

# ANNUAL REPORT

**DYSTONIA  
EUROPE  
2022**

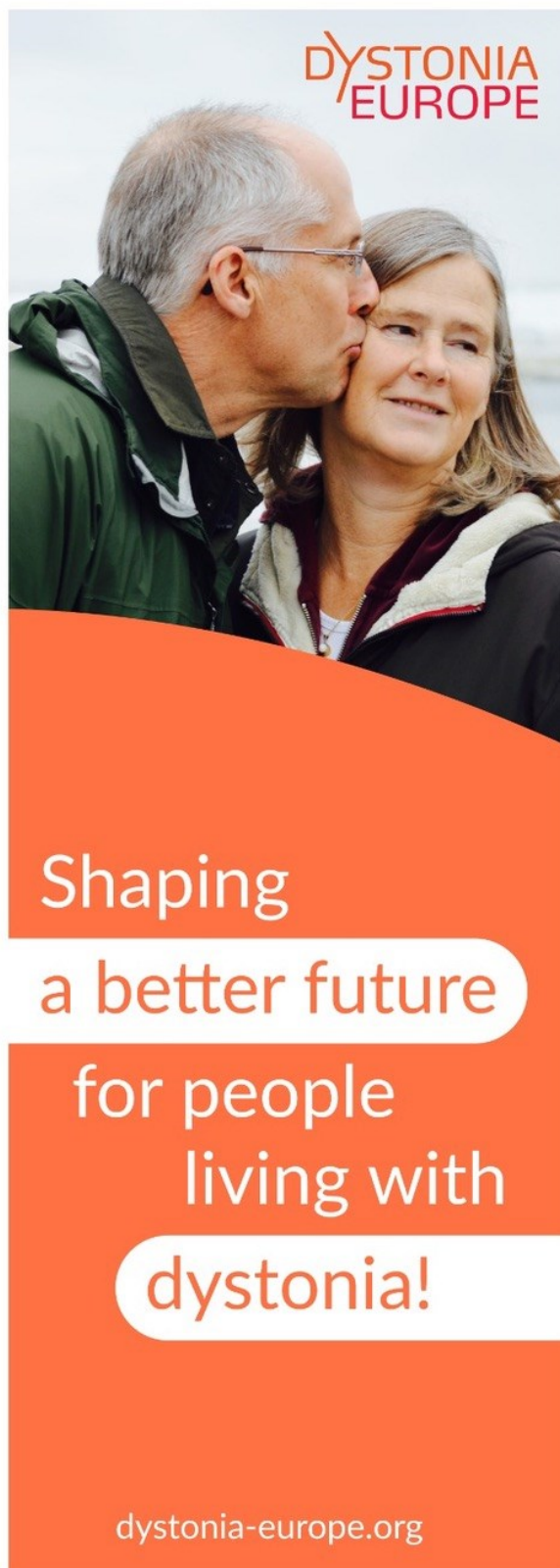
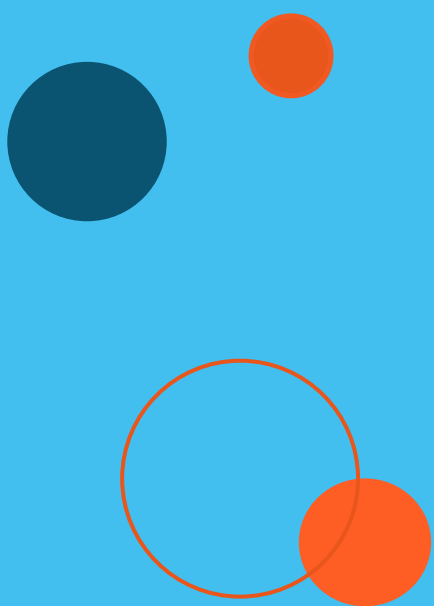
DYSTONIA  
EUROPE



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## ANNUAL REPORT 2022

*Brussels 17 May, 2023*

### Message from President and Executive Director

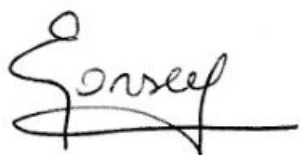
Looking back at 2022 it was a very difficult year for Dystonia Europe. At the end of the year we received the sad news of our President Adam Kalinowski's passing due to a tragic accident. It is still hard to fathom and we miss him every day as a colleague and friend.

