

DYSTONIA

NEWS

SUMMER | 2 - 2023



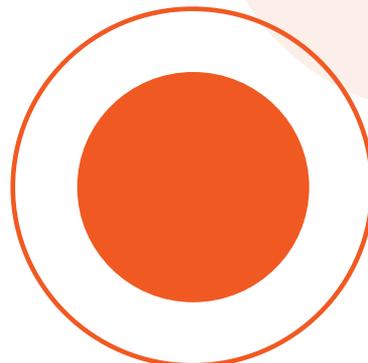
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DYSTONIA
EUROPE



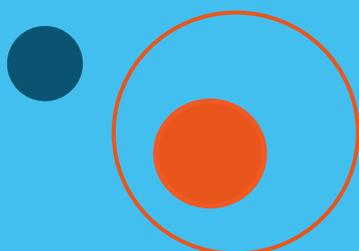
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Photos on pages 3, 4, 5, 6 and 7 in this newsletter were taken by photographer Doreen Kennedy, Ireland. She is also a dystonia patient.

Photo front page:

Executive Director DE Monika Benson, President Dystonia Ireland Maria Hickey and Dr Conor Fearon



Dear readers,

I hope that you had a lovely summer, and that you didn't have to suffer too much from the heat in certain regions, some are still planning for annual leave in September.

Dystonia Europe held its Dystonia Days in the beginning of June together with Dystonia Ireland, and you can read more about it in this newsletter. It is also the 30th Anniversary of Dystonia Europe this year and we had an Anniversary Dinner with our members and stakeholders.

We would like to thank you for your loyalty, friendship and support over the years.

We had also the opportunity to attend the 30th Anniversary congress and dinner of the German organization, DDG (Deutsche Dystonie Gesellschaft) end of August.

In this newsletter, you will read more about the David Marsden Award, which has been awarded this year to Dr. Michael Zech, from the Institute of Human Genetics, Technical University of Munich and the Institute of Neurogenomics, Helmholtz Zentrum München, in Munich, Germany. He is a neurologist and focuses his work on the genetics of movement disorders, especially dystonia.

We held a webinar on DBS last June and the recording is now available on our YouTube channel, if you have wishes for future webinars, just let us know.

DE Executive Director Monika Benson attended the EAN (European Academy of Neurology) 2023 Congress in July in Budapest, Hungary. The Cervical Dystonia Patient Journey Theatre Performance was developed with the support of actress Carmel Stephens from Ireland.

You will also read Raquel and Milagros's testimonies, about cervical dystonia and pregnancy, or being a volunteer with dystonia.

September is the symbolic month of the start of the new school year, and I have two messages to emphasise:

September is Dystonia Awareness Month. Follow us on our social media channels! This year the theme is #dystonialife. Please share, leave your comments, participate, and spread the word about dystonia.

September is also the month of good resolutions. We were saddened to learn of the closure of ADDER, patients' organization in the North East of England, UK.

National patients' organizations do a great job, throughout the year, to support patients, to raise awareness of our rare and chronic disease, to encourage research and to facilitate access to diagnosis and treatment.

There is a shortage of volunteers everywhere. 90% of them are people with dystonia who work for others. Without volunteers, the national associations cannot function, yet they are essential to our healthcare systems.

If you have a little time, a few skills and the desire to help, don't hesitate to contact your national organisation. It's also a very rewarding adventure!

The entire DE team and I wish you all the best for the new school year and hope to see you soon,

Take care of yourself.



Edwige Ponsel
President
Dystonia Europe

Dystonia Europe Meetings in Dublin

We were all looking forward to meeting in Dublin on Wednesday 31st May, after the covid pandemic prevented us from meeting for more than 2 years we have a new appreciation of meeting in person!

My flight to Dublin from Newcastle, England was very short and comfortable, on arrival at Dublin airport there were no queues for passport control and even my suitcase came onto the belt very quickly! A short bus ride into Dublin and I was standing in the hotel reception ready to check in.

Our first board meeting began as soon as I arrived so no time to unpack yet! It was lovely to see most of my friends from Dystonia Europe (DE), there were still two more to arrive, Edwige who arrived a little after me and Catalina who arrived in the evening. This meeting was to finalise any last minute preparations for our activities over the next few days as well as discussing our usual business. We finished the meeting at around 6:15pm then we had 45 minutes to unpack, freshen up and get ready for our first evening meal together in The Quays Restaurant, Temple Bar. We had a lovely walk to the restaurant along the river side and crossed over the Halfpenny Bridge. We all enjoyed a tasty meal there with very big portions, no room for dessert! We then had a pleasant walk back to the hotel along the riverside and back over the river to the Riu Plaza, The Gresham Hotel.

The first day for DE began around 9:30am at the 6th International Dystonia Symposium in Croke Park, Monika started her day much earlier arriving at Croke Park around 7:30am so she could set up our stall with DE information and meet a few people, making connections. The conference was held in a huge room and almost all seats were full, I don't know how many attendees there were but maybe around 400! We were sat in the back row and the presenter looked tiny, a bit like being at the back for a pop concert. We listened to some excellent presentations on topics such as Guiding Principles for Treatment, Experimental Drug Therapies, Types of Botox, Patient Experiences, Methods of measuring brain activity, Immunology (survey had revealed a link between Cervical Dystonia and thyroid disease) and many more topics, all in one day!

