

Connecting people for dystonia

DYSTONIA EUROPE

NEWS

SUMMER 2018



Dystonia Europe D-DAYS and 25th Anniversary
Read more on pages 4-13

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Connecting people for dystonia

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

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President's Message



Dear all,

It is with great pleasure we present this very special Anniversary Edition of our Dystonia Europe Newsletter. You will learn about our 25 year history and also get the latest news from our Anniversary events that took place in Brussels last April.

Our Anniversary celebrations kicked off with a special lunch event in the European Parliament in Brussels, hosted by MEP Merja Kyllönen from Finland. For the first time ever there was an event exclusively on dystonia in the Parliament. Seven MEPs (from Sweden, Romania, Ireland, Croatia, Romania, Italy) were present to connect with Dystonia Europe delegates from their countries.

We were delighted that two of the founders from 1993, Alistair Newton and Prof Maja Relja attended our meeting and participated in the program. Alistair's presentation about the history of Dystonia Europe you will find on pages 14-20. Prof Relja gave the keynote address in the Parliament. Here she presented the preliminary results of her ongoing Dystonia Survey about time of diagnosis, access to treatment and quality of life. Read about it on page 8.

In this special Anniversary Edition you also find stories and information on activities organised by our member associations. It is the national organisations that form Dystonia Europe and we value their work very much. Thanks for all that you do for dystonia patients and their families in your countries.

At our last General Assembly in Brussels the recently formed German dystonia association 'Dystonie und Du' became a member of DE.

We are now 22 member associations from 18 countries in Europe. Read more about them on page 46.

Many thanks to the Dystonia Europe board members, our advisors and all the medical professionals and researchers who work in the interest of people with dystonia. You all make a huge difference for those affected by this neurological disorder that presents itself in so many different ways.

We are also very grateful to our partners and sponsors for their support and collaboration. Many years of us all working together laid the foundation for what Dystonia Europe is today.

We also have followers around the world who contribute to raise awareness of dystonia. Working together is the only way forward!

Last but not least, the Dystonia Europe staff, our Executive Director Monika Benson, who exceeds all expectations of what an employer could ask for. Her dedication and hard work throughout so many years, first as President for 6 years, and since 2013 as our Executive Director. It is a pleasure to work together. Her energy is an inspiration and her first priority is always those affected by dystonia, the patients and their families, thank you!

This newsletter is our largest newsletter ever, but we also celebrate 25 years of work and collaboration for dystonia across Europe. We hope you will take the time to read it and please let us know if there is anything special you would like to see featured in our next issue. On behalf of the Dystonia Europe Team I wish you a wonderful summer.

*Dystonia Europe
Merete Avery
President*

Dystonia Europe 25th Anniversary Celebrations and D-DAYS 2018 in Brussels

On 12, 13 and 14 April the Dystonia Europe 25th Anniversary celebrations took place in Brussels, Belgium with several events and activities.

Dystonia Europe Delegates from 16 member organizations participated and arrived in Brussels already on Thursday. They were from Denmark, Finland, Sweden, Norway, France, Belgium, Ireland, Croatia, Italy, Switzerland, Romania, Germany, Poland.

The highlight of the weekend was the special EU lunch event held in one of the Members' Salons in the EU Parliament. The lunch was hosted by Finnish MEP Merja Kyllönen and she welcomed speakers and the 70 guests. The keynote address was given by Professor Maja Relja who presented the preliminary results of the dystonia survey about time of diagnosis, access to treatment and quality of life. Read more about this event on page 7 or on our website: <https://dystonia-europe.org/activities/events/dystonia-europe-2018-brussels/eu-lunch-event/>.

Friday morning the formal Annual General Assembly took place. After President Merete Avery's welcome address Executive Director Monika Benson, gave an overview of the activities and projects that had taken place during 2017. This was all described in the Annual Report that had been sent out to all delegates in advance of the meeting. You find it on the DE website: <https://dystonia-europe.org/media/annual-reports/>

Treasurer Erhard Mätzener presented the 2017 annual accounts and the budget for 2018 which were both unanimously approved.



Treasurer Erhard Mätzener

Photo: Stephan Röhl

A new application for membership of Dystonia Europe had been submitted by the German dystonia association "Dystonie und Du". Its President Volker Kreiss presented the organization and its goals and activities. The General Assembly approved their membership.

For the Sharing Best Practice session three of our members presented some interesting projects. Catalina Cranic from Children's Joy Association in Romania, Maria Hickey, from Dystonia Ireland and Edwige Ponseel from AMADYS, France. Read more about it in this newsletter.



Delegates at the General Assembly



Delegates at the General Assembly

Photos: Stephan Röhl

Latest News

The actual D-DAYS conference opened after lunch and there were not many empty chairs in the conference room. The 100 participants were welcomed by a special Dystonia Europe 25th Anniversary Movie, followed by DE President Merete Avery who wished everybody some fruitful and interesting days. Martine de Wilde of the Belgian Dystonia Association welcomed the Belgian members and the international guests and wished them a nice weekend in Brussels.

On the first day the sessions focused on dystonia history and research and on Saturday it was about treatment and rehabilitation. For the first time we had dystonia patient stories on the programme and this was very much appreciated. We heard Amybel from the United Kingdom. She was diagnosed as a child with generalized dystonia. She was treated with DBS (Deep Brain Stimulation) and has recovered well. Recently she graduated from Medical School. Cristina from Italy gave everybody an insight in how it is to live with musicians dystonia and what therapies worked well for her. Erhard from Switzerland has blepharospasm and his strategy to handle the symptoms is to hum and sing.

All presentations were livestreamed and video recorded and are available on the Dystonia Europe Youtube Channel: <https://www.youtube.com/user/DystoniaEurope/videos>. On our website you will find the Abstract Book, containing most of the presentations.

The 25th Anniversary Dinner Celebration took place at the KWINT restaurant overlooking Brussels. Networking and sharing of ideas and experiences was mixed with some fun. Speeches and gifts were handed over by some of the member organizations. DE Board member Adam Kalinowski had prepared a Quiz and the winning team received Belgian chocolate of course. Then followed some Dance for Dystonia.

Saturday evening Dystonia Europe delegates and guests went on a guided tour of Brussels followed by dinner. The rain was pouring down but people were just as happy. After dinner some of the members headed over to Grand Place and in spite of the rain did some jumps for dystonia in the Belgian capital.

From the evaluations and feedback we have so far received we understand that it was a successful event.

It was very nice to work in close partnership with the



Members and partners of Dystonia Europe

Belgian Dystonia Association and we would like to thank them for all their support with various matters. We also would like to thank all of our sponsors, whose generous contributions made this meeting possible. They are: Boston Scientific, Foundation for Dystonia Research, Ipsen, Medtronic, Merz, and VIB.

Next year we are heading to London for our **D-DAYS 2019**. Date and venue will soon be announced.

We hope to see you there!

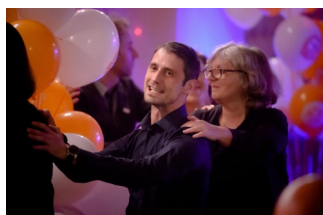
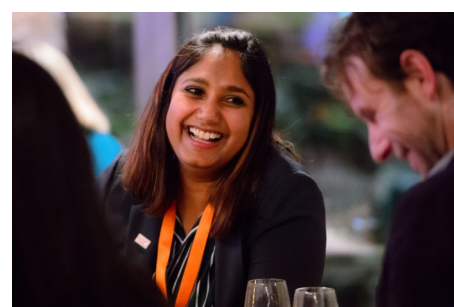
*Monika Benson
Executive Director
Dystonia Europe*



*Members of the Board Belgian Dystonia Association with
Rob van der Linden Merz, Netherlands*

Photos: Stephan Röhl

Latest News



Members and partners of Dystonia Europe photos: Stephan Röhl

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The challenges of Dystonia: a snapshot across Europe

12 April 2018, D-Days lunch in European Parliament Salon

For our 25th Anniversary event we were welcomed into the European Parliament, Brussels by Finnish Member of the European Parliament (MEP) **Merja Kyllönen**. She explained how she had become involved with Dystonia Europe when she agreed to do a Jump for Dystonia, she just hadn't realised it would be out of an aircraft! She described it as the most fun you can have with your clothes on! She also said it helped her to understand how we are all prisoners of our bodies and dystonia patients more than most. 'We need to look at the health gains and socio-economic impacts resulting from best health interventions in comparison with current care, and compare this with no treatment at all' she said. 'We need to map care pathways for the disorder along the whole care process in order to identify the major unmet needs and causes for treatment gaps.'



MEP Merja Kyllönen, Finland

Photo: Stephan Röhl

Donna Walsh, from the European Federation of Neurological Associations, then thanked MEP Kyllönen for the warm welcome. Donna explained EFNA is an umbrella of pan-European patient groups including Dystonia Europe, working at EU level to include a socio-economic angle in their policy messages to match the priorities of the European Union in terms of economic growth and social progress.

'The economics are something that we have been working on for a long time in the area of neurology. The European Brain Council conducted a Cost of Brain Disorders Study in 2006, repeated in 2010 – showing the cost of brain disorders to the European economy is 800 billion euro per year. More costly than cancer, cardiovascular disease and diabetes combined. A figure that is growing. A figure that includes 40% indirect costs – e.g. not being able to work, the need for infor-



Executive director
EFNA,
Donna Walsh
Photo:
Stephan Röhl

mal care, etc. And this makes it a scary figure, because how do we tackle such a large and complex challenge?

'So last year the EBC and its partners tried to simplify the challenge by proposing real solutions. Doing exactly what you mentioned MEP Kyllönen, instead of looking at cost, we looked at value – the value of treatment. We mapped the patient journey and costed the desired/best practice approach to care versus current care, or no care – illustrating the cost savings that can be made if things are done right.

Adam Kalinowski, a 34-year-old Pole living in Ireland then gave the patient's view. Adam has cervical Dystonia and detailed his difficulties in day to day life – going to the barber or dentist, even crossing the street. He was initially referred to a psychiatrist, he was fortunate that he was quickly referred on to a neurologist who after an MRI scan quickly diagnosed dystonia.

He is aware that not all have such a quick diagnosis 'Someone I know waited thirty years' he said. His treatment was the standard botulinum toxin but over the years this became ineffective. He lived with 'horrible pain' couldn't drive or leave his home for years. Then a different botulinum toxin was made available. 'My body posture was still not normal but what really mattered to me was two things: no pain and the ability to look straight ahead without holding my head with my hands. But for my employer it was not enough. I told them that there was no cure for my disease, but they only wanted from me the date when I would be healthy and capable of returning to work. Finally, I was dismissed on disciplinary grounds. It was a job in a supermarket. My employer employs a few hundred people in very different roles, but they never offered me a different job to suit me. The company's approach was: either you are 100% healthy or you cannot work.

So, I lost my source of income and had to apply for social assistance. I got an illness benefit but it ended after some time. The Irish welfare system is based on a similar view as that of my employer: you are either healthy or disabled. Nothing in between.'



Adam Kalinowski

Photo: Stephan Röhl

Professor Maja Relja, from the University of Zagreb, told the audience 'Dystonia is an odd movement disorder, however, not every odd movement is dystonia!' She then presented the first results of the survey to assess challenges patients face in accessing correct diagnosis and treatments and measuring satisfaction with the treatments.

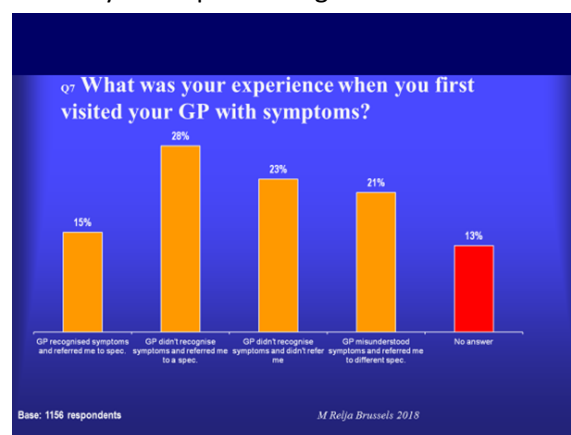


Prof Maja Relja

Photo: Stephan Röhl

She said most people who responded to the survey were in their most productive years 21-60 years old. In answer to the question What was your experience when you first visited your General Practitioner (GP) with symptoms? 23% said the GP did not recognise my symptoms and did not refer me to a specialist and 21% said the GP misunderstood my symptoms and referred me to an incorrect specialist. Correct diagnosis for 12% of people took over 10 years.

Most people received extra information about dystonia via a dystonia patient organisation.



Professor Maja Relja then gave Prof. Guenther Deuschl's presentation, in his absence for family reasons. Points to note on the Importance of prompt diagnosis and treatment are:

- Diagnosis is not easy, treatments are limited, and not always effective so many patients suffer from a remaining disability.
- Many countries do not refund botulinum toxin or Deep Brain Stimulation (DBS)
- Expert long-term care is rare yet with correct diagnosis, treatment and care a near-normal life can be achieved.
- Studies are needed to understand the current situation of the patients in Europe and guidance to cost-efficient structures for care
- and more research is needed.

What are the major research gaps to understand the condition



- Basic science to understand the functional abnormalities of the disease
- Genetic studies
- Large scale trials to establish new treatments
- Establishing expert centers to probe optimal treatment
- Healthcare studies understanding the current situation of the patients in Europe and guidance to cost-efficient structures for care

Prof. Rose Goodchild, University of Leuven, explained that in the fifteen years she has worked in the dystonia field there have been no new therapies over this period. 'The largest funder in Europe is a private research foundation. Dystonia research lacks stimulation of fresh ideas and clinical trials, and the field has plateaued. We don't know enough even to look for new drugs' she said.

‘What stands out is the limited amount of research into the molecular and cellular mechanisms. In fact, only 5% of dystonia research examines the pathways. Huntington’s and Alzheimer’s have novel therapies based on mechanistic understanding in clinical trials and that is what dystonia lacks.’

