Connecting people for dystonia

DYSTONIA EUROPE

1 - 2020

SPRING NEWSLETTER

Think Tank Participants in Lund, Sweden in February 2020

Contents:

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

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The best wishes for a safe and healthy summer!

From Dystonia Europe to all of you,

President's Message

Adam Kalinowski
Photo: Stephan Röhl www.stephan-roehl.de

Dear all,

Welcome to the first issue of our Dystonia Europe News in 2020. Here we wish to keep you informed about the latest activities and projects of Dystonia Europe as well as providing updates on what is happening in our member organisations. You will also find the latest news on research, campaigns and events from around Europe and beyond.

We already know that 2020 will be very different compared to other years. In just a few weeks our lives have changed dramatically. We understand that this is a difficult time for everybody around the globe. Many people with dystonia are already struggling with isolation and anxiety and are therefore greatly affected by the pandemic situation.

Additionally, with maybe no access to BTX treatment, and the limited contact with family and friends may have an impact on dystonia symptoms.

We know that our member organisations do what they can to support you in this difficult situation. On our website we have collected some materials to support dystonia patients:

www.dystonia-europe.org/dystonia-without-botulinum-toxin-covid-19/

We are also very sorry that we had to cancel our annual D-DAYs conference and we won't get to meet our dystonia friends. In order to meet these changes the Dystonia Europe Board has had to rethink our activities this year. We will carry out a series of webinars with dystonia specialists which you will be able to attend and ask questions. We are working on a dystonia awareness campaign in September.

Above all, we should remember that this situation will not last forever and remain patient and positive.

Finally, I want to express my gratitude to all professions, organisations and individuals for their contribution in helping not only patients with neurological diseases but in the fight against the Covid-19 pandemic.

I wish you all healthy and safe summer,

Adam Kalinowski
President

Latest News

The D-DAYs 2020 is postponed until 2021

Due to the situation with the Pandemic Covid 19, it has been decided to postpone the D-DAYs in Dublin until next year. We plan to hold the event in 2021 in Dublin, Ireland, along with the 6th Samuel Belzberg Dystonia Symposium.

These measurements have been taken to ensure the health and safety of all our members, patients and families, the speakers and health professionals, and all others involved in the event, which is extremely important to us.

More information on the conference that will take place in 2021 will follow. If you have any questions, please contact us by email to sec@dystonia-europe.org

The 6th Samuel Belzberg Dystonia Symposium is postponed and will be held in 2021

Due to the COVID-19 (Coronavirus) pandemic and the many travel bans and other precautions being taken to limit the spread of the virus, the Samuel Belzberg 6th International Dystonia Symposium (SBIDS6) will not be held in Dublin on 4th to 6th of June, 2020 as planned.

This decision was not made easily but the Dystonia Medical Research Foundation and Dystonia Europe, working with the leadership of the Scientific Program Committee, feel strongly that this is the best course of action at this time. The health, safety and well-being of participants, faculty and sponsors and the dystonia community is our priority.

We appreciate that many of you have personally committed time and finances to join us for this meeting and you may have questions regarding cancelling your plans and reimbursement of registration fees etc. Please also allow us time to gather this information and we will provide an update for you as soon as possible.

We are grateful to Drs. Jinnah and Pisani and the Members of the Scientific Program Committee for their hard work in developing the outstanding program for this meeting. We want to thank the program faculty who agreed to speak in June and to those who submitted over 100 abstracts for the meeting. We will provide more specific information in the coming weeks and thank you for your understanding.

DYSTONIA
MEDICAL RESEARCH FOUNDATION

DYSTONIA
EUROPE

SAMUEL BELZBERG
INTERNATIONAL
DYSTONIA
SYMPOSIUM

The Symposium is named in honor of Sam Belzberg, co-Founder of the Dystonia Medical Research Foundation (DMRF), who passed away in 2018. Sam founded the DMRF in 1976 with his wife Frances, shortly after their daughter was diagnosed with dystonia and he was relentless in his drive to find a cure and to provide services for families, like his, whose lives were upended by the disorder.

Dystonia & Covid-19 Pandemic

What is Coronavirus and Covid-19?

COVID-19 (Coronavirus disease 2019) is a new disease that can affect your lungs and airways. It's caused by a virus called coronavirus. Symptoms include fever, tiredness and dry cough, and there is currently no treatment.

For detailed information on the corona virus and Covid-19 and the most updated advice and guidelines on how to behave to reduce the risk of spreading or catching the infection, we refer to the following pages:

- WHO - World Health Organisation https://www.who.int/news-room/q-a-detail/q-a-coronaviruses

- ECDC – European Center for Disease Prevention and Control https://www.ecdc.europa.eu/en/covid-19-pandemic

In addition to the above, national governments of European and non-European countries have published or are publishing country-specific guidelines, measures and actions.

Please ensure you follow the advice and recommendations in the country where you are based.

Some simple preventive methods you can think of to avoid catching or spreading the infection:

- **Wash your hands often**
- **Don't touch your face.**
- **Sneeze in your elbow.**
- **Social distancing – work from home and do not see older people.**

Are dystonia patients at a higher risk? What can you do if you cannot have your BTX treatment?

We have asked some dystonia experts for their recommendations and advice.

Professor Tom Warner at Queen Square Institute of Neurology in London, says:

As for dystonia I do not think focal dystonia will have any impact on whether people get sicker with covid infection, or are at higher risk.

The important thing is dystonia does not affect the immune system and most people with focal dystonia are otherwise fit and active. The same would apply for laryngeal dysphonia as it does not usually affect the swallow.

The only factor is age, and that is the same for all people as outcomes as we get older are less good with covid infection. The other risk factors are the same as for other people. If you have another disease such as diabetes, cardiovascular, high blood pressure you are at a higher risk.

The only cases of dystonia who will be more vulnerable will be those with severe and generalized forms which limit mobility or secondary cases where there are additional features including swallowing problems. These people would be expected to isolate and reduce contact to minimum in UK to reduce risk of picking up covid infection."

Dr. Francesca Morgante, Neurologist at St Georges Hospital in London, recommends for Dystonia patients in Europe to learn how to manage dystonia without botulinum toxin, while they cannot have access to Clinics.

Contact the treating neurologist and ask about oral medications which might ease the amount of pain and involuntary movements. An important aid at the moment may come from physiotherapy exercises, as provided by doctors Anna Castagna, Elisa Andrenelli, Marina Ramella.

For DBS patients the situation is a bit different since they surely can cope better in this situation as their DBS device can also be managed remotely if needed, through the remote control and telemedicine assessments. Dr. Morgante's advice is to contact the neurologist or DBS nurse if they have sudden lack of control of their symptoms.

