DYSTONIA NEWS

SPRING|1 - 2024

IN THIS ISSUE

DYSTONIA EUROPE

CONTENT

Dear readers,

This is already our Spring newsletter and our team is in full preparation for the Dystonia Europe Members' Meeting 2024 in Timisoara in Romania.

This year our Dystonia Days will be an on-line event on Saturday Sept 21. Save the date and follow the news from our website and social channels to learn more about the program which will include expert presentations and patients' testimonies.

There will also be an online meeting/webinar, on 18 June where we will present our organization's activities in greater detail and exchange ideas. Watch out for more information on our social networks!

The Board team has met in Paris with our sponsors end of February.

We discussed current activities and future projects as well as various ways of fund-raising to make everything possible and to ensure a sustainable organization. These are always important and productive meetings.

As every year, we're also preparing the Dystonia Awareness Month of September, which we hope will be innovative and in tune with the latest news in our community.

Monika participated in the Toxins 2024 Congress in Berlin, Germany, in January and in a meeting of the Boston Scientific Foundation Europe in March in France.

Merete tells us more about European Patients Forum.

In this edition you will also discover the latest news from our members in Sweden, Romania and UK, read the story of Line from Norway, and our last articles on research.

We would like to thank our members, staff, advisors and sponsors for their ongoing support in ensuring the continuity and quality of our work.

On behalf of the Dystonia Europe team I would like to wish you all a relaxing and nice summer

Edwige Ponseel
President
Dystonia Europe

Board Meeting and Think Tank in Paris

When my dystonia first started I found it very debilitating and would not leave the house on my own. Fast forward a few years, and lots of rounds of botulinum toxin, and here I am travelling around Europe on my own!

I love my work with Dystonia Europe and it has given me lots of opportunities to travel and do things I never thought I would be able to do.

Travelling alone is something I always dreaded, even before dystonia struck, and even now sometimes I get a bit nervous when going somewhere I have not been before.

My trip to Paris to attend the Think Tank with the Dystonia Europe Board and our sponsors was one of those trips that I was nervous about.

I have been to Charles De Gaul airport before but only to change flights and travel somewhere else and I wasn't alone. I felt rather nervous about finding my way through the airport to the train station and then of course get on the correct train to take me into Paris!

When I arrived at the airport I was awestruck at how big it is, however there were plenty of signs showing me the way thank goodness. I did eventually get to the baggage belt and then onto the train platform. I was still nervous about getting on the train but a lovely lady working on the platform assured me I was in the right place to get the train to Paris. I had been in touch with the other board members also arriving the same day so arranged to wait for Jukka who was arriving shortly after me.

We met on the train platform and got onto a very full train, we then stood all the way to Gare Du Nord station. I was so pleased I was with Jukka as even the train station was huge! Thanks to Jukka we found our way out of the station and then finding the hotel was very straight forward, phew!

It was lovely to see all my friends from the board and relax with them for a little while before we started work. In fact, unusually, we had no formal meetings until the next morning so our first afternoon/evening was all about catching up with each other and having a nice meal. Our restaurant was just next door to the hotel and the food was lovely, although when we first got there they didn't have our booking! Thankfully Edwige managed to sort it out and of course we had a lovely meal.

The next morning our Board Meeting started at 9am and we had a great deal to discuss. We frequently meet online using Zoom but we always manage to discuss more and make more decisions when we meet face to face. Does anyone else experience that I wonder?

We had a busy morning discussing topics such as the current finances and how we are doing with our budget and whether we have enough to complete all the projects we are involved in. Funding is always a concern, we rely totally on funding from our sponsors, donations from our supporters and fees from consultancy work and of course that is not a guaranteed income. We had various discussions about how to generate more income and/or save money wherever we can.

Lunch break came around very quickly and we had a lovely lunch in the same restaurant next door to our hotel.

As soon as we were finished we got straight back to work and the afternoon went by so quickly we were all quite shocked when we realised it was 5pm! One of the discussions we had was about succession plans for board members and staff. We have a few who wish to retire in two or three years so it is important we have new people joining the board and/or being trained to join the staff. We got through most of the agenda but had to leave one or two topics for our next meeting.

There was just time to freshen up before dinner where we would meet our sponsors. We had 2 representatives from Ipsen, Susanne and Oleks and 1 from Merz, Petra.

After a short walk we found our restaurant and sat down for dinner. We had an amusing waiter who was very funny while taking our orders, it was a bit like being in the school canteen and the dinner lady shouting out 'Put your hand up if you would like casserole!'. We all enjoyed a really lovely meal and walked back to the hotel feeling very full!

Our meeting with the sponsors was 9am the following morning and when I woke up I was still so full from the evening before that I just had a coffee in my room and didn't bother going down for breakfast!

We all gathered in the meeting room ready to start at 9am for another very full agenda. This meeting was due to finish around 2pm so we could all get to the airport in time for our flights home. We did have plenty of time to discuss important issues like, how to attract more funding, what we could do to earn more from consultancy fees etc and how to progress our projects. Monika also gave our sponsors, Susanne, Oleks and Petra, a detailed update of progress on projects and increases in our social media followers. We also asked them for advice about raising awareness especially during September, Dystonia Awareness Month.