After 2 years of Covid and travel restriction we could travel to meetings again in 2022. Nevertheless many meetings were still held on-line. The mix of on-line meetings and some face-to-face meetings seem to be the new normal allowing for more meetings and at less cost.

In 2022 it was also the first face-to-face Dystonia Days since 2019 in London. It was a happy reunion of our members that was held at Hotel Scandic Copenhagen in Denmark in May.

At the 29<sup>th</sup> Dystonia Europe Annual General Assembly we were happy to have a new member organisation join us, the Slovenian Dystonia Association.

Dystonia Europe now has 23 national member organisations from 20 countries across Europe. 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 2022 and we look further to continue our cooperation and work together during 2023 and beyond.

A handwritten signature in black ink, appearing to read 'E. Ponseel'.

Edwige Ponseel  
President

A handwritten signature in black ink, appearing to read 'Monika Benson'.

Monika Benson  
Executive Director

## BOARD, STAFF & ADVISORS

### Board

President until 10 November – Adam Kalinowski,  
Poland  
President, from 1 December 2022 - Edwige Ponseel,  
France  
Vice President until 30 November - Edwige Ponseel,  
France  
Vice President and 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  
Research – Alistair Newton, UK  
Photographer – Stephan Röhl, Germany  
Medical – Prof Maja Relja, Croatia  
Social Media – Amanda Benson, US  
Accounting – Yves Mottet, Belgium

Executive Director - Monika Benson, Sweden  
Operations Manager - Merete Avery, Norway

### Board Review

A total of 10 board meetings were held during the year, some of these board meetings with a preplanned schedule over more than one day. 8 board meetings were held on-line, and 2 board meetings were held face-to-face, one during the Dystonia Days in Copenhagen and one in Lund, Sweden.

Below from left, Monika Benson, Jukka Sillanpää, Sissel Buskerud, Gill Ainsley, Catalina Crainic, Edwige Ponseel, Merete Avery







[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 2000 visits/month.

### Newsletter

From 2020 the DE Newsletter has been issued three times per year: in spring, summer and winter. The newsletters were sent by email to our 23 member organisation and to about 750 contacts. In addition the DE Newsletter is available on our website

<https://dystonia-europe.org/media/newsletter/>

### Printed Materials

Various materials such as Dystonia Europe Newsletter, Patient Journey flyer and Dystonia Physio Exercise Hub, were printed for the Dystonia Days 2022 in Copenhagen and other congresses.

### Social Media

Dystonia Europe is present on the following social media channels: Facebook, Instagram, Youtube, 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:

	2021	2022	Growth:
Facebook	5466	5985	+ 9 %
Instagram	2191	2549	+ 15 %
Twitter	1195	1342	+ 12 %
YouTube	1210	1821	+ 50 %
Linked-In	447	644	+ 44 %

### NEWSLETTER

**3 times/year**

No 1 - May submit by 31 March

No 2 - September, submit by 1 August

No 3 - December, submit by 20 November

**We are always looking for  
articles and stories**



### The 29<sup>th</sup> Dystonia Europe General Assembly

On May 20, 2022, the 29th General Assembly took place at Scandic Hotel Copenhagen in Denmark. President Adam Kalinowski welcomed the 27 participants from 13 member associations. There was a new member application from a recently founded patient organisation in Slovenia and their membership was approved by the General Assembly. Dystonia Europe now has 23 member organisations from 20 countries in Europe.

The DE Team presented the work of 2022 and the final accounts. After the formal GA meeting Dystonia Europe informed about ongoing projects, Dystonia Awareness Month, MyBrainNet and MyDystonia APP 2.0, DE Newsletter, the Physiotherapy Project, and the launch of the new survey – Dystonia and Diet by Kasia Smilowska, and the Awareness Campaign I am... It took....

The Dystonia Europe Board, Staff and Delegates Jumping for Dystonia after the General Assembly in Copenhagen 2022

### Dystonia-Days 2022

The Dystonia Day 2022 was held Saturday 21 May at Scandic Hotel Copenhagen. After an introduction by the President Adam Kalinowski, there were presentations by Prof Tobias Bäumer, Prof Lena Hjerminde, Prof Espen Dietrichs, Prof Annemette Lökkegaard Prof Jean Pierre Lin, Physiotherapist Johanna Blom and last a video presentation by Prof Marjan Jahanshahi.

In addition, a video presentation by patient Tracey McCann from Ireland and Sandra Theil Sørensen, daughter of Yvonne Sørensen who has generalised dystonia, presented her story of growing up with a mother affected by dystonia.