She concludes: ”I would like to let all dystonia patients know that neurologists across Europe are making plans to safely start botulinum toxin clinics again, especially for those patients who have urgent need to be treated because of severe symptoms. However, this needs accurate plans in order to minimise risks of infection to patients and health professionals. We are seriously working on that. ”

Prof Emeritus Marjan Jahanshahi, Queen Square Institute of Neurology in London, says: ”Remain hopeful: This will also pass. The pandemic is temporary and will end.”

Read her advice and recommendations on page 7.

On-line Support

On our special Covid-19 and dystonia web-page, which is updated on a regular basis, you find more tips and support:

https://dystonia-europe.org/dystonia-without-botulinum-toxin-covid-19/

Monika Benson
Executive Director

Professor Tom Warner at Queen Square Institute of Neurology in London

Dr. Francesca Morgante, Neurologist at St Georges Hospital in London

Prof Emeritus Marjan Jahanshahi, Queen Square Institute of Neurology in London

Living through Corona Virus Pandemic

No botulinum injections - try to get a realistic perspective
Remind yourself that not having the botulinum toxin injections at your regular interval of every 12 weeks or so is *disruptive but is not disastrous.* The disastrous outcome is the loss of life we are all witnessing throughout the world. Missing your regular botulinum injections may mean that your dystonia symptoms return and that you experience some pain and discomfort. You are strong and you can cope with these. Try to shift your attention away from your dystonia symptoms and pain by distracting yourself through reading, chatting with friends or family or watching TV. Remind yourself that you did cope with your dystonia symptoms, the discomfort and the pain before your started botulinum toxin injections and you can cope with these again.

Obtain alternative medical treatment
If the dystonia symptoms and the pain are difficult to cope with, ask your GP or neurologist for alternative medical treatments such as anticholinergic medication, muscle relaxant medication and painkillers.

Establish a daily routine
In these challenging and unusual times, having a daily routine is helpful as it creates a sense of normality. So, create a daily routine for yourself. Regularly engage in the self-care, cooking/eating, working, exercising, leisure activities, and social networking that will give your daily life a pattern of normality even when you are staying at home and self-isolating.

Remain positive
Stress and anxiety reduce the body's immunity and ability to fight against viruses. While everyone is naturally worried about their own and their families' safety during the pandemic, it is important to remain positive. Banish negative thoughts, and engage in positive self-talk, reassure yourself that you and your family will be fine. Think back about all the good times you had as a family and plan and imagine future pleasurable activities. Your mind's eye allows you to travel in time and space, engage in pleasant visual imagery and imagine yourself in better times in exotic destinations. Laughter provides the body and mind relief from tension. Use the internet or your TV to watch comedy and to laugh out loud.

Stop obsessively tracking the news
While it is important to be up to date with your government's instructions about handwashing, social distancing and staying at home, but constant and obsessive tracking of the news about the impact of corona virus nationally and internationally may magnify the sense of 'doom and gloom'. Be mindful of 'overdosing' on the corona virus news and limit yourself to one news programme every couple of days.

Keep in touch with friends and family
At challenging times, social support acts as a protection against the effects of stress on the body and the mind. Friends and family are a wonderful source of social support, allowing you to share and air your thoughts and feelings, to share memories, and to have a laugh. During this period of 'staying at home' and self-isolating, keeping in touch with your friends and family by telephone or Facetime/skype/zoom on a daily and weekly basis will also prevent a sense of loneliness for both you and them.

Remain hopeful
This will also pass. The pandemic is temporary and will end.

Prof Emeritus Marjan Jahanshahi, Queen Square Institute of Neurology in London

Dystonia Work during the Pandemic

It seems like only a few weeks ago life was totally normal and the Dystonia Europe Team was in the middle of preparing for our big annual conference D(ystonia)-DAYs 2020 to be held in Dublin next June. Bookings of venue and accommodations were made, speakers were confirmed and social activities being planned when it all of a sudden came to a stop. We had all heard about the new virus spreading in China back in January but who would have thought that it would spread so rapidly across the world? Soon cities and regions closed and then one country after the other closed as well. We had to face the fact that no one would be able to travel to Dublin and therefore no D-DAYs this year. The health and well-being of our colleagues, members and partners are the most important and the DE Board agreed it would be better to not hold the D-DAYs at all this year. Now we have cancelled all the bookings and we are aiming for the event to take place in Dublin in 2021 instead. We hope that this will be all over by then. As soon as we have the new dates we will let you know.

The Covid-19 pandemic crisis is affecting all levels of society across the globe. Cities, countries, borders have closed down. Healthcare systems are under extreme pressure. Early in the crisis we heard about dystonia patients across Europe not being able to have their Botulinum Toxin Treatment and therefore causing a lot of stress and anxiety.

Member organisations reacted quickly and organised webinars with experts to give advice and support. Dystonia Europe has created a special web-page with important information and links that can be of help and support. https://dystonia-europe.org/dystonia-without-botulinum-toxin-covid-19/

We are in contact with members to follow the developements and we hope treatment will soon be available again.

For the team of Dystonia Euorpe it also means that we are not able to travel to any meetings. We are therefore keeping close contact via zoom, where we have regular board meetings. This is also the platform where we will hold our Annual General Assembly 2020 for our members. Many of our partners also hold their meetings here. EFNA will be hosting their General Assembly on Zoom as well.

The activities and work of Dystonia Europe will continue as usual but in a slightly different way this year. Since we are not able to meet in Dublin for our annual event we are planning several new digital activities. We will launch a series of Dystonia Webinars where you will learn the latest within treatment and research from dystonia experts. We are working on our new dystonia podcast series. In September it is Dystonia Awareness month where we hope you will join the exciting relaunch of our Jump for dystonia campaign, share our dystonia facts and inspirational quotes. Together we will make dystonia better known.

But for now it is really about taking one day at a time, one week at a time, listen to the advice of national authorities and do all we can to help in stopping the virus to spread. Be strong during these difficult and unusual times. One day it will come to an end.

Take care and stay healthy!

Monika Benson
Dystonia Europe

DE Board meeting virtually

Winter Think Tank 2020

Dystonia Europe Winter Think Tank was held in Lund, Sweden 14 February 2020. DE had a Board Meeting the day before, and the Think Tank members joined that evening for dinner. Members of the Think Tank are our Platinum sponsors: Boston Scientific, Ipsen, Medtronic and Merz.

The Think Tank was held on Valentine's Day and we used the opportunetiy to celebrate with a Valentine's Photo

President Adam Kalinowski welcomed all to the Think Tank meeting and Executive Director Monika Benson gave an update on the activities that DE has been involved in during the last year.

DE collaborated with EFNA on the «Brain Life Goal» project, raising awareness of brain diseases. DE supported the project during D-DAYs in London, adding their own hashtag «Dystonia Life Goals».