The meeting closed promptly at 2pm and some of my friends from the board had to leave straight away in order to catch their flights. We all said an emotional goodbye and wished each other a safe journey home. Some of the board had to get 2 or more flights to get home but this time I was lucky enough to have a direct flight from Paris to my local airport in Newcastle upon Tyne.

I travelled back to the airport with Monika and she got off the train one stop before me as we left from different terminals at the airport. My journey through the airport was much simpler than when I arrived and also much quicker, I was pleasantly surprised to find no long queues anywhere!

I found my departure gate then returned to the duty free shops to buy small gifts for my 3 grandchildren, Emily 9, Phoebe 7 and Alfred 3 months old. That didn't take long so I got back to my departure gate in plenty of time.

The flight home was straight forward with no delays and when I landed at Newcastle I texted my husband John to let him know it was time to pick me up. However, when he didn't arrive after 10 minutes (he was waiting close by) I checked my phone and realised I had sent the text to my brother by mistake and he lives in Plymouth which is 420 miles from Newcastle! My brother and I laughed at my mistake and then I contacted John who arrived 3 minutes later to pick me up.

I got home around 10:30pm and had to be at my son's house for 7am the following morning to look after the girls and take them to school so it was straight to bed for me!

Our two days of meetings were really productive and I was so pleased to see everyone. It was sad to say goodbye but we will meet again in Timisoara, Romania at the end of May.

Gill Ainsley
Secretary and Vice President
Dystonia Europe

SPRINT PROGRAM: Sensorimotor Retraining Program For The Re-habilitation of Isolated Cervical Dystonia in Conjunction with Neurobotulinum Toxin

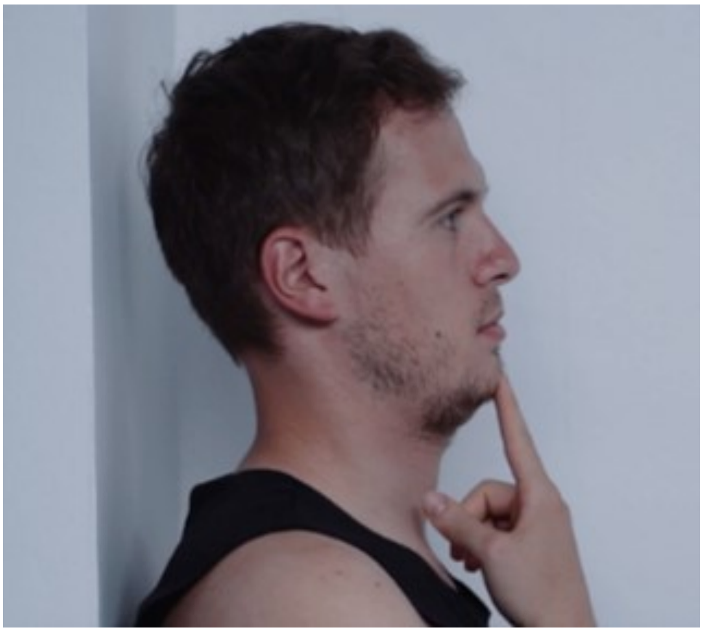
Enrico Saibene, A. Crippa, M. Ramella, G. Giacobbi, C. Corrini, D. Anastasi, A Castagna

Isolated Cervical dystonia (ICD) is a movement disorder characterised by intermittent or sustained involuntary contractions that cause altered postures or abnormal movements, also tremors, of the head, neck, with occasional involvement of the shoulders. For about thirty years, the efficacy of botulinum toxin as symptomatic treatment of this pathology has been demonstrated, but there are still no shared guidelines regarding the role of rehabilitative interventions. Although the combination of different rehabilitation techniques such as passive mobilisation, muscle stretching, antagonist muscle recruitment, relaxation techniques, and the use of biofeedback for motor control are suggested as useful in dystonia in several studies, there are no clear guidelines about definition of goals of treatment and outcome measures due to the lack of standardised protocol studies.

From 2014 in the Research Hospital Fondazione Don Gnocchi Santa Maria Nascente of Milan, in Italy, thanks to the strong collaboration between a neurologist expert in cervical dystonia, motor learning strategies and botulinum toxin treatment, Dr Anna Castagna, a PMR doctor Dr Marina Ramella with a special expertise in visuo spatial and perceptive rehabilitation and a group of talented physiotherapists, Alessandro Crippa, inventor of biofeedback system Leonardo, Giulia Giacobbi, Chiara Corrini, Denise Anastasi and Enrico Saibene expert in perceptive approaches, an effort in the field of rehabilitation treatment of ICD has been conducted firstly with a pilot research protocol, and then with a transfer over the years into the daily life clinical practice, treating hundreds of persons with iCD successfully.

