

# DYSTONIA EUROPE



## 2019 Annual Report

**Dystonia Europe  
connecting people to  
spread information,  
raise awareness &  
promote research**

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## **Dystonia**

**is a chronic neurological movement disorder affecting one or more muscle groups, causing sustained muscle contractions and leading to twisting and repetitive movements or abnormal postures.**

**Dystonia can affect both men and women of all ages. When onset occurs in childhood it is often particularly disabling. The best medical estimates suggest that there are more than half a million people living with dystonia in Europe. Treatments exist to minimize the symptoms but there is still no cure.**

## MESSAGE FROM PRESIDENT & EXECUTIVE DIRECTOR



*Adam Kalinowski*  
*President*



*Monika Benson*  
*Executive Director*

Dear all,

It is a great pleasure for us to present the Annual Report of 2019. We can look back at a year filled with special events and activities.

The 26th Dystonia Europe Annual General Assembly was held in London on 5 July, the day before the Dystonia Day. The D-Day conference was held in London on Saturday 6 July, in cooperation with Dystonia UK. The conference was live-streamed and you find the presentations and more on our YouTube channel.

Dystonia Europe has 22 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 their substantial contributions to the achievements of the past year.

We look forward to our continued association with you all, and invite you to join us in our mission to connect people for dystonia in the year ahead.

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

Adam Kalinowski  
President

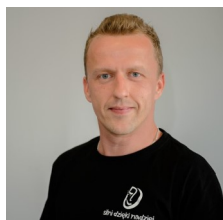
A handwritten signature in black ink that reads "Monika Benson".

Monika Benson  
Executive Director



## MANAGEMENT & ADVISORS

### Board of Directors - Dystonia Europe is governed by a volunteer Board of Directors.



**Adam Kalinowski,  
President, Poland**

Adam has had dystonia since 2006. He founded an online support group for patients from Poland, which

marked the start of his career as a patient advocate. In 2016, he became a member of the Polish Dystonia Association where he currently acts as a Board Secretary. In the same year he became Ambassador for the MyDystonia application.

Adam was elected to the DE Board in 2017. One of his roles is the coordination of the MyDystonia Ambassador program. Adam is a very dedicated advocate for dystonia patients and has spoken about dystonia in the EU Parliament in 2018. He is also an administrator of his own website called 'Dystonia Good Story'. He is Polish but he lives in Ireland where he studies graphic design. Adam was re-elected to the Dystonia Europe board in London 2019, and is now the President of Dystonia Europe.



**Edwige Ponseel,  
Vice President,  
France**

Edwige is the Chairwoman of the French Dystonia Association, Amadys. The

objectives of the association are to provide support to dystonia patients, to raise public awareness, to promote research and to organize meetings and events. Edwige works in the purchasing and marketing department of a company near Paris. She was diagnosed in 1994 with cervical dystonia.

She was elected to the DE Board at the General Assembly in Rome in 2017. She was re-elected at the last GA in London and she is now the Vice President of Dystonia Europe.



**Gill Ainsley,  
Secretary, UK**

Gill is Board Member of A.D.D.E.R. (Action for Dystonia, Diagnosis, Education and Research), United Kingdom. Gill is very

interested in raising awareness of dystonia and in research that would lead to a cure for dystonia. Gill's first language is English, she is also a skilled computer operator. Gill's profession is engineering and she worked for many years as an Electromagnetic Compatibility Test Engineer on aircrafts.

Gill was nominated and elected as Board Member to Dystonia Europe in 2019 and is the Secretary of Dystonia Europe.



**Sissel Buskerud,  
Treasurer, Norway**

Sissel is the Treasurer/Accountant responsible and Board Member of the Norwegian Dystonia Association for the last 7 yrs. Sissel

has experience for more than 25 yrs. as an Accountant for a Norwegian Security Company. Sissel was elected to the DE Board at the GA in London in 2019 and is the Treasurer of Dystonia Europe.



