

Connecting People for Dystonia

DYSTONIA EUROPE NEWS

Summer 2014
Dystonia Europe On Tour



Dystonia Europe Executive Director Monika Benson together with EFNA delegates at the joint EFNS and ENS Congress in Istanbul, Turkey last May.

www.dystonia-europe.org

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

Contacts & Secretariat

President

Robert Scholten

E-mail: robert.scholten@dystonia-europe.org

Registered Office

Dystonia Europe

37 Square de Meeus, 4th Floor,

B-1000 Brussels, Belgium

E-mail: monika.benson@dystonia.europe.org

Executive Director

Monika Benson

E-mail: monika.benson@dystonia.europe.org

Communication

Newsletter

Sölvi E. G. Engeland, Norway

E-mail: g-engela@online.no

Photos from Edinburgh:

Stephan Röhl

E-mail: info@stephan-roehl

Meet us @

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

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

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

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President's Message



Robert Scholten.

Dystonia Europe: Connecting People for Dystonia

Dear Friends,

It was an extremely busy and exciting last year, and in my role as the new Dystonia Europe President I met a lot of new people: patients, doctors, researchers and representatives of the pharmaceutical and the medical device companies. And I have to agree that it's not always easy to remember all the names, but I do my best. I met a lot of people who are very dedicated to patients and patients' daily life. We were successful in raising funds for various projects which we hope will help to improve the quality of life for dystonia patients.

In October we will hold our 21st Annual Conference and General Assembly in Paris and I look forward to meet a lot of new people. Many French dystonia patients have registered for the event and it will be a pleasure to meet and talk to them. At the General Assembly I hope to tell you more about our new slogan for the next few years: Connecting People for Dystonia.

It is my belief that we must try to connect more people for dystonia. Not only patients to patients, but also neurologists to neurologists, and researchers to researchers. This will improve and enhance our good cause and ambition: to increase awareness and knowledge, to help and support, and on a longer term, to find a cure. When connecting people for dystonia we plan to focus particularly on three items:

A Digital Platform for Dystonia

In today's society we are increasingly sharing information and experiences through internet and social media. It is therefore important that all people with an interest in dystonia easily can be connected. We would like to facilitate these activities by creating **a digital platform for dystonia** over the next few years. In Paris we will launch the first draft of this platform and I look forward to discuss how we can improve it further.

One of the features of the platform is a patient APP - a dystonia diary which will give patients the opportunity to regularly record their dystonia symptoms and daily activities, in order to better manage their condition and to communicate this with their treating neurologist.

D-DAYS

The annual Dystonia Europe Conference and General Assembly is an important occasion for interaction between member representatives. To increase these face-to-face contacts, one idea could be to combine the Dystonia Europe Annual Meeting with the meetings of national member associations. We call it the annual D-DAYS. This year the French Dystonia Association AMADYS is already participating in the D-DAYS in Paris. In 2015 the Dutch Dystonia Association and Dystonia Europe will jointly organize the D-DAYS on 2, 3 and 4 October in Rotterdam, the Netherlands.

In the next few years we will try to develop the D-DAYS to become an annual highlight for dystonia in Europe.

Awareness Campaign 2014: Jump for Dystonia

There is still a lot of misunderstanding about dystonia and it's crucial to continue the work of raising awareness and spreading information about the disease. Our next awareness campaign called 'Jump for dystonia' will be launched at the Annual Conference in Paris.

There is a lot going on and I invite you to join in this exciting journey to work for improved public awareness of dystonia, better treatments, increased research and one day, hopefully a cure.

Best regards,
Robert Scholten
President.

Dystonia Europe at the MDS in Stockholm

The 18th International Congress of Parkinson's Disease and Movement Disorders was held in Stockholm beginning of June. About 4500 people from 86 countries attended the congress where the presentations were about the latest within movement disorders. Dystonia Europe was there with a booth in the exhibition hall to distribute material, to network and connect with partners from the medical profession and from the industry. Many visitors stopped by and also contributed with a Jump for Dystonia - our next awareness campaign that will soon go on-line! One evening Medtronic hosted a networking event for about 200 invited guests, mainly neurologists and neurosurgeons, where Dystonia Europe President Robert Scholten together with EPDA (European Parkinson's Disease Association) President Knut-Johan Onarheim, were asked to give a short speech each.

The DE President Robert Scholten encouraged the guests "to join Dystonia Europe on the journey towards our 30th Anniversary and take part in the building of a digital platform for dystonia with the aim to connect, to exchange, to inform, to inspire, to give hope, to develop, to improve, and a better quality of life for all of those affected by dystonia."

The next MDS congress will be held in San Diego USA, 14-18 June in 2015.



Alongside the congress in Stockholm Dystonia Europe held the second board meeting of the year.



During the Movement Disorder Congress in Stockholm, the speakers' dinner was held at the Stockholm City Hall, the building where the Nobel dinner takes place every year. This was a great opportunity to take a photo of all female speakers who were gathered for the congress. They all hope to inspire many young female researchers to continue and develop their work within in the exciting field of movement disorders.

Dystonia Europe Attends EFNA General Assembly 2014 in Istanbul



EFNA Executive Director Donna Walsh preparing to receive visitors in the Patient Corner at the Congress in Istanbul.

EFNA, the European Association for Neurological Association, held its General Assembly 2014 alongside the EFNS & ENS joint congress of neurology in Istanbul last May. Dystonia Europe is a member of EFNA together with 19 other patient associations within neurology. President Audrey Craven opened the meeting and welcomed the delegates. After the formal business meeting where the annual report 2013/2014, the annual accounts 2013 and the budget for 2014 were approved, followed the session: "Ideas Exchange Forum". After various presentations such as: the EBC project "Year of the Brain in Europe", the EFNA project "Development of National Neurological Alliances", and the EFNA Neurology Patient Survey, there was plenty of time for the delegates to discuss and share their views and ideas regarding all projects. Dystonia Europe will follow the development of these projects.

For more information about EFNA and their activities visit their website: www.efna.net

Dystonia Europe at the joint EFNS and ENS Congress for Neurology in Istanbul

Professor Maja Relja and Executive Director Monika Benson of Dystonia Europe were present at the international neurology congress held in Istanbul last May. The congress attracted professionals within the field of neurology from all over the world.

Dystonia Europe had a booth with information about the organisation and various flyers such as the up-coming D-DAYS in Paris 2014 and in Rotterdam 2015.

Our EFNA colleagues were present in the Patient Corner, where 10 of its member organisations had the opportunity to promote awareness and spread information of their individual patient organisation and disease areas.

Another exhibitor was the EAYNT – the European Association of Young Neurologists and Trainees. This is a non-profit organization focused on networking amongst neurology trainees and aiming at supporting neurological research and education.

In advance of the congress EFNA had worked with the EFNS to include patient representatives in the relevant scientist panels/sub-committees. DE Executive Director Monika Benson took part in the meeting of the Movement Disorders Scientific Panel.



Visitors at the Dystonia Europe stand at the Congress in Istanbul.

European Academy of Neurology - EAN - Founded in Istanbul

On June 3rd 2014 the European Academy of Neurology (EAN) was founded. The new EAN is a merger of the European Federation of Neurological Societies (EFNS) and the European Neurological Society (ENS).

During its first General Assembly, the 72 institutional and individual delegates from 45 member countries of the Society elected the Officers of the Board. The results of this vote are below and the new Officers pictured:



President: Günther Deuschl, Germany, Vice President: Franz Fazekas, Austria, Secretary General: Didier Leys, France, Treasurer: Marianne de Visser, The Netherlands, Chair Scientific Committee: Antonio Federico, Italy, Chair Liaison Committee: David B. Vodusek, Slovenia, Member at Large: Per Soelberg Sørensen, Denmark.

The purpose of the recently founded EAN is to:

- increase the availability and standards of neurological services;
- advance the development of neurology as the major medical specialty caring for patients with neurological disorders;
- encourage collaboration between European national neurological societies;
- strengthen collaboration between clinical neurology and related professional and lay organisations;

- support neurological research, encourage research collaboration, and promote dissemination of research results;
- strengthen the standard, availability and equality of neurological education for neurologists and affiliated/related health professionals;
- raise awareness among the lay public, media, health care providers and other stakeholders, as well as law and policy makers about the burden and cost of neurological disorders and the benefits which clinical neurology can bring;
- collaborate with international, national and regional neurological associations and related international health organisations.