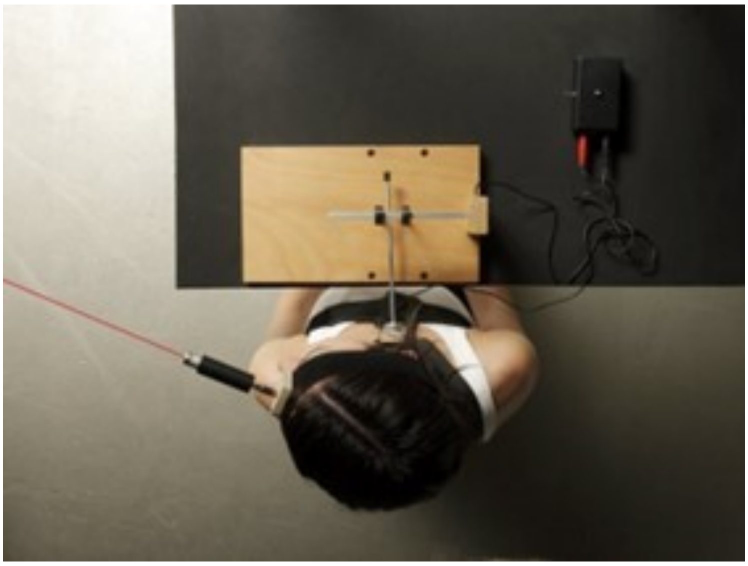
The goal of the first study published on Clinical trial.gov NCT03247868 was to evaluate the effectiveness in the same patient of a combined sensorimotor relearning strategy using biofeedback techniques and visuo-spatial rehabilitation, (SPRInt, Sensorimotor Perceptive Rehabilitative Integrated program) in conjunction with BoNTA injection versus the gold standard botulinum toxin treatment. This pilot study, published as an original paper in 2019 in Neurological Sciences verified that SPRINT and BoNTA gave iCD patients a significant increase in the quality of life compared to therapy with botulinum toxin alone, in terms of quantity and duration of benefit.

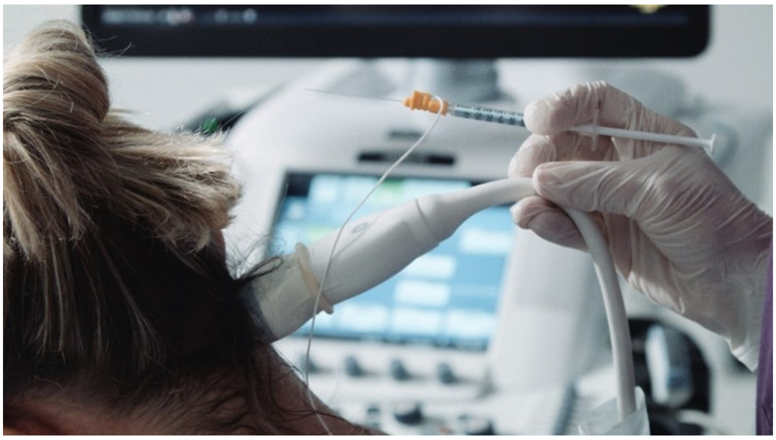
In detail this trial was designed as 6 months duration and was conducted, involving 11 patients (5 males and 6 females) with isolated idiopathic cervical dystonia. Each patient initially undergoes a neurological evaluation and is injected with botulinum toxin according to a personalised scheme (T0), then re-evaluated at 6 and 12 weeks (T1 and T2). At time T2, each patient is again injected with BoNT and begins a rehabilitation cycle according to the SPRInt rehabilitative approach (18 sessions, three times a week, lasting 45 minutes each). At the end of the rehabilitation cycle (T3) and as a follow-up (T4), 6 months from T0, each patient is re-evaluated. Each clinical evaluation is associated with cervical district kinematic analysis and the administration of three scales: Toronto Western Spasmodic Torticollis Rating Scale (TWSTRS severity, disability, pain), EQ-5D5L for quality of life, and Self Anxiety Scale (SAS), to assess patients' psychological characteristics.



Results

Preliminary data obtained in the pilot study show that at the end of the evaluation period (follow-up), the painful symptoms, the severity of the pathology, and the disability resulting from the disease are reduced compared to the initial evaluation. In particular, the total score of the TWSTRS scale, from 39.0 ± 10.9 (calculated data with median and IQR) at T0, decreased to 30.50 ± 17.75 at follow-up ($p<0.01$). Performing post-hoc analysis of the data obtained for each field evaluated within the TWSTRS, it was observed that the disability reported by the patient decreased more after combined treatment (SPRInt), compared to treatment with botulinum toxin alone, and that this change was partially but significantly maintained at follow-up ($p<0.01$). The severity of the pathology was reduced after combined treatment, from a score of 19.0 ± 4.5 to 12.0 ± 5.0, partially persisting over time (14.0 ± 3.5), while regarding the painful symptoms, there was no variation after combined therapy compared to sole botulinum toxin injection.





Conclusions

Although botulinum toxin currently represents the gold standard in the treatment of isolated cervical dystonia, the effect of the drug is not long-lasting and totally effective for the complete resolution of the complex symptomatology complained of by the patients which presents different motor and non motor phenomenology. The experimental SPRInt approach inspired by the concept of sensorimotor relearning through feedback and visuo-spatial rehabilitation focused on personalised goals and specific needs, could interact more effectively with dystonia complexity, improving the quality of life of patients. Regarding painful symptoms, botulinum toxin seems to represent the most effective solution. Furthermore, further systematic research is needed to clarify the role of rehabilitation within the treatment of dystonia and to give the people affected the opportunity to be treated all over the world with tested and specific exercises in conjunction with botulinum toxin injections.

