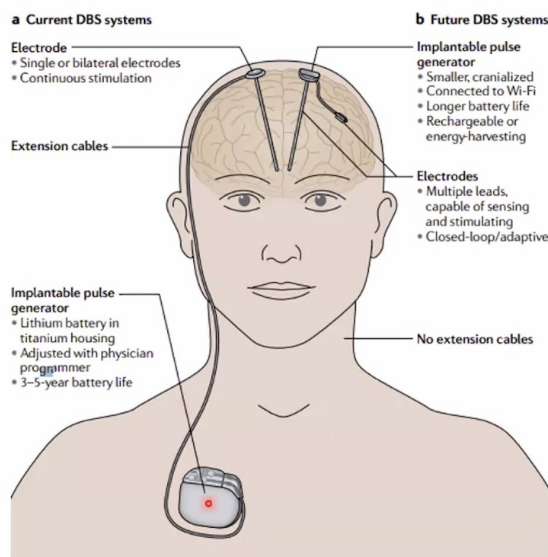
The Dystonia Europe Board decided that this year our annual conference day would be held online using zoom. We used this method during the covid restrictions and not only did it work really well it was also a great deal cheaper than a face to face meeting.

We all still prefer face to face meetings but in these days of ever increasing costs we thought it was important to save money by hosting the event online,

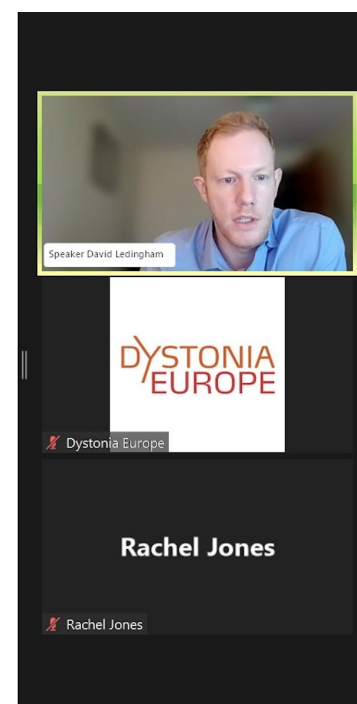
She was really good at keeping everything flowing and to time and she was so impressed with our work that she had moderated every Dystonia Europe (DE) conference since and not charged us!

Once the introductions were done our first speaker was Dr D Ledingham, a consultant neurologist in my home town of Newcastle upon Tyne, England. Dr Ledingham spoke about his work with Deep Brain Stimulation (DBS) patients and began by explaining that DBS can help several different conditions and many thousands of people have had the procedure.

Future Directions for DBS



Krauss et al 2020



of course it also saves our members money on travel and accommodation.

We had a couple of practice runs with Edwige, our president and webinar expert, so she could sort out any problems before the big day.

The day began at 10am Central European Time with an introduction from Edwige and our volunteer moderator Rachel. We met Rachel a few years ago when we employed her to moderate our conference in London.

DBS has been performed for about 30 years but the idea of it has been around for much longer than that.

The procedure can be done with the patient awake or asleep depending what the surgeon prefers. In Newcastle where Dr Ledingham is based the surgery is done under general anaesthetic. For this method the location of the electrodes is thoroughly researched and mapped before the surgery begins, then the surgeon knows exactly where to place them.

Surgeons who prefer their patient to be awake use patient reactions to determine the correct placement of electrodes.

The stimulator is usually placed in the chest wall and

the electrodes run up the neck to the required place in the brain. In the early days batteries did not last long however, the batteries are getting smaller and are rechargeable by the user so no need for frequent visits to hospital to get batteries changed. They do need to be changed eventually and nowadays can last 15 years, maybe longer. Dr Ledingham explained that the patient may not see a difference in their condition immediately, they are usually recalled to hospital about 1 month after surgery for a 2 hour appointment where the level of stimulation will be set and adjusted as necessary. It can take a few appointments to get the level right but the best outcome is generally between 6 and 12 months after the operation.

Technology is improving the design of the stimulators and an adaptive stimulator has recently been developed for patients with Parkinsons. This type of stimulator detects the faulty signals from the brain and adjusts the level of stimulation instantly to counteract the faulty signal.

Before a patient is approved for DBS they have several tests and assessments including a Magnetic Resonance

Imaging (MRI) scan, a neuropsychological assessment and an assessment of how it would improve their quality of life etc.

Dr Ledingham then took lots of questions, too many to list here but a lot of them were about recovery time and Dr Ledingham told us the patient would be in hospital only 1 -2 days and recover at home in about 2 weeks.

A really interesting presentation on DBS which prompted lots of questions!

Next up was Dr Stavros Tsagkaris, who is this years David Marsden Award (DMA) winner. He presented the paper which won him the award and I have to be honest and say it was a bit too technical for me and I didn't understand it all. Please forgive me if I get this wrong but my understanding was that he tested the glucose uptake (also known as metabolism) in children with dystonia. He found some correlation with hypometabolism and hypermetabolism and their dystonia. Dystonia has so far been thought to be a problem in the basal ganglia but Dr Tsagkaris' study has shown that it is a problem in other parts of the brain and there were some common results in different types of genetic dystonia.

His results will give the medical world a better understanding of the pathophysiology of dystonia and this could lead to better targeted treatment. Another really good presentation.

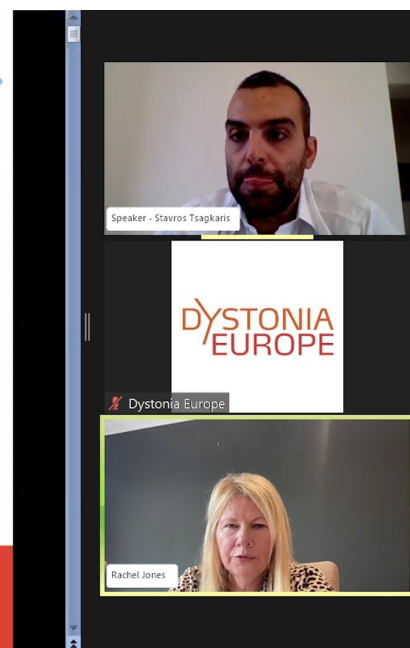
**DYSTONIA
EUROPE**



Metabolic patterns in Brain [¹⁸F]fluorodeoxyglucose PET relate to aetiology in paediatric dystonia

Tsagkaris S, Yau EKC, McClelland VM, Papandreou A, Siddiqui A, Lumsden DE, Kaminska M, Guedj E, Hammers A & Lin JP

Dystonia Europe Study Day
21st September 2024



LATEST NEWS

We then went into a break for 30 minutes or so, time to refresh my coffee and use the bathroom. During the break Edwige played a short film that has been made of the Cervical Dystonia Patient Journey. The actress playing the part of the patient has become a friend of DE since she worked with Monika, our executive director on a short play she performed about dystonia. She portrays the condition really well and has obviously got a deep understanding of what happens to dystonia patients when they are first diagnosed, or even before diagnosis which for some of us took a long time. This film covered that journey so well that it brought tears to my eyes. I could connect with every part of the journey even though it wasn't identical to my own journey it still brought many memories back of how hard it was in the early days. The film then went on to show that with the correct treatment we can get our lives back, for some of us that life is a little bit different to before but is just as fulfilling and enjoyable.

The next presentation was by a Dysphonia ENT specialist from Norway called Dr Jens Øyvind Loven. Dr Loven gave a really good and concise description of dystonia. I know we probably all know exactly what

dystonia is but I always find it reassuring to hear a medical professional describe it so well.

He explained that in dysphonia the laryngeal muscles will either close, adduction, or open, abduction.

Adduction is used normally to speak and abduction allows you to breathe. He showed us a video of someone without dysphonia who could talk normally and someone with dysphonia who could only whisper or had a hoarse voice. The voice can also be jerky and sound like groaning. Lots of different types of treatment have been tried over the years including, speech therapy, psychotherapy, nerves to vocal cords severed but nothing was really successful until in the 1980s a Dr called Blitzer treated dysphonia with botulinum toxin. This was the Dr who trained Dr Loven, so he learned from the best!

Dr Loven now treats up to 200 dysphonia patients with botulinum toxin and gets best results with patients who have primary dysphonia. Their treatment is successful for around 3 to 4 months when their injections are repeated. In all the time he has been treating dysphonia he has only seen 8 patients have spontaneous remission.

Save the date

Dystonia Day 2024

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

Expert
speakers

Patient
testimony

Q & A



Dr Jens Øyvind Loven

LATEST NEWS

He did agree with many other dystonia specialists that stress makes the condition worse and I think we can all empathise with that!

Dr Loven recommended that patients in Norway should see an ENT specialist who will then refer them to one of only 3 treatment centres in Norway. Currently there are around 300 dysphonia patients in Norway and 67% of them are female.

Rachel thanked Dr Loven for his excellent presentation and it was time to move on to Dr Dressler.

Dr Dressler is from the Medical School in Hanover, Germany but he did his presentation from somewhere in Japan and for him it was the middle of the night! We are very grateful that he agreed to do his presentation.

the stressful situations his patients had experienced, such as being a refugee from a troubled country, being a prison inmate, severe physical trauma to name a few. All patients selected had rapid onset dystonia and all showed robust improvement with treatment. He found solid evidence of a correlation between excessive stress and presentation of dystonia.

100 patients took part in his study and all had rapid onset dystonia with symptoms much more severe than idiopathic or secondary dystonia.

All the patients experienced a reduction in spasms/symptoms when their stressful situation was resolved. However most of them still needed to have treatment with botulinum toxin.



He has worked on stress induced dystonia for around 40 years and recently produced scientific data on the subject.