Another awareness project that DE started last autumn is «Dystonia Talks», which consists of video interviews. Videos have already been published on Dystonia Europe's You Tube Channel https://www.youtube.com/user/DystoniaEurope/videos . More videos will be published this year.

Prof Maja Relja, School of Medicine University in Zagreb, Croatia, held a presentation on the preliminary results of her study Dystonia Survey in Europe, - Mapping Patients With Dystonia.

An update of how DE progress on Social Media was presented. The amount of people reached on facebook keeps growing. We are very pleased to see how engagements, shares and likes increase continously. It is important that people become more aware to fight stigma, achieve earlier diagnosis and receive treatment. This will help to improve the quality of life for those affected.

Part of the TT meeting was dedicated to discuss how to relaunch the Jump for Dystonia Campaign. There were some very good ideas and you can read more about our plans on page 20. We hope you will join us in this fun activity.

We hope to hold the next Think Tank Meeting in the autumn in Lund, Sweden or online.

Merete Avery
Dystonia Europe

DE Board Members from left,
Gill and Catalina celebrating Valentine's Day

Participants of the Winter Think Tank 2020 in Lund, Sweden

ERN-RND ePAGs visiting Crona Clinic in Tübingen

The ERN-RND is a European Reference Network established by the EU to support patients and families affected by **rare neurological diseases** (RND) which requires much specialised knowledge, treatment and resources. Some diseases are so rare that the necessary knowledge might not be available in the patient's nearest health centre or country. The patient doesn't travel but knowledge does.

The diseases ERN-RND covers are:

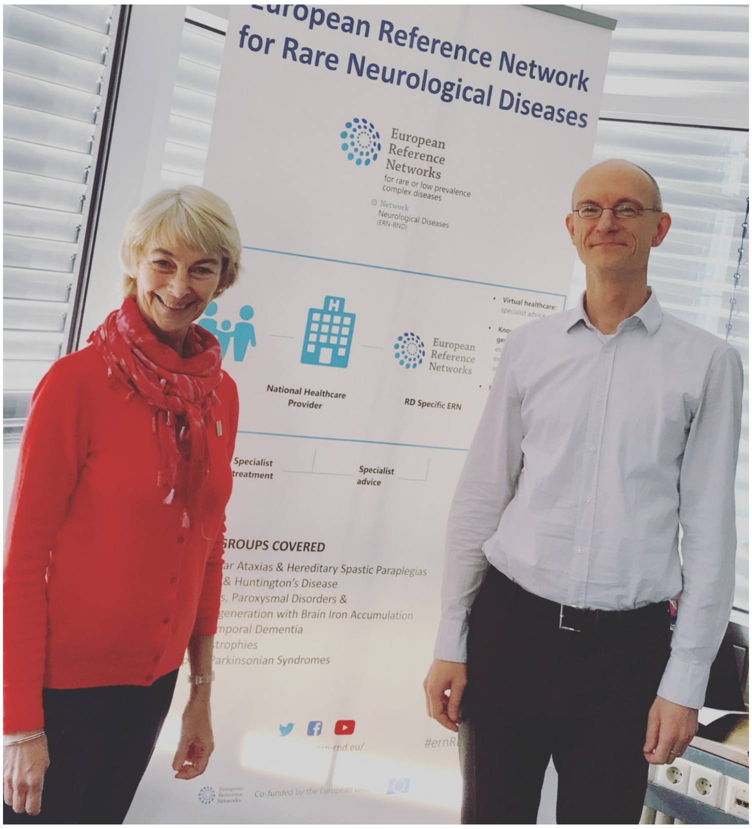
- Cerebellar Ataxia & Hereditary Spastic Paraplegias (HSPs)
- Chorea & Huntington's disease
- Dystonias, Neurodegeneration with Brain Iron Accumulation (NBIA) & ParoxysmalDisorders
- Frontotemporal Dementia
- Leukodystrophies
- Atypical Parkinsonism: Multiple System Atrophy (MSA), Progressive Supranuclear Palsy (PSP) & Genetic Parkinson's Disease

ERN-RND unites 32 of Europe's leading expert centers in 13 Member States and includes highly active patient organizations. Centers are located in Belgium, Bulgaria, Czech Republic, France, Germany, Hungary, Italy, Lithuania, Netherlands, Poland, Slovenia, Spain and the Netherlands.

The European Reference Networks (ERNs) are virtual networks connecting healthcare professionals around Europe with expertise in rare diseases which allows them to discuss a patient's diagnosis and care, with their consent, via an online IT platform (CPSM).

ERN-RND ePAGs in Tübingen

ERN-RND ePAGs visiting Crona Clinic in Tübingen



Monika Benson and Prof Holm Graessner

Important partners in the reference network are the different patient advocacy groups. Last week of January the ePAG (European Patient Advocacy Group) representatives met at the Crona Clinic in Tübingen, Germany. Network Coordinator Professor Holmes and his team informed about various network activities and we discussed how we can work together.

Some of the upcoming work is to create Patient Journeys for the various diseases. We will also develop promotional material that we in the different disease groups can bring to meetings and congresses we attend. We will share news and events for each other to raise awareness of the diseases and the work we do.

The different webinars are a popular activity. This is a joint educational programme launched by the two ERNs for Rare Neurological Diseases and Rare Neuromuscular Diseases (ERN-EuroNMD) in collaboration with EAN (the European Academy of Neurology).

The goal is to share knowledge on rare neurological, movement and neuromuscular disorders and fill the gap in the educational offer in these fields. The target audience are clinical specialists (neurologists, paediatric neurologists, geneticists), neurology trainees and other paramedical staff involved in patient care. The webinars will treat different aspects of the disease groups covered in our networks such as clinical features, disease diagnosis and management, use of scales and flowcharts, and possible therapeutic interventions. Topics relevant for adult and paediatric cases will have an equal share in our curriculum.All webinars held can be found on the ERN-RND Youtube channel https://www.youtube.com/channel/UCLpEdEyhGnQpdmLLzqNXkTg

During the last few months there were webinars on dystonia organised by the Network. One of them with Prof Kailash Bhatia from UCL Queen Square Institute of Neurology in London who spoke about **"Clinical evaluation of dystonia"**. You find the webinar here: https://www.youtube.com/watch?v=J0-J1umdarA

For more information on the ERNs, background and what they do, go to: https://ec.europa.eu/health/ern_en

Monika Benson
ePAG Representative ERN-RND
Dystonia Europe

The following article, page 12, make reference to certain companies and their products and any opinions expressed should not be taken to be the views of Dystonia Europe or its members.

The articles are written by respected authors and are provided for the information of Dystonia Europe News readers.

Medtronic's new DBS software aims for more personalised treatment of Movement Disorders like Dystonia

Medtronic Receives CE (Conformité Européenne) Mark Approval for the Percept™ PC Neurostimulator DBS System with BrainSense™ Technology.