Basic research supplies ideas to the pipeline



‘Dystonia is locked out of funding as it is neither a neurodegenerative disease or a mental illness’ she called for more flexibility of EU funding. ‘the European Research Council is a good model of bottom up, investigator led research funding’ Goodchild said.

<https://erc.europa.eu/about-erc/mission>.

Nicola Bedlington, Director European Patients Forum (EPF) spoke on Access to Healthcare. ‘Patients across the EU are reporting multiple barriers to access healthcare, sometimes it is not available, or not adapted to needs, or not affordable. EU Member States need to achieve universal health coverage and improve access to healthcare by 2030 according to the UN Sustainable Development Goals’ (SDG) <https://bit.ly/2d4dcA4>

This year a patient led campaign on access to healthcare will be based on the previous work EPF has done. It will support the 2030 Agenda focusing on the SDG 3 on health, build on the outcomes of 2017 campaign and will link to other EPF work, e.g. on non-discrimination, quality of care and access to medicines. ‘In our future multi annual programme, EPF have committed to delivering information tools of the UN SDG on health and we will organise a UHC Conference in 2020’ Bedlington said.

Brando Benifei MEP from Italy who sits on the Committee on Employment and Social Affairs then took the podium. He commended the dystonia survey



Prof Rose Goodchild

Photo: Stephan Röhl



Nicola Bedlington

Photo: Stephan Röhl

which should help inform policy. He said MEPs were looking at post 2020 funding. ‘We have to look at more money for research to find new treatments for a better quality of life.’ But he said ‘research alone is not enough, social support is also needed.’

Nessa Childers MEP, from Ireland who is Chair of the Access to Medicines interest group then spoke. She said that for rarer diseases, such as dystonia, research collaboration across the EU was a way forward. She said Brexit put both collaborative research and treatment at risk. She said in the event of a hard border Irish patients would no longer be able to access deep brain stimulation in UK facilities.

Adina Vălean MEP from Romania, sits on the European Parliament Environment and Health Committee. She spoke of the importance of keeping funding for the EU Health Programme. She said it is a vital enabler for health policy formulation and for effective implementation. She also said that the challenges for neurology research can be solved by collaboration at EU level.

MEP Marian Harkin from Ireland who is a member of the Committee on Employment and Social Affairs agreed saying there is a real threat to the EU Health Programme as health is not a priority for the Commission. Although it is definitely a priority for European citizens and this should be noted by the EU President.

Dr Jean-Pierre Lin, consultant paediatric neurologist in the general neurology and complex motor disorders service at Evelina London Children's Hospital then spoke. He said dystonia in childhood is often severely disabling, unremitting and unrecognised. Its link with cerebral palsy (CP) is misrepresented and this means dystonia is not such a rare disorder. Commenting on Prof. Goodchild's presentation he said if dystonia was locked out of general calls for research funding childhood dystonia was doubly so.

Prof. Marjan Jahanshahi, said that in her 35 years as a professional little had changed for the patient experience. Dystonia is often still misdiagnosed or takes too long to diagnose. We have had botulinum toxin now for 35 years and DBS for 25 years, but new treatments are still needed. Her question to Nicola Bedlington was we have seen some improvements in medicine but how can we improve the patient journey?



President Dystonia Europe Merete Avery

Photos: Stephan Röhl

Nicola Bedlington replied 'We need meaningful patient involvement with healthcare professional and real involvement of patients in research. We need to keep health on the agenda at member state level. Dystonia patients go back to your governments and engage with them.'

Donna Walsh said 'It is important to raise awareness with employers, healthcare professionals and policy makers. We need epidemiological surveys and above all a holistic approach.'

President Dystonia Europe, Merete Avery then thanked everyone, especially the MEPs. 'It is my hope, being a dystonia patient myself, that all the people affected by dystonia now, and in the future will not have to wait too long before they get the correct diagnosis, will receive treatment and support and therefore can lead a fulfilling life - working, studying, travelling and taking part in society!'

*Heather Clarke,
EU Consultant
Brussels, Belgium*



EU Consultant Heather Clarke

Report from the Dystonia Europe conference 12-14 April 2018

Advertised as 'D-Days 2018' this conference in Brussels marked the 25th anniversary of Dystonia Europe. After an introductory session and three presentations in the European Parliament where several MEPs were present and involved on Thursday 12 April we were given a guided tour of the heart of this huge building complex. Already a theme was coming through – although the UK is dealing with Brexit many joint European project and research initiatives would continue.

On Friday 13 April the President of Dystonia Europe Merete Avery opened the conference. She outlined the mission of Dystonia Europe; 'to obtain a better quality of life for people with dystonia and through supporting research improve their quality of life'. Diagnosed with cervical dystonia in 2006 she became a member of the Norwegian Dystonia Association and her life rapidly changed from that point on as she became involved with Dystonia Europe.

First came a presentation on the history of dystonia by Professor Patrick Santens from Ghent University Hospital. He reminded us all that dystonia dates back to the ancient and medieval worlds despite not being medically defined until the early twentieth century. Then Alistair Newton from St. Andrews, Scotland set the historical context for 25 years of Dystonia Europe. As he was one of the founders of the organisation he was perfectly placed to celebrate this 25th anniversary conference. His passion for creating a Europe wide organisation to help those with dystonia had the effect he said of 'making him work harder than he had ever worked before'. He reminded people that worldwide there are over 6 million people with dystonia; the third most common movement disorder. He ended by telling us there are now 18 European countries with National Patient Group members working together under the Dystonia Europe umbrella. He said that the whole process of seeing the organisation grow and the meetings and yearly conferences in many cities had felt like riding in an international express train. It had taken him all around Europe, given him many new friends and great enjoyment in his work.

Monika Benson, President of Dystonia Europe from 2007-2013 and now the Executive Director, then gave a brief overview of the David Marsden award.

Started in 2003 by Dystonia Europe it is an award of 10,000 euros to young clinical researchers papers showing innovative and ground-breaking published research into different aspects of dystonia and it is given out every two years see: <http://davidmarsdenaward.org/> for full details. Like Avery with whom she works with closely Monika has cervical dystonia too. Whilst being unable to do things properly when she first developed symptoms she says in her Youtube dystonia story that it made her think 'Where is the old Monika' until treatment gave her old self back again. Helpful, encouraging, speaking to many and encouraging people to be part of the 'dystogram' shots in break times between talks. The dystogram was a large cardboard frame which people posed behind to be photographed by the excellent on-site photographer Stephan Röhl who has worked on the Dystonia Europe conference photography since 2012. Monika helped carry the whole event with her energetic approach.

Also in the morning; a joint presentation with a wider picture about two important European initiatives. Donna Walsh talked about the European Federation of Neurological Associations (EFNA) an umbrella group representing European neurology patient groups (including Dystonia Europe) with a vision of creating a better quality of life for people across Europe with a neurological disorder. Then Frederic Destrebecq following on from Donna's presentation on the European Brain Council (EBC) based in Brussels. The EBC comprises of the major organisations in the field of brain research and brain disorders. This contains a vast network of patients, scientists and doctors, working in partnership with the pharmaceutical and medical devices industries. During questions taken at the end of the presentation we could see that these organisations worked closely together.

What had come over on the Thursday meeting at the European Parliament was that 1 in 3 people will suffer from a brain disorder in their lifetime and it costs European countries about 800 billion euros a year in treatment costs. The single biggest economic challenge to the European health care systems. This is where organisations that lobby on behalf of the patient and conduct research become so important.

Latest News

In the afternoon of the first day Professor Klein told us of a German Government funded project looking at all 7,000 known rare diseases in 10 funded networks. For DysTract – the part of the project looking at the dystonias – she explained that researchers were looking at the entire disease path of dystonia upwards. That is from the molecular level to the main exhibiting symptoms. So often it is looked at and treated from the symptoms downwards. Interestingly she felt DBS, now routinely used in treating Parkinsons, could be more widely used for dystonia.

Professor Maja Relja from Croatia presented her findings on her research project to train family doctors in diagnosing dystonia effectively. A local GP is the first and most important contact point for anyone looking for a diagnosis. Over her 5 year project Professor Relja worked on improving the doctors diagnosis of dystonia. In 2010 in her survey only 27% of patients had their dystonia diagnosed within a year and for 14% it took more than 10 years. However after 5 years continuous dystonia education training instigated by Prof. Relja the patient numbers had risen to 35% for diagnosis within a year and dropped to 7% waiting more than 10 years. At the end of the presentation the inevitable question was asked; why wasn't this work being done more widely throughout Europe in a co-ordinated way? Training of the family doctor remains a crucial part of timely and effective treatment for dystonia and a Europe-wide approach felt like a good idea.

In the evening many of us walked to a restaurant named 'Kwint' some 20 minutes away walking up a

gentle slope we ended up with a panoramic view of part of the city. A small bus offered others an alternative way of getting to and from the restaurant. The evening sun shone and we all drank a glass of champagne on the terrace and admired the view. The perfect antidote to a day of presentations. After a group photo with many people sporting the Dystonia Europe 'Jump for Dystonia' T shirts we went in for dinner. Good food and talk was followed by a quiz and then music and dancing. Soon many people were on the floor doing their thing – including me! On the walk home many of the 25th anniversary party balloons from the restaurant were carried back to the hotel celebrating the ending of a great evening out.

On Saturday 14 April we saw the welcome addition of three personal accounts of patients experience of living with dystonia. This carried on the work of a series of dystonia stories launched by Dystonia Europe in 2013 – available to view on the Dystonia Europe Youtube Channel at <http://www.youtube.com/user/DystoniaEurope>. The first 'My Dystonia Story' was from Amybel Taylor from the UK. Her story was inspirational. Diagnosed with dystonia as a child she had lived with her symptoms until her late teens. Then after deciding it would benefit her she had DBS in 2010. This transformed her life and she went on to university and is now training as a Junior Doctor. She feels that her experience of dystonia will really help her as a clinician when dealing with patients with dystonia.



Celebrating Dystonia Europe's 25th Anniversary at the Kwint

Photo: Stephan Röhl



*Joost van Den
Dool*

Photo: Stephan Röhl

In the afternoon physiotherapy for cervical dystonia was covered firstly by Joost van Den Dool from the University of Applied Sciences, Amsterdam. He concluded that a specialised programme of physiotherapy for patients worked better than generalised physiotherapy and was more cost-effective. Patients were more motivated and felt they got more from it. Then a man who has specialised in physiotherapy for cervical dystonia all his career; Dr John-Pierre Bleton gave a practical demonstration with a man who was a motorcycle rider. 'Do you suffer from twisting of the neck when riding your motorcycle?' he asked. 'No' came the reply, 'Not at all'. 'This is why' Dr Bleton replied 'you turn your neck continually and slowly to steer the motorcycle'. In saying this he showed how the daily exercises of gently turning the head in both directions slowly and without forcing muscles helps ease the very tight muscles on one side and activate the under-used ones on the other.

Professor Marjan Jahanshahi then gave a very good talk on living well with dystonia taken from many years of researching this area. Based at the Institute of Neurology at the University College London she reminded us that the medical model is of doctors simply rescuing patients from their illness. But also there is a self-management model that patients can work with to live well with a chronic condition in addition to their medical care. From this she gave her '23 commandments' for effective self-management. Amongst them were gaining information about dystonia (information is power), finding flexible and adaptive ways of coping, maintaining your self-esteem (a person is more than just their dystonia). A sense of identity, kindness to others and oneself and intelligence are important as is knowing what we can control and understanding our limitations and what we can't control. Mindfulness and a positive mental attitude coupled with an appreciation of friends and family are helpful as is finding ways of building resilience. A theme I recognised was the need to develop self-compassion and switch off that internal and often quite self-critical voice. Jahanshahi recommended al-

ways keeping time for leisure activities and not being tempted to cut down on them. If necessary speaking to your GP if there is a period of depression or anxiety, communicating with family pro-actively and maintaining a good social support network. It was a talk which gave much to empower a person suffering from dystonia and gave a great deal to take away and think about and work on.

Finally there is a way we can all be involved. Adam Kalinowski, a young Polish man working for Dystonia Europe explained the My Dystonia App. A disease diary for dystonia that is available to download onto your phone after registering at <https://www.mydystonia.com/> and activating your profile. The diary then asks you questions which can be answered each day or periodically about how you feel and are coping. Over time you can generate a report from the information you put in and the data can be shared with your doctor or physician to aid treatment. So far 1700 people have used this and the hope was that this would keep on growing.

I came away from the conference being very impressed with the close commitment and teamwork involved with group of Dystonia Europe staff organising it and their openness and helpful approach. The President Merete Avery working closely with Monika Benson the Executive Director alongside Adam Kalinowski and Sorin Ionescu, also the photographer Stephan Röhl and then everyone behind the scenes including staff translating all the talks for Flemish delegates. Between them they did a great job. The evening meals, a final coach tour of the city of Brussels on the second day of the conference and meal and all the group photographs enthusiastically and professionally organised by Stephan Röhl all built in a feeling that we were one group not groups of specialists, patients and organisers all feeling slightly separate from each other. Here's to a very successful follow up 2019 conference in London!

*Andrew Russel,
The Dystonia Society, UK*

Photo: Stephan Röhl



A HISTORY OF DYSTONIA EUROPE – FIRST 25 YEARS - 1993 -2018

How did Dystonia Europe begin, why was it needed, and who are the people and organisations who have contributed over the past 25 years?

THE FORMALITIES

The organisation was formed as an association of national dystonia patient groups in Spoleto, Italy, on 18 June, 1993. The name was European Dystonia Federation (EDF) and the office address was at The Dystonia Society, in London. In 2003, EDF was formally registered in Belgium as an Association Internationale Sans But Lucratif (AISBL) a not-for-profit organisation - and the registered address ('siege') at an address in Brussels.