Until then the evidence of stress induced dystonia was all anecdotal. He asked us to understand that he is not talking about psychogenic or functional dystonia but dystonia induced by very severe stress. Dr Dressler took us through the scientific parameters used to select the patients for the study. He explained some of

I found this study very interesting. I think most of you will agree that stress makes dystonia worse, but I hadn't realised that there was a now recognised type of dystonia which was induced by extreme stress.

Dr Dressler took a few questions and then left, I hope he managed to get some sleep!

Next up was Johanna Blom, a physiotherapist from Sweden with 17 years experience of treating Cervical Dystonia.

Johanna explained the importance of physio for dystonia and that it can retrain the brain to help with pain and spasms. Physiotherapy can be used to activate the opposite muscle directions in dystonia patients which can help to reduce the severity of the spasms and therefore the pain.

She impressed upon us how important it is for the patient to be dedicated to keeping up the subscribed exercises each day. This repetition is what is required in order to retrain the brain.

Johanna with support from Dystonia Europe, Eelco Uytterhoeven and Boston Scientific Foundation Europe (BSFE) has developed an extensive database of physiotherapy exercises for Cervical Dystonia patients.

The online platform has 115 exercises so far, some of which are animated. Professional physiotherapists need to register and then they can have free access to the platform. Then when they have a dystonia patient they can create an individual programme of exercises for each patient, they then give their patient an access code for them to access their own tailored programme.

Currently Johanna has 428 physiotherapists from 27

different countries and so far over 600 individual programmes have been created!

Johanna is determined to increase the number of physiotherapists who can treat dystonia around Europe and beyond. I think she has already made a difference and I am personally grateful to her, without her platform I would not be able to have physiotherapy.

Last but by no means least was Prof Jens Volkman with an update on his research. Prof Volkman has been doing research into the genetics of dystonia and why some people with the dystonia genes will not develop the condition.

Prof Volkman explained that 70% of patients with the faulty genes will develop dystonia. There is often a trigger such as physical trauma or overuse. Writers' cramps and musicians' dystonia are both caused by many repetitive movements.

Also brain lesions can trigger dystonia. When a patient has the faulty gene they will have a predisposition to developing dystonia due to environmental factors. Prof Volkman was helped by a consortium of people including our very own Monika Benson. In order for them to explore the disease mechanisms they used mice who had been given the faulty gene.

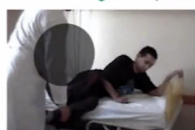
Causes of dystonia

monogenetic



DYT1-25+

low Penetrance (>40%)

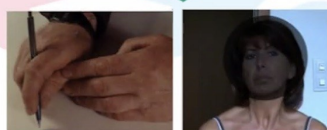


trauma/overuse

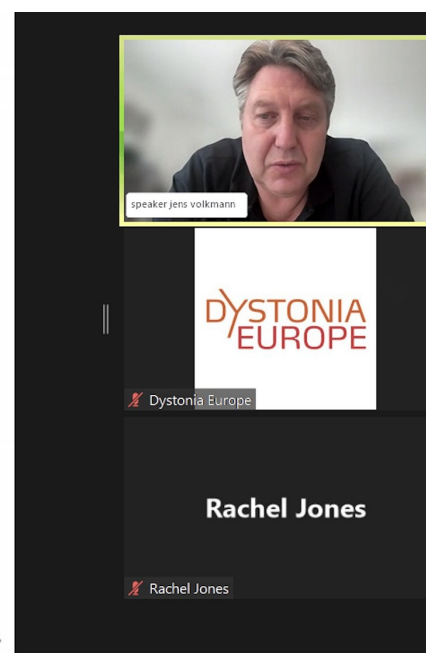
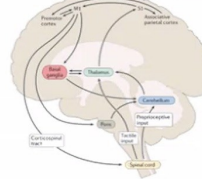


abnormal plasticity

low risk



brain disease
(lesion, neurotransmitter dysfunction)



LATEST NEWS

They observed that the mice without any environmental trigger did not develop dystonia, however, the mice who developed overuse injuries did develop dystonia. They also performed DBS on mice trying different electrode placement and analysed the results.

They then did some video analysis of the success of DBS on cervical dystonia patients and showed that those with a tremor had a better result than those with a fixed head position. In summary the team found that dystonia has multiple disease causes but one common network dysfunction.

Their new rodent model is allowing them to study the interaction between genetic causes and environmental causes. They are also developing a new analysis method for the objective measurement of dystonia.

In question time Prof Volkman told us that there have been some studies into non-invasive brain stimulation but it will be at least 4 years before this is properly understood.

I must admit that I didn't understand all of this presentation so I apologise if I have not understood correctly, but the main thing that I took from this presentation was that we need to understand why only 70% of people with the faulty gene develop dystonia. Wouldn't it be great if that was fully understood? What have those people got that we haven't? If that could be bottled it could be used to treat or cure dystonia or even prevent it from happening in the first place!

I suspect that is a pipe dream though, we all know that currently there is no cure, but it is heartening to learn that so much research is being done and one day we may all benefit.

Our moderator Rachel thanked everyone for attending and asking so many questions, and Edwige, our president, also thanked everyone for listening and of course they both thanked all our speakers for giving up their valuable time to speak to Dystonia Europe, members and friends.

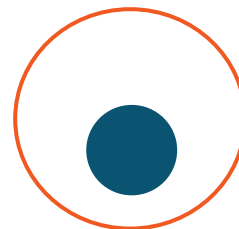
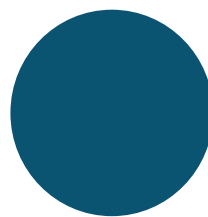
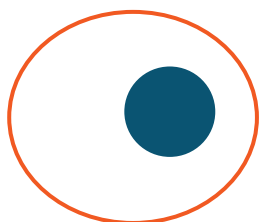
I hope you all enjoyed the conference too but don't worry if you missed it. Each presentation will be on our youtube channel very soon.

Take care everyone.

Gill Ainsley
Secretary and Vice President
Dystonia Europe

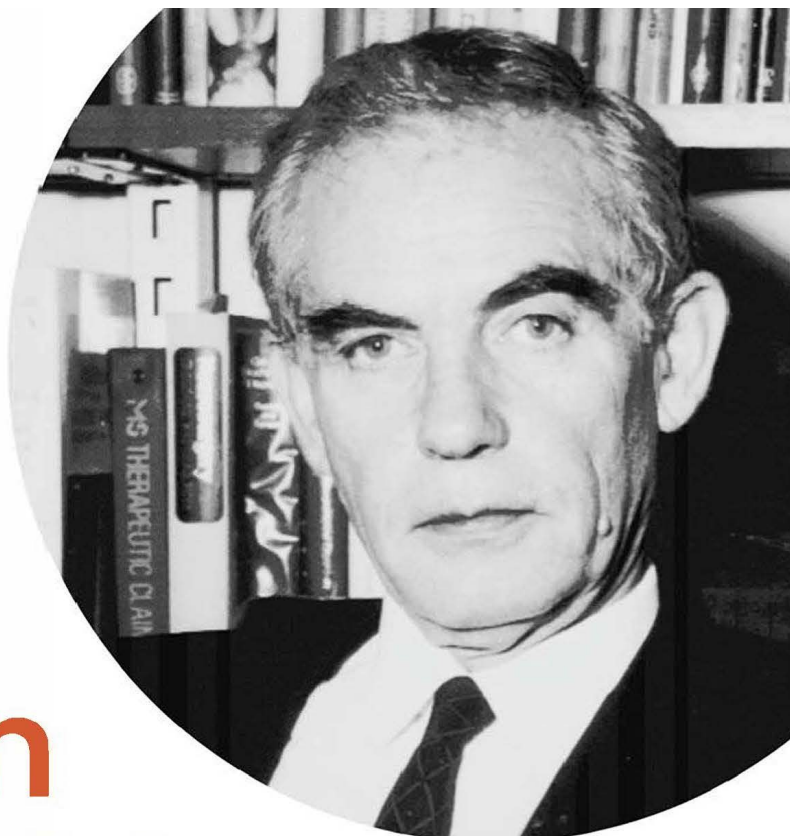


Physiotherapist Johanna Blom



**DYSTONIA
EUROPE**

The David Marsden Award 2025



€10.000
to stimulate research on dystonia

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

The deadline for submissions is **28 February 2025**

All information regarding the 2025 David Marsden award are available at
www.davidmarsdenaward.org

With the support from **DYSTONIA
EUROPE**

Analysis of Movement Disorders in Cervical Dystonia Through Three Clinical Studies

1. Biomechanical analysis of cervical rotation movement

Publication of the study funded by the Breughel grant (AMADYS)



Jean-Pierre Bleton, Doctor in Human Movement Sciences, Researcher, physiotherapist, Adolphe de Rothschild Foundation Hospital (Paris)

Clinical Biomechanics 107 (2023) 106037



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Clinical Biomechanics

journal homepage: www.elsevier.com/locate/clinbiomech



Assessment of axial rotation movement in cervical dystonia using cone-beam computed tomography

Jean-Pierre Bleton^{a,b,*}, Raphaël Portero^b, Kévin Zuber^b, Sophie Sangla^a, Jean-Philippe Brandel^a, Marie Vidailhet^{c,d,g}, Serge Mesure^e, Marc Williams^f, Julien Savatovsky^f

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The study on “Assessment of axial rotation movement in cervical dystonia using cone-beam computed tomography” involved researchers from the A. de Rothschild Foundation Hospital (Jean-Pierre Bleton PT, PhD, Kévin Zuber MSc, Sophie Sangla, MD, Jean-Philippe Brandel MD, Marc Williams MD, Julien Savatovsky MD), Paris-Est Créteil University (Raphaël Portero PhD), Salpêtrière Hospital and Brain Institute (Marie Vidailhet MD, PU-PH) and Aix-Marseille University (Serge Mesure PT, PhD).