This new system can sense and record brain signals while delivering therapy to patients with neurologic disorders, such as Dystonia. This enables physicians to deliver more data-driven, personal neurostimulation treatment. The neurostimulator has been approved in the EU for treatment of symptoms associated with essential tremor, primary dystonia, epilepsy, parkinsons disease (PD) and obsessive-compulsive disorder (OCD). It is also currently under review by the U.S. Food and Drug Administration.

The Percept PC neurostimulatar will be available in Western Europe beginning January 15th and will launch in additional regions based on local regulations.

For more information you can read the press release and go to the Medtronic website:

Medtronic Receives CE Mark Approval for the Percept™ PC Neurostimulator DBS System with BrainSense™ Technology – press release

http://newsroom.medtronic.com/news-releases/news-release-details/medtronic-receives-ce-mark-approval-percepttm-pc-neurostimulator

Medtronic global website

https://www.medtronic.com/

Medtronic

BS Foundation Grant Opportunities

In 2018, Boston Scientific, innovative medical solutions provider, launched its Boston Scientific Foundation for the EMEA region (Europe, Middle East and Africa) to contribute to society by supporting people in the communities.

The mission of the Foundation is to support well-being through innovative solutions.

Its strategic focus is to address issues of public interest in disease prevention or management, using digital or innovative solutions by:

- improving the health of individuals and communities with unmet needs.
- facilitating access to prevention and awareness programs.
- supporting research programs aimed at improving prevention or disease management.
- using innovative solutions such as apps, e-platforms, social media, optimizing impact on well-being.

Should you be willing to know more visit http://www.bostonscientific.com/en-EU/about-us/corporate

Monika Benson
Executive Director
Dystonia Europe

Dystonia Facts - a New Video Series

The Dystona Facst is a new Video Series explaining dystonia. Last January Monika and her daughter Amanda spent 4 days in London to meet with dystonia experts and make video-recordings of them explaining dystonia.

Dr. Jean-Pierre Lin at the Evelina Children's Hospital spent a morning with DE to tell us all the facts about Children's dystonia, symptoms and treatments available.

Day 2 the duo travelled to St Georges Hospital in south London and met up with Dr. Francesca Morgante and Prof Mark Edwards. They had both been given various topics of dystonia that they told the camera about.

Day 3 the recordings took place at the Queen Square Institute of Neurology, with Prof Tom Warner who spoke about dystonia research. The 5th and last person to interview and record was Prof Marjan Jahanshahi who spoke about dystonia from a mental perspective.

These videos are now being edited and will soon be available on the DE Youtube channel and the DE website.

The hope is that these videos will better explain what dystonia is and what kind of treatments are available. The videos can support patients and their family members when looking for information on dystonia.

Monika Benson
Dystonia Europe

Amanda Benson and Dr. Jean-Pierre Lin outside the Evelina Children's Hospital in London.

Dr. Jean-Pierre Lin being interviewed and filmed by Amanda Benson

Amanda Benson

Busy week in Brussels

Last week of February Dystonia Europe attended the event ***'Brain Health as a Global Priority – Time for the EU to Act Now'*** in the EU Parliament in Brussels.

The meeting was organized by EFNA – European Federation of Neurological Associations, in collaboration with EAN – European Academy of Neurology, and EBC – the European Brain Council.
MEP Jaroslaw Duda, from Poland, welcomed the 100 participants and said that "each one of us knows somebody who is affected by a brain disorder such as MS, Parkinsons, Epilepsy, and the brain's health is crucial for progress".

Presidents of EAN and EFNA: Prof Claudio Bassetti and Ms Joke Jaarsma welcomed the audience and then followed speakers who gave an update on the current situation regarding neurology in Europe from different perspectives such as the patient's and the researchers' as well as from some of the EU institutions.

Dr. Anette Storstein, Head of the Board of the Norwegian Brain Council, shared work on the brain plan in Norway. She concluded "there is no health without brain health".

A very emotional presentation was the one from Dr. Francesca Sofia, member of the European Regional Executive Committee of the International Bureau of Epilepsy. She shared what it's like when your daughter is affected by a rare form of epilepsy. "We all have an inner force that we can use to make changes. I am not alone – I share this destiny with millions of others and I have the responsibility to make my voice heard to help others", she said.

Ms Nina Renshaw, Director of Policy and Advocacy at the NCD – Non Communicable Disease Alliance, shared facts about research investments in different disease groups. There are 300 times more investment in other disease areas compared to neurology.

EU Parliament

Meeting in EU Parliament - speakers

MEPs Tilly Metz and Miriam Dalli promised their full support in the continued work to make brain health a priority.

The Call to Action from today's meeting is:

- Acknowledge and use latest data demonstrating the exceptionally high burden of brain disorders in terms of mortality, disability, prevalence and economic impact.
- Give more visibility and priority to neurological health.
- Give more attention to improving brain health, as a whole, in European and national policy priority settings. As such the EU should develop a unified strategy to promote brain health.
- Support the development of national brain health plans in the EU countries.
- Continue to invest in brain research and innovation to better understand the brain; and to treat and cure its diseases.

Meeting outside of Parliament

A full report and all presentations are available at the EFNA website https://www.efna.net/brain-health-as-a-global-priority-time-for-the-eu-to-act-now-2/

On the same day, a few floors up in the EU parliament building, EURORDIS organised the event "Bigger than Life" an exhibition by artist Phil L. Herold's on the occasion of the Rare Disease Day 2020, co-hosted by MEP Tomislav Sokol, MEP Loucas Fourlas and MEP Stelios Kympouropoulos.

In the afternoon EFNA organised a workshop with invited participants to begin planning an advocacy strategy for neurology, work which will continue throughout 2020.

From the EFNA workshop

The last day of this busy week in Brussels the first EFNA board meeting of the year took place. The group discussed the strategy for the next 5 years as well as this year's projects and activities. Next time we meet will be at the EAN Congress in Paris in May, for the EFNA General Assembly and other members' activities. *

For Dystonia Europe it is important to take part in this European collaboration between neurology patient associations. Together we are stronger and can make the voice of neurology patients better heard.

Monika Benson
Executive Director

*Due to the Covid-19 pandemic EFNA General Assembly and other meetings will be held on-line.