A lot of the medical/technical information was above my head but I understood enough to get the gist of what these experts were talking about. It was lovely to see our advisor and friend Prof Maja Relja take an active part in the conference. Each speaker had slides to illustrate their presentation and there were several screens making it easy for everyone to see. In fact one screen was on the back wall and as we were in the back row Jukka cleverly suggested we turn our chairs around! We did get a few funny looks but when others realised what we were doing they also turned their chairs around to get a better view of the slides. Thank you for suggesting this Jukka!

We had a lunch break of course but while eating lunch we listened to a presentation sponsored by Merz on Cervical Dystonia and Pain. This was very interesting and I felt like they were describing my own pain, especially the pain that starts in my shoulders and shoots down my arms. Prof Albanese and Prof Jinnah also talked about the link between botulinum toxin treatment and pain relief.

There were more presentations to listen to after lunch but I have to admit that my brain was full at this point. I did listen to another few presentations but didn't really take them in although I was interested in Dr Balints talk about Dystonia in Rheumatology, another autoimmune disease so maybe the link is similar to that with thyroid disease? At about 3:30pm my brain was beginning to rebel and my concentration level was zero so I decided to return to the hotel for a rest, a few other members of the board joined me as they too were experiencing very low energy levels. We got back to the hotel and enjoyed a drink in the sunshine before going to our rooms to rest and get refreshed ready for another big day the next day.



Chairwoman Dystonia Ireland Maria Hickey

LATEST NEWS

That evening Monika and Edwige had a business meeting over dinner so the rest of us walked to a local pub called The Black Sheep. Our waiter was new (his first day) he messed up our order and Sissel almost got 4 pints of beer just for her! We managed to change the order, phew, but then realised he had not ordered any of our food. The manager was very helpful and put our food order in as a priority and gave us a free round of drinks. When it eventually arrived the food was lovely.

I always get a little nervous for this meeting as the formalities are so important and I take the minutes so want to make sure I record every item and every decision correctly. The business side of the meeting went very smoothly and I managed to pay attention throughout! After the formal meeting was closed we enjoyed presentations from Catalina about her home association 'Children's Joy' and all they have achieved. Alain from Amadys told us about their structure and how they help their members and John from the Norwegian Dystonia Society told us about their work and how they integrate members who need help with running their local branch.

All 3 presentations were well received and personally I was very impressed with all of them. They all help dystonia patients in different ways and all provide exceptional support to their members. We all know that this doesn't just happen, it takes a lot of hard work and dedication, and we know that all our member organisations work hard to support dystonia patients.

Presenters after the formal part of the General Assembly:



Catalina Crainic, Romania



John Berget, Norway

Alain Faucon,
France



Friday evening we all met in the foyer in time to get a coach to The Taylors Three Rock Hotel which is about 40 minutes outside of Dublin. The journey was so lovely moving from the city to a more rural area and I was very impressed with the lovely houses and gardens, it helped that the sun was shining too!

We got to the venue and took our seats where we enjoyed a 3 course meal while being entertained by the in-house singers and dancers. I was hoping they would do some traditional Irish dancing and they did not disappoint, they were amazing. The young men and women must be extremely fit, have you seen how fast their feet move?! The show was excellent but over too soon, then we got back on the bus to go back to our hotel. By the time I got into my room I was exhausted! Not only am I getting older (who isn't?) but since having dystonia I tire more easily so it was good to get to bed for a good night's sleep. As a bonus we weren't starting til 9:30 the next morning, ooh a lie in!

After breakfast on Saturday I met with Monika and Edwige and we got a taxi to The Mansion House for the Dystonia Patient Meeting organised by Dystonia Ireland. The 3 of us got our stall set up with leaflets and information and got ready to enjoy the conference. We had presentations from various medical professionals from Australia, Ireland, United Kingdom and USA to name but a few. They told us about brain plasticity and how brains can be re-trained to ease dystonia symptoms, how dystonia causes pain and affects sleep, the history of dystonia, research, the rarity of dystonia and classifications of dystonia. These presentations were really interesting and easy for me to understand, I was even brave enough to put my hand up and ask a question! When the morning presentations were all done, Edwige spoke about Dystonia Europe and all the projects we are involved with. Monika presented our Dystonia Awareness Campaign for 2023 which is a series of videos about living with dystonia. Our late president, Adam, had worked on the development and production of these videos and they were his idea in the first place. The videos were met with appreciation and personally I felt very emotional, not only did I feel a true connection to patients in the videos but also of course it was emotional to see Adam in one of the videos, we miss him a great deal.

We were served a very nice lunch of soup and sandwiches and I have to say the selection of biscuits were just my cup of tea! The presentations carried on after lunch with information about DBS, longer acting botulinum toxin, cognitive degradation particularly in recognising facial expressions and quality of life.

The conference ended with Maria Hickey from Dystonia Ireland thanking everyone for their help and involvement, then Monika presented Maria with a well deserved bouquet of flowers. Maria and Dystonia Ireland had worked very hard to pull this conference together and I am sure everyone present will agree it was a huge success.

Finally our big celebration was here! Saturday evening was our conference dinner and Dystonia Europe's 30th Anniversary! Definitely something to celebrate. We had the meal all planned out and my task before we got there was to organise balloons and helium but the less said about the helium the better, we ended up using hand pumps to blow up all the balloons and thankfully the restaurant staff helped us. Our celebratory dinner went very well, the food was delicious and we had a glass or two of wine. Dystonia Europe received gifts from the Norwegian and Danish organisations which was very thoughtful and much appreciated. Edwige did a small talk about how proud we all are of 30 years of helping dystonia patients lead a better life. Professor Maja Relja, who was there in Spoleto in 1993 when it all started, gave a nice speech about the founding of EDF, now DE. Myself and Monika led 'Happy Birthday' and everyone joined in even though 'Dystonia Europe' didn't really fit into the song ha ha.

