ANNUAL REPORT
2020

DYSTONIA EUROPE

CONTENT

Connecting people to

spread information

raise awareness

promote research

Message from President and Executive Director

Brussels 30 May, 2021

Dear all,

2020 was a very different year due to the Covid-19 pandemic. From March 2020 when countries started to close borders and went into lock-down, Dystonia Europe also had to change direction, the way we work and what activities we do.

Just like many others we got a Zoom account and the Board started to meet on-line on a regular basis. One of the first things we did was to create a special Covid-19 page on the Dystonia Europe website with information and videos to support our members.

Together with DMRF, the American Dystonia Association, we had planned the 6th International Dystonia Symposium to be held in Dublin in June of 2020 alongside our annual Dystonia Days but all of this had to be postponed. The Symposium is now planned for June 2023 to be sure that we have come out of the pandemic.

The 27th Dystonia Europe Annual General Assembly was held on-line via Zoom with most of our members attending. Instead of face-to-face meetings we changed to new activities and we launched a Dystonia Webinar Series and a Dystonia Podcast The Positive Twist.

Dystonia Europe now has 21 national member associations from 18 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 this difficult, past year.

This spring, with the on-going vaccination programme across Europe, we see the light at the end of the tunnel and we really hope we can meet face-to-face next year.

Adam Kalinowski
President

Monika Benson
Executive Director

BOARD, STAFF & ADVISORS

Board
President – Adam Kalinowski, Poland
Vice President – Edwige Ponseel, France
Treasurer – Sissel Buskerud, Norway
Secretary – Gill Ainsley, United Kingdom
Board Member – Catalina Crainic, Romania

Advisors
IT – Eelco Uytterhoeven, The Netherlands
Research – MBE 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 8 board meetings were held during the year. The only face-to-face meeting was the first board meeting of the year, in February, alongside the Winter Think Tank Meeting. After the pandemic spread across Europe all meetings were moved on-line.

From left: Monika Benson, Sissel Buskerud, Adam Kalinowski, Gill Ainsley, Catalinia Crainic, Edwige Ponseel

www.dystonia-europe.org

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 aways looking for articles and stories

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 1700 visits/ month.

Newsletter

From 2020 the DE Newsletter is issued three times per year: in spring, summer and winter. The three issues were sent by email to members and about 500 contacts.

Printed Materials

Due to the fact that Dystonia Europe did not take part in any face-to-face meetings or congresses there was no material printed this year.

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:

	2019	2020	Growth
Facebook	4258	5017	+17,8%
Instagram	1044	1865	+78,6%
Twitter	756	972	+28,6%
YouTube	318	679	+114%
Linked-In	196	288	+47%

ACTIVITIES & PROJECTS

The 27th Dystonia Europe General Assembly

On June 7 2020 the 27th General Assembly took place on Zoom. President Adam Kalinowski welcomed the 25 participants from 15 countries. The DE Team presented the work of 2019 and the final accounts. Some members presented their national work.

Digital Dystonia-Days 2020

Since there were no face-to-face Dystonia Days including presentations from Dystonia experts the DE team decided to launch the Digital Dystonia Days taking place on-line throughout the year. The project included the launch of a dystonia webinars series and a dystonia podcast.

Dystonia Webinar Series

It was decided that the series would include a total of 10 sessions with dystonia experts on various topics. In 2020 there were four webinars. They included topics such as Living well with dystonia; DBS and dystonia; Botulinum Toxin for dystonia and Rehabilitation and dystonia. The webinars were recorded and are available on the YouTube channel:

https://www.youtube.com/playlist?list=PLFvCc6fYkjEt_7GhGF9OwEElXo2iBeVRk

Dystonia Podcast – The Positive Twist

At the end of Dystonia Awareness month the podcast was launched. Host Amanda Benson from the Rise Factory invited 1-2 guests for each episode. There was a nice mix of dystonia experts, researchers and patients. The first episode included an interview with Stephen a dystonia patient who had had DBS. This first season will include 7 episodes. In 2020 there were 4 episodes and they were published on the 4th Wednesday of the month. These can be found on various channels where you find podcasts.