The European Academy of Neurology will base its activities on the following five values:

- Professionalism. The EAN will strive to reach the highest scientific standards and to deliver unbiased information in its research and educational activities.
- High ethical standards. The EAN will apply high ethical standards in all its activities within science, education, liaison, and administration, complying with applicable regulations and codes of ethics.
- Involvement. The EAN will strive to involve its members and collaborators in the organisation of research, education and liaison activities.
- Independence. The EAN will operate as a professional and scientific organization, independent from the political or commercial interests of external companies or organisations.
- Transparency. The EAN will provide transparency in the organisation of all its scientific and administrative activities.

The first Congress of the European Academy of Neurology will take place in Berlin, Germany June 20-23, 2015.



Neurologists and Dystonia Europe at Merz Austria Annual Expert Meeting “Science on Top”

Merz Austria’s annual meeting “Science on Top” took place last May, in Kitzbühel, Austria. On Friday evening CEO of Merz Austria Karsten Schlemm opened the 2-day meeting and welcomed the 50 participants to a weekend of presentations, sharing best practice and a workshop in hands-on-training of ultrasound. Opening speakers were Professor Jörg Müller from Berlin who spoke about “Botulinum toxin – yesterday – today – tomorrow”, then followed by Dystonia Europe Executive Director Monika Benson who shared her “Dystonia Story”. Saturday’s meeting took place at Alpenhaus, on Kitzbüheler Horn at 1600 meters. The mountain with surroundings were covered in snow and created a focused and intense meeting with lively discussions. Among the presentations were topics such as: flexible injection intervals, ultrasound guided injections, treatment failure etc. Thank you to Merz Austria: Karsten Schlemm, Bettina Zadera and Anna Lang, for the organization of a very interesting and important meeting to help improve the treatment procedures of patients in Austria suffering from dystonia and spasticity.



Merz Austria CEO Karsten Schlemm, Bettina Zadera and Anna Lang together with Monika Benson.

Great Success When the Medtronic Mission in Motion Team Organized Jump for Dystonia



Medtronic Jumps for Dystonia!

Beginning of July the Medtronic Mission in Motion Team organized a Jump for Dystonia event at the Medtronic European Headquarters in Tolochenaz Switzerland. The « Mission in Motion » team is a group of colleagues representing Medtronic as a social entity which aims to act for its community.

Nathalie Courtine, one of the initiators of the event, explains: “Our role as Mission in Motion Ambassadors is to allow all employees to fulfil the 6th tenant of the Medtronic Mission: “To maintain good citizenship as a company”. To reach this goal, we believe there is no better way than to roll up your sleeves! We organize various projects to allow employees to “put our mission in motion”, such as volunteering activities to help associations or charities, or run donation events. The successes of the last projects show that with the motivation of employees, it is possible to make a difference in our community!”

The Jumping took place in the cafeteria where people were asked to contribute with a Jump for Dystonia and have their photo taken.

Dystonia Europe's Monika Benson joined the event, and together with the Mission in Motion Ambassadors, they encouraged the Medtronic staff to jump and distributed Dystonia information leaflets and Jump for Dystonia pens. By the end of the day the team had collected 222 jumps. Medtronic contributed with € 4.-per jump to support Dystonia Europe in our work to continue raise awareness of dystonia. By the end of the day at least € 1000.- was raised. We thank the Medtronic Mission in Motion Team and all the Medtronic staff for their great jumps and such valuable support.

Boston Scientific Creating Awareness with Jump for Dystonia

Last autumn in 2013 the Boston Scientific DBS device was approved for the treatment of dystonia. About the same time BS signed a contract with Dystonia Europe to become a Gold Sponsor for the next few years.

A few months after the agreement Boston Scientific decided to bring the Jump for Dystonia initiative within the company to raise awareness about dystonia. And what a big surprise for Dystonia Europe since we did not know anything about it. The JUMP FOR DYSTONIA initiative helped Boston Scientific raise awareness about Dystonia amongst all the Company employees and their families – more than 2000 people in Europe! BS will continue this wonderful initiative since pictures are still coming in.

Additionally - € 5000 were raised among BS staff and family. The Check together with a Poster of Boston Scientific Jumps were presented to Robert Scholten and Monika Benson at a surprise event held in Paris last March. Dystonia Europe is extremely grateful to the Boston Scientific Management Team and all their staff and family for their great and generous support! THANK YOU to all of you!



We have Jumped for Dystonia!



Boston Scientific: Lisa Murphy, Michael Onuscheck, Sophie Araujo, Vincent Sourdain, Maulik Nanavaty, together with DE President Robert Scholten and Monika Benson.

Dystonia Europe Poster Prize in Physiotherapy - Hannover 2013

Physiotherapy is now considered as an associated treatment of focal dystonia. It is most commonly associated with treatment by injections of botulinum neurotoxin. Nevertheless, treatment standards and treatment guidelines in the field of rehabilitation have not yet been developed. Scales and scores to classify patients for comparison and to evaluate therapeutic effects are also needed. Treatment in the field of rehabilitation is too often based on empirical experience, common sense and low power studies rather than on controlled studies with an incontestable methodology.

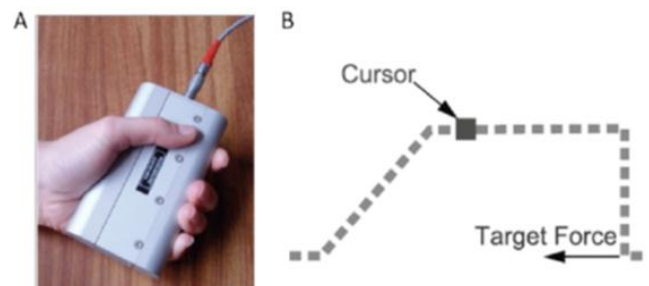
Calls for research projects, research grants and rewards for research works are a powerful encouragement to validate the most effective rehabilitative approaches. With a group of multidisciplinary researchers involving several physiotherapists from different universities (Paris V – René Descartes, Paris VI - Pierre et Marie Curie, Institut du Cerveau et de la moelle épinière and Aix-Marseille Universities), we have conducted a study on writer's cramp and presented the results at the Physiotherapy Poster session organized by Dystonia Europe at the 2nd Treatment Congress of Dystonia in Hannover in April 2013.

The authors of this poster, entitled "*Impaired bilateral control of grip forces in writer's cramp suggesting an endophenotype related to sensorimotor integration*", were Jean-Pierre Bleton, Maxime Teremetz, Marie Vidailhet, Serge Mesure, Marc Maier and Pavel Lindberg.

Previous studies on *writer's cramp* have revealed a characteristic pathological muscular overactivity and lack of fine motor control. The muscular tone disorganization increases the finger pressure on the pen body causing local pain and difficulties in moving the pen on the sheet.

Although *writer's cramp* is considered a task-specific and unilateral form of dystonia, abnormal cortical processing of sensory inputs has been found bilaterally. Behavioural evidence for a bilateral disorganization in sensorimotor processing is, however, lacking. This study has tested the hypothesis that patients with *writer's cramp* have an impaired ability to adjust grip forces according to visual and somatosensory cues in both hands.

In order to test this hypothesis we have proposed a visuomotor task of modulated degree of force, which has allowed quantifying the motor performances by the mean of a manipulandum (sensor of pressure which records the force of the hand). The subject is seated on a chair in front of the screen of a computer, holding a manipulandum similar to the one below (figure 1).



A unimanual visuomotor force-tracking task and a bimanual sense of effort force-matching task were performed by *writer's cramp* patients and healthy controls at low (5 Newtons) and great force level (10% of maximal voluntary force).

Accuracy of performance (error), force variability and time taken to release force was measured during visuomotor tracking. The grip force difference between hands was measured during sense of effort force-matching.

In visuomotor tracking, the *writer's cramp* patients showed increased error, greater variability and longer release duration than the healthy control group.

These group differences were greatest at the low force level. In the force-matching task, the patient group underestimated the force applied in the other hand, while the healthy control group overestimated it.

This study provides behavioural evidence of a similar bilateral impairment in grip force control in *writer's cramp*. Visuomotor tracking as well as sense-of-effort matching tasks were affected, suggesting a generalized subclinical deficit in sensorimotor control in *writer's cramp*. This may potentially provide a new approach to *writer's cramp* rehabilitation, where sensory inputs and fine motor control of hand pressure while writing, would be trained specially.