We all retired to our rooms with full stomachs and full hearts, I always make friends at our conferences and this one was no exception.

On Sunday most of our delegates were travelling home or on to a holiday in Ireland and I hope everyone had good journeys, wherever they were going.

The Dystonia Europe Board had a quick meeting to appoint/agree positions on the board after the elections on Friday and then we had a meeting with one of our sponsors. Finally by Sunday lunch time we were all finished and ready to go home.

My journey is usually one of the longest amongst board members but from Dublin to Newcastle is only a 50 minute flight so a nice short journey for me this time.....apart from the 2 hours delay!

Last year in Copenhagen my smart watch told me I had walked over 50 000 steps, I thought this year it would be much less, it was just over 45 000 steps!

I hope you all have a good and healthy year and I look forward to seeing you all again in 2024.

Take care all

Gill Ainsley

Secretary and Vice President
Dystonia Europe



DE Board and Staff

Back row: Monika Benson, Jukka Sillanpää, Merete Avery, Edwige Ponseel

Front row: Sissel Buskerud, Gill Ainsley, Catalina Crainic

LATEST NEWS



LATEST NEWS



ADDER Comes to an End

I have very mixed feelings as I write this notice, I am sad but proud at the same time.

I help to run the charity Action for Dystonia, Diagnosis, Education and Research (ADDER) in the North East of England, UK. We held an extraordinary general meeting recently to discuss the closure of the charity.

The committee (who all help to run this charity) all feel that we have achieved our objective of raising awareness. We have worked hard for over 20 years raising awareness amongst medical professionals and members of the public. While this work hasn't finished, we feel we have achieved all that we can with the resources we have. Nowadays more and more General Practitioners are aware of Dystonia as are the general public. I recently learned that on a University Degree course (in the UK) for physiotherapists they were taught a little about Dystonia. I hope one day they will be taught a great deal about Dystonia.

We have also worked hard to promote the diagnosis and treatment of Dystonia patients and certainly in our local area the clinics are now well established and run smoothly most of the time. Even during the Covid 19 pandemic patients in the North East of England (and other parts of the UK) received their treatment at their usual intervals.

Our membership has been decreasing for the last few years, we currently have only 170 members and it is rare for new or young patients to join our charity, I firmly believe that this is because there is now so much information about Dystonia freely available on the internet. This has also had an effect on the number of phone calls we receive asking for help, advice and understanding, I can't remember the last time anyone rang us to ask for help. I also believe that is as a result of us and others raising awareness.

We are still struggling to get our research project off the ground, we do have a researcher interested in completing the study but as the data is now quite old and Dr Butler who collated all the information has passed away it is proving difficult for our researcher to access the files.

If we don't carry on with that research then the money raised will be donated to a similar charity hopefully for a research project. I can't confirm that yet though, but whatever happens the money will be put to very good use for Dystonia patients.

We have struggled to attract new volunteers to help run ADDER, most of the current committee have been members for many years, so many years we had to change our constitution a few years ago to allow several committee members to stay on the board longer than the maximum term of 6 years. Some of us are now ready to retire and we have no volunteers to take over.

There is still a large charity in the UK called Dystonia UK so I know anyone who does need help will still get some.

On a personal note I will carry on with my work with Dystonia Europe until my next term of office is complete.

As I said at the beginning I am sad that we are closing ADDER but at the same time I am proud of all we have achieved, we have worked very hard to achieve our objectives and with our current resources we cannot take this any further. It wouldn't be right for us to carry on raising money and accepting donations when we really can't do any more than we have already done.

I have made many friends during my time working with ADDER and we will continue to meet whenever we can. ADDER may be closing but our friendship is for life and the work we have done will carry on helping Dystonia patients all over the UK.

Gill Ainsley

ADDER Volunteer

DE Vice President and Secretary.



Gill Ainsley, Mel Moore, Chairperson and his wife Maureen Moore who was previously a committee member

Note from DE Board:

We are sorry to hear that ADDER is closing down their organisation. They have done a lot for dystonia patients and their families in the North East of England for over 20 years.

It is not easy to run a small charity these days. Many of us struggle with finding funding and it is not always easy to find people who will carry on the work forward.

Many thanks to ADDER board and members for what they have done and achieved.

Dystonia Infographics

We have decided to develop a series of infographics on dystonia covering various topics such as what is dystonia, different treatments etc. These will be used to raise awareness and share information on our various channels. You find them on our social channels.

DEEP BRAIN STIMULATION

DBS is a surgical treatment for dystonia.

It's like a pacemaker where electrical pulses disrupt the brain's own signals that cause dystonia

The device is implanted by a neurosurgeon.

The electrodes are placed in a specific area of the brain with extension wires to a battery placed in the chest.

Electrical pulses help control muscle contractions.

The battery is programmed by a neurologist to deliver stimulation to reduce the dystonia symptoms.

DBS improves quality of movements, postures and the ability to perform daily activities.

It reduces pain.

Talk to your doctor or neurologist to learn more. Find out if DBS could help you!

@dystoniaeurope

Dystonia is...
a neurological movement disorder

the 3rd most common movement disorder after Parkinson's and Essential Tremor

it can affect any part of the body

It is caused by incorrect signals from the brain

resulting in involuntary, often painful muscle contractions

there is no cure, but plenty of treatment options

estimated to affect over 3 million people worldwide

dystonia is a chronic, lifelong condition.

Join the cause!
Like, share, comment, and subscribe. Every little action helps raise awareness!!!