EU Activities

Rare Disease Day

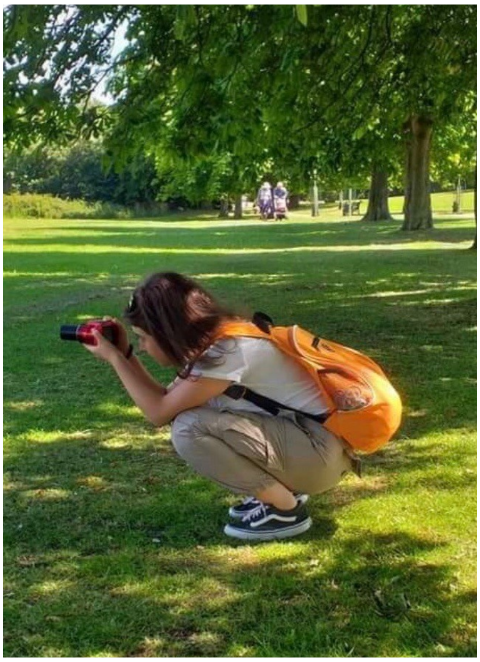
Rare Disease Day takes place on **the last day of February each year.** The main objective of Rare Disease Day is to **raise awareness** amongst the general public and decision-makers about **rare diseases and their impact on patients' lives**.

The campaign targets primarily the general public and also seeks to raise awareness amongst policy makers, public authorities, industry representatives, researchers, health professionals and anyone who has a genuine interest in rare diseases.

Building awareness of rare diseases is so important because 1 in 20 people will live with a rare disease at some point in their life. Despite this, there is no cure for the majority of rare diseases and many go undiagnosed. Rare Disease Day improves knowledge amongst the general public of rare diseases while encouraging researchers and decision makers to address the needs of those living with rare diseases.

The first Rare Disease Day was celebrated in 2008 on 29 February, a ‘rare’ date that happens only once every four years. Ever since then, Rare Disease Day has taken place on the last day of February, a month known for having a ‘rare’ number of days.

This information is from: https://www.rarediseaseday.org/article/what-is-rare-disease-day



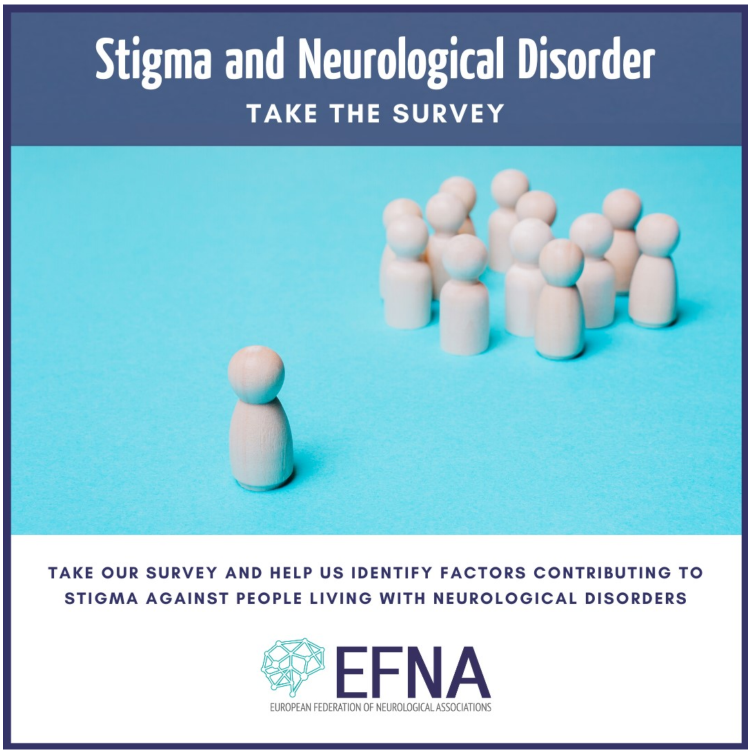
Participate in a Study by EFNA on Stigma and Neurological Conditions

During Awareness Week 2020 The European Federation of Neurological Associations (EFNA), launched a survey on Stigma and Neurological Conditions .

EFNA represents 20 European and International associations across a wide variety of neurological disease areas, such as multiple sclerosis, epilepsy, migraine, ADHD, Movement Disorders such as Dystonia and Parkinson's, to mention just a few.

In 2018, EFNA conducted a survey of young people affected by a neurological disorder, to assess the impact of these conditions on their lives. Stigma was identified as one of the biggest issues affecting respondents, after access to medication/ treatment and isolation.

As a result, EFNA has decided to develop a new survey, delving deeper into this issue, exploring the areas where stigma is felt and the situations which give rise to it.



By identifying these areas EFNA can focus attention where it is most required and move to develop strategies that will combat stigma.

Purpose of The Study

The purpose of this survey is to identify factors contributing to stigma against people living with neurological disorders in order to develop strategies that will help to combat it.

What is Stigma?

Stigma and discrimination occur when people are treated unfairly because they are seen as being different from others. This survey will explore how you have been affected by stigma due to living with a neurological disorder.

This survey is open to anyone who is living with a neurological disorder, resident in Europe. The survey is available in 8 languages and will remain open until June 15th 2020.

Stigma is very often a problem for people living with dystonia and ask that you participate in the survey. When the results from the survey is published we hope this can be used for more knowledge on Neurological diseases and how to fight Stigma.

Take the survey here:
www.surveymonkey.com/r/EFNA-stigma

The survey is open until 15 June 2020.

EFNA #BrainLifeGoals Project Grants and #BrainLifeGoal Photo Competition

EFNA #BrainLifeGoals Project Grants

During Brain Awareness week EFNA launched the 2020 round of #BrainLifeGoals Project Grants. This year the focus will be on:

Ensuring Equitable Access to Treatment, Services and Support for Neurology Patients and their Carers.

Access to treatment is one of the central #BrainLifeGoals of many neurology patients, and EFNA want to help make that a reality across Europe. EFNA will provide grants of €3,000 each to up to 10 selected organisations.

Projects should be proposed by a non-profit organisation, registered and operating in Europe.

Deadline for application is extended to Friday, May 31st.

Full information and application guidelines are available at: www.efna.net/BLGgrants

#BrainLifeGoals Project Grants

You can find out more about the campaign itself at www.efna.net/brainlifegoals and by following the #BrainLifeGoals hashtag on social media.

Full information and application criteria are available here: http://www.efna.net/BLGgrants/

#BrainLifeGoal Photo Competition

In support of the **#BrainLifeGoals** campaign, EFNA last year ran a photo competition.

1st prize - Girlfriends for Life - Josef Hinterleitner (Austria) "Karin's best friend Aischa has MS, but despite the disability they are a heart and a soul."

To read more and to get involved follow this link to the EFNA website https://www.efna.net/brainlifegoals/

Congratulations to Susan Bagust (Australia), runner-up in the #BrainLifeGoals photo competition with this entry, 'Making a splash'.

Read more about Susan's story and the winning entries here: https://www.facebook.com/EFNA.net/photos/a.209789096207015/821396368379615/?type=3&theater

Jump for Dystonia

For this year's dystonia awareness month we are planning a relaunch of our popular Jump for Dystonia activity! With a new touch and special surprises for you!