Thus we have, using a new behavioural task, been able to show that people suffering from focal dystonia, such as *writer's cramp*, have problems evaluating their grip force. We have also shown that writer's cramp is not a focal symptom localized in the writing upper limb but part of a larger phenomenon, which can also affect the opposite hand.

To further this study, we should extend the protocol to other forms of focal dystonia, affecting other parts of the body, such as spasmodic torticollis. Then we would be able to conclude that, if the same problem of sense-of-effort is found, it might well be associated with dystonia in general, not necessarily related to the function or location to which it is linked. This would be useful data to set up the rehabilitative training programme for focal dystonia.

The poster of this study was the prize-winner of the "Physiotherapy Poster Prize" and the team of researchers received the €500 award from Dystonia Europe, the organizer of the event. The study was published by Bleton JP, et al. in the medical journal: *Movement Disorders*. 2014 jan; 29 (1):130-4. The prize will be a financial support for further study in the field of dystonia. Presently, studies on cervical active movements in spasmodic torticollis are underway.

The results of these studies will be reported in future congresses on dystonia.

The whole research team thanks Dystonia Europe for focussing the attention on their study and giving them the opportunity to carry on with research on dystonia physiotherapy.

Jean-Pierre Bleton
Unité James Parkinson
Fondation Ophtamologique de Rothschild
Paris, France.



Jean-Pierre Bleton.

European Dystonia Research Network

(European Network for the Study of Dystonia Syndromes) Funded by **COST** (Co-operation in Science and Technology) The basic structure of the Network was outlined in an article in DE News earlier this year.

Network news for the third year of operation – 2014/15

The 3rd Grant Period has begun for the European Dystonia Research Network, and the workplan and budget is being finalised. Last year's successes were achieved despite mid-year changes by COST in the budget and the end date of the 2nd Grant period. This year, the Network try even harder to use the COST budget as wisely as possible. Dystonia Europe, as the Network Grantholder, will provide as much support as possible.

Meetings - A Steering Committee meeting was held in Stockholm, during the Movement Disorder Society congress in June, where the activities for the year ahead were discussed, along with longer-term plans for the future. Telephone conferences and further meetings of this group, and of the three Workgroups in Genetics, Clinical Studies and Animal Models, are planned for the 3rd Grant Period ending on 31 May 2015. These Workgroups will push forward the research activities in their respective areas of interest, among the many countries and dystonia specialists involved.

Training Course - A third Training Course for young clinicians and researchers will be held in Groningen, The Netherlands, in April 2015 and will be organised by Prof Marina de Koning-Tijssen. Prof de Koning-Tijssen is a member of the Dystonia Europe Managing Board and the Medical and Scientific Advisory Board. Grants will again be available to support the travel and accommodation costs of the trainees. The programme is currently being finalised and will

be announced very soon, when applications for places on the course will be invited from young scientists.

Short-term Scientific Missions (STSMs)

This area of the Network's activities allows young researchers to obtain more experience by travelling to other countries in Europe for short-term assignments on specific projects under the direct supervision of top-class dystonia specialists.

During the operational year just completed, a total of 19 grants (for a total of €44,000) were provided to scientists from Italy, Germany, Romania, Croatia, Hungary, Israel, Czech Republic, Poland and UK. The centres where they carried out their projects were in The Netherlands, France, UK, Belgium, Italy, Spain and Portugal. Prominent among the specialists who acted as hosts for these missions were members of DE's Medical and Scientific Advisory Board - Profs Marie Vidailhet, Marina de Koning-Tijssen, Rose Goodchild, Alberto Albanese, and Kailash Bhatia. Prof Bhatia's institution in London hosted no less than 8 projects.

The number of grants available was exceptionally high in 2013/2014, and a smaller number of grants have been estimated for the Research Network's work plan and budget of the year ahead.

Alistair Newton.



Profs Marina de Koning-Tijssen, Alberto Albanese, Rose Goodchild, Marie Vidailhet and Kailash Bhatia.

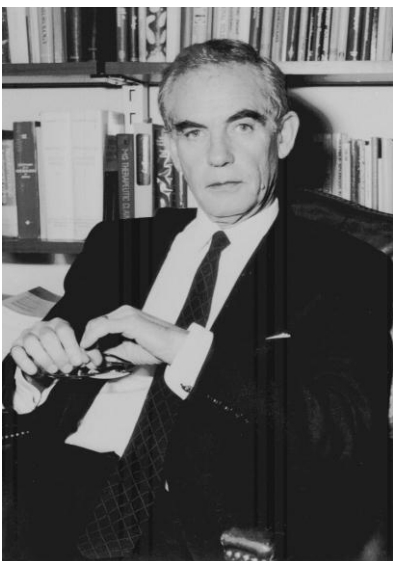
Call for Submissions for the 7th David Marsden Award – DMA 2015

The award was introduced by Dystonia Europe (DE) in 2003, and is presented every two years to stimulate research on dystonia.

Professor David Marsden (1938 – 1998), as Dean of the Institute of Neurology in London, was one of the leading neurologists in Europe. In the early days of scientific knowledge of dystonia, he pioneered interest in the syndrome among his colleagues across the world and especially in Europe. DE continues to honour the enormous part he played in developing greater clinical expertise on the condition, and encouraging more attention in scientific research. The Award of € 10,000 is intended to encourage further research into dystonia in all European countries, especially by young scientists.

Dystonia Europe is grateful for the generous sponsorship we have received for this Award since 2003, particularly by Ipsen Pharma in 2011 and 2013, and their continued support for the upcoming awards of 2015 and 2017.

For more information about the award and the application process please visit the DE website at: <http://dystonia-europe.org/activities/awards/>



David Marsden (1938 – 1998)

Foundation for Dystonia Research Invests 600.000 Euro in Basic Research



*Peter Raeymaekers,
Science Consultant, FDR.*

The Foundation for Dystonia Research (FDR), based in Belgium, supports and promotes scientific research related to dystonia. “Research is the starting point in our endeavor to find a better treatment and hopefully a cure for dystonia”, says Greet Ruelens, who is, years after the diagnosis, still seeking for an optimal treatment to improve her quality of life. Greet, together with her partner and former fashion designer Lieve Van Gorp, founded FDR in 2009.

Last year, FDR launched an international call for research projects related to the pathogenesis of primary dystonia and dystonia plus syndromes. “The mechanisms leading to most forms of dystonia are still poorly understood, despite being the third most common movement disorder”, says Peter Raeymaekers, FDR’s science consultant. “Since most forms of primary dystonia constitute a neurophysiological dysfunction, rather than a neurodegenerative disease, it may ultimately be possible to correct the underlying defects once they are fully elucidated. Therefore, in this call for research projects we placed emphasis on illuminating the

defects causing dystonia at the molecular, cellular or systems level.” FDR was aiming at three projects with a foreseen maximum budget of 200.000 euro per research proposal.

A unique feature was the ‘collaborative’ nature of the research projects. In order to be eligible for support, projects had to be submitted by two or more research groups working jointly on the project. The coordinating lab had to be based in Europe, participating research centers could be located in Europe, the US or elsewhere.

Ultimately the FDR Science Committee selected the following proposals: ‘The role of the dopaminergic signal transduction pathway in primary dystonia in animal models’, a project submitted by Prof. Antonio Pisani from the University of Rome Tor Vergata (Italy) together with Prof. Kathrin Grundmann, University of Tuebingen (Germany) and Prof. Rose Goodchild, University of Leuven (KU Leuven)/ Vlaams Instituut voor Biotechnologie (VIB) (Belgium). The collaboration will focus on how deficiency of GNAL – one of the recently discovered primary dystonia genes - affects striatal electrophysiology and information processing in a novel rat model of primary dystonia. Furthermore, they will test which elements of striatal signal transduction are a common node in primary dystonia pathogenesis in existing mouse models of dystonia. The project will benefit from the different expertise of each group: electrophysiology (Pisani); molecular genetics, generation of rodent models and behavioral analysis (Grundmann); and biochemistry and functional genetics (Goodchild).

