

ANNUAL REPORT

**DYSTONIA
EUROPE
2021**

DYSTONIA
EUROPE



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**Connecting people to
spread information
raise awareness
promote research**



ANNUAL REPORT 2021

Brussel 1 May, 2022

Message from President and Executive Director

Dear all,

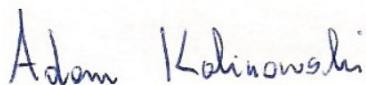
2021 followed in the footsteps of 2020 where the Covid-19 pandemic continued to impact our work. All board meetings, Think-Tank meetings, our annual general assembly and the Dystonia Day 2022 were held online using Zoom.

For the last two years there have been no face-to-face meetings. In the beginning of the pandemic we were all quite confused on how to work and move the organisation forward. Luckily we quite soon found new ways of working. By using digital tools we created new activities and new projects were developed. Less time was spent on travelling allowing more time to focus on work from the office. You will read in this annual report about these new projects such as the Podcast The Positive Twist and the Dystonia Physio Exercise Hub – a digital platform with exercises for cervical dystonia patient.

Now slowly leaving the pandemic behind and returning to normal we will use the good experiences and learnings to form the future work of DE. We will for example continue to hold board meetings on-line every 6-8 weeks. We will not travel to meetings unless it is necessary to be there for more than one day.

It is with great anticipation though, we are looking forward to our Dystonia Day 2022 and our annual meeting in Copenhagen in May 2022. It will be great to meet all of our members face-to-face again and to chat over a cup of coffee and have dinner together again.

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 for the past year. We look forward to working together in 2022.

A handwritten signature in blue ink that reads "Adam Kalinowski".

Adam Kalinowski
President

A handwritten signature in blue ink that reads "Monika Benson".

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
Board Member – Jukka Sillanää, Finland

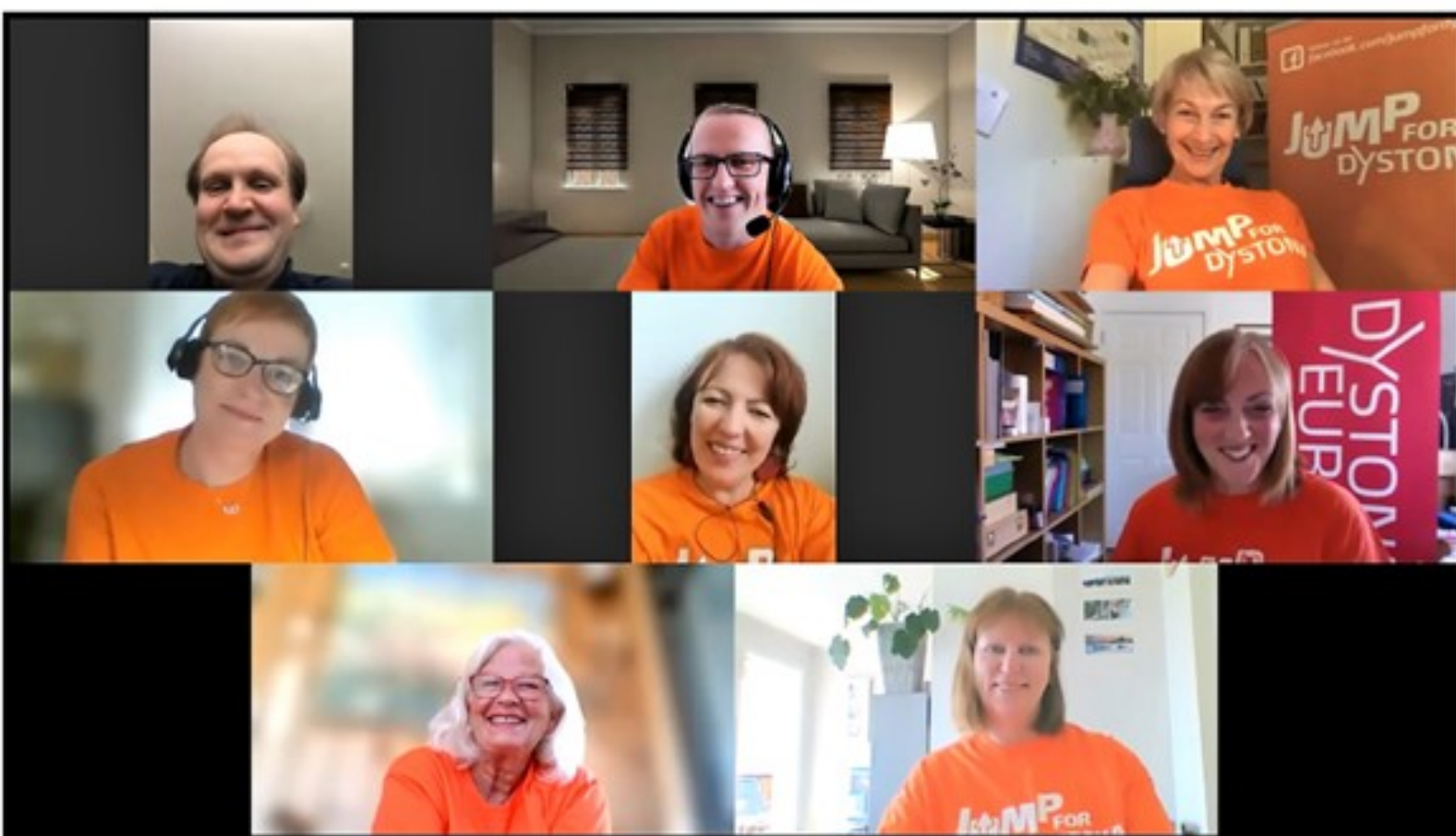
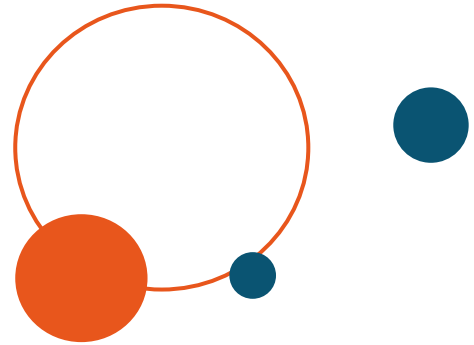
Advisors

