

DYSTONIA EUROPE NEWS

Winter 2013



DE delegates from the pier in Croatia.

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Monika Benson

Dear all,

Reaching the end of a year usually makes us look back at the achievements of the previous twelve months, but also stimulates thoughts about what the future will bring.

For Dystonia Europe it has been a year of both good and sad. As we announced in the 2012 summer edition, we were shocked by the sudden passing of our Board Member and former Vice President Dr. Anthony G. Butler and were sorry to receive the resignation of our Treasurer Herman De Craecker for health reasons. Both have been long-standing members of our board and we have missed them at our last two meetings.

Despite this bad news in spring the work for dystonia had to move on. Promoting awareness and education and stimulating research remain our two main areas of focus, and our involvement has deepened in the work of what is now the Dystonia Europe Research Network. In this newsletter you can read about the success of the dystonia training school in Bol, Croatia with almost 100 participants, as well as the development of various other projects such as COMPASS and the "International Cervical Dystonia

Patient Survey." Progress has also been made in reaching out to countries where there are still no dystonia patient support groups.

One of the highlights of every year is to meet many of you at our annual conference and general assembly. This year the event took place in Bol, Croatia. I would especially like to thank Professor Maja Relja who had done an excellent job making sure everything was very well organised. There was an interesting programme of speakers but we also had plenty of opportunity to meet one another and share thoughts and ideas. The fact that so many scientists from the Research Network and young trainees were such an important part of the event in Bol was a tremendous bonus. I truly enjoyed it and thank you to all of you who were there.

Around Europe you continue to work hard to raise awareness, and support people who are affected by dystonia. Read on page 10 about the Swedish initiative to organise a workshop on physiotherapy for cervical dystonia.

Moving into 2013 marks the beginning of the year of the 20th Anniversary of Dystonia Europe, formerly European Dystonia Federation. From 11 groups in 1993 we are today 18 member organisations from 16 countries. We should be very proud of our organisation and what we have achieved. The year will be highlighted with the awareness campaign "Dystonia Stories", consisting of filmed interviews, where patients, well-known medical specialists, and many others give their personal relationship with dystonia.

Finally I would like to thank you for all you do to help dystonia patients. You may be working in a patient organisation or as a clinician, a researcher or some other organisation interested in dystonia at the European level. Whatever your commitment to improving the lives of dystonia patients, all of your efforts in our partnership create our Dystonia Europe.

I wish you all the best for 2013!

Monika Benson
President

Research Network Training Course, DE Annual Conference and General Assembly – Bol, island of Brac, Croatia. 20 – 23 September 2013



*Merete Haaseth Avery,
Chairwoman Norwegian Dystonia Association*

I attended Dystonia Europe’s Annual Conference, General Assembly and some of the lectures in the Training Course with some of my colleagues from Norsk Dystoniforening.

On the first day, many of the sessions were specifically for medical students, so we had a few hours to ourselves to explore the area and relax after our travel. After unpacking we enjoyed a cup of coffee in Bol at a local café while watching the waves hitting the rocks on the other side of the street.

On Friday and Saturday we attended the teaching sessions most of the day where we took a lot of notes. We will try to share the information as much as possible with our members through our member magazine. Very interesting subjects were addressed in the lectures of the Training School like Genetics, Treatment with Botulinum toxin, DBS surgery, Physical Therapy and more.

In the evenings we enjoyed dinner at hotel Elaphusa. One night there were also local musicians while we were dining. It was very nice to experience some of the local culture.



Merete telling about a Norwegian project at the GA

On Sunday the delegates from the various European member countries gathered for Dystonia Europe’s General Assembly 2012. The member countries were in advance invited to share ideas about their recent work/projects which proved to be a great idea, and we learned a lot from each other. There are many interesting projects on dystonia being carried out in Europe. Especially, I think the CD/DVD on Physical therapy being developed by AMADYS (France) with Jean-Pierre Bleton from Paris. There were discussions on translating these into English so it could benefit patients around the world.

Bol was a beautiful location that I hope to return to one day. The food was excellent, the climate very pleasant. The village centre was only a 10 minute walk from Hotel Elaphusa which was very comfortable, yet affordable and with excellent conference facilities.

I want to thank DE for its great work in arranging this event and all the other worthwhile work they do for the benefit of dystonia patients.