JUST PUBLISHED:

The Third New Edition of The Manual of Botulinum Toxin Therapy

The year 2024 begins with a new book: The Manual of Botulinum Toxin Therapy, one of the best-selling botulinum toxin books, has now been published in its third new edition by Cambridge University Press. 'We are delighted that this book has been able to establish itself over the years as the standard work on botulinum toxin therapy and that it has found such worldwide distribution,' says Prof Dr Dr Dirk Dressler, Head of the Movement Disorders Section at Hannover Medical School and one of the editors. The book is characterised by its comprehensive coverage of the entire spectrum of current botulinum toxin therapy indications by an international panel of high-calibre authors. 'We have emphasised practical aspects as much as possible, which is reflected in the large number of very clear and instructive illustrations,' says Dressler. Translations into numerous languages are planned again to meet global demand.

https://de.wikipedia.org/wiki/Dirk_Dressler

Dirk Dressler, MD, PhD
Professor of Neurology
Head of Movement Disorders Section
Department of Neurology
Hannover Medical School
Carl-Neuberg-Str. 1
D-30625 Hannover, Germany
dressler.dirk@mh-hannover.de

Empowering digital health advocacy – the inaugural Ambassador Seminar of the Boston Scientific Foundation Europe

In March, Monika Benson participated in a meeting of the Boston Scientific Foundation Europe (BSFE), which convened her fellow Board members and Ambassador representatives from across Europe. The two-day meeting was filled with purpose and enthusiasm, focusing on upskilling the Ambassadors to enable them to effectively fulfil their roles with support from Monika sharing her expertise to guide them in best practices when working with patient advocacy groups. Held at the Centre Pédiatrique des Côtes in France, a rehabilitation hospital for disabled children with cardiac problems, the attendees had the chance to see first-hand how a digital health solution could have a life-changing impact. The BSFE-sponsored augmented communication tool uses eye-recognition software to give a voice to children who previously did not have the ability to communicate.

BSFE is a non-profit organisation dedicated to helping communities improve their health and well-being by supporting innovative digital health solutions. They are passionate about the ability for digital solutions to reduce health inequalities by enabling people to access health information and resources to better manage their health and care. The Dystonia Physio Exercise Hub is a great example of this, now assisting almost 500 people with cervical dystonia across Europe!

BSFE accepts applications all year round. Please visit the website to discover how your organisation can apply, or get in touch with the local BSFE Ambassador by contacting them by email: BsciEuropefoundation@bsci.com.

Christine Chapman
Communications
Boston Scientific Foundation Europe

Panel discussion with Monika Benson(Dystonia Europe), Elena Moya (Asociación Española contra la Meningitis) and Sylvain Thimotee (Centre Pédiatrique des Côtes)

Toxins 2024 Congress in Berlin

Mid January the Toxins 2024 congress was held at the Estrel Conference Center in Berlin in Germany. The conference was a great success with over 1200 participants from 59 countries.

Executive Director of Dystonia Europe, Monika Benson, took part as the only non-profit organization. With a small table with information material in the exhibition hall she met with physicians from various countries and shared information on Dystonia Europe and our activities.

There were plenty of presentations for the participants to choose from and some of them on the various forms of dystonia and its treatments.

Dystonia and pain was discussed in one session and the efficacy of botulinum toxin treatment. Another session was on the trial results of the long-lasting botulinum toxin daxibotulinum, which was FDA approved last year in the US for treatment of Cervical Dystonia. Read more here:

https://investors.revance.com/investors/Press-Releases/news-details/2023/U.S.-FDA-Approves-First-Therapeutic-Indication-for-Revances-DAXXIFY-DaxibotulinumtoxinA-lanm-for-Injection-for-the-Treatment-of-Cervical-Dystonia/default.aspx

This congress is organized every other year and is all about the botulinum toxin treatment. Main sponsors of the event were Ipsen, Merz and AbbVie.

Monika Benson
Executive Director
Dystonia Europe

Monika Benson and Prof Brigitte Girard

EPF Leadership Meeting & AGM in Brussel

Dystonia Europe is a member of European Patient Forum (EPF) and participated at the leadership meeting 13 April and at the Annual General Assembly 14 April in Brussel.

The leadership meeting started with opening remarks by Marco Greco, EPF President.

Patient organisations face a new environment with AI (Artificial Intelligence) and it is essential with boundaries regarding ethics. Ownership of data needs to be established and patients and patients organisations need to be updated and be part of the process of AI being implemented within healthcare. The necessity of patients to be involved is to take care of the needs of the patient.

Ildik Vajda, senior policy officer in Digital Health at Patiëntenfederatie Nederland, held a presentation on 101 AI and Data Saves Lives. This presentation gave us a little insight in how complicated AI is and stated that it is a new system technology and the algorithm needs to be error free. Models can be very complex and maintenance of the program is necessary. There is a lot of work behind the scene.

Antonio Andreu, Scientific Director in EATRIS (European Infrastructure for Translational Medicine) spoke about AI in the medical and research area and how to ensure that the data respect the patient. There is a shortage of health care professionals and it can be a tool to assist in diagnosing and treatment of patients.

We need to not be afraid of using AI but to be alert so it is in the best interest of patients. AI is already used widely in the health care systems today. Examples are robotics surgery with supervision from the surgeon and AI can assist to help diagnose the severity of a stroke, which again will determine which treatment is best for the patient.

The AGM was held 14 April in the morning and in the afternoon. EPF closed the AGM (Annual General Assembly) with a presentation from Claudia Louati, EPF Head of Policy on our #Vote4Patients campaign!
To achieve truly equitable and participatory healthcare, what matters the most is the involvement of patients. Without their first-hand knowledge, no health policy can be satisfying and representative of the needs of the community we represent at EPF.
In the EPF Patient Organisations’ Manifesto, there are defined 10 principles to guide policymakers in better engaging with organisations advocating for patient rights. Take a moment to go through them and sign the EPF petition - check out the links below!