It was published in the July 2023 issue of *Clinical biomechanics*.

Cervical dystonia is characterised by localised abnormal movements and/or postures of the head and neck. A general consensus defines four unidirectional dystonic patterns of the head and neck: torticollis (axial rotation in the transverse plane), laterocollis (lateral bending in the coronal plane), and retrocollis or antecollis (extension or flexion in the sagittal plane).

The cervical dystonia analysis grid proposed by Reichel Gerhard (*Basal Ganglia*, 2009) combines biomechanical analyses of the cervical spine with neuro-pathological knowledge of cervical dystonia. It distinguishes two subtypes: the upper cervical spine subtype (caput or CAP) and the lower cervical spine subtype (collum or COL). The CAP subtype covers the upper cervical spine (from the occipital bone to the second cervical vertebra, or axis), while the COL subtype covers the lower cervical spine (from the third to the seventh cervical vertebra).

The aim of this study was to analyse the location of bad positioning and head rotation difficulties induced by cervical dystonia, distinguishing between segments of the cervical spine (COL and/or CAP).

Analysis of neck and head postures and movements was carried out using a cone beam scanner. This X-ray imaging technique provides 2D and 3D images similar to those obtained with conventional scanners, with the advantage that they can be obtained in a seated position (i.e. in a natural posture).

Twenty volunteers took part in the study: ten suffering from cervical dystonia with rotatory predominance (study group) and ten without dystonia (control group), matched for age, sex and laterality. Their postures and cervical rotation movements were measured at each joint complex in three situations: head in natural position, right rotation and left rotation.

The results showed that:

1. Posture: In the natural position, the total cervical spine is significantly further from the neutral position (axis of symmetry) in people with cervical dystonia than in the unaffected control group.
2. Range of rotation: The range of rotation of the cervical spine is significantly reduced in participants with cervical dystonia, particularly in the upper cervical spine.

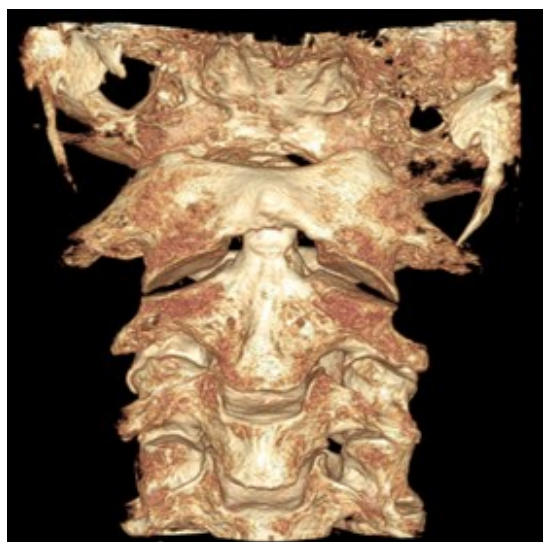
Conclusion:

These results confirm that it is essential to take into account the involvement of rotator muscles at the upper cervical level in treatments with botulinum toxin injections and when designing rehabilitation programs.

Front view of the cervical region from the base of the occipital bone to the 4th cervical vertebra (C4), showing the alignment of the cervical region in a non-dystonic person (left view) and the dystonic rotation between the atlas (C1) and axis (C2) in a person with cervical dystonia (right view).

The results of this study underline the importance of analysing and understanding the role of the muscles responsible for rotation between the Atlas (C1) and Axis (C2) vertebrae, in particular that of the inferior oblique head muscle (OCI). A new study is currently underway to investigate this further (see [clinicalTrials.gov - NCT: 05327985](https://clinicaltrials.gov/ct2/show/study/NCT05327985))

Non-dystonic person front view



**Dystonic person front view
(right rotatory torticollis)**





2. Perception disorders of the straight-ahead positionAnnals of Physical and Rehabilitation
Medicine

Volume 66, Issue 8, November 2023, 101753



Letter to the editor

Repositioning errors of the head in straight-ahead position in cervical dystonia: Influence of clinical features and movement planes

Jean-Pierre Bleton^{a b}  , Sophie Sangla^a, Raphaël Portero^b, Dominique Garric^c, Vincent Guiraud^d, Pierre Portero^c, Jean-Philippe Brandel^a, Marie Vidailhet^{e f g h}, Serge Mesureⁱ

The study on “*Repositioning Errors of the head in straight-ahead position in cervical dystonia: Influence of clinical features and movement planes*” involved researchers from the A. de Rothschild Foundation Hospital (Jean-Pierre Bleton PT, PhD, Sophie Sangla, MD, Jean-Philippe Brandel MD), Paris-Est Créteil University (Raphaël Portero PhD, Dominique Garric PhD, Pierre Portero PhD, PU-PH), University Hospital Group Paris psychiatry and neurosciences (Vincent Guiraud), Salpêtrière Hospital and Brain Institute (Marie Vidailhet MD, PU-PH) and Aix-Marseille University (Serge Mesure PT, PhD). It was published in the journal *Annals of Physical and Rehabilitation Medicine* in November 2023.

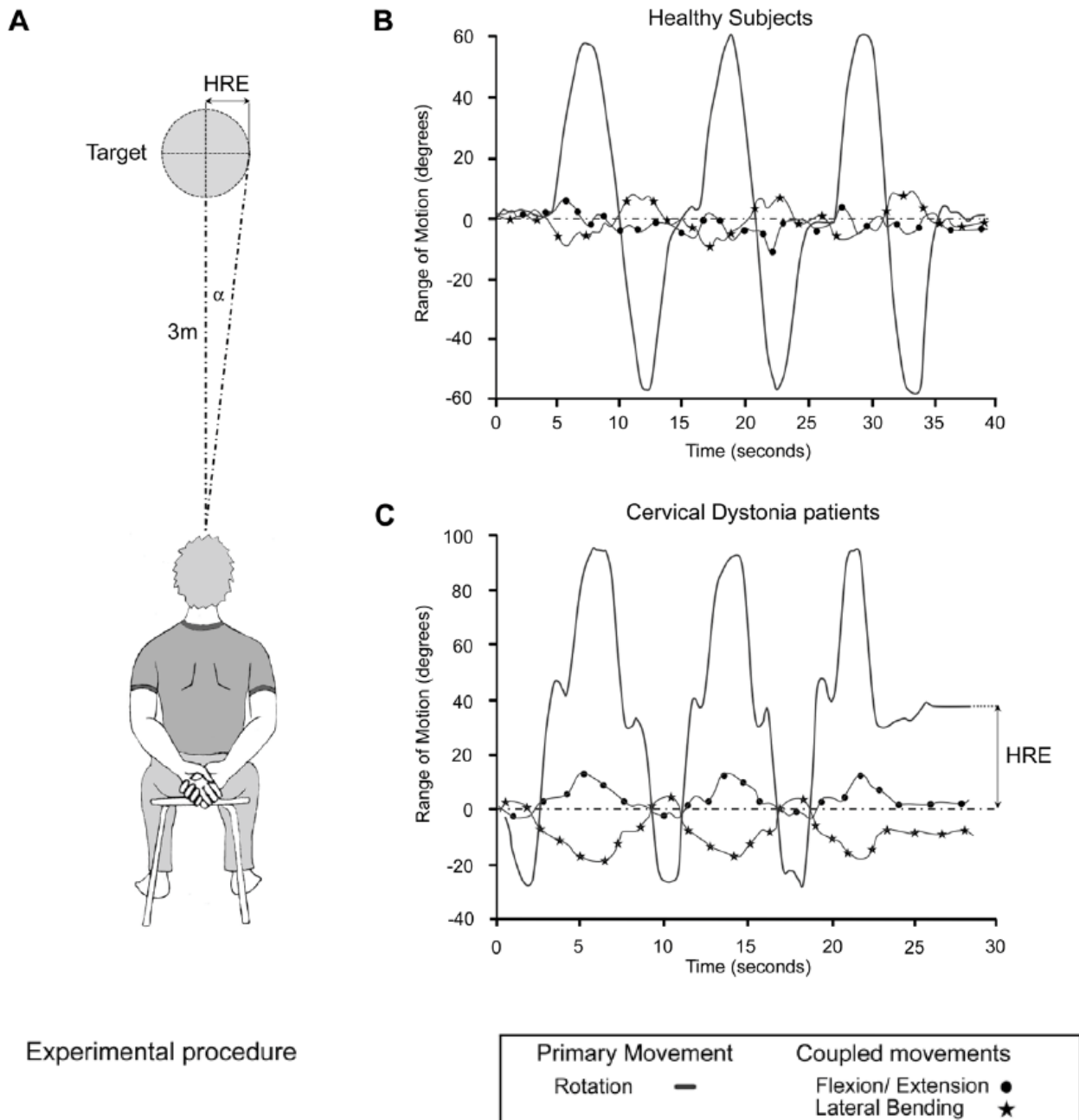
The most visible symptoms of cervical dystonia are bad head positioning and uncontrolled neck movements. But other systems can also be affected, such as the system for sensing and integrating information on body position, known as proprioception.

Proprioception is the ability to perceive and regulate the position of different parts of the body without using sight. In the case of cervical dystonia, perception of the position and movement of the head in space may be impaired.

The present study sought to understand the impact of cervical dystonia on proprioception. To this end, researchers assessed the accuracy with which participants could reposition their heads to a neutral position (straight ahead) with their eyes closed. 29 people with cervical dystonia and 29 without participated in the study. Participants were seated in a rigid chair, with their backs resting against the backrest. Each participant's 3D head position was measured using a small electronic sensor placed on the forehead, capable of measuring head orientation and movement. To obtain the initial neutral head position, participants had to look at a target 3 meters away at eye level. Then, with their eyes closed, they had to move their head and try to return to the initial position.

