DYSTONIA NEWS

SUMMER|2 - 2021

DYSTONIA EUROPE

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Connecting people to

spread information

raise awareness

promote research

Adam Kalinowski
Dystonia Europe
President

Welcome to the Summer issue of Dystonia Europe News.

We're happy to approach our Dystonia Day 2021, taking place virtually on September 4. This will be the 27th edition of our annual conference dedicated to patients, their relatives, and others with an interest in dystonia.

September was marked as Dystonia Awareness Month years ago and is a very important time in our calendar. Our team worked on preparing activities for this special month. Not only for the dystonia community, but also for spreading dystonia awareness outside this group. Some of the activities are posts with important facts about dystonia such as easy-to-share infographics based on the results of the survey, which was completed by thousands of people with dystonia.

We are also excited to introduce you to the campaign we call Escape Dystonia that aims to directly engage dystonia patients. We encourage you to follow the activity on our social media, engaging and sharing.

In addition to preparing for the annual conference and awareness month, we are also working on various projects. There are many ongoing projects on our desks, including the new version of the MyDystonia app - a digital diary for patients; and the Dystonia Survey - to support researchers.

There are several events that have happened in the recent months, such as the continuation of the webinar series, our Annual General Assembly and the meeting of the MyDystonia app ambassadors.

In our newsletter we also share what's new within research, information from our members and partners, and stories from people with dystonia. We hope you will find a lot of interesting content here.

We wish you a pleasant and relaxing autumn!

Dr. Martin Reich Receives the David Marsden Award

Dr Martin Reich
Julius Maximilian's University,
Department of Neurology in Würzburg, Germany

Our congratulations to Dr. Martin Reich, from Julius Maximilian's University, department of Neurology in Würzburg, Germany and the David Marsden Award winner 2021 for his paper: Probalistic mapping of the antidystonic effect of pallidal neurostimulation: a multi-centre imaging study.

Dr. Reich was presented with the award by Dystonia Europe President Adam Kalinowski at the Basal Ganglia Session at the on-line EAN (European Academy of Neurology) Congress 2021. Dr Reich expressed his thanks to DE and Ipsen for the award and then presented the work of his research.

About the winner:
During Medical School in Kiel, Germany, Dr. Reich got interested in movement disorders and the fascinating therapeutic potential of deep brain stimulation (DBS). In 2008 he started his doctoral thesis in this field with Professors Jens Volkmann and Guenther Deuschl. After completing a clinical scientist trial he went to Harvard Medical School in Boston for a postdoc stay in the group of Michael Fox. Since 2017 he has been leading the visual DBS lab in Würzburg focusing on neuroplasticity and network-wide effects of neuromodulation therapies. Additionally he is a senior consultant at the department of Neurology.

About the research:
The dystonias are a heterogeneous group of movement disorders sharing the core clinical feature of abnormal involuntary muscle contractions. Pallidal deep brain stimulation by surgically implanted electrodes is an established therapy for severe cases with an average improvement of 50-60% in dystonia severity. However, outcomes are variable, difficult to predict and clinical studies report up to 25% of non-responders. Variability in electrode placement and inappropriate stimulation settings may account for a large proportion of this outcome variability. Moreover, dystonia improvement is delayed, often days to weeks after changing DBS therapy, which complicates programming.

Our group has recently identified the location and extent of the volume of tissue activated (VTA) as the most important factor for the therapeutic efficacy of DBS in dystonia. Furthermore, we developed a computer model to predict optimal individual stimulation settings in patients based on the outcome of a large cohort of long term patients by using their pre- and postoperative brain images. Computer simulated testing has predicted a 16.3% better mean group improvement with computer-selected programming choices compared to physician-based programming and a drastic reduction of non-responders (from 25% to 5%). This study raises hope that in the future computational models may assist lead positioning and programming and provide more consistent outcomes of the surgical therapy in dystonias.

The Award is supported by:

IPSEN
Innovation for patient care

Dystonia Europe Annual General Assembly GA 2021

At our Annual General Assembly we had a formal part presenting finances 2020, budget 2021, voting and the Annual Report from 2020. We also received a new application for membership from Dystonie Vereiniging in The Netherlands, which was approved by the members. There are now 22 member organisations in DE. At the GA there were 20 persons from 18 member organisations representing 16 countries. Germany have 3 member organisations and 2 were present and UK have 2 member organisations and both were present

After the formal part of the Annual General Assembly 2021, Dystonia Europe announced the new Board as following:

President - Adam Kalinowski
Vice President - Edwige Ponseel
Treasurer - Sissel Buskerud
Secretary - Gill Ainsley
Board Member - Catalina Crainic
Board Member - Jukka Sillianpää

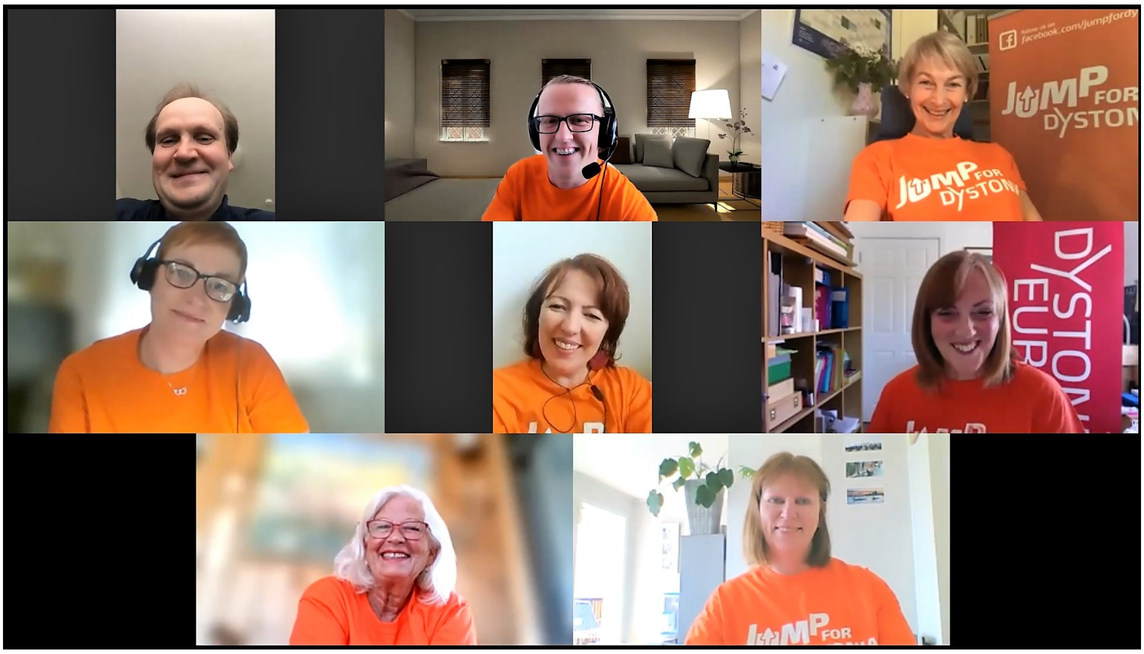
Other information at the non formal part of the meeting

All member organisations of DE may use the DE zoom account for webinars at a national level in their national language, the member organisation would be responsible for: the topic, title, speakers, moderators, agreeing the date with DE, participants' invitation and hosting on the day. This initiative will start in September 2021.

MyDystonia APP

Eelco Uytterhoeven, DE advisor on IT reported on the new MyDystonia 2.0 APP. The new version of the APP is now ready and available on the Google Play store and on the Apple app store. This has taken a great deal of work over approximately 3 years. So far it is only available in English but it will be translated to 5 other European languages later this year. More translations will be done next year.

Merete Avery
Operations Manager



The DE Board and Staff

Newsletter

The Dystonia Europe Newsletter is being published 3 times per year. We have a new layout created by the President of DE Adam Kalinowski, who is studying design. We really like the new layout and hope you do as well! The newsletter contains information on projects, patient stories, activities from member countries, news on research and more.

Launch of new Dystonia Surveys

Dr Kasia Smilowska presented two new Dystonia surveys. Kasia is a neurologist from Poland with a special interest in dystonia.

The first surveys - **Sexuality and Dystonia,** developed by Dr Smilowska and Dr Daniel J. van Wamelen, is already launched and you can take the survey by following this link https://dystonia-europe.org/projects-1/projects/dystonia-survey/ . The survey is in 15 languages and available until the end of 2021. The aim of the survey is to identify if dystonia affects sexuality, and if it does, how we can help dystonia patients to manage this.

The other survey is **Diet and Dystonia** and will be launched early 2022. All the data is recorded anonymously. There will be an opportunity to request the overall results at the end of the survey for those who have provided an email address when taking the survey.