The second project, submitted by Prof. Ulrike Kutay from ETH Zurich (Switzerland) and Prof. Thomas U. Schwartz from MIT in Cambridge (USA) will focus on the structural and biochemical analysis of Torsin 1A (TOR1A). A three base pair deletion in TOR1A was the first identified primary dystonia mutation, discovered already in 1997. The Kutay/Schwartz collaboration intends to find and characterize new binding partners of

Torsin1A, characterize the spatiotemporal relationship between wild type and mutant Torsin1A (with and without binding partners) and determine the crystal structures of these protein complexes. The investigators will approach these challenges using a comprehensive set of cell biological, biochemical, and structural tools. These include pulldown methods for substrate identification established in the Kutay lab and various imaging techniques including fluorescence recovery after photobleaching (FRAP). The Schwartz lab will use its extensive expertise in X-ray crystallography to tackle the difficult problem of identifying the three dimensional structure of Torsin1A. The two groups have worked together very successfully in the past, and have published important results on the structure and function of the LINC complex, a potential substrate for Torsin1A.

The third project will be using exome sequencing and abnormal temporal discrimination, a mediational endophenotype for dystonia, to identify new genes in adult onset primary torsion dystonia. This project is a collaborative study between Prof. Michael Hutchinson from St. Vincent’s Hospital in Dublin (Ireland) and Prof. Laurie Ozelius from the Icahn School of Medicine at Mount Sinai (New York, US). The temporal discrimination threshold (TDT) is the shortest time interval at which two stimuli appear asynchronous. According to research performed in Prof. Michael Hutchinson’s group an abnormal TDT is an endophenotype of gene carriage in primary dystonia. The aims of this research project are to identify, by exome sequencing, genetic mutations responsible for the commonest forms of cervical dystonia and validate the TDT endophenotype.

Also an ‘Encouragement grant’ of 20.000 euro was given to Prof. Monica Holmberg from Umeå University (Sweden) and Prof. Laurie Ozelius from the Icahn School of Medicine at Mount Sinai New York, US) to identify the DYT21 gene using next generation DNA sequencing. The DYT21 gene was recently mapped to chromosome 2q21.1-21.3

using a large North-Swedish family. The dystonia gene in this family is of a mixed type and shows an unusually high penetrance, with as many as 90% of the carriers expressing the phenotype.

All projects have started at the beginning of 2014 and preliminary results are expected in 2015. The call was an unexpected success.

Greet Ruelens and Lieve Van Gorp: “We had expected five to seven applications. By the end of the day, we received 19 research proposals, submitted by a total of 52 research teams from 15 different countries. We were certainly overwhelmed by this tsunami of proposals. It gave the five members of FDR’s Science Committee more work than originally anticipated and it was a challenge to convince enough peer reviewers to assess these proposals. On the other hand, it gave FDR the opportunity to be selective and to start partnerships with top scientists around the globe who devote their time and effort to dystonia. Although, we also realize that we had to refuse some high quality and interesting proposals.”

“I find it, as a patient, very important that this research will lead to a better understanding of dystonia”, concludes Greet Ruelens. “But the brain is a very complex organ. The step from new physiological insights to a new treatment is gigantic and will take many years. That is not a nice thought. But the fact that FDR can put things in motion, that we can work with leaders in the field and that these investigators are willing to collaborate between countries and continents, creates hope and makes the disease for me much more acceptable.”

More information about FDR and its activities:
www.foundationdystoniaresearch.org

*Peter Raeymaekers,
Science Consultant, FDR*

FDR and the Art Project ‘1/125 sec’ of Photographer Lieve Blancquaert

Belgian photographer Lieve Blancquaert (www.lieveblancquaert.be) in her own intense and very personal way portrays six persons with dystonia. ‘1/125 sec’ refers to the shutter speed she used to slide in between the strange and often uncontrolled movements of her models to catch a glimpse of the person behind the dystonia. A search that proved difficult at times... perfectly illustrating the impact the disease has on their everyday lives. More portraits at: <http://www.foundationdystoniaresearch.org/about-fdr/cases>.



Greet



Medina

Greet was a dynamic and energetic entrepreneur. For years, she travelled to Tokyo, Paris and New York building her business. Dystonia made her ‘dependent’. Now, even leaving the house requires help and preparation.

Medina 16 years old, especially loves the photos in which she’s sitting up straight with her sparkling eyes wide open. Photos as beautiful as that don’t come along often, she says. Usually her eyes are closed and sitting up straight without help doesn’t happen all that often either.

Comic Collaboration: Superheroes to the Rescue



Children are able to demonstrate a remarkable resilience when confronted by disability and medical conditions. Despite these often high levels of resilience, studies have revealed that medical procedures are the most fearful and distressing aspect of their condition¹. Supporting children to improve their overall experiences of procedures, from an emotional perspective, is becoming an increasingly high priority for health care professionals in order to reduce distress and trauma.

Due to the vast array of conditions and procedures, there is often a lack of information available for children and families. This is particularly true of rarer conditions and surgeries and a prime example of this is childhood dystonia and deep brain stimulation surgery. Deep brain stimulation (known as DBS) is a form of functional brain surgery and involves an operation to insert a brain “pacemaker”-like device which sends electrical impulses to specific parts of the brain. DBS in select brain regions has been shown to provide therapeutic benefits for otherwise-treatment-resistant movement disorders.

A recent qualitative study² has revealed that there is frequently anticipatory anxiety associated with DBS surgery in children with dystonia. One young person reported that they felt “scared something was going to happen” while another child described their response to the operating environment stating, “it’s quite scary looking at (the operating equipment),

because the machine’s like a big grey block of metal and that’s really all you can see when you’re ten”. Feedback from children about their experiences of this kind of surgery has highlighted the importance of supporting children with their understanding and coping with DBS.

In response to the recognised lack of child-friendly information about DBS for children, Medtronic collaborated with Medikidz to produce a comic that would address this unmet need. Medikidz is an initiative which was set up by doctors to explain medical information to children. Medikidz have created five superheroes (such as Axon the brain specialist) and these characters are used within a comic strip style story to explain medical conditions and surgical procedures to young patients. The Evelina Children’s Hospital in London was also involved in a peer review of the comic.

The Medikidz DBS comic is an accessible way of educating children about DBS, in a humorous and child-friendly way. It takes a realistic approach, with the main character experiencing anxiety about the procedure and also provides sensory information about the surgery (e.g. experiences of pain during surgery). These have both been reported as being helpful ways of preparing children for surgical procedures³.

At the Evelina Children’s Hospital we have used the Medikidz comic with our children with primary dystonia and have found it to be a very useful adjunct to the DBS preparation process. It has been our experience that the comic brings the surgical process to life in a way that is non-threatening and easy to understand. Children and young people alike have enjoyed reading it and have engaged very well with the material. It has also provided an excellent forum for further discussion and exploring whether our patients have similar fears to the character in the comic.

We have also found the comic helpful in supporting siblings to understand DBS. Siblings often have a lack of understanding about procedures as they are usually at school while their brothers and sisters attend hospital appointments. Many siblings do present with concerns about the fact that their brother or sister will be undergoing surgery and it is important that they are given appropriate information about DBS and an opportunity to explore their anxieties. Managing the overall anxiety levels within the child's home environment can then have a positive impact on the patient's own anxiety levels. In this vein, we have used the Medikidz comic with siblings of our patients, to help explain the process to them. Again, this has been positively experienced and has given siblings an opportunity to hear, first hand and in a child friendly way, about DBS.

Well produced, child friendly information about surgical procedures is invaluable to support both children and their families with the overall surgical process and we rely on these to give patients a more positive experience and to avoid surgical cancellations. As a service, we are excited by new developments in this area, such as the Medikidz comic*, as it means providing better overall care for our children.

Dr. Jean Pierre Lin & Dr. Tamsin Owen.

*To receive a Medikidz brochure please contact Dystonia Europe (sec@dystonia-europe.org)

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Dr Tamsin Owen

is a Clinical Psychologist and Lecturer working in both the Complex Motor Disorders Service at the Evelina Children's Hospital and Royal Holloway University of London. She has a special interest in the area of paediatric movement disorders.



Dr Jean-Pierre Lin

is a Consultant Paediatric Neurologist at Evelina Children's Hospital, Guy's and St Thomas' NHS Foundation Trust in London and is also on the medical and scientific advisory board for Dystonia Europe.



"We are the Superheroes and we explain medical conditions and surgical procedures to young patients!"

Dystonia Down Under

A small group of researchers led by Associate Professor Lynley Bradnam, a neuroscientist and physiotherapist at Flinders University in Adelaide, Australia are investigating whether a novel treatment can improve the symptoms of cervical dystonia.

Transcranial direct current stimulation (TDCS) is delivered by a small electrical device that passes a weak current through the brain using electrodes placed on the surface of the head.