Merete Haaseth Avery

The Ixcellence Network



The Ixcellence Meet IN

Dystonia is an illness which has been difficult to treat successfully, and few effective treatments are available. The treatment of choice for focal dystonias is now provided by injections of type A botulinum toxin (BONT) and is widely used in clinics across Europe. Although this form of BONT was first developed to treat strabismus, it came into use for blepharospasm and then for other focal dystonias, particularly cervical dystonia which is the most prevalent form. It is now used to treat a large number of focal dystonia patients in many countries, with excellent results for many patients but not for all.

It is acknowledged that skilful diagnosis of dystonia requires considerable clinical experience and, similarly, the overall level of effective administration of BONT could be greatly improved by training and exchange of expertise. The basic concept of the Ixcellence Network Medical Educational Programme is to encourage this exchange of knowledge. In collaboration with a number of leading clinicians in several centres, Ipsen Pharma has developed a network in which specialists share their expertise across local and national boundaries to increase the ability of other specialists in their treatment of dystonia and other illnesses which benefit from BONT.

In October 2012, our Executive Director was invited to make a presentation at the first

Ixcellence Network event, in Cascais, Portugal, to inform the invited specialists on the results of the recent Cervical Dystonia Patient Survey, which had over 1000 respondees. This survey concentrated on the patients' views of treatment and their relationships with their medical advisers.

Although the data shows clearly that BONT is very beneficial for many patients and a majority had a positive relationship with their doctors, many were not satisfied by the level of improvement in their symptoms produced by the treatment, and a substantial proportion of patients were unhappy with their relationships with the professionals. The final results of the survey will be published in the coming months.

In addition to the plenary session, training workshops were held on several different topics, where specialists were able to share information and ask questions in a 'tutorial' atmosphere. These workshops were very much enjoyed by the attendees who were very positive in their feedback on the value of the event.

This first Ixcellence meeting was a great success and several other similar treatment networking events are planned for 2013 in other centres. If you want more information please contact your nearest Ipsen representative.

Alistair Newton



Alistair Newton, Executive Director DE

News from the Dystonia Research Network

COST Action BM1101 – European Network for the Study of Dystonia Syndromes



Dystonia Europe's involvement with the new Research Network has developed very strongly over the past year, and we co-ordinated and administered many of the arrangements for this first Training School, which will be an annual feature of the Network's activities.



Dystonia trainees and trainers at the September 2012 Training School in Bol, Croatia

The Training School programme was organised by Prof Maja Relja, in collaboration with other scientists from the Network and with the Movement Disorder Society. Grants were made from the COST Action budget to 34 young dystonia trainees to support their travel and accommodation costs to attend the event.

Over 3 days in the beautiful setting of Bol – a well-known holiday resort on the island of Brac in Croatia, a very experienced team of 16 dystonia experts from across our continent provided training for young specialists in many aspects of this difficult neurological movement disorder.

The interaction outside the training sessions, among the trainers and trainees, provided a real opportunity to ask questions and get into useful discussions in smaller groups plus, in the later stages of the School, to meet the patient group leaders who were beginning to assemble for Dystonia Europe's 2012 annual conference.

The attendees were extremely positive about their experiences in Bol and the excellent opportunity to increase their knowledge of dystonia.

Alistair Newton

Dystonia Europe Goes East: Dystonia Europe in Lithuania

After negotiations over many months regarding the possibility of promoting the formation of a patient group in Lithuania, Alistair Newton and I were invited to a 2-day meeting in Vilnius in August. On the first day, Rita Juraitė-Jankauskiene of Ipsen Lithuania had invited dystonia patients and their families to a meeting at the University hospital of Vilnius. There were 34 patients, and including friends and family, a total of 50 people had come. A translator was provided to relate our presentations to the audience.



Dr. Ausra Klimasauskiene from the University Hospital of Vilnius

Neurologist dr. Ausra Klimasauskiene of the University Hospital of Vilnius opened the meeting with a thorough presentation on the various forms of dystonia, symptoms and treatments available. Alistair and I then followed with presentations which were more about our personal experiences of dystonia, how we got involved in patient advocacy and the importance of being an "active" patient for the benefit of other patients as well as yourself. As an example of dystonia patient work on a national level I used my involvement in the Swedish dystonia association and how we work and what we do.

Alistair presented Dystonia Europe and the advantages of working in partnership all over our continent.