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 9 board meetings were held during the year, some of these board meetings with a preplanned schedule over more than one day. All meetings were held on-line, due to the pandemic. Also two Think Tank meetings were held on-line.



The DE Board and Staff

From top left: Jukka Sillanpää, Adam Kalinowski, Monika Benson, In the middle from left: Edwige Ponseel, Catalina Crainic, Gill Ainsley and at the bottom from left: Sissel Buskerud, Merete Avery



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 had a total of 25 000 visits during the year.

Newsletter

In 2021 the Dystonia Europe newsletter design was updated with a new look including some shades of light blue. The newsletter is issued three times per year: in spring, summer and winter. It's sent out by email to members and about 650 individual contacts.

Printed Materials

Due to the ongoing Covid-19 pandemic and the fact that most activities and meetings were held online, no material was 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:

	2020	2021	Growth:
Facebook	5017	5466	+ 9 %
Instagram	1865	2191	+17,5 %
Twitter	972	1195	+23 %
YouTube	679	1210	+78 %
Linked-In	288	447	+55 %

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

ACTIVITIES & PROJECTS



Photo from online General Assembly

The 28th Dystonia Europe General Assembly

On May 30th 2021, the 28th General Assembly took place on-line on Zoom. President Adam Kalinowski welcomed the 28 participants from 16 countries. The DE Team presented the work of 2020 and the final accounts. The members also approved the membership application of the Dutch Dystonia Association. There are now 22 members of Dystonia Europe.

After the formal part of the meeting there was information about ongoing projects such as Dystonia Awareness Month 2021, MyBrainNet and MyDystonia APP 2.0, DE Newsletter, Physiotherapy Project, and the launch of the new surveys of Dr. Kasia Smilowska: Dystonia and Sexuality and Dystonia and Diet (to be launched in 2022).