“Research from experiments in animals has found an area of the brain called the cerebellum is likely to be involved in dystonia, although the exact role is still unclear”, explains Dr Bradnam.

“As the cerebellum is a vital part of the brain for controlling movement, we decided to see if TDCS of the cerebellum could improve handwriting in a small group of people with focal hand dystonia or cervical dystonia. Our results for the handwriting tasks were actually quite minimal and a bit disappointing”, Dr Bradnam says. “But surprisingly, we had reports from people with cervical dystonia of a momentary ‘freeing up’ of their neck muscles after stimulation”.

To try and measure this effect, the researchers began a randomised, blinded clinical trial, where people with cervical dystonia have ten sessions of either real or sham brain stimulation delivered daily over two weeks.

Data collection is about half completed and there are no results to report as yet. However, this small research team is not letting the grass grow under their feet. This year the group began a new study where participants have twice weekly treatments of brain stimulation for 12 weeks between botulinum toxin injections. People from the initial studies were asked what they thought should be the next step for this research. Together it was decided that brain stimulation should be given over a longer period.



“We designed this as a case series,” explains Dr Bradnam, “as randomised sham controlled trials are challenging in Australia due to our relatively small population of people with dystonia. Australia has been slow to recognise and support dystonia compared to other neurological disorders. In fact, we are only just setting up our national organisation (Dystonia Network Australia, DNA) and our affiliation with Dystonia Europe is important to us”, Dr Bradnam says. “The downside of a case study design from an experimental viewpoint is that people know they are getting real stimulation which can bias the outcome.”



Research

On the other hand, it does place TDCS in a clinically relevant context by treating people regularly over an extended period”, says Dr Bradnam.

“The early results are encouraging. Our first participant had a 19 point reduction in the Toronto Western Spasmodic Torticollis Rating Scale (TWSTRS) which was independently assessed by her neurologist at two consecutive appointments”, Dr Bradnam says.

This compares well with results from large clinical trials of botulinum toxin injections, where 10 points is the average improvement 3 months after treatment.

Our cases so far have reported marked improvements in quality of life, including a reduction in pain, and importantly there were no adverse reactions during the extended number of sessions. Dr Bradnam explains that while results are encouraging, it is too soon to get excited about brain stimulation as treatment for people with cervical dystonia. We need to reproduce these results in many more people and do experiments that increase our understanding of the mechanisms underlying any clinical benefits and we need to test the most effective parameters such as electrode placement and stimulation time.

“It is important that researchers across the world collaborate in these experiments”, Dr Bradnam says.



The researchers thank the Brain Foundation Australia and members of the Australian Dystonia Support Network (ADSN) for their support.

*Ass. Prof. Lynley Bradnam
Flinders University, Adelaide, Australia.*



Finland

The Finnish Dystonia Association and Peer Support through Dystonia Clubs



The Finnish Dystonia Association was founded in 1998 with the aim to provide information about the neurological movement disorder Dystonia, and to offer support to those affected by dystonia and their families.

The national association, totally run on a voluntary basis, has now been around for 15 years and relies on the knowledge, proficiency and resources of those volunteering.

The activities of the Finnish Dystonia Association are among other things to provide local peer support. There are 20 local clubs in various parts of Finland. The association and the clubs provide various recreational activities: there are club nights, specialist lectures, as well as physical and leisure activities. The members can also take part in the activities organised by the umbrella organisation, the Finnish Parkinsons' Association. By taking part in these social activities, people with this rare disease, gain not only information and peer support, but also have the opportunity, together with others, to find new life enhancing forms of thinking and operating.

The Finnish Dystonia Association has about 800 members and we publish a bulletin every three months about our activities. The Association has two phone lines for peer support and these are operated by people affected by dystonia. There is also a forum on the website, www.dystoniayhdistys.com where you can anonymously ask questions and take part in discussions on any topic related to the disease.

In September, during the national Dystonia week, dystonia patients from all over Finland gather for the Dystonia Days. To be fair to all members these events take place in different parts of the country every year. In 2014 the Dystonia Days will be held in Turku.

The activities of the clubs slow down during summer to once again pick up with renewed enthusiasm in the autumn. Below you find examples of some clubs' activities during May 2014.

Local Club Activities

The first **Dystonia Club was founded in Turku**. It started operating already before the founding of the Finnish Dystonia Association and actually celebrated 20 years of activities in 2013. The members of the club are pictured at a meeting while planning the 2014 Dystonia Days to be held in Turku in September.



The **Tampere Dystonia Club** traditionally organises an annual spring happening at the end of May. Around 25-30 people took part in this event. There are various activities which you can participate in: nature walk, boot throwing, dart competitions, and games like molkky (a special Finnish game) and bowling. A small attendance fee covers some refreshments like coffee and barbecue snacks. If you feel like it you can use the sauna or go swimming. There is also a lottery where every ticket is a winner.



The Lappeenranta Dystonia Club organized for its members the chance to take part in a "floating in drysuits" -event in Lake Saimaa, the fourth largest lake of Europe. It was a cloudy but warm day and it was exciting walking in the drysuit to the lake. It felt like being dressed in space suits. When floating in the lake the feeling was simultaneously heavy and light - like a summer cloud in the sky. All in all it was a nice, relaxing and safe experience.

We decided to try this floating exercise because relaxation is an important part of the self-management for dystonia patients.

Thank you to Saimaa Adventures and Ville Harinen.



The Pohjois-Savo Dystonia Club has decided to organise an annual guided exercise day. The purpose of the day is to remind everyone of the importance of exercise. Exercising in a group also brings pleasure and companionship. The format made it an unforgettable day and we swapped our traditional coffee event held in March in Lounas-Salonki for this "exercise and Zumba day." The Zumba music is both relaxing and encouraging. We experienced it to be a versatile activity for the whole body. Looking at people's faces you could sense the joy and the feeling of achievement despite suffering from dystonia. It is important to do these pleasant activities together; we will not let the pain caused by dystonia take over, we want to distance ourselves from the pain and live with it in harmony. The support of the group is invaluable. The group encourages you to test your limits and the peer support is the basis for everything - it makes it possible to achieve things with your equals. But it is important to remember that you only have to do what you feel capable of. An open mind is a door to a more active and varied life.

*Told by the Club's chair
Arja Tikkanen
and
Information Secretary
Taina Lehtinen*

Netherlands

8 % Membership Increase in 8 Months

In winter's issue of the Dystonia Europe News you could read about the recruitment campaign for new members of the Dutch Dystonia Association. We have now received the first results. From January 2014 until now we welcomed 148 new members to our association.

The Netherlands has approximately 18.000 dystonia patients of which 1800 are members of the Dutch Dystonia Association, about 10% of all dystonia patients.

We were wondering if it would be possible to increase the number of members and therefore we launched a Membership Recruitment Tool, consisting of a display box with cards. The card has information about the Dutch Dystonia Association and how to become a member. Last December we sent the display box to all neurologists treating dystonia patients in the Netherlands and we asked them to place our display box in their waiting room.

We are very satisfied with the 8% membership increase in only 8 months. It is especially satisfying to know that the help and support our association offers, has reached dystonia patients who might not have found us, if it weren't for the Recruitment Display Box!

President Robert Scholten
Dutch Dystonia Association



Norway

Project on Physiotherapy for Cervical Dystonia

The Norwegian Dystonia Association (NDF) received 450.000 Norwegian Crowns (approximately € 55.000) from the Norwegian Foundation for Health and Rehabilitation ("ExtraStiftelsen Helse og Rehabilitering").



The funding is for a project to train physiotherapists in the latest evidence-based treatment of cervical dystonia.

The Norwegian "ExtraFoundation for Health and Rehabilitation" is an institution consisting of 28 non-profit health and rehabilitation organizations. The foundation is licensed to operate the national TV game "EXTRA". Proceeds from the game go towards strengthening the work of non-profit humanitarian organizations in preventive health care, rehabilitation and research in Norway. All non-profit humanitarian/socially dedicated organizations as well as professional organizations for the functionally disabled in Norway, may apply for funding, regardless of membership of the Foundation.

The chairwoman of the Norwegian Dystonia Association, Anniken H. Hagen, in cooperation with Neurologist Jeanette Koht, invested much time and effort into the description of the project and the application to "Extrastiftelsen". The effort paid off, and on November 26th 2013, it was announced that NDF would receive the funding.