Alistair telling about his personal experiences of dystonia

We were quite moved by the warm reception we received from all the people who had come and we felt that there is a strong need for a support group in Lithuania. Some people stayed and wanted more information on how to move on. Hopefully, we have inspired some of them to take that first step to organise a support group, and Dystonia Europe will, of course, coach in the best way we can.

The following day Dystonia Europe attended a meeting of Ipsen staff from several eastern European countries, where we talked about our personal experiences of dystonia as well as the work of DE and national patient organisations. Contacts were made with people from Latvia, Estonia and Hungary and we discussed what we can do to help start dystonia patient support groups there.

The work of Dystonia Europe continues in our efforts to move further East and try to reach out to dystonia patients in countries where there are no groups yet. Meetings are being planned in Russia, Czech Republic and Romania. It is a very positive development and eventually national dystonia groups may be established there. No dystonia patient should be left without this kind of support, if possible.

Monika Benson

Dystonia Europe Goes East: Dystonia Europe in Russia

At the beginning of December Dystonia Europe was invited to Russia to participate in the Russian Patient Congress. We were invited to make a presentation on European patient advocacy and also to talk to Russian dystonia patients to encourage them to set up a Dystonia Patient support group.



Monika Benson and Olga Romanova

Olga Romanova – Product Manager for Ipsen operations in Russia had arranged everything and met DE President Monika Benson at the Sokolniki hotel where the Russian Patient Congress was taking place. The presentation had been sent to the organisers in advance and all slides had been translated into Russian. Victoria Shikhat, Coordinator for the "All-Russian Union of Patient s"(www.patients.ru) and responsible for



Delegates at the Russian Patient Congress

the congress, said It was the first time a European patient leader had been invited to present the work of a European organisation at one of their meetings. Monika gave the presentation in English while it was simultaneously translated into Russian for an audience of about 80 people. There were Russian patient leaders from organisations representing MS, Diabetes and Haemophilia as well as dystonia patients.



Videoconference at the Ipsen office in Moscow

In the afternoon a video-conference was organised from the Ipsen office. From about 20 offices in cities all over Russia, 5-10 people joined the conference at each location. They could see the slides while Monika gave the presentation together with a translator. Afterwards there were many questions from all over Russia about treatment, how to start a patient group etc. There was interest from a few dystonia patients and a neurologist to get involved in organising a dystonia support group and Dystonia Europe will help them in the best way we can.

Monika Benson

Dystonia Europe at the EFNS Congress in Stockholm, Sweden

Dystonia Europe participated and had a stand in the exhibition hall at the 16th Congress of the European Federation of Neurological Societies (EFNS) in Stockholm, Sweden last September.



The EFNS President, Professor Richard Hughes opened the congress and welcomed the participants to this very last EFNS congress. Next year's congress will be combined with the World Congress of Neurology which will take place in Vienna and, in the near future the two major European neurological organisations EFNS and ENS – European Neurological Society – will join forces to become the European Academy of Neurology. In 2014 there will be a joint EFNS-ENS congress in Istanbul and in 2015 the new organisation will be established and the first EAN Congress will take place in Berlin. The new organisation will attract as many as 8000 participants to its congresses.

The Swedish Neurological Society, created in 1938 and with 400 members, was very honoured to host this last EFNS congress, which attracted as many as 5200 registered participants and 2200 abstracts had been received. The Chair of the programme committee, Professor Nils-Erik Gilhus, pointed out that 55% of the participants were younger than age 45 and the top 5 countries represented were Spain, Germany, Sweden, Turkey and Russia. He stressed the importance of this kind of specialised congress,

where the participants learn about new treatment strategies and the most recent research. He encouraged the audience to return home and make use of their new knowledge to the benefit of both colleagues and patients.

One of the days EFNA – European Federation of Neurological Associations – organised **the Good Life Session**, a session intended to highlight how arts and a positive approach to life and disease can often bring unexpected bonuses. In this year's program Professor Eckart Altenmüller, of the Institute of Music Physiology and Musicians' Medicine in Hannover, gave a historical overview highlighting Robert Schumann as well as novel theories on musicians' dystonia. He also presented music therapy in neurology: "Music as a way to heal" - stroke rehabilitation with piano playing.