Merete Avery
Operations Manager

Participants of the DE Annual General Assembly 2021

Dystonia Awareness Month 2021

Welcome to September and Dystonia Awareness Month 2021!

The Dystonia Europe Team is very excited about the upcoming awareness month and all the activities that will take place.

We kick off the month with our Annual Dystonia Conference: **Dystonia Day 2021** on Saturday 4 September. For program, speakers and link to registration see:

https://dystonia-europe.org/dystonia-day-2021-online/

We hope to see a big audience from around the world for this event.

After the conference you will have a better idea of what dystonia is, what treatments are available and what is going on in the field of research.

On our social media channels we encourage you to engage with us and let us know what you do to **Escape Dystonia**! During the month you will see the Dystonia Europe Board Members and Staff and hear what they do to escape dystonia, manage symptoms and feel better. Dystonia Europe Treasurer, Sissel Buskerud, says: *”I have a puppy called Alfred. To take care of him makes me happy. He is the reason why I live well with my Dystonia.”*

President Adam Kalinowski says: *”For me doing yoga exercises help me feel better not only physically but also mentally, in life with cervical dystonia”.*

What do you do to escape dystonia and feel better? Do you engage in a sport or a hobby? Do you have a passion for something that helps you forget about your dystonia?

Let us know how you manage your dystonia and send a photo or video of yourself. You can either share on our social media channels or you can send to: sec@dystonia-europe.org

We will share the photos and stories we receive.

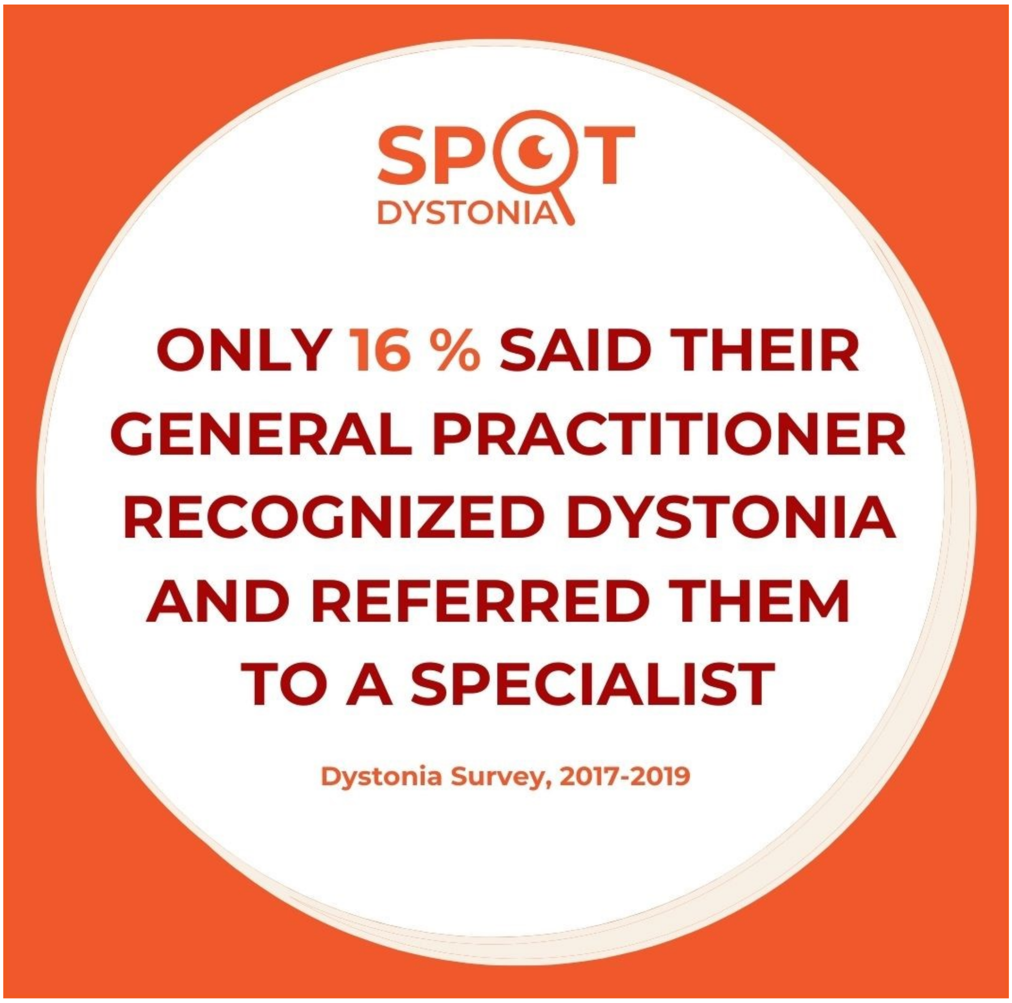
Our other initiative during awareness month is the **Spot Dystonia** series where you will find highlights from the findings of the Dystonia Survey run by Prof Maja Relja, School of Medicine, University of Zagreb, Croatia and Dystonia Europe in 2017-2019 to find out about access to diagnosis, treatment, and quality of life of dystonia patients. The survey had over 3000 participants in European countries, and included all types of dystonias. The survey highlighted the lack of knowledge among the medical profession and how it affects dystonia patients and access to diagnosis and treatment. This post below is an excerpt from the findings of that survey, *Relja et al, EAN Oslo 2019:* http://bit.ly/dystonia-survey

Please help us share these messages to increase awareness of dystonia.

Make sure to follow us on our social media channels (Facebook, Instagram, Linked-In, Twitter and YouTube). Every day of the month there will be a post on dystonia. Along with the initiatives above there will be posts covering: dystonia facts, inspirational quotes and dystonia patient stories.

We invite you join us and together let's make dystonia better known.

Monika Benson
Executive Director



SPOT DYSTONIA

ONLY 16 % SAID THEIR GENERAL PRACTITIONER RECOGNIZED DYSTONIA AND REFERRED THEM TO A SPECIALIST

Dystonia Survey, 2017-2019

"Dystonia can be overcome!" says Maestro Accardo

Maestro Accardo

Taking part in the first National Day against this rare condition, the famous violinist said:" At the Don Gnocchi Foundation I found outstanding doctors and physiotherapists, thanks to whom I've learnt to understand my body"

Salvatore Accardo, the internationally acclaimed violinist, was a testimonial of the professionalism and humanity of the doctors and health workers who within the Don Gnocchi Foundation are committed to treating neurological conditions, and dystonia in particular. This happened during the first edition of the National Dystonia Day, promoted last September in virtual mode by ARD (the Italian Research on Dystonia Association) together with the Foundation, and the contribution of experts, patients and their relatives.

Maestro Accardo, together with his wife Laura Gorna - also an internationally renowned violinist - talked about his experience with doctors Anna Castagna and Rosa Maria Converti. Dr Castagna, neurologist, is head of the Movement Disorders' and Botulinum Toxin Clinic of the IRCCS (Scientific Institute for Hospitalisation and Treatment) "Don Gnocchi" in Milan. Dr Converti, medical physiatrist, in charge of the "Sol Diesis Clinic " of the same IRCCS. Both doctors have been working for years on the treatment of dystonia, and both are passionate about music, and with music degrees too.

Music moves hearts, and often helps to overcome difficult moments. How did music help you, Maestro, to address and overcome dystonia?

Music really is therapeutic, as it helps to overcome difficult, sensitive issues: not only dystonia, but also, for example, autistic disorders and many others. Music- and specially for me Mozart, whom I believe was a really magnificent composer- has offered me an extra hand in my specific path as musician. Mozart's music puts you in touch with something pointing to divinity; he is the best. During the past few years I have been lucky enough to tackle these scores of Mozart's with my daughter, and you may well imagine the incredible emotional value of deepening these masterworks together with a ten- year -old...

What changes in your personal and professional life has dystonia brought? What has having a movement disorder allowed you to discover, maybe about yourself?

As professor Albanese, who was the first doctor I contacted at the start of my disorder in the Eighties, can testify, at first I simply could not understand what was happening, why this could be possible.... Then, as time went on, this condition has allowed me to know my body better, much better than I did before.

When you start playing at a young age, everything is done by instinct, with little or no understanding. This disorder, on the contrary, offers you the opportunity to understand what's going on in your muscles and in your tendons. Thanks to the care and help I've received from professionals these last years- and I'm talking especially about the splendid team of the Milan IRCCS Don Gnocchi Foundation- I've come to understand what happens when you do a certain sort of movement, and how it is possible to make a different and more helpful one instead. It would be important that these facts and suggestions were made known to all musicians at the start of their career.