Look out for information when we come closer to September!

This Dystonia Awareness Month we will:

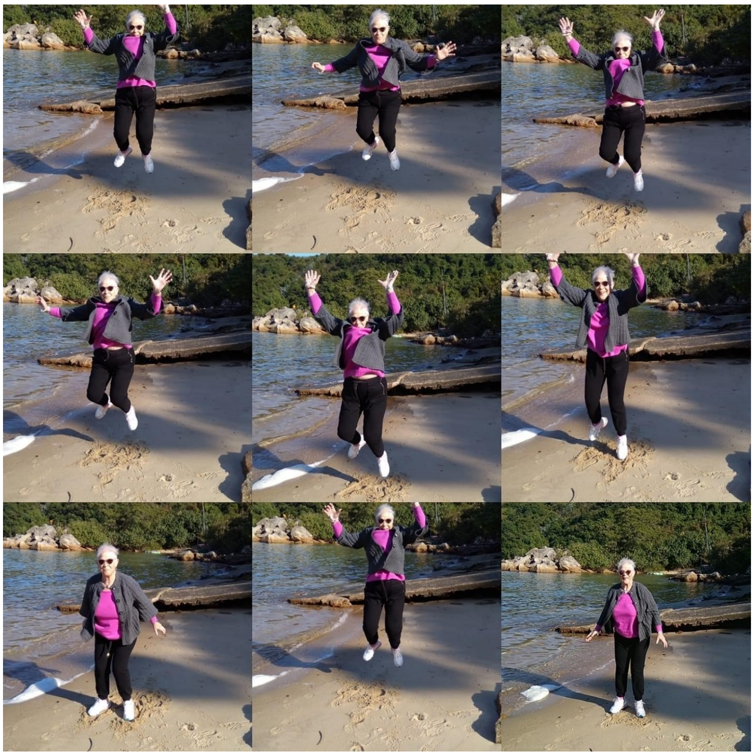
Here is Yvonne's sister in law, Colllette, jumping for dystonia in Ireland.

Another fantastic Jump for dystonia Ambassador is Yvonne Maxwell in Ireland. She asks people to jump for dystonia and she jumps a lot herself.

Jump for Dystonia

Three photos at the top:
Sabina from Romania started the Romanian dystonia association. She has been treated with DBS for her dystonia. She helps out in raising awareness of dystonia with her happy jumps!

To the left: If you cannot jump to raise awareness of dystonia you can do something else. Here is Monika, our Executive Director, in the mountains of Sweden. At the time she had hurt her back and no jumping was possible! Raising your arms can also be a Jump for Dystonia!



One of our Jump for Dystonia experts is Carina Mok in Ireland. She has jumped many, many times to help raise awareness of dystonia. Here she is jumping for dystonia in Hoi Ha Beach, Sai Kung National Park, in Hong Kong last autumn. Carina says: "I can still jump!"

At every meeting Dystonia Europe organises there is always a jump for dystonia. This was at our last Think Tank and Board Meeting in Lund Sweden. Not very co-ordinated but filled with energy and joy!

Hello There!

Meet Dystonia Europe Board Member Catalina from Romania

My name is Catalina Crainic and I am one of thousands of cervical dystonia patients.

Catalina Crainic, Romania

What is your work experience and how does it relate to dystonia?

My experience was a new way of my life, it is an experience from which I have continued to learn. At first everything was confusing, unclear and hopeless, then life provided me with experiences that define me as a person without dystonia I couldn't have been me, the present one. Over time I learned to live with dystonia, managing it so that it does not take over my entire person and daily life. When I became ill, there was no access to treatment in Romania for people with dystonia and the path to diagnosis was quite difficult. I went to several neurologists, and I received the diagnosis only after 1 year and a half. I received treatment for 4 years in Hungary and it costs a lot of money.

My husband had 3 jobs in order to support our family, it was very hard but otherwise I could not benefit from treatment. In a short time I realized that I'm not the only one who goes through something like this so I looked for people who were in the same situation like me.

I found the Association Children's Joy which was founded by Sabina Gall before she suffered from Dystonia and was intended for children from vulnerable environments until Sabina became sick. Then its activity was directed to people with Dystonia due to Sabina's experience.

I got in touch with Sabina and her mother, I felt that I should get involved in the fight that they had started. I was involved in their work, I made requests to authorities by myself and together with the association, various events, meetings with patients, all in order to obtain botulinum toxin treatment, enclose for the degree of disability and other rights for patients so that their life and ours would be better and have access to treatment. After 4 years of attempting, we succeeded and received a positive response from the authorities. The botulinum toxin treatment was finally approved and our work was not in vain. After a while Sabina's situation got worse and I needed to take over the association's leadership. I moved the activity of our association to the city where I live, Timisoara, where together with volunteers of the association, I set up and renovated its headquarters, where we carry out painting workshops for children to pay the expenses of the association. Here we often have informative meetings with patients, groups or individuals and various activities for them. Currently we want to arrange the space for rehabilitation workshops for people with Dystonia.

Why do you like helping others?

I think that helping others with various problems is a natural thing for me, it is the greatest joy. I went through many difficult situations, I learned to manage them and I just want to share them so that those who come on my path and ask for my help can easily access what I couldn't access when I got sick. The fact that I guide people towards specialists and access to treatment, that I give them information that will make them more easily overcome the problems caused by dystonia, is a way of life for me, it's my way to show that life is worth living. Things done for others give me the power to move on, bring good people to my life and help me see that the good exists and it's free, it's just a form to express my gratitude for the good and support I received in my turn.

What are the benefits of working within the organisation in your country Romania and with Dystonia Europe?

Meeting unknown people who come up with a problem and I can help make that problem easier to solve or remove it, it is a feeling that cannot be described in words.

Hello There!

I was glad to be part of Dystonia Europe, first as a member and then as a board member, it is a privilege and an honor for our association. People in my country see this connection with our organization as a guarantee that what we do is good, we have visibility at a European level. I know that our voice can be heard better and they have the guarantee that with other countries we can raise our voice together.

The work of the Dystonia Europe team is quite important, patients in Europe have access to concrete information from the specialists, it is a good opportunity to interconnect different countries. I would not see the world of dystonia without Dystonia Europe. Personally Dystonia Europe gives me hope that one day a cure for dystonia will be found and until then we are doing what we can to help patients with dystonia. This organization is like a mother who is trying hard to raise her children, educate and protect them with all her powers.

How do you like spending your free time?

There are many things that motivate me**,** especially my family, and then the thought that there are people who need my continued support, for this reason last year I started my university studies in psychology, because I think the emotional side has quite a big impact on people with dystonia. As we stay more optimistic, we can improve our condition. I consider that each person is unique, it is only necessary to discover and experiment, to explore what beautiful things life offers to them outside the problems related to dystonia.