The Importance of Physiotherapy

Physiotherapy treatment is very important for most dystonia patients and can be vital to keep the best possible functionality. Exercise and physiotherapy are most likely the most unrecognized choices of treatment for dystonia. Knowledge of physiotherapy and exercise methods for dystonia are unfortunately very limited in Norway. There is a great need to increase the knowledge of which methods of physiotherapy treatment are best suited for dystonia patients. Low aerobic intensity, with focus on improving posture and strength, together with special exercises for increased stability of surrounding muscles, as well as stretching, are important elements in the training/rehabilitation. Different types of stretching techniques are very important to avoid shortening of the muscles.

The Project

The main goal of the project is to educate 60 physiotherapists in Norway within 3 years. The project started this year, and 50 physiotherapists have already attended part 1 of the course! This proves that the demand for knowledge in the field of physiotherapy for dystonia is increasing.

Part 2 will be held in the autumn of 2014. All physiotherapists who participated in part 1 and 2 will receive a certificate after completion of the course, which this year is held in Bergen and Oslo. In 2015 and 2016, the course will be held in other cities in Norway.

Anniken H. Hagen, who is herself a physiotherapist and diagnosed with dystonia, was in Paris in August 2013 to learn more about physiotherapy treatment for dystonia from Jean-Pierre Bleton. In October 2013, Anniken together with neurologist Jeanette Koht of Drammen University Hospital attended the workshop on physiotherapy for cervical dystonia held in Malmö, Sweden. The Swedish Dystonia Association organized the workshop which was led by physiotherapist Johanna Blom of Malmö University Hospital.

NDF has been aiming at a high level of expertise and therefore involved experts from abroad. Physiotherapist Johanna Blom from Sweden and physiotherapist Jean-Pierre Bleton from Paris, France came to Bergen to give presentations and to demonstrate their evidence-based methods, together

with neurologist Jeanette Koht and neurologist Charalampos Tzouliz. When the course was held in Oslo, neurologist Inger Marie Skogseid and neurologist Jeanette Koht gave presentations together with physiotherapist Johanna Blom.



Neurologist Jeanette Koht and Anniken H Hagen, Chairwoman, Norwegian Dystonia Association.

A few members of the Norwegian Dystonia Association, all with various forms of cervical dystonia, attended the course in order for the trainers to demonstrate to the audience how physiotherapy treatment on dystonia can be carried out. NDF will publish the names of the physiotherapists who have been certified through NDF on their website and in the member magazine "Dystoni Nytt". It will be of help for dystonia patients when seeking treatment in his/her region from a physiotherapist with special knowledge in dystonia. Many of the physiotherapists are specialized within neurology and work in public hospitals or private rehabilitation centers as well as at physiotherapy centers. Very often dystonia is not easily recognized and many patients go untreated for years. In Norway many patients with dystonic symptoms are referred to a physiotherapist before they are diagnosed. Those physiotherapists who have attended the NDF physiotherapy course will hopefully be able to distinguish more easily between dystonia and other diagnosis.

NDF believes that the increased knowledge about dystonia among physiotherapists, will lead to faster diagnosis of those who suffer from the disorder in Norway.

*Anniken H Hagen & Merete Avery
Chairwoman Secretary
Norwegian Dystonia Association.*

Spain

Meet ALDEC - the Spanish Dystonia Association in Catalonia

First of all ALDEC, the Spanish Dystonia Association in Catalonia, would like to send their greetings to all member associations of Dystonia Europe, and especially to the Dystonia Europe Board of Directors, for their outstanding work for dystonia in Europe and the world.



ALDEC is located in Catalonia. It's a very active association and we work to inform and raise awareness of dystonia among the public. ALDEC is the voice of those affected by dystonia. We represent and defend their rights, and we raise funds to be able to offer various services to our members.

We collaborate with similar associations, public and private institutions, as well as scientific bodies and we encourage research. The organisation is working very closely with those affected by dystonia and their families.

Some of the services that ALDEC offers to its members are: legal and social care, support to old people with dystonia, support for individualized rehabilitation and physiotherapy, as well as psychological support. We offer support groups, a transportation service for people with severe dystonia and we provide services to inform and spread awareness.

We offer activities such as: cultural events, entertainment, tours, and meetings with families for sharing experiences.

The Annual Dystonia Day is the main activity of ALDEC to spread information and update on the latest news about dystonia.

Every year, on November 15th, to mark the "European Day of Dystonia", we dedicate a day to inform on the latest advances within dystonia. In 2013, the "Ninth Day of Dystonia" in Catalonia was held at the Hospital de Sant Pau, Barcelona, supported by the health authorities and by the Government of Catalonia. Prominent participants such as representatives from the Government of Catalonia, the Barcelona City Council, and the management of the Hospital de Sant Pau attended the event. Presentations were given by several dystonia experts such as: Dr. Jaume Kulisevsky with "Surgery for dystonia?". Dr. Javier Pagonabarraga spoke about "Cervical dystonia and blepharospasm". Dr. Elena Serrano gave a presentation on "The Role of Banks in Bio-translational research" and Dr. María Palacín on "Resilience, the strength to go forward." These were presentations that informed us about various aspects of dystonia. For more information, see a summary of the presentations of the "9th Dystonia Day on the ALDEC website: www.infodoctor.org/aldec

On February 18, 2014, we organised a one-day training course on "Rehabilitation of Movements and Physiotherapy in Dystonia" aimed exclusively for professionals within the field of rehabilitation and physiotherapy in Catalonia. The goal of the conference is to encourage the participants reflection, as well as learning about rehabilitation strategies for dystonia. Physiotherapy plays an important role in the rehabilitation of dystonia. The Conference was supported by the Department of Health (Cat Salut), and the Advisory Committee on Minority Diseases of the Catalan Government.

Around Europe & Beyond

Presentations were: "What is dystonia?" by Dr. María Josep Martí, neurologist at the Hospital Clinic of Barcelona and also member of the Scientific Advisory Committee of ALDEC; "Focus on dystonia in the context of care for rare diseases in Catalonia" by Dr. Pilar Magrinyà, Secretary of the Advisory Committee of Minority Health Disease Department of the Government of Catalonia; "Experience in physiotherapy with a spasmodic torticollis patient in Catalonia", Mrs. Emma Ludeña, physiotherapist of neurodegenerative diseases at "Hospital de Día de Hospital Clínic de Barcelona"; and "Overview of rehabilitation in dystonia" with physiotherapist Jean Pierre Bleton, PhD and physiotherapist at the "Std Unité James Parkinson Ophtalmologique Fondation Rothschild" in Paris.



Sra. Ana Sánchez and PhD Jean Pierre Bleton.

In addition to Jean-Pierre's presentation, he held a "hands-on-workshop on rehabilitation in cervical dystonia and writer's cramp" demonstrating treatment methods and exercises on two patients. The conference was attended by rehabilitation professionals and physiotherapists from all over Catalonia. For more information on the training course visit the ALDEC website.

ALDEC has created a special "information card" for people with dystonia for medical visits and emergencies. It aims to facilitate the patient-doctor communication, and is thereby a complementary communication tool. For example the card contains a list of medications to

avoid for dystonia patients. This "information card" is recommended by our Medical and Scientific Advisory Board, consisting of neurology experts in movement disorders.

During the year of 2013 we published a book to help affected families, caregivers, families, etc. entitled: "The family before the disease and how it affects all family members", written by doctors in Social Psychology at the University of Barcelona and Montserrat Aiger and María Palacín. This book is edited by ALDEC and published by Editorial Milenio.

We have published a "Guide of practice for professionals" This guide is the scientific evidence by Dr. Teresa Buongiorno, neurologist at Hospital Clínic de Barcelona, with the support of the Catalan Society for Neurology. It's a tool to support the clinical practice of the professionals who care for people affected by dystonia. It contains the most important sections of the pathophysiology, epidemiology, diagnosis, prognosis, treatment, rehabilitation and references to literature on dystonia. It's written in a clear and rigorous language from a scientific point of view.

Other publications of the associations available are: The Annual Report of our activities, an annual newsletter for our members, a special ALDEC annual calendar, a poster of the "Annual European Day of Dystonia", Christmas greeting cards, leaflets on dystonia and a continuously updated website. For further information please visit our website: www.infodoctor.org/aldec.

Thank you very much for allowing us to publish this article in the Dystonia Europe News and to let us inform about ALDEC and our activities and services for people affected by dystonia and their families in Catalonia.

We send our warmest greetings to all the members belonging to the European Dystonia family.