Sign the petition: https://bit.ly/3uyqDo4
Read EPF’s Manifesto: https://bit.ly/3HHUm0U

Merete Avery
Operations Manager
Dystonia Europe

EPF European Patients Forum

Cervical Dystonia Patient Journey

The cervical dystonia patient journey was published two years ago.

Currently is is being translated into more languages. These are published on the ERN-RND (The European Reference Network for Rare Neurological Diseases) website.

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

We hope that this patient experience map will support patients who are newly diagnosed as well as other dystonia patients and their caregivers. It is also an important tool for the medical profession to better understand the situation of their cervical dystonia patients.

The patient journey was last year dramatized and performed at the EAN congress in Hungary. This performance has now been adapted into a short film that soon will be released. We hope the film will help to improve awareness and understanding of dystonia, as well as supporting education and training of the medical profession.

We thank actress Carmel Stephens for her fantastic work on both the manuscript and the performance and filmmaker Andrew Keogh for producing it. Also a great thank you to ERN-RND for supporting this project.

Monika Benson

ePAG ERN-RND

Annual Meeting 2024 of the Swedish Dystonia Association

Beginning of February the Swedish Dystonia Association held its Annual General Assembly in Stockholm. About 20 people attended the event and there was also a representative from the Norwegian Dystonia Association. At the formal meeting a new Chairman was elected. His name is Mats Nyberg and he is a teacher in physics and math at a senior high school in central Stockholm. He succeeds Bengt-Erik Calles who held the post for many years. Bengt-Erik remains a board member. After the formal meeting there was a coffee break.

Then followed a presentation with Dystonia Europe Executive Director Monika Benson who presented the work and activities of Dystonia Europe. There were many questions from the audience. It was suggested that there is more information in the newsletter of the Swedish Dystonia Association to inform them about the latest news of Dystonia Europe, what videos are available, invitations to webinars etc. This is something that can be considered in many other national newsletters.

We wish Mats and his team much success in their work for dystonia patients in Sweden.

Monika Benson
Executive Director
Dystonia Europe

The new SDF President Mats Nyberg and his team

Passion in Motion: Supporting Rare Disease Day in Romania

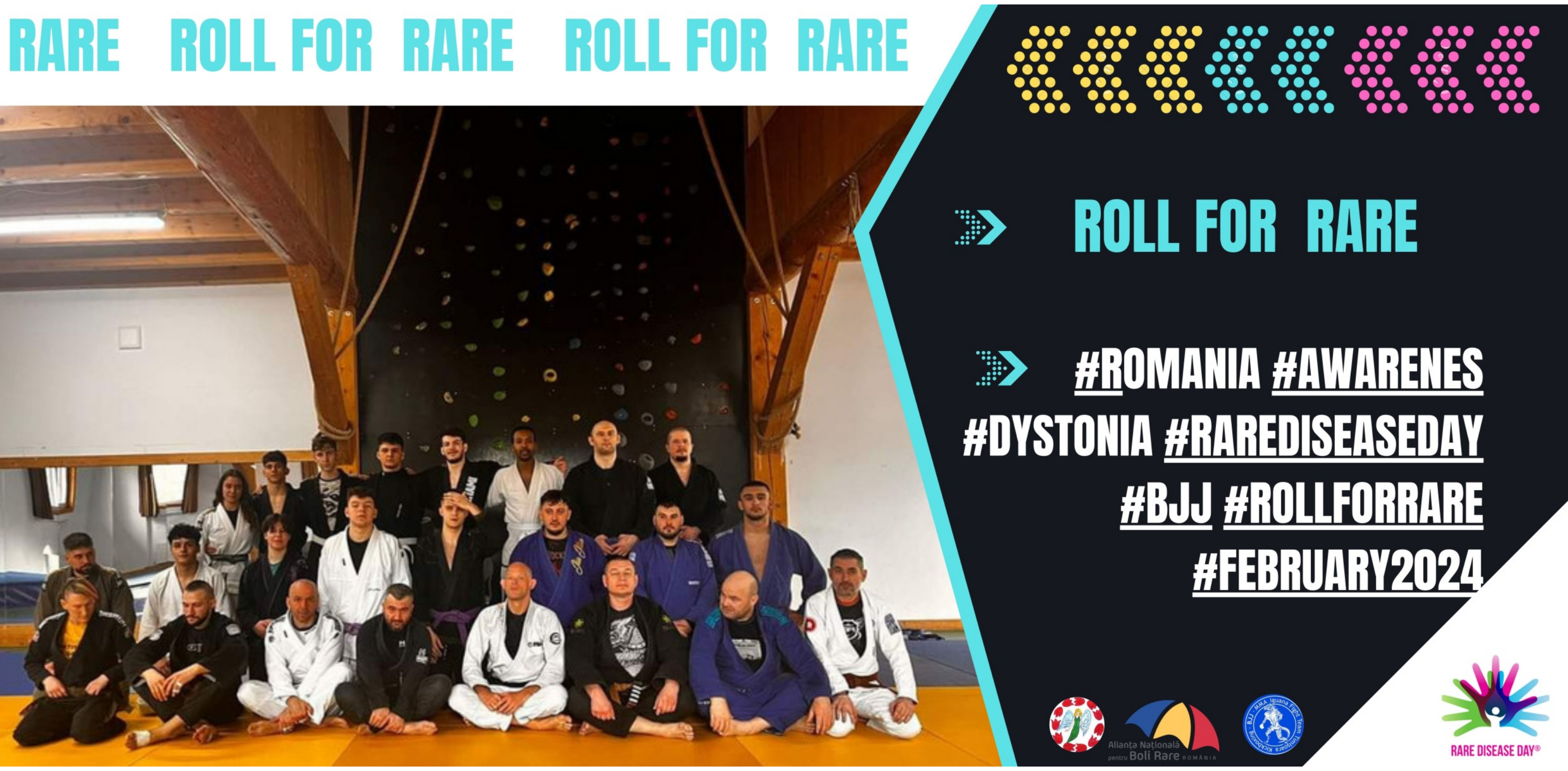
In an effort to bring light and hope into the lives of those affected by rare diseases, an innovative project has taken root in the heart of the Brazilian Jiu-Jitsu (BJJ) community in Romania. Under the motto "Rolling for Rare," this project was initiated by the Children's Joy Association for Dystonia together with the Iguana Fight Team Association of contact Sports, aiming to unite forces to support the cause of rare diseases through art and sport.