Our brain's ability to correct and overcome dystonia is fundamental. How important was it for you to have the assistance of experts (neurologists, physiatrists, physiotherapists) and to be able to discuss your problems with them? At our Foundation we try to divulge the idea of tackling dystonia in many different ways, sometimes even by means of a psychological approach, trying to understand our reactions.

I would say that it's not just important to receive medical, neurological and psychological integrated support; rather, it is essential. In the Eighties, when I began to have my first problems, I was even afraid of having to stop playing. It is important to understand that it is instead possible to move forward, to fight this disease, to live with these disorders.

We musicians are also lucky enough to be involved in music, and music is that therapeutic help, as we have already said, that can make you get through the most difficult patches.

Research on dystonia also is of basic importance, as we haven't yet well understood which are the pathophysiological causes of this disorder. We have to continue studying because we have to understand what happens in our brain before we can put forward a good rehabilitation project. We need everyone's help, and holding events like this one is very useful. The slogan for this day is very meaningful: a rare disease doesn't mean an invisible one, and together we are stronger!

What would you like to say to people suffering from this disorder?

You can overcome dystonia, especially if you are lucky enough to meet doctors like the ones I did at Fondazione Don Gnocchi. So: take heart! I'm also sure that we will be more and more involved in this field . And as musicians we say: up with music. Because I'm persuaded that- as Nietzche says - "Without music, life would become impossible!"

In these years we have been lucky enough to also get to know a superb musician, Laura Gorna, wife of maestro Accardo and she too is an internationally renowned violinist. She also teaches music. How important is it in your opinion, Mrs Accardo, to give students in Music Conservatories and Musical Academies correct information about preventing disorders like dystonia?

Focal dystonia, the disorder that has affected my husband, has given me the opportunity to get to know some wonderful people and a splendid professional team. I've come to understand how important their work is, not only in overcoming the disorders, but also in helping to face the many other problems that can affect us musicians. As all categories of workers we too have our occupational diseases. Athletes are closely followed, whereas we are often without this focus on body awareness. I have also realised that as teachers, both of children and young adults, we have important responsibilities. We often have students with great technical abilities and noticeable musical knowledge but no body awareness- though the latter is of paramount importance. I would like to put forward a proposal in this direction, seeing that we have some extra courses in the biennium and Bachelor's degree. It is essential to play well, to study a lot, to nurture talent, to know music theory and harmony, with the addition of the ability to assert oneself, and much more; but it is no less important to have a correct body awareness.

This cannot be reduced to a mere exercise class, but should be conceived in Musical Conservatories, Academies and Schools as a multidisciplinary course led by teams like those working in the "Sol Diesis" Don Gnocchi Foundation's clinic. Often, when students have a problem, they go to their general practitioner, who then refers them to a specialist- but often these medical and paramedical figures don't talk to each other. On the contrary, work done at the Foundation is guaranteed to be multidisciplinary: they all speak to each other, work with the musicians themselves with shared purposes, and devote themselves to the musician and his problem. And they do this with competence and passion: the best guarantee for the patient's health.

Milan's Clinic for movement disorders, Botulinum toxin and personalised rehabilitation plans

The *Sol Diesis* clinic for musicians, that has been running since 2004 within the IRCCS Don Gnocchi Foundation, is devoted to the prevention and treatment of neuromuscular diseases of professional and amateur musicians.

"*The patient's medical and musical history, and a careful observation of the musician when he performs-* **says doctor Rosa Maria Converti,** *head of the clinic- allow us to identify necessities and problems connected to playing that particular instrument, so as to put forward specific rehabilitation programs for every professional pathology and every type of musical instrument: from physiatric examinations focusing on musicians' professional pathologies, to global postural rehabilitation and examining the techniques for playing an instrument to the Feldenkrais method, to adapting and putting in place ergonomic aids and functional splints.*

Examination of movements is carried out through the collaboration of SAFLO (Service for Motor Function Analysis). The Sol Diesis clinic works together with the Botulinum Toxin clinic, which focuses on treating movement disorders, for example focal dystonia in musicians- also known as "musician's cramp ".

"*During the Covid -19 pandemic-* **adds doctor Converti-** *the clinic has put in place two important remote services: teleconsultation and tele-rehabilitation. The former includes a physiatric examination, a posture evaluation and examining the technical gesture related to the musical instrument; the latter aimed to treating the musician's specific disorders, e.g. postural changes, muscle-tendineous pathologies, focal dystonia...*"

To receive more information or to make a reservation, send an email to: ambulatoriosoldiesis@dongnocchi.it

Maestro Salvatore Accardo with doctors form IRCCS Center, Milan, from left Maria Ramella, Rosa Maria Converti and Anna Castagna

The golden rules for musicians

set out by Milan's " Sol Diesis" clinic's experts

1) Do warm- up exercises before playing. It improves your performance

2) Do a progressive technical warm-up with your instrument. A musician is comparable to an athlete, and as such must warm up before a training session

3) Pause for 5/10 minutes every 40/50 minutes in a practice session. Body and mind need to pause to learn

4) Do some stretching exercises when you've finished. It improves the qualities of the muscle and helps eliminate the waste products

5) Take a correct posture during practice. Maintaining the best possible alignment when playing your instrument, for example avoiding excessive rotations of the torso, prevents overloads and therefore pain

6) Make sure you're practicing in suitable conditions; check lighting, seat height, the music stand's position

7) If necessary, introduce ergonomic adaptations: devices such as support belts, chin rests, shoulder pads, and adapting the instrument (e.g. changing the keys) can prevent pain. It is important that the instrument is adapted to the musician, and not vice versa

8) Vary repertoire and music styles. Repeating the same passage again and again can cause overloads and thence pain

9) Avoid excessive increases in practice time. Sudden increases before a concert or an exam can led to overload and pain

10) Avoid staying for long without playing; keep up a minimum of practice with your instrument even during times of rest

11) Get to know your body better so as to loosen muscular tension; there are many non medical approaches available such as the Feldenkreis method, the Alexander method, Tai-chi, yoga…

12) Keep stress and anxiety under control; mindfulness techniques can be helpful

13) Beware of carrying heavy weights and doing strenuous physical exercise: they may cause overload and pain

14) In everyday life it is important to follow a healthy diet, have an adequate hydration, sleep well and exercise regularly; it's better to avoid alcohol and smoking

15) Never play if it hurts. The motto "No pain, no gain" is not true! The onset of pain is a warning signal which should always be taken seriously

16) Should you experience pain which doesn't go away consult a specialist (physiatrist, orthopaedic); self-medication is dangerous and it is essential to get a diagnosis before starting any kind of treatment.

Anna Castagna

Neurologist & Head movement Disorders
and Botulinum Toxin Clinic

IRCCS Fondazione Don Gnocchi
Milan, Italy

The Deep Brain Stimulation Nurses Association –

‘Improving the quality of life for individuals with DBS through clinical care, education, research and innovation.’

The deep brain stimulation nurse association (DBSNA) was founded in 2013 after a small group of deep brain stimulation (DBS) nurse specialists met at a movement disorder conference and the idea for an association was born. The DBSNA has moved from strength to strength following these humble beginnings. All of our Association’s work is carried out in our own free time and is purely voluntary. DBSNA is a UK-based organisation with the main objective being to promote the improvement of the quality of patients’ lives through clinical care, education, research and innovation. The DBSNA aims to facilitate high standards of patient care by sharing knowledge, promoting best practice amongst nurses/allied health care professionals and then directly and indirectly delivering care to patients with DBS implants. We aim to promote the highest standards of care in DBS surgery and to enable the optimal patient experience. This is achieved by setting standards through nursing competencies and applying them to our practice which in turn develops the skills and knowledge of DBS nurses delivering care to patients with DBS.

We are represented by an elected committee which guides our work and we are also supported by our patrons who are specialist movement disorder consultants who practice within both adult and paediatric DBS centres. We host an annual conference at a different implanting centre each year and this year’s event will be held in Oxford. We also host an annual DBS programming course, which aims to improve standards of patient care by improving knowledge and skills focusing on safe and evidence-based programming of DBS therapy.

Our latest projects have been to develop a website www.dbsnurseassociation.org which we use to promote our membership, events and new developments. We also completed a major piece of work and produced a written competency document, which has been endorsed by the Royal College of Nursing. This gives a framework from which the DBS nurse working in this highly specialised area can use as a guide to their practice development. Since the formation of our organisation, we have seen the benefits of the DBSNA grow and grow. We now have members and contacts from across the world and we have developed an extensive network of nurses and allied health care professionals. We find that this is invaluable when we are working within the highly specialised field of deep brain stimulation programming.

