

# ANNUAL REPORT

**DYSTONIA  
EUROPE  
2023**

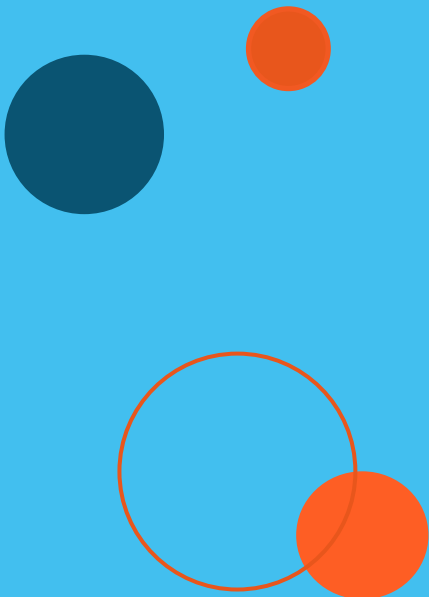
DYSTONIA  
EUROPE



# CONTENT

---

|   |    |
|---|----|
| Message from President and Executive Director | 3  |
| Board, Staff and Advisors                     | 4  |
| Communication Resources                       | 5  |
| Activities and Projects                       | 6  |
| European partnerships                         | 11 |
| 2023 & Beyond                                 | 13 |
| Final Accounts 2022                           | 16 |
| Members, Partners & Sponsors, Contact         | 17 |
| Member Countries                              | 18 |
| Sponsors                                      | 19 |



**DYSTONIA  
EUROPE**

Shaping  
a better future  
for people  
living with  
dystonia!

[dystonia-europe.org](https://dystonia-europe.org)

The cover image features a photograph of an older man with glasses kissing a woman on the cheek. The text 'DYSTONIA EUROPE' is in the top right corner. The main title 'Shaping a better future for people living with dystonia!' is centered in white text on an orange background. The website address 'dystonia-europe.org' is at the bottom.

**Message from President and Executive Director**

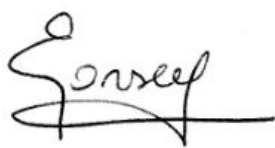
Dear all,

In 2023 we celebrated 30 years of our organization. Dystonia Europe, former EDF – The European Dystonia Federation, was founded in 1993 by 10 national member organisations in Spoleto, Italy. Since then our organization has grown and has today 22 national member associations from 20 European countries.

During the Dystonia Days 2023 in Dublin many of the members were gathered for the 30<sup>th</sup> Annual General Assembly and the Anniversary dinner.

During these days the scientific congress the 6<sup>th</sup> International Dystonia Symposium was also held in Dublin. Over 300 dystonia experts from all over the world had gathered to share knowledge and to network.

We would like to take this opportunity to thank all of our member organisations, their board members and delegates, and our partners for your commitment and work during 2023 and we are looking forward to continue our cooperation and work together during 2024 and beyond.



Edwige Ponseel  
President



Monika Benson  
Executive Director

## BOARD, STAFF & ADVISORS

### Board

President Edwige Ponseel, France

Vice President & Secretary – Gill Ainsley, United Kingdom

Treasurer – Sissel Buskerud, Norway

Board Member – Catalina Crainic, Romania

Board Member – Jukka Sillanpää, Finland

### Advisors

IT – Eelco Uytterhoeven, The Netherlands

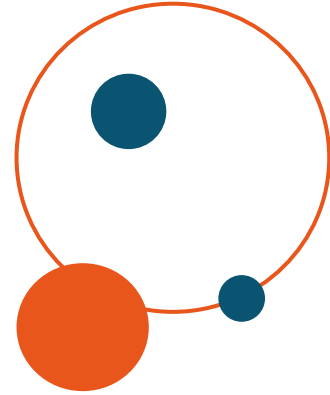
Photographer – Stephan Röhl, Germany

Social Media – Amanda Benson, US

Accounting – Yves Mottet, Belgium

Alistair Newton, UK

Prof Maja Relja, Croatia



**Executive Director** - Monika Benson, Sweden

**Operations Manager** - Merete Avery, Norway

### Board Review

A total of 9 board meetings were held in 2023. 7 board meetings were held on-line, and 2 board meetings were held face-to-face. A total of 2 Think Tank meetings were held in 2023. One Think Tank meeting was held online and one took place in Brussels.