@dystoniaeurope

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: Dutch, English, French, German, Spanish, Swedish

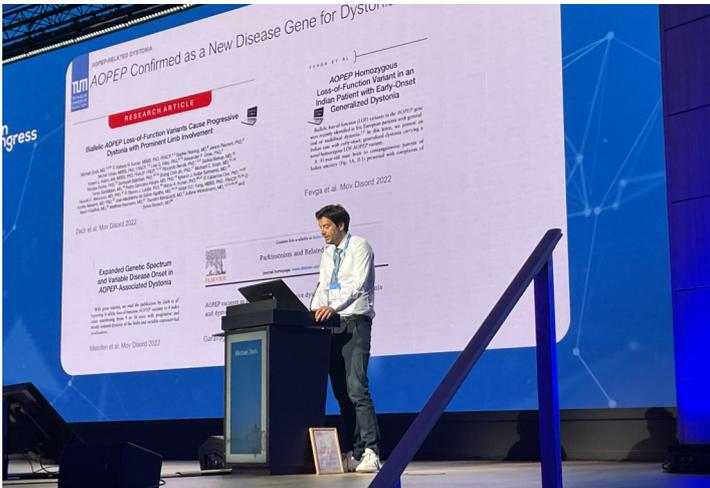
physioexercise.org



Dr. Michael Zech Receives the David Marsden Award 2023

Our congratulations to Dr. Michael Zech, from the Institute of Human Genetics, Technical University of Munich and the Institute of Neurogenomics, Helmholtz Zentrum München, in Munich, Germany and the David Marsden Award 2023 for his paper: *Biallelic AOPEP Loss-of-Function Variants Cause Progressive Dystonia with Prominent Limb Involvement*.

Last July Dr. Zech was presented with the award by Dystonia Europe Executive Director Monika Benson at the Basal Ganglia Session at the 9th EAN (European Academy of Neurology) Congress in Budapest, Hungary. Dr Zech expressed his thanks to Dystonia Europe for the award and then presented the work of his research.



About the winner:

Dr Zech completed his studies in Medicine at the Technical University of Munich, Germany, following internships at the University of Zurich, Switzerland, and Cornell University New York, USA. Dr Zech is a board-certified neurologist and received research fellowships to investigate the genetic underpinnings of neurological disorders at Helmholtz Center Munich, Germany. His work focusses on the genetics of movement disorders, especially dystonia. He was a guest researcher at the Department of Neurology and Neurological Sciences of Stanford University School of Medicine, USA, and has obtained a specialization in Human Genetics.



Dr. Michael Zech receives the David Marsden Award 2023

About the research:

The awarded paper reports the discovery of a new hereditary form of dystonia. Despite successes in the identification of dystonia-causal gene defects in recent years, one of the great challenges in dystonia research is to understand the full spectrum of genetic causes for the disease. Still, more than 90% of affected persons with isolated dystonia remain undiagnosed after maximal genetic investigation. By worldwide collaboration, Zech and colleagues found that mutations in a gene named AOPEP represent a comparatively frequent cause of recessively inherited isolated dystonia in different populations.

AOPEP-related dystonia is characterized by focal, multifocal, or generalized distribution of symptoms, and shows a wide range of onset ages (childhood to late adulthood). The discovery opens new avenues into the study of underlying molecular determinants of dystonia, potentially advancing a better understanding of converging disease pathways

Moreover, the finding helped to provide improved accurate diagnoses to affected patients and families, with implications for counseling and clinical management. The study highlights that international collaborative efforts in the field are essential to promote gene discovery and more efficient research for dystonia.

Monika Benson
Executive Director
Dystonia Europe



Webinar on DBS for Dystonia

Last June there was a webinar on DBS (Deep Brain Stimulation). This webinar was mainly for patients and focused on the benefits of DBS for dystonia patients that does not have sufficient effect from other treatments like for example botulinumtoxin and other medication.

After Edwige Ponseel, President of Dystonia Europe opened the webinar and welcomed all, neurologist Prof Laura Cif held a presentation on DBS, who may benefit from this surgery and the process of the surgery. Prof Cif went deep into subject.

Next Thomas Brionne, Medtronic is an expert on research and presented new technologies within DBS.

Jan Bodenbach, who is a patient that have underwent the surgery and whose life was completely changed after DBS, was supposed to tell about his experience but was unfortunately not able to attend. His story was in the last DE Newsletter and you can read it here:

<https://dystonia-europe.org/2023/05/my-dystonia-story-jan-bodenbach/>

If you have ideas for future webinars let us know and drop us a note on sec@dystonia-europe.org

You can see the webinar here:

<https://www.youtube.com/watch?v=u4lfCjfpVH0>

Patient Live Webinar on DBS

19 June, 2023
18:00 - 19:15 CET
on Zoom



1st Talk

DBS, benefits for dystonia patients, who is it for?

Prof Laura Cif



2nd Talk

Latest technologies in DBS
Thomas Brionne, Medtronic



3rd Talk

The Patient Experience with DBS

Jan Bodenbach

DYSTONIA EUROPE

Dystonia Video Project Update

When you are reading this we are already in the month of September and our annual Dystonia Awareness Month. From the first of September until the last day of the month there will be at least one post per day on our social media channels. As usual we will share information on the various diagnosis & treatments, inspirational stories & quotes.

This year's theme is #dystonialife. Last year, late Dystonia Europe President Adam Kalinowski, worked very hard on this project. We now have five really good short videos featuring daily life situations for dystonia patients. We hope you like them. The videos will be posted throughout September and we would appreciate it if you share them within your networks.