Sporting and awareness activities were made possible at a camp organised at Cheile Grădiștei, an important tourist destination in Romania. Here, passionate Brazilian Jiu-Jitsu athletes not only from Romania but also from other corners of the world, such as England (London) and Germany (Berlin), gathered to improve their skills in the art of Brazilian Jiu-Jitsu, supporting the Children's Joy Association's initiative for Rare Disease Day. In this energetic and determined atmosphere, messages of solidarity and awareness were passionately conveyed. Through videos and photos distributed on social media, their messages travelled from Cheile Grădiștei to people's homes around the world, contributing to the popularisation and awareness of rare diseases. Brazilian Jiu-Jitsu is not just a sport but also a strong community dedicated to health, respect and personal improvement. Within this community, BJJ enthusiasts use their skills and passion to support causes that truly matter. Through the "Rolling for Rare" project, they aim to combine their love for BJJ with efforts to raise awareness and support for rare diseases.

During Brazilian Jiu-Jitsu fights, qualities such as physical and mental resilience, adaptability, determination, and community support are developed. The analogy between improving these qualities in sports and fighting against rare diseases shows us that the efforts and qualities needed to overcome obstacles are universal, whether physical or emotional.

A second extraordinary initiative took place at the MC Gym Motion sports hall, a concept that combines sports activities with recovery. Here, an art and sports exhibition dedicated to Rare Disease Day brought together a selection of paintings created by local artists and children, each expressing a unique story about the life and experience of those affected by rare diseases.

Marius and Catalina Crainic



The exhibition served as a centre for awareness and education about rare diseases, providing participants with detailed information and informative materials about rare conditions, treatments and support resources. To intensify the impact of the event, messages, photographs, and videos were distributed during the exhibition period. Furthermore, sports practitioners who came to train in the sports hall had the opportunity to visit it over a 30-day period for awareness and popularisation.

This art and sports exhibition dedicated to Rare Disease Day represents an effort to bring these often overlooked conditions to the forefront and to encourage empathy and support in our community.

By getting involved in this noble cause, members of the sports community and combat sports have shown not only their sporting skills but also their generosity and compassion, demonstrating that together we can make a significant difference in raising awareness of Rare Disease Day.

Our association is a national member of the National Alliance for Rare Diseases but also a member of Dystonia Europe

Through our activism within these organisations, we can contribute to raising awareness about these diseases, improving access to treatments and enhancing the quality of life for individuals affected.

Catalina Crainic
Board Member
Dystonia Europe

Voices from the community – the Dystonia Matters Podcast

In 2020, Dystonia UK launched the Dystonia Matters podcast as a powerful platform to give our community a voice. The podcast series allows us to share the stories of people living with dystonia, whether they've been diagnosed themselves, or care for someone with the condition. Our hope is that through telling the tales of our community we can help people living with dystonia know they are not alone and raise awareness.

"I've listened to the podcast... and cried. It is wonderful to realise you're not alone and agree that it would be lovely to get to the point where people don't say 'What IS dystonia?'"

With each episode, guests sit down with Dystonia UK's Director of Fundraising and Communications, Dayna Ferdinandi, to have an honest conversation about their unique experiences navigating life with dystonia. What makes this podcast so special is the blend of authenticity and lightness of the conversations which not only educates, but also provides a sense of solace and connection for those also affected tuning in.

No matter the guest, whether it's the remarkable rising social media star and Dystonia UK ambassador Ella Middleton (Season 2 Episode 1), Dystonia UK fundraisers (Season 1 Episode 4) or Claire Taggart, a boccia Paralympic champion (Season 3 Episode 4), one thing is for certain: you'll come away from each episode with a renewed sense of empathy, and a heartfelt connection to the resilience of the dystonia community.

Rebecca

In 2020, Dystonia UK launched the Dystonia Matters podcast as a powerful platform to give our community a voice.