At the General Assembly in Barcelona on 23 October, 2011, the delegates accepted the Board's proposals to modernise the organisation and to change the name to Dystonia Europe (DE). The focus of activities also changed, to allow DE to provide a more effective 'platform' for partnerships for dystonia with scientists, patient organisations and others. The legal process was completed in 2012, with our registered office remaining in Brussels.

THE WORLD OF PATIENT ADVOCACY IN 1993

Dystonia – unknown to many people

Many people reading this in 2018 might not understand that dystonia wasn't well-known or well-understood twenty-five or thirty years ago. In the 1980s and early 1990s, there were still very few specialists with knowledge of dystonia, and diagnosis and treatment were very hard to find in most countries across Europe. We needed to find ways to stimulate interest in dystonia among the younger clinicians and researchers.

Dystonia is a small-scale illness with relatively low numbers of patients - only one of a group of neurological movement disorders, a group which forms only a small section of all neurological illness. Neurology itself, although extremely important in terms of human brain function, forms only a small proportion of the total of all medical conditions – in numbers of patients.

Dystonia prevalence in the context of other illnesses

Many estimates of the total number of human illnesses suggest that there are around 30,000 and some of them have huge numbers of patients across the world. WHO (World Health Organisation) data tells us that there are more than 600 neurological illnesses affecting almost 1 billion people in the world.

Accurate estimates are difficult to calculate because of lack of data – even for the “big” illnesses. For **epilepsy**, the estimated number of patients is **50 million**. For the **dementias** – **24 million**. **Parkinson's** disease is estimated to have perhaps **10 million** patients. The world figure for **dystonia**, based on estimates in Europe, would be around **6 million**. But there is not enough clear data available on which to base a reliable total number.

Dystonia patient groups in the early 1990s

“Patient advocacy” was just beginning in many areas of health. Very few national dystonia patient groups existed in Europe, and almost all of those were only a few years old. All of these groups started by focussing on the important basic functions of providing contact between patients, good information on the illness and how to find a diagnosis – “patient support”. More advanced ‘advocacy’ was the next step. Representing the interests of patients by providing useful and credible information to healthcare providers and decision-makers on what support and treatment patients and their families really need.

The need for partnerships in dystonia

In 1993, it was clear that national dystonia patient organisations in Europe should come together in partnership to learn from one another. They also needed to promote the interests of their members with healthcare decision-makers at all levels, including the European Union.

Although, in the EU, healthcare is considered to be an issue for national governments, many decisions are made in Brussels which affect aspects of healthcare in all member states.



European Parliament - Brussels

The stimulus of some specialists in dystonia - Professors Fahn and Marsden

By the 1980s, the level of knowledge of dystonia was still low among the majority of the broad medical profession. But two specialists in particular began to bring colleagues and young neurologists into their sphere of interest - dystonia.

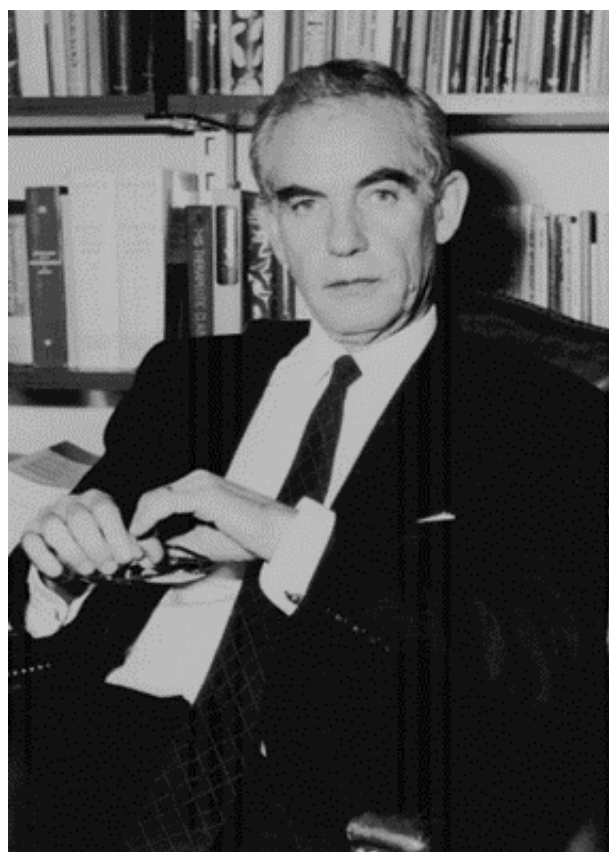
Stanley Fahn in New York and David Marsden in London had both developed clinical and research interests in dystonia and movement disorders generally. They became good friends and close scientific collaborators on dystonia and other topics. Prof Fahn remains a very senior world figure in movement disorders, and a strong supporter of patient advocacy.

Sadly, Prof Marsden died suddenly at a relatively young age in 1998, but his reputation lives on as a pre-eminent scientist in his field. His crucial work in establishing dystonia as an organic illness is commemorated

by the David Marsden Award.

Created by Dystonia Europe in 2003, this Award is presented every two years for the best scientific paper on dystonia from a young scientist.

By the mid 1980s, Profs Fahn, Marsden and others had the idea to form a worldwide scientific organisation to promote Parkinson's disease, dystonia and other movement disorders. That was the beginning of the Movement Disorder Society, which has grown to be an extremely influential global professional association.



*Prof David
Marsden*

Why did we need to create a pan-European patient organisation in 1993?

- The illness was not well-recognised and diagnosis and treatment were difficult to find .
- Drugs and surgery had been tried by the few dystonia specialists, but with limited success.
- Botulinum toxin was only starting to be used in some European countries in the early/mid 1990s.
- Only a few patient groups existed, they were very new and still trying to establish themselves.
- Many of the national groups focussed on only one type of dystonia (blepharospasm, torticollis, dysphonia, etc).
- We needed to work together as patient advocacy groups and become more 'professional' in our activities.
- Clinicians and researchers were working in international partnerships more and more and we needed to create a unified organisation of patients to work with them in a professional way.
- The influence of European Union decisions on national practices was increasing in the field of health.

The Founding of EDF – Spoleto, Italy, 18 June 1993

This process took almost a year, with our first contacts at a workshop in Munich, followed by two preparatory meetings in Barcelona and Paris.

It should be mentioned that, in 1993, international communications were much more basic than they are today. No email. No mobile phones. No Skype. No internet available to the public. Certainly, no Facebook..... We used the telephone, ordinary mail and fax machines. Sending a 10-page fax to 12 or more people in different countries took a long time and was also quite expensive!



Back row: Didi Jackson, Germany; Alistair Newton, UK; Feli Justo Alonso, Spain; Alan Leng, UK; Gunilla Norden, Sweden. **Front row:** Tore Wirgenes, Norway; Jean-Marc Bildan, France; Laura Latini, Italy; Maja Relja, Croatia; Beppy Smitshoek, Netherlands. **Absent:** Kai Naunung, Denmark.

THE MANAGEMENT OF THE ORGANISATION OVER 25 YEARS

Board Members and Officers

I was honoured to be elected at the Spoleto meeting as the Founder President and Laura Latini The Founding Committee of European Dystonia Federation in 1993 from Italy became Vice President. Alan Leng, Chief Executive of The Dystonia Society, was appointed as Secretary-General – an unpaid role which he filled with energy and skill until 2001. After a few years, Feli Justo Alonso from Spain followed Laura as Vice President, then Didi Jackson from Germany who later became President and served with enthusiasm, grace and dignity for 6 years in that position, until she retired in 2007. Didi, sadly, passed away quite recently, in February 2018.

Prof Maja Relja

Maja Relja from Croatia, pictured above in Spoleto, became our Vice President in 2012 and has only recently retired from that post. She has been a constant and positive presence for European Dystonia Federation/Dystonia Europe since 1993, and remains a warm and supportive friend as a member of our Medical and Scientific Advisory Board.

Ginger Butler, was a very warm and larger than life character from the North East of England, with a deep wish to help dystonia patients. He contributed greatly to our Board meetings, as Vice President from 2001 to 2008 and again, as a Board Member, from 2009 until 2012.

Despite having no earlier training in medical science, he gained a PhD based on epidemiology in dystonia and carried out several dystonia research studies before he passed away, sadly and unexpectedly in 2012.



*Dr A G Butler
("Ginger")*

Readjustment of Board responsibilities in 2001

By 2001, it was clear to me that the hugely increased workload of the President could no longer be continued by one person alone, even though I had taken early retirement from my business career some years before. Fundraising, daily financial control, all documentation, website, legal, accounting, publicity, very frequent travel to Brussels and many other countries, all had become impossible to sustain.

A strategy plan was created, to restructure the organisation, employ a part-time Executive Director, and ensure that the Board members took more responsibility for decisions. I had intended to retire completely at that point, but the Board asked me to remain and take the position of Executive Director, to provide continuity. With the new distribution of responsibilities, this was a realistic solution and I retired from the Presidency at the General Assembly in 2001, to become the first Executive Director.

A new beginning for European Dystonia Federation

In 2006, one year before Didi Jackson's term of office as President would end, there was no obvious successor. Then, at the 2006 General Assembly, we met a new delegate from Sweden, Monika Benson. It was clear from that first meeting that Monika had the personality and capabilities to lead our federation into the next stage of its life, and she eventually agreed to be nominated by the Swedish association. Monika was appointed as our President in 2007.

Many things in the world had changed since 1993 and, after a period of 'settling in', Monika began to make differences in our approach to match the new generation of people, organisations and institutions which had developed. We changed the name and 'image' from the old blue and white to a much warmer and more modern presentation of colours and messages for Dystonia Europe, on a new website and letterhead.

New activities and projects followed and our members, dystonia clinicians and researchers, partner organisations and our sponsors all responded very positively.

When Monika's term of office as President ended in 2013, the post of Executive Director was vacant, and she agreed to be appointed to the job, to provide continuity and support the new President, Robert Scholten, from The Netherlands. Robert decided to retire from his post after one term of office, and Merete Avery from Norway was appointed as President in 2015. Merete has already provided great stability and, no doubt, some future historian will comment warmly on her very hard work after her term of office ends!

List of all Board Members and Officers

Many others have served terms as Board members and Officers of DE over the past 25 years. Our organisation is grateful to them all for their time and their energies.



Robert Scholten



Merete Avery



Monika Benson

*Photos:
Stephan Röhl*

Our Medical and Scientific Advisory Board (MSAB)



Prof Alfredo Berardelli, Rome; Prof Eduardo Tolosa, Barcelona; Prof Rose Goodchild, Leuven; Prof Marie Vidailhet, Paris; Prof Dirk Dressler, Hannover; Prof Maja Relja, Zagreb; Prof Joachim Krauss, Hannover; Prof Kailash Bhatia, London; Dr Jean-Pierre Lin, London; Prof Marina De Koning Tijssen, Groningen; Prof Alberto Albanese, Milan.

Photo: Stephan Röhl

A number of specialists from across Europe, who have become senior figures in movement disorders, have been appointed to our MSAB and many of them are pictured above at our 20th Anniversary meeting in Edinburgh in 2013.

We are grateful to them all for the support they have given EDF/DE over the past 25 years.

Two MSAB members deserve special mention – Profs Tom Warner and Alberto Albanese



*Prof Tom Warner,
London*



*Prof Alberto Albanese
Milan*

The two neurologists pictured above (who were both young in 1993!) have been especially close to EDF/DE ever since it was founded. **Tom Warner** was our sole medical adviser for many years, until we appointed a Medical and Scientific Advisory Board. He has contributed many ideas and gently guided us away from many mistakes, with great sensitivity, humour and quiet wisdom.

In the early years, he organised EDF's first research project – An Epidemiological Study of Dystonia in Europe, under Prof Marsden as the Principal Scientist. He has been involved in many other activities with us since then, and remains a close friend of DE.

Our relationship with **Alberto Albanese** also stretches back to the founding of DE in 1993, and we have collaborated with him on many projects. The most recent, of course, was the European Dystonia Research Network which he chaired during the 4 years funded by the COST (Co-operation in Science and Technology) grant which he obtained in 2011.

Dystonia Europe was elected by the scientists to act centrally, as Grantholder and Administrator of the project. The Network not only stimulated collaborative research partnerships, but provided grants to young scientists for short term scientific missions, and grants to attend dystonia training courses which the Network organised. Prof Albanese also remains a good friend of Dystonia Europe.



Scientists from the European Dystonia Research Network – Dublin, June, 2012

DEVELOPMENTS IN CLINICAL AND RESEARCH INTEREST IN DYSTONIA

Let's take a look at how the interest in dystonia by medical professionals has changed over these 25 years.

First, the number of people attending **Movement Disorder Society congresses** has increased substantially..... from 1280 attendees at their first congress in 1992, to 5,500 attendees in 2016.

European Academy of Neurology (formerly European Federation of Neurological Societies) has developed a strong relationship over many years with MDS. EAN annual congresses increasingly feature dystonia sessions. This year, 2018, several of Dystonia Europe's Medical and Scientific Advisory Board are speakers in a special session on dystonia and another session features the David Marsden Lecture. This will be presented by the outgoing EAN President, Prof Gunther Deuschl, who is a renowned movement disorder specialist.

We must also mention the 3 excellent conferences on **Treatment of Dystonia**, which have been organised in Hannover, by 3 more friends and supporters of Dystonia Europe, Profs Eckhart Altenmueller, Joachim Krauss and Dirk Dressler. Conference attendees: 2010 – 250; 2013 – 500+; 2016 – 500+.

Dystonia Europe has also been successful in organising large-scale international scientific conferences, focussed on dystonia. In 2008, we attracted 250+ specialists to our 2-day event in Hamburg and, in 2011, we welcomed around 550 dystonia specialists from 39 countries to the **5th International Dystonia Symposium** in Barcelona, with a scientific programme of 50+

speakers. On this occasion, we were delighted to be joined in the organising of the 3-day event by the Dystonia Coalition and Dystonia Medical Research Foundation, both from USA. All previous Symposia in this series have taken place in USA and the 4th Symposium was held in Atlanta in 2002.