**Dystonia Europe Board and Staff 2023.**

Back row from left: Executive Monika Benson, Board Member Jukka Sillanpää, Operations Manager Merete Haaseth Avery and President Edwige Ponseel

Front row from left: Treasurer Sissel Buskerud, Vice President and Secretary Gill Ainsley and Board Member Catalina Crainic





[www.dystonia-europe.org](http://www.dystonia-europe.org)

## COMMUNICATION RESOURCES

### Website

The Dystonia Europe website is the main channel for information and news to anybody interested in finding out about dystonia and Dystonia Europe. The news section is updated on a regular basis with reports on Dystonia Europe activities, members' activities and research news. The website has an average of about 1500 visits/month.

### Newsletter

The Dystonia Europe Newsletter is issued three times per year: in spring, summer and winter. The newsletter is published on the Dystonia Europe website and sent out to members, partners and about 800 contacts. After the publication all articles of the newsletter are published separately on the Dystonia Europe News blog, which then are shared on all social media channels.

### Printed Materials

The following materials were produced and printed:  
 The Annual Report 2022; Dystonia Physio Hub Flyer; David Marsden Award 2024 flyer; Cervical Dystonia Patient Journey leaflet. New banners were designed and printed for the Dystonia Days in Dublin.

### Social Media

Dystonia Europe is present on the following social media channels: Facebook, Instagram, Youtube, X (former Twitter) and Linked-In. Together with the social media consultant there is a content calendar planned for each channel. The content posted consists of dystonia facts, inspirational quotes, testimonials and videos as well as sharing of relevant information from other accounts. The trend with an annual increase of followers continues:

|             | 2022 | 2023 | Growth: |
|-------------|------|------|---------|
| Facebook    | 5985 | 6345 | + 6 %   |
| Instagram   | 2549 | 2789 | + 9,5 % |
| X (Twitter) | 1342 | 1409 | + 5 %   |
| YouTube     | 1821 | 2234 | + 23 %  |
| Linked-In   | 644  | 785  | + 22 %  |



## ACTIVITIES & PROJECTS

---



The Dystonia Europe Board, Staff and Delegates after the General Assembly in Dublin 2023

### The 30<sup>th</sup> Dystonia Europe General Assembly

The 30th Dystonia Europe General Assembly 2023 took place at The Gresham Hotel in Dublin, Ireland on Friday 2nd June. President Edwige Ponseel welcomed the participants from 14 member associations. During 2023 ADDER, one of the dystonia organisations in the UK, closed down and is therefore no longer a member of Dystonia Europe. The total membership is now 22 member organisations from 20 countries in Europe. The DE Team presented the work of 2023 and the final accounts. After the formal meeting Dystonia Europe informed about ongoing projects. During the session Sharing Best Practise three member organisations presented the work within their national organisations:

- Alain Faucon, France
- Catalina Crainic, Romania
- John Berget, Norway

### Dystonia-Days 2023

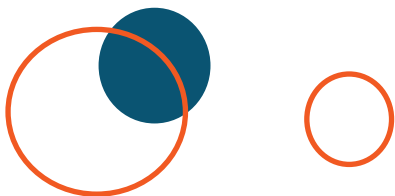
The Dystonia Days 2023 was held 2-3 June in Dublin in collaboration with Dystonia Ireland and alongside the 6th International Dystonia Symposium, Dublin, Ireland 1-3 June.

On Saturday 3 June a dystonia patient meeting was held at the Mansion House in Dublin.

Over 100 patients from all over Ireland came to the meeting. There were both Irish dystonia experts giving presentations as well as international experts who kindly joined from the international dystonia congress.







### David Marsden Award 2023

Dystonia Europe Executive Director Monika Benson presented the winner of the David Marsden Award at the EAN 2023 Basal Ganglia Club Session, in Budapest, Hungary.

Winner of the award was Dr. Michael Zech, Institute of Human Genetics, Technical University of Munich and the Institute of Neurogenomics, Helmholtz Zentrum München, in Munich, Germany with his paper, "Biallelic AOPEP Loss-of-Function Variants Cause Progressive Dystonia with Prominent Limb Involvement".