Cristina Frosini, an Italian pianist who had suffered from musicians' dystonia, has made such a good recovery through retraining and rehabilitation that she can perform again, (see her own article on page 14). With Massimiliano Baggio, Cristina played duets from the works of Schumann and Brahms and the many neurologists who had come to this very different session for a medical congress, enjoyed the experience.

For Dystonia Europe it was a good opportunity to be present and network and spread information about the organisation and what we do, to both companies and the medical profession. There was a lot of interest in the research network and our training schools and I also made sure to talk about the next congress on dystonia, to be held in Hannover next spring: "The Second International Congress on Treatment of Dystonia".

Monika Benson

COMPASS continues

The project was launched at the beginning of 2012 and has developed very successfully. New funds were recently granted from Medtronic Foundation to allow the project to run for another year. Monika Benson continues to lead the project which involves:

- face-to-face meetings with main industrial partners and new ones.
- visits to several member groups to establish closer contact within DE and to identify potential future board members
- establishing contacts for development of new patient groups in Czech Republic, Russia, Lithuania, Romania and Hungary.
- involvement in the COST funded research project The European Network for the Study of Dystonia Syndromes.

Monika Benson



Bengt-Eric Calles Sweden, Monika Benson Dystonia Europe, Erhard Mätzener Switzerland, John Whitaker United Kingdom, Paolo Corsi Italy, Maria Hickey Ireland

Dystonia Stories – an Awareness Campaign



Monika and Amanda Benson

2013, is the 20th Anniversary of Dystonia Europe. The celebration will be featured by a dystonia awareness campaign throughout Europe leading up to the 20th Anniversary Conference to be held in Edinburgh in September 2013.

The meetings in Croatia last September, were documented on photo and film. Participants at the meetings, such as patient leaders, medical experts, students and representatives from the pharma and medical device industries were interviewed about their relationships with dystonia.

The videos are now being edited into clips that will be uploaded on the DE website and through the various social media channels. The more visible dystonia is the better known it will be! If we all together can increase the awareness of dystonia, not only patients and their families will be better understood but scientists who are working hard to find the causes of dystonia and a cure, will be more likely to be understood and get support for their research.

I encourage you to participate in the campaign by sharing and spreading the information forward as much as you can!

Monika Benson

Discovery of New Dystonia Genes

The following information has been obtained from the website of the UCL National Institute for Health Research, London, UK and from a pressrelease of Mount Sinai Hospital, New York, USA:

United Kingdom: New Dystonia Gene discovered by UCL, Institute of Neurology

Researchers from UCL's Institute of Neurology have identified mutations in the gene ANO3 as the cause of a familial form of cranio-cervical Dystonia.



Professor Kailash Bhatia

The team of researchers, led by Professors Nick Wood and Kailash Bhatia, found six changes throughout the gene that might be linked to cranio-cervical dystonia, which triggers abnormal twisting or tremulous movements affecting the face, neck and arms. Of these six changes, three have shown to segregate with disease in three separate families.

The new ANO3 gene determines a channel that is found in the striatum, a part of the brain concerned with movement. To date this is the first work implicating an ion channel as the cause of dystonia.

Professor Bhatia said: " This finding is particularly important as the abnormality here pertains to an ion channel dysfunction. There are hopes that better understanding of this will lead to new treatments for thousands of patients."

The research is particularly innovative as is hoped that insights into the causes of rarer, familial forms of the disease will help shed light on the cellular pathways involved in the disease as a whole. Furthermore, it raises the question of whether medications could be targeted at the channel to compensate for improper functioning.

USA: Scientists Discover New Genetic Basis for Dystonia

Researchers from the Icahn School of Medicine at Mount Sinai, New York have, in collaboration with researchers from other institutions, identified a causative gene for primary torsion dystonia (PTD), a debilitating movement disorder that impacts more than half a million Europeans.

The research study was led by Professor Laurie Ozelius and the discovery identifies the human G α olf (GNAL) gene, the first PTD gene that directly points to the dopamine signal transduction system as the origin of pathophysiology.

Laurie Ozelius said: "The successful application of exome sequencing for the identification of the GNAL gene proves that this is a powerful and efficient tool which will rapidly accelerate the pace of dystonia gene discovery and consequently, our understanding of the pathways involved in PTD."