We are always keen to forge stronger links with fellow professionals and organisations such as Dystonia Europe. It is a privilege to be asked by the Dystonia Europe team to write a short piece for their newsletter and I hope this helps build stronger links between our organisations and has helped you understand the aims and objectives of the DBSNA.

If you want to ask me any questions or have any queries please do not hesitate to contact me by email at russell.mills4@nhs.net

Russell Mills
Deep Brain Stimulation (DBS) Nurse Specialist
The Newcastle Upon Tyne Hospital NHS Foundation Trust

DBS Nurse Association

Former President Merete Avery and Russel Mills at a Dystonia Conference in Hannover

The following article, page 13-18, makes 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.

Improving quality of life of people living with Dystonia

Deep Brain Stimulation (DBS) is a safe and well-established therapy that can alleviate the symptoms of dystonia. When used in conjunction with visualisation software, such as GUIDE™ XT, it becomes a more efficient and effective therapy.

Following on our recent newsletter in Dystonia Europe (Spring 2021 Edition, page 9-10) presenting the benefits of GUIDE™ XT by Prof Volkmann, Dr Reich and Dr Capetian[1], we wanted to provide patients with the same platform to highlight their experience.

"*I was 9 years old when my teacher first noticed that I was not working properly, because of my legs. She called my parents and we went to the doctor, but they did not know what was wrong*". As his symptoms worsened, he started walking on his toes. Mark was prescribed a muscle relaxant in addition to Sinemet (a Parkinson's disease medication), but at this time they could not establish a diagnosis,

"I was walking on my toes between the ages of 9 and 11 and I was taking 18 tablets per day, it was a really trying time ".

At 11 years old, Mark finally met a specialist in Newcastle, close to where he lived. "*The specialist made me walk down the corridor, and as soon as he saw me walking he told my family that I had dystonia and as my mother was there with me, he also informed her that she had dystonia too, even if her was not as pronounced as mine*".

This was a life changing experience for Mark. To finally have a diagnosis meant he could finally receive the correct treatment. "*The doctor put me on Trihexyphenidyl, and I no longer stood on my tip toes. This was the first time I was walking properly. I was 11 and I hadn't walked correctly for 2 years between the time I had my first symptoms and the time where I was properly diagnosed*".

Mark's first symptoms of dystonia in his neck appeared when he was 18 years old. For 12 years, between the ages of 18 to 30, Mark had to content with his neck being turned to one side. The continued worsening of his condition meant the next 8 years were a particularly challenging time for Mark. "*When I was 30, I was doing a lot of manual labour in my job and I was working my neck muscle a lot. At this time is where I started to be in pain all day and that it became really difficult to cope with my condition*".

At 38 years old, Mark's sister pushed him to see a specialist again. He was prescribed botulinum toxin therapy injections to stop his nerves from causing his muscles to contract. Even after a course of six injections separated by 12 weeks between shots, he had seen no improvement in his condition. Finally, Mark was referred to a Deep Brain Stimulation (DBS) treatment centre in 2017. "*I was 42 years old by that time and I had to wait a year to have the surgery done*".

Mark's treatment with DBS transformed his life. "*DBS helped with all my symptoms. I could walk properly again, but the best thing for me was that the pain in my neck had gone.*

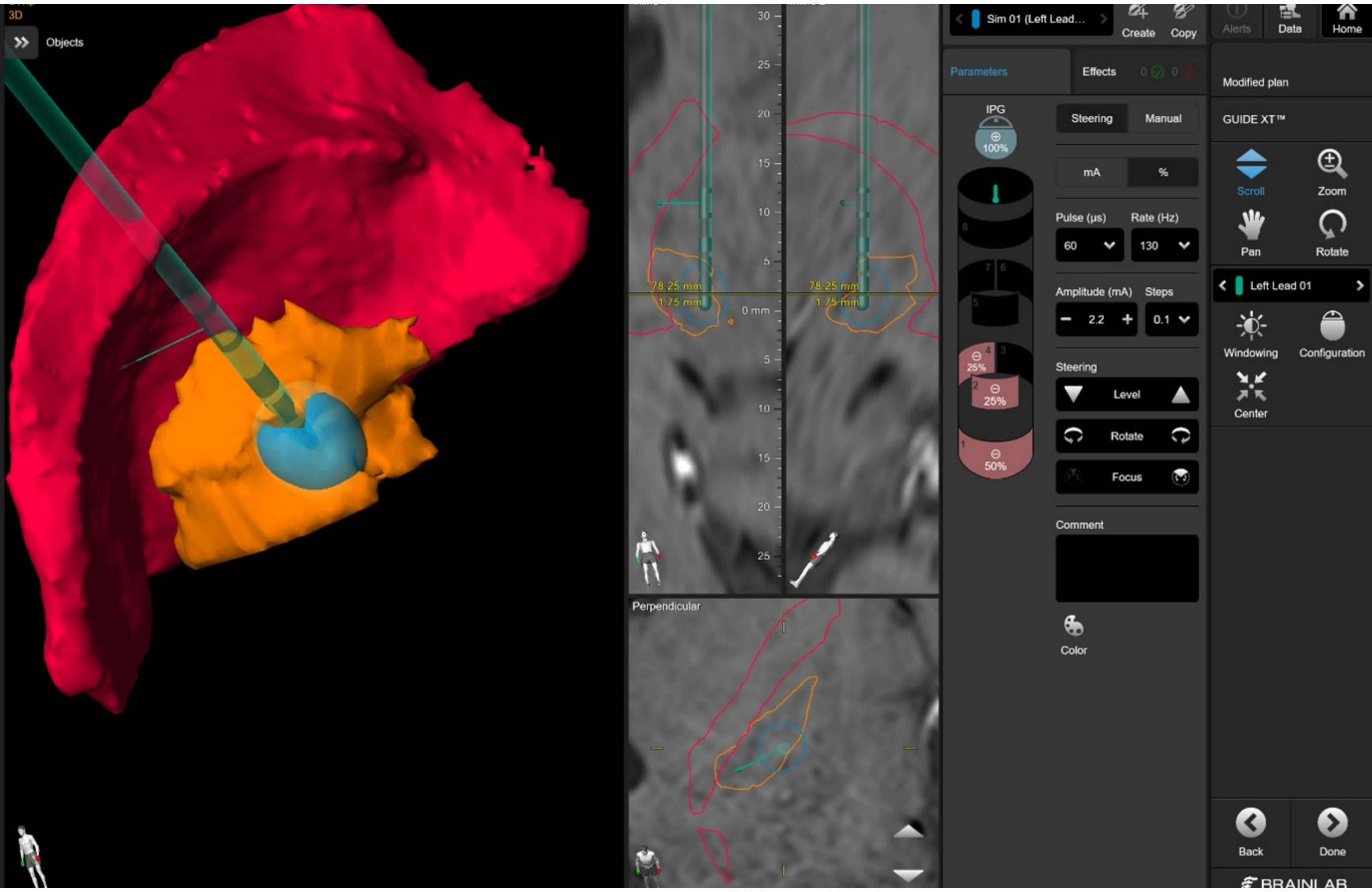
I hadn't been able to look straight when talking to people prior the DBS surgery and I was so embarrassed and ashamed of it, that it was stopping me from living a normal life. So in that sense the DBS surgery really changed my life, it gave me back my confidence, and I did not have any pain.”

As time passed some of Mark's symptoms, such as his speech, had began to worsen. After 2 and half years, he went back to see his DBS team. “*I got* programmed with some new software they called *GUIDE^{TM} XT, for the first 2-3 days my speech actually got a bit worse but after that it improved and a few days* later my speech was completely normal *again and all of my other symptoms were well controlled and I was still pain free*”.

GUIDETM XT a Boston Scientific visualisation software. It uses images of your brain taken at the time of the surgery and provide the DBS programming team with a 3D representation of your Brain. This provides your DBS team not only with your brain anatomy but also your specific lead placement.

Using these new tools allows the DBS team to offer you a more personalized treatment, allowing them to find the best outcomes for you faster.

Whilst the improvement in his symptoms was such a dramatic development, another positive point of being programmed with GUIDETM XT for Mark was it has reduced the frequency that he has to go to the hospital. “I am going less to the hospital since I get programmed with GUIDETM XT. Before I was going there every 3 months, but I am now going every 6 months and if at my next appointment everything is still going well, I won't have to go back there for a year, which I am really happy about”.



IPG 100%

Pulse (µs) 60

Rate (Hz) 130

Amplitude (mA) 2.2

Steps 0.1

25%

25%

50%

GUIDE^{TM} XT software with a representation of the left Globus Pallidus Internus (GPI, in orange. GPI is known to be the target for dystonia) with the electrode (green) in place. The surrounding structures are segmented for patient's specific anatomy. The programming settings created by the clinician are displayed on the right side of the screen and represented in blue on the left side as the region that will be activated to provide the best outcomes for this patient.