What keeps you motivated on the tough days?

On hard days I think that there are only episodes that will pass, and then it will be better. I will be able to continue my activities that I like, then it is time to do things that excite and relax me, I read a lot, I paint, I do handmade things, gardening, I like to take pictures, take small trips and to plan trips.

When I feel I am overwhelmed I withdraw into nature and painting, then come back with new forces to continue.

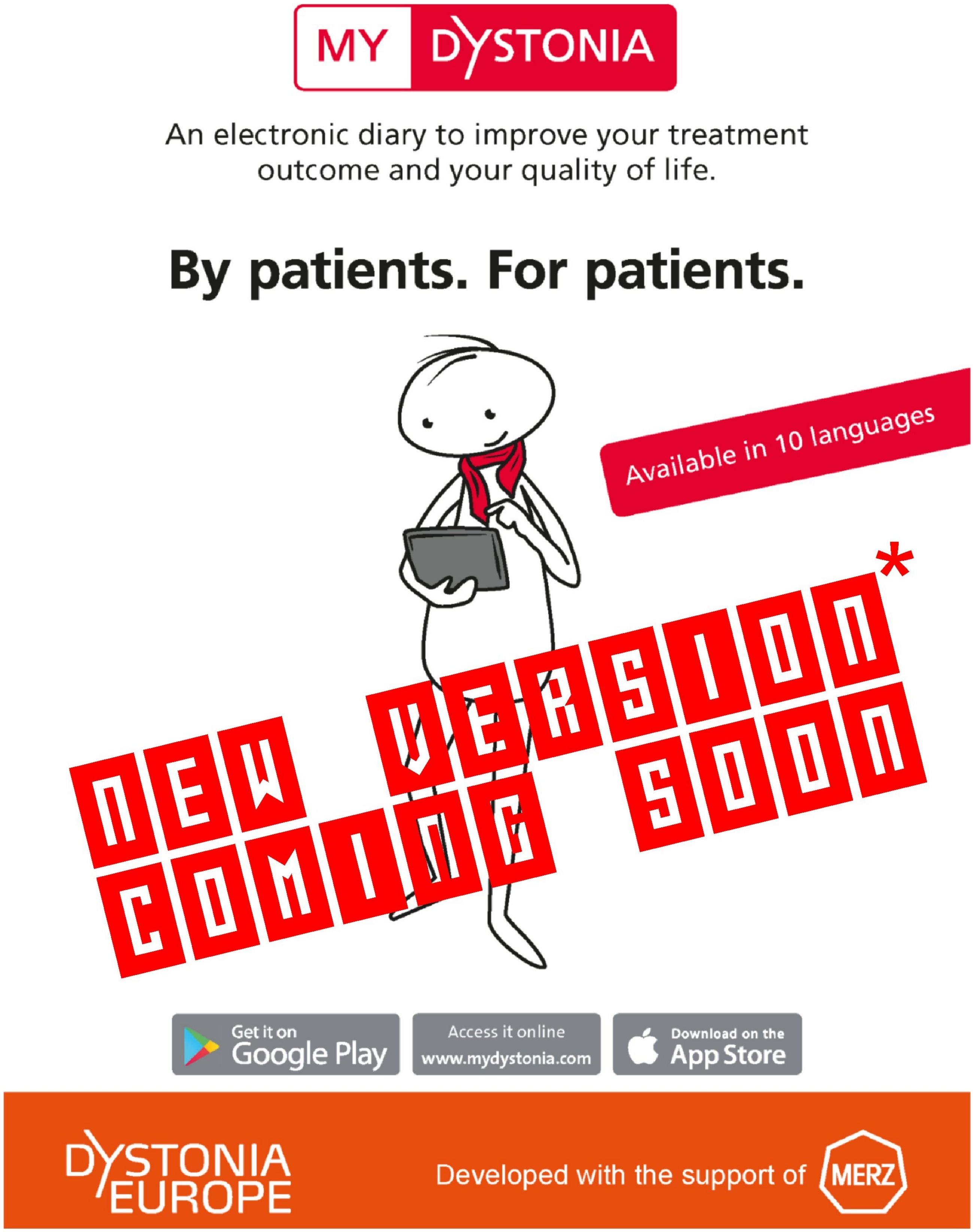
What makes you angry?

What make me angry is the injustice that causes imbalances in various situations, and discrimination. But I think that anger is a strong emotion that does nothing but stop us from thinking, so I focus on leading a life in balance, both with myself and those around me, and I try to create successful strategies to avoid producing situations that will unbalance me.

I strongly believe that it is within my power to build my future as I wish. The more I believe in my dreams, the more they can become achievable, I just have to believe and not give up, to fight for them and to enjoy every little thing that life offers me, and in the end when I will draw a line, after each fulfilled dream to have a heart filled with joy and to have our life is like a clear sky.

Catalina Crainic, participating in the "Under the Umbrella" campaign.

Catalina is the President of Association Children's Joy and Board Member of Dystonia Europe



MY DYSTONIA

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DYSTONIA EUROPE

Developed with the support of MERZ

*** At Dystonia Europe, we're working on updating MyDystonia to version 2.0, which we plan to launch in autumn 2020.**

Italy

A.R.D and COVID-19

On February 21 the first person with a COVID-19 diagnosis was reported in Lombardy, 60 km from Milan. Starting from that date, the number of persons infected with this virus began to increase rapidly in Northern Italy and slowly in the rest of the country. On March 11 our governement decided for a lockdown of the whole country, with the slogan "stay at home". We were allowed to leave home only when strictly necessary, certifying the reason to the police who could stop us.

Our hospitals were full of persons with serious breathing problems, doctors had to take care of too many of them at the same time, for some weeks the healthcare personnel has been in the trenches against this new, scarcely investigated, sneaky virus. All the routine visits in hospitals were cancelled, mainly in order to prevent that patients could be infected, and also for diverting most doctors to assist COVID-19 infected patients. Neurological departments have been closed too, therefore many dystonia patients could not have their botulinum toxin injections; since therapists could not work any longer in the hospital nor at home, also rehabilitation therapies were cancelled.

Many dystonia patients turned to A.R.D. asking for help. On March 13 we posted on our FB page a statement by our Scientific Committee who informed that dystonia or drugs against it do not increase vulnerability to COVID-19, the botulinum toxin does not reduce immune defense, DBS device is not infected by this virus.

We created a new e-mail address for questions concerning COVID-19 and Dystonia, so that patients who could not get in touch with their doctor could nonetheless get some answers. Furthermore, a toll free telephone number was established, where two hours a day, five days a week, a neurologist could give information about this matter. Some doctors accepted video calls by patients, with the possibility of remote diagnosis and help.

