DYSTONIA NEWS

SUMMER|2 - 2022

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DYSTONIA EUROPE

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CALENDAR

September 1 - 30	Dystonia Awareness Month
September 15 - 18	MDS Congress, Madrid, Spain
September 20	Dystonia Europe Board Meeting, Lund, Sweden
October 20	Summer Think Tank 2022
October 29 - 1 November	ERN-RND Annual Meeting,
October 20	Dystonia Europe Board Meeting
November 25	Dystonia Europe Board Meeting

Adam Kalinowski
Dystonia Europe
President

Dear readers,

Welcome to the summer issue of Dystonia News. We hope you had a chance to relax and enjoy the weather this season.

We are more than happy that this year, after a two-year break, we had the pleasure of meeting our members and organizing the 29th Dystonia Day Conference in Copenhagen live! Seeing feedback, we can say that it was a very successful event. Thanks to our participants and lecturers, the atmosphere was amazing. Now we look forward to the next meeting in 2023, which will take place in Dublin.

September is marked in the calendar as Dystonia Awareness Month. As every year, the Dystonia Europe team worked on preparing online activities for this special month. This year, in addition to traditional posts like educational materials and stories, we have something special - #dystoniajourney campaign that highlights an important aspect in the lives of people with dystonia. You can find out more about this campaign in this newsletter and by following our social media. We strongly encourage you to participate.

In addition to preparing for awareness month, we also worked on several important projects including the new season of the 'Positive Twist' podcast, Dystonia Awareness Video project, Dystonia Patient Journey and many more.

In our news we also share what's new within research, information from our members and partners, and stories from people with dystonia. Enjoy the read!

We wish you a pleasant and relaxing autumn!

Dystonia Europe Annual General Assembly 2022

Dystonia Europe held its 29th Annual General Assembly on 20 May at Hotel Scandic Copenhagen in Copenhagen, Denmark. It was a wonderful reunion for many of the DE members who had not met face-to-face since London 2019.

A total of 27 participants from 13 member associations participated. Dystonia Europe President Adam Kalinowski welcomed all and then everyone present at the meeting introduced themselves.

There was a new member application from a recently founded dystonia patient association in Slovenia. After the founder and President Tedy Grbec had presented the organisation the members all approved the membership. It is exciting to see Dystonia Europe growing and there are now 23 member organisations from 20 countries in Europe.

The members also agreed to keep the membership fee at €100 per year.

There was neither re-election nor election to the board. The current board consists of:

President Adam Kalinowski, Poland
Vice President Edwige Ponseel, France
Treasurer Sissel Buskerud, Norway
Secretary Gill Ainsley, UK
Board Member Catalina Crainic, Romania
Board Member Jukka Sillanpää, Finland

Staff members are: Executive Director Monika Benson from Sweden and Operations Manager Merete Avery from Norway.

Paid consultants are: IT developer Eelco Uytterhoeven, The Netherlands, and Social Media Specialist Amanda Benson, US.

Due to new regulations of the Belgian law for non-profit organisations work is being done to update the Dystonia Europe statutes accordingly. Information about this work will be sent out to members at the beginning of autumn.

As usual Monika presented the work of the organisation for the past year. All of this can also be read in the Annual Report 2021. Sissel presented the Annual Accounts 2021 which showed a positive result. The Budget for 2022 was also approved by the delegates.

Dystonia Europe IT Advisor Eelco Uytterhoeven was connected via Zoom and gave a presentation on the latest developments of MyDystonia 2.0. The plan is to promote the App in the coming months and the next step will be to translate into other languages.

Monika shared some of the plans for the upcoming Dystonia Awareness month next September, and how we will work on sharing dystonia facts, inspirational quotes and dystonia testimonies throughout the month. More information on what we plan to do on page 14.

Next year it is the 30th Anniversary of Dystonia Europe. This will take place in Dublin alongside the International Dystonia Symposium 1-3 June.
We hope to see as many members as possible there.

Monika Benson
Executive Director
Dystonia Europe

From left:

Monika Benson,
Gill Ainsley,
Sissel Buskerud,
Adam Kalinowski,
Catalina Crainic,
Merete Avery and
Jukka Sillanpää

Vice President
Edwige Ponseel
not present.

Dystonia Europe General Assembly and Dystonia Days 2022

Our last face to face meeting with members was in June 2019 so I was really looking forward to meeting my friends on the Dystonia Europe Board and our members who were able to join us for the weekend.

I left my home at 03:30 for my 06:00 flight to Copenhagen via Amsterdam and arrived at the Scandic Copenhagen hotel at around lunch time, very tired and rather hot and sweaty!

I met with my friends on the Board for a quick lunch and then we were straight to work with a Board Meeting to discuss final arrangements for the weekend's meetings and activities and also to discuss other DE business.

Once we were all together again my fatigue disappeared and I was left feeling energised and ready to work!

Our first evening together was spent in a local restaurant where we ate lovely food and chatted the evening away.

The following morning (Friday) we were straight to business after breakfast and some of us began by putting together the information packs for the General Assembly that afternoon and the conference on Saturday. Some Board members took part in the 'Patient Journey' video project to be used for Dystonia Awareness in September.

Tedy Grbec, founder and President of the Slovenian Dystonia Association, new member of Dystonia Europe

President Adam Kalinowski opening Dystonia Day 2022

All the time we were busy, Stephan, our photographer was taking photos of us sometimes discreetly and sometimes not so discreetly! He really knows how to get the best pictures out of us all!

The time for the General Assembly came around very quickly and was well attended by our members. Monika, Adam and Sissel all gave excellent presentations on all our achievements and our finances.

As usual Adam had us all giggling when during the agenda point 'Membership Fees' he asked our members if they would like to raise the annual fee!

We had a very emotional presentation by Tedy from the Slovenian Dystonia Society. He told us his 'Dystonia Story' and the long and difficult path he had before he got a correct diagnosis and effective treatment. I was very pleased that the General Assembly approved their membership of Dystonia Europe, we can now help each other.

We had a short break during the meeting where we enjoyed coffee, cake and chatting to each other.

That evening we had a coach tour around Copenhagen and the highlight was a trip to the Christiansborg Palace.

It is such a beautiful building furnished and decorated exquisitely. That was followed by a very special dinner at The Opera House. Also a beautiful building but very modern and very different to the Castle.

The big day finally got underway when the Board Members met in the conference room at 07:30 to prepare everything ready for our guests, speakers and delegates arriving from 08:30.

That hour before people began to arrive was hectic! We prepared the registration desk, we moved furniture, we decorated the room with posters and balloons, we put up our banners and somewhere in between all of that we had breakfast, phew!

Adam began the conference by introducing Dystonia Europe (DE) and giving us a brief history of the organisation. The conference was very well attended with people from all over Europe and only a few empty seats in the large conference room..