Ana Sanchez, Vice President, ALDEC.

United Kingdom

My Dystonia Story – about Diagnosis, Treatment & Daily Life after DBS

MY DIAGNOSIS

When I was about 3 and half years old my mum was trying to get me dressed for my sister's birthday party. When she tried to put on my dress I appeared to refuse to lift up my right arm however, it soon became apparent that I wasn't being difficult; I just could not lift my right arm. My parents began to notice that I would always hold my arm in the same position. They soon took me to the doctors who referred me to Accident and Emergency, where the doctors incorrectly diagnosed me with a broken arm. The next day I returned to the hospital and the senior consultant devoted his entire afternoon to me. At the end of the day he said "I cannot tell you what is wrong with your daughter's arm but I can tell you that it is not broken and it is not dislocated". I was discharged as there was nothing else they could do for me. My mum took me to a local child-development doctor who said that I was suffering from some sort of palsy. She referred me to Guys and St Thomas' Hospital and Dr Lin, a paediatric neurologist. Dr Lin immediately diagnosed me with dystonia.

SYMPTOMS

My first symptom was my right arm being unable to move. My right arm was locked behind my back. It did not cause me pain and I was very unbothered about it. As I grew older my symptoms changed. My right arm was no longer fixed behind my back but still had dystonic movements, such as jolts and tremors. The dystonia started appearing in other areas of my body; my right leg, left arm and the muscles around my mouth. My symptoms fluctuated throughout my childhood both daily and on a longer term basis. When I was between 6 and 15 years old my dystonia stayed *relatively* constant. I

had good weeks and bad weeks, but on the whole I was coping pretty well. It made my life a little tricky, but I was *coping* fine. At this stage my Dystonia wasn't specifically stopping me from doing anything (except putting in my contact lenses) but everything was more effort- it was like an obstacle to overcome. It made me more tired than my peers, and I also had to eat more.

However, during the ages of 15 to 17 my dystonia really did start to impact my life in a negative way. Not only were the symptoms themselves getting worse, but also the way I wanted to live my life as I was no longer a child. The abnormal posturing/twitching/tension in my arms became the 'norm.' What would have been originally classified as a 'bad day' became an everyday occurrence. I was getting very tired and had to stop doing things, such as go out with my friends as I was just too tired. Cutting up food, getting dressed, putting on make-up, pouring and carrying liquids: these were all the things I found VERY difficult. I couldn't tie up my hair for school and it wasn't nice still having my mum do my hair for school when I was 17.

TREATMENT

On the 23rd of February 2010, I had Deep-brain Stimulation (DBS) at Kings College London. Making the decision to have the surgery was not easy; my parents and I anguished over it for weeks. I was scared and did not want to entertain the idea of someone messing with my brain! Dr Lin and the DBS team were great. They showed me patience and could understand the fear and concern. Dr Lin said that he really wanted me to do it as he believed that it could make a real difference to my life and that it was good time to do it while I was still under his care (I was still in the childrens' hospital). After lots of deliberation I decided to have the procedure as I could see that my dystonia had got worse. I had always coped with a difficult arm but the tipping point that made me seriously consider DBS was the way the dystonia was affecting me when I wasn't even performing a manual task. I would be sitting

down watching a film with my friends and I couldn't stop moving. My arm wouldn't relax and just stop. I would be sitting in the cinema nudging the stranger next to me because I couldn't stop my arm moving. The dystonia in my face was another pivotal symptom. The muscles around my mouth used to contract slightly, causing my speech to become slightly slurred. It was also uncomfortable and annoying, I was always aware of it, and was very self-conscious. I became a quieter person and less confident.

DBS IMPACT

I was unable to cook, put in my contact lenses, drive, go out late and many other things. I was very frustrated and tired all the time and my confidence was low. I was not independent and I dreaded the thought of university. Now, I wear my contact lenses almost everyday, I put them in with no difficulty. I am able to go to university and not have to worry about sitting in lectures. I can perform lab practicals and even pour hot liquids. I can keep up with writing the lecture notes and tie up my hair. I can stay out late with my friends and not worry about being too tired. I can catch the bus and not be reliant on my parents.

My dystonia isn't completely gone. I still do have to ask people in lab classes to pour or do something which is particularly fiddly. My arm still does the odd twitch in lectures, but its not continuous. My leg still twitches, but that doesn't really affect me. My speech still isn't very clear BUT has improved tremendously. The DBS has made me an independent student, which I couldn't have been with my Dystonia. Anymore questions let me know!

Amybel Taylor
amybeltaylor@mac.com



Amybel Taylor ©
2014

Amybel Taylor.

United Kingdom

Finding Relief from Dystonia Through Art Therapy

Lisa Todd, a resident of the UK, was a busy working mother with a great career in interior design and a busy, active social life. Then dystonia struck, forcing her into early retirement. "It's totally changed my life," says Lisa.

Lisa traces the onset of her dystonia to an injury she sustained in 2003. She and a friend visited a spa for a relaxing day of pampering. After a massage, the two relaxed in lounge chairs by the spa's pool, enjoying a cup of tea. Lisa didn't realize her chair was broken until it suddenly collapsed, throwing her backwards and jarring her between the shoulder blades. The next day her head was pulling to the left "as if it was being pulled by an invisible dog collar," she recalls. She was in excruciating pain.

The next several weeks were a blur of doctor's appointments, but no one could tell Lisa what was wrong. She couldn't work, drive, or cook a meal. After much trial and error, she saw a neurologist nine weeks after her injury who made a proper diagnosis and recommended botulinum toxin injections.

At first, the injections didn't seem to provide much relief. Her neck pain and spasms continued. So she devised her own rehab regimen, which included osteopathic manipulative therapy, massage, acupuncture, pilates and gentle swimming exercises. Her insurance covered none of these expensive services, straining her financially. She continued the injections and gradually began to feel better, but unfortunately remained unable to work or engage in many other activities she'd once enjoyed.

Lisa missed her career, but eventually discovered a different form of therapy that helped fill the void. "A friend took me to an art class and I began to paint and found that I loved it," she says. "I've always had a passion for colour and pattern." She soon found she loved creating art. Her paintings are beautiful riots of colour.

"Art has been my salvation," she notes. "It helps me leave the four walls and isolation of my house and has improved my physical, mental, and emotional well-being. It brings me a huge sense of achievement as well."

Lisa has just launched Lisa Todd Designs, "Lisa creates beautiful paintings for homeware designed for individuals seeking unique, individual, uplifting pieces. Each design is painted by hand in Windsor. All products are hand finished and designed to complement contemporary and traditional interiors."

For more information on Lisa Todd and her Designs connect with her on facebook: <https://www.facebook.com/lisatodd designs>

Lisa Todd.



Meet the Dystonia Europe Secretary: Merete Avery

My husband Leroy and I live in Molde, a small city on the west coast of Norway, with about 25 000 inhabitants. Molde is situated by a fjord and surrounded by mountains. We have two children Veronica 22 years old and Nicholas 24 years old.



Merete and their daughter Veronica.

When I was young, my parents often took my sister and me on great Sunday trips to the mountains. In the summer we went by foot and in the winter we went skiing. We lived so close to the mountains we often walked from our house. I am no longer able to walk for long distances due to my dystonia getting worse. However, I still enjoy the mountains by walking short distances and I try to do so at least 3 – 4 times a week. I cannot reach many of the mountaintops anymore, except those not too high and the few ones at driving distance. In addition, and luckily for me, I can still do a little cross-country skiing in wintertime. I also enjoy reading books, travel and spending time with family and friends. In 2006 I was diagnosed with cervical dystonia, and I started treatment with botulinum toxin every three months since 2007. Over the years, it seems that the treatment is working better and better, although I still have symptoms of dystonia, especially just before and after treatment.

Every week I see my physiotherapist and I also do some "physio pilates". With dystonia I have to rest much more than before which require some planning. I have just begun to practice mindfulness and I am reading a book on the subject called "Full catastrophe living" by Jon Kabat-Zinn.



Merete's husband Leroy and their son Nicholas.

I work as a receptionist and travel coordinator for "National Oilwell Varco Norway" in Molde. After I was diagnosed with dystonia I work 50%.

Since 2009 I have been involved in voluntary work for dystonia. The first year as a leader of a local dystonia group of the Norwegian Dystonia Association and between 2010 and 2013 I was Chairwoman for the Norwegian Dystonia Association, and since 2013 Secretary. Last year I was also appointed Secretary of Dystonia Europe, and it is with great pleasure I take part in the important work of both organizations. It is my hope that dystonia and other movement disorders will be better understood in the future.