PARTNERSHIPS WITH OTHER ORGANISATIONS AT THE EUROPEAN LEVEL

European Federation of Neurological Associations (EFNA) – Founded 1997

European Brain Council (EBC) – Founded 2002

Dystonia Europe was very involved in the founding of both of these organisations, and in their development during the years since then.

EFNA is an 'umbrella' group for pan-European neurological federations, such as Dystonia Europe. In fact, a federation of federations! It represents many neurological illnesses and a large scientific organisation like EAN (European Academy of Neurology) which covers all of neurology, finds it easier to work in partnership with an organisation with a similar spread of interest, instead of having separate relationships with individual groups. This same principle of bringing together many different strands of the same area of health also appeals greatly to politicians. EFNA quickly became a very successful initiative, and has developed even more in recent years.

EBC is a high-level scientific organisation which has successfully combined the efforts of pan-European psychiatric and neurological organisations, from both scientific and patient areas and from the pharma and medical device industries. This gives EBC enormous credibility as a lobbying organisation.

Latest News

EFNA is a founder member of EBC and Dystonia Europe's representatives have played central roles in both organisations since they were founded.

The main aim of EBC is to clarify the realities of brain illnesses in an ageing population, and to use its credibility to influence the views of the European Institutions. Among a number of important research projects, EBC has shown that the societal costs of "Brain Illness" in Europe amount to at least €800 Billion per year. This is a staggering amount of money, but is actually less than the probable real total, as many 'smaller' illnesses like dystonia do not have enough research data available to be included in the study.

However, the credibility of EBC and its research is so strong that there has been a very considerable increase in the amount of EU research funding made available for brain illness projects over the past 15 years, and also in the number and value of grants allocated in that area. When EBC was founded, the word "brain" did not appear anywhere in the European Commission's calls for grant applications to the Framework Pro-

gramme..... A huge positive change has taken place.

Foundation for Dystonia Research (FDR) – is a private foundation, based in Belgium, which focusses on promoting research in dystonia. In partnership with the Belgian Government, it has co-funded a chair and a department in the University of Leuven, headed by Professor Rose Goodchild, who is a member of Dystonia Europe's Medical and Scientific Advisory Board. The Foundation has also given strong support to DE for the 5th International Dystonia Symposium, Barcelona 2011.

Partnerships with the industry

Five companies have given us tremendous sponsorship support, some of them over many years. **Allergan**, in particular, provided crucial support right at the start and for the first few years, when no other companies were in the dystonia 'market' in Europe. In more recent years, our partnerships with Ipsen, Medtronic, Merz and Boston Scientific have developed very successfully, and DE enjoys good, transparent relationships with the industry, and without conflicts of interest.

SO – WE HAVE ARRIVED IN 2018! HOW DID WE GET HERE?

Here is a **contrast** between Spoleto in 1993 and today's Dystonia Europe!



These two photographs, I think, show how European Dystonia Federation and Dystonia Europe have developed, to keep up with scientific and societal change in the dystonia community and its needs. Our organisation has initiated and supported many worthwhile projects, which have contributed to improving the lives of dystonia patients. That provides an excellent platform for more developments in the future and, on behalf of Dystonia Europe, I thank all the fine people – patients and their families, medical and healthcare professionals, industry and other supporters and many other people who have contributed so much to that work over the past 25 years.

A much more lively photograph in Croatia, a few years ago. But didn't we all **look very young** in 1993!



Alistair Newton – June 2018 photo: Stephan Röhl

Didi Jackson – in memoriam

Dystonia Europe announces, with great sadness, the passing of our former President, Didi Jackson on 14 February, 2018.

The 1980s and early 1990s were the early days of dystonia becoming better-understood by the medical profession, and it was very difficult for patients to obtain good information and medical advice. Didi received her own diagnosis and treatment from a doctor in the United States in 1989, and decided that she would create an organisation in Germany to improve the situation for dysphonia patients. This was Selbsthilfe-Gruppe Dysphonie, based at her home in Hamburg.

By 1993, Didi had realised the broader understanding of dystonia as a syndrome with different presentations of symptoms, and changed the format of her group to become the Deutsche Dystonie Gesellschaft (DDG). DDG joined the European Dystonia Federation (EDF) at its founding meeting in Spoleto, Italy, in June that same year.

Didi joined the EDF Board in 1995 and was appointed Treasurer in 1997. In 1999 she became Vice President and served as President from 2001 until 2007. On her retirement, she was elected as an Honorary Member of our organisation.

Didi worked tirelessly to help dystonia patients over all these years and was a fine advocate for dystonia patients.

There were many highlights during her presidency. Particularly, the introduction of the David Marsden Award for young dystonia scientists and EDF's 10th Anniversary – both in 2003, and the preparations for EDF's scientific conference on dystonia in Hamburg, 2008. This was a great success, attended by 250 dystonia specialists from across the world, and was a real innovation as it was organised by a patient group.



Didi Jackson

Didi Jackson fulfilled her duties as our President with much hard work, but also with grace and dignity and we are grateful for all that she contributed to our success over those years of service.

Barry, her husband of many years, predeceased her in 2017 and she is survived by her two sons, Lenard and Dennis and their families, to whom we offer our sincere condolences.

*Alistair Newton
Honorary Member
Dystonia Europe*

Latest News

Have you sent a Dystogram?

At our 25th Anniversary in Brussels we invited speakers and guests to send a 'dystogram'.

Boston Scientific generously supported the project and produced the specially designed frame.

We encouraged participants to get social and get together in the frame, take a photo and post on Facebook, Instagram or Twitter to congratulate DE and use the hashtag: #DE25years.

Here are some of the greetings!



www.dystonia-europe.org

Scientific Report D-DAYS Brussels

The 25th anniversary of Dystonia Europe was held in beautiful city of Brussel between April 12th-14th. The breakdown of D-Days 2018 brought together patients, their care partners and family members, physicians, clinicians, scientists, physiotherapists, and pharmaceutical industry members to discuss cutting edge science in the growing field of dystonia.

The conference program included a visit to the European Parliament and two days of highly involving plenary symposium. There were three main parts in the Conference program, namely: (1) The history of Dystonia Europe; (2) patient's testimonies and (3) scientific lectures. The history of Dystonia Europe development was presented by Alistair Newton, the Founder of the Association. He took us on a beautiful, historic journey to show the tremendous achievements in connecting patients and doctors to spread awareness about the disease. Very important part of the Conference was *My dystonia story*, when patients presented their own experiences with the disease. This was usually a long and hobbling journey from the first symptoms to the final proper diagnosis. Meaningfully, patients share their experiences and contributed to better future management tips for others. Finally, the scientific lectures focused on updates on recent developments in dystonia research, with the disease pharmacological treatment options and physiotherapy.

Research in dystonia

Professor Rose Goodchild presented highlights of current basic research in dystonia including implicating glial cell defects and novel information about the molecules and signals, disturbed in dystonia, that might be potential therapeutic targets in future. In an excited presentation, professor Maja Relja showed first results of an international survey on quality of life, satisfaction and access to treatment of over 1000 dystonia patients across Europe. Professor Maja Relja shared also her experience on training family doctors in dystonia and proved that sharing knowledge about this disease leads to improvement in multiple aspects of dystonia management especially in diagnosis and treatment.

Another highlight during the Conference presented by prof. Christine Klein was the DYSTRACK Consortium, a German, multicentre, research network. This outstanding program covers multiple aspects of dystonia including basic research on animal models, threw genetics of dystonia to clinical trial of novel treatment approach.

Additionally, research on musician's dystonia are also a part of the DYSTRACK initiative. Prof. Alexander Schmidt presented risk factors and genetic contribution to musician's dystonia. Interestingly, he also established a unique program for professional musicians to prevent musician's dystonia by minimising risk factors (e.g. stress associated with musical activity) at The Kurt Singer Institute for Music Physiology and Musicians' Health.

The venue covered also management of movement disorders in children presented by Dr. Jean-Pierre Linform London. This is a very important topic in terms of recognizing potentially curable dystonia in childhood from cerebral palsy.

Professor Brigitte Girard from Paris gave a lecture about early signs and symptoms of blepharospasm accompanied by diagnostic and treatment approaches. All delegates received her book about this type of focal dystonia.



Prof Rose Goodchild

Treatment options

Treatment options featured many topics, namely: botulinum toxin injections, physiotherapy and deep brain stimulation (DBS) in dystonia. Professor Dirk Dressler showed that despite long lasting history of botulinum toxin in neurology high quality research is still needed to explore for example new modes of action. Dr. Jean-Pierre Bleton showed how important it is with activation of the inhibited, anti-dystonic corrective muscles. Professor Marie Vidailhet spoke about transcranial magnetic stimulation and its potential usefulness in the treatment strategies for dystonia. DBS was introduced by Prof. Marwan Hariz and Dr. Laura Cif. The presentation took us step by step from qualification criteria and the best time to do DBS, preparation before the procedure, surgery itself and then management after the operation. The presentation pointed out that DBS is usually more beneficial for patients with primary dystonia then for those with secondary dystonia and better in mobile than fixed dystonic postures.

Also regarding treatment strategies for dystonia, I would like to mention a powerful lecture delivered by Prof. Marjan Jahanshahi about self-management strategies for living well with dystonia. She presented 23 commandments which should be incorporated in daily living with chronic disease to empower coping mechanism and for living better. The delegates make-up created a true cross section of the dystonia community. Monika Benson along with Dystonia Europe board, again launched a very successful meeting with a focus not only on the current state of dystonia (e.g. science and care) but also in an emerging innovated format of scientific meetings for the dystonia patient community, a format that integrates all engaged professionals and patients. The idea of integrating dystonia community will hopefully lead to interesting collaborations. Again Dystonia Europe proved that we are stronger together.

Katarzyna Smilowska MD, PhD
Silesian Center of Neurology
Katowice, Poland



Katarzyna Smilowska MD, PhD

Hannover Congress Interview with Professor Dressler

DE: Congratulations for your new book. What was the idea behind it?

DD: The book is based on the concept of our 'International Congresses on Treatment of Dystonia', a congress series well established over the last ten years. We want to focus on one disorder only. And for this disorder we want to combine all therapeutic approaches. Most of the time meetings are focused on special methods and treatments. We believe, this will narrow down the therapeutic options. This is especially the case in a disorder like dystonia where there is no causal and definite treatment available. With this book we strongly advocate multidisciplinary treatment strategies.

DE: What therapies are you covering?

DD: We focus on botulinum toxin therapy as the treatment of choice for most of the patients with dystonia. We also cover deep brain stimulation, conventional pharmacotherapy, rehabilitation, conventional surgical treatments and emerging therapies.

DE: Are you also dealing with the disorder itself?

DD: Yes, we update our readers on classification, pathophysiology, epidemiology, genetics, imaging, animal models and scales for documenting dystonia.

DE: What about special forms of dystonia?

DD: We have sections on musician's dystonia, on pediatric dystonia, on psychogenic dystonia and on symptomatic dystonia.

DE: What is the target audience?

DD: We pulled the book together for 'All who care for Patients with Dystonia' including physicians and allied health care professionals. The medical areas covered include neurology, neurosurgery, neuropaediatrics and neurorehabilitation.

DE: Do you think that also patients may benefit from this book?

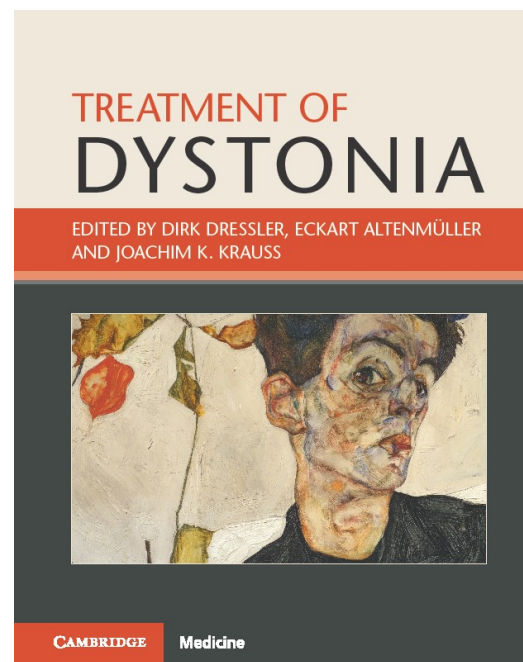
DD: We know that there is a substantial proportion of dystonia patients interested in understanding their disorder and their treatments. Many of them are actually members of those patient organisations you are representing with Dystonia Europe.

We put special emphasis on a plain and clear language patients will easily understand. Even relatives might want to get some background information, so that they can better support their patients.

DE: We wish this book good luck!



*Prof
Dirk
Dressler*



www.cambridge.org/treatmentofdystonia

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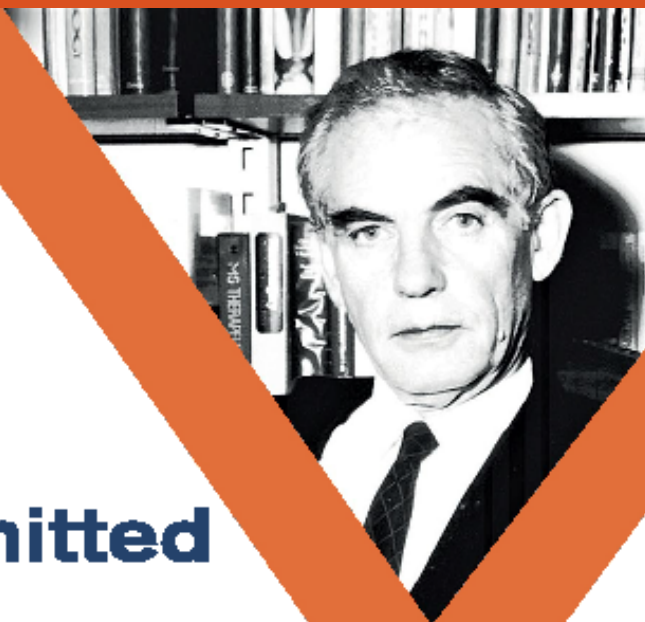
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DYSTONIA
EUROPE



**Ipsen committed
to **patient** care
over the long term
supporting**

The David Marsden Award 2019

10 000€

to stimulate research on dystonia

The award, introduced by Dystonia Europe in 2003 is presented every two years to stimulate developing knowledge of and interest in dystonia through publications on aetiology, pathogenesis, diagnosis or therapies in dystonia or on the psycho social effects.