https://dystoniaeurope.buzzsprout.com/1337749

Dystonia Fact Videos

In January 2020 Monika and Amanda travelled to London and met up with 5 different dystonia experts. The experts were filmed and recorded while describing the various types of dystonia, the different treatments, coping strategies, research. The 32 videos are available on the DE YouTube Channel:

https://www.youtube.com/playlist?list=PLFvCc6fYkjEu_33mOzHqpnOhXB2t-LeKj

Dystonia Europe Think Tank

Two Dystonia Europe Think Tank meetings were held. The first one was face-to-face in Lund, Sweden in mid February, and the second meeting took place in September via Zoom. 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.

David Marsden Award 2021

In June 2020 the call for applications for the David Marsden Award 2021 was launched on the special David Marsden Award website www.davidmarsdenaward.org
The 2021 Award of €10,000 is generously sponsored by Ipsen Pharma. Promotion was done with the support of the Dystonia Europe Medical and Scientific Advisory Board, EAN Pages and our partners.

Dystonia Europe Connecting with Dystonia Patient Associations

On 19 September the Danish Dystonia Association organised a Members Meeting on the Faroe Islands. DE Executive Director had been invited to join but due to the Covid-19 pandemic she joined via Zoom from her home office in Sweden. Monika presented the work of Dystonia Europe and then answered questions.

Think Tank Meeting, Lund, February 2020

Boston Scientific

Medtronic
Further, Together

IPSEN
Innovation for patient care

MERZ THERAPEUTICS
Better outcomes for more patients.

Dystonia Stories

QUOTES:
"I was busy today."
"I was busy calming my nerves" "I was busy managing my pains"
"I was busy taking my med"

September Dystonia Awareness Month 2020 & Jump for Dystonia

For the fourth 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 we had decided to relaunch our Jump for Dystonia campaign and with the support of a grant from the EFNA #brainlifegoal project, we developed special graphics together with a quiz about dystonia. In order to engage with the community there was a photo competition with cash prizes.

A total of 100 photos were received on our social media channels and 8 winners were selected. https://dystonia-europe.org/projects-1/projects/jump-dystonia/jumpfordystonia2020-photo-competition-results/

MyDystonia Ambassador Programme

The MyDystonia Ambassador Programme was launched in 2016 to support the roll-out of the MyDystonia APP in Europe. The main task of the Ambassadors is to support the users in their national language. For this purpose we developed the on-line tool “MyDystonia AmbassadorNet” where the Ambassadors can help resolve users’ issues and have access to support materials, videos etc. In 2020 there were no meetings.

MyBrainNet

MyBrainNet is a project that was started in 2018 and is sponsored by the BMP grant. The Brain, Mind, and Pain Patient-Centred Innovation Grant has been initiated by Pain Alliance Europe and supported by Grünenthal Group with the main aim of encouraging patient-centered innovation, resulting in better quality of life for patients suffering from pain, or neurological disorders.

Learn more about the grant here: http://bmp-grant.eu

In 2019 Ipsen contributed with a grant for this project.

The MyBrainNet platform has made it possible to update our digital diary MyDystonia. The App is redesigned making it suitable for all kinds of dystonias and the different treatments.

The MyBrainNet platform is now live and allows other patient organisations to join the project and have an app of their own. We hope that other patient organisations working in the field of brain diseases will take advantage of the platform. At a very low cost a new App for another disease can be developed, using the functionalities that are already there.

We think this an interesting offer especially for the small patient organisations of other rare neurological diseases.

Although we may all have a different neurological condition, we are faced with the same kind of challenges, wishes and hopes. MyBrainNet is a project of collaboration and sharing, in order to create an awesome platform. By working together we can much better use available funding, use the time spent on the project more efficiently as well as benefiting from the same legal framework.