Given the differences that can be achieved through generalised vs personalised medicine, this form of programming, using visualisation, is more likely to become the new norm. Mark was highly supportive of this idea. “*Medical companies should continue to develop software that helps patients to have a more personalised therapy like GUIDE™ XT, as there are different types of dystonia and not everybody has the same symptoms, take my mother and I for example, so I think it is really important. Patients need to be aware of this new programming software. All I can say is that it is a miracle basically, and I stand there sometimes forgetting how it was before. I will not let them change anything. I feel so much better in myself”.*

Do not let your symptoms take control of your life - If you would like to know more about DBS therapy, please don’t hesitate to speak to your doctor or neurologist to be referred to a specific DBS centre to review your eligibility for this treatment.

To find out more about Boston Scientific latest technology, Vercise Genus™ DBS system and *GUIDE™ XT*, please visit: the Boston Scientific European website or ask your DBS centre.

“CAUTION: The law restricts these devices to sale by or on the order of a physician. Indications, contraindications, warnings and instructions for use can be found in the product labelling supplied with each device.

Products shown for INFORMATION purposes only and may not be approved or for sale in certain countries. This material not intended for use in France”.

Reference:

https://dystonia-europe.org/wp-content/uploads/2021/05/DE-Newsletter-1-2021-Spring.pdf

Boston Scientific
Advancing science for life™

INNOVATION IN DYSTONIA TREATMENT

More than **500,000 people**
across Europe are living with dystonia[1]

Treatment options:

Injections
Botulinum toxin temporarily weakens affected muscles and reduces spasms

Surgery
Lesioning of nerves that control the muscles causing spasms

Medication
A number of medicines can help regulate neurotransmission

Deep Brain Stimulation (DBS)
Brain stimulation can reduce symptoms of dystonia significantly

More than **150,000 people** worldwide
already **treated with DBS**[2]

What is DBS?

implantation of brain stimulator that helps regulate neural signaling

Vercise Directional System*
powered with Current Steering technology is designed for

- Greater precision for improved patient outcomes
- Reduction of potential side effects
- Flexible programming to treat a greater range of patients

Boston Scientific in DBS

- Contoured edges designed for patient comfort
- Directional leads for less side effects
- Leads compatible with MRI**
- Full body MRI conditional***

89% of treating physicians think that a directional lead should be used for all their patients[3]

DBS may reduce dystonia symptoms such as:

- Tremor, cramps
- Pain
- Strangled or whispering voice
- Muscle spasms
- Rapid eyelid blinking
- Painful neck spasms

Improvements of 50-60 % in general, some patients experiencing a 90 % reduction in symptoms[4]

Talk to your doctor about how DBS could help you and find out more here:
https://www.bostonscientific.com/en-EU/health-conditions/dystonia.html

References:
[1] http://www.braincouncil.eu/wp-content/uploads/2015/07/Dystonia-fact-sheet-August-2011.pdf
[2] https://www.neuromodulation.com/deep-brain-stimulation
[3] DBS Masters Debate, November 2015.
[4] https://www.dystonia-foundation.org/living-with-dystonia/neurosurgery/brain-surgeries/deep-brain-stimulation last access October 21, 2016.

* A System that includes the Vercise™ PC, Vercise Gevia™, or Vercise Genus™ IPG and Vercise Cartesia™ Directional Lead(s) forms the Vercise Directional System.

** The Vercise Genus or Vercise Gevia™ DBS System and Vercise DBS Lead-only system (before Stimulator is implanted) provide safe access to full-body MRI scans when used with specific components and the patient is exposed to the MRI environment under specific conditions defined in the supplemental manual ImageReady™ MRI Guidelines for Boston Scientific DBS Systems.

*** MRI Conditional when all conditions of use are met.

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Emma, one patient who underwent DBS for dystonia and taught me a lesson

Benedetta Storti[1,2], Camillo Foresti[2], Roberto Donati [3]

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Introduction

Dystonia associated with DYT1 mutation is an early-onset isolated dystonia usually first apparent with focal symptoms. Over time, the contractions spread to other body regions and become evident and debilitating. However, disease severity varies considerably even within the same family and isolated writer's cramp may be the only sign. Emma is a brave girl affected by a severe form of DYT1 Dystonia who underwent deep brain stimulation (DBS) implant in March 2021. She has taught me a lesson of courage and determination I would like to share.

CASE REPORT

At the very starting point of the novel “Emma”, Jane Austen reveals to the readers: “I am going to take a heroine whom no one but myself will much like". Accordingly, or, better to say, dis-accordingly, in this letter I would tell the story of another Emma, whom everyone will much like. Emma Woodhouse, in the novel, “had lived nearly twenty-one years in the world with very little to distress or vex her"; contrarily, Emma R., who was twenty-two when I first met her, had left behind normality when she was thirteen. Indeed, Emma R. was diagnosed with DYT-1 dystonia at that age. When she was attending the third year of secondary school, she progressively developed difficulties in writing with her right hand: it writhed involuntarily and caused the pencil to fall down. She was forced to write with her left hand and she became left-handed with much practice and many troubles; until the spared hand turned to be dystonic too.
As years went by, the muscles abnormal contractions spread to her right leg and she had to give up horse riding at about sixteen. In spite of the disturbing movement disorder, Emma R. finished her study, got engaged to a solid boy and found a job as a secretary in a private office. Even though she was widely affected by torsion dystonia, it was difficult to notice that at first glance. She had developed several different tricks that reduced the dystonic symptoms: one of these was placing her right foot behind the left one while sitting. Nevertheless, dystonia was always lying in wait, and it was sufficient to sit by her at lunch to observe the exhausting battle against the knife and the fork she was fighting. When Emma first developed the symptoms, they were not a surprise. In fact, when she was eight, all paternal relatives had undergone genetic screening because of an early-onset dystonia in a father’s aunt. Emma’s father had pathogenic TOR1A three base-pair deletion (c.907_909 GAG), and so did Emma. However, he was totally asymptomatic, Emma was not. DYT1 dystonia is an autosomal dominant pathology with penetrance of about 30% (1). As follows, the child of a mutation carrier has a change of 50% of inheriting the variant and, if inherited, a 30% chance of developing symptoms. Emma had a 15% chance of winning this lottery and, unfortunately, she did. With the spreading of the symptoms, Emma started to suffer continuous pain and cramping due to involuntary muscle movements. She was visited by several different movement disorder specialists and she tried most of the available treatments to treat dystonia (trihexyphenidyl, baclofen, benzodiazepines, tetrabenazine) (2). Every drug was quite ineffective. According to the DYT1 pathology, a trial of dopamine medication, rather useful in Segawa syndrome, was not performed (3). Emma had first-hand experience of many adverse effects and felt partial relief only with botulinum toxin injections and off-label oral preparations containing Δ^9-tetrahydrocannabinol (4).

Emma came to our hospital the first time when she was twenty-two. Involuntary intermittent contraction of muscles involved the four limbs and were present also at rest. She had a multifocal dystonia, with the trunk being spared. A surgical approach was proposed and after months of thoughtful reflection Emma agreed.

The deep brain stimulation (DBS) implant (Activa RC, Medtronic Inc.) was performed in March 2021 and Emma underwent it under local anaesthesia: she was totally awake and actively participating in neurostimulator placement. At a certain point, when the left electrode was approaching the target on the globus pallidus and she was asked to open and close her right hand quickly, she emotionally said: I haven't been able to do this movement for the last 10 years and now I can.

Emma was lucky. Even though the DBS surgery was scheduled months in advance, there was a high risk it would be cancelled due to the COVID-19 emergency: in March, half of the elective surgical activity in our hospital was postponed due to the third wave of the pandemic.

Only a few months after the procedure Emma is making great progress. She is relearning how to use her right hand and she is dreaming of buying a pair of high heels shoes.

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Information contained herein does not replace the recommendations of your healthcare professional. See the device manual for detailed information regarding the instructions for use, indications, contraindications, warnings, precautions, and potential adverse events. For further information, contact your Health Care Professional.

Medical Schools and Patient Involvement

A local medical school

In my home town, St Andrews in Scotland, we have an ancient university with a fine medical school. A few years ago, the tutors created a Patient Partnership group, inviting local people with several different types of illness, to meet students in special tutorial sessions.

These sessions are based on questions from the students about the patient and his/her symptoms, family health history, lifestyle, etc. There is no physical examination and the tutorials have continued by Zoom during the Covid 19 pandemic.

Students are very interested to meet patients, of course, especially when they discover that the medical condition is unusual and has interesting features, such as the many different types. https://dystonia-europe.org/about-dystonia/types/ .