The deadline for submissions is 31 January 2019

All information regarding the 2019 David Marsden Award are available at www.davidmarsdenaward.org

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The following articles, page 30–34, make reference to certain companies and their products and any opinions expressed should not be taken to be the views of Dystonia Europe or its members.

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

Clinical Study results for Healthcare Professionals;

Efficacy of pallidal stimulation in isolated dystonia: a systematic review and meta-analysis

E. Moro, MD, C. LeReun, MSE, J. K. Krauss, MD, A. Albanese, MD, J.-P. Lin, MBChB, S. Walleser Autiero, MPH, T. C. Brionne, PhD, M. Vidailhet, MD,
European Journal of Neurology 2017, 24: 552–560 (Impact factor 2015: 3.956) available open access:
<http://onlinelibrary.wiley.com/doi/10.1111/ene.13255/epdf>

WHY THIS STUDY IS IMPORTANT

- It presents strong evidence (a meta-analysis) on the efficacy of DBS in isolated dystonia.
- As such, it will facilitate clinical & economic decision making in support of patient access to DBS.

- This study adds strong evidence that bilateral GPi-DBS has a significant beneficial clinical impact on patients with isolated dystonia.
- Benefits are maintained in the long-term (up to 3-years follow-up).
- DBS may be more effective if patients are treated at younger age, suggesting a possible beneficial effect also, in childhood.

TAKEAWAY MESSAGES

DISCLOSURE

This study was a collaboration between global dystonia expert physicians (E. Moro, J. K. Krauss, A. Albanese, J.-P. Lin, M. Vidailhet), Medtronic Health Economics and Clinical experts (S. Walleser-Autiero and T.C. Brionne) and an independent statistician hired by Medtronic (C. LeReun)

METHODS

SYSTEMATIC REVIEW:

- Databases were searched (Jan 1990 - Nov 2015) and publications were selected that reported results of treatment of isolated dystonia with DBS.
- Extracted data on study and patient characteristics, DBS efficacy and safety, and quality of life (QoL).

META-ANALYSIS : absolute and percentage changes from baseline in the Burke-Fahn-Marsden Dystonia Rating Scale (BFMDRS) motor and disability scores were pooled from individual studies.

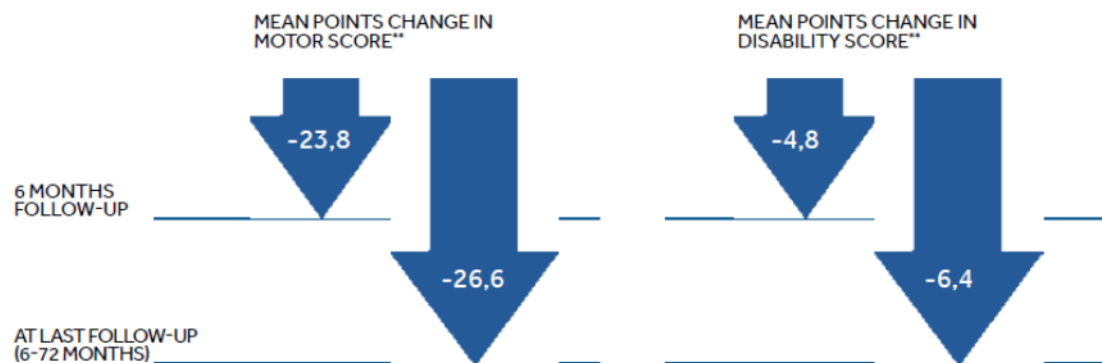
RESULTS

▪The search yielded 54 studies; 24 included in the meta-analysis (3 controlled studies¹⁻³ including randomized controlled trials^{1,2}).

▪Demographic characteristics of these 24 studies:

- Total number of patients: 523
- Male patients % (mean): 52%
- Paediatric patients* (mean): 29% (10 studies only)
- Age at surgery (mean): 35.1 years

▪BFMDRS motor and disability scores improved significantly between baseline and 6 months after DBS implant and at the final follow-up. All changes in absolute scores from baseline are statistically significant at $p < 0.001$.



**A negative change in score indicates an improvement.

The analyses scores indicate that patients with a greater impairment at baseline and a younger age at surgery had greater improvements.

STRENGTHS

- A large patient population relative to previously published meta-analyses⁴⁻⁵
- State of the art statistical analysis
- Outcomes that are meaningful to physicians and patients: absolute and % changes in BFMDRS
- Large effect sizes across all 24 studies resulting in pooled effects that are clinically relevant and statistically significant

LIMITATIONS

- Due to inconsistent reporting and lack of details presented in the 54 studies yielded by the search, 38% were excluded, and HRQoL and adverse event data were excluded

¹ Kupsch A, Benecke R, Mueller J, et al. Pallidal deep-brain stimulation in primary generalized or segmental dystonia. New England Journal of Medicine 2006; 355(19): 1978–90.

² Volkmann J, Mueller J, Deuschl G, et al. Pallidal neurostimulation in patients with medication-refractory cervical dystonia: a randomised, sham-controlled trial. Lancet Neurol 2014; 13(9): 875–84.

³ Vidailhet M, Vercueil L, Houeto J, et al. Bilateral deep-brain stimulation of the globus pallidus in primary generalized dystonia. New England Journal of Medicine 2005; 352(5): 459–67.

⁴ Holloway K, Baron M, Brown R, Cifu D, Carne W, Ramakrishnan V. Deep brain stimulation for dystonia: a meta-analysis. Neuromodulation 2006; 9(4): 253–61.

⁵ Andrews C, Aviles-Olmos I, Hariz M, Foltynie T. Which patients with dystonia benefit from deep brain stimulation? A metaregression of individual patient outcomes. Journal of Neurology, Neurosurgery & Psychiatry 2010; 81(12): 1383–9.

INNOVATION IN DYSTONIA TREATMENT

**Boston
Scientific**
Advancing science for life™

More than **500,000 people**
across Europe are living with dystonia¹



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 **120,000 people** worldwide
already treated with DBS²



What is DBS?

implantation of brain
stimulator that helps
regulate neural signaling



Vercise Directional System...

...powered with Current Steering technology is
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Boston Scientific in DBS



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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



Strained or
whispering voice



Muscle spasms



Rapid eyelid blinking



Painful neck spasms

improvements of 50-60 % in general, some patients experiencing a 90 % reduction in symptoms⁴



Talk to your doctor about how DBS could help you and find out more here:
<http://www.bostonscientific.com/en-EU/disclaimer-2.html?disclaimer=en-EU/products/deep-brain-stimulation-systems/Vercise-PC-DBS/Patient-Resources.html#value>

References:

¹ Epidemiological Study of Dystonia in Europe (ESDE) Collaborative Group. *J Neurol*. 2003; 247(10):767-82.

² Pabayo C, Yamamoto T. *Neurol Med Chir*. 2015; 55(5):422-31.

³ DBS Matters Debate, November 2015.

⁴ <http://www.dystonia-foundation.org/living-with-dystonia/neurosurgery/brain-surgery/deep-brain-stimulation> last access October 27, 2016.



* Vercise DBS Lead-only system (before Stimulator is implanted) is MRI conditional. An MRI examination can be conducted safely when all instructions in the supplemental manual MRI

Guidelines for Boston Scientific DBS Systems are followed.

** The Vercise Genu DBS System is MRI conditional for all body parts.

A System that includes the Vercise PC or Vercise Genu (PG and Vercise Cerebral Directional Leads) form the Vercise Directional System.

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MM-399107-A6_JUNE2017

DBS: Effective Therapy for Dystonia Patients

Interview with Professor Andrea Kühn from the Charité, University Hospital in Berlin, Germany

The Charité University Medicine in Berlin is Europe's largest university hospital and offers a comprehensive treatment spectrum at the forefront of medical care for patients from all over the world. One of the clinic's focuses is the treatment of patients with movement disorders such as dystonia, Parkinson's disease or essential tremor. Professor Kühn leads the movement disorders and neuromodulation unit at the department of neurology. For the treatment of dystonia patients, she has been working with the so-called Deep Brain Stimulation (DBS) and has achieved good results.

How long have you been working with DBS?

Professor Kühn: Deep Brain Stimulation (DBS) is a method that the Charité has been using since the late 90s to treat patients with Parkinson's disease. Already in the year 2000, we have also operated our first patient with generalized dystonia. By now, DBS is a well-established treatment option and increases the patients' quality of life by improving their ability to move. The Charité is broadly positioned in therapy and research, and besides DBS, also offers all other available treatment options for dystonia patients, also children.

How does DBS work?

Professor Kühn: Dystonia can be lead back to wrong regulations in brain circuits, namely information flow between the cerebral cortex and the basal ganglia (deep areas of the brain). DBS modulates neuronal activity in these areas by the use of high-frequency stimulation with 130 Hertz via deep brain electrodes that suppress the abnormal brain rhythms. Stimulation very successfully reduces involuntary movements in our patients. However, we are still investigating how exactly this works.

Who is suitable for a DBS therapy?

Professor Kühn: DBS is very effective for isolated dystonia and some forms of combined dystonia such as myoclonus-dystonia syndrome. Especially patients with severe generalised and cervical dystonia benefit from it. We also treat children from up to five years that suffer from genetically conditioned generalised dystonia. After the operation, these children can actively participate in life again.

What does the therapy look like?

Professor Kühn: DBS is teamwork, especially between neurologists and neurosurgeons. Only experienced neurosurgeons perform the operation. Under anaesthetic, two holes are drilled into the skull through which, depending on the size of the target area, electrodes with four to eight contacts are placed. These are connected to a stimulator that is implanted under the skin. Small, rechargeable stimulators last for up to 25 years and need to be charged about once a week via transmission. To reach an optimum effect of the therapy, the stimulator is set up and adjusted in the department of neurology.

What are the opportunities and risks of DBS?

Professor Kühn: The earlier we find the correct diagnosis and treatment is initiated, the higher the chances for beneficial outcome that allows the patient to benefit from the increased quality of life. The effect of DBS builds up slowly and gets more and more noticeable each month. Complications can occur during the surgery or through an infection. Possible side effects of the stimulation can be speech disorders and slower movement. Of course, we consult with every patients about all possible consequences before deciding for or against DBS.

How does the Charité act in this area of research?

Professor Kühn: In our research projects, we focus on neurophysiological measures of brain activity to better understand the reason why patients develop dystonia and how DBS acts to suppress involuntary movements. We are working to find biomarkers of the disease that can help to adjust DBS to individual needs by so-called adaptive, closed-loop stimulation. We also developed a software to localize the DBS electrodes after surgery that we use to find the best location for the stimulation.

The Charité is involved in different clinical trials that test DBS for isolated dystonia. Moreover, we aim to find out who else could benefit from DBS, e.g. patients that suffer from dystonia after brain damage.

To better understand dystonia and therefore offer better consultation for patients, we keep key data points of every patient in a multinational register study. The Charité also plays an active role in the dystonia network for rare diseases (DYSTRACT, headed by Prof. Volkmann/Prof. Klein) and there works together closely with other centres in Germany.

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10117 Berlin

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Visit the website at www.charite.de



Professor Andrea Kühn

Karl Speech App

New KarlSpeech AAC App Launched June 2018

– Developed by Dystonia Sufferer's Parents

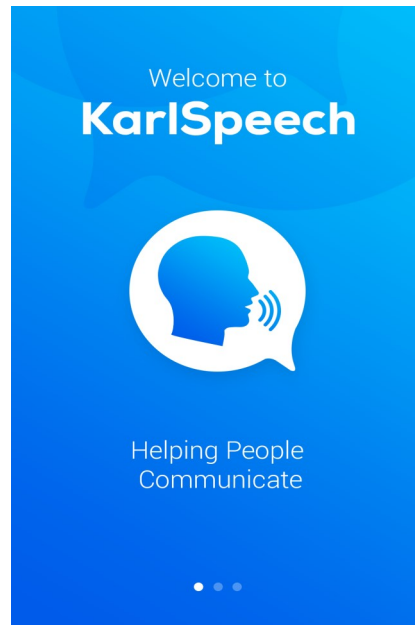
The KarlSpeech Smart Device App is an Augmentative Communications App (AAC) for people with severe Speech & Communications Difficulties. Designed specifically for Apple iPhone, iPad and iPod Touch, The App is integrated with Universal Symbols provided by SymbolStix.

The KarlSpeech Story

It all began when Karl a 24-year-old Dystonia sufferer needed something that would help him communicate with his family and friends. Karl is nonverbal, and his parents used several AAC communications apps but didn't find a solution that suited Karl's needs. There are many great AAC apps on the market, but Karl wanted something that was very straight forward, and he found that lots of existing App screens were cluttered and confusing.

After trying lots of options Karl's parents decided to embark on trying to get an AAC App developed that would enable their son Karl to communicate more effectively and the KarlSpeech App is the result of a lot of deliberation, testing, trialling and development.