### David Marsden Award 2022

President Adam Kalinowski presented the winner of the David Marsden Award, Dr Susanne Knorr, senior consultant neurologist and researcher at Würzburg University Hospital.

Susanne presented her paper, “The evolution of dystonia-like movements in TOR1A rats after transient nerve injury is accompanied by dopaminergic dysregulation and abnormal oscillatory activity of a central motor network”. She succeeded in creating the model and could also show that DBS reduced the dystonic symptoms.



Dr Susanne Knorr

Adam Kalinowski also introduced the DMA winner Dr Susanne Knorr at the EAN 2022 Basal Ganglia Club Session. European Academy of Neurology is a non-profit, independent organisation representing more than 45,000 members, as well as 47 European national societies.

This took place at the 8th Congress of the EAN (European Academy of Neurology) in Vienna, Austria in June. This congress is one of the biggest neurological events in Europe. In 2022 there were 380 lecturers and 5300 onsite participants took part in the event. The award has been presented every year since 2021 before that it was presented every two years.

[www.davidmarsdenaward.org](http://www.davidmarsdenaward.org) .

### Dystonia Podcast – The Positive Twist

We continued to promote the 7 episodes of season 1 of our podcast. These episodes have now been downloaded over 2900 times. A second season with 5 episodes has been planned for launch mid 2023. The podcast can be found on various channels where you find podcasts.

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



### Dystonia Awareness Video Project

This project was planned in 2021 and the work started in 2022. It is a series of short videos that aim to show the symptoms of different types of dystonia for better understanding by people who have never heard of this disorder. The filming took place during May in Dublin.

These videos will be finalised in 2023.

## Cervical Dystonia Patient Journey

In 2021 the work started on the Patient Journey project and it was finalised in 2022. The development of the patient experience map was initiated by ERN-RND and a collaboration between them, Dystonia Europe and Ipsen. Dystonia patients in the UK, Italy and France took part in a survey about onset of symptoms, time of diagnosis, access to treatment and living with dystonia. The findings show the changing emotional and medical experiences present during different stages of dystonia.

It revealed that the experience of living with this neurological movement disorder was often associated with multiple barriers to accessing holistic care, from pre-diagnosis to long-term management. Findings showed that patients were referred to up to 10 different specialists for diagnosis and over half (53.3%) had received  $\geq 1$  misdiagnosis.

Even after a diagnosis and treatment plan are in place, people living with cervical dystonia

have reported a “roller coaster” of relief associated with treatment of symptoms and the associated impact on daily life towards the end of a treatment cycle.

The cervical dystonia patient experience map was published in February in the peer-reviewed publication, the Orphanet Journal of Rare Disease. You can read the full publication here: <https://ojrd.biomedcentral.com/articles/10.1186/s13023-022-02270-4>

The Cervical Dystonia Patient Journey was presented at various meetings such as Dystonia Days 2022 in Copenhagen, at the Movement Disorder Congress in Madrid and at The Reuter's Pharma Event in Nice.

Dystonia Europe and Ipsen have continued to develop communication material (short videos and social media posts) around the Patient Journey and these will be published during 2023.

Patient Journeys are info-graphical overviews that visualize patients' needs in the care of their rare disease. Because Patient Journeys are designed from the patient's perspective, they allow clinicians to effectively address the needs of rare disease patients.

For more information, please visit:  
<https://www.ern-rnd.eu/patient-journey-cervical-dystonia/>



## 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**



## September Dystonia Awareness Month 2022

For the sixth 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.

Focus this year was the Patient Journey, a series of carousel posts on our social media, describing a fictional cervical dystonia patient called Lilly. Many followed Lilly and her journey with dystonia from the first symptoms, through the various stages of diagnosis, treatment and living with dystonia also the emotional stages.

In addition we asked the dystonia patient community to do a short recording of how long it took to get diagnosed and send it to us. We call this activity I am... It took.

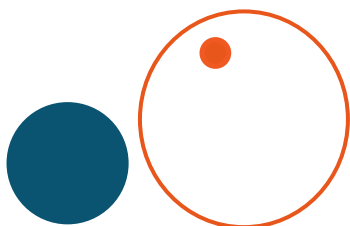
<https://dystonia-europe.org/i-am-it-took>

## Dystonia Europe Think Tank 2022

Members of the Think Tank are the Dystonia Europe Board and representatives of our Platinum sponsors: Boston Scientific, 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.

Two on-line meetings were held on Zoom: one in February and one in October.