How this can promote interest in dystonia

A consultation with a patient is often an opportunity for the doctor to learn about an unusual illness, which they may not have seen before. Yes – like dystonia! And the bizarre symptoms of dystonia attract the attention of intelligent and interested young people like medical students. They will also remember the symptoms if they see them again!

So – a tutorial can help the students to learn how to deal with patients in the clinic, but it is also an opportunity for the patient to help a group of young trainee doctors to learn and remember a few basic points about dystonia……. It means that more young people in the medical profession will hear about dystonia, actually talk to a dystonia patient and see the symptoms.

Then there is a greater chance that more new dystonia patients in the future will receive a faster diagnosis and better treatment.

Other interesting aspects the patient could mention, such as:

- The 'geste antagoniste' or 'antagonistic gesture' in cervical dystonia - where, by touching the chin or some other point on the head or neck, the dystonic movements will reduce or even stop temorarily. https://pubmed.ncbi.nlm.nih.gov/11499637/

Holding a pen or pencil in the hand can sometimes have a similar effect in hand dystonia/writer's cramp. Singing or humming a tune has also been shown to reduce or even stop symptoms temporarily for some patients, in some types of the illness. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4747630/

Background information about the illness

The students usually ask for more detail about the illness, such as cause, symptoms and treatments. https://dystonia-europe.org/about-dystonia/treatments-dystonia/ It is useful if the patient can provide some general background information for this little-known illness, but not too much detail. For example:

Studies suggest that more than 500,000 people in Europe have some form of dystonia.

Researchers believe dystonia results from an abnormality in or damage to the basal ganglia or other brain regions that control movement.

In most cases, the cause is unclear. Cervical dystonia is the most common type. Genetic links have been identified for some, but not all types of dystonia.

The response of the students and tutors

Students and tutors respond positively, and tutors (many of whom are local doctors or researchers) say that this is new information for them.

Many medical schools in Europe already have tutorial programmes like the one in St Andrews. If you feel that you are able to help students in this way, you can contact your local medical school and ask them if they have a similar programme.

MBE Alistair Newton
Advisor Dystonia Europe

New Survey
Sexuality and Dystonia

Dystonia Europe works to support researchers in moving forward research that could lead to better understanding, future treatments, and finally cures for dystonia. One of the projects supporting this action is our special survey platform that we make available to researchers.

We want to invite you to join the new survey 'Sexuality and Dystonia'. This survey is anonymous and available in 15 languages until end of the 2021. If you suffer from dystonia please answer questions on how dystonia affects your relationship and sexuality.

Help us by filling out the survey. Your personal dystonia experience and input can benefit the dystonia community today and in the future. Take part and help to improve the knowledge of what it is like to live with dystonia. We thank you in advance for your participation!

Survey link: https://surveys.dystonia-europe.org/survey/list

Survey developed by:
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Parkinson's Foundation Centre of Excellence at King's College Hospital NHS Foundation Trust, London, United Kingdom

Sexuality and Dystonia

Take a survey for change!

Register
If you want to take part
in the survey register on
surveys.dystonia-europe.org

Answer
Answer questions on the effects
of dystonia on relationships.

Change
Your experience is valuable
and can help specjalists address
the problems of patients with dystonia!

surveys.dystonia-europe.org

VOT2 Case Studies on Rare Diseases & Mental Disorders present findings at Synthesis Meeting on 8 June 2021

On 8 June 2021, EBC hosted a virtual Synthesis Meeting for the Value of Treatment 2 case study working groups to present their preliminary findings.

The Value of Treatment for Brain Disorders (VOT) is a health economics and outcomes research project coordinated by the European Brain Council (EBC). EBC conceptualized in 2015 the Value of Treatment research framework with a first VOT study to address the increasing all-age burden of brain disorders–both neurological and mental alike.

Risk reduction, preclinical and early detection, and timely intervention are seen as the solutions to help national health systems and society cope. In 2019, in order for the research to dig deeper into the current unmet needs in health care using a value-based approach, a second round (VOT2) on new therapeutic areas was launched; focusing on **The Value of Early Coordinated Care for Rare Diseases (Ataxia, Dystonia and Phenylketonuria)** and **The Value of Early Intervention and Continuity of Care for Mental Disorders (Anorexia Nervosa, Autism Spectrum Disorder and Major Depressive Disorder)**.

Throughout 2020, joint working sessions aimed to exchange and build synergy between the research-work and the European Commission DG Sante Rare Diseases European Reference Networks (ERN-RND and MetabERN) as well as the EU H2020 PECUNIA project on mental health services.

Moving towards the project's last phase (Phase 3 "final results and publications"), EBC together with its members (EAN, EANS, ECNP, EFNA, EPA, EPNS, EUFAMI, FENS, GAMIAN Europe, IBRO) and experts who are participating in the research convened a meeting on 8 June 2021 to present a synthesis of the VOT2 research project results so far. The meeting brought together all experts from within VOT2 as well as external experts and a wider audience from the community. The experts presented their preliminary findings, which can be read in more detail in the full event report, downloadable below.

Both EBC position papers will be released on 7 December 2021 to be followed by scientific publications (Q1 2022). Beyond the research design and considering current context, the impact of Covid-19 on treatment and healthcare transformation will also be further explored.

Read more in the event report:
https://www.braincouncil.eu/wp-content/uploads/2021/06/VOT2-SYNTHESIS-MEETING-SUMMARY-AND-NEXT-STEPS.pdf

This summary is from the EBC website, 28 June 2021

Monika Benson
Executive Director

Achieving Health Equity After The COVID-19 Pandemic

On 15 June 2021, the MEP Interest Group on Brain, Mind and Pain organised a virtual working session. The event's main objective was to understand the long-term impact of the Covid-19 outbreak on different population groups affected by BMP disorders, and to define and frame the inequalities and challenges they experience. The working session was attended by EU policy-makers, healthcare professionals, patient organisations and industry representatives.

Attendees were welcomed by Ms Joke Jaarsma, President of the European Federation of Neurological Associations (EFNA). Ms Jaarsma highlighted in her opening remarks that the Covid-19 pandemic has further strained health inequalities within the EU and its Member States, impacting deeply people living with BMP disorders. She also underlined the need to urgently address these inequalities, touching upon the complexities of healthcare disparities and the required political commitments.

Mr Joop van Griensven, President of Pain Alliance Europe (PAE) discussed, the impact of Covid-19 on BMP patients and vulnerable groups, highlighting that the aftermath of the pandemic will be a critical point in ensuring that those living with life-limiting conditions are not socially excluded and are meaningfully involved in all policy discussions.

Ms Donna Walsh, Executive Director of EFNA and Ms Deirdre Ryan, Presidential Candidate of PAE presented the results of two recent surveys that looked at the impact of Covid-19 on those living with neurological and chronic pain in Europe. The two surveys had similar findings, with almost 45% neurological patients and 48% chronic pain patients experiencing difficulties in receiving appropriate care during the pandemic. Based on these and other results in the surveys, EFNA and PAE presented their key conclusions and recommendations to policy-makers.

After the initial presentations, the audience was provided with the EU institutional perspective by Ms Katarzyna Ptak-Bufkens from the European Commission and the Interest Group's co-chair, MEP Tilly Metz (Greens / EFA, Luxembourg). Ms Ptak-Bufkens referenced some of the Commission's ongoing complementary policy tools to address health inequalities, including the European Pillar of Social Rights and Action Plan, and the Health Systems Performance Assessment (HSPA), highlighting that a ‘one size fits all’ solution is impractical and that tools should serve the national and subnational context and help those most vulnerable. MEP Metz welcomed Ms Ptak-Bufkens' remarks while strongly emphasising the importance of putting non-communicable and chronic diseases, such as BMP disorders, at the forefront of future-proofing and building resiliency of European healthcare systems.

Following the opening plenary, three parallel workshops allowed for a more interactive discussion on the Interest Group's core themes: stigma, access and patient empowerment.

Through this exercise of gathering insights from different players in the healthcare arena and promoting a co-decision approach, the challenges experienced by people with BMP disorders were better framed, and this will ultimately contribute to identifying more person-centred solutions.

#1: “Covid-19 and the future of ageing: intergenerational connections” (stigma, discrimination and isolation)
Participants in this workshop agreed that the most solvable challenge in the short term for ageing patients was the lack of public awareness of BMP disorders, highlighting that better information, including via improved digital literacy, could contribute to increased social inclusion.

#2: “Addressing access challenges and geographical disparities experienced by vulnerable groups across Europe” (access to treatment, services and support)
At the beginning of the workshop, Mr Stanimir Hasardzhiev, Secretary-General of the Patient Access Partnership (PACT), delivered a presentation on “*Addressing access challenges and geographical disparities experienced by vulnerable groups across Europe*”. access to healthcare.