**Catalina Crainic,  
Board Member,  
Romania**

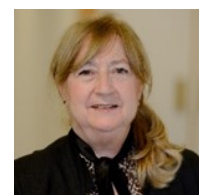
Catalina Mariana Crainic is the President of the Romanian Dystonia Organisation,

Associatia Childrens Joy and a Board Member of National Alliance of Rare Diseases, Romania. Catalina has broad training, within Art and Painting and also in Educator Recovery within the field of Social and Pedagogical for people with special needs. She also has training in Rare Diseases for Journalists and Effective Communication with the press, representing patients organisations. Catalina was elected to the DE Board in 2019



**Alistair Newton, MBE  
Advisor, UK**

After several years as Vice Chair of the Dystonia Society in the UK, Alistair founded European Dystonia Federation, now Dystonia Europe, in 1993. He served 8 years as President and was the Executive Director between 2001 and 2013. He was appointed to the Dystonia Europe Board with special responsibility of the Dystonia Research Network. Alistair also co-founded EFNA – the European Federation of Neurological Associations – in 2000, where he acted as Treasurer and Secretary-General until 2011. In 2003, he was involved in the founding of the EBC – the European Brain Council, where he was a board member and a treasurer for many years. He is now an advisor to DE on special projects. In 2019 Alistair received an MBE – Member of the British Empire for his work for neurology patients in Europe and especially for those affected by dystonia.



**Maja Relja,  
Advisor, Croatia**

Maja is a professor of neurology, in charge of the movement disorders section at Zagreb University Hospital. She founded the

Croatian Dystonia Association and has served as its President for over 20 years. In 2011, she was elected to the board of Dystonia Europe, Between 2011 and 2017 Maja was the Vice President of DE. At present she is the project leader of the Value of Treatment project regarding dystonia. .



**Eelco Uytterhoeven,  
Advisor, The Netherlands**

Eelco has been a professional IT-consultant and developer since 1999.

For the last few years, since 2016 he has been working as a freelance developer on several internet projects related to Dystonia Europe. Since the beginning of 2016 he is responsible for the maintenance and further development of the MyDystonia platform. Together with the board Eelco wants to raise the professional level of the IT projects of Dystonia Europe and assist in creating new possibilities for the future.

## STAFF



**Monika Benson,**  
**Board Member and Executive Director,**  
**Sweden**

Monika was elected President of EDF, now Dystonia Europe, in 2007. She was re-elected for a second term in 2010. Monika stepped down as President in 2013 after serving the maximum period of 6 years. She took over as Executive Director after Alistair Newton's retirement. Monika has cervical dystonia and was a board member of the Swedish Dystonia Association for 10 years. Monika has been working as a coordinator of work-shops, courses and lectures at a school in Lund, Sweden.



**Merete Avery,**  
**Operations Manager, Norway**

Merete was appointed to the board of Dystonia Europe in 2013 and was Secretary from 2013-2015. Merete was appointed President at the Board Meeting, following the GA, in Rotterdam 2015. She stepped down as President in 2019 after the maximum period of 6 years in the DE Board. She was diagnosed with cervical dystonia in 2006 and was Chairwoman of the Norwegian Dystonia Association between 2010-2013. Merete has been working with customer service, accounting and finance in Molde, Norway.

## MEDICAL & SCIENTIFIC ADVISORY BOARD

Prof Alberto Albanese – Milan

Prof Alfredo Berardelli – Rome

Prof Kailash Bhatia – London

Prof Rose Goodchild – Leuven

Prof Marina de Koning-Tijssen – Groningen

Prof Joachim Krauss – Hannover

Dr Francesca Morgante— London

Prof Tom Warner – London

Dr Jean-Pierre Lin – London

Prof Maja Relja – Zagreb

Prof Eduardo Tolosa – Barcelona

Prof Marie Vidailhet – Paris

Prof Marjan Jahanshahi—London

## BOARD REVIEW

Three board meetings were held during the year. The first one in February when the Board gathered in Lund, Sweden alongside the 7th Think Tank meeting. The next board meeting took place in July, alongside the D-DAYS 2019 in London. The third board meeting of the year was once again held in Lund, before the Summer Think Tank meeting in September.



*The Dystonia Europe Board*

## 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 1500 visits/month.

### Newsletter

DE News was issued two times in 2019, in summer and winter. The two issues were sent by email to members and about 400 contacts in July and December.