The results showed that people with cervical dystonia made greater repositioning errors than those without, particularly in the rotational plane for those with torticollis and in the sagittal plane for those with antecollis. These results confirm that rotation is a major feature of cervical dystonia.

They also show the importance of analysing this condition in its three-dimensional aspects, and of proposing proprioception rehabilitation programs to complement botulinum toxin injections and motor rehabilitation.



Experimental procedure

A- Experimental position

B- Rotational displacement and replacement in neutral position with eyes closed of a control subject

C- Same test performed by a person suffering from cervical dystonia, showing a replacement error (HRE - Head Repositioning Error)

3. Cerebellum and neuroplasticity: a path to be explored to acquire the right movement



Front Neurol. 2024; 15: 1381390.

PMCID: PMC11091337

Published online 2024 Apr 30. doi: [10.3389/fneur.2024.1381390](https://doi.org/10.3389/fneur.2024.1381390)

PMID: [38746658](https://pubmed.ncbi.nlm.nih.gov/38746658/)

Combination of anodal tDCS of the cerebellum with a goal-oriented motor training to treat cervical dystonia: a pilot case series

Jean-Pierre Bleton,¹ Charlotte Cossé,² Tiphane Caloc'h,² Alcira Suarez Moreno,² Elisabeth Diverres,² Pascal Derkinderen,³ Julien Nizard,^{4, 5} Jean-Pascal Lefaucheur,^{5, 6, *} and Jean-Paul Nguyen²

The study on “Combination of anodal tDCS of the cerebellum with a goal-oriented motor training to treat cervical dystonia: a pilot cases series” involved researchers from the Parkinson's Unit/Neurology Department of the A. de Rothschild Foundation Hospital (Jean-Pierre Bleton PT, PhD), Transcranial Stimulation Unit, Bretéché Clinc, Elsan Group, Nantes (Jean-Paul Nguyen MD, PU-PH, Charlotte Cossé, Tiphane Caloc'h, Alcira Suarez Moreno MD and Elisabeth Diverres PT), Neurology Department, Nantes University Hospital Center (Pascal Derkinderen MD, PhD, PU-PH), Pain, Palliative and Support Care Department and UIC22, Hôpital Laennec Hospital, Nantes University Hospital Center (Julien Nizard MD, PhD, PU-PH), Clinical Neurophysiology Unit, Henri Mondor Hospital, Créteil (Jean-Pascal Lefaucheur MD, PhD, PU-PH). It was published in the journal *Frontiers in Neurology* in April 2024.

Cerebral plasticity, or neuroplasticity, is the brain's ability to remodel itself in response to experience or learning. The cerebellum plays a crucial role in brain plasticity and motor learning.

Dystonia is associated with poorly adaptive plasticity.

Transcranial Direct Current Stimulation (tDCS), which applies a small, constant electrical current to the scalp to modulate neuronal excitability, could improve symptoms of dystonia by altering the excitability of neurons in the cerebellum and basal ganglia. This could help restore more normal plasticity.

In this pilot study, tDCS of the cerebellum was combined with specific motor rehabilitation programs (motor training) in people suffering from cervical dystonia poorly controlled by botulinum toxin injections.

The first phase involved administration of the tDCS protocol alone (three or five daily 20-minute sessions over one week). The second phase combined administration of the tDCS protocol (also three or five daily sessions over one week) with motor training. The 20-minute motor training protocol was adapted to the clinical characteristics of each patient and carried out during the tDCS sessions.

Analysis of the study results revealed that a personalised motor rehabilitation program combined with tDCS of the cerebellum resulted in significant and longer-lasting improvements than stimulation alone.

This study suggests that combining tDCS with a personalised motor rehabilitation program could promote more adaptive brain plasticity, thus contributing to the reduction of motor symptoms. However, further studies involving larger numbers of subjects are needed to confirm these results.

The researchers would like to express their sincere thanks to the people with cervical dystonia who agreed to take part in these studies. Their contribution is invaluable. We would also like to thank the AMADYS Association for its unwavering support for research, without which these advances would not have been possible.

AMADYS and DYSTONIA EUROPE would like to thank Jean-Pierre Bleton for providing patients with a comprehensible summary of these scientific articles.

Translated from French to English by
E. Ponseel and G. Ainsley.

The Positive Twist Podcast Season Three is Launched



NEW EPISODE
DBS Treatment and The
Importance of Team Effort
with Prof. Alfonso Fasano

During Dystonia Awareness Month 2024 season three of the Dystonia Europe podcast was launched. The first episode (of five) features Professor Alfonso Fasano from the Toronto University Hospital. In this episode we have an informative and fascinating conversation about dystonia and DBS. We walk through everything from finding help initially, to diagnosis, treatment, the DBS option and the importance of a multidisciplinary approach - it's a team effort!

This is a great episode for anyone with dystonia!

<https://bit.ly/TPTPAfonsoFasano>

The Positive Twist podcast was launched in 2020 and there are a total of 15 episodes so far.

There are interviews with both experts talking about treatment and research as well as dystonia patients sharing their stories.

The podcast has listeners from all over the world and has until now been downloaded more than 5000 times.

You can find the podcast on Spotify and Buzzsprout.

Think Tank Meeting Autumn 2024

The 18th Think Tank was held on the last Monday of October on Zoom. Participants of this meeting were the Dystonia Europe staff and board members and representatives of the Platinum partners. These are Ipsen, Medtronic and Merz.

These meetings take place twice a year: once in late winter and once in the autumn.

The purpose of these meetings is to meet and discuss activities and projects that benefit the dystonia patient community. Focus this time was next year's activities such as the Dystonia Awareness Month 2025; what webinars to organize and Dystonia Days 2025.

We thank all our partners for their valuable support and strong commitment for dystonia patients.

Next meeting will be a face-to-face meeting in Lund, Sweden, beginning of March 2025.



THERAPEUTICS

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Traveling with Dystonia

I love visiting different countries finding out about their history, culture, fashions and food.

My husband and I have a little more time to travel now that we are both retired plus our sons are grown up and have their own children so our money goes a little further too!

I can remember very well the first time we went on holiday without our sons, we couldn't quite believe how much cheaper it was and how little money we spent while there!

When I first developed dystonia I thought I would never travel long distances again, how wrong could I be?!

The early days of coping with dystonia were very hard and I thought that I wouldn't be able to do any of the fun things that I loved doing. However, in time, I realised that it was wrong of me to let my dystonia rule my life and I decided that I must take control!

Slowly I began to build up my social life again, began to meet friends for coffee, have meals out with family and friends, go shopping on my own and start to make plans for all the travelling that me and my husband always wanted to do.

Our first big trip was to Australia, we don't do things by halves! Our trip included a few days in Dubai, 3 weeks in Australia and then a long weekend with our family in South Africa. I was particularly nervous about how I would cope on such long flights. One of the things I find relaxing is knitting and I knew there wouldn't really be room to knit during the flight and wasn't even sure if I could take my knitting on board!

First things first though, I needed to make sure I was in a good part of my treatment cycle. I mentioned it to my consultant and of course the dates we wanted to go weren't in a good part of my cycle and in fact I would have missed an appointment. The consultant I had at the time was such a lovely man he told me he would not let me go on such a special holiday without having my injections and he arranged an extra clinic for 3 weeks before we went!

While making plans and preparing I tried not to worry about how I would cope but made sure I had plenty to keep me occupied during the flights. When it was time to go I was more concerned about forgetting my passport and never even thought about my dystonia. We got on board the first flight and got settled in. The first flight was around 8 hours to Dubai. We each had our own media screen and could choose from lots of movies, tv programmes, books and games. I also had



my kindle and a couple of puzzle books, doing puzzles is another way I have of 'controlling' my dystonia. So I spent the first flight doing various things to keep busy and I was very surprised that I wasn't in a lot of pain and my dystonia while it was still there seemed to fade into the background.

We had a lovely few days in Dubai and of course while in the hotel I could do my knitting when we had time between visiting tourist attractions. This helped me relax enough to sleep, I don't know about anyone else but if I have slept well I can cope with pretty much anything my dystonia throws at me!

The next flight was much longer, all the way to Sydney Australia. However, I followed the same routine as on the previous flight and again found myself feeling quite comfortable. The 3 weeks in Australia went by in a whirl, we visited Sydney where we climbed to the top of Sydney Harbour Bridge, Uluru, Cairns, Daintree rainforest, Barrier Reef and had a week on the idyllic Hamilton Island where we did my favourite holiday activity, kayaking! We loved Australia and especially Hamilton Island.

I had stopped even thinking about how I would manage on a long haul flight and our next flights back to Dubai and then on to South Africa went by without any trouble from the big D at all. Of course we had a wonderful time visiting our family in South Africa but it was only for a few days then time to fly home.

As we had done the journey with Emirates airline we had built up enough loyalty points for our last flight to be upgraded to business class. What a treat! We could lie down to have a sleep, the food was lovely and we got proper cutlery, dishes and glasses, ha ha, such an improvement on economy class. I think because we had more room and were much more comfortable I had no trouble at all with my dystonia but I did think that I would never want to travel economy again!

OTHER NEWS

Our next big trip was a few years later, after saving up again. We decided we would like to go to Fiji. This time we used a travel agent called Trailfinders who were excellent! We arranged to have a few days in Singapore, then go on to Fiji and join a small cruise around the islands and then stop off at Hong Kong on the return journey.

Singapore was lovely, and while my head was still shaking it never caused me a problem and didn't stop me from trying anything. Singapore is a very clean city and we felt safe all the time.