Professor Tania Fuchs, instructor at the same department said: "Any new gene offers the potential to develop new therapeutics, but because GNAL belongs to a well-studied signal transduction pathway, other components in this pathway may also be targets for drug development,"

The IMMM: An Institute devoted to research and treatment of musician's dystonia

Introduction and History

The Institute for Music Physiology and Musicians' Medicine of the University of Music, Drama and Media in Hannover is a unique institution, devoted to the teaching of music students, research into playing-related disorders such as musician's dystonia, and treatment of musicians and music students suffering from movement disorders. When the Institute was founded in 1974 by the then president of the University, Prof. Richard Jakoby, his idea was to establish a "scientific basis" of playing a musical instrument comparable to sport sciences.



The Institute for Music Physiology and Musicians' Medicine of the University of Music, Drama and Media in Hannover

Dr. med. Christoph Wagner directed the institute from 1974 until 1993 and focussed on research into the bodily prerequisites of playing a musical instrument. He founded a huge database on the anthropometrics of hands, aiming to identify physiological factors, such as size of hands, span of digits, stiffness of tissues, which could predict success or failure of a musical career. This has been summarized in a book in German language, entitled "Die Hand des Musikers" (The musician's Hand).

My friend, who had lost his flute-playing skills

In 1994, I succeeded Dr. Wagner as head of the institute and chair in Music Physiology and Musician's medicine. Since I was trained as a neurologist and neurophysiologist I decided to focus on the "Neurosciences of Music". Already during my time as a major in flute at the Conservatoire in Freiburg in the late seventies and early eighties, I recognized that movement disorders in professional musicians are not uncommon conditions. However, I felt that knowledge about the origins and treatment of this condition was almost lacking. At that time, musicians suffering from focal dystonia were largely left alone with their problem, frequently considered as "neurotic" and not helped in an adequate way. Especially the tragedy of a close friend of mine, who was a brilliant award-winning flutist and who lost the control of the rapid finger-movements of his right hand when playing the flute, motivated me to dive into research into this strange condition. My friend had to stop to play the flute, became depressive, full with guilt-feelings, - having "overworked" his hand, - and shame, - being unable to do the things people expected to do him due to a "psychiatric" condition. We had many nightly discussions about his "stubborn" right hand and I am afraid that at that time I was not very helpful in teaching him anatomy and physiology of tendons and muscles in the forearm and the hand. In common with many other people, I believed that a peripheral weakness, some abnormal tendons, might be the origin of the cramp in his right hand. Finally, in 1983, he found help in psychological counselling, regular Yoga and Feldenkrais training, and started to study medicine. He is now a professor in a university hospital in Germany, but is not playing the flute any more. Of course, this happened before we learned how helpful focussed retraining, anticholinergic drugs and local injections of Botulinum toxin could be.

What to do in the Institute?

I realized that we first had to understand the central nervous mechanisms of the acquisition of highly skilled movements in musicians. Therefore, I applied for grants to understand how musicians learn to play an instrument in such an accomplished way. We started a research program into sensorimotor learning in musicians, with special focus on what we call “audio-motor integration”. One of the most prominent features in music is, that all movements are under the unrelenting control of the auditory system, and that our ear is an extremely precise sense, allowing us to detect the smallest deviations in timing and movement accuracy. This, of course, produces an enormous pressure for musicians, since the quality of their play is frequently judged according to temporo-spatial precision. We also learned that long practice sessions may lead not to a further improvement but, on the contrary, to deterioration of movements and we realized that many musicians suffer from anxieties and behave in a ‘perfectionist’ manner. We soon realized also that these features might constitute risk factors for musicians losing control of their movements (Enders et al. 2011).

Research into musician’s dystonia: Brain Imaging and Risk factors

Our clinical research program emerged more or less automatically from our clinic: we aimed at a better understanding of the two central challenges in Musicians’ Medicine: Focal dystonia in musicians and pain syndromes in musicians. Musicians’ dystonia is a task-specific movement disorder, which manifests itself as a loss of voluntary motor control in extensively trained movements. In many cases, the disorder terminates the careers of affected musicians. According to our epidemiological data, in Germany, approximately 1-2% of all professional musicians are affected. Currently, the pathophysiology of the disorder is unclear. Our neuroimaging studies (and also the work of many colleagues) point at dysfunctional neuroplasticity

as being involved in the etiology (Haslinger et al. 2010, Herrojo-Ruiz et al. 2011). Support for this theory comes from a functional brain imaging study we performed in musicians with focal dystonia in collaboration with the University of Münster. In contrast to healthy musicians, musicians with hand dystonia showed a fusion of the digital representations in the somatosensory cortex, reflected in a decreased distance between the representation of the index finger and the little finger when compared to healthy musicians (Elbert et al., 1998). Since skilled motor actions are necessarily bound to intact sensorimotor feedback loops, it is possible that the loss of motor control in musician’s dystonia might be induced by the aforementioned alterations. At present, however, it cannot be completely excluded that the observed fusion of the digital representations may alternatively be a consequence of musician’s dystonia.