EUROPEAN PARTNERSHIPS

Member of EFNA

Dystonia Europe is a member of EFNA, European Federation of Neurological Diseases. EFNA is an umbrella group representing pan-European neurology patient groups. DE Executive Director Monika Benson is a board member of EFNA.

EFNA held its General Assembly 2020 via Zoom.

https://www.efna.net

On World Brain Day, 23 July, EFNA published a series of patient videos on the theme goal-oriented healthcare. President Adam Kalinowski took part in the initiative.

Member of EPF

Dystonia Europe is a member of 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 patients advocates. Operations Manager Merete Avery took part in the EPF General Assembly 2020.
http://www.eu-patient.eu

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 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 with various activities such as information about the project, recruitment of patients etc.

Project with EBC (European Brain Council): Value of Treatment Phase 2

Continuing with the VOT – Value of Treatment research activities, new case studies have been developed on new therapeutic areas. In 2018, EBC in collaboration with EAN, ECNP, EFNA, EPA and GAMIAN Europe launched a second round of VoT2 case studies on Rare Neurological Disorders (RNDs) focusing upon Ataxia, Phenylketonuria and Dystonia. Prof Maja Relja is the project leader. For more information about the project visit:
https://www.braincouncil.eu/projects-and-initiatives/vot2/

2021 & 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 2021

Due to the COVID-19 pandemic the plans for this year's work continues in the same way as started in 2020. We will continue to work according to our vision and mission but due to the various restrictions and regulations across Europe most of our activities this year will take place on-line.

Board Meetings

Due to the Covid-19 pandemic all meetings for 2021 are planned to take place on-line via Zoom. On-line board meetings are shorter but take place more often than when we used to have face-to-face meetings. The Board finds it useful to meet about once a month.

Think Tank Meetings

Two meetings are planned for 2021 in February and September. The meetings will take place on-line.

Connecting with Dystonia Patients

Dystonia Europe continues its work to reach out to dystonia patients/groups in other countries. Due to the pandemic there will be no travelling to meetings of any of our national members. If they organise on-line meetings we are happy to take part.

Communication

To stay in touch with our members and all stake-holders we continue our work to develop our various communication channels such as:

Website – is being updated and re-structured. Due to a grant from "Google for non-profits" we aim to improve all information available on the webpages in order to increase awareness and visits to website via Google Ads.

Dystonia Europe News – our newsletter is issued three times per year: in May, September and December.

Social Media Channels – we are present at Twitter, Linked-In, Instagram, YouTube and Facebook. We continue to work with an external social media consultant to provide our followers with a content that is informative, inspirational and supporting.

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 28th Annual General Assembly

On 30 May the 28th Annual General Assembly will take place on-line via Zoom.

Digital Dystonia Days 2020

The Digital Dystonia Days project launched in 2020 to replace the face-to-face annual meeting contin-ues in the first half of 2021. Six webinars on various topics will be held and the last three episodes of the Podcast Series will be launched.

Dystonia Day 2021

On Saturday 4 September there will be an on-line Dystonia Day 2021 event from about 10.30 until 15.30 (CET). The day will include expert presentations on dystonia, patient testimonies and information from Dystonia Europe.

The David Marsden Award 2021

The Award is given every other year and is once again sponsored by Ipsen.

This year it will be the 10th time it takes place. The Award will be presented by President Adam Kalinowski at the European Basal Ganglia Club Session at the EAN Congress on 19 June.
The winner will also make a presentation at the on-line Dystonia Day on 4 September.

The winner will be featured in the DE Newsletter, on the DE News blog and on the special DMA website where you also find information on all past winners: https://davidmarsdenaward.org

Dystonia Patient Journey

In the ERN-RND network it has been decided that the members should create disease specific patient journeys to better understand the situation of those affected and to learn from their experiences.
Together with Ipsen and patient engagement consultants from Partnerseitz, Dystonia Europe will develop a Cervical Dystonia Patient Journey. This will consider life with Cervical dystonia including emotional and medical aspects of the disease in order to find any gaps and difficulties dystonia patients face to help them better manage their disease.