### Printed Materials

The Dystonia Europe printed materials such as information leaflets and newsletters were distributed at various meetings and congresses: the

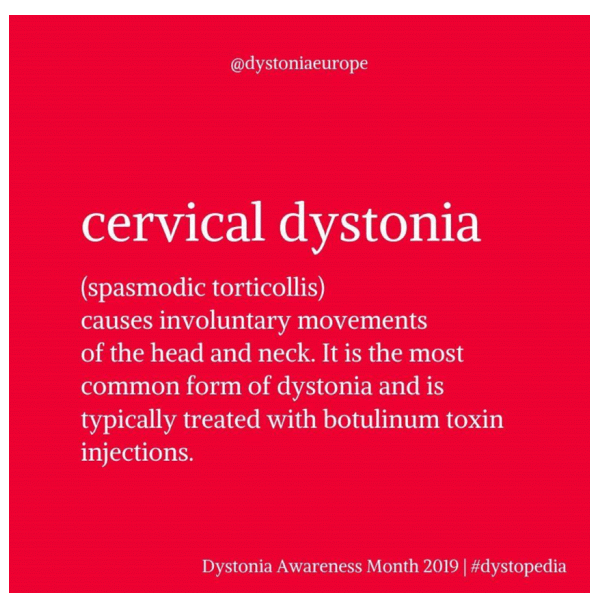
Toxins Congress 2019 in Copenhagen, the International Congress on Dystonia Treatment in Hannover, the EAN Congress in Oslo, the International Movement Disorder Congress in Nice, and at the Dystonia Europe 26th Annual Conference/D-DAYS 2019 in London.

### 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.

In the last year the amount of followers has increased substantially:

	2018	2019	Growth:
Facebook	3361	4258	+ 27%
Instagram	463	1044	+ 125%
Twitter	438	756	+ 73%
YouTube	137	318	+ 132%
Linked-In	150	196	+ 31%





## ACTIVITIES & PROJECTS

### David Marsden Award 2019

The 2019 Award of € 10,000 was generously sponsored by Ipsen Pharma. In June 2018 the call for applications was launched on the special David Marsden Award website [www.davidmarsdenaward.org](http://www.davidmarsdenaward.org).

The winner of the DMA 2019 was Anne Weissbach for her paper “[Alcohol improves cerebellar learning deficit in myoclonus-dystonia: A clinical and electrophysiological investigation](#)”.

The winner Dr. Weissbach is a neurologist and clinician-scientist in Prof Christine Klein’s team at the Institute of Neurogenetics in Lübeck. She studied Medicine at the University of Lübeck and finished her residency in Neurology at the Clinic of Neurology at the University. The Award was given to Dr. Weissbach at the Dystonia Day in London where she also gave a presentation of her research.



DMA winner 2019  
Dr. Anne Weissbach

### Dystonia Europe Connecting with Dystonia Patient Associations

#### • Swedish Dystonia Association 25th Anniversary

In February the SDF – the Swedish Dystonia Association celebrated its 25th Anniversary in Stockholm, Sweden. The organisation held its Annual General Assembly and about 35 members attended. After the formal part three physiotherapists gave a workshop on physiotherapy and dystonia. Representatives of Dystonia Europe, NDF (Norwegian Dystonia Association) and DDF (the Danish Dystonia Association) joined the celebration.

#### • Norwegian Dystonia Association Spring Meeting and General Assembly, Norway

In April the Norwegian Dystonia Association (NDF) held its national spring meeting at Hotel Olavsgaard, Skjetten nearby Oslo. The President Johan Arnfinn Warvik opened the meeting and talked about activities and meetings they attend, like the Norwegian Dystonia Network (a network of medical professionals, where also NDF is invited to participate) and the National Competence Centre for Movement Disorders at Stavanger University Hospital, to mention some. Then Dystonia Europe President Merete Avery, gave a presentation on the work and activities of Dystonia Europe.

## ACTIVITIES & PROJECTS

### **The 26th Dystonia Europe Annual Conference & General Assembly 2019 & the 6th D-DAYS**

The Dystonia Europe 26th Annual Conference & the D-DAYS 2019 were held at the Novotel Hammersmith Hotel in London, UK. A total of 178 participants joined the event, making it one of the largest D-DAYS we have ever organised.

The audience consisted of national dystonia patient group leaders from all over Europe and dystonia patients and family members from United Kingdom. The conference was a close collaboration with Dystonia UK. An external moderator guided the audience through a variety of sessions. The patient testimonies were very much appreciated. Dystonia experts from the UK and elsewhere presented the latest on research and treatment.

The event was live-streamed and recorded and all presentations are available on the Dystonia Europe YouTube channel.