We had presentations and videos from a wide range of specialists and patients. Tracey McCann made a video of her 'Patient Journey' which was emotional and inspirational. You can find her presentations on 'Ted Talks'.

Prof Tobias Bäumer explained the benefits of guided botulinum toxin injections and Prof Lena Hjermind explained the genetics of Dystonia.

Prof Tobias Bäumer

Prof Lena Hjermind

After coffee Prof Espen Dietrichs explained plasticity in our nervous system. I found this particularly interesting as I previously knew nothing about plasticity and the part it plays in our nervous system particularly for dystonia patients. He was followed by Prof Annemette Lökkegaard who gave us a really good explanation of Deep Brain Stimulation (DBS) for dystonia patients.

Prof Espen Dietrichs

Prof Annemette Lökkegaard

We then had a lunch break and I could feel my energy levels getting really low but of course we still had the afternoon to do! I took myself off to a quiet part of the hotel and just sat, all alone with my eyes closed and relaxed for 20 minutes before the afternoon session began. This really helped me to focus on the afternoon speakers.

The first speaker of the afternoon was our long-term friend and supporter Dr Jean-Pierre Lin who specialises in children's dystonia and DBS treatment for children. As usual he was very informative and presented a lot of evidence to show that children respond really well to DBS.

Dr Jean Pierre Lin

Our next speaker was physiotherapist Johanna Blom who has created a database of physiotherapy exercises especially for dystonia patients. The database was developed with a grant from Boston Scientific Foundation and is currently available in Sweden but will be available to other parts of Europe very soon.

Physiotherapist Johanna Blom

We then had the pleasure of a video presentation from Prof Marjan Jahanshahi who spoke about living well with dystonia. She advised that we should all be kind to ourselves and take time when we need it to rest and practice mindfulness. I realised as she was explaining this that I had done that for myself at lunch time!

Monika then gave us a presentation of the 'Patient Journey' which was a study of patients with Cervical Dystonia. The results of the study were used to create the first cervical dystonia patient experience map. This was done with support from Ipsen and a lot of input from DE and their members.

The results have now been published in the Orphanet Journal of Rare Diseases. Monika also asked everyone present to take part in a short video project where dystonia patients answer three questions, 'I am ___name, From ____ Country, It took _____ years/months (for diagnosis). These videos which will be short and to the point will be used as part of our Awareness campaign in September.

Monika was followed by Adam telling us about the latest version of the MyDystonia app. We would like many more people to use this useful app, we are sure they will find it helpful for monitoring their own dystonia and discussing their symptoms with their consultant.

Dr Katarzyna Smilowska then joined us by video to present the results of her survey, 'Dystonia and Sexuality'. After yet another interesting presentation Katarzyna concluded that participants who were sexually active were young and in a relationship, and she found no differences in terms of gender, type and duration of dystonia and percentage of those receiving treatment.

At this point my energy levels were taking a serious nose dive and sadly I had to leave the conference room and rest for a short while so that I had the energy to help clean up the conference room and set up the room for our Gala Dinner that evening.

I know from my friends that the last speaker, Sandra Theil, was also very good and of course I wish I hadn't missed her, but I will watch her video on our YouTube channel!

This excellent conference came to end with Adam thanking everyone for attending, presenting and working to make the day such a success.

As people began to leave the conference room all Board Members helped to tidy all the material away and to decorate the room next door for our Gala Dinner.

Time was running short and we all had to get changed ready for the dinner, so we went our separate ways and I had a very quick shower and change of clothes and then went back downstairs for drinks before the dinner. We had a lovely three course dinner, beautifully presented and perfectly cooked. There were a lot of tired but happy faces around the tables, we all agreed the weekend had been a huge success.

Thank you to all the people who worked hard to arrange the weekend from our General Assembly to our Conference and all the food and entertainment!

See you all in Dublin June 1st to 3rd 2023!

Gill Ainsley
Secretary
Dystonia Europe

PS: My smart watch showed that I had walked over 50,000 steps over the weekend!

From left: President Adam Kalinowski, Dr Susanne Knorr and Executive Director Monika Benson

After our final coffee break of the day Adam presented the David Marsden Award to Dr Susanne Knorr from the University Hospital in Würzburg Germany, coincidentally the same place that last year's winner was from.

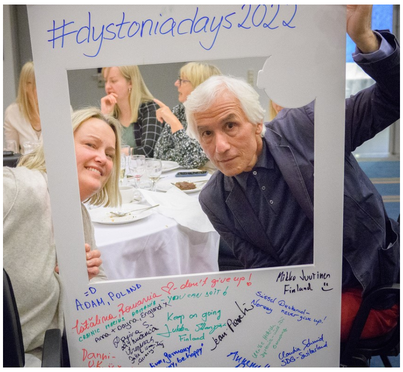
Susanne then went on to present her research *'The evolution of dystonia-like movements in TOR1A rats after transient nerve injury is accompanied by dopaminergic dysregulation and abnormal oscillatory activity of a central motor network'*. Quite a mouthful for those of us who aren't researchers! My own understanding of the research is that Susanne wanted to create an animal model which was similar to a human patient with a type of dystonia. The animals were rats and they were given a crush injury of the sciatic nerve after which they displayed dystonia like movements. She succeeded in creating the model and could also show that DBS reduced the dystonic symptoms. This is only my own interpretation and I am not a medical researcher so please watch her video on our YouTube channel!

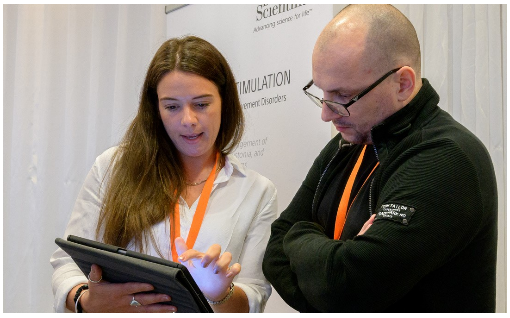
Gill Ainsley
Secretary
Dystonia Europe

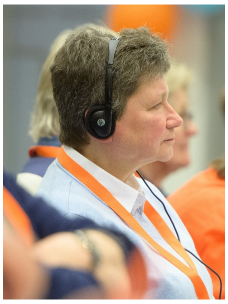
Dr Knorr said:

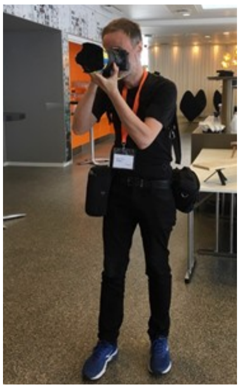
"Winning the David Marsden Award is a great honour for me, to see that basic scientific research in the field of dystonia has achieved recognition, because we first need to understand the pathomechanism of dystonia, then we can finally establish new treatment strategies for dystonia patients."