*Merete Avery
Secretary
Dystonia Europe.*

Medtronic Acquires Sapiens Steering Brain Stimulation

Last August Medtronic announced the acquisition of Sapiens Steering Brain Stimulation, a privately-held developer of deep brain stimulation technology located in Eindhoven, the Netherlands.

Sapiens SBS, is developing a DBS system that features an advanced DBS lead with 40 individual stimulation points. This advanced system is designed to allow more precise stimulation of the intended target in the brain. For more information see the press release at:

<http://newsroom.medtronic.com/phoenix.zhtml?c=251324&p=irol-newsArticle&ID=1960861&highlight=>

The Medtronic DBS system was approved for treatment of dystonia in 2003.

Jump for Dystonia Pens

There are now special Jump for Dystonia pens. The production of these pens was sponsored by Merz and we are very grateful for this generous support. The pens are brought to congresses and Jump for Dystonia events and handed out to people connecting with Dystonia Europe or supporting us with a Jump!



Join the Movement: Jump for Dystonia!



At the D-DAYS in Paris the official launch of this fun and exciting campaign will take place. But already at last year's Anniversary Conference in Edinburgh, the participants were challenged to JUMP for Dystonia. Over the last year JUMP photos have been collected at congresses and meetings. Special JUMP for Dystonia events were also initiated by some of our partners. Read more about this on page 7 and 8.

Dystonia is a movement disorder and therefore we want to spread awareness with a move around the world – this move being a JUMP. We invite everybody to join in the campaign and if you cannot JUMP you can make a movement with your arms, eyes – use your imagination! Take a photo and upload it to the Jump for Dystonia Facebook page: and challenge your friends and family to JUMP as well!

Will you help us reach as many JUMPS as possible for Dystonia?

We Have Jumped for Dystonia!



Events

2014

9 October, Dystonia Europe Board Meeting, Paris, France

10-12 October, Dystonia Europe D-DAYS 21st Annual Conference & General Assembly, Paris, France

6-7 November, Dystonia Coalition Annual Meeting, St Louis, USA

2015

14-17 January, Toxins 2015, Lisbon, Portugal

27-30 May, European Paediatric Neurology Society Congress, Vienna, Austria

14-18 June, MDS Congress, San Diego, USA

20-23 June, 1st Congress of European Academy of Neurology, Berlin, Germany

2-4 October, Dystonia Europe D-DAYS - 22nd Annual Conference and General Assembly, Rotterdam, The Netherlands

12-14 April, Dystonia Training School, Groningen, The Netherlands

2016

4-7 May, 3rd International Congress on Treatment of Dystonia, Hannover, Germany



AMADYS
En parler, c'est déjà aider !

DYSTONIA EUROPE

21ST ANNUAL CONFERENCE

D-DAYS

OCTOBER 10, 11 & 12, 2014

PARIS, FRANCE

For information and registration:
www.dystonia-europe.org

Invitation, Dear Colleagues,

Dystonias are amongst the most common movement disorders. Botulinum toxin and deep brain stimulation have revolutionized their therapy. However, there are still considerable unmet therapeutic needs. This was the reason to organise the First and the Second International Congress on Treatment of Dystonia in the years 2010 and 2013. The response was overwhelming: More than 500 participants from over 45 countries came to Hannover for intense 3 day programs, respectively. With this continued support from the international dystonia experts our audience we are now calling for the third congress of this series.

As before, we decided to continue with our 3 year rhythm: Shorter intervals would bear the risk of repetition thus spoiling scientific credibility and longer intervals might sever predictability. So, good luck with producing exiting new data we can present to improve our contents. We would be very grateful if you could make suggestions on emerging topics in order to do provide the best service for

'For all who care for People with Dystonia'

Cordially,



E. Altenmüller, D. Dressler and J. K. Krauss



THIRD INTERNATIONAL CONGRESS ON TREATMENT OF DYSTONIA

2016

For all who take care of people with dystonia

May 4th - 7th, 2016 | Hannover Congress Centrum



22ND ANNUAL CONFERENCE

D-DAYS

OCTOBER 2, 3 & 4, 2015
ROTTERDAM, THE NETHERLANDS

ANNUAL EUROPEAN
DYSTONIA DAYS



SAVE THE DATES



Organized by Dystonia Europe and the Dutch Dystonia Association

PRELIMINARY PROGRAMME

Dystonia Europe 22nd Annual Conference
&
Dutch Dystonia Association 30th
Anniversary

Rotterdam, the Netherlands

- **FRIDAY, 2 OCTOBER**

Lectures about dystonia

- **SATURDAY, 3 OCTOBER**

Family day (expecting 500 members of the Dutch Dystonia Association). In the morning free activities for families, and in the afternoon workshops and lectures about dystonia. There will also be an information corner.

SATURDAY EVENING

30th Anniversary Gala Dinner
Dutch Dystonia Association

- **SUNDAY 4 OCTOBER**

Dystonia Europe 22nd General Assembly
For members only



Information & Registration: www.dystonia-europe.org

Members

Dystonia Europe consists of 20 national member groups from 17 European countries and they are: Austria, Belgium, Croatia, Denmark, France, Germany, Ireland, Italy, Netherlands, Norway, Poland, Portugal, Romania, Spain, Sweden, Switzerland 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.

Thank you for supporting Dystonia Europe!

Medical & Scientific Advisory Board

Prof Alberto Albanese – Milan
Prof Alfredo Berardelli – Rome
Prof Kailash Bhatia – London
Prof Rose Goodchild – Leuven
Prof Marina de Koning-Tijssen – Groningen
Prof Joachim Krauss – Hannover
Prof Tom Warner – London
Dr Jean-Pierre Lin – London
Prof Maja Relja – Zagreb
Prof Eduardo Tolosa – Barcelona
Prof Marie Vidailhet – Paris



Board of Directors

Dystonia Europe is governed by a volunteer Board of Directors.



Robert Scholten, President, Netherlands

Robert was elected President of Dystonia Europe at the General Assembly in Edinburgh in 2013. He is from the Netherlands and he is also the President of the Dutch Dystonia Association. Robert is working in the field of communication, marketing and public affairs. He has had cervical dystonia since 2000.



Maja Relja, Vice President, 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, and appointed Vice President in 2012. She also serves on the DE Medical and Scientific Advisory Board and is heavily involved in the COST-funded Dystonia Research Network.



Marina de Koning-Tijssen, Board Member, Netherlands

Marina is a professor in charge of the movement disorders department at Groningen University Hospital and has been committed to supporting the Netherlands dystonia patient organisation for a number of years as a member (and chair) of its Scientific Advisory Board. She was elected to the board of Dystonia Europe in 2011, is a member of our Medical and Scientific Advisory Board and heavily involved in the COST-funded Dystonia Research Network.



Sölvi Engeland, Board Member, Newsletter, Norway

Sölvi was elected to the board of EDF, now Dystonia Europe, in 2009 and she was re-elected for a second term in 2012. Sölvi was diagnosed with cervical dystonia and blepharospasm in 1989. Since 2001 she is also a board member of the Norwegian Dystonia Association. Sölvi's professional training is within management, strategy, sales and marketing. Sölvi is responsible for layout and design for Newsletter and Annual Report.



Merete Avery, Board member, Norway

Merete was appointed to the board of Dystonia Europe in 2013. She was diagnosed with cervical dystonia in 2006 and she was Chairwoman of the Norwegian Dystonia Association from 2010-2013. In 2013 she was elected Secretary to the Board of the Norwegian Dystonia Association. Merete works with clerical work and customer service for a company in Molde, Norway.



Alistair Newton, Board Member, Scotland

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 has been appointed to the Dystonia Europe Board with special responsibility of the Dystonia Research Network. Alistair also co-funded EFNA – the European Federation of Neurological Associations – in 1999, 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, and has been a board member and Treasurer ever since. Alistair has had cervical dystonia for 30 yrs.



Heike Wolf, Board Member, Treasure, Germany

Heike is a member of the German Dystonia Association and a delegate to Dystonia Europe since 2012. She was elected to the board of Dystonia Europe in 2013. After three years of professional training as a tax consultant assistant Heike has been working within this field in Berlin since 1997. Heike has cervical dystonia.



Monika Benson, 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.

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.