During the workshop, participants discussed the geographical disparities and access challenges that people living with BMP disorders experience, and identified the **lack of appropriate information on the disease and its management** as the most solvable challenge in the short term. Participants have highlighted that in order to address this unmet need, no legislation changes are necessary. Moreover, patient organisations at national level can take the lead and ensure that patients have access to relevant information, thus supporting them in making informed decisions that will ultimately improve patient outcomes.

#3: “Empowering women with BMP disorders and carers in the aftermath of Covid-19” (patient empowerment)

Ms Peggy Maguire, Director General of the European Institute of Women's Health, opened the workshop with a presentation on *“Health Promoting Gender Equity in EU Health Policy”,* and referenced figures and studies highlighting the gender gaps in BMP research in Europe, including women's under-representation in clinical trials. Ms Maguire concluded her presentation by sharing a snapshot of recent policy developments on the topic.

Based on the identified challenges, the Interest Group will now look to assess how EU-level action can help to support the advancement of the priority issues identified. Best practice interventions in the wider healthcare space will be sought via desk research and a call for solutions. Shortlisted solutions will be presented and discussed with key stakeholders at the next meeting of the Interest Group that will take place on 19 November, and will form the basis of the MEP Interest Group’s direction/workplan in 2022.

MEP Duda noted the importance of raising awareness of BMP disorders to reduce stigma and discrimination, highlighting the need to move towards increased health equity in a post-Covid world.

Before concluding the event, EFNA awarded Mr Joop van Griensven the Lifetime Achievement Award for his tireless work and support in raising awareness and improving the lives of those living with chronic pain.

Summary from EFNA’s Report on the meeting
Merete Avery

EFNA
EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

BRAIN MIND PAIN
Member of the European Parliament
INTEREST GROUP ON
BRAIN, MIND AND PAIN

One Neurology

Dystonia Europe participated in a Global Advocacy Workshop 29th July on One Neurology.

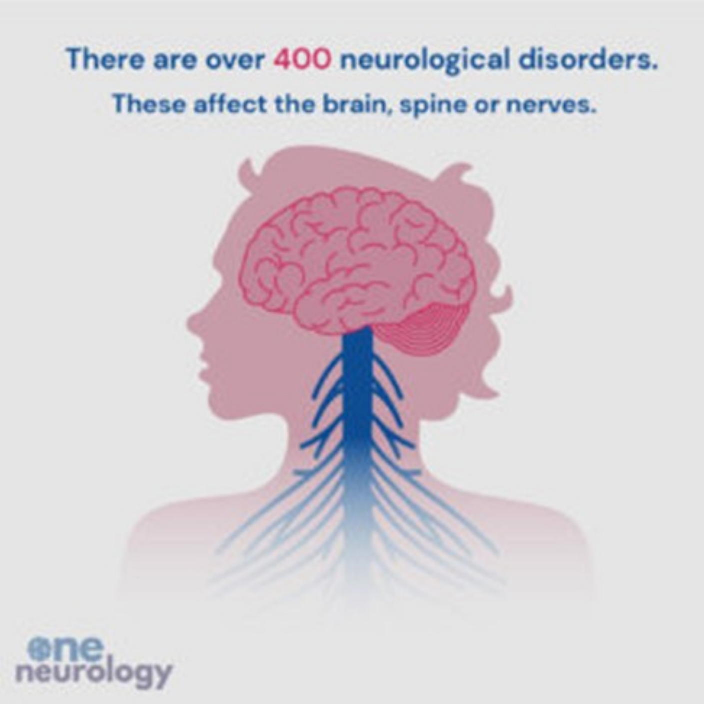
One Neurology is an initiative that aims to unite and strengthen neurology-related groups to collaborative advocacy, action and accountability for the prevention, treatment and management of neurological disorders worldwide. EFNA (www.efna.net) together with the European Academy of Neurology (EAN), founded this patient-driven initiative, which includes a multi-stakeholder global partnership.

Neurology is the most frequent, disabling and costly of all Non Communicable Diseases (NCD's). International neurological organisations and regional umbrellas are teaming up to make neurology a global public health priority.

OneNeurology aims to create a favourable policy environment for action on neurology, providing a platform for disease specific advocacy efforts at all levels.

Global Action plan

In 2020 the World Health Assembly adopted a resolution on Global actions on epilepsy and other neurological disorders, which requested the World Health Organisation (WHO) to develop an intersectoral global action plan. As a first step, WHO developed the discussion paper. It includes the proposed vision, strategic objectives and a set of recommended actions.



One of the speakers at this workshop was Dr Tarun Dua, Head of The World Health Organisation's Brain Health Unit, and she expressed that "It is extremely important to work together for the sake of neurological illness".

During the workshop there were also breakout sessions on high income countries/regions and on lower and middle income countries and regions. There were good opportunities to ask questions and share comments.

You can read more on this project at www.oneneurology.net (under partnership you can find Dystonia Europe as one of the endorsers) and you can also find a link to the podcast on One Neurology. You can also read more on EFNA's website www.efna.net/oneneurology-launch/ .

Merete Avery

Dystonia Europe Operations Manager

MyDystonia App Ambassador Meeting

MyDystonia is an electronic diary created for people with dystonia. This diary enables patients to monitor their symptoms and how those symptoms affect daily life. Patients can share insights with their doctor to discuss how to optimize their treatment approach. After years of experience and feedback from users, app ambassadors and advisors, in May 2021 we launched a new, improved version of the application. The new MyDystonia is very different from the previous one.

The Ambassador Programme was launched in 2016 to support the roll-out of the MyDystonia App in Europe. Ambassadors are also responsible for supporting application users at the national level in their native language. Now we have representatives for 12 countries on board: Belgium, Denmark, Finland, France, Germany, Ireland, Italy, Norway, Poland, Romania, Sweden and UK. The ambassador role is voluntary. If you think you can support the program and want to become an MyDystonia Ambassador for a European country not listed above please contact us.

Ambassadors meet once a year. This year the meeting took place on June 26, 2021. It was the sixth meeting and the first online since the launch of the MyDystonia. 12 participants from 10 countries including Dystonia Europe representatives met to hear an update on the new MyDystonia version, share feedback and plan next steps. We were very pleased to be joined by new ambassadors: Ulf Borg from Sweden, Thijs R.C. Vandewoude from Belgium and Martina Kühn from Germany.

After the welcome to the meeting by the DE president Adam Kalinowski and introduction of participants, DE IT advisor Eelco Uytterhoeven gave a presentation and took ambassadors through the new version of the app showing all its added functionality. After the presentation, the meeting participants had the opportunity to ask questions and contribute their ideas. The participants also talked about future plans such as translating MyDystonia into different languages, promoting and engaging specialists treating dystonia patients to use the application reports to improve the treatment.

The new version is available in English only, but new languages will be added at the end of this year or the first half of 2022. The ambassadors agreed to help with the translation. The whole meeting lasted two hours and was very productive.

Thank you to all ambassadors for their dedication and great support in working on the application. The next ambassador meeting is scheduled for 22nd May. We hope this meeting will be held face to face in Copenhagen, alongside Dystonia Day 2022.

You can find out more about the MyDystonia on our website: https://dystonia-europe.org/projects-1/projects/mydystonia/

Adam Kalinowski
MyDystonia Coordinator
Dystonia Europe President

From top left:
Gill Ainsley - app ambassador for UK and DE rep.
Adam Kalinowski – app ambassador for Poland and Ireland, DE rep.
Ulf Borg – app ambassador for Sweden
Sissel Buskerud – app ambassador for Norway and DE rep.
Thijs R.C. Vandewoude – app ambassador for Belgium
Ulrike Halsch – app ambassador for Germany
Tiina Pellinen – app ambassador for Finland
Edwige Ponseel – app ambassador for France and DE rep.
Raquel Vacas – app ambassador for Italy
Martina Kühn – app ambassador for Germany
Eelco Uytterhoeven – DE IT advisor
Merete Avery – DE rep.

MY DYSTONIA

An electronic diary to improve your treatment outcome and quality of life

Search 19:23 19%

2021-04-23

Sleep — Did you experience sleeping pro...

Pain — How much pain did you experien...

Impairment — How do you keep up with house... Great difficulties

Impairment — Does your dystonia affect your r... A bit

Impairment — Do you have any difficulties usin... Nearly impossible

Impairment — Do you have difficulties speaking No difficulties

Impairment — Do you have difficulties working... Great difficulties

17:12 89%

report

chart

19 April 2021 - 26 April 2021

Did you experience sleeping problems related to your dystonia?