Digital Dystonia-Day 2021

The Dystonia Day 2021 was held on Saturday 4 September. It was an on-line meeting with over 100 participants. After an introduction by President Adam Kalinowski, there were presentations by Prof Mark Edwards, Dr Francesca Morgante and Prof Kailash Bhatia. The winner of the David Marsden Award 2021, Dr Martin Reich presented his research. There was also the opportunity to ask questions in the Q & A sessions. The whole event was recorded and is available on the Dystonia Europe YouTube channel.

David Marsden Award 2021

The 2021 Award of € 10,000 was generously sponsored by Ipsen Pharma. In June 2020 the call for applications was launched on the special David Marsden Award website

www.davidmarsdenaward.org . There was a total of 8 applications.

The David Marsden Award 2021 was awarded to Dr. Martin Reich, Julius Maximilian's University, department of Neurology in Würzburg, Germany for his paper:

Probabilistic mapping of the antidystonic effect of Pallidal neurostimulation: a multi-centre imaging study.



Dr Martin Reich

Dr. Reich was presented with the award by Dystonia Europe President Adam Kalinowski at the Basal Ganglia Session at the on-line EAN (European Academy of Neurology) Congress on 19 June 2021, and at the digital Dystonia-Days 2021 held on 5 September. Dr Reich expressed his thanks to DE and Ipsen for the award and then presented the work of his research. From 2021 the award will be presented every year.

Dystonia Webinar Series

It was decided that the webinar series would include a total of 10 sessions with dystonia experts and various topics. In 2020 there were four webinars and in 2021 there were another five webinars. These were available on both zoom and facebook. Between 30-60 people attended each webinar. The 10th webinar will take place at the beginning of 2022.

This year's webinars included topics such as Neuro-modulation for dystonia in childhood; Dystonia & Covid-19; Writer's cramp; DBS for dystonia; Eur dyscover research network update. The webinars were recorded and are available on the Dystonia Europe YouTube channel: https://www.youtube.com/playlist?list=PLFvCc6fYkjEt_7GhGF9OwEELXo2iBeVRk

Dystonia Podcast – The Positive Twist

In 2020 the Positive Twist podcast was launched with host Amanda Benson who invited 1-2 guests for each episode. In 2021 there were four episodes. There was a good mix of dystonia experts, researchers and patients. There has been a total of over 2000 downloads of the podcast episodes. The most popular episodes are:

1. The Importance of Physiotherapy with Johanna Blom
2. Making Dystonia your Friend, Monika Benson
3. Finding Success in Career, Love and Life, Emmanuel Dalmas

These can be found on various channels where you find podcasts.

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



Dystonia Europe Connecting with Dystonia Patient Associations

• ARD – Annual Dystonia Day

President Adam Kalinowski took part in the annual Dystonia Day of ARD, the Italian Dystonia Association, where he presented the work of Dystonia Europe. The meeting was held on-line.

• ALDE 30th Anniversary

DE President Adam Kalinowski participated at the celebration of the 30th Anniversary of the Spanish Dystonia Association, ALDE—Asociación de Lucha Contra la Distrofía en España. The event took place in Madrid on 20 November. ALDE, with its former President Felisa Justo Alonso, was one of the founding members of Dystonia Europe in 1993.

• DDG on-line meeting on Dystonia

On 18 November, Merete Avery attended an on-line meeting by DDG (the German Dystonia Association) in coalition with the Medical Professionals, Prof Eckart Altenmüller, Prof Joakim Krauss, and Prof Dirk Dressler, who gave an on-line workshop on dystonia. The focus was on Musicians' Dystonia, Treatment of Dystonia, DBS and Botulinumtoxin.

Dystonia Europe Think Tank

Two Dystonia Europe Think Tank meetings were held in 2021. Both meetings were held on Zoom due to the pandemic, the first in February and the second in September. Members of the Think Tank are the Dystonia Europe Board members and the 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.