This infographic was our most shared post on social media during Dystonia Awareness Month 2022.

## I am...It took

In 2022 Dystonia Europe launched a new Awareness Campaign to focus on the fact that many patients with dystonia, still go undiagnosed and without treatment for many, many years.

This campaign also allows the patient to take part.

<https://dystonia-europe.org/i-am-it-took>



## 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 physiotherapy exercises for dystonia.

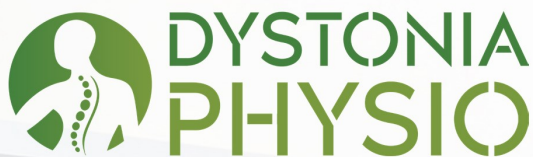
The project was launched in Sweden in November 2021. During 2022 it was translated to German, French, Spanish, Dutch and English in addition to Swedish. It was further developed from 100 exercises to 115 exercises in 2022 and some of them are animated. The updated version of the platform was launched in December 2022.

It is an international online platform with special physiotherapy exercises for cervical dystonia patients. The users of the platform will be physiotherapists and other medical professionals and dystonia patients.

On the platform the physiotherapist is able to choose from 115 different exercises and can thereby 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.

The project is supported by Boston Scientific Foundation Europe.

Johanna Blom and Monika Benson took part in the ECRD (European Conference on Rare Diseases) in June to present the Physio Exercise Hub as a best practice project.



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](https://physioexercise.org)





## EUROPEAN PARTNERSHIPS

### Member of EFNA

Dystonia Europe is a member of EFNA, European Federation of Neurological Diseases. EFNA is an umbrella organisation representing pan-European neurology patient groups. DE Executive Director Monika Benson is a board member of EFNA, and participated at the EFNA 21st Anniversary Celebration & EFNA Advocacy Awards 2022 Brussels. The organisation was founded in 2001 and the initial plan was to hold the 20th Anniversary event in December 2021. Due to the pandemic it had to be postponed. It was a happy reunion in Brussels where many participants had not met in over two years. There were 34 guests, including representatives of 14 of EFNA's 20 member organisations, along with representatives from EBC, EAN and industry partner groups.

<https://www.efna.net>

### 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 online EPF General Assembly 2022 on 23<sup>rd</sup> April. She also took part in the 2-day EPF Congress in June, in Brussels, Belgium. AI (Artificial Intelligence) was also on the agenda at the online meeting after the AGM on 23<sup>rd</sup> April. AI can improve and lower the costs of healthcare. There are many things to consider such as ethics and it is important that patients are a part of the discussions on how AI systems should be implemented and used. EPF held the Final Conference Advocacy Event COMAR-EU in November in Brussels.

Merete Avery participated at the meeting which lasted 2 days. COMAR-EU is a multimethod, interdisciplinary project that will contribute to bridging the gap between current knowledge and practice of self-management interventions.

<http://www.eu-patient.eu>



In 2021 Donna Walsh left her position as Executive Director at EFNA. She attended the event as well and Joke gave a presentation to her and thanked her with gifts and a memory book.



Presentation by Dr. David Novillo Ortiz at the EPF Congress in June 2022 in Brussels



### **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 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.

For more information:  
<http://bostonscientific.eu/foundation>

### **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 on-line meetings throughout the year.

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

### **Partner in a European Research Project: EurDyscover**

In 2019 Prof Volkmann and partners were granted funding for a 3-year project from the European Program on Rare Diseases (<https://www.ejprarediseases.org/index.php/funded-projects/>) specifically for Pathophysiology of dystonia – role of gene-environment interaction and common pathophysiological pathways.

Coordinator is Jens Volkmann (DE) and partners are: Albino Oliveira-Maia (PT) – Antonio Pisani (IT) - Andrea Kühn (DE) – Robert Jech (CZ) – Marie Vidailhet (FR). Dystonia Europe is a partner in this project and supports various activities such as information about the project, recruitment of patients etc.



**Members of the European Reference Network for Rare Neurological Diseases (ERN- RND), established by the EU**



## 2023 & BEYOND

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### 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

#### Board Meetings

For 2023 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 2023 one face-to-face on 1 March in Brussels, Belgium and one in October using Zoom.

#### 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.

DE representatives will attend the NDF 30th Anniversary in Oslo, Norway and the Annual Meeting of DDG in Germany.

### 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 2023 in Budapest, Hungary; Movement Disorder Congress in Copenhagen, Denmark and at the ESSFN Congress in Stockholm, Sweden.