How much pain did you experience related to your dystonia?

How satisfied are you with your entire treatment plan?

How are you coping with your dystonia?

Do you experience stress?

NEW VERSION*

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DYSTONIA EUROPE

Paula Happonen

Meet Paula Happonen, Board Member of the Finnish Dystona Association

What is your name?

My name is Paula Happonen.

What are the benefits of working within a patient organisation?

By volunteering I am able to contribute to well-being of other people who live with dystonia. I am able to provide and receive support. I have made good friends and I also have received meaningful content to my life.

How do you like spending your free time?

I like to exercise in nature and take care of my garden. In addition, I like to stay in our cottage with my family.

What keeps you motivated on the tough days?

On the tough days I try to think about what good I have in my life and I think that the issues could be worse. I can only do my best and I have to be merciful to myself. On the tough days I often think that tomorrow will be a better day.

What makes you angry or frustrated?

Sometimes people do not understand the dystonia is very multifaced disease and the disease does not always show outwards. In some situations in the hospital I am so frustrated and I think healthcare professionals should have more knowledge about dystonia.

Paula Happonen
Board Member Finish Dystonia Association

Members meeting face to face in Norway

Members of a local group in The Norwegian Dystonia Association (NDF) gathered for a 2 day meeting on August 24th, in the beautiful Rømskog SPA outside Oslo, Norway.

This was the first face to face meeting since the pandemic started and the members were very pleased to meet again.

The program:

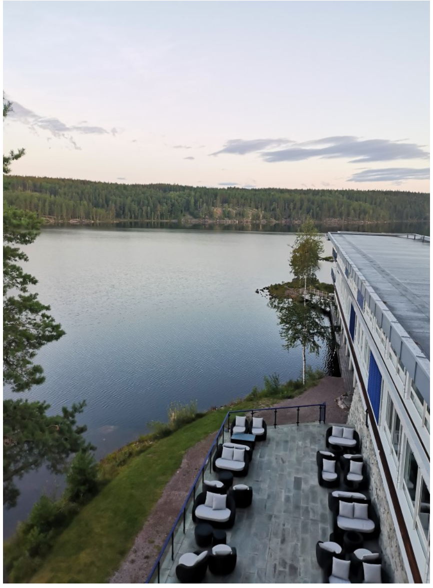
- Information of what NDF had done during the pandemic to keep in contact with the members.
- Information of future activities in 2021. NDF will arrange several meetings during this autumn
- Information on the MyDystonia app 2.0
- “Believe and trust“ a lecture by Tore Sannum

We shared experiences and learned from each other.

Sissel Buskerud
Vice President Norway and Treasurer DE

Dystonia Europe hope that the pandemic situation will improve soon in all countries and that people with dystonia can meet face to face again.

To the right:
View from Rømskog



Below: At last, we had the opportunity to speak together face to face.

Hello everybody in Europe from Tuscany, Italy!

I'm Annalisa and I have been suffering from cervical dystonia since 1995, when I was 28 years old. Most of you will probably know what cervical dystonia or spasmodic torticollis is. It affects the muscles of your neck and consequently your head and shoulders, with a strong impact on the whole body. In my case the muscles involved make my head bend on the right shoulder and turn to the left. It all happened suddenly at the beginning of February 1995. The muscles in my trunk started to twitch and my neck started to bend. Luckily I didn't feel pain, but it took me a few months to get a diagnosis: I was suffering from dystonia.

Since then I've been through three phases of my life with dystonia. At first, my world was turned upside down, I was shocked and I couldn't see any way out. At the end of my second hospitalisation botulinum toxin was injected into my "ill" muscles and my neck was unblocked ... however it was too much, because my head kept swinging while I was walking. Nevertheless the sense of relief was enormous, even if I had to spend most of my day lying down and resting because of the intense contractions of my muscles. My body required a lot of energy and I needed to relax. Of course I had to leave my job, but luckily I had, and still have, a wonderful family and my boyfriend - later my husband - at my side.

Lizzy's Story

The second phase I lived was the one I would describe as "submission or compliance" to your neurologist and your beloved ones: I tried to do everything I was told to. When you suffer from cervical dystonia your body takes abnormal postures in an effort to rebalance your head. In order to improve this situation I was encouraged to practice yoga and swimming, which helped me a lot: yoga helps you give the right attention to your body, relax and stretch your muscles, just like swimming does.

Another piece of advice or "order" I was given by my neurologist was that I should have physiotherapy in a specialised centre, which would help improve and extend the effects of botulinum toxin. I put myself through that with reluctance, but I soon had to change my mind, as it turned out to be very helpful.

And then came the third phase of my life with dystonia: awareness.

The exercises I learnt from my excellent physiotherapist, the use of bio-feedback and yoga have taught me to listen to my body and try to control my rebel muscles by assuming postures that help keep them relaxed. I started to examine everything I did in a critical way, in order to improve my condition and choose what made and still makes me feel better. As an example, I try to avoid sitting as much as I can, especially when I'm at home. I read, watch TV or work on the computer lying on the sofa.

Since the beginning I have been trying not to let dystonia take over, and despite the moments of frustration I have always tried to maintain a positive attitude, which involved soliciting information from my doctors about everything I was going through and increasing my knowledge about dystonia.

Rather than isolating myself I have always maintained my social relations (even if the question "Have you got torticollis ?" has tormented me more than once a day!) and I have tried different therapeutic options.

For all that I have to thank my family's constant support and my husband's patience.

I have also had the opportunity to shape a job around my abilities: I have been running a B&B in Tuscany since 2004 and this job allows me to have several moments of rest during my day but, most of all, I don't have to go to work, but it's work that comes to me!

Every three months I have botulinum toxin injections; in spite of their efficacy having lowered, they remain the main treatment; I take less tablets, I practise yoga and go swimming once a week: you need to learn to give priority to yourself and your body, even if that is not always easy.

Joining A.R.D. (the Italian Dystonia Association) was very important to me: I have met wonderful people affected by dystonia themselves, who know what living with dystonia means and how it makes you feel. They have given me the strength and courage to live with dignity. Having the chance to share your problems and not feeling lonely in this daily fight have been fundamental to me.

All the best from Tuscany and if you want to come and visit me, look for A Casa di Lizzy B&B! Ciao!

Annalisa Sironi

My home

Calendar 2021

September	
1 - 30	Dystonia Awareness Month
4	Dystonia Day, on-line via Zoom
8 - 11	ESSFN, Marseille http://essfncongress.org/en/
17 - 22	International Parkinson’s and Movement Disorder Society Congress 2021, virtual https://www.mdscongress.org/Congress-2021.htm

For more information and registration visit:

https://dystonia-europe.org/dystonia-day-2021-online/

Members

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

Austria, Belgium, Croatia, Czech Republic, Denmark, Finland, France, Germany, Ireland, Italy, Norway, Poland, Romania, Spain, Sweden, Switzerland, Ukraine and United Kingdom.

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 Marie Vidailhet – Paris
Prof Marjan Jahanshahi— London

Connecting People for Dystonia

Staff

Monika Benson
Board Member
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

Adam Kalinowski

President

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 Polish but he lives in Ireland where he studies graphic design. Adam was re-elected to the Dystonia Europe board in 2019 and 2021. Now he is the President of Dystonia Europe.

Edwige Ponseel

Vice President

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 for a 3rd period in 2021, she is now the Vice President of Dystonia Europe.

Gill Ainsley

Secretary

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 re-elected in 2021. She is the Secretary of Dystonia Europe.

Catalina Crainic

Board Member

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 and re-elected in 2021.

Jukka Sillanpää

Board Member

Jukka has been the President of the Finnish Dystonia Association since 2018. The main targets of the association are to provide the members with support and to increase dystonia awareness among the healthcare professionals in Finland. Jukka has also been a Board Member of the Finnish Parkinson Association since 2020. Jukka has a university degree in accounting and finance. He has much experience in management and financial accounting as well as business planning in his working life. He has a lot of experience in different roles in many associations. Jukka has Cervical Dystonia. Jukka was elected to the Dystonia Europe board in 2021. .

Sissel Buskerud

Treasurer

Sissel is the Vice President 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.

ADVISORS AND CONTACT

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.

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

IT 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.

Contact

President
Adam Kalinowski

Executive Director
Monika Benson

Operations Manager
Merete Avery

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Photos from Dystonia Days and portrait photos:

Stephan Röhl, www.stephan-roehl.de

Meet us @

Website:
http://dystonia-europe.org
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LinkedIn:
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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.

Donation and 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 our 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!

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PLATINIUM

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IPSEN
Innovation for patient care

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Further, Together

MERZ THERAPEUTICS
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