Fiji was even more beautiful and our cruise was lovely, we visited 5 different little islands and even went to see a school. The children travel to this school each day from a few of the islands and they are aged 5 to 18. They had recently got solar panels so they could have a reliable supply of electricity and they had only 2 or 3 computers to share between all the pupils. It saddened me to see that most of the children had no shoes and their clothes had clearly been passed down through several children, but every one of them was really happy and they all looked well fed and healthy. It made me count my blessings and be grateful for what I have.

Interestingly, our cruise was small with only 60 tourists on board. I saw another 3 people on that same cruise all with symptoms of dystonia! One man had head shakes similar to me, another young lady had tremors in both arms and a 3rd lady had cerebral palsy with some dystonia in her hands. I thought, well isn't that unusual in a group of 60 unrelated people from all corners of the world that 4 have dystonia. Then my next thought was that maybe having dystonia makes us more adventurous!

Of course we had to have our own adventure and John (husband) went snorkelling with a group to see some small sharks and I went kayaking around the bay we were moored in, such lovely clear blue waters and I could see hundreds of fish and other sea life.

We then moved on to Hong Kong which was interesting but so busy! One thing I noticed was that everywhere was super clean, and in public places people were employed to keep sanitising hand rails, door handles etc etc. At the time this was spring 2019 and I thought well it is lovely and clean but I'm sure that money could be put to better use, little did I know that less than a year later we would all be grateful for those workers who sanitise everything we touch!

The time of covid was hard on us all and of course all travel plans were cancelled. It was such a strange time in the world, during which the planet had some breathing space and recovery from all the damage we humans had caused. I was pleased when it was over of course and couldn't wait to start travelling again.

Our next big trip was to see our family in South Africa and stay for a month, such a treat to be able to see them all and spend that time together. South Africa is a beautiful country but as you will know it does have its problems. I am not going to go into politics but I can say that the balance between all the people who live there is improving but it still has a way to go.

While there we enjoyed a great week at Marloth Park, a conservation village where you can stay in various holiday lodges and the wild animals come over from Kruger Park and wander through the streets. The more dangerous animals would be sedated and taken back to Kruger Park thankfully but we regularly had Zebras, Giraffes, Warthogs, Kudus and other antelopes all wander through the garden of our lodge.

We finished off the month with a stay at Sun City, totally opposite to Marloth Park but still enjoyable. It is a man made resort with lots of swimming pools, casinos and other entertainment.

Our most recent adventure was earlier this year when we went to Alaska and Canada. I have always wanted to go to Alaska since I used to watch a TV series called Northern Exposure set in a small Alaskan town. In the series everyone was so nice and kind, they all helped each other and were all friends.



The main thing that made me want to go there though was in the opening credits a Moose walked down the main street and I really wanted to see that!

Alaska was everything I thought it would be, friendly, small towns, very remote at times and very mountainous. We hired a motorhome while there and travelled over 1 200 miles in 2 weeks! And yes, I did see a moose with her baby walking in between two houses. We also managed to do our favourite holiday activity and kayaked along a lovely river for a couple of hours during which time a bald eagle flew right past us.

From Alaska we went to Vancouver and over to Vancouver Island which is another beautiful part of the world. Our adventures continued with bear watching and whale watching. We had a truly wonderful holiday.

I have just realised that in this article I have not mentioned my dystonia since Fiji, and that pretty much sums up how I feel about it when I am on holiday. It doesn't go away, my head shakes and I still get pain in my neck and shoulders but I don't let it spoil my holiday and I will never let it spoil my sense of adventure!

Gill Ainsley

Vice President and Secretary
Dystonia Europe



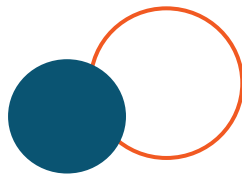
Ipsen 4th Global Patient Organizations Advisory Board

Both global and national patient leaders gathered for 2 days at the Marriott Opera Ambassador Hotel in Paris.

The objective of the meeting was to collaborate with the Ipsen team members on shaping the Ipsen Global Patient-Driven Strategy and Roadmap, the creation of a Patient Charter and ultimately to foster ongoing collaboration between Ipsen and the patient organisations.

It was some intense days with fruitful and engaging discussions.

Monika Benson
Executive Director
Dystonia Europe



Leading a patient driven strategy together

Project Cervical Dystonia Patient Journey Update

The work on the project Cervical Dystonia Patient Journey continues. It all started four years ago when we developed a patient journey/patient experience map for people living with cervical dystonia in Europe.

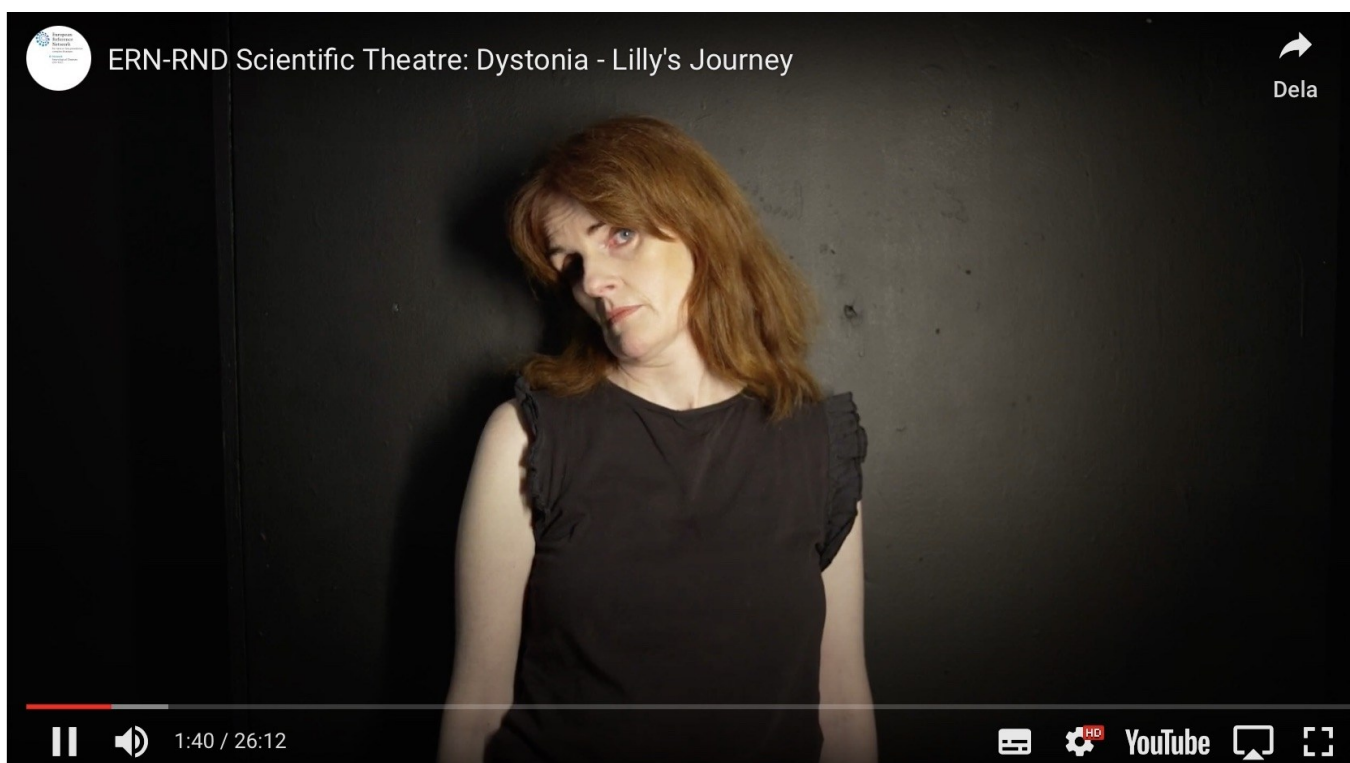
It is being translated into other languages and these are all available on the ERN-RND website.

<https://www.ern-rnd.eu/disease-knowledge-hub/dystonia/>

There you find the cervical dystonia patient journey in: English, Czech, Dutch, Finnish, French, German, Hungarian, Italian, Norwegian, Polish, Portuguese and Spanish. The goal is to have it translated to most European languages.

Last year at the EAN Congress in Budapest an actress performed the Cervical Dystonia Patient Journey in the Scientific Theatre. The ERN-RND team thought this was so good that they decided to record it in a more professional way.

At our annual meeting in Timisoara, we were delighted to show for the very first time “Lilly’s Journey” – a 25-minute long video with actress Carmel Stephens from Ireland.



She is doing a wonderful interpretation of the many stages of the patient journey such as: what it is like to discover the first strange symptoms of dystonia, the struggle to find out what it is, the search for the best treatment and how to learn to live with it.

You find the video here:

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

We hope this video will help to raise awareness and spread knowledge about dystonia.

Monika Benson
Executive Director
Dystonia Europe

Workshop Presentation: "Advancing Together: Shaping a Brighter Future for NMD Patients"

On October 25-26, 2024, Ljubljana hosted a workshop entitled "Advancing Together: Shaping a Brighter Future for NMD Patients," an event dedicated to addressing the challenges and opportunities in the field of NMD (Neuromuscular Disorders) across Europe.

Day 1: Challenges and Opportunities in Neuromuscular Disorders in Europe

The workshop commenced with an official opening where the organisers presented the event's objectives and the agenda for the day. This introduction highlighted the importance of collaboration between specialists and patient organisations to improve the lives of those affected by NMD.

The first panel, titled "The Diagnostic Odyssey and Newborn Screening (NBS)," tackled the discrepancies in diagnostic processes for NMDs across various European

countries. Discussions focused on the role of newborn screening in the early detection of these conditions. Speaker Kacper Rucinski provided a detailed perspective on the challenges faced in diagnostics and the benefits of implementing screening programs.