European Academy of Neurology is a non-profit, independent organisation representing more than 45,000 members, as well as 47 European national societies. For the last few years Dystonia Europe is given the opportunity to present the David Marsden Award winner during this Movement Disorder session at the EAN. [www.davidmarsdenaward.org](http://www.davidmarsdenaward.org).



Dr. Michael Zech



### Dystonia Webinars

In 2023 there was one webinar organized. The topic was DBS treatment. Dr Laura Cif gave an overview of the treatment and how it works. Thomas Brionne from Medtronic presented the latest technical advances and there was also a video shown with a dystonia patient who had been successfully treated with DBS.

DE has organized webinars since 2020 and they have all been recorded and are available on the Dystonia Europe YouTube channel:

[https://www.youtube.com/playlist?list=PLFvCc6fYkjEt\\_7GhGF9OwEEIXo2iBeVRk](https://www.youtube.com/playlist?list=PLFvCc6fYkjEt_7GhGF9OwEEIXo2iBeVRk)

### 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



#### 3rd Talk

The Patient Experience with DBS  
Jan Bodenbach



#### 2nd Talk

Latest technologies in DBS  
Thomas Brionne, Medtronic

DYSTONIA EUROPE

### Dystonia Podcast – The Positive Twist

In 2023 the second season of the Dystonia Europe Podcast: The Positive Twist was launched. The season has five episodes. The podcast has been live since 2020 and the total of 12 episodes has over 4000 downloads. These can be found on various channels where you find podcasts.

<https://dystoniaeurope.buzzsprout.com/1337749>

### DystoniaLife Video Project

The project was planned in 2021 and the work started in 2022. It's a series of five short videos with the aim to show how everyday life situations can be for people living with dystonia.

The videos were finalized in 2023 and published during the Dystonia Awareness Month.

## Dystonia Europe Connecting with Dystonia Patient Organisations

### Norwegian Dystonia Association 30th Anniversary and General Assembly

In April the Norwegian Dystonia Association (NDF), held their Annual General meeting and 30th Anniversary Celebration at Quality Hotel Olavsgaard, Skjetten, Norway. Dystonia Europe was invited and Operations Manager Merete Avery attended. Board member Jukka Sillanpää was also present and represented the Finnish Dystonia Association.

### Deutsche Dystonigesellschaft (DDG), Germany 30th Anniversary

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

### Dystonia Europe Think Tank

One Dystonia Europe Think Tank meeting was held in March in Brussels and one Dystonia Europe Think Tank meeting was held on zoom in October. Members of the Think Tank are the Dystonia Europe Board and representatives of our Platinum sponsors: Ipsen, Medtronic and Merz.

The purpose of these meetings is to provide a platform for the DE Board and the Platinum sponsors to meet and discuss activities and projects that can benefit dystonia patients.



Winter Think Tank in Brussels 2023. From left: Monika Benson, Merete Avery, Jukka Sillanpää, Catalina Crainic, Sissel Buskerud, Susanne Proesche, Ipsen, Gill Ainsley, Oleks Gorbenko – Ipsen and Abdullah Alghourani – Merz