If you have anything you'd like to share from your #dystonialife please do so, we are happy to repost.

Let's work together and share as much information as possible during these weeks to increase the awareness of the dystonia.

Monika Benson
Executive Director
Dystonia Europe



Unlocking Minds and Opening Doors

As a member of the committee (board) for Action for Dystonia, Diagnosis, Education and Research (ADDER), I was recently asked by our local Neurological Alliance (Neuro Key) to help produce a leaflet as part of their 'Open Door' campaign.

The campaign has produced several leaflets each one about a different neurological condition with the aim of raising awareness and helping people to understand just how it feels to live with a neurological condition.

Of course this leaflet would be all about dystonia patients and their own dystonia story.

It didn't take long for me to find a few volunteers to take part and provide their own story for the leaflet. I also took part of course and wrote my own dystonia story. Our Open Door leaflet has four different stories from four dystonia patients and between them it gives the reader a really good picture of what it is like to have dystonia and how it impacts on our daily lives.

The leaflet concludes with some learning outcomes which are aimed at medical professionals who treat dystonia.

You will have read in another article in this newsletter that the charity ADDER will soon close its doors permanently but we hope this Open Door leaflet is our legacy to patients to show them they are not alone, and to medical professionals to help them better understand dystonia patients.

If you would like to read this leaflet you can open and download it from the Dystonia Europe website at <https://dystonia-europe.org/wp-content/uploads/2023/07/NeuroKey-Dystonia-web.pdf>

NEURO KEY

An Alliance supporting people with neurological conditions

DYSTONIA

'Unlocking minds and opening doors'

Open Door series by Neuro Key

Gill Ainsley

Vice President & Secretary
Dystonia Europe



Cervical Dystonia Patient Journey Performance at EAN Congress

At the beginning of July the EAN (European Academy of Neurology) 2023 Congress was held in Budapest, Hungary. DE Executive Director Monika Benson attended the event.

As reported earlier Dystonia Europe has together with Ipsen and ERN-RND (European Reference Network for Rare Neurological Diseases) developed the Cervical Dystonia Patient Journey which was published in 2022.

A few months ago it was decided that the Cervical Dystonia and the Huntington's Patient Journeys were going to be developed into short theatrical performances. Actress Carmel Stephens from Ireland agreed to help. Based upon the patient journeys, interviews and research on the diseases she created two scripts which she performed at the Scientific Theatre in the Exhibition Area of the congress. It was a great success and the audience of neurologists, experts and patients were moved by her performance!

Now, with ERN-RND, we are looking into how we can record these two sessions. They are about 20 minutes each and could be very valuable resources in order to inform and raise awareness of both dystonia and Huntington's.

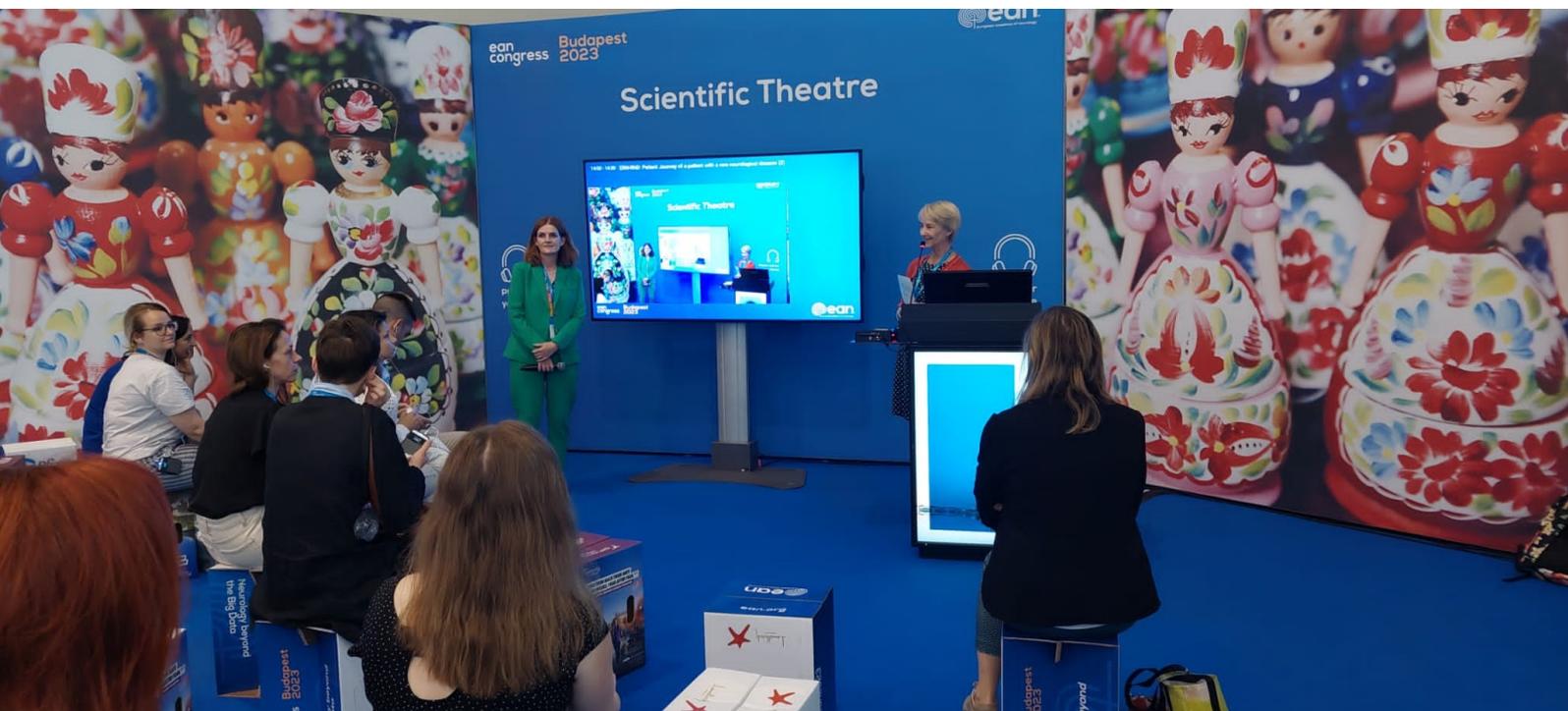
We thank [Ern-Rnd European Reference Network for Rare Neurological Diseases](#) for collaborating and supporting this initiative.