We have increased the updating of our FB page, posting every day useful information, stories of patients, surveys or questionnaires which had a great success. As people were compelled to stay at home, using social media was a good way of spending time and being informed.

With the cooperation of LIMPE Foundation for Parkinson, some webinars have been acccomplished, during which neurologists, physiotherapists and representatives of patient associations (Dystonia and Parkinson) shared experiences and information.

Another great help was quickly prepared by three doctors who are consultants in neurorehabilitation: Anna Castagna (who is a neurologist too), Elisa Andrenelli and Marina Ramella. In a very short time they have carried out a guide for patients with dystonia, who were facing many problems due to being without their botulinum toxin treatment. The idea about a self-help guide was initiated by Dr.Francesca Morgante who works in London and is always a great supporter of our Association.
The title of the Guide is "Managing dystonia without Botulin toxin - exercises and tips". It gives some valuable advice and tips, including breathing and stretching exercises, postural rules, yoga exercises and kinesio-taping . Many pictures and drawings illustrate all the exercises, therefore it is easy to use. It can be requested for free through at our website. By mid April this guide was translated into English and posted on the Dystonia Europe FB page too. It is available here: https://dystonia-europe.org/wp-content/uploads/2020/04/Managing-dystonia-without-botulinum-toxin.pdf

As the Coronavirus phase 2 has been put in place and hospitals are re-opening for usual treatments, our Scientific Committee has diffused some suggestions concerning both patients and doctors when they meet in hospital for visit or injection treatment; as their distance is obviously less than 1 meter, doctors must wear adequate protections and patients must be protected too, with the only exception of the skin areas to be treated. Up to now no interaction has been reported between COVID-19 and botulinum toxin, therefore patients previously infected may be treated after being tested negative to the virus.

Maria Carla Tarocchi
Vice President, ARD, Italy

United Kingdom

Dystonia UK - Reach Out, Reach All

The **Reach Out, Reach All** project aims to bring the dystonia community together, through film, animation, podcasts and webinars. Dystonia can be an isolating condition. It can be scary not knowing what the diagnosis means, not only for yourself but also how it might affect your friends and family. Although the community is large, individuals can be geographically dispersed which can leave people feeling isolated, alone and unsure.

Reach Out, Reach All was created by Dystonia UK to not only speak to our current members and supporters but to the whole of the dystonia community, the people who feel alone and do not know of anyone else with the condition, those who may not want to go to a support group or may not have one within easy travelling distance. Through this project we aim to tackle this social isolation as well as combat the lack of knowledge around the condition in some parts of the medical community and the general public. These videos, podcasts and animations will be readily available to be shared all over the UK which will not only allow easier access to leading medical professionals in the field but also to other people living with the condition, whose personal stories and journeys will help inform and engage our entire community.

Last year, we partnered with the Aviva Community Fund and used their platform to crowdfund the seed funding for this project. With the amazing support from you and the rest of the dystonia community, in just 4 weeks we raised over £5,000 online and a further £5,000 offline, and even had more funding pledged in the following weeks. We are so incredibly grateful and in awe of the way the community rallied around this project, demonstrating just how needed it is.

We had some amazing feedback during this time, including:

“Having seen how invaluable this information would be for everyone from before diagnosis and throughout their journey, this project absolutely deserves to be funded, you have my support!”

“This is a brilliant initiative that will support thousands of people across the UK. I'm really happy to add my support alongside so many others.”

The crowdfunding was only the start of a multi-faceted, multi-phased project that will continue to grow and meet the needs of our community. The current funding will be used to make the first of 4 videos. This video will answer the question “What is dystonia?” to help increase the general understanding of the condition. This will be followed by another 3 videos, the themes of which will be chosen by a panel of our supporters. We will be launching these during Dystonia Awareness Month in September and cannot wait to see all the effort, energy and enthusiasm behind this idea come to life.

To help us develop the project further, we are also discussing opportunities to be involved in funding the next stages with charitable trusts and foundations as well as our medical advisors, corporate partners, and pharmaceutical partnerships. We believe that this, along with your continued support, will help drive this project forward and guide our way in the future.

We realise this has the potential to have a considerable positive impact on the dystonia community and so are thrilled to have the first phase funded and backed by our supporters. We will be updating you regularly on the progress of the project and look forward to sharing these developments with you.

Around Europe and Beyond

In this time of uncertainty and social isolation, this project is vitally important, the next phase in the project "Dystonia Around the World" an awareness and fundraising campaign, where with the help of our supporters we will send Dystonia around the world from our London office and back again will be launching in the next month, check out our website for more details and how you can be involved www.dystonia.org.uk

Dayna Ferdinandi
Head of Fundraising and Communications
Dystonia UK

Events

Calendar 2020

May

15-16	10th European Conference on Rare Diseases and Orphan Products, online
23-26	EAN Congress, online
25-26	EFNA Annual Meeting & General Assembly 2020, online

June

7	DE General Assembly 2020, online

July

22	World Brain Day

September

TBC	Dystonia Europe Board Meeting and 10th Think Tank Meeting
1-30	Dystonia Awareness Month
12-18	MDS – International Parkinsons and Movement Disorder Society Congress 2020, Virtual Congress https://www.mdscongress.org/Congress-2020.htm
23-26	ESSFN, Marseille http://www.essfn.org/en/congress-courses/essfn_congress/

October

5-6	EFNA Annual Partners Meeting

November

26-27	EFNA Meetings

Calendar 2021

June

1-5	EPNS Congress https://www.epns.info/epns-congresses/epns-congress-2021/ Glasgow, UK

Calendar 2022

January

12-14	Toxins 2022, Gothenburg, Sweden, https://www.neurotoxins.org/toxins-2021/

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 and United Kingdom.

Donation & Support

Dystonia Europe welcomes and greatly appreciates any donations/support from organisations and individuals to further develop all the work for dystonia in Europe by funding research, awareness and education. If you would like to support the work of Dystonia Europe please contact us at sec@dystonia-europe.org to discuss the possibilities.

To donate directly you can use the online button DONATE on or website.

When making a payment please include a reference to allow us to identify the donor.

You can also use the donate button on the Dystonia Europe website, which will take you to the following page: https://dystonia-europe.org/donate/

Thank you for supporting Dystonia Europe!

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

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.

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,
Board Member,
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 deptartment 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, Associata 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,
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.

Partners & Sponsors

We have good working relations on a variety of topics with:
DMRF – Dystonia Medical Research Foundation, FDR – Foundation for Dystonia Research, Dystonia Coalition, EFNA – European Federation of Neurological Associations, EBC – the European Brain Council, EAN – European Academy of Neurology, MDS – International Parkinson and Movement Disorder Society.

We thank all our partners for their support and collaboration.

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