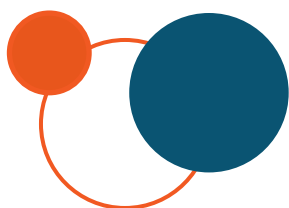
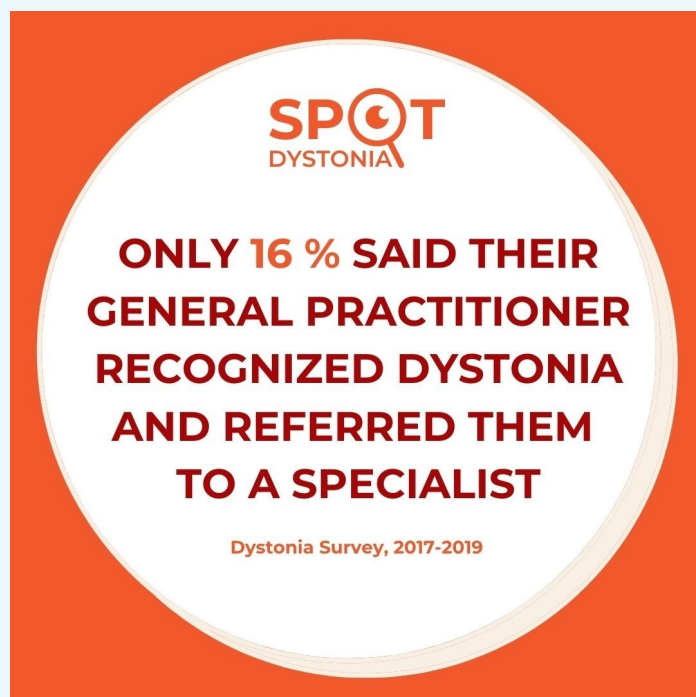


September Dystonia Awareness Month 2021

For the fifth 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 a special campaign called Escape Dystonia. Can a passion for a certain hobby or sport help manage dystonia symptoms? With #Escape Dystonia, we shared posts with photos illustrating what helps different patients to ease symptoms and manage their dystonia. Many dystonia patients engaged on social media and shared their experience with activities they do to cope and escape dystonia such as yoga, painting, go for a walk and engage with animals. Some of the content received may be used for future inspirational quotes and posts on our social media channels.

Based on the first results of Professor Maja Relja's survey on time of diagnosis, treatment and quality of life we created the #spotdystonia series. Infographic showing some of the survey results.



MyDystonia

MyDystonia 2.0 was launched in 2021 www.mydystonia.com and is the digital diary for dystonia patients where you can monitor symptoms, health and daily well-being by answering some pre-defined questions. The data can be downloaded into a PDF-file which can be shared with the treating physician to optimise treatment and improve quality of life.

In 2019 the work of updating the App was started with the advice and support from both dystonia patients and a team of medical experts. The work on the App has been delayed due to the Covid-19 pandemic and was finally launched in 2021, for now only in English. We plan to launch the APP in 5 more languages in 2022.

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 2021 the Ambassadors’ Meeting was held on-line end of June. Ambassadors from countries attended the meeting led by Dystonia Europe President Adam Kalinowski. 7 countries participated. During the year tests have been carried out in the development of the APP 2.0 with Ambassadors and our Medical Specialists.



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 Grönenthal 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>

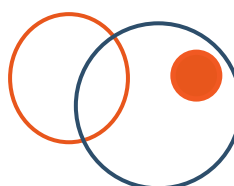
In 2019 Ipsen contributed with a grant for this project.

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.



Dystonia Pyshio 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 started this year with phase 1 and the development of the platform and was launched in Sweden in November.

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.

About 50 physiotherapists in Sweden have registered for the platform and are using it for their dystonia patients. So far the user feedback has been positive.



Physiotherapist Johanna Blom

Cervical Dystonia Patient Journey

In the ERN-RND network it has been agreed to 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 has developed 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.

15 cervical dystonia patients from three countries (UK, France and Italy) answered a questionnaire including 45 questions. The CD literature and various patient testimonies were used to design the survey questionnaire which was later refined by the project team.

The survey results served to create the persona Lilly, to describe her medical and emotional experience during her journey, to define her treatment pathway and to identify her needs & challenges.