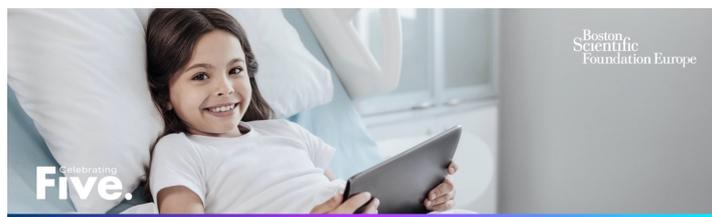
Monika Benson, Carmel Stephens, Astri Arnesen



Dr. Carola Reinhard, Monika Benson, Carmel Stephens, Dr. Anna Castagna



Boston Scientific Foundation Europe Celebrating Five



Five years ago the Boston Scientific Foundation Europe (BSFE) was established and set up to champion the uprising of digital health by supporting innovative solutions that aim to improve people's health and well-being.

In those five years 20 projects have been funded from 16 non-profit organisations in Europe reaching more than 50 countries in the EMEA region.

The projects have educated and empowered patients. They have improved clinical practice and upskilled patient advocates. They have challenged the norm with innovation in research. The Foundation has also supported humanitarian relief agencies in fighting the impact of disasters and emergencies.



The very first project funded was the Mécénat Chirurgie Cardiaque and they created the 5/5 mobile-learning programme to improve the diagnosis of heart defects in children living in underdeveloped countries.

“The training is very intuitive and simple and has very good recorded lessons with good examples that have allowed us to access paediatric cardiology.” says cardiologist Dominique Honoré Saka from Benin.

Now 550 doctors across Africa and the Caribbean have been trained.

In a first-of-its-kind platform, the [Dystonia Physio Exercise Hub](#) was developed to allow patients access to individualized online physiotherapy programmes.

“The physio hub helps me at home with doing my exercises. I can do my exercises more often. I get reminded of doing my exercises. The animations make you remember how to do the exercises. It gets like a daily routine. Physiotherapy helps my condition to loosen up the muscles. It helps me to have a more normal life. To make you feel better. Be more happy and live your life”, says Roger Funhagen from Sweden.

The Foundation is grateful to the hard-working partners who have insured that the support has maximum impact. BSFE President Simonetta Balbi says: “We are here to make a difference, and this milestone is only the beginning.”

Watch the full story here!

<https://tinyurl.com/FindOutMoreOnBSFE>

If you are interested in finding out more about the Foundation and how to apply for a grant visit:

www.BostonScientific.EU/Foundation



Roger Funhagen, Sweden



Physiotherapist Johanna Blom and Roger Funhagen, Sweden

EPF Webinar on Medicine Shortages

The New EMA Mandate

On 23 June European Patient Forum (EPF) held a webinar on shortages of medicinal products.

Elena Balestra, Head of Membership, Governance and Capacity Building at the European Patients' Forum, welcomed all attendees and opened the webinar.

Claudia Louati, Head of Policy at the European Patients' Forum held a brief introduction on shortages, explaining what it means. 'A shortage of a medicinal product for human or veterinary use occurs when supply does not meet demand at a national level'. Until a few years ago there was no real unified definition of shortages in the EU. It has been an increased amount of medicine shortages the last few years, and some countries in the EU have been more affected than others.

A study on shortages was done a few years ago. It is very hard to pinpoint the direct cause and often the causes are multifactorial. Often the cause can be traced back to lack of quality and manufacturing. Outsourcing of production to far away countries, and price policies have also had an impact on shortages. In addition, there is an increase in demand.

Regulatory authorities both within and outside Europe are increasingly working together to prevent shortages and to limit their impact whenever they occur.

Siofradh McMahon, Supply and Availability of Medicines and Medical Devices Workstream at the European Medicines Agency (EMA).

EMA is a decentralised agency of the European Union (EU) responsible for the scientific evaluation, supervision and safety monitoring of medicines in the EU. Their mandate includes:

- Review of new medicines to determine whether they are safe, efficacious, and of high quality before they can be authorized for sale in the EU
- Continuous work on, and monitoring of, safety, efficacy, and quality of existing authorized medicines Authorization of a product by EMA allows a manufacturer to access the market in each EU/EEA country

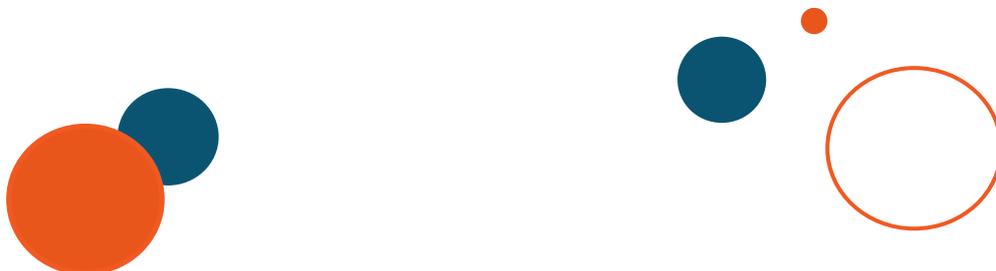
The individual healthcare systems implement this separately in each country, according to local needs.