Memories from Dystonia Days 2022









All photos by photographer Stephan Röhl

Winner of the David Marsden Award 2022 Dr. Susanne Knorr

Susanne Knorr
Senior Consultant Neurologist and Researcher
Würzburg University Hospital
Photo by Stephan Röhl

Our congratulations to Dr. Susanne Knorr, department of Neurology, University Hospital of Würzburg, Germany and the David Marsden Award 2022 winner for her paper:

"The evolution of dystonia-like movements in TOR1A rats after transient nerve injury is accompanied by dopaminergic dysregulation and abnormal oscillatory activity of a central motor network."

Dr. Knorr was presented with the award by Dystonia Europe (DE) President Adam Kalinowski at the Dystonia Europe 29th Annual Conference and Dystonia Days 2022 in Copenhagen, Denmark last May.

Dr. Knorr expressed her thanks to the judging panel, DE and Ipsen for selecting her paper. She then presented her work.

About the winner:
Dr. Knorr is an expert in basic research of movement disorders. She studied biology at the University of Würzburg. In 2015, she started her PhD thesis in the field of dystonia in the lab of Chi Wang Ip and Jens Volkmann. Currently she is a postdoctoral research associate in the experimental movement disorder group of Chi Wang Ip.

During her many years of experience as a technician and a biologist in basic research, she gained a wide range of knowledge in molecular biology, biochemistry, behavior analysis, animal stereotactic surgeries, and experimental Deep Brain Stimulation (DBS).

About the research:
Basic research is important to deepen our understanding of disease pathomechanisms and finding new therapy strategies. For this, the use of a suitable disease model is crucial.

In dystonia research, animal models are highly relevant, because it is assumed that the network of the brain is affected by the disease and therefore we need a model comprising different cell populations, different brain structures and interconnections, which cannot be guaranteed in petri dish experiments. However, for DYT-TOR1A dystonia no animal model exists that reflects every aspect of the disease pathology. Either the DYT-TOR1A models are genetically modified animals without showing a dystonic phenotype, or the animals show a dystonic phenotype without a genetic background. Our aim was to generate an animal model, which mimics human dystonia by combining a known genetic dystonia background with a dystonic phenotype. In the genetically modified DYT-TOR1A rat model ΔETorA, which expresses the human mutant TOR1A protein, a crush injury of the right sciatic nerve was implemented as an environmental factor to trigger a dystonic phenotype. Behavioral analysis revealed dystonia-like movements in the nerve-injured ΔETorA rats. Further analysis of this model showed abnormalities in the striatal dopamine metabolism as well as alteration of theta and beta oscillations in the brain network of nerve-injured ΔETorA rats. In addition, we could demonstrate that deep brain stimulation in dystonic ΔETorA rats reduced dystonia and normalized pathologic brain network oscillations. This study forms the foundation for further analysis of pathomechanisms and treatment strategies by providing a new DYT-TOR1A rodent model.

Prof. Tom Warner, Queen Square London: About the Research of Dr. Susanne Knorr, the David Marsden Award Winner 2022

The changes in the brain that lead to dystonic movements have been the subject of extensive investigation, particularly for the genetic forms. DYT1 dystonia is the commonest genetic cause of childhood onset dystonia and various studies in cell, animal and human studies suggest it is due to a problem with circuits controlling movement, focused on structures deep in the brain called the basal ganglia. There is some evidence to suggest it involves the chemical messenger dopamine, and also that peripheral trauma may cause the dystonic movements to manifest.

The importance of the work published by Knorr et al is that, for the first time, an animal model has been produced that brings together all these features. They studied a rat model that carries the same mutation in the DYT1 gene that humans have. They compared these to normal rats and caused a nerve injury to one leg to mimic trauma. This caused dystonic-like movements of the leg which were persistent in those rats with the abnormal DYT1 gene. In these rats when they studied the chemistry of the basal ganglia they found increased dopamine metabolism (turnover) and also changes in the electrical signals measured in the basal ganglia which were similar to those seen in humans. Study of the basal ganglia under the microscope did not show any evidence of cell damage or loss, which again is believed to be the case in humans. Finally, the investigators performed deep brain stimulation to an area of the brain which correlates with the area targeted in patients with dystonia. They found, as is the case in patients, that the DBS improved the dystonic movements.


Dr Susanne Knorr

So in one paper, the researchers helped confirm many separate findings which will cement our understanding of dystonic movements. It also helped back up the view that trauma can be the trigger for the development of dystonia, particularly in genetic types. The improvement of the dystonia with DBS also helps us to continue the focus on what is going on in the basal ganglia. There has not been a study which recapitulates the clinical, biochemical and electrophysiological features of DYT1 dystonia in one model. This makes this animal model important to really drill down on the cell and circuit changes underlying dystonia. It also represents a good model for testing new treatment strategies.

Professor Tom Warner
Professor of Clinical Neurology BA BM BCh Phd FRCP
Director of Reta Lila Weston Institute for Neurological Studies
Head of Queen Square Brain Bank
UCL Queen Square Institute of Neurology and National Hospital for Neurology
London, UK

Photo by Stephan Röhl

Presentation of the DMA at the EAN 2022 Basal Ganglia Club Session

European Academy of Neurology is a non-profit, independent organisation representing more than 45,000 members, as well as 47 European national societies.

The 8th Congress of the EAN took place in Vienna in June this year. EAN Congress is one of the biggest neurological events in Europe. This year 380 lecturers and 5300 onsite participants took part in the event. Among them was the winner of this year's Dystonia Europe David Marsden Award - Dr Susan Knorr and president Dystonia Europe - Adam Kalinowski. During the European Basal Ganglia Club special session, Adam had the pleasure to introduce the award winner, who presented the results of her research.

For the first time, Dystonia Europe has had the opportunity to present the David Marsden Award at this annual congress. This is a big step, and we believe the award will now attract more researchers and stimulate dystonia research.

Adam Kalinowski
President
Dystonia Europe

Dystonia Awareness Month 2022: I AM… IT TOOK…

Monika Benson
Executive Director Dystonia Europe
Photo by Stephan Röhl

Come join us in this year's dystonia awareness month with focus on #dystoniajourney.

In our recent work with the dystonia patient journey and also the dystonia survey of Prof Relja in 2019 we have seen that the time of diagnosis can differ from a few months to several years.

Very often it depends on where you live and which doctor you come to and if they have any knowledge of dystonia. This is not OK and we want to make a change. More awareness and improved knowledge of dystonia is needed among health care professionals.

Therefore during this awareness month we would like to hear your experience on diagnosis. Here are what some participants at the Dystonia Days 2022 in Copenhagen said: https://bit.ly/3z1RhDU

Take part and let us know what was your time to diagnosis!