A virtual focus group, composed of the executive director of Dystonia Europe (DE) and members of the leadership team of the patient associations (PAs) of each country, was used to validate the findings of the survey – to make sure that the data truly represent a generic European patient.

It was also agreed to start the work to publish the results in appropriate journals.

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) was launched end of May and was available until 28 February 2022. 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.

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 the Vice President of EFNA. EFNA held its General Assembly 2021 via Zoom. <https://www.efna.net>

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 2021 online and also in the EPF Congress in October, which lasted for four days on-line. In addition Merete Avery participated in 2 meetings online held by EPF on Artificial Intelligence within healthcare, at these meetings representatives from the EU held presentations on how AI can improve and lower the costs of healthcare and in addition discussed ethics on AI. <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>

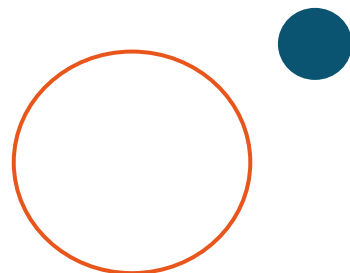
Participation as ePAG

(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.

Publications planned for the beginning of 2022. Prof Maja Relja is the project leader. For more information about the project visit:

<https://www.braincouncil.eu/projects-and-initiatives/vot2/>



On November 16, Monika Benson attended the annual meeting of the EurDyscover Consortium that was held on-line. Specialists from dystonia expert centers in Germany, Czech Republic, France, Italy and Portugal were present.



2022 & 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.
- **Encourage the search for a cure** by working in close partnership with the dystonia **research** community.

Activities & Projects

Board Meetings

Due to the Covid-19 pandemic we have had all meetings the last two years on-line, but for 2022 we plan to start meeting face-to-face again (alongside Dystonia Days 2022 in Copenhagen and alongside the Summer Think Tank 2022). In addition we plan to continue on-line board meetings on a regular schedule.

Think Tank Meetings

Two meetings are planned for 2022 in February and September. The first meeting is planned to be held on-line while the meeting in September will hopefully take place face-to-face in Lund, Sweden.

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 – is continuously 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.

This year we will attend the EAN Congress in Vienna end of June and the MDS Congress in Madrid in September.

Dystonia Webinars

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 and in 2021 there were another 5 webinars. The 10th webinar will be in the beginning of 2022. We will continue to organize webinars. We offer to our members to use our Zoom account and to organize national webinars. We support the setting up of such an event and can also assist during the event. Speaker and panelist have to be organized by the national team as well as the national promotion of the event.

Dystonia Podcast: The Positive Twist

The first season of our podcast: The Positive Twist has had more than 2000 downloads and much positive feedback. In 2022 we are launching season two with new episodes covering different topics with dystonia patients and dystonia experts.

Dystonia Europe 29th Annual General Assembly

On 20 May the 29th Annual General Assembly will take place at the ScandicCopenhagen in Copenhagen, Denmark.

Dystonia Day 2022

On Saturday 21 May, there will be Dystonia Day 2022 at the ScandicCopenhagen in Copenhagen. The day will include expert presentations on dystonia, patient testimony and information from Dystonia Europe.

Dystonia Days 2023 & Dystonia Europe 30th Annual General Assembly alongside International Dystonia Congress and the 6th International Dystonia Symposium

The Dystonia Europe Anniversary and General Assembly will be held in Dublin, Ireland alongside the 6th International Dystonia Symposium, 1-3 June. This medical congress has been postponed from 2020 due to the Covid-19 pandemic.

David Marsden Award 2022

The Award is from 2021 given every year instead of every other year and is once again this year sponsored by Ipsen.

This year it will be the 11th time it takes place. The Award will be presented by President Adam Kalinowski at the Dystonia Day in Copenhagen and at the European Basal Ganglia Club Session at the EAN Congress on 26 June in Vienna.

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>

David Marsden Award 2023

In Autumn 2022 the call for applications for the David Marsden Award 2023 will be launched on the special David Marsden Award website

www.davidmarsdenaward.org.

The 2023 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.