EMA works very closely with Marketing Authorisation Holders, European Commission and other institutions like WHO (World Health Organisation), National Competent Authorities, Ministries of Health, Pharmacists, Distributors, Patient Organisations on behalf of patients and all stakeholders that are involved. In addition EMA works worldwide with global regulators to share best practices and to understand the situation on a global level and how the situation can be best managed in Europe.

The aim is to pinpoint and reduce or eliminate the gap between supply and demand.

In the link you can find more information on the work of EMA <https://www.ema.europa.eu/en>.

In the link below, you can explore public information on medicine shortages specifically within the EU and EEA member countries.



<https://www.ema.europa.eu/en/human-regulatory/post-authorisation/availability-medicines/public-information-medicine-shortages>

Agendas and meeting summaries from some of the work EMA does is also available on their website.

One of the key aims of the new EMA mandate is to bring everybody closer together where the member states have visibility to their neighboring states and that all EU member states have joint meetings typically every month.

Regulation (EU) 2022/123 and shortage This regulation formalises some of the structures and processes EMA set up in the COVID-19 pandemic and assigns new tasks to EMA in the following areas: Monitoring and mitigating potential or actual shortages of critical medicinal products, medical devices and in-vitro diagnostics Providing scientific support to the development of high quality, safe, and effective medicines during public health emergencies Ensuring the smooth functioning of expert panels to assess high-risk medical devices and advise on crisis preparation and management

Link to the EU Regulation 2022/123:

<https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32022R0123>

Marko Karenjak, President European Liver Patient Association, Member of PCWP at EMA representing liver patients and member of PRAC. Marko is a patient advocate and spoke about how we can further enhance the voice of the patients regarding medicines that are taken off the market or not available.

A strong patient voice can show where the shortage still is, even if the government representatives says that the problem is solved. To engage on a national level and make changes as patient representatives, Marko emphasized that you need to be in touch with national regulatory representatives and the ministry of health, so you have a close relationship with the stakeholders which are the official representatives in your country. It is important to monitor and engage in the implementation of the new EMA mandate, and as member of PRAC and co-chair of PCWP, Marko attends meetings within EMA and make sure that the patient voice is heard.

Merete Avery
Operations Manager
Dystonia Europe



Siofradh McMahon
Supply and Availability of Medicines and Medical Devices Workstream at the European Medicines Agency



Marko Karenjak
President of the European Liver Patient Association



Claudia Louati
Head of Policy at the European Patients' Forum



Elena Balestra
Head of Membership, Governance and Capacity Building at the European Patients' Forum

30th Anniversary Deutsche Dystonie Gesellschaft

Saturday 26 August DDG Dystonia Dystonie Gesellschaft had a member meeting in Fulda at hotel Esperanto. This also marked 30 years of the organisation and in the evening there was a Anniversary Dinner. Dystonia Europe was invited and President Edwige Ponsse and Operations Manager Merete Avery attended.

The meeting started 9.15 in the morning with President Hedwig Hagg welcoming all, followed by the Mayor of Fulda Dag H. Wehner who said that the patient organisation play an important role, where patients can learn more about dystonia and meet other and share experiences and how to live with best possible quality of life.

Next Prof. Dr. Dr. Dirk Dressler held a very informative presentation on Cervical Dystonia. One of the points he made was that if one has their first symptoms when 40—65, often the course of the dystonia will stabilize after 3-5 yrs. This is important for patients to know as compared to many other degenerative neurological illnesses, cervical dystonia mostly does not progress after it has stabilized.

Also when treated with botulinumtoxin it may take more than 1-3 treatments before the effect is at its best, and even then the effect may vary some from treatment to treatment.

After a break where people connected while enjoying good food, Lilli held a show for us, called «laugh with Lilli». We laughed a lot.



Prof. Dr. Dr. Dirk Dressler



PD Dr Tacik



President Hedwig Hagg thanks Dr Zech for his presentation



Jennifer Sixt



Susanne Mombers



President Hedwig Hagg DDG

Then there were four more presentations. PD Dr Tacik held a presentation on «It is impossible to hide dystonia and information about new therapies». Many try to hide the symptoms when they first appear as there is unfortunately a lot of stigma when you do not have control over the movements that comes with the dystonia and the body does not function the way you want it to and there are involuntary movements. Dr Zech spoke about research, this was very high level presentation.

Susanne Mombers spoke about «Courage and follow your own heart». Jennifer Sixt held a presentation on «Alexander Technik as a Retraining Method for musicians Dystonia».

Merete Avery
Operations Manager
Dystonia Europe



Milagros López Morales

Meet Milagros, Spain

What is your name?

My name is Milagros López Morales. I live with my husband and my two children in Madrid. I have dystonia for thirty years, which has not prevented me from achieving my goals. I have a degree in Fine Arts and in Information Sciences and I have worked for 25 years as an art teacher in a public high school, until I was retired because of my dystonia.

I have been a member of Dystonía España-ALDE since almost its beginning but I did not start collaborating with the association until 2018. I joined the board as general secretary and since October 2022 I am the president.

What are the benefits of working within a patient organisation?