The Dystonia Europe members also took part in the formal General Assembly and a strategy workshop over the weekend. Dystonia Europe consists of 22 member associations from 18 countries in Europe.

We are very grateful to our Platinum sponsors: Boston Scientific, Ipsen Pharma, Medtronic and Merz for their valuable support of our annual meeting. They all had stands with information material in the exhibition area.



*Members and Stakeholders of Dystonia Europe, make a "Jump for Dystonia" in London during the Dystonia Days in 2019*



## ACTIVITIES & PROJECTS

### Dystonia Europe Think Tank

Two Dystonia Europe Think Tank meetings were held, one in the middle of February and one in September. Members of the Think Tank are the Dystonia Europe Board and representatives of our Platinum sponsors: Boston Scientific, Ipsen Pharma, 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. Both meetings were held in Lund, Sweden where Executive Director Monika Benson can arrange for meeting rooms free of charge.

*Right: The participants of the Summer Think Tank 2019 in Lund, Sweden*



*The Think Tank Participants make a «Jump for Dystonia»*

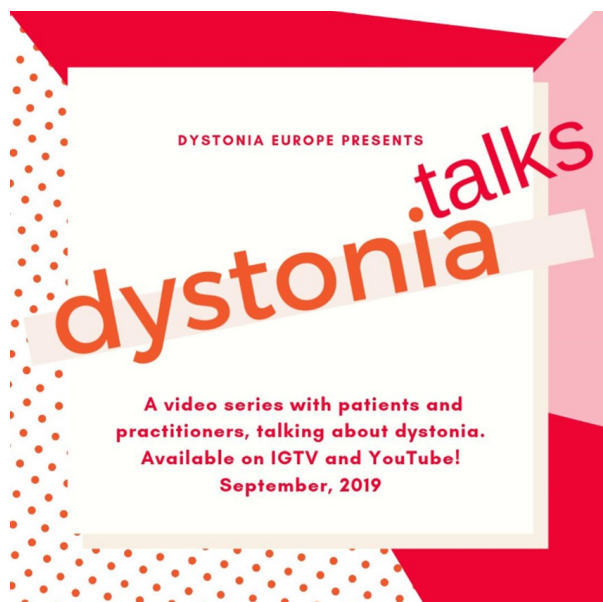
## ACTIVITIES & PROJECTS

### Dystonia Awareness Month – September 2019

For the third 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. Dystonia Europe has in the past two years prepared special material to be posted during the month. Reports show that this material engages our followers and creates an increased visibility of our channels. For this year's awareness month we had prepared short videos (Dystonia Talks), special dystonia fact posts (dystopedia) inspirational quotes, which were all shared on all social media channels during the month. Since we record our D-DAYS presentation we always promote these as well during the month. There was a substantial increase of activities and engagements, and our posts reached over 120 000 people compared to 77 000 in 2018. The top post of the month was a dystonia fact box explaining what cervical dystonia is.

### Dystonia Talks

At our last conference D-DAYS 2019 in London we launched **Dystonia Talks** – a digital project to raise awareness of dystonia, funded by a grant from Boston Scientific Foundation. During the D-DAYS we invited patients, carers, dystonia patient leaders from across Europe, experts, researchers and industry to be interviewed and video-recorded.



*The Dystonia Europe Board promoting Awareness Month*

A total of 21 videos have been developed. Eight of those were ready to be published during the Awareness Month and the others have followed. They can all be found on our YouTube Channel. We believe these videos can be re-posted, shared and used for the next few years.





## ACTIVITIES & PROJECTS

### Jump for Dystonia

Our dystonia awareness campaign "Jump for dystonia" was launched in Paris in 2014. It reached its peak during 2015 and all together over 10 000 jump photos were submitted. People have been asked to Jump for Dystonia and the photos have been uploaded to a special Jump for Dystonia facebook page: [Jump for Dystonia](#). The campaign has engaged and inspired dystonia patients all over the world.

In 2019 we did not work actively with the campaign. Once in a while we receive photos and video clips with jumps and therefore we keep the dedicated facebook page live.

When Dystonia Europe takes part in meetings we very often ask to do a joint Jump for Dystonia.

This Dystonia  
Awareness  
Month we will:



### MyDystonia

MyDystonia [www.mydystonia.com](http://www.mydystonia.com) is the digital diary for dystonia patients where you can monitor symptoms, health and daily well-being by answering some predefined questions. The data can be downloaded into a PDF-file which can be shared with the treating physician to optimize treatment and improve quality of life.