Karl uses the KarlSpeech App all the time and it is also used by Karl's parents as they organise Karl's groups and library of phrases. Karl's father Hugh says "The biggest challenge was to design a Speech App that would be suitable for a variety of users with



different levels of intellectual and speech deficits. No App is perfect for everyone's needs but the KarlSpeech App has been designed to appeal to the majority. "

Planned Future developments for the KarlSpeech App

The KarlSpeech App will be evolving in the future. New native language versions will be introduced including Spanish, Portuguese, French and more. Keep informed by subscribing to our newsletter at www.karlspeech.com or Email: info@karlspeech.com

James Conlon, Ireland

KarlSpeech App Features

- Can be used with iPhone, iPad or iPod Touch
- Allows the user to communicate using text and images
- No active internet connection needed (except when first downloading the App via the Apple store)
- Male & Female Gender Voice
- Intuitive, uncluttered design interface
- Easy to Use with quick and easy customization
- Easy to build library phrases and categorize phrases into groups
- Easy to Add, Edit & Re-arrange Groups 'on the fly'
- Add & Save Phrases to Library or use the Quick Speak Option for 'one off' phrases
- • Backup to Dropbox or to your computer using iTunes File Sharing.
- Recent Phrases instantly available
- Access to more than 20,000 SymbolStix symbols or you can use your own photos
- Language currently supported: English
- Ad Free
- No In-App Purchases offered

Winter Think Tank 2018

5th Dystonia Europe Think Tank in Lund Sweden

The 5th Dystonia Europe Think Tank meeting was held in Lund, Sweden beginning of February. The DE Board and representatives of our 4 platinum sponsors: Boston Scientific, Ipsen, Medtronic & Merz gathered to discuss projects & activities of 2018.

In our discussions we are guided by the Dystonia Europe Vision & Mission:

The Dystonia Europe Vision is better quality of lives for people living with Dystonia in Europe, while supporting the search for a cure.

We hope to achieve our vision through the following core activities:

Raise awareness and be the leading voice in Europe on the impact of Dystonia.

Share the knowledge – provide the latest information and resources for our members and also be the source of information for the other stakeholders.

Connect people with Dystonia, member organizations, healthcare professionals, European policy-makers and the treatment industry to close the gaps of today's dystonia treatments.

Foster training and education and educate multidisciplinary teams and stakeholders along the dystonia journey to optimize care and improve quality of life.

We thank everybody for their valuable input, support and great collaboration.



Think Tank members



Being diagnosed with dystonia is challenging and may lead to multiple questions. We would like to offer you an opportunity to ask questions to our MD. You can send questions to the mail box: sec@dystonia-europe.org.

Then, answers prepared by a MD will be published in the next newsletter and on the Dystonia Europe webpage.

We believe it will be a great opportunity to build and strengthen connections between members, identify what are the needs and learn more about the condition.

Dystonia Europe on Youtube

Have you seen our Youtube channel?

<https://www.youtube.com/user/DystoniaEurope>

Follow us here to get our latest videos!

At our 25th Anniversary Conference and D-DAYS 2018 in Brussels we livestreamed and video-recorded our event for the first time. About 500 people watched the livestream during the two-day conference. Now all presentations are available on the Dystonia Europe youtube channel. So if you missed the livestream and if you could not come to Brussels you can still see all of the scientific presentations and learn about the latest within dystonia treatment and research.

We hope to be able to continue to stream and record our annual conferences in the future so where ever you are you can take part in our D(ystonia)-Days.

And don't forget to share the videos to educate and raise awareness of dystonia. Only by getting together, working together we can make a difference.

Thanks for watching us!

Neurology training in Lisbon - Value of Patient Perspectives and Preferences

Training Initiatives for Neurology Advocates [TINA] workshop took place at the Champalimaud Foundation in Lisbon 17th and 18th of April 2018.

The TINA workshops project was launched in 2016 by the European Federation of Neurological Association [EFNA] and is being continued to teach patients how to use the theoretical knowledge gained on these processes, and the wider research and development cycle, in a more practical way.

This time the TINA took place under the theme Value - Patient Preferences and Perspectives and was open to neurology patient advocates from across Europe. Dystonia Europe Board Member - Adam Kalinowski participated in this event to gain knowledge to be a more effective advocate for patients with dystonia. The central focus of this workshop was to explore patient engagement in Health Technology Assessment [HTA] across Europe – with a particular emphasis on the specificities in the field of neurology.

Health technology assessment (HTA) refers to the systematic evaluation of properties, effects, and/or impacts of health technology. It is a multidisciplinary process to evaluate the social, economic, organizational and ethical issues of a health intervention or health technology. The main purpose of conducting an assessment is to inform a policy decision making.

Considering the definition of health technology, as the application of organized knowledge and skills in the form of medicines, medical devices, vaccines, procedures and systems developed to solve a health problem and improve quality of life. (World Health Organization www.who.int).

On the first day, Donna Walsh - EFNA Executive Director opened the event by discussing EFNA's ongoing project on neurology patient engagement in the HTA process.

Donna pointed out that there are channels of patient engagement in many countries, but we are not sure if this involvement has a real impact on the final decisions. She added that in neurology, real engagement is really important. Many of the neurological disorders are chronic but fluctuating and it is therefore very difficult to illustrate the cost-effectiveness. Also, because

the symptoms are often secondary (eg pain, fatigue) can not be directly measured and the involvement of patients is needed.

She asked the upcoming speakers to consider how we can ensure that we value what matters most to patients.

The first speaker was Dr Iñaki Gutierrez Ibarluzea (Vice-Chair HTAi & Knowledge Manager, Osteba, Basque Office for HTA, Ministry for Health, Basque Government) who spoke about value beyond cost effectiveness. He explained the subject by showing very simple examples. This presentation was to help us answer the question: What can we as patient advocates be doing to ensure that we are capturing the value of new treatments/services (from a patient perspective) – and how can this be fed into the decision-making process?

After the break Prof. António Vaz Carneiro (Head of the Centre for Evidence Based Medicine & International Consortia for Health Outcomes Measurement [ICHOM], Cochrane Portugal) discussed 'Developing and Integrating Patient Relevant Outcome Measures' and presented the project ICHOM – non-profit organization with the purpose to transform health care systems worldwide by measuring and reporting patient outcomes in standardized way.

The next speaker explained what are Value Added Medicines. Prof. Mondher Toumi (Professor of Public Health, Aix-Marseille University) began with the definition of Value added medicines: *"medicines based on known molecules that address healthcare needs and deliver relevant improvements for patients, healthcare professionals and/or payers"*.

Then the professor talked about: What innovation is and whether it must cost a lot of money? What are the benefits of value added medicine? Why do value added medicines pose a problem for HTA and what can be done? How can patient advocates help bring about changes and push for innovative approaches to ensure value added medicines can be accurately assessed by decision-makers?

The first day of the event was ended with a panel discussion with all speakers, including questions from audience.

EU Activities

Day Two of the workshop featured a joint session hosted by EFNA with the European Brain Council [EBC]. This was moderated by John Bowis (former British Conservative MP and MEP).

The session began with Patrice Boyer (Vice-President, European Brain Council) presenting the Value of Treatment for Brain Disorders project and posed the question "How do we foster a new paradigm in value based, innovative, patient-centred healthcare?"

Then the topic was covered by representatives of various 'sectors':

- The European Policy-Maker
Flora Giorgio, Head of Sector Health Technology Assessment, European Commission
 - The Industry
 - Nuno Silverio, Director of Market Access & Governmental Affairs, Merck
 - Caroline Daly, Associate Director, Public Affairs | Patient Advocacy, Biogen
 - The Patient
Donna Walsh, Executive Director, European Federation of Neurological Associations
 - The National Regulator
Maria do Céu Machado, President, INFARMED - National Authority of Medicines and Health Products
- After this session, participants took part in a guided tour of the Champalimaud Foundation - private biomedical research foundation, created in 2004 according to the will of the late entrepreneur António de Sommer Champalimaud, where the workshops were

held. The mission of the Foundation is "to develop programmes of advanced biomedical research and provide clinical care of excellence, with a focus on translating pioneering scientific discoveries into solutions which can improve the quality of life of individuals around the world." The foundation undertakes research in the fields of neuroscience and oncology at the modernistic building designed by the architect Charles Correa, "...seeks to raise architecture to the level of sculpture, sculpture to the level of beauty and beauty to the level of therapy – in order to honour the centre's work."

The workshop finished with a group exercise; mapping next steps for EFNA Training Initiatives for Neurology Advocates (TINA), with feedback on TINA initiatives to date and an assessment of the current training/capacity building needs of neurology patient groups. This two-day workshop definitely explored patient engagement in Health Technology Assessment across Europe, with a focus on the most Patient Relevant Outcome Measures and how these can be better integrated and reflected in the decisions taken to reimburse new treatments.

Certainly the topic of HTA could be very difficult, for many Patients Advocates who often have no academic titles and are "simply patients". Therefore, we thank EFNA for giving us the opportunity to raise our knowledge through this type of workshops.

*Adam Kalinowski
Board Member
Dystonia Europe*



*The participants
at the TINA
workshop in
Lisbon*

EFNA / BMP UPDATE

It's been a busy start to 2018 for the European Federation of Neurological Associations [EFNA].

Training Initiatives for Neurology Advocates

Already, there has been two workshops as part of its Training Initiatives for Neurology Advocates [TINA]—with both including dystonia delegates.

The first was another national workshop in Romania, to celebrate Brain Awareness Week 2018. This focused on the brain, cognition and personalized medicines.



EFNA workshop in Romania

The second was a pan-European event at the Champalimaud Foundation in Lisbon which explored patient preferences and perspectives on 'value'. This two-day meeting was held in partnership with the European Brain Council, and featured a joint session to discuss the EBC's Value of Treatment study. Other presentations focused on Health Technology Assessment, Patient Reported Outcomes Measures and Value Added Medicines.

Reports and presentations from these events can be accessed at: <https://www.efna.net/tina/>

The next workshop will take place in Berlin on July 6th and 7th and will explore Science for Advocates, in partnership with the Federation of European Neuroscience Societies. The aim is to upskill advocates in how they can access, understand and communicate credible scientific evidence to improve their advocacy activities.

There will also be a regional meeting for central and eastern European countries in Bucharest on October 14th and 15th. The theme is 'Cooperation Beyond Borders' and it will explore how EU initiatives can be leveraged and implemented at the national level – in terms of funding and policy.

MEP Interest Group on Brain, Mind and Pain Disorders

In the first half of 2018, there have been two meetings of this MEP Interest Group.

The first took place in February and focused on how the EU could #MakeWorkWork for young people living with brain, mind and pain disorders. The second explored how Patient Relevant Outcome Measures could be optimized to ensure strong economies and sustainable healthcare systems. The reports of these meetings can be found at: www.brainmindpain.eu

The final meeting on 2018 will take place on November 21st and will explore the Future of Healthcare in Europe for Brain, Mind and Pain. The aim will be to assess the progress of the interest group during the current parliamentary term, and to discuss where the policy focus should lie in advance of, and following, the EU election in 2019.



*BMP meeting
MEP Marian Harkin*

Young People and Health Advocacy

In 2018, EFNA has focused on raising awareness of the issues affecting young adults (18-35) living with neurological disorders. The results of a survey conducted in recent months will be disseminated on World Brain Day 2018 (July 22nd) via the #lifegoals vs. #brainlifegoals social media campaign. The aim will be to highlight the goals of those living with brain disorders in comparison to those who are not affected. The dystonia community are encouraged to join in! Keep an eye on our website to find out more closer to the date: <https://www.efna.net/young-advocates/>

Preliminary survey results were presented at the annual congress of the European Academy of Neurology, at EFNA's stand in the exhibition centre. Dystonia Europe board member, Adam Kalinowski, was one of the young advocates manning the stand.

On November 19th and 20th in Brussels, we will be hosting a workshop for young advocates – aged 18-35. We will explore the theme of: Health Advocacy in the Digital World, and we would encourage young people living with dystonia to come along.

Wider Engagement

EFNA has also been busy representing its members externally.

For example: The Annual Congress of the European Academy of Neurology from June 16th to 19th, saw an EFNA stand in the exhibition centre, a special session, presentations at the Scientific Theatre, patient choice sessions, patient participation on the scientific panels and taskforces, EFNA representation on the training & education and communications committees, meetings with the leadership and so on! EFNA's own general assembly took place to coincide, with active participation from Dystonia Europe throughout.

EFNA's annual partners meeting will take place on Friday, September 21st in Brussels – with a dinner the evening before. Here there will be discussions on the operational plan for 2019 – and the new strategic plan which will come into effect in 2020. And of course the perspective from the Dystonia community will be welcomed and integrated into the work!

Donna Walsh
Executive Director
EFNA



Donna Walsh

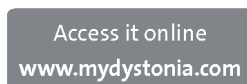


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Jump for Dystonia

Jump for Dystonia



Anna Gray from the UK



Kai and Phoenix jumping off daddy's truck in Miami



Yvonne Maxwell from Ireland



Carina Mok from Ireland



Carina Mok's daughter Alwex with partner and friend jumping at the Olympic Museum in Lausanne, Switzerland.

Meet Dystonia Europe Board Member Adam Kalinowski

Hello everyone, My name is Adam. I am a Board Member of Dystonia Europe and Board Secretary of the Polish Dystonia Association. I am also a founder of a Facebook support group for dystonia patients and I run a website called "Dystonia Good Story". I am Polish but I live in Ireland.

Paradoxically, my work as a Patient Advocate began in the most difficult period of my life. I noticed the first symptoms of dystonia right before my final high school exams, when I was 22 (I'm 34 now). It began from shaking of the head in stressful situations. Then, when I started my first job, my neck muscles started to cramp and turn my head to the right. I decided to talk to my mom about what happened to me. Soon afterwards I visited a neurologist who diagnosed my condition as cervical dystonia.

I did not break down. I was glad that I knew what caused my problems and that there was a method to alleviate the symptoms. I got my first botulinum toxin injection which worked well for me. The symptoms did not disappear entirely but for the next 8 years I was able to work and live an almost normal life. I moved to Ireland because I couldn't find a well-paid job in Poland. In Ireland I worked, passed the driving test and bought my first car. Fascinated by the Irish landscapes, I passionately travelled around the island and particularly enjoyed mountain climbing. My neck was still far from ideal and I had a lot of complexes about it but thanks to botulinum toxin injections I felt no pain and the symptoms were so mild that the people around would not notice them.