Grab a camera, take a video of yourself and say (exactly like the participants in the video):
I am… (your name)

From… (your country)

It took… (how long did it take for you to get diagnosed)

Post and share the video using the hashtag #dystoniajourney! We will collect all these videos and share them as well.

By collecting these stories of time to diagnosis we hope to raise awareness of this major barrier in the dystonia journey and hopefully we can contribute and improve the situation for dystonia patients in the future.

Look forward to seeing you!

Monika Benson
Executive Director
Dystonia Europe

SUFFER FROM DYSTONIA?

How long did it take for you to get diagnosed?

1 grab your camera

take a video 2

and say:
I am…
from…
it took…

3 share & add hashtag #DystoniaJourney

Raise awareness!
Help speed up time to diagnosis for future dystonia patients.

DYSTONIA EUROPE

For more information see here:

Dystonia Patient Journey
https://dystonia-europe.org/2022/05/first-ever-patient-experience-map-in-cervical-dystonia-reveals-multiple-barriers/

Dystonia survey of Prof Relja
https://buff.ly/2VFLqo4

Dystonia Awareness Campaign
https://dystonia-europe.org/i-am-it-took/

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.

NM-399107-AC_AUG2020.

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Dystonia and Relationships: Preliminary Survey Results

In addition to the well-known motor features of people with dystonia, also many have been reporting non-motor symptoms. Functional impairment, pain, social embarrassment, anxiety, social phobia, and stigmatisation seem particularly common and have a clear impact on the quality of life. This might considerably influence self-confidence and could, therefore, have an impact on relationship and sexuality. Nevertheless, surprisingly little is known about sexual issues in people with dystonia. Therefore, with support of Dystonia Europe and Dystonia Community we set up an international online survey to assess views and perceptions of people with dystonia and the impact of their illness and its treatment on sexuality and relationship.

We received 620 responses from participants from a total of 43 countries. Based on the replies, the main finding was the frequent dissatisfaction with the level of intimacy and sexuality in people with dystonia. In fact, half of participants in this survey were not satisfied with their current intimacy and over half of participants declared that they have stopped being sexually active because of dystonia or experienced problems in sexual relationships because of dystonia symptoms. Furthermore, these problems seem to have contributed to the breakup of one third of relationships. The presence of non-motor symptoms should be adequately recognised and their importance in patients with dystonia acknowledged, in particular regarding sexual and relationship problems, in order to plan individualised treatments and improve quality of life.

Dr Katarzyna Śmiłowska

Dr Katarzyna Śmiłowska

Silesian Center of Neurology, Katowice, Poland

Dr Daniel J. van Wamelen

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United Kingdom

DIET AND DYSTONIA

Take a survey for change!

- ☑ Take the survey
- ☑ Support research
- ☑ Anonymous
- ☑ 16 languages

surveys.dystonia-europe.org

Dystonia survey

As many of you may remember, the 'Sexuality and Dystonia' survey was available on our dedicated platform for a few months. This poll was created by researchers with a special interest in movement disorders, including dystonia. The survey has been closed and its first results were presented at the Dystonia Day 2022 conference in Copenhagen. We want to thank everyone who participated.

A new survey 'Diet and Dystonia' will be open this autumn on our platform. The main goal of this research is to examine how diet affects dystonia, and if so how dystonia specialists could address these problems. The survey is completely anonymous, which means that no personal information will be collected.

We will be very grateful if you decide to support research by completing this online questionnaire. https://surveys.dystonia-europe.org/

Survey developed by:

Dr Katarzyna Śmiłowska – Silesian Center of Neurology, Katowice, Poland

Dr Daniel J. van Wamelen – Institute of Psychiatry, Psychology & Neuroscience, Department of Basic & Clinical Neuroscience, King's College London, London, United Kingdom Parkinson's Foundation Centre of Excellence at King's College Hospital NHS Foundation Trust, London, United Kingdom

Supervisors:

Prof Kailash P. Bhatia – Department of Clinical and Movement Neurosciences, UCL Queen Square Institute of Neurology, University College London, London, United Kingdom

Prof K. Ray Chaudhuri – Institute of Psychiatry, Psychology & Neuroscience, Department of Basic & Clinical Neuroscience, King's College London, London, United Kingdom Parkinson's Foundation Centre of Excellence at King's College Hospital NHS Foundation Trust, London, United Kingdom.

Dystonia Physio Exercise Hub Project Presented at the ECRD 2022

On June 28th Physiotherapist Johanna Blom and Monika Benson presented the Dystonia Physio Exercise Hub at the European Conference for Rare Diseases.

The goal of the ECRD 2022 is to solve the complex challenges faced by people living with rare diseases in Europe and to demonstrate the support to keep rare diseases a priority on the EU scene.

The time is right to consider a new strategy for rare diseases in Europe and provide an opportunity to set **three ambitious goals**, each aligned with a **United Nations Sustainable Development Goal**: **promoting health and well-being, reducing inequalities, and fostering rare disease research and innovation**.

"We need to enable all people living with a rare disease to receive an accurate diagnosis, care, and available therapy within six months of coming to medical attention," says Yann Le Cam, EURORDIS Chief Executive Officer.

The 4-day virtual conference attracted about 850 participants such as patient advocates, healthcare professionals, policy makers and industry.

Monika and Johanna had been invited to take part in the Tuesday afternoon session: **Strengthening national health systems to improve access to effective diagnostic testing technologies, care and treatments,** to present the good practice of the Dystonia Physio Exercise Hub. The goal of the session was to present evidence and good practice along the continuum of care to **inspire short-term policy action at EU and/or national leve**l. Participants learnt about the main personal and external factors affecting patients' access to diagnosis, according to the findings of the latest Rare Barometer Voices survey on diagnosis. Another speaker presented how well-designed care pathways, that optimise access to rare disease Expert Centres, may improve patients' experience with care.

The two case studies: ParkinsonNet and Dystonia Physio Exercise Hub both demonstrated what can be done to improve quality of life until a curative treatment is available.

For more information on the conference see: https://www.rare-diseases.eu

Monika Benson
Executive Director
Dystonia Europe

DYSTONIA PHYSIO

From left: Monika Benson, Executive Director, Dystonia Europe and project leader and platform creator is physiotherapist Johanna Blom at Malmö University Hospital in Malmö, Sweden.

OTHER NEWS

Dystonia Awareness Video Project

As we informed you in an earlier our newsletter, we are working on a very exciting project - a series of dystonia awareness videos. The aim of these videos is to show the symptoms of different types of dystonia for better understanding by people who have never heard of this disorder.

The videos will be short and will not contain any dialogue. We believe that this will make them more likely to be shared and the message will be understood regardless of the viewer's language. The series will include 5 videos showing the following types of dystonia: cervical dystonia, writer's cramp and blepharospasm. Some of the main roles have been played by real patients.