The APP is available on-line as well as in APP-Store and Google Play. It's available in 10 languages (English, German, French, Spanish, Italian, Danish, Norwegian, Swedish, Finnish, Russian) and has a little more than 2600 users. During the year substantial work has been done on the updated version MyDystonia 2.0 which is planned to be launched in 2020.





## ACTIVITIES & PROJECTS

### MyDystonia Ambassador Programme

The MyDystonia Ambassador Programme was launched in 2016 to support the roll-out of the MyDystonia APP in Europe. The fourth meeting took place on 25-27 October in Newcastle, UK. MyDystonia Ambassador Gill Ainsley organized the event along with Adam Kalinowski the MyDystonia Coordinator.

*MyDystonia Ambassadors  
meeting in Newcastle*



Ambassadors from the UK, Germany, Ireland/Poland, Spain/Italy and Norway, Finland and Denmark attended. 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 share issues and have access to support materials, videos etc.

### MyBrainNet

The 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. With MyBrainNet it will be possible for other patient organisations to join the project and have an app of their own. We aim to share this platform with other patient organisations working in the field of brain diseases. We believe it's 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 will be 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 Europe Patient Survey

Professor Maja Relja, Medical School of Zagreb, Croatia, has developed the Dystonia Survey where patients are asked questions on time of diagnosis, access to treatment and quality of life. The Survey has been translated to 21 languages and was accessed via a special Dystonia Europe Survey platform: <https://surveys.dystonia-europe.org>.

The Survey was launched in September 2017. The preliminary results were first presented at a special lunch in the EU Parliament during the 25<sup>th</sup> Anniversary conference in Brussels in 2018, and then again during the Dystonia meeting alongside EAN Congress in Oslo June 2019. The survey closed on 1 October 2019. The first results show that 40 % of patients wait for 3-10 years before diagnosis and 35 % of the patients say dystonia affects all aspects of life. The data of the survey is being processed and the final results are expected to be presented in 2020.

## PARTICIPATION AT MEETINGS & CONGRESSES

### 4th TOXINS Conference

The International Neurotoxin Association (INA), arranged the TOXINS 2019, Basic Science and Clinical Aspects of Botulinum and Other Neurotoxins, 16-19 January, 2019, in Copenhagen, Denmark.

Dystonia Europe had a stand at the conference with information on Dystonia Europe and its members, ongoing projects, like the MyDystonia App, the David Marsden Award, the dystonia survey etc. President Merete Avery and Executive Director Monika Benson represented DE. Some of the highlights of the conference were workshops on ultrasound guided treatment of botulinum toxin. You can read more about INA and the TOXINS Conference at [www.neurotoxins.org](http://www.neurotoxins.org)



### EPF Capacity building on Empowering Leadership and Positive Organisational Governance

Dystonia is a member of the European Patients Forum (EPF). This gives us the possibility to take part in various workshops and meetings. The first meeting of the Capacity building workshop was held in March in Brussels, Belgium and the second meeting in September in Sofia, Bulgaria. This training lasted from March to September with two face-to-face meetings and six online sessions. Dystonia Europe Operations Manager Merete Avery took part in the training.

### 4th International Congress on Treatment of Dystonia

The Congress was held on 8-11 May in Hannover, Germany. Almost 400 participants from 4 continents together with a faculty of more than 70 world-leading experts from the fields of neurology, neurosurgery, neuropaediatrics, neurogenetics, basic sciences and allied health sciences. The congress's emphasis was on novel treatments for all forms of dystonia, including botulinum toxin therapy, deep brain stimulation, various behavioural methods and new emerging strategies to improve or even prevent the development of dystonia. There were nine hands-on workshops and focused lunch time satellite symposia supplemented the conference and contributed to the vivid exchange of ideas.

The highlight of the congress was the Keynote Lecture by Alan B Scott and Eric A Johnson on the 'Invention of the Botulinum Toxin Therapy'. It was the first time that the 'fathers of botulinum toxin therapy' appeared on one stage and shared their personal recollections of the early days of botulinum toxin therapy.

From Dystonia Europe President Merete Avery, Vice President Edwige Ponsel and Executive Director Monika Benson took part.