Dystonia Physio Exercise Hub

Physiotherapist Johanna Blom at the Neurology Department of the University Hospital of Skåne in Malmö, Sweden, has together with Dystonia Europe received a grant from Boston Scientific Foundation to create an on-line platform with physiotherapy exercises for dystonia.
The 2-year project aims to create 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 will be able to choose from about 100 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.
In the first year, phase one, the work will focus on developing the platform, creating/ adding the exercises, and launch the platform in Sweden.
During the second year, phase two, the aim is to launch the platform in five other European countries. In this phase the exercises will be animated and one of the aims is also to connect the exercise program to the MyDystonia digital diary.

Dystonia Surveys on Sexuality and Diet

Dr. Kasia Smilowska, Department of Neurology, Regional Specialist Hospital in Sosnowiec, Poland, has initiated two different surveys for people living with dystonia. The main goal of these surveys are to examine how diet affects dystonia and how dystonia influences sexual life and if so how doctors could address these problems.
The first survey (on Sexuality) will be launched end of May and be available until end of 2021.
The second survey (on Diet) is planned for the first half of 2022. The surveys will be available in 15 languages on the Dystonia Europe Survey platform.

MyBrainNet, MyDystonia & MyDystonia Ambassador Programme

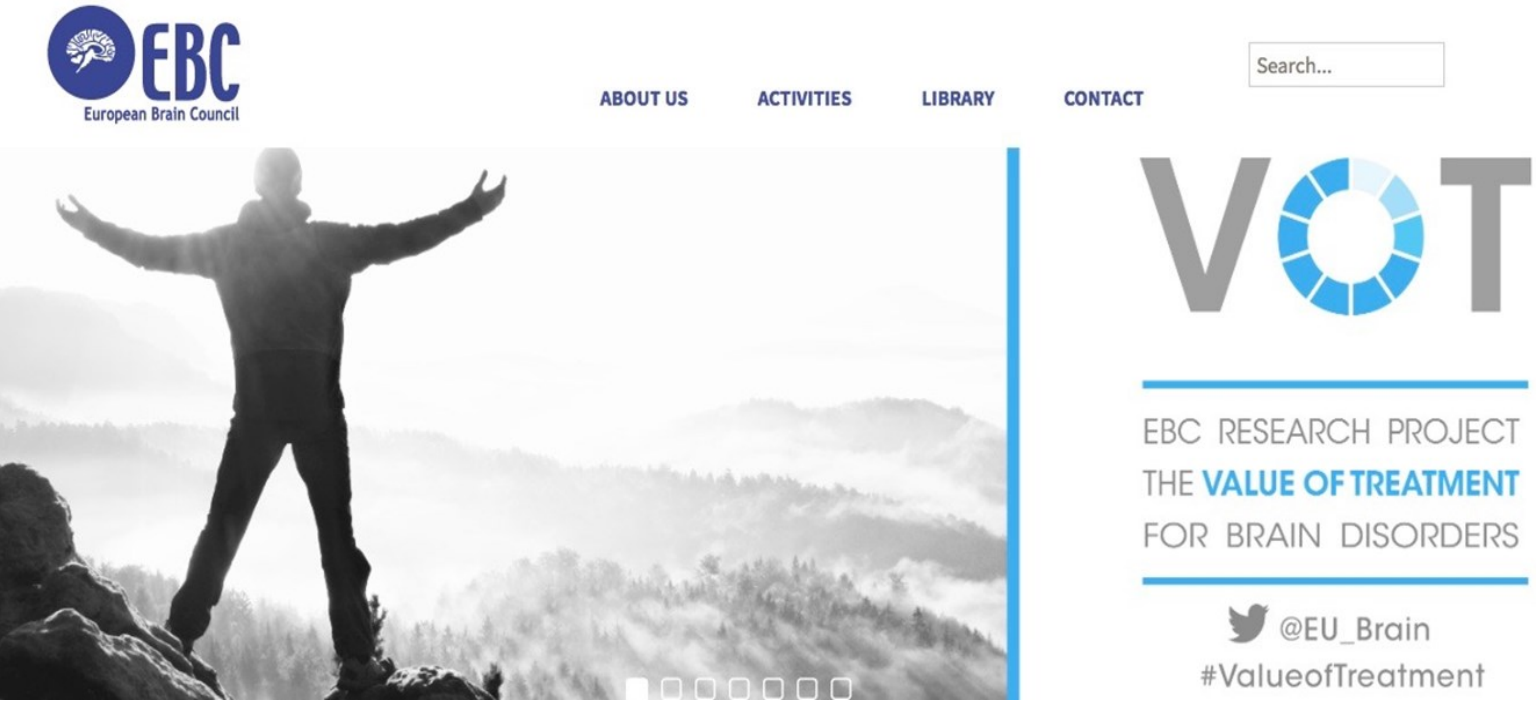
This year we will share the MyBrainNet platform with other organisations and hopefully there will be other patient organisations who want to develop their App.
The updated MyDystonia will be launched and an on-line MyDystonia Ambassadors Meeting is planned for June 26.