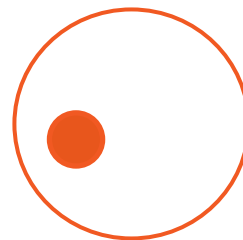
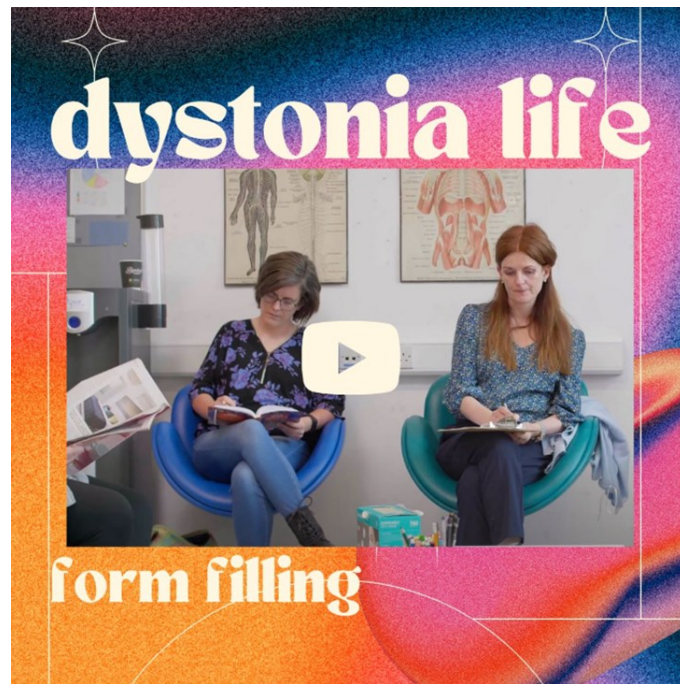
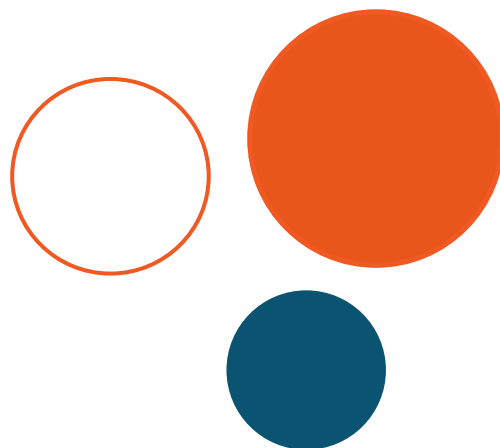
## September Dystonia Awareness Month 2023

For the seventh year Dystonia Europe took part in the activities of the International Dystonia Awareness month. The whole month of September is dedicated to raising awareness of dystonia around the world and we take the opportunity to post daily content such as dystonia facts, inspirational quotes, dystonia videos, dystonia patient stories.

This year focus was very much on the five Dystonia Life videos showing how normal daily life activities can be if you are affected by dystonia.

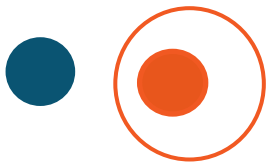
These videos are available on our YouTube channel:

[https://www.youtube.com/playlist?list=PLFvCc6fYkjEv6xOCqGpg\\_UALiLd8TbBYL](https://www.youtube.com/playlist?list=PLFvCc6fYkjEv6xOCqGpg_UALiLd8TbBYL)



## Dystonia Pyshio Exercise Hub

Physiotherapist Johanna Blom, at the Neurology Department of the University Hospital of Skåne in Malmö, Sweden, together with Dystonia Europe, received a grant from Boston Scientific Foundation to create an on-line platform with special physiotherapy exercises for cervical dystonia patients. The project was launched in Sweden in 2021. The following year it was translated and launched in German, French, Spanish, Dutch and English. The users of the platform are physiotherapists and other medical professionals and dystonia patients. The platform contains 115 exercises and some of them are animated. The physiotherapists using the platform can choose from the different exercises and customise a physiotherapy exercise program for each individual patient. The patient will receive log-in details for his/her specific exercise program on the platform. In 2023 the project received a second grant from Boston Scientific Foundation to continue developing the platform. New features will be a Physiofinder, a communication tool for the platform users and educational videos. There will also be more languages added. So far there are 377 physiotherapists from 6 continents registered on the platform.



## The Cervical Dystonia Patient Journey

This patient experience map was developed and published in 2022 in collaboration with Ipsen and ERN-RND. The leaflet is distributed at meetings and congresses. A special webpage was created on the DE website which includes all the information about the PJ.

<https://dystonia-europe.org/about-dystonia/patient-journey/>

During 2023 an actress from Ireland, Carmel Stephens, produced a manuscript in order to act the patient journey of a cervical dystonia patient. ERN-RND supported Carmel to come to the EAN Congress in Budapest, Hungary, where she gave a performance at the Scientific Theatre.





## Dystonia Survey on Diet and Dystonia

Dr. Kasia Smilowska, Department of Neurology, Regional Specialist Hospital in Sosnowiec, Poland, initiated the survey on Diet and Dystonia. The main goal of this survey is to examine how diet affects dystonia, and if so how doctors could address these problems. The survey was available in 15 languages on the Dystonia Europe Survey platform and had over 1500 participants when it closed end of July. Now Dr. Smilowska will analyze the answers.