Associations of patients with rare diseases such as dystonia are essential to offer information and support to affected people and their families. I am happy to make the association better as an entity but above all to know that associations are really necessary to help people.

People are the most important aim for Dystonía España-ALDE and offer my experience and knowledge to the people with dystonia gives me great satisfaction. Especially, helping newly diagnosed people in the difficult process of accepting the disease and offering them empathy and hope.

Patient associations are the transmission chain of patient needs with public administrations, health professionals, pharmaceutical companies, the media... Our role is essential to give voice and visibility to the group, establish relationships among patients, promote research, promote social action and claim rights... and sign agreements with entities that benefit associated people.

How do you like spending your free time?

I really like art, I'm passionate about original version cinema and I'm a great reader, but since I've been on the board I have less free time than before, because I dedicate part of that time to working on new ideas and projects to implement in association. But what I like the most is sharing time with my children because I am aware that they will leave home soon and I really enjoy every moment I spend with them. We like to make trips through natural landscapes and enjoy our cultural heritage.

And when I have some extra time I continue to write film criticism for the online film magazine <https://encadenados.org/>, with whom I have collaborated for more than twenty years.

What keeps you motivated on the tough days?

My children have been the support of my life in difficult times. They have always known their mother with dystonia and that has made them more supportive and empathetic towards people with disabilities. Their presence in my life motivates me daily.

The cinema has been another of my faithful allies with the most complicated moments in my life and still it is today. A good movie fixes up a bad day for me, but also having tea with a good friend or a home gardening working session.

What makes you angry or frustrated?

I try every day not to get angry about anything, but I don't always succeed. I am frustrated by the incompetence, the lack of honesty and commitment of people. But I learn every day to be tolerant and have a constructive spirit and to get over the adversity.

Milagros López Morales
ALDE
Spain

Raquel Vaqas



Raquel Vaqas

My name is Raquel, I'm Spanish but I have been living in Italy since 2005. I was diagnosed with cervical dystonia in 2013, symptoms started early 2010. I had selective denervation surgery and since then I've been getting botulinum toxin injections every 4 months.



I wished to become a mother but I was afraid about how my condition could get worse, because during pregnancy botulinum toxin injections cannot be done. There is not much information about dystonia and pregnancy so I felt lost and alone.

My referring neurologist for botulinum toxin injections said to wait 3 months after injections before trying to get pregnant but this was very stressful especially because I started to have more symptoms and pain. I had the opportunity to talk with an important Hospital (Clínica Mangiagalli in Milan) specialising in difficult pregnancy; they checked with the Poison Control Center of Bergamo and explained to me that I could try to get pregnant without waiting 3 months after injections. I was 41 years old so we decided to undergo a fertility program scheduled for January 2022, but we were very lucky and I got pregnant naturally late October 2021 and my last treatment was in August, so the timing was perfect!





Raquel and Martina

My gynaecologist put me on maternity leave from my job due to a high-risk pregnancy so I was at home from the second month. In this way I could rest from my job and take care of myself. During the pregnancy I did my physiotherapy exercises, acupuncture and *auriculotherapy in the Therapy pain centre Piero Palagi Hospital in Florence. My daughter Martina was born on July 17th 2022

**Auriculotherapy (also auricular therapy, ear acupuncture, and auriculoacupuncture) is a form of alternative medicine based on the idea that the ear is a micro system and an external organ, which reflects the entire body, represented on the [auricle](#), the outer portion of the ear. - Source Wikipedia*

by natural childbirth taking 3 hours, my neurologist recommended natural childbirth if possible.

After childbirth, due to hormones circulating I was in great shape, I felt less pain and had better mobility. I breastfed Martina for 4 months and then in December I finally did my botulinum toxin treatment. The motherhood experience teaches me that despite dystonia we can almost achieve everything, even if in a different way and with some limitations. I found it very useful to share my emotions and concerns about my medical condition with professionals; being part of the Italian Association ARD helps me to feel better.

Raquel Vaqas
ARD, Italy

Calendar Autumn 2023 & Winter 2024

September

- 16-17 Dystonia Days 2023 in Pori, Finland
- 19-21 ERN-RND Annual Meeting, Leuven, Belgium
- 27-30 ESSFN Congress, Stockholm, Sweden

October

- 2-3 Nordic Conference on Rare Diseases, Stockholm, Sweden
- 24 Dystonia Europe Think Tank Meeting, online

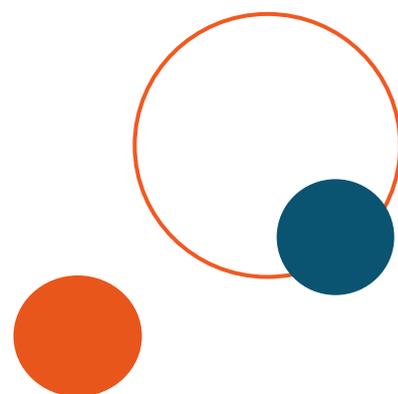
2024

January

- 17-20 Toxins Congress, Berlin, Germany

February

- 29 Rare Disease Day



Dystonia Europe at the MDS Congress in Copenhagen

Last week of August the MDS Congress took place in Copenhagen, Denmark with over 5000 participants. Dystonia Europe had a stand where we informed about our activities and projects.

It was great to reconnect with many of our medical contacts as well as industry partners.

Monika Benson
Executive Director
Dystonia Europe



**Monika Benson and
Dr. Kasia Smilowska**



**Pia Sørensen Vejle and Birthe Bernhard Hansen from
the Danish Dystonia Association**

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.

**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>

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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!

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