The scenarios were created based on real stories. Before filming began, the director, actors and patients met to discuss and correct the scripts so that the films showed the symptoms of dystonia as real as possible. Filming took place in May this year in Dublin. During post-production, Dystonia Europe consulted the producer to finally get good quality films. Now we are in the final phase of the project.

The films will premiere this autumn on Dystonia Europe channels as well as channels of our member organizations.

We believe this campaign will be very powerful for dystonia awareness.

Adam Kalinowski
President
Dystonia Europe

Under Production: Season 2 of Dystonia Europe Podcast - The Positive Twist

The first season of our podcast: The Positive Twist was launched during the pandemic, autumn 2020. We have received much positive feedback and until now the podcast has had over 2300 downloads.

We have therefore decided to work on a second season. Interviews and recordings are now taking place for 6 new episodes. First episode is planned to be launched in the beginning of 2023. Stay tuned for more information on our social media channels.

And if you have ideas for podcast topics and guests please let us know by sending an email to: sec@dystonia-europe.org

View the podcast here:
https://dystoniaeurope.buzzsprout.com/1337749

Monika Benson
Executive Director
Dystonia Europe

Filmcrew and actors participating in filming of the videos.

EPF AGM 2022

On the 23rd April, EPF held their Annual General Meeting online. Dystonia Europe is a member of EPF (European Patient Forum).

An opening speech was given by Marco Greco, EPF President and Anca Toma, EPF Executive Director.

EPF is the leading voice of patient organisations in Europe and promotes patient advocacy. They bring together people, knowledge and expertise between the patient community and EU policymakers, by providing a cross-disease perspective based on issues that have a direct impact on patiens’ lives.

The minutes from the AGM 2021 were approved and the Annual Report 2021 was presented. These documents had been sent out to all participants before the meeting. Also financial reports were presented and approved.

Capacity Programs

EPF has various capacity programs for their member organisations. One of the ongoing programs is building the capacity of EPF members on AI (Artificial Intelligence) using publications and webinars. Another newly launched program is the 101 online self-learning course on advocacy for young patients advocates.

AI (Artificial Intelligence) in healthcare from a patient perspective

Last on the agenda was “AI (Artificial Intelligence) in healthcare from a patient perspective – latest developments” presented by Kaisa Immonen, EPF Policy Director and Lydia Nicholas, independent researcher. The following is some information from the AI presentations.

- The European Commission’s priorities for 2019 - 2024 “ is to make Europe fit for the Digital Age”.
- There is a European Commission’s AI package and there is focus on communication to foster a European approach to AI.
- EPF have developed a policy briefing for patient organisations on big data and artificial intelligence.
- EPF has done a membership survey on artificial intelligence in healthcare.
- Two reports are being made on AI from a patient perspective and on EU legislation on AI.
- Despite concerns most patients are hopeful about AI.
- It is important for patients to be meaningfully involved in the development of AI technology and policies that affect them.

You can read more about EPF here www.eu-patient.eu

Merete Avery
Operations Manager
Dystonia Europe

EFNA
21st Anniversary Celebration in Brussels & EFNA Advocacy Awards 2022

Last May EFNA, the European Federation of Neurological Associations, celebrated its 21st Anniversary in Brussels, Belgium. The organization was founded in 2001 and the initial plan was to hold the 20th Anniversary event last December in 2021. Due to the pandemic it had to be postponed.

It was a happy reunion in Brussels where many participants had not met in over two years. There were 34 guests, including representatives of 14 of EFNA's 20 member organisations, along with representatives from EBC, EAN and industry partner groups.

EFNA President Joke Jaarsma welcomed the participants and wished everybody a joyful evening. Then followed EFNA Past President Audrey Craven from Ireland who shared some good memories from the history of EFNA.

Last year Donna Walsh left her position as Executive Director at EFNA. She attended the event as well and Joke gave a presentation to her and thanked her with gifts and a memory book.

Left: Donna Walsh with the memory book

The second half of the evening was dedicated to the EFNA Advocacy Awards Ceremony. These awards recognise the contribution of an individual or group to the development and promotion of advocacy for people with neurological disorders in Europe. This year, the awards focus on the topic of ***'Advocating for Gender Equity in Neurology'***.

Gender equity means fairness of treatment for women and men, according to their respective needs. This may include equal treatment or treatment that is different, but which is considered equivalent in terms of rights, benefits, obligations, and opportunities.

This year's Awards have three categories – Outstanding achievement by an individual advocate, Outstanding achievement by a medical professional/researcher and Outstanding achievement by an organisation. Through these Awards we can recognise the efforts of those whose work has raised awareness of the difference in impact of neurological disorders on women and men, has led to concrete actions and has addressed identified challenges.

The winners are:
Chantel Fouche, Treasurer of ADHD Europe, Belgium
Outstanding achievement by an individual

Prof. med Mauro Manconi, Switzerland
Outstanding achievement by a medical professional/researcher

The Neurological Alliance (England)
Outstanding achievement by an organization (represented by Georgina Carr)

EFNA President , Joke Jaarsma handing out awards

For more information on the winners and their achievements see: https://www.efna.net/advocacyawards2022-winners/

Monika Benson
EFNA Vice President and Executive Director Dystonia Europe

EFNA
Board Meeting in Brussels

The following day there was an EFNA board meeting. Orla Galvin, EFNA Executive Director, presented the preliminary results of the survey on assessing diagnosis and care pathways of people living with neurological disorders in Europe. Over 1000 participants from 23 different countries participated in the survey. Some of the results show that:

- 32% of people have not been given the opportunity to speak to their doctor about treatment satisfaction or to make adjustments to treatment and for those who were, 35% felt they were not taken seriously.
- 42% of people felt they had to justify their first visit to their doctor.
- 55% of people say the response of the doctor or health-care professional did not meet their expectations.
- Long time to diagnosis – 20% waited for 4 years and more.

This survey shows similar results as the dystonia survey of Prof Maja Relja in 2019 and also the recent dystonia patient journey. The above findings will be used to increase awareness among HCPs and decision makers.

Some of the comments were:

"My initial visits were dismissed or met with indifference – just a wrong diagnosis of depression and anxiety."

"There was no treatment, just told to go home and mind myself."

"I wasn't given any education about my condition, there was no referral to specialists, also no education about the prescribed medication".