“Everything I’d imagined for myself had been taken away. And no one had said it gets better. And I feel like because no one had that conversation or even said you’re allowed to imagine it getting better, I think I’d allowed that fear to completely take over.” Rebecca

The podcast naturally covers a broad spectrum of important topics. Many episodes feature guests who share their personal journey to diagnosis and explain their experiences within the healthcare system. In some episodes we delve into specific and nuanced aspects of life with dystonia, such as the unique challenges faced by parents raising children with the condition. These discussions shed light on the emotional, practical, and medical considerations, as well as exploring the intricacies of young adults' experiences with dystonia, covering topics such as managing school life, social interactions, and fostering independence. Additionally, we’ve had conversations with individuals navigating the complexities of working, keeping active and managing their mental health all while living with dystonia.

Dystonia UK strives to create a podcast that speaks to the experiences of everyone within our community. Our aim is to provide a platform where every listener can find validation and solidarity, fostering a sense of belonging and empowerment as they navigate their own dystonia journey.

“… dystonia matters, because we matter as people, and we are all inspirational people that have a voice, and our voices deserve to be known.” Ella Middleton

Tune in to hear the true stories of our remarkable guests. Available on the Dystonia UK website www.bit.ly/DystoniaMattersPodcastDE and all major streaming platforms.

Dystonia UK

Meet Line from Norway

My story started the summer of 2009, with much discomfort in my eyes. January 2010 I had to stop working and was on sick leave due to extreme sensitivity to light and headaches. I was burned out.

I was examined for Sjögren's disease, infection and different illnesses of the eyes without any results. My eyes became worse and my eyelids started to spasm. My eyes would just stay closed and I had big problems with getting around. I had to stop driving and I became very dependent of my family to be able to move around outside. I also had to use sunglasses both inside and outside.

I was despaired over my situation but I received a lot of help from the social system in Norway (NAV) and the Norwegian aid and assistive technology centre (Hjelpemiddelsentralen)

As a member of the Norwegian Association for the Blind and they came for a home visit and informed me of any aids I could apply for.

This is the help I received:

New lighting in our entire house so I would not be blinded by the light.

Sunscreen on the windows in the living room and in the kitchen where I spend most of my time

A scale that would read out loud to use for myself and a scale that would read out lowud to use for cooking

A machine that reads all types of letters, newspapers etc.

New key board for the computer with larger letters

White cane to use as an “information cane” and that was foldable

A service in Norway called TT card that provides some free taxi

Assistant to help me up to 4 times a week

Accompanying certificate that allows a companion to travel for free when travelling with me

Access to the Norwegian Association for the blind with access to a library for audio books with 150 000 titles to choose from.

Bent Arild Mathiesen
and Line Mathiesen

Photo: Private

I searched on the internet regarding what my illness could be and I found an article on Blepharospasm. Then I contacted my General Physician and explained my symptoms and what I had found on the internet. He did not think I had Blepharospasm but he referred me to a neurologist.

After five minutes with the neurologist he confirmed I suffered from Blepharospasm. I received treatment with botulinum toxin the same day. I had some improvement but I was far from well. The dosage of botulinum toxin was increased but then my eyelids drooped which made the situation worse.

I was wondering if I had to live like this for the rest of my life and decided to not isolate myself. I have participated in all activities that life has to offer, using sunglasses both inside and outside. People are very understanding when I explain what is wrong with me and I have been very open about this.

In connection with a 50 year Anniversary in my family we stayed at Olavsgård Hotel near Oslo in Norway. Sunday morning at breakfast my husband discovered that several other guests had tremor and that some had dark eyeglasses like me. We talked to a lady at our table and it turned out that the Norwegian Dystonia Association had their spring meeting there. What a coincidence!

She told us about a man that had received great help at Stavanger Hospital for blepharospasm. Anniken Hagen who was at the time President for the Norwegian Dystonia Association helped me with getting in touch with this man, so that I could receive information on the physician that he was treated by. Unfortunately I was turned down twice due to capacity problems. I then contacted Anniken who said she could ask her neurologist Charalampos Tzolis to ask if it was possible to get an appointment with him.

19 August 2014 started my new life after treatment at Haukeland Hospital in Bergen. I was injected with botulinum toxin in the eyelids, under and a little around the eyes. After two days I could open my eyes and keep them open. I have started to drive again and I can move around freely by myself. It feels fantastic and with this I want to thank the Norwegian Dystonia Association, Anniken Hagen and Charalampos Tzolis for all the help I have received.

Line Mathiesen

Photos

Above: Line with her grandchild

Right: Line, photo by Merz

Marius Crainic

Meet Marius, Romania

What is your name?
I'm Crainic Marius, I live in Timisoara, Romania.

What are the benefits of working within a patient organisation?
Working in an NGO (non-governmental organisation / non-profit organisation) brings numerous benefits, including positive social impact, personal and professional satisfaction, skill development, building networks, learning and awareness opportunities, diversity and flexibility in the work environment, as well as the chance to engage in volunteering and community involvement. Every moment spent with our organization and the wonderful people we've met there fills me with gratitude and satisfaction. These individuals with dystonia, the ones I've met, with their fearless courage and unwavering perseverance, have inspired and motivated me to be a better version of myself. Through the experience of my wife, living with dystonia, I've learned to look beyond the boundaries imposed by an illness and see in her an inner strength I never thought was possible.

How do you like spending your free time?
My free time is an oasis of joy and connection. I spend time with my family and close friends, always seeking activities that delight and inspire us. Whether we're strolling through nature or visiting new places, each moment is precious and full of meaning.