*From right: Prof. Steven Frucht, Prof. Eckart Altenmüller, Monika Benson, Merete Avery, Prof. Joachim K. Krauss and Prof. Dirk Dressler*



## PARTICIPATION AT MEETINGS & CONGRESSES

### The 5th EAN – European Academy of Neurology – Oslo, Norway

Dystonia Europe was present with a booth in the exhibition hall at the congress and many visitors from European countries and from outside Europe stopped by the stand. DE focussed on networking, distributing brochures and newsletters, spreading awareness of dystonia and sharing the important work of patient organisations.

This year The Norwegian Dystonia Association supported Dystonia Europe. The President of NDF, Johan Arnfinn Warvik, Treasurer Sissel Buskerud and Board Member Rolf Villanger were present at the booth to help spread information about DE and all the work we do.

It is very valuable for Dystonia Europe to be able to connect with the medical profession and the industry at these special congresses. It gives DE the opportunity to share our work and experiences which may lead to new partnerships as well as providing us with updates on the latest developments within the field. More than 6800 neurologists, specialists etc. took part in the EAN Conference.

### MDS Congress, Nice, France

The international congress of the “International Parkinson and Movement Disorder Society” was held in Nice in September, attracting about 6000 movement disorder specialists from all over the world. Monika Benson and Edwige Ponseel participated from Dystonia Europe and had a booth in the exhibition hall.

The day before the congress there was a charity walk to run along the famous Promenade des Anglais. Monika took part in the walk and Edwige was in charge of the information booth.



Monika Benson and Edwige Ponseel at the MDS in Nice



### SIP 10th Anniversary Conference

The Societal Impact of Pain – SIP Platform was celebrating its 10th Anniversary in November in Brussels. SIP is a collaboration between: Pain Alliance Europe, European Pain Federation EFIC, Active Citizenship Network and Grünenthal. The goal of SIP is to achieve improved care and pain management across the EU to reduce the societal impact of the disease, which touches upon all aspects of life. 1 in 5 people in Europe experience chronic pain.

In Europe more than 150 million people suffer from chronic pain. Chronic pain costs the EU €240 billion a year.

For more information visit:

<https://www.sip-platform.eu/en> .

About 100 participants had joined the one-day conference and Dystonia Europe Executive Director Monika Benson attended the meeting for the first time.





## PARTICIPATION AT MEETINGS & CONGRESSES

### World Brain Day – EFNA events in 4 EU capitals



To the left, Dystonia Europe President Adam Kalinowski

The event in Warsaw was attended by Adam Kalinowski, the President of Dystonia Europe, and also a representative of the Polish Dystonia Association. To celebrate World Brain Day (July 22nd), the European Federation of Neurological Associations (EFNA) co-hosted events in four European capitals – Brussels, Bucharest, Dublin and Warsaw! The conference was organized by EFNA as one of four that day in various European countries. The event was linked to the EFNA campaign: #BrainLifeGoals, to raise awareness of the impact of neurological diseases by exploring the dreams and aspirations of those living with a brain disorder.

The aim of these events was to hear what matters most to neurology patients in terms of their health outcomes – #BrainLifeGoals – and to discuss how this can be better integrated in the policy and decision-making at both the national and EU level. The event in Poland was celebrated in Warsaw and marked the launch of the Polish Brain Plan prepared by Foundation Neuropozytywni, in collaboration with the Polish Brain Council, Polish Neurological Society, Lazarski University and DZP law firm.



### EFNA Workshop advocating for Access to Neurology Treatment, Services and Supports

Dystonia Europe President Adam Kalinowski participated in this workshop as part of the Training Initiatives for Neurology Advocates (TINA) by EFNA - European Federation of Neurological Associations. The workshop took place on 28-29 October in Warsaw and gave participants the opportunity to discuss specific access challenges in their countries/disease areas and reach consensus on the main barriers to equitable access to neurology treatment in Europe.

### EBrains

EBrains is working on building a shared digital brain research infrastructure for the EU. It started with the Human Brain Project, whose goals are to interconnect computer science, medicine and neuroscience to accelerate the understanding of the human brain and its diseases, and to bring this knowledge to the benefits of patients and society. To achieve this, the Human Brain Project has built EBRAINS – the world's first integrated ICT infrastructure for brain research and development. EBrains invited scientists, patient organisation representatives, IT specialists involved in the project and other specialists to their second meeting that took place in Brussels on 9 and 10 December 2019. Dystonia Europe was invited and Merete Avery represented the organisation at the meeting. Patients along with all the other participants could voice their opinion about the future aspects of EBrains. The project is co-funded by the European Union.