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 the activity Escape Dystonia. With #Escape Dystonia we hope to engage with the dystonia community and our followers to find out what they do to manage, cope and escape dystonia. Can a passion for a certain hobby or sports help to manage dystonic symptoms? We hope that the content received can be used for future inspirational quotes and posts on our social media channels.

EurDyscover

DE continues its involvement in the research project EurDyscover, initiated by Prof Volkmann and partners in 2019. On 19 July there will be a webinar with the leaders of the project to inform and share about the activities.



Value of Treatment Project

EBC in collaboration with the European Academy of Neurology (EAN) and the European Federation of Neurological Associations (EFNA) launched a second round of case studies on Rare Neurological Disorders (RNDs) focusing upon Ataxia, Dystonia and Phenylketonuria. RNDs challenges are major. Analysing the treatment gap and underlying causes, particularly related to health services delivery, remains central in the study. The study's research framework includes the development of a series of qualitative and quantitative benchmarks to identify treatment gaps "barriers to care" and causal factors along the continuum of care from early diagnosis to disease management including rehabilitation and patient empowerment (patient care pathway analysis) as well as to estimate the socioeconomic impact and health gains from best practice healthcare interventions in comparison with current care (economic evaluation/cost-consequences analysis). The two-year study on the value of early diagnosis and intervention for rare neurological disorders will aim to assess the benefits of coordinated care and multidisciplinary care patterns on patient outcomes. The overall objective is to propose policy recommendations on how to provide optimal care in the disease area under study by addressing the current treatment gaps/unmet needs.

Prof Relja is leading the work on dystonia and will be using the dystonia survey results from 4 countries: UK, Italy, Germany and Croatia in the project.

The research findings will be published in 2021.

Final accounts 2020

Dystonia Europe 2020

Annual Accounts January 1st - December 31th

Income and Expenditure

INCOME	**Euro**
Membership Fees	1 818
Core Grants	95 000
Project Income	48 667
Other Income	3 172
Total Income	**148 657**
EXPENDITURE	
Core Costs (Office,board meetings,staff,travel etc)	101 527
Project costs	37 893
Total Expenditure	**139 420**
RESULT OF THE YEAR	**9 237**
BALANCE SHEET	
Cash at bank and in hand	219 252
Result of previous years	189 342
Result of the year 2020	**9 237**

Members

Dystonia Europe consists of 21 national member groups from 18 European countries and they are: Austria, Belgium, Croatia, Czech Republic, Denmark, Finland, France, Germany, Ireland, Italy, Norway, Poland, Romania, 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.

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

Silver:
Revance

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.

PLATINIUM

Boston Scientific

IPSEN
Innovation for patient care

Medtronic
Further, Together

MERZ THERAPEUTICS
Better outcomes for more patients.

SILVER

revance