Staff at EFNA from left: Elizabeth Cunningham, Tadeusz Hawrot and Orla Galvin

Photo: Monika Benson, Executive Director, Dystonia Europe and Russell Patten, Director General, EPDA (European Parkinson's Disease Association)

Monika Benson
EFNA Vice President

EPF CONGRESS 2022

Dystonia Europe attended the EPF (European Patient Forum) Congress held in Brussels, Belgium 23rd and 24th of June. Dystonia Europe is a member of EPF,

Rau Ganesco, Treasurer of EPF gave an opening speech on behalf of Marco Greco, President of EPF, who could not attend the Congress. Next Stella Kyriakydes, European Commissioner of Health gave us insight in digital information of health care. She spoke about the European Data Health System. Health care needs to be more efficient and we need better health care across the EU.

There were two days of learning and exploring ideas and solutions within AI (Artificial Intelligence). The focus was on good practice in patient empowerment and involvement and how to move forward on the much-needed policy commitments in this area, gaining a greater and better understanding of the knowledge and expertise that patients bring to health systems.

There were nearly 300 participants, mostly from patient organisations, but also from other stakeholders. Some participated on-line, however the connections made during coffee breaks, lunch and dinner played a vital and important part of the conference with extended learning and discussion of ideas. This cannot be done to the same extent online. Discussions and further work will continue online.

AI is being used today within health care and it is believed that it will further improve health care in the future. There are many aspects that need to be taken into consideration so that AI is developed in a way that benefits the patients and the medical system. Training of healthcare providers is an important aspect, but also information and training of patients is equally important.

More information enables patients to be aware, distinguish between options and be a part of their treatment process. It was stressed at the Congress that it is very important that patients, for example through patient organisations, voice their opinions today on the impact of AI in the future!

Collecting data for studies is important. The Health Minister of France gave a presentation on the role of AI in the French healthcare system. There are many issues to be considered such as ethics and cybersecurity.

The use of artificial intelligence in healthcare can be described as the application of machines learning algorithms and software to imitate human cognition in the evaluation, presentation, and comprehension of complex medical data. AI programs are applied to treatment protocol development, drug development, personalised medication, and patient monitoring.

Merete Avery
Operations Manager
Dystonia Europe

European Commission

European Health Data Space

Harnessing the power of health data for people, patients and innovation

June 2022

European Health Data Space

#EHDS #HealthUnion

From top left: Dr David Novillo Ortiz, WHO European Region and Programme Manager Digital Health,
Dr Mélodie Bernaux, French Ministry of Health

EPF European Patients Forum

New, improved MyDystonia app!

We are happy to announce that the new version of the application for dystonia patients and physicians is now available!

After many years of experience, feedback from users and experts, we have created the new MyDystonia, which is very different from the previous one.

MyDystonia is an electronic diary created for people with dystonia. The App was developed with the collaboration of dystonia patients and a group of medical experts. This electronic diary enables patients to monitor their symptoms and how those symptoms affect daily life. You can monitor your dystonia by answering a series of predefined questions (e.g. core symptoms like overactive muscles or pain; impact on daily living) – wherever and whenever you like.

With MyDystonia you create an accurate picture of your disease and treatment outcome over time. Now you can share insights with your doctor to discuss how to optimize your treatment approach. Reports created using MyDystonia can be printed or shared electronically.

Benefit immediately from MyDystonia and create your own account. Download for free from the Apple App Store or Google Play.

The new version is available in English only , but we will be working on adding more languages in the future.

You can download MyDystonia on the Google Play Store on an iOS

“Once upon a time” a Short Film on Dystonia and DBS Treatment

Pierre Colback

My name is Pierre Colback. I'm 24 years old and I was a student in Visual Effects at the Haute Ecole Albert Jacquard based in Namur, Belgium.

Being affected by a form of primary dystonia since I was 10 years old officially but unofficially longer I think. For me, it seemed obvious to study this subject because there is very little information on this disease unfortunately. So I thought why not use my knowledge from my studies and my background.

Once I had the mental map of how this little movie would unfold, I started to create it.

This film named Once Upon A Time With Dystonia took 1 year to create from the first draft to the final presentation which took place recently. The hardest part was to find the plot and how to arrange the film. So I decided to explain in 3 minutes all the steps to do this. I used a small wooden dummy, so each person can recognize him/her self in the video, and not compare themselves with another person.

For me, the DBS was a turning point in my life because I was lucky that it worked directly as it should or almost despite a repositioning of the electrodes.

Now I have resumed an almost normal life, I can do sports again, travel, go out and work like almost everyone else.

Pierre Colback

You can view Pierre’s film here

30th Anniversary of the Danish Dystonia Association

Turning 30 always requires a lot of support. The entertainer Hans Pilgaard helped the Danish Dystonia Association on its way, both with the funny and the more thoughtful. After an extremely successful AGM, it was time for a well-deserved break with coffee and side dishes. The next item on today's program was a lecture with the well-known TV star Hans Pilgaard with the headline:

"THE FIGHT FOR A MORE FUN LIFE"

In these times of all sorts of diseases, accidents, disasters and wars, it is safe to say that amusing moments are needed more than usual.. Over the course of 2x45 minutes, he took us on a tour through his own experiences, both positive and negative, that make up being human.

Through his work and in his personal life, he has learned many things from the people he has encountered. You have to be and live in the moment, be less anxious, this is fundamentally important. Pippi Longstocking's optimism, he believes, is the way forward, especially for us adults who are a little too preoccupied with living while we wait. Here are 3 quotes that Hans Pilgaard thinks we can learn from:
"If you are going through hell, keep going", Winston Churchill.
"Life is what happens, when you are busy making other plans", John Lennon.
"I haven't tried that before, so I'll definitely do that," Pippi Longstocking.

After an hour and a half of good entertainment, Hans Pilgaard thanked the Danish Dystonia Association for letting him share his story and he received a warm and well-deserved applause from the audience.

The party continued until 11 p.m. There was nice entertainment along the way during and after the party dinner, so people could enjoy music all the time. The first feature was Tim Schou, who showed up with his guitar that follows him everywhere.

The second musical feature was the Vingard Band. Tine Vingaard, as she is called, really plays American music that is extremely harmonious and melodic. Today she has a great career in Berlin. The audience enjoyed her music.

The board says thank you for a lovely anniversary and looks forward to the next one.

Birthe Bernhard Hansen
Photos: Pia Sørensen Vejle
Danish Dystonia Association

Annual Meeting in the Norwegian Dystonia Association

To the left, Johan Arnfinn Warvik, President of the Norwegian Dystonia Association.

The frame around NDF (Norsk Dystoniforening's) annual meeting in April couldn't be better. Spring had arrived and Trondheim was bathed in sunlight with nice spring temperatures. Here 47 members were gathered for a weekend that included meetings, guided sightseeing around the city, social fellowship and good food.

The chairman of the board, Johan Arnfinn Warvik summarised the year that had gone by. He informed us that 2021 had been a very active year for Norsk Dystoniforening (NDF). Despite the corona pandemic and outbreaks of the virus NDF managed to arrange seven physical local meetings. There was education and training of contact persons in Lillestrøm, a special meeting with partners and one meeting face to face with leaders of local networks. NDF also succeeded in gathering 60 people from the whole country at the autumn meeting in Lillehammer.