What keeps you motivated on the tough days?
My motivation is fueled by my passion for sports and the desire to constantly learn something new. As a contact sports coach, every day is a challenge and an opportunity for growth and fulfillment. And, of course, my wonderful family is my source of strength and inspiration, pushing me to give my best at all times.

What makes you angry or frustrated?
Injustice and discrimination drive me up the wall. I believe that every person deserves respect and equality, and when I see these values violated, I feel fury inside me that compels me to take action and fight for the rights and dignity of people in need.

Marius Crainic
Romania

Calendar Spring & Summer 2024

May

30	DE Board Meeting, Timisoara, Romania
31	DE General Assembly 2024, Timisoara, Romania

June

1	DE Members' Meeting 2024, Timisoara, Romania
18	Dystonia Europe Live Webinar: About Dystonia Europe and what we do
29-30	EAN Congress, Helsinki, Finland
	David Marsden Award 2024 Winner and Presentation, Basal Ganglia Club, EAN Helsinki

July

1-2	EAN Congress, Helsinki, Finland
22	World Brain Day

September

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

October

10-11	ERN-RND Annual Meeting, Ljubljana, Slovenia
17-18	Dystonia Physio Workshop, Newcastle, UK

Dystonia Europe Members' Meeting 2024 in Timisoara in Romania

For 2024 the Dystonia Europe Board has decided to organize a Dystonia Europe Members' Meeting in Timisoara in Romania. This meeting will be only for delegates of Dystonia Europe.

The meeting will take place at the Hotel Timisoara on 31 May and 1 June. On the agenda we will have the Annual General Assembly and presentations and there will also be the opportunity for members for a session on sharing best practice.

We wish our members welcome to Timisoara in springtime.

Dystonia Days 2024

This year our Dystonia Days will be an on-line event. Save the date Saturday 21 September in your calendars. We are still working on the program but we can already promise that there will be expert presentations as well as dystonia patients sharing their stories. Look out for more information on our website and social channels when we get closer to the event.

Hotel Timisoara, Romania

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
Prof Joachim Krauss – Hannover
Dr Francesca Morgante — London
Prof Tom Warner – London
Dr Jean-Pierre Lin – London
Prof Maja Relja – Zagreb
Prof Marie Vidailhet – Paris
Prof Marjan Jahanshahi— London

Shaping a Better Future for People Living with Dystonia

Staff

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.

ADVISORS AND CONTACT

Alistair Newton

Advisor, UK

After several years as Vice Chair of the Dystonia Society in the UK, Alistair founded European Dystonia Federation, now Dystonia Europe, in 1993. He served 8 years as President and was the Executive Director between 2001 and 2013. He was appointed to the Dystonia Europe Board with special responsibility of the Dystonia Research Network. Alistair also co-founded EFNA – the European Federation of Neurological Associations – in 2000, where he acted as Treasurer and Secretary-General until 2011. In 2003, he was involved in the founding of the EBC – the European Brain Council, where he was a board member and a treasurer for many years He is now an advisor to DE on special projects.

Maja Relja

Advisor, Croatia

Maja is a professor of neurology, in charge of the movement disorders section at Zagreb University Hospital. She founded the Croatian Dystonia Association and has served as its President for over 20 years. In 2011, she was elected to the board of Dystonia Europe, Between 2011 and 2017 Maja was the Vice President of DE. At present she is the project leader of the Value of Treatment project regarding dystonia.

Eelco Uytterhoeven

IT Advisor, The Netherlands

Eelco has been a professional IT-consultant and developer since 1999. For the last few years, since 2016 he has been working as a freelance developer on several internet projects related to Dystonia Europe. Since the beginning of 2016 he is responsible for the maintenance and further development of the MyDystonia platform. Together with the board Eelco wants to raise the professional level of the IT projects of Dystonia Europe and assist in creating new possibilities for the future.

Contact

President

Edwige Ponseel

Executive Director

Monika Benson

Operations Manager

Merete Avery

Registered Office

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

B-1000 Brussels, Belgium

E-mail: sec@dystonia-europe.org

Photos from Dystonia Days and portrait photos:

Stephan Röhl, www.stephan-roehl.de

Meet us @

Website:
http://dystonia-europe.org
Facebook:
https://www.facebook.com/dystonia.europe
YouTube:
http://www.youtube.com/user/DystoniaEurope
Twitter:
https://twitter.com/dystoniaeurope
Instagram:
https://www.instagram.com/dystoniaeurope/
LinkedIn:
https://linkedin.com/company/dystonia-europe/

We have good working relations on a variety of topics with: DMRF – Dystonia Medical Research Foundation, FDR – Foundation for Dystonia Research, Dystonia Coalition, EFNA – European Federation of Neurological Associations, EBC – the European Brain Council, EAN – European Academy of Neurology, MDS – International Parkinson and Movement Disorder Society.

We thank all our partners for their support and collaboration.

Donation and Support

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

You can also use the donate button on the Dystonia Europe website, which will take you to the following page: https://dystonia-europe.org/donate/

Thank you for supporting Dystonia Europe!

Disclaimer

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

PLATINIUM

IPSEN
Innovation for patient care

Medtronic
Engineering the extraordinary

MERZ THERAPEUTICS
Better outcomes for more patients.