The next panel, "Standards of Care and Access to Therapies for NMD Patients," led by Sandra Blum, underscored the variability in patient care standards and the solutions needed to ensure equitable access to necessary treatments. This session was crucial for identifying gaps in care and for establishing more rigorous standards.

Panel 3 was dedicated to "Research and Clinical Trials," where Grainne Crowley presented current research initiatives and the ways in which patients can access relevant clinical studies for their conditions. This discussion highlighted the importance of collaboration between researchers and patients in the development of new therapies.

In the afternoon session, discussions revolved around "Building Bridges in the NMD Field." An important presentation was dedicated to European Reference Networks, where François Lamy discussed the role of EURO-NMD ERN and its impact at the European level. You can read more about EURO-NMD ERN here

<https://ern-euro-nmd.eu/>





The concept of patient-centred care at the European level was explored, along with a presentation on the EAMDA NMD Resource Hub project, a centralised resource system aimed at improving support for patients across Europe.

At the end of the day, a recap of the discussions was conducted, offering a preview for the following day and reinforcing the participants' commitment to ongoing collaboration.

Day 2: Strengthening Organisations and Advancing Together

On the second day of the workshop, activities began with a group discussion for patient organisations. Catalina Crainic, representing Dystonia Europe, contributed a presentation on organisational aspects. The participating organisations discussed the services provided to their members, the challenges and needs at both the organisational and national levels, as well as the distinctive characteristics and strengths of each organisation.

The educational sessions continued with presentations dedicated to sharing knowledge for patient representatives. Arabela Acalinei highlighted initiatives such as EUPATI, which aims to empower patients in clinical trials, and the EURORDIS (Rare Diseases Europe) Open Academy, which has developed advocacy skills for rare diseases. Additionally, the EPF program provided training in leadership and management for patient advocates, while EFNA's e-learning modules focused on enhancing patient involvement in health research. The experience of the Czech Republic in establishing an academy for patient organisations served as an example of best practices.

The workshop concluded with an official closing session, summarising the main outcomes of the event and expressing gratitude to the participants.

This workshop represented a valuable opportunity to advance together in support of patients with neuromuscular disorders, strengthening the networks and resources available at the European level.

Catalina Crainic
Board Member
Dystonia Europe

Personalised Digital Medication Management Webinar EPF

On 23 October Dystonia Europe attended a webinar arranged by EPF (European Patients Forum) as part of the Member Circle on Personalised Digital Medication Management. Here you can read a short summary of the webinar

First João Almeida held a presentation and explained work on making an APP to give patients easy access to medical pamphlets in their language. Almeida is an IT Pharmacist, Chair and Tech Lead at HL7 Portugal, overseeing technical developments in Gravitare-Health whose mission is Empowering and Equipping Europeans with Health Information for Active, Personal Health Management and Adherence to Treatment.

Almeida held a presentation on the Gravitare-Health's work on research to find "How to apply an open access digital platform with trusted Digital health Information to transform the way patients access and understand health information, and apply this in personal health for adherence to treatment, risk minimization and quality of life" They focus on the following points

- Facilitate access to medication information, especially the one contained in the pamphlets.
- Gravitare-Health wants to leverage technology and the digitalization of this information to enhance this information.
- Improve medication adherence, information, satisfaction and/or quality of life.

The key assets to achieve the Gravitare-Health purpose is the following:

Electronic Product Information (ePI), a pivotal source of regulated and scientifically validated information that assists healthcare professionals in prescribing and dispensing the medicine and informs consumers about its safe use.

International Patient Summary (IPS) which is an electronic health record extract containing essential healthcare information about a subject of care. It is designed to support the use of case scenario for cross border care.

Educational Material which is additional support material

Having a standard such as HL7 FHIR not only accelerated development but also creates a path for everyone to know how to use the services provided—open—source specification.

You can read more about what HL7 FHIR (Fast Healthcare Interoperability Resources) here:

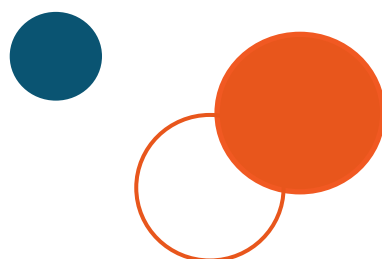
<chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://www.healthit.gov/sites/default/files/page/2021-04/What%20Is%20FHIR%20Fact%20Sheet.pdf>

Lene Lunde also attended the webinar with further insights in the Project. Lene Lunde is a researcher at the University of Oslo, specializing in the use of technology and digital media as a platform for health education and she also works as a task leader in Gravitare Health.

<https://www.gravitarehealth.eu/>

Leading and coordinating the webinar was Estefania Callejas De Luca, Membership and Governance Officer at EPF and Yasemin Zeisl, Project Coordinator at EPF.

Merete Avery
Operations Manager
Dystonia Europe



ERN-RND Network Annual Meeting 2024

On 10 and 11 of October the Annual Meeting of the ERN-RND network took place in Ljubljana in Slovenia.

About 60 experts from all over Europe travelled to take part while 30 participants and some of the speakers joined via Zoom.

Local organiser Dr. Ales Maver and ERN-RND project leader Prof Holm Graessner from Tübingen, Germany welcomed the participants.

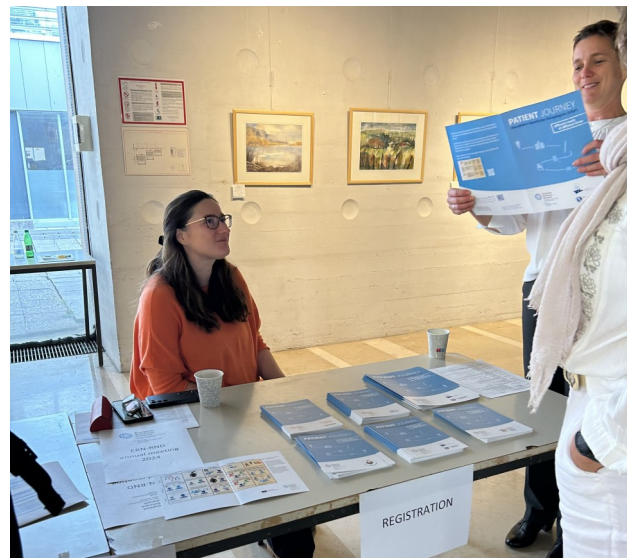
Prof Graessner gave a report on the activities of the past year. There are now 68 expert centres including 4 supporting centres, in 24 EU countries taking part serving all together over 44 000 patients.

The core activities of the network are:

- Cross border healthcare/CPMS
- Training and education of healthcare professionals
- ERN-RND Registry
- Guidelines and Clinical Decision Support Tools/care standards
- Patient journeys
- Dissemination

The ePAGs (patient representatives) of the network: Astri Arnesen, John Gerbild and Monika Benson then gave a presentation on 'How to make the patient journey better?'

A powerful video from the WHO about people-centred care was shown. If you are interested you can watch it here: <https://www.youtube.com/watch?v=pj-AvT0dk2Q>



John Gerbild from Denmark gave a moving testimony of an ataxia patient he met some time ago and this man mostly misses being able to cook delicious meals.

Monika showed the Dystonia Physio Hub and how this can be one of the tools/steps to a multidisciplinary care for cervical dystonia patients.

After lunch we attended the scientific symposium with various expert presentations on EU initiatives on rare diseases and research opportunities, training programs, drug development.

The second day there were meetings for the different working groups. One of them focused on Dystonia, NBIA (Neurodegeneration with Brain Iron Accumulation) and Paroxysmal Disorders. Here is the opportunity for the specialists to share updates on various activities and projects as well as discussing new ideas.

For more information on the ERN-RND visit:

<https://www.ern-rnd.eu>

Monika Benson
Executive Director
Dystonia Europe



ERN-RND patients representatives in front of the University Hospital, Ljubljana Slovenia

Luc Montigaud: a Tour of France for Dystonia, Research and Promoting Disability in the Workplace!



Luc Montigaud is a 24-year-old Business School graduate living near Aix-en-Provence. He has suffered from dystonia since birth, which causes him difficulties with speech and fine motor skills.

At the General Assembly in Paris, May 2023, Luc presented his crazy project to AMADYS members: to complete the Tour de France by duathlon (10km run each morning, 40km bike ride each afternoon), i.e. 3,285km in 99 days and 76 stages!

The aim of the tour was to raise awareness of dystonia, collect donations for research and raise awareness of disability in the workplace.



Volunteers and members accompanied him in the regions, and his stages were regularly relayed on social media, which also showed the way to participate in the online donations for dystonia research. Luc was the subject of numerous articles in the regional press and on television during his tour, which raised the profile of him and his cause.

He set off from Aubagne on 3/09/2023, and completed his feat by arriving in Auriol on 9/12/2023 (southern France).





On 26/04/2024, Luc invited AMADYS President, E. Ponseel to a convivial evening conference to share his adventures, encounters, joys and sorrows, and to present AMADYS with the cheque for the donations collected for dystonia research.

A total of €12,025 has been generously donated by all donors during this tour!

Luc was also followed by a film crew during his tour, and a film about his adventure hit the screens on 7/06/2024 in La Ciotat. Let's hope it will be distributed more widely in France and that everyone will be able to go and see it!