In 2016, the injections stopped working for me and my head was turning more and more to one side. I learned that my body was producing antibodies to the toxin and that I had developed resistance to it. With time, my head was permanently turned to one side but my brain was telling the muscles to pull it further, as if it wanted to twist my head around. The pain became unbearable. I had to quit work, I couldn't drive a car, I stopped meeting people and travelling was not a pleasure anymore. Dystonia took everything away from me. In that difficult period of my life, I really

needed to talk to someone who would understand me. I also needed information which I could not find anywhere, so I decided to launch a support group on Facebook for people with dystonia in Poland. I didn't realize at the time how big a need there was for such support. The group was growing fast and today has nearly 350 members and is an official support group of the Polish Dystonia Association.

Through the group, I met the president of the Polish association and we began to work together. Soon afterwards I was nominated and elected a secretary of the association's board. Around that time I got interested in the MyDystonia application, a digital diary for dystonia patients. The application is not available in the Polish language so I decided to create video tutorials with Polish translation to help Polish patients use the application in the English language.

Dystonia Europe quickly noticed my videos on the Internet and invited me to a meeting of the application ambassadors and I became MyDystonia ambassador to Poland.



Adam Kalinowski



Adam Kalinowski

My cooperation with Dystonia Europe was gradually developing and I finally was nominated as a candidate for the board. In 2017, during the general assembly of Dystonia Europe, my nomination was formally approved. Today, as a DE board member I am responsible for coordinating the activities of MyDystonia ambassadors across Europe.

Around the time of my appointment, a new hope occurred for the alleviation of my dystonia symptoms. My neurologist told me that a new type of botulinum toxin was available which could be effective in my case. I began to receive injections with botulinum toxin type B. From my support group I also learned about craniosacral therapy which helped some people with cervical dystonia. I decided to try it and thanks to the combination of the therapies and the new toxin type, I was able again to look straight ahead without holding my head with my hands. The pain was also gone al-

most entirely which was the most important to me.

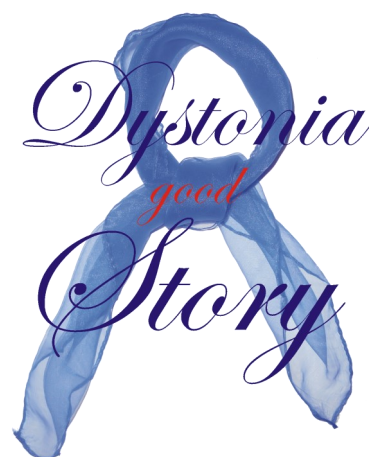
Because of a long-term medical leave my employer discharged me. Then I decided to change my career and start working online. I began to learn about internet marketing, in particular the social media marketing. I set up my own company.

Today, my neck is still not good but I believe that the exacerbation of my condition was for some purpose. I found my mission in working for the patient organization. I attend many conferences and workshops across Europe to develop my Patient Advocate's competences. After spending eight years doing a job which I didn't like, I finally do the things that give me pleasure. I cannot drive a car yet but I can climb mountains again.

My personal experience taught me that the most important thing is never to give up and look for inspiration from other patients who successfully dealt with dystonia. I founded a website called "Dystonia Good Story". I wanted to find people who managed to overcome the limitations caused by dystonia and publish their stories on my site. The stories are meant to inspire other people and give them hope to return to normal life. If you have such a story and wish to share it with others, please get in touch with me on dystoniastory.com.

Always dream. Never give up!

Adam Kalinowski
Board Member
Dystonia Europe



From one of
Adam's hiking
trips in Ireland



Around Europe and Beyond

France

Lifting the Lid

Professor Brigitte Girard is a specialized ophthalmologist located in Paris, famous in dystonia and blepharospasm.

She's the Vice-President of AMADYS (French dystonia association) Scientific Committee for many years. She's so dedicated to her patients and her field of work that she has decided to write a book on blepharospasm during her spare time and holidays!

Her book reaches different goals: to raise awareness of blepharospasm, the second largest form of dystonia; to help doctors to identify this rare disease and reduce misdiagnosis; to support patients when they need to explain their symptoms or when they feel alone or misunderstood.

"Lifting the Lid" was first published in French ("Mots pour Maux") in September 2017, for the AMADYS 30th anniversary celebration. It was published in English just in time for the Dystonia Europe 25 year anniversary this year.

It will be available for free for the members of Dystonia Europe.

We look forward to see translations in other languages as well as audio recordings.

We thank Prof Girard for this huge work and Merz for their full support for this project.

To order the book, contact your national dystonia member organization or Dystonia Europe at: sec@dystonia-europe.org

We hope you will enjoy the book! Don't hesitate to order some copies and participate in raising awareness on blepharospasm!

*Edwige Ponseel
AMADYS President
Dystonia Europe board member*



*From left:
Prof Brigitte Girard
and
Edwige Ponseel,
AMADYS President
Photo: Stephan Röhl*

Germany

Dystonie-und-Du

On October 14 2017, former members of the self-help group Mannheim / Ludwigshafen decided to found a new SHG: the group Rhein / Neckar. At the same time, the plan to create a new association for people suffering from dystonia matured.

Finally, on November 11, Evelyn & Volker Kreiss, Elke & Horst Roth, Susanne & Edwin Kerschbaum, Dr. Anja Dellmann and Daniela Jäger met in Mannheim to found the association „Dystonie-und-Du“ ("dystonia-and-you"). Since then, the following SHGs have been formed within the association:

Rhine / Neckar
Karlsruhe
Heilbronn and Schwetzingen
Nationwide the SHG "deep brain stimulation" group
Berlin, Hannover and Dresden will follow later this year

Initially being limited to the state of Baden-Württemberg, the preparations for going nationwide are now in full swing. Our goal is to be a federal association from 2019. Therefore we have quickly removed the initial "BW" in the club name and logo, so that brochures, business cards, roll ups etc. will not have to be changed and redesigned next year.

We, as all of you, have made our mission to help people with the disease dystonia, to support them and to communicate with each other. Our motto is: Not lonely - rather together

And: not the association, the person affected by the disease is important.

Patients first.

Six of our seven board members are provided with dbs and therefore the main focus of our association is the Deep brain stimulation.

We are glad, proud and happy to have already gained many members. Especially in the beginning the costs and expenses are high. When we hosted our first big event in April 2018 in Bad Herrenalb, we did not know to what extent the Health insurance companies and the industry would participate in it.

But we took the risk of having to cover the costs ourselves deliberately in the interests of all patients to quickly proceed forward.

Despite the headwind coming from certain directions, we have continued to go our own way. We have mastered this with the knowledge of the trust of our members and we hope to be able to continue this journey with our members.

We are already looking forward to November, 10 2018, when we will host our "anniversary event" (one year of DyD) in Karlsruhe under the motto "... about dystonia ...". More information about this event can be found soon on www.dysd.de.

Volker Kreiss
President

(translated by Juliane Halsch)



President of Dystonie-und-Du Volker Kreiss

Photo: Stephan Röhl

Ireland

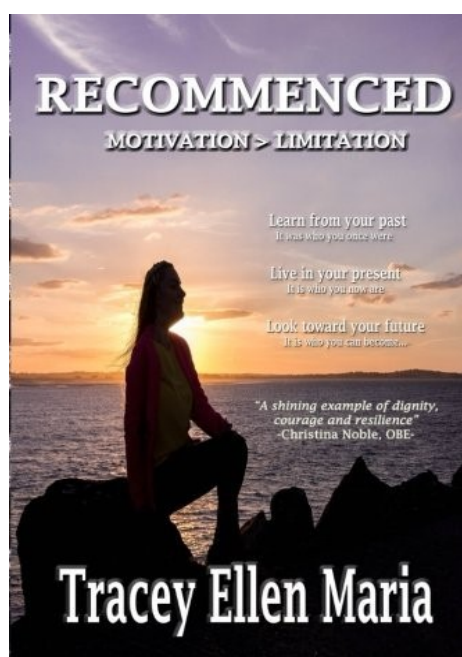
Book launch: Recommended

My name is Tracey McCann and I was born in Dublin, Ireland in 1988. I was a healthy and able-bodied child, who upon birth showed no indications of ever having anything other than a 'normal' life. However, when I was 8 years old my life took a massive turn when I was diagnosed with a disability known as Rapid On-Set Muscular Dystonia. This disability rocked both the lives of my family and me as we had to come to terms with the sudden reality of my situation.

Presently, I am a 30 year old woman who has experienced many moments of negativity, social isolation and self pity. I have also however, experienced positive moments and am now actively involved in a large network of people who all share the same goal as myself, making our own lives and everyone who we meet, meaningful and positive.

I am a Best Selling Author, Public Speaker, Life Coach, Disabled Advocate and Travel Entrepreneur. I have travelled to 16 countries within the past 5 and a half years. Some of these countries have been based within the continent Europe; while others have been further afield, e.g. Australia, New Zealand and even Panama.

My book is called "Recommended: Motivation > Limitation" By Tracey Ellen Maria, which is my pen name.



Tracey Ellen Maria

This book is available for purchase on Amazon. It was a bestseller within the first 48 hours following its launch.

I am also, as I have said above, a public speaker. I perform this task through the help of assistive technology. You can have a look at some of my talks that I have posted on my website.

www.traceyellenmaria.ie

Nothing is impossible, unless you yourself believe it to be.

"Metamorphosis is not just reserved for the moths and the butterflies" -

Tracey Ellen Maria
Ireland

Italy

Run 4 Dystonia in Milan

On April 8 the 18th edition of the Milan Marathon took place on a warm and sunny spring Sunday. It consisted of 2 different races, with the same itinerary of 42 Km. : one classic agonistic marathon and a relay race organized by Charity Program, a great solidarity project created and supported by Milano Marathon , which allows persons to run for a non-profit association, helping it to collect funds.

The relay race was divided into 4 sections, each between 7 and 13 Km and was reserved to non-profit organizations. They could buy runners registrations at a special rate, and give them to a team, which then donates a sum or takes part in the fundraising on “Rete del Dono”, the largest platform in Italy for crowdfunding and personal fundraising. This event had a great success. There were 6900 runners for the agonistic race and more than 3000 teams were registered for the relay race.

Our “Associazione per la Ricerca sulla Dystonia” has participated with 6 teams (with 4runners each). The persons who have accepted to “ run 4 Dystonia” are runners who in some cases even don’t know the disease, but agreed to donate a sum for our project about phisiotherapy (training some physioterapists and specialising them in dystonia). The runners were supported by friends and relatives.

There were around 100 persons gathered by A.R.D motto: “Insieme si può” (together we can).

A.R.D. had a special runner too, Roberta Valeri. She is a Roman lady who has always loved and practised sports, such as swimming, cycling, and running. Some years ago she began to have symptoms of dystonia, starting from the right foot and then involving the whole right side of her body, which eventually compelled her on a wheelchair. She decided to have a DBS implantation, and in May 2017 she had it done at the “Istituto Besta” in Milan. Roberta had a very good recovery and with determination and strength of mind she began to train again as a sports woman. In Milan she ran a long section of the race (11,7 km) crossing the finishing line tired, but very happy and proud of herself! We are all proud of her strong power of will. She is a very good testimonial for A.R.D and for all people living with dystonia.

*Maria Carla Tarocchi
Vice President, ARD
Rome, Italy*



Annual Meeting of the Associazione Italiana per la Ricerca sulla Dystonia

On February 3, 2018 A.R.D. held its annual meeting, hosted by Professor Alberto Albanese at the "Istituto Ospedaliero Humanitas" in Rozzano near Milan.

Usually our annual meeting is divided into two parts. During the first part in the morning some speakers illustrate some different aspects of dystonia. After the lunch break the General assembly for members is held.

The title of this year's meeting was "Dystonia beyond a motor disorder" as we wanted to focus on some alternative therapies and different strategies of how to manage the disease.

Dr. Antoniangela Cocco from "Istituto Humanitas" presented her study about "Effects of repetitive Transcranial Magnetic Stimulation in cervical dystonia"

The stimulation is given by a small plastic cap on the head, which leads a light electric current to the cerebral cortex and may reduce the excessive excitability connected to dystonia. As this study is still in progress, Dr.Cocco asked for some volunteer participants.

Dr. Anna Castagna from "Istituto Don Gnocchi" in Milan, spoke about "A multidisciplinary care for dystonia patients". This approach is used in her hospital, where a team composed by neurologists, physiotherapists, psychologists, orthopedists and speech therapists take care of the dystonia patient using therapies like motor learning, stretching, biofeedback techniques, relaxation training, and cognitive behavioral therapies. It is the so called "SPRINT approach - "Sensorimotor/Perceptive/Rehabilitation/INTegrated".

Dr. Wolfgang Ulrich, a psychologist working in her team illustrated a "Mind-body therapy to stimulate new learning for dystonia patients" starting from your own body as a source of self-esteem.

Barbara Meda from Merz illustrated the app MyDystonia, which was created 3 years ago. Unfortunately the APP does at present not have as many users in Italy as in other countries. She illustrated the app, showing how easy it is to use the digital diary on a daily or weekly basis. You capture physical symptoms, exercise, pain etc and before you see your treating neurologist you can create a report which demonstrates your well-being over time.

There were two young neurologists who presented their studies. One was by Dr. Giovanni Flamma from "Civil Hospital of Senigallia", Ancona. With his "Neuropsychiatric dimension of focal dystonia: a qualitative analysis" he won the 2017 A.R.D. Award for "Best study about dystonia by young doctors". His study analysed the psychic symptoms

of 63 dystonia patients, examining how much their quality of life is affected by the disease. One finding is that botulinum toxin injections improve quality of life but do not reduce anxiety and depressive disorders.