Launch of Dystonia Europe Clinical Fellowship

One of the most popular and successful initiatives of the COST program for Dystonia was the STSM program, allowing young neurologists to spend some time in another department in Europe. This program provided additional knowledge and strengthened the link between countries and between people. Now, many of the STSM talents are promising of confirmed doctors and/or scientists. Other programs are offered at the moment (e.g. European Academy of Neurology fellowships) but the duration is short (up to 12 weeks)

Until now, most of the initiatives have focused on Parkinson's disease (e.g. MJ Fox foundation) or neurosciences (research fellowships are part of educational programs of scientific societies). But very little is done to offer the opportunity to gain high quality clinical experience in rare diseases, especially Dystonia.

Therefore, 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.

This pioneer program of clinical Fellowship in Dystonia will be:

- a successful investment for the patients to ensure that their future doctors will have a solid knowledge and a wide experience and will provide a high standard of care.
- connected with efficient European network of highly specialized doctors, dedicated to Dystonia and related disorders.

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.

Dystonia Patient Journey

The work on the Patient Journey project continues together with Ipsen and the results were submitted and accepted for publication in the *Journal of Dystonia*. The next steps will be to use the findings of the PJ to create awareness material to share during awareness month; present the findings at different meetings and congresses. It has also been suggested that the journey should be translated to Italian and French since the dystonia patient organisations from these countries were also involved in the project.

Dystonia Physio Exercise Hub

In the second year of this project Physiotherapist Johanna Blom at the Neurology Department of the University Hospital of Skåne in Malmö, Sweden, will form a small international team of physiotherapists specialised in dystonia. With their advice and support the aim is to launch the platform in five new languages.

In this year's phase the exercises in 3D-models will be animated. One of the aims is also to connect the exercise program to the MyDystonia digital diary.

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 program.

The project is supported by a 2-year grant from Boston Scientific Foundation Europe.

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 results of the survey (on Sexuality) that closed end of February 2022 will be presented at the Dystonia Day conference in Copenhagen. The second survey (on Diet) is planned to be launched on 1 May. The survey 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 has over 300 users. User feedback is coming in and we are working on further improvements. The plan is to start translation to other languages this year.

The next MyDystonia Ambassadors Meeting may take place at the end of the year.

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, Twitter and Linked-In. The content will consist of informative facts, inspirational quotes, and sharing of dystonia patients' stories.

New for this year's awareness month will be the infographics and material created from the Patient Journey and the short videos from the video project (see below).

Dystonia Videos

Together with the Irish company we embark on a project to produce 5 short videos to show what everyday life situations can be like for people living with dystonia. President Adam Kalinowski is working together with Dystonia Ireland to identify dystonia patients for a meeting with the producer in order for him to have a full picture of what it means to have dystonia. There will be both real patients and actors in the videos.

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 socio-economic impact and health gains from best practice healthcare interventions in comparison with current care (economic evaluation/cost-consequences analysis).