– I guess we have been lucky, said Johan Arnfinn, known as Joff by his friends. He added that of course NDF like many others had felt the consequences of the pandemic and also had to adapt to the digital way of meeting.

At the annual meeting Dystonia Europe was represented by Executive Director Monika Benson. She hadn't participated in a physical meeting since 2020. Therefore, she was very happy for the invitation and enjoyed being in Trondheim and we enjoyed having her with us. Two other Swedish guests were also represented; Yvonne Fredriksen and Bengt-Erik Calles from Svensk Dystoniforening, which underlined the good relationship and cooperation over the border.

Monika informed us about the work that Dystonia Europe do and gave the latest updates on dystonia research and treatment. She and Joff gave the audience their own personal experiences of living with the brain disorder. The key message was; it's important to focus on possibilities and what you still are able to do despite the illness and not focus on what you cannot do. Then you will have a better life. This was a very useful message.

During the two day long meeting there was also room for a guided bus tour around the city that is the capital of Mid-Norway and has a rich history. Visiting highlights like the Kristiansten Fortress and Nidaros Cathedral with weather on our side was nice. At the end every member of the board was re-elected for a new period, which Johan Arnfinn was thankful for. One of the main focuses for the period to come is to bring up the level of activity in the local associations.

In the evening we gathered for a tasty meal where we enjoyed each other's company. This was a nice way to end off our stay at Scandic Nidelven.

Above: Members of NDF making a «Jump for Dystonia» with a view of Trondheim in the background.

Right: A stop by the Cathedral Nidarosdomen.

Left: Sightseeing at Kristiansten Fortress

Vidar Bjørkli
Norwegian Dystonia Association

Meet Sandra from Denmark: My Journey with Dystonia

My name is Sandra, and I am from an island called Fyn in Denmark. I do not have dystonia myself, but my mom does. She has generalised dystonia and uses a wheelchair. My story will not be about having dystonia. My dystonia story will be about my experience growing up with a parent with dystonia.

My mom had shown symptoms of dystonia since she was 4 years old, but it was not until I was about 9, that she was diagnosed. Like many other people with dystonia, it took years before the doctors got it right.

Over the years she had many different diagnoses, and she was on a lot of different medications. Medication that she did not need, and therefore it did not always have the best effect. One day, when I was in school, she hallucinated that I was in the room with her sitting at the dinner table doing homework. She was 100% sure that I already left for school, and for that reason she called her doctor and demanded to stop the medication that she was on. Thankfully the doctor let her gradually reduce her medication. But she was still affected for a time and afterwards there was new medication that she needed to try.

It was around the time, when she was diagnosed, that her cramps and convulsions got worse. She would have cramps that would last up to 4 hours at a time, and it became more and more frequent. That was when the local authority started to investigate what changes were needed to make our living condition to be the best it could be.

Now, I am happy to be in a country where this help does not cost us personally anything. We would not have been able to afford an electric wheelchair and many other things, if it was not for the welfare state we live in, and I am grateful for that. But when things like this are free, it takes a lot of time for everything to be set in motion. And even though you can meet a lot of nice and realistic people you can also meet people, who may be more focused on budget cuts than the actual people they need to help. So it took time before the right help arrived and, in the meantime, I was alone with my mother watching her get worse.

Even though my mom always tried to have a brave face, it was easy for me to see, when she was laying on the floor, cramps in her whole body, being stuck in a doorway or under a bed, that things were not okay and that *she* was not okay. She would always tell me to call someone from my family to come help us and in the meantime, I would do my homework or play computer games. She did not want me to see her in so much pain, but I could still hear her from the other room.

The big, long lasting cramps is something I got more used to the older I got, but when I was a kid I remember I was really scared of them. And even though I do not remember this myself, my mom has told me that one day I said to her that “if she was going to die, then I wish that she would die now”. Now my mom lost her mom at a young age so she kind of understood where it came from, even though she was a bit freaked out. She understood that I did not wish for her to *die.* I just did not want her to suffer if she was going to die of the cramps anyway.

The thought of my mom dying came from the fact that I did not understand what was happening. In my head I was seeing her in pain and as a kid I thought that meant that she was going to die. So, when my mother heard this, she sat down with me and talked to me, and she let me explain what I meant and let me ask all the questions that I wanted.

I also got to say that I wish she had never gotten me, because then her life would be a lot easier if she did not have to take care of me, but every time I said that, she would tell me that the reason she has all this energy and the reason she keeps going is because of me and that I should never think anything else. Now I have met kids, who also have parents with dystonia or other diseases, but where it was not talked about. It was hidden away to protect the children. I understand the protective thought behind the action, but that does not necessarily mean that the outcome will be the best.

I think that is the best advice I can give to parents with dystonia: Speak to your children.

It may seem like you are protecting them but children see a lot more than you expect, and imagination can be much more horrible than reality. Had I not spoken to my mom and had she not told me that she would not die from dystonia, I would have gone through my childhood thinking that one day she would die in one of her cramps while I was sitting in the living room doing my homework.

MY DYSTONIA STORY

I think that is the best advice I can give to parents with dystonia: Speak to your children.

It may seem like you are protecting them but children see a lot more than you expect, and imagination can be much more horrible than reality. Had I not spoken to my mom and had she not told me that she would not die from dystonia, I would have gone through my childhood thinking that one day she would die in one of her cramps while I was sitting in the living room doing my homework.

Today I do not believe that my mom will die during one of her cramps but the memory of seeing her in so much pain is something I still must deal with. Because when she was lying there even though I knew she would not die I still felt very helpless. Because I could not help her and I could not take her pain away, I needed to accept that I never will. I can say that I have not totally accepted it yet and I think that is something most next of kin can relate to. Because you will never not want to take your loved one's pain away.

My mom also knew this, and she also knew that as a kid I should not end up staying at home taking care of her. That also meant that I had A LOT of after school activities. I sometimes had so many that I started to neglect some of them, because it was simply too much. I would play handball twice a week and on weekends, I would play drums once a week and I should have practiced 1-2 hours a day, but that never really happened. Then I was also in after school care almost every day, where I had a rabbit I needed to take care of. In the end it was too much because I actually wanted to be home sometimes, not to necessarily take care of my mom but just to be home.

I know that it was a way to protect me, but I think finding a middle way is the best way to make sure that the child does not become the adult, but also to make sure that it is possible for the child to be at home and to not be overwhelmed. It did not feel like my mom did not want me in the house, but it did sometimes feel like she was hiding how bad she was.