## ACHIEVEMENTS & AWARDS

**Founding President and honorary member of Dystonia Europe honoured by Queen Elizabeth II for his 30 years' work for dystonia and other neurological patients across Europe.**

Our founding President, Alistair Newton, received the honour of becoming a Member of the Ancient Order of the British Empire (MBE) for services to dystonia and other neurology patients across Europe. The Award was presented in February 2019 at a ceremony in Buckingham Palace, London, by Prince William, Duke of Cambridge, on behalf of Her Majesty the Queen.



*MBE Alistair Newton, one of the Founders and the first President of Dystonia Europe receives honour at Buckingham Palace*

Alistair's work for dystonia patients started in 1987, just a few years after his own diagnosis with cervical dystonia, and he was Vice-Chair of **The Dystonia Society** for many years, until he retired from that board in 2000. During his time at The Dystonia Society, in 1993, he brought national dystonia patient groups in Europe together, to create the **European Dystonia Federation (EDF)** and was the President until 2001. He then became Executive Director until 2013, and remained a Board Member of **Dystonia Europe** until he retired in 2015.

Alistair was also a founding committee member and a long-serving officer of both **European**

**Federation of Neurological Associations (EFNA)** -2000-2011, and **European Brain Council (EBC)** – 2003-2014.

**Active Citizenship Network: the 2nd Edition of the European Civic Prize on Chronic Pain** held its prize ceremony of the 2nd Edition of the European Civic Prize on Chronic Pain at the Concert Noble in Brussels. The four categories were: Patients' Empowerment, Innovation, Professional Education, Clinical Practices. Dystonia Europe had submitted an application for the Patients' Empowerment Prize for the project MyDystonia and was selected by the Jury with the motivation: *"Good sensible project with great organisation to overcome identified obstacles. It is a superb opportunity for increased communication between patients and physicians and improved collaboration between patients with dystonia across Europe."*

Dystonia Europe President Adam Kalinowski had made a video-recording explaining MyDystonia and how it works. Executive Director Monika Benson received the prize from Ilaria Giannico (Secretary-General of European Union of Private Hospitals) and Liisa Jutila, Vice President of PAE – Pain Alliance Europe, at the opening ceremony of the SIP 10th Anniversary Conference.

*Dystonia Europe receives the European Civic Prize.*

*From left Vice President Pain Alliance Europe Liisa Jutila, Finland, Monika Benson Dystonia Europe and Ilari Giannico, Secretary General of European Union of Private Hospitals.*





## 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 2019, in Oslo, alongside the 6<sup>th</sup> EAN Congress. DE was represented by Merete Avery. <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 2019.

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



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

In the continuity of 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/activities/projects/the-value-of-treatment>

### 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 about the foundation:

<http://www.bostonscientific.com/en-EU/aboutus/corporate-social-responsibility/practices/foundation.html>





## EUROPEAN PARTNERSHIPS

### 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 co-ordination and knowledge transfer, ERN-RND shall establish a patient-centred network to address the needs of patients with 11 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 disease represented are Ataxia, Huntington's and Dystonia. The network is also represented by patients in a specific ePAG - European Patient Advocacy Group. Dystonia Europe is a member of this ePAG group. Monika Benson attended the annual meeting of the Network in Sienna, Italy. More information: <http://www.ern-rnd.eu>



### Partner in a European Research Project: EurDyscover

Last October 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/fundedprojects/>) for the project: 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 will be a partner in this project and support with various activities such as information about the project, recruitment of patients etc.



ePAG (European Patient Advocacy Group)

### 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 optimize care and improve quality of life.

### ACTIVITIES & PROJECTS 2020

*Due to the COVID-19 pandemic the plans for this year's work have been adapted to suit the current situation. 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 online.*

### Board Meetings

Meetings are planned to be held in February and due to the Covid-19 pandemic it is unsure whether there will be any more face-to-face meetings. Instead we plan for regular online board meetings via the Zoom platform.

### Think Tank Meetings

Two meetings are planned for 2020 in February and September, in Lund, Sweden. Due to the Covid-19 pandemic the September meeting will probably 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 Covid-19 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 stakeholders we continue our work to develop our various communication channels such as:

**Website** – will be 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 Facts** – is a series of videos with dystonia experts explaining dystonia. These videos will be posted on our website to give better information on dystonia and its treatments.