## EUROPEAN PARTNERSHIPS

### Member of EFNA

Dystonia Europe is a member of EFNA, European Federation of Neurological Associations. EFNA is an umbrella organisation representing pan-European neurology patient groups. At the Annual General Assembly in May Monika Benson stepped down as a board member of EFNA after 6 years of service. She continues in an advisory role by representing EFNA in the Education Committee of EAN, European Academy of Neurology.

Dystonia Europe board member Jukka Sillanpää attended the EFNA's neurology advocacy workshop 'Stronger Connected' held in Dublin, Ireland.

<https://www.efna.net>



Monika Benson, Executive Director Dystonia Europe and previous Board Member EFNA and Joke Jaarsma previous President EFNA.

Monika and Joke will remain as EFNA representatives in a few committees to support the continued work of EFNA.

### Member of EPF

Dystonia Europe is a member of the European Patients Forum. EPF has over 70 members who represent specific chronic disease groups at EU level or are national coalitions of patients. The EPF vision is that all patients with chronic and/or lifelong conditions in the EU, have access to high quality, patient-centred equitable health and social care. There are many benefits for DE being a member of EPF. Dystonia Europe is included in a large European Patient Advocate network and opportunities for partnership and collaboration increase. EPF also offer various training initiatives and workshops for patient advocates. Operations Manager Merete Avery took part in the EPF General Assembly 20th Anniversary 2023 on 28-29 April in Brussels. /[www.eu-patient.eu](http://www.eu-patient.eu)



Networking with other organisations at EPF AGM 2023. From left: Merete Avery, Dystonia Europe, Katerina Koutsogianni-Tzigounak, The Greek Umbrella Patient Organisation and Sanna Kaijanen, The Finnish Federation of Hard of Hearing



From right: Jukka Sillanpää, Board Member of Dystonia Europe and Astri Arnesen, President of the European Huntington Association and President of EFNA



### **Boston Scientific Foundation**

Boston Scientific Foundation for the EMEA region (Europe, Middle East and Africa) was established in 2018. The mission of the Foundation is to support well-being through innovative digital solutions. It is managed by a board of nine individuals comprised of six Boston Scientific employees and three external members representing the voice of patients and the medical community. DE Executive Director Monika Benson has a place on the board. The Board meets face-to-face once a year and there are 4-5 on-line meetings.

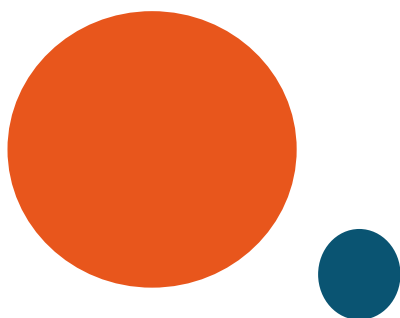
In 2023 it was the 5 year anniversary of the Foundation. For this celebration the Foundation had decided to create a video of the most successful projects they support.

The PhysioExerciseHub was one of these projects and the filming took place at the University Hospital in Malmö, Sweden in May. The video has been provided to Dystonia Europe to use as well.

For more information:

<http://bostonscientific.eu/foundation>

**Boston  
Scientific  
Foundation Europe**



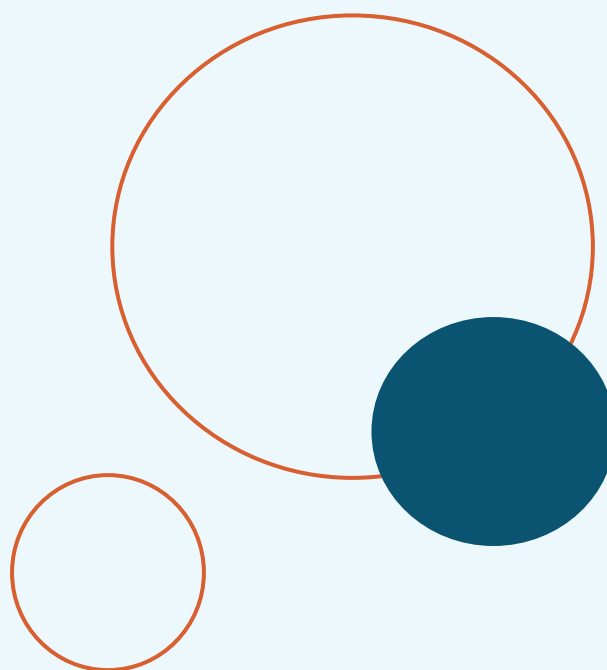
### **Participation as ePAG**

#### **(European Patient Advocate Group) of ERN-RND**

The European Reference Network for Rare Neurological Diseases (ERN- RND), established by the EU, aims to address the unmet needs of more than 500,000 people living with RNDs in Europe. 60% of those are still undiagnosed. Through coordination and knowledge transfer, ERN-RND shall establish a patient-centred network to address the needs of patients with RND of all age groups, with or without a definite diagnosis, by implementing an infrastructure for diagnosis, evidence-based management, treatment and collection of patient data. Some of the rare diseases represented are Ataxia, Huntington's and Dystonia.

The network is also represented by patients in specific ePAG (European Patient Advocacy Group). Dystonia Europe is a member of this ePAG group. Monika Benson attended the online meetings throughout the year.

More information: <http://www.ern-rnd.eu>



## 2024 & BEYOND

---

### Vision & Mission

**The Dystonia Europe Vision is better quality of lives for people living with Dystonia in Europe, while supporting the search for a cure.**

We will achieve our vision through the following core activities:

- **Raise awareness** and be the leading voice in Europe on the impact of Dystonia.
- **Share the knowledge** – provide the latest information and resources for our members and also be the source of information for the other stakeholders.
- **Connect people** with Dystonia, member organisations, healthcare professionals, European policymakers and the treatment industry to close the gaps of today's dystonia treatments.
- **Foster training and education** and educate multidisciplinary teams and stakeholders along the dystonia journey to optimise care and improve quality of life.

### ACTIVITIES & PROJECTS 2024

#### Board Meetings

For 2024 we plan to meet for two face-to-face board meetings. In between these there will be on-line board meetings using Zoom. The Board finds it useful to meet every 6 weeks.

#### Think Tank Meetings

Two meetings are planned for 2024 one face-to-face end of February in Paris, France and one in October using Zoom.

#### Dystonia Days 2024 and the 31st Annual General Assembly

The annual dystonia days will take place in Timisoara, Romania. Local organiser is Catalina Crainic. The two-day event will include the formal meeting, presentations from invited speakers and also various social activities.

#### Connecting with Dystonia Patients

Dystonia Europe continues its work to reach out to dystonia patients/groups in other countries. We hope to take part in meetings with our national members, either face-to-face or on-line.

### Communication

To stay in touch with our members and all stakeholders we continue our work to develop our various communication channels such as: Website, Dystonia Europe News and our Social Media Channels.

#### Dystonia Europe at Congresses, Meetings, Boards & Committees

Representatives of Dystonia Europe will take part in on-line meetings and events organised by our partners and others, such as EPF, EFNA, Dystonia Coalition, EAN, EBC. The involvement on various boards and committees (EFNA, BSFE, ERN-RND ePAG) continues. Dystonia Europe will take part in the EAN Congress 2024 in Helsinki, Finland.

#### Dystonia Webinars

2-3 webinars with experts and patients are planned to take place throughout the year.

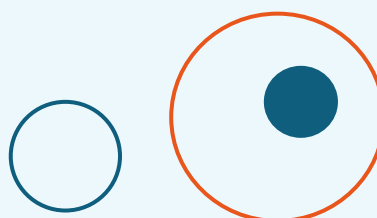
#### The Positive Twist Podcast Season 3

We will continue to invite interesting guests (experts and patients) to our podcast The Positive Twist. Season 3 will have 7 episodes and first episode will be launched during Dystonia Awareness Month.

Dystonia Awareness Month in September We continue our on-line awareness activities during the awareness month with at least one post per day on Facebook, Instagram and Twitter. The content will consist of informative facts, inspirational quotes, and sharing of dystonia patients' stories. This year's theme is #volunteerfordystonia.

#### Dystonia Awareness Month in September

We continue our on-line awareness activities during the awareness month with at least one post per day on Facebook, Instagram and Twitter. The content will consist of informative facts, inspirational quotes, and sharing of dystonia patients' stories. This year's theme is #volunteerfordystonia.



### David Marsden Award 2024

The 12th David Marsden Award will be presented at the European Basal Ganglia Club Session at the EAN Congress in Helsinki in Finland. The winner of the award will also have the opportunity to present his/her research to the audience.