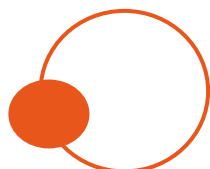
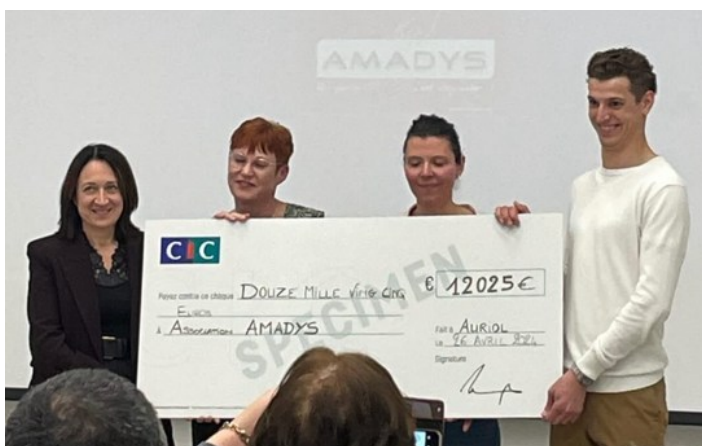
Luc with the flame

Thanks to his exploits and notoriety, Luc was lucky enough to carry the Paralympic flame in Paris on 28/08/2024 and to appear on the television news.

We wish Luc all the best for the future, and thank him for his feat, his dynamism, his kindness and his friendship.

Thank you for raising awareness of dystonia, and for calling for donations for research!

For AMADYS, France, Edwige Ponseel
President
Dystonia Europe



Walking with Alpacas Happiness on Four Legs

Our Berlin dystonia group "DyD" (Dystonia and You) enthusiastically accepted a suggestion from a fellow group member to take a group trip to Brandenburg and go on an alpaca hike.

Fortunately, we found the wonderful alpaca farm in Pausin, about a 1.5 hours drive from Berlin. The farm made a pleasant impression on us and the price was affordable for chronically ill patients and the self-help group. The planning and registrations were made a few weeks in advance and it seemed like a good idea to make the trip at the end of June, as the weather is usually stable and warm at this time of year. However, on the morning of the excursion, we discovered that it was raining heavily, even though the weather forecast had not predicted any rain. We decided to give it a go despite the rain and set off.

On arrival, we were greeted by the farm owner. He was very nice and could tell us a lot about his alpacas. We got to know the animals and each participant was assigned an alpaca. The look of the alpacas, the way they moved and the sounds they made quickly put us in a joyful mood. But we also quickly realised that leading an alpaca on a leash is an exciting experience, as it is very different from a dog or pony. The route we took with our alpacas led through the middle of a beautiful forest, which actually protected us quite well from the rain. The route was also not too long and easy to manage on foot, and even our wheelchair user was able to take part in the hike.

Everyone increasingly realised that the initial excitement quickly turned into relaxation when walking through the forest with their alpaca. This is because when you walk with alpacas, you slow down. The animals don't have any urgent appointments or deadlines - so they are utterly relaxed when out and about. At some point, the leash becomes weightless, the feet detach from gravity and the walk starts to feel like a meditation. In addition, the walk in nature and the sense of community simply feels good. One participant in our group reported that she no longer even noticed her dystonia during the walk and her pain also seemed to disappear.

After the hike, we all needed some refreshment: So the alpacas got something to eat and we also had coffee and delicious cake. We took the opportunity to talk to each other without just talking about our chronic illness. These are always very valuable moments for all of us. The symptoms of dystonia only returned for most of us on the return journey. Some feedback from the group was: "It was a great opportunity to forget about our illness and to talk about other topics." "I really enjoyed chatting with everyone and having fun. The cute alpacas were adorable." "It was a really nice day with everyone. The alpacas were all really cute and it was great to learn all about them and then go on the great hike with them. It was just great." So all in all, it was a beautiful day for all of us and we can only recommend a trip with alpacas!"

Julia Kühne
Dystonie und Du
Germany



5th National Dystonia Day in Italy



On September 28th Associazione per la Ricerca sulla Distonia (A.R.D.) celebrated the 5th National Dystonia Day with a convention in Rome. The previous 4 Dystonia Days were online events, this year we decided to meet again in person but the whole Day was broadcast live on our social media for all those who could not be in Rome.

The title of our meeting was “Dystonia, disability and work: building an inclusive future” as we focused on the legislation about benefits for disabled people, in order to avoid discrimination for workers and caregivers. In our previous Dystonia Days we had always dealt with medical topics concerning dystonia, but the disease creates problems at work too and we receive many requests concerning assistance on this matter. We have taken a cue from a recent Italian law issued in May 2024 which modifies some rules about benefits for disabled people.

Our speakers were : Luciano Ciocchetti (Vice President of the Social Affairs Commission in the Chamber of Deputies of our Parliament) ; a labour law lawyer, a citizen advice bureau consultant and a legal consultant.

The labour law lawyer and the citizen advice bureau consultant illustrated the procedure: Persons with medical problems may request social benefits simply by addressing their own GP, who sends the patients’ medical story to our National Social Insurance Agency ; an inspection commissioner visits the patients verifying their conditions and attributing a level of disability.

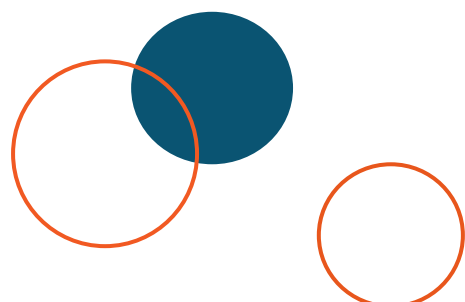


Luciano Ciocchetti

On the basis of their disability, patients and caregivers are entitled to various benefits such as:

- tax relief and tax deductions for medical treatments, social benefits, technical and informatic devices, removal of architectural barriers etc.;
- economic allowance for disabled children;
- 3 free working days a month , special leave, part time job , remote home working and early retirement for workers;
- economic allowance for civil disability, according to reduction of working ability and income .

The current bureaucratic process to achieve these benefits is not easy for dystonic people, as in many cases dystonia is not acknowledged by the inspection commission : usually no neurologist is part of the assessment . The new legislation will overcome this obstacle by allowing one to be assisted by one’s own neurologist.



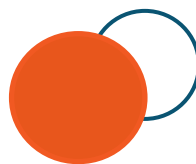
AROUND EUROPE AND BEYOND | ITALY

Luciano Ciocchetti focused on some key issues of the new legislation: the new definition of disabled person based on the International Classification of Functioning, Disability and Health (ICF) of the World Health Organisation ; a multidimensional assessment of patients' difficulties; a new electronic dossier which will report all the data about the patient and, as already mentioned, the assistance of one's own referring doctor during the visit ascertaining the disability; for rare diseases such as dystonia this is an important turning point to pave the way towards an easier access to law benefits.

After this long session concerning legislation rules, our member Francesca told us her story of discrimination at work due to her disphonia which began 18 years ago: she remained totally voiceless for 6 months , later she could speak but not fluently. At first she could remain employed in her firm which accepted her protected status for handicap, later she was considered no longer suitable and was fired.

She regrets that people are labelled from their sanitary status rather than from their professional skills and reaffirms the right to live without social prejudices.

The following session concerned caregivers, people who take care of young or adult patients; often their daily demanding job is not adequately considered , often at work they are not allowed to receive the benefits they are entitled to. The President of the Italian Federation of Rare Diseases spoke about protections and opportunities for caregivers, who are estimated to be some million persons in Italy, mainly women. She herself is her son's caregiver. Our member Eleonora went to our meeting pushing her husband's wheelchair: she is his caregiver ; 21 years ago an autoimmune disease caused him a spastic tetraparesis, followed by a multifocal dystonia; their children were 9 and 3 years old, and Eleonora had to help her husband in everything; she tried to continue to work asking for a reduction of her job too, but at last some years ago she was fired. In her long experience her basic points to face situations have been organisation, resilience, equilibrium and empathy.



After a light lunch our meeting continued concerning musician dystonia.

Luigi (a pianist with right hand dystonia) told us about his rehabilitation process still in progress in University La Sapienza in Rome and proposed a video where he is playing a charming piano piece created by himself; he can still continue his career as a musician.

On the other hand, the story of Maurizio showed us that dystonia put an end to his career as trombonist in Santa Cecilia Orchestra in Rome :he could no longer play due to a mouth dystonia and eventually he was fired. 2 years ago Maurizio began the long bureaucratic procedures to get recognition of his dystonia as a work related illness, in order to get the State benefits related to occupational diseases. The legal consultant who helped him informed us that at last Maurizio got the recognition , therefore in Italy he is the first musician whose dystonia has been acknowledged as an occupational disease (in Germany this rule has existed since 2017). This certification could open the way to similar procedures for dystonia caused by other types of work.

At 4 pm our meeting ended, after 5 intense hours of information, personal stories and discussion; we received very good feedback, the event registered a very large number of views in our social media and we have received many requests concerning the bureaucratic rules, which have been clearly explained, pointing patients to the right procedures.



3 days before our Convention we had the opportunity to hold a press conference in the building of our Parliament, in the press room of the Chamber of Deputies. We spoke about the disease, the story and the mission of A.R.D in spreading awareness ; Walter Rizzetto, Deputy of our Parliament, took part in the press conference guaranteeing his support for our next actions.

The poster of our meeting shows a puzzle under the title “Dystonia, disability and work: building an inclusive future “ as we are aware that building an inclusive future is a puzzle; its pieces are in the hands of State institutions, sanitary institutions, doctors, patients and A.R.D. : only if everyone puts its piece in the right way the puzzle will be completed and a better future for people with dystonia will be possible.

Maria Carla Tarocchi
A.R.D.
Italy



Autumn Meeting with a Focus on Breathing and Relaxation

For us with dystonia we can never get enough of learning more about breathing, relaxation and the importance of bending and stretching. At the autumn meeting of the Norwegian Dystonia Association in Tromsø on 21 September Ina Borch gave us new and exciting approaches in this regard.

– We take our breath for granted, and that's a good thing. What's nice to know is that we can use our breath consciously to connect with the internal systems in our body. Breathing is our only direct link to the nervous system, Borch explained to us gathered in the conference room at Clarion Hotel The Edge in Tromsø this rainy Saturday in September.