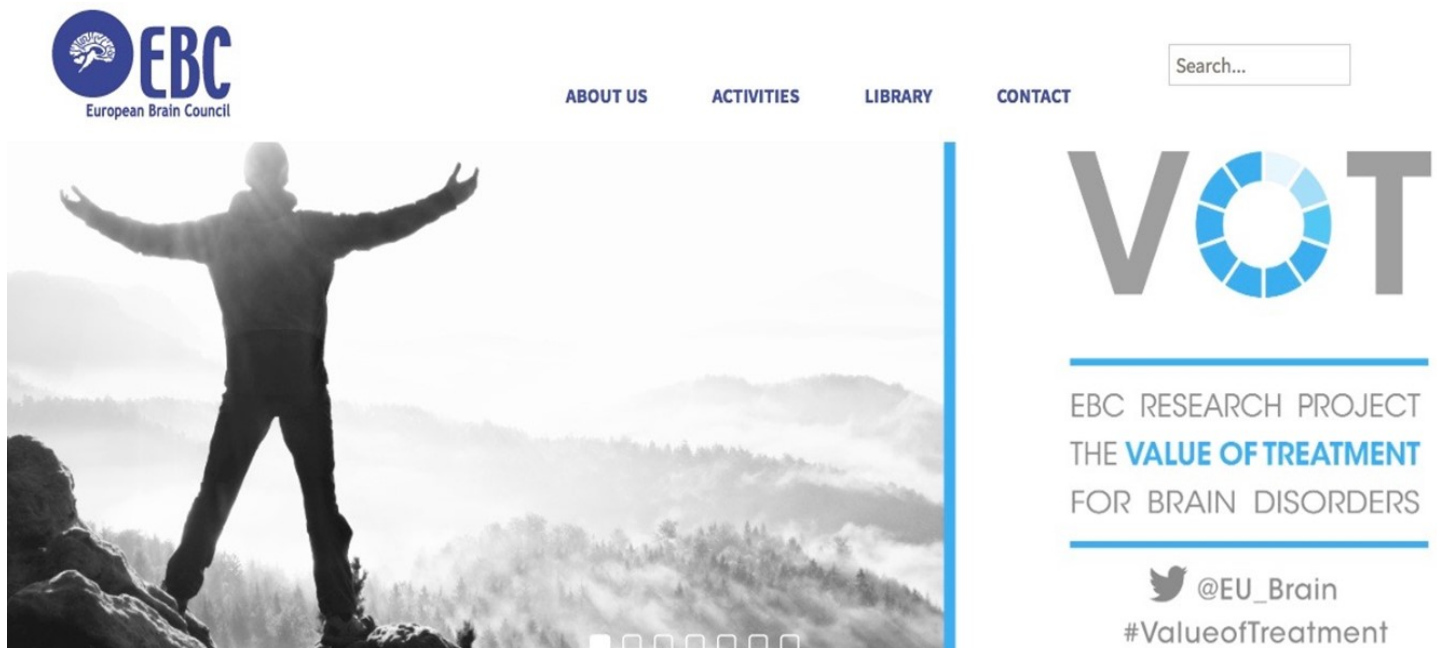
The two-year study on the value of early diagnosis and intervention for rare neurological disorders will aim to assess the benefits of coordinated care and multidisciplinary care patterns on patient outcomes. The overall objective is to propose policy recommendations on how to provide optimal care in 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 2022.

EurDyscover

DE continues its involvement in the research project EurDyscover, initiated by Prof Volkmann and partners in 2019.



EBC
European Brain Council

ABOUT US ACTIVITIES LIBRARY CONTACT

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VOT

EBC RESEARCH PROJECT
THE **VALUE OF TREATMENT**
FOR BRAIN DISORDERS

@EU_Brain
#ValueofTreatment

Final Accounts 2021

Dystonia Europe 2021

Annual Accounts January 1st - December 31th

Income and Expenditure	Euro
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Income	
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Membership Fees	330
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Core Grants	100000
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Project Income	77293
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Other Income	1573
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Total Income	179196
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Expenditure	
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Core Costs	
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(Office,Board meetings,Staff,Travel etc)	100436
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Project Costs	58352
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Total Expenditure	158788
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Result of the Year	20408
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Balance Sheet	
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Cash at Bank and in Hand	249762
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Result of Previous Years	198579
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Result of year 2021	20408
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Members

Dystonia Europe consists of 22 national member groups from 19 European countries and they are:

Austria, Belgium, Croatia, Czech Republic, Denmark, Finland, France, Germany, Ireland, Italy, Norway, Poland, The Netherlands, 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.

Contact

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Telephone: +46 739 984961

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www.dystonia-europe.org

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

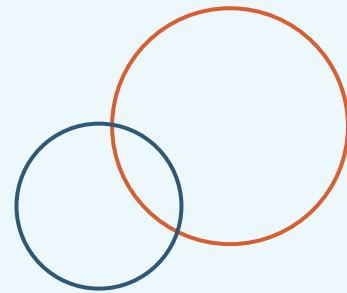
We thank the following partners for their generous support:

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 over where Dystonia Europe members are located



PLATINIUM

Boston
Scientific



Medtronic

Further, Together



THERAPEUTICS

Better outcomes for more patients.