**Dystonia Europe News** – from this year our newsletter will be 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 a content to our followers that is informative, inspirational and supporting.

### **Dystonia Europe at Congresses**

Dystonia Europe had planned to be present at several congresses this year but due to the Covid-19 pandemic some have been cancelled and some are moved on-line. If possible DE will be present at the on-line meetings.

**Dystonia Europe 27th Annual Conference, D-DAYS 2020 and the 6th International Dystonia Symposium** in Dublin are postponed.

### **Dystonia Europe 27th General Assembly & Digital Dystonia Days 2020**

The General Assembly, for DE members only, will take place on-line on 7<sup>th</sup> June. Our D-DAYS lectures will also move on-line in the shape of a series of webinars that will be held from May until December 2020. There are also plans to launch a dystonia podcast.

### **The David Marsden Award 2021**

The Award is given every other year and is once again sponsored by Ipsen Pharma. Call for submissions will start in June. The 2021 Award will be the 10<sup>th</sup> time it takes place and will be given at the D-DAYS 2021. 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>

The David Marsden Award 2021 is supported by a grant from Ipsen to Dystonia Europe. Ipsen has no control over the award, including evaluation of papers and selection of winner.

#### **The David Marsden Award 2021**

The aim of this award is to stimulate developing knowledge of and interest in dystonia through publications of aetiology, pathogenesis, diagnosis in dystonia or on the psycho social effects.

**€ 10.000,-**



# DYSTONIA FACTS

COMING IN 2020



### **MyDystonia/MyBrainNet & MyDystonia Ambassador Programme**

The work to update MyDystonia 2.0 within the project MyBrainNet continues. Planned launch is in 2020. There are no plans on face-to-face meetings in 2020.

### **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. We will collaborate with the wider dystonia community with the hashtag #dystoniaworld. Our awareness campaign Jump for Dystonia will have a new touch and feel and will be relaunched during the month.

### **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.

### **ERN-RND – ePAG activities**

Dystonia Europe continues its involvement in this important network. Many patients in the network are connected with EURORDIS and DE is planning to apply for a membership here.

### **EurDyscover**

The research project will be launched this year and there will be a start-up meeting to decide on the various activities and involvement of Dystonia Europe.

## Dystonia Europe AISBL

### Annual Accounts for period 1 January - 31 December 2019

#### Income and Expenditure

<b>INCOME</b>	<b>Euro</b>
Membership Fees	1.818,10
Core Grants	111.491,98
Project Income	144.400,70
Other Income	159,12
<b>Total Income</b>	<b>257.869,90</b>
 <b>EXPENDITURE</b>	
Core Costs (Office,board meetings,staff,travel etc)	112.671,31
Project costs	141.041,42
 Total Expenditure	<b>253.712,73</b>
 <b>RESULT OF THE YEAR</b>	<b>4.157,17</b>
 <b>BALANCE SHEET</b>	
Cash at bank and in hand	147.385,72
 Result of previous years	185.184,95
<b>Result of the year 2019</b>	<b>4.157,17</b>

Accounts audited by Yves Mottet at MATS s.a., Chartered Accountants and Tax Advisors, Waterloo, Belgium



## MEMBERS

Dystonia Europe consists of 22 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:



Live better. Feel better. Look better.



### Silver:



We also would like to thank the following partners for their support of various projects:

MyDystonia & MyDystonia Ambassadors Programme – Merz

D-DAYS 2019 – Boston Scientific, Ipsen Pharma, Medtronic, Merz

David Marsden Award 2019 – Ipsen Pharma

MyBrainNet – Ipsen Pharma

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 – 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.

## CONTACT

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### Photos from Dystonia Days 2019:

Stephan Röhl, [www.stephan-roehl.de](http://www.stephan-roehl.de)

### Meet us @

Website: <http://dystonia-europe.org>

Facebook: <https://www.facebook.com/dystonia.europe>

YouTube: <http://www.youtube.com/user/DystoniaEurope>

Twitter: <https://twitter.com/dystoniaeurope>

Instagram: <https://www.instagram.com/dystoniaeurope/>

LinkedIn: <https://linkedin.com/company/dystonia-europe/>



*Dystonia Days Conference in London 2019*