What I did appreciate with all these activities was that every time I had a show or a game my mom would always be there. Even though me playing drums would make her cramp she always showed up at least for the first 10 minutes until she had to walk out. She always used to say that she would cramp the most when the music she was listening to was REALLY good. So if she left early that meant that I was playing REALLY well. I do not know if it was the truth but it did make me happy and it made it alright for her to leave if she had to. So even though other people would think she was weird for leaving, it was never weird for us.

Photo below is private.

Photo is private

I have heard many stories about kids being bullied because their mom or dad was disabled. But weirdly enough that was not the case at my first school. It was probably because it was not just me who had a parent that was a bit different. Even when I was getting bullied for other reasons no one would ever want to use that against me, and I hope it was because they knew that it was wrong.

But people I meet outside of this school did not always have the same mindset.

Especially when I had to change schools. It was the first time where I could really see how ignorant people could be when it came to just being around a person in a wheelchair. Some of my friends would just stare at my mom and some would not answer her when she spoke to them. Not necessarily because they wanted to be mean, they just had no idea how to act. I would always tell them beforehand that my mom was in a wheelchair, so they would not be surprised or get worried. So it was not the surprise that made them act like this. I didn't really ask them why they acted like they did, I just hoped that they had never really interacted with someone who was in a wheelchair. And I remember it made me think that I was happy that I did not grow up like that.

I could let it go when it was with my friends who did not know what to do, because they were kids like me. And when I got older most friends did not have a problem new or old, because they were used to it. What I could not let go of was, when grownups acted like a person in a wheelchair was the most interesting thing they had ever seen. I cannot count how many times random people would come up to my mom and pinch her toes, usually followed up with “oooh, my little friend, why haven’t they put any shoes on your feet”. This was not young people; it was often middle-aged people, who would touch the toes of someone they did not know. When people did that it would often lead to my mom cramping. And in the beginning I would stand there looking, not being able to say anything and just be sad.

I could not understand how I as a child knew what was right and what was wrong, when a grown-up did not. The older I got the more I started to really understand what was happening. It used to make me so angry when people would disrespect my mom with their assumption that when she was in a wheelchair she must be mentally handicapped. I usually would not say anything to these people because I was so angry, that if I opened my mouth it would not be pretty words that came out and I knew my mom did not want that.

So then I would stand there looking not being able to say anything and just be so angry.

But fortunately, when I was about 12 or 13, I matured a bit and I somehow stopped being angry. I started to feel sorry for the people who were touching my mom and who were saying all these weird things. Because if the most exciting thing in a person's life is a person in a wheelchair they must have a sad and boring life. So instead of being sad or angry I just started thinking that these people really needed a hobby to keep them entertained. I sometimes also thought inside my head "my mom is a chemistry engineer, what are you" and I would often in conversations mention that she was a chemistry engineer. Not because I wanted to be on a high horse or to be mean, but it was a coping mechanism to think it and a way to make people understand that there was nothing wrong with her brain. It was just her body that did not want to do the things that she wanted to do.

Now years have gone by and we live in a smaller city, so it does not happen very often anymore but when it does happen, we make the person stop and I think the same thing, that the person needs a hobby and then we can laugh at it later. Because that is something that we have always done and something I think has helped me get out of the sadness and the anger. We have always been able to laugh in the most absurd times. It has sometimes worried people when we have laughed after my mom cramping for three hours, but we did and do not care because it is a way of coping with what is happening. Especially as a child, seeing my mom making these horrible episodes into something less horrible by joking and laughing has made it a lot easier to live with what I had to see, hear, and feel.

I have also been sad seeing some of my mom's friends disappear from her life. She has put so much laughter into my childhood, that I did not see how much it affected her that most of her friends were not around anymore.

I have been to two boarding schools, been an au-pair in London, travelled in Asia for months and I did not realise the effect this had on my mom before I moved out and into my own apartment. Because now I did not see her as much but when I saw her, I could see that she missed having people around joking and having fun with. It made me sad because when I realised this, I knew that it did not happen overnight. I then tried to push her into speaking with her old friends and reminded her to talk with her new friends. I can see that it has made her a lot happier and has given her more energy. I wish I had seen it sooner. I wish I could have pushed her in that direction earlier. I know it was not my responsibility as a kid, but I also know that she would have been happier, and it would have been easier for her to be the smiling and happy mom that I remember.

With this speech I wanted to give some advice to people who are in a similar situation. Things we did that were helpful but also things we could have done differently. I think the most important thing is to be open about the disease, do not overdo it but it's important not to hide it. We cannot expect the rest of the world to know and understand dystonia if we cannot talk about it in our own house.

Do not make kids the grown-ups and let them still spend time at home. It is important to find a middle way.

Try not to get cut up in emotions like sadness and anger. I wish I would have stopped being angry much earlier, because these bad emotions drain your energy. Energy you could use on activities or just to be happy.

At last, use laughter to overcome your own fears for the disease. But also for the children's fears. It helps to see parents laugh even in the hard times because it is reassuring that things will be alright.

I hope some will be able to use them, thanks for listening to me and my dystonia story.

From left:
Sandra with her mom Yvonne

Photo: Stephan Röhl

Sandra Valenzuela

Meet Sandra Valenzuela, Italy

What is your name?

My name is Sandra Valenzuela. I am 51 and I am Argentinian but I have been living in Italy since 1992. I am a classical and Spanish dance teacher but due to dystonia I could not work as a professional. During my last years of high school I realised that something was wrong with me. My hands started shaking and it was difficult to write. I also was ashamed in social situations.

What are the benefits of working within a patient organisation?

The same year I was diagnosed with dystonia I became a member of ARD (Associazione Italiana per la Ricerca sulla Distonia) and then a board member. Taking part with ARD allows me to help other dystonia patients, I feel as well helped and not alone. Participating in ARD gives me the opportunity to know more about dystonia and to meet patients and Medical Experts.

How do you like spending your free time?

I love my job as a waitress because I feel it gives me strength and I feel I am able to do it well enough. In my free time I like taking a walk, cycling and reading.

What keeps you motivated on the tough days?

On the tough days I try to do things that keep me joyful and calm. It fills my heart talking to my nephews and my niece in Argentina and thinking that seeing them soon will help me to overcome difficulties.

What makes you angry or frustrated?

I do not usually get angry, I keep calm and I let negative things pass. I do not like superficial and egocentric people as well as unkind and arrogant doctors.

I feel I am a positive person and take life events in an ironic way, hoping changes will arrive for the better.

Sandra Valenzuela
Board Member ARD
Italy

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, The Netherlands, Ukraine and United Kingdom.

Medical & Scientific Advisory Board

Prof Alberto Albanese – Milan
Prof Alfredo Berardelli – Rome
Prof Kailash Bhatia – London
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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.

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 reelected 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.

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.

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Meet us @

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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.

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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