### Dystonia Webinars

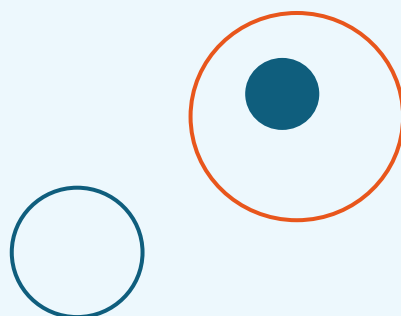
A few webinars with experts and patients are planned to take place throughout the year.

### The David Marsden Award 2023

This year it will be the 12<sup>th</sup> time it takes place. The Award will be presented by Executive Director Monika Benson at the European Basal Ganglia Club Session at the EAN Congress in Budapest, Hungary.

### David Marsden Award 2024

In Autumn 2023 the call for applications for the David Marsden Award 2024 will be launched on the special David Marsden Award website [www.davidmarsdenaward.org](http://www.davidmarsdenaward.org).



# DIET AND DYSTONIA

## Take a survey for change!



- ✓ Take the survey
- ✓ Support research
- ✓ Anonymous
- ✓ 16 languages

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

### **Cervical Dystonia Patient Journey**

In 2023 the patient journey leaflet will be printed and distributed at various meetings. A special webpage will be launched which includes all the information about the PJ. Promotional material will be created in order to use on social media.

### **Dystonia Physio Exercise Hub**

In 2023 we will submit an application to Boston Scientific Foundation Europe in order to continue the work and development of the physio exercise project.

The plan is to translate the platform to more European languages, add more exercises, develop educational material etc.

### **Dystonia Surveys on Diet and Dystonia**

Dr. Kasia Smilowska, Department of Neurology, Regional Specialist Hospital in Sosnowiec, Poland, has 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 is available in 15 languages on the Dystonia Europe Survey platform and will close on 31 July.

### **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.

Special for this year's awareness month is that we will launch the five dystonia awareness videos using the hashtag #dystonialife. The titles are also translated to several languages.





**Prof Marie Vidahielt**

### **Launch of Dystonia Europe Clinical Fellowship**

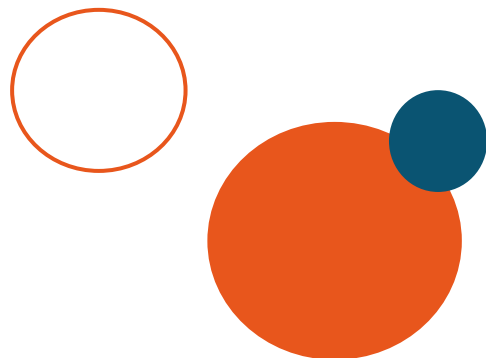
We are proud to announce a new initiative for a prolonged, comprehensive training in Dystonia, in order to get fully experienced doctors that will provide high quality care for patients, disseminate knowledge, connect with Patients associations (in their own country and at the international level (i.e. 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 pediatric to adult forms).

This project is supported by a grant from Merz.



# THERAPEUTICS

Better outcomes for more patients.

## Final Accounts 2022

Dystonia Europe 2022  
Annual Accounts January 1st - December 31th

<b>Income and Expenditure</b>	<b>Euro</b>
<b>Income</b>	
Membership Fees (23 Members)	1818
Other Income	2313
Core Grants	100000
Project Income	93977
<b>Total Income</b>	<b>198108</b>
<b>Expenditure</b>	
Core Costs (Office, Board meetings, Staff, Travel etc)	120530
Project Costs	104960
<b>Total Expenditure</b>	<b>225490</b>
<b>Result of the Year</b>	<b>- 27382</b>
<b>Balance Sheet</b>	
Cash at Bank and in Hand	234268
Result of Previous Years	218987



## 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, 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.

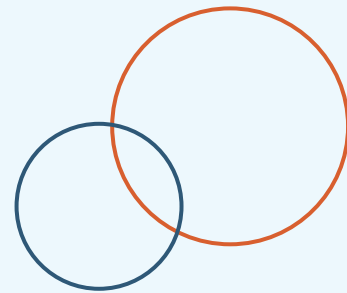
We thank the following partners for their generous support:

### Platinum:

Boston Scientific, 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, BSFE – Boston Scientific Foundation Europe, 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:

**Boston  
Scientific**



**Medtronic**  
Further, Together



**THERAPEUTICS**

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Better outcomes for more patients.