### David Marsden Award 2025

In Autumn 2024 the call for applications for the David Marsden Award 2025 will be launched on the special David Marsden Award website [www.davidmarsdenaward.org](http://www.davidmarsdenaward.org).

### Cervical Dystonia Patient Journey

In 2024 the patient journey will be translated to most European languages. We will continue to hand out leaflets at meetings and congresses. Promotional material will be created in order to use on social media.

The Cervical Dystonia Patient Journey performance from last year will be recorded in order to produce a video that can be used for education and awareness.

### Dystonia Physio Exercise Hub in 2024

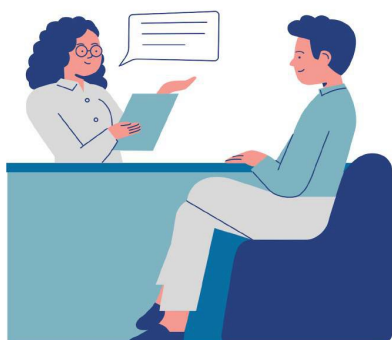
We are very grateful to have received a second 2-year-grant from Boston Scientific Foundation Europe in 2023. This year we will focus on extending the platform to more countries. We will recruit physiotherapists interested in working for the platform in their country from Finland, Greece, Denmark, Romania, Poland and Italy. The platform will be translated to these languages. New features will also be added such as a Physiofinder; a communication tool, educational videos and additional exercises.

### Dystonia Physio Workshop in Newcastle, UK

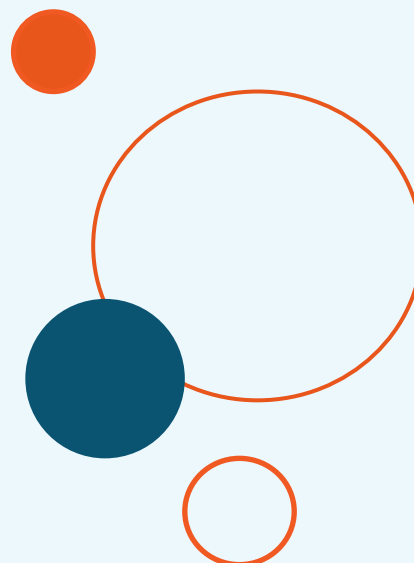
In the autumn of 2024 there will be a dystonia physio workshop in Newcastle, UK. Thanks to a grant from the patient organisation ADDER, which unfortunately had to close down in 2023, we can organise this course for physiotherapist in the Newcastle area. Physiotherapist Johanna Blom will hold the one-day workshop. If this is successful we hope to be able to organise more workshops in 2025.

## Cervical Dystonia

### The patient journey



A visual description of what patients need and how clinicians can address them



**DYSTONIA**  
**EUROPE**

 **European Reference Network**  
for rare or low prevalence complex diseases  
 **Network Neurological Diseases (ERN-RND)**

 **IPSEN**  
Innovation for patient care

GLOBAL  
MEDICAL AFFAIRS





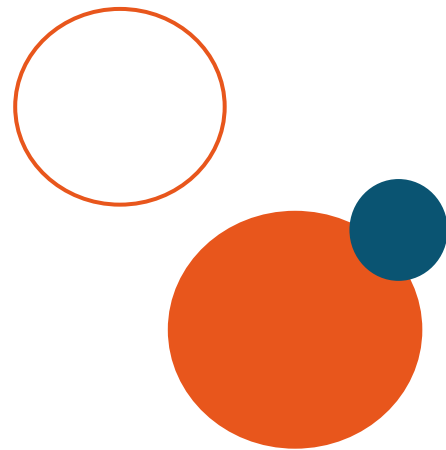
Prof Marie Vidahielt

### Launch of Dystonia Europe Clinical Fellowship

We are proud to announce a new initiative for a prolonged, comprehensive training in Dystonia, in order to get fully experienced doctors that will provide high quality care for patients, disseminate knowledge, connect with Patients associations (in their own country and at the international level (i.e. Dystonia Europe) and will be integrated into the medical and scientific community of the movement disorders doctors.

The dystonia Europe fellows will be selected among those who pursue an academic and medical career and will share the knowledge with their peers, trainees and patients within their own countries and over Europe.