In total, we were 31 members represented from south to north who had found their way to this autumn's peer meeting. The southernmost participant came from Drammen while the northernmost participant came from Alta and Hammerfest.



Leader of the Norwegian Dystonia Association Johan Arnfinn Warvik thanks Ina Borch

– Very nice and great to see that so many have shown up, said the leader of the local team Nord, Lise Bakken, as she, together with her colleague on the board of the local team Line Mathiesen and the national board chairman Johan Arnfinn Warvik, welcomed everyone.

Breathing can provide control

The choice of topic was not accidental. Johan Arnfinn pointed out that those of us affected by dystonia can experience a wave of muscle pain and painful thoughts. He himself had received good help from a physiotherapist who had taught him techniques for relaxation.

Ina Borch's message to those present in this regard was to work with our breathing more consciously.

– If you feel uncomfortable you can use your breath to gain more control over your bodily reactions, Borch pointed out. Borch runs Ina Yoga in Tromsø on a daily basis.

She thanked us for allowing her to come to the autumn meeting and said she was happy to have been invited.

– We don't have to think about our breath, it's there all the time. At the same time, it's one of the automatic processes we can physically control. Breathing is like a bridge to the nervous system. Today we're going to try to get in touch with and focus on our breath, Borch explained to the gathering.

– We have two nervous systems, the autonomic and the somatic. We're going to try to reach the parasympathetic nervous system in the autonomic nervous system, where we find calm and can feel safe. Borch then took us through several different breathing exercises and techniques.





Inside Tromsødomkirken also called the the Arctic Cathedral

Inspired

During the session, she included bending, stretching and balancing exercises to the full effort of everyone in the room. Finally, she took us on a meditative relaxation journey. With eyes closed and with calm background music, she let us turn our attention to one body part at a time from the bottom of our feet to the top of our heads, a method known to have a stress-relieving effect.

"I think you look a little more peaceful now than when I came in," Ina Borch summed up with a smile as everyone opened their eyes.

She received applause. Dystoni-nytt received a comment from Berit Lysaker, local team leader in Oslo and Akershus, afterwards. "Awesome!," she called what Borch had taken us through and she thought the exercises that were demonstrated inspired us to follow up.



View over Tromsø and the surroundings

Lunch and sightseeing

The good conversation continued during lunch. After the meal it was time to get to know Tromsø better. For several of the visitors from the south, this was their first time in Tromsø and the region.

Johan Arnfinn was able to state that a boat trip had actually been booked for everyone. But at the last minute, the shipping company cancelled the booking with the dystonia association and instead entered into a contract with a group from Spain who they wanted to make more money from. Such treatment of customers can quickly backfire on the tourism industry itself, said Johan Arnfinn.

As a substitute, a trip to the "Fjellheisen" (which is a Gondola that takes you from the city to a mountaintop) with a visit to the Arctic Cathedral was organized at the last minute. Some chose the alternative, which was a city walk on a strategic route that gave the opportunity to take a closer look at the artwork of city girl Marit Bockelie on the walls of houses in the city centre, as well as her latest creation "the portal" in the new Vervet district.

Everyone enjoyed the trip, and even the weather gods changed their minds and showed a kinder side. For those who took the Fjellheisen, the weather cleared up enough to make it possible to enjoy the view of Tromsø and the surrounding islands.

Text and photo:

Vidar Bjørkli

Norwegian Dystonia Association



Meet Mikko from Finland

My name is Mikko Juutinen. I am 43 years old, and I live in Muhos, Finland. I have a wife Riikka and we have two children. I am a dentist, but I haven't done any clinical work for almost two and half years. I am specialising in healthcare. I work as a specialist dentist. I am responsible unit manager for wellbeing in the county of North Bothnia. I also work as a part time university teacher in the University of Oulu. I teach dentistry students in my specialised field. Also, I teach first- and second-year students about what it is like to work as a dentist and how to connect with patients.

My first symptoms of Dystonia were with my left thumb in 2017. It started during patient work. First it was a few times a day but in a few weeks the symptoms were worse and I had to go to an occupational health doctor. First, she sent me to a hand surgeon and after that my hand was getting MRI-examination. There wasn't anything that caused the symptoms so next I went to a clinical neurophysiologist, and she examined me and also found nothing which caused my symptoms. She said it could be a neurological condition. My occupational health doctor didn't know what was wrong with me either and at the same time symptoms started with my right hand thumb. I was in a seminar where we were having dinner and there was a neurologist on the same table. We were having coffee with cognac, and I asked about my symptoms and that clinical neurophysiologist also said it could be a neurological condition. Right away I was told my symptoms were neurological and that it is task-specific dystonia which can be treated with botulinum toxin injections. Next week I visited my occupational health doctor, and she said to me that she doesn't know at all what is causing the symptoms. I told her about the talk with a neurologist who said that it is task-specific dystonia. After that she called the university hospital clinic of neurology and sent me there.



It took almost a year before my first injections. They wanted to do head and neck MRI-examinations and take a lot of blood tests. During that year both of my big toes started to have the same symptoms as my thumbs. In 2019 when I first got my injections, my neurologist and I were looking in an anatomy book to determine the correct muscles to be injected to allow me to continue my work as a dentist.

I have been injected four times a year since then. My dystonia symptoms have also spread, my both calves and 2nd-finger and upper back are affected and now on my injection list. Now a total of 12 muscles are injected. My cousin also has dystonia. He has cervical dystonia and spasmodic dysphonia. We live in different areas, but we can support each other.

I struggled with my work for three years, and it started to get harder and harder. Sometimes I thought that I might be more of a danger to the patient than a help. But it was such an important thing for me to work as a dentist and I liked that a lot.

During those years I had to re-think my occupation and I decided to apply for specialised studies. Now I don't have to do any patient work but still have a lot of knowledge from the years I worked with patients and I can use that experience in my work today.

My hobbies have also changed with dystonia. Before I was a runner, but now I can't take two running steps. I have learned to make knives and sometimes I think I should try that again. I am a big fan of football and Arsenal is my club. Scouting has been my hobby for a decade, and it is still my most important hobby. Also, organisation work is my hobby. When I got diagnosed with Dystonia I became a member of the Finnish dystonia association. I was a member for a few years when they asked me to become a member of the board. I was a member of the board for three years when I was asked to become the next president of the Finnish dystonia association. I have been a delegate on Dystonia Europe's Ddays in Copenhagen, Dublin and Timișoara. It has been a good time every time and it has been a privilege to get to know people around Europe with dystonia. At the beginning of 2024 I started a new role as President of the Finnish Dystonia Association and it has been a busy year! Also, I have done my specialised studies during this year. Luckily there is only one year left with this study.

Mikko Juutinen

President Finnish Dystonia Association



From left: Mikko Juutinen from Finland, Vidar Bjørkli from Norway and Jukka Sillanpää from Finland





Elizabeth Cunningham

Meet Elizabeth, Ireland

What is your name? Elizabeth Cunningham

What are the benefits of working within a patient organization?

I have been a communications professional with patient organisations for ten years and find it extremely rewarding. I came to this career because I live with a chronic neurological condition (migraine). From an early age, I knew that my best option would be to be self-employed, as I needed a level of flexibility that working in many companies could not offer.

Initially, I worked as a digital media developer with corporate clients, but I never found that work truly fulfilling. Working with patient organisations changed that. The primary difference is the people. I have the pleasure of working with and for wonderful people, and I feel that my work can have a positive impact.

What keeps you motivated?

Unfortunately, my migraine attacks are frequent and often mean that I need to spend days in bed in the darkness. To keep motivated, I remind myself that the attack will pass and that although I can't do what I want on that day, there will be another opportunity.

Once I am well, I have so much appreciation for being pain-free that I try to make the most of life! I enjoy family time with my husband and little girl, and I make sure to have some 'me' time, when I like to make ceramics at a local studio.

What makes you frustrated?

It is frustrating to see that stigma remains a huge issue for those affected by neurological conditions, including dystonia. I am impatient for the day when better understanding at all levels of society will mean people are treated and respected as equals. Equality must extend to all areas, including affordable access to treatments for all, regardless of where they live.

Elizabeth Cunningham

Communications Manager

Dystonia Europe

And Senior Communications Manager

EFNA



Elizabeth and her daughter Holly



Calendar Winter 2025

January

29 Webinar: Children, Dystonia & DBS

February

28 Rare Disease Day

March

5 DE Board Meeting, Lund, Sweden

6 DE Think Tank Meeting, Lund Sweden

10-16 Brain Awareness Week

April

24-25 Physio Course second part, Newcastle, UK

26-27 NDF Annual Meeting, Oslo, Norway

May

9-10 Dystonia Europe Annual Meeting

SAVE THE DATE!

Wednesday, 29 January, 2025, 18.00 - 19.30hrs CET

**DYSTONIA
EUROPE**

UPCOMING WEBINAR:

CHILDREN, DYSTONIA & DBS

HEAR FROM MEDICAL EXPERTS AND PEOPLE'S LIVED EXPERIENCES

Moderated by:



Prof Alfonso Fasano
Toronto University Hospital

Speakers:



Dr. Margaret Kaminska
Evelina Children Hospital,
London, UK



Sarah Perides
Advanced Nurse Practitioner,
Evelina Children Hospital

Members

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

Prof Alberto Albanese – Milan

Prof Alfredo Berardelli – Rome

Prof Kailash Bhatia – London

Prof Marina de Koning-Tijssen – Groningen

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Prof Maja Relja – Zagreb

Prof Marie Vidailhet – Paris

Prof Marjan Jahanshahi – London

Shaping a Better
Future for
People
Living with
Dystonia

Staff



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.

**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.

**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.

**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.

**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.



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.

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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 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!

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