Dr. Chiara Scaratti from "Istituto Carlo Besta" in Milan presented her "Experiences of life - DBS Stories". This is a specific project about DBS in young people with dystonia. It is a pilot study with a small number of patients followed by "Besta Neurological Institute", looking at the quality of life and the body experience of patients who underwent Deep Brain Stimulation when very young. Now they are teenagers or adults and the study examines the impact DBS has had and has on them. There are very few studies on children with dystonia.

The last two speakers were dystonia patients who have faced and now manage their disease using alternative therapies as well. The journalist Paola Emilia Cicerone was diagnosed with blepharospasm but did not want botulinum toxin injections. Instead she used acupuncture, psychotherapy and mindfulness meditation. At present she has no longer any symptoms, and she does not know whether she has totally recovered or not. She wrote a book "Clandestine blindness" where she describes her experiences.

ARD member Maria Gabriella Manfredini had serious dystonia symptoms in her arm and could not use it any longer. She went to "Istituto Don Gnocchi" in Milan where she had some botulinum toxin injections. She began to practise Tai Chi, the Chinese martial art and gymnastics, which is also an active way of meditation. She felt she could improve her body control and now, after three years, she has totally recovered. She came to our meeting with her Tai Chi teacher (who is black belt 2° Chieh) and both performed some Tai Chi exercises for ten minutes in front of us, with harmonious movements and very high control of the whole body, which is a great success for somebody with dystonia. Mrs. Manfredini said that Tai Chi allowed her to restore muscle tone, agility, breath control and balance.

Around 80 persons took part in the meeting, most of them were A.R.D. members coming mainly from Northern Italy. Some were new members who had never participated to such an event. They were all very glad to be able to attend a meeting, where all the focus was on dystonia. During a whole day they could learn and better understand the disease as well as meeting others in the same situation.

*Maria Carla Tarocchi
Vice President, ARD
Rome, Italy*

Around Europe and Beyond

Norway

Norwegian Dystonia Association 25 years

The week after the Dystonia Europe 25th Anniversary events, NDF, the Norwegian Dystonia Association, held its 25th Anniversary celebration and Annual General Assembly at hotel Olavsgaard, just outside of Oslo.

75 dystonia patients and family members from across Norway had come to the event.

Saturday morning, after registration, NDF Chairman Johann Arnfinn Warvik, welcomed everybody to a weekend of celebrations. He introduced his team the NDF Board: Vice Chairwoman & Treasurer Sissel Buskerud, board members: Inger Johanne Nielsen, Line Mathiesen, Tove Nielsen and Rolf Villanger, who had written a dystonia poem especially for the occasion, which he read to the audience.

Johann welcomed the international guests: Mette Spangsborg, Vice Chairwoman of the Danish Dystonia Association, Bengt-Erik Calles, Chairman of the Swedish Dystonia Association and from Dystonia Europe, President Merete Avery and Executive Director Monika Benson.

Then followed a presentation of some of the activities and projects that had taken place over the last year. There had been many regional meetings for dystonia patients in different places across Norway. Two large members' meetings are organized every year: one in the autumn, which took place in Tromsø, and one alongside the annual meeting in spring. The 2018 autumn meeting will take place in Stavanger beginning of October.

The international collaboration is important to receive information and share experiences and ideas with other organisations.

Representatives of the NDF Board took part in:

the General Assembly of the Swedish Dystonia Association last February; the 25th Anniversary event of the Danish Dystonia Association last October in Århus and the recent D-DAYS 2018 and 25th Anniversary conference of Dystonia Europe in Brussels last April.

During the D-DAYS in Brussels the Scandinavian associations from Finland, Sweden, Denmark and Norway organized an informal meeting to see how they can work more together and collaborate on dystonia subjects such as for example awareness across the Nordic borders.

NDF has also been involved in the organization of a physiotherapy course held at Ullevål Hospital in Oslo. The course was aimed for physiotherapists in the Oslo region and to increase their knowledge on physiotherapy and dystonia.



Prof Inger Marie Skogseid,

Dr Jannicke Koldeus-Falch

Lisbeth Fladby, physical therapist and Johan Arnfinn Warvik

In Norway there is a National Neurology Network which meets once a year to share experiences and ideas on how to inform and educate the medical profession better in dystonia.

Vice Chairwoman Sissel Buskerud talked a little bit about the MyDystonia App and encouraged the audience to use it. She also pointed out that there is a lot of work involved to run an organization like NDF, such as talk to members, look for sponsors, contact with authorities and many administrative tasks.

Around Europe and Beyond

The key note speaker of the day was Professor Espen Dietrichs of Oslo University Hospital who held a presentation on plasticity and dystonia. Plasticity is the ability of the brain to change throughout an individual's life - brain activity associated with a given function can be transferred to a different location, the proportion of grey matter can change, and synapses may strengthen or weaken over time. There are theories that plastic changes in the cerebral cortex as well as in the basal ganglia can contribute to cause dystonia. But the plasticity of the brain can also be used when re-learning and retraining when you have dystonia.



Prof Espen Dietrichs, Oslo University Hospital

After lunch there was an Expert Panel of two neurologists Inger Marie Skogseide from Rikshospitalet in Oslo, Jannicke Koldeus-Falch from Ahus, and physiotherapist Lizbeth Fladby, also from Rikshospitalet. The audience could ask anything they wanted to know about dystonia and there were many different questions on the various types of dystonias, different treatments and its effects. The low level of knowledge about dystonia among the GPs was also discussed and what to do about it. Monika Benson shared that this is similar in other European countries. One idea could be for the national dystonia association to connect with the association for GPs in the country.

The Norwegian Dystonia Association Board



Maybe it could be possible to be included in the program at one of their conferences and share a dystonia patient story? Inger Marie also urged for more dystonia awareness to raise awareness among the public as well as influence decision makers. She suggested that the Dystonia Association maybe should work together with Tremor patients to become a larger, stronger and more influential group.

In the evening there was an Anniversary dinner for the participants. The history of the organization had been collected and members of the NDF Board took us on a Norwegian Dystonia Patient Association journey from 1993 until today 2018. It was a pleasure to hear about all that has been achieved and how many people have been involved in leading the association forward throughout the years. Many, many thanks to all of them.

The NDF Board was presented with gifts from the Danish and the Swedish associations. From Dystonia Europe, Merete and Monika, thanked the board for their outstanding work for dystonia patients in Norway, as well as regional representatives who do an important work in their local networks supporting patients and their family members. Merete said: "it is always so positive to come to our meetings, and that is such a good feeling."

We wish NDF much success in all their important work in the years to come.

Around Europe and Beyond

Romania

Children's Joy Association represents people with dystonia in Romania and they organised a national painting exhibition with the title: ***Captive in my body***. The event was dedicated to people with dystonia and it started at the end of February. The last day of February is dedicated to being the International Day of Rare Diseases, and this day is a good occasion to draw attention to the diagnosis of dystonia. At this event, artists from Romania were invited to display their paintings, working on the vicious postures of patients with dystonia, known as the "disease that the body no longer listens to you".

We also wanted to know how this issue is seen from the outside. We chose the artistic perspective because it gives us the opportunity to see things deeper, from an angle of beauty.

Dystonia is a particularly serious neurological disorder that causes the affected people in vicious positions, involuntary movements, and even leading to disability. We hope this theme was a challenge for artists and the public, being an unusual event in Romania. This event is also aimed at raising funds from selling the 40 paintings that the artists have donated. Our Association wishes to organize a recovery workshop for patients with dystonia in Romania on 8 September 2018. The funds raised will be used for this purpose. The audience has the opportunity to watch this exhibition for 6 months at the Theresia Bastion in Timisoara, National Museum of Banat.

This event attempts to change the opinions and behaviors of Romanians, but also to remove their prejudices against various people with specific problems.

The Romanian dystonia association aims to highlight the inner strength of the affected people by continuing to fight for this difficult diagnosis in a society where



outer beauty prevails. Even though we are different, we can not be marginalized by society.

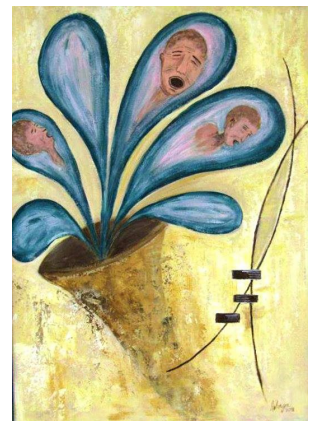
Children's Joy Association, has its headquarters in Timisoara, where it organizes regular meetings with adult patients, as well as volunteers. It can be creative activities dedicated to children, creative workshops, patient information events for medical conferences dedicated to them.

Children's Joy Association is visible at national level as a member of the National Rare Diseases Association (ANBR) and at the European level by being a member of Dystonia Europe, here represented by Mrs. Catalina Cranic, President of the Association. "We trust that together we can succeed. The ability that we have are more than the "-dis" prefix of (ability). Society needs strong people, and we are some of them. We have courage, faith and hope! "

We invite everybody to visit our exhibition, in an artistic spirit, those who, without fear, say YES to the differences between us and NO to the misconceptions!

More information is available at <https://dystonianational.ro> and <https://www.rarediseaseday.org/country/ro/romania>

*Catalina Cranic
President
Children's Joy Association*



Events

2018

July

20 25th Anniversary Conference, DDG, Kassel, Germany

21 World Brain Day

September

1-30 Dystonia Awareness Month

26-29 23rd Congress of ESSFN – European Society for Stereotactic and Functional Surgery, Edinburgh, Scotland

28-29 5th Toxins Nordic Congress, Örenäs, Sweden

October

5-9 MDS – International Parkinsons and Movement Disorder Society Congress 2018, Hong-Kong

19-21 MyDystonia Ambassador Meeting, Dublin, Ireland

2019

January

16-19 Toxins 2019, Copenhagen, Denmark

February

TBC Dystonia Europe Board Meeting & Winter Think Tank, Lund, Sweden

May

8-11 4th International Congress on Treatment of Dystonia, Hannover, Germany

TBC D-DAYS 2019, London, United Kingdom



www.dystonia-europe.org

Members

Dystonia Europe consists of 22 national member groups from 18 European countries and they are:

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

Donation & Support

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

To donate directly please use the following on-line banking details:

Accountholder: Dystonia Europe

BANK:	KBC Bank, 16a Tervurenlaan, 1040 Brussels
IBAN number:	BE83 7350 0508 5515
SWIFT/BIC	KREDBEBB

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

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

Thank you for supporting Dystonia Europe!

Medical & Scientific Advisory Board

Prof Alberto Albanese – Milan
Prof Alfredo Berardelli – Rome
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Prof Rose Goodchild – Leuven
Prof Marina de Koning-Tijssen – Groningen
Prof Joachim Krauss – Hannover
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Prof Eduardo Tolosa – Barcelona
Prof Marie Vidailhet – Paris



Management & Staff

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



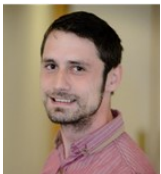
**Merete Avery,
President,
Norway**

Merete was appointed to the board of Dystonia Europe in 2013 and has held the position as Secretary from 2013-2015. Merete was appointed President at the Board Meeting, following the GA, in Rotterdam 2015 and re-elected at the GA in 2017. She was diagnosed with cervical dystonia in 2006 and was Chairwoman of the Norwegian Dystonia Association between 2010-2013. Merete is working with customer service, accounting and finance in Molde, Norway.



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

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



**Sorin Ionescu,
Board Member,
Romania**

Sorin is the founder and President of the Romanian Dystonia Association, Asociatia Distonia.

The objectives of the association are to raise public awareness, provide support and advice to dystonia patients and their families and to promote research. Sorin has a degree in social science and is a writer, painter and has been involved in social activities since 2010. He was diagnosed with Generalised Dystonia in 2012.



**Adam Kalinowski,
Board Member,
Poland**

Adam has suffered from 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 association where he currently acts as a Board Member and public relation expert. In the same year he became ambassador for the MyDystonia application. In 2017, at the Rome meeting, Adam was elected a DE Board Member. He is also an administrator of his own website called 'Dystonia Good Story'. He is Polish but he lives permanently in Ireland where he is trying to develop his own Social Media Marketing business.



**Erhard Mätzener,
Treasurer,
Switzerland**

Erhard was appointed Treasurer by the Dystonia Europe Board in November 2015. He is a member of the Swiss Dystonia Association SDG since 2008, and from 2010 he is their auditor/controller. In 2012 he was appointed the SDG delegate to Dystonia Europe. Erhard is an economist and was working as an investment advisor for a Swiss Private Bank for more than 20 years until he retired in 2002. Erhard suffers from blepharospasm.



**Edwige Ponseel,
Board Member,
France**

Edwige is the Chairwoman of the French Dystonia Association, Amadys. The objectives of the association are to provide support to dystonia patients, to raise public awareness, to promote research and to organize meetings and events. Edwige works in the purchasing and marketing 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.



**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. Alistair has had cervical dystonia for 30 years.



**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, Vice President in 2012. She has now served the maximum period on the board, but remain as an advisor to the DE board. She also serves on the DE Medical and Scientific Advisory Board and is heavily involved in the COST-funded Dystonia Research Network.



**Eelco Uytterhoeven,
Advisor,
The Netherlands**

Eelco has been a professional IT-consultant and developer since 1999. For the last 2 years he has been working as a freelance developer on several internet projects related to Dystonia Europe. Since beginning of 2016 he is responsible for the maintenance and further development of the MyDystonia platform. Eelco was asked to become a special IT advisor to the Dystonia Europe board at the D-Days 2016 in Oslo. Together with the board Eelco wants to raise the professional level of the IT projects of Dystonia Europe and assist in creating new possibilities for the future.

Partners & Sponsors

We have good working relations on a variety of topics with:

DMRF – Dystonia Medical Research Foundation, FDR – Foundation for Dystonia Research, Dystonia Coalition, EFNA – European Federation of Neurological Associations, EBC – the European Brain Council, EAN – European Academy of Neurology, MDS – International Parkinson and Movement Disorder Society.



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