The clinical training fellowship will: • be of 12 months duration for young doctors in training who might not have the opportunity to get prolonged experience in the field of dystonia and to be in contact with large number of patients with rare and frequent forms. • have well-defined objectives: need to gain specific expertise (ultrasounds and botulinum toxin, deep brain stimulation, neuroimaging and physiological characterisation of rare forms of dystonia, genetic and metabolic disorders, and transition from paediatric to adult forms). This project is supported by a grant from Merz. This project has been delayed but the aim is for it to start in autumn of 2024.



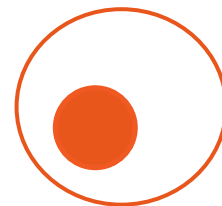
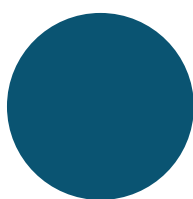
# THERAPEUTICS

Better outcomes for more patients.

**Final Accounts 2023**

Dystonia Europe 2023  
Annual Accounts January 1st - December 31th

| <b>Income and Expenditure</b> | <b>Euro</b>    |
|-------------------------------|----------------|
| Membership fee (23 members)   | 1 818          |
| Other income                  | 8 991          |
| Core grants                   | 75 000         |
| Project income                | 63 720         |
|                               | <b>149 529</b> |
| <b>Expenditure</b>            |                |
| Core cost                     | 126 167        |
| Project cost                  | 61 261         |
| <b>Result of the year</b>     | <b>-37 899</b> |
| <b>Balance sheet</b>          |                |
| Cash at Bank and in hand      | 255 996        |
| Result of previous years      | 153 706        |



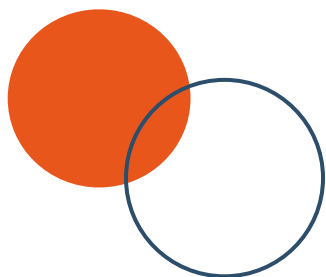
## Members

Dystonia Europe consists of 22 national member groups from 20 European countries and they are:

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

## Partners & Sponsors

In order to ensure its operations, Dystonia Europe relies on partnerships with external organisations. However, to ensure transparency and independence, the DE Board is careful to ensure that any funds or other support received do not influence our organisation's ethical position or credibility.



## Contact

Registered office:

Dystonia Europe

37 Square de Meeus, 4<sup>th</sup> Floor

B-1000 Brussels, Belgium

Telephone: +46 739 984961

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

[www.dystonia-europe.org](http://www.dystonia-europe.org)

There are 4 levels of core sponsorship: Platinum, Gold, Silver and Bronze.

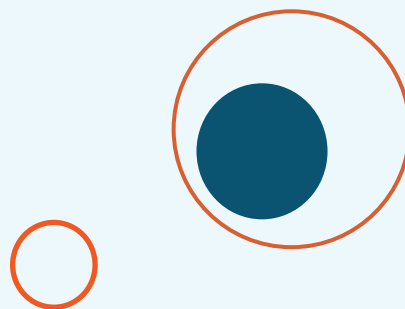
We thank the following partners for their generous support:

### Platinum:

Ipsen Pharma, Medtronic & Merz

Dystonia Europe is grateful to all other partners and supporters for their continued interest and work in joint projects with DE. We look forward to working closely with them all in the future.

They are: DMRF – the Dystonia Medical Research Foundation, FDR – Foundation for Dystonia Research, Dystonia Coalition, EAN – European Academy of Neurology, EFNA – European Federation of Neurological Associations, EPF – European Patients Forum, EBC – European Brain Council, MDS – International Parkinson and Movement Disorder Society.





# Map of Dystonia Europe Members 2023



We thank our Platinum sponsors for their generous support:



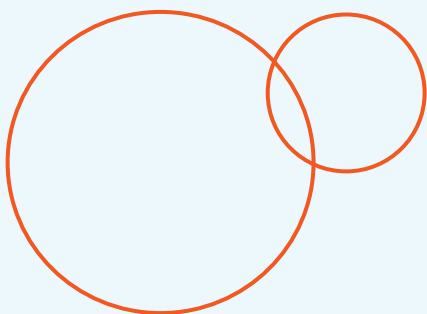
**Medtronic**  
Further, Together



**THERAPEUTICS**

---

Better outcomes for more patients.



# DYSTONIA EUROPE