Epidemiological data have demonstrated a higher risk for those musicians who play instruments requiring a maximum of fine-motor skills.



In instruments with different work loads for each hand, focal dystonia appears more often in the more heavily used hand. These findings strengthen the assumption that behavioural factors may be involved in the etiology of musician’s dystonia (Jabusch et al., 2005, Altenmüller and Jabusch, 2010 Baur et al. 2011). Furthermore, recent data suggest that if a musician takes up the instrument after age 10, there might be a strong risk factor towards developing dystonia! Another interesting and novel piece of information which emerged from

our research is that hereditary factors may play a greater role than previously assumed. In several studies it turned out that, in families of musician's suffering from musician's dystonia, other dystonias such as writer's cramp are not infrequent and may afflict up to 34% of other family members (Schmidt et al. 2009). These findings suggest a genetic contribution to focal task specific dystonia with phenotypic variations including musician's dystonia.

How to help musicians suffering from dystonia?

Of course, the important question is: "How to help musicians?". At present, the outpatient clinic of the Institute offers medical care for more than 600 musicians suffering from focal dystonia, coming from all over central Europe. Already the augmented knowledge of the disorder and the information on origin and risk factors is utilized to better counsel our patients. This is perceived as extremely helpful and relieving by most patients suffering from dystonia. Medical treatment options, offered in the IMMM include therapy with Botulinum toxin (Schuele et al. 2005), other pharmaceutical approaches such as treatment with anticholinergics, retraining therapies and ergonomic modifications in the playing of the instrument (see Altenmüller and Jabusch 2010). Current research projects aim at improving the treatments. Local injections with Botulinum toxin are performed with ultra-sound location of the muscular fascicles and electromyographic control of muscular activity during the injection. Thus, we achieve an extremely high precision of the localisation of the affect muscular fascicles and have excellent results. Retraining is refined and we are currently investigating how the guidance of attention away from the affected hand, - a so called external focussing - may facilitate retraining. Furthermore we try to support retraining with brain stimulation, applying weak electric currents to the motor cortex (Buttkus et al 2011).

Where to go?

I have still 10 years to work until my retirement from the university, and I surely will continue to

work after that time. My personal goal and ambition is to find a solution for musician's dystonia and improve prevention and treatment so that this disorder will lose its threat to a musical career.



In the near future, we also have to improve our diagnostic tools to better monitor dystonic movements (Jabusch et al. 2004). This is important for objective assessment of the various therapies and for scientific exchange. Therefore we have established an international collaboration with colleagues from USA and Spain to reach progress in movement analysis and measurements. Furthermore, we plan to explore the therapeutic potential of Cannabinoids, since we have already proven in pilot experiments that this group of substances may be extremely helpful for some patients (Jabusch et al. 2004). And finally, I am convinced that new ways of electric stimulation of the motor cortex, such as so called 'Theta-burst' stimulation of the brain, will be a promising means to "force" the neural networks back to a normal function. Besides doing clinical studies it is important to have a regular exchange with colleagues. Therefore, together with Profs Dirk Dressler and Joachim Krauss from the Hannover Medical University, we organize the International Meetings on Treatment of Dystonia. The next will take place from May 9-11 this year in Hannover.

For me, the most important goal is to prevent musician's dystonia. We now have a lot of information, so that we can inform young musicians in music schools about the best way to practice and to avoid overuse, anxiety and perfectionism. This has to be started in infancy. Finally, the role of the societal constraints should

not be neglected. In the past few decades, the classical sector has been inundated by CD-recordings of the supreme virtuosi in all fields of music. They frequently create unrealistic expectations in listeners and interpreters, adding stress for the performers. As a consequence, we therefore should correct our expectations and listening habits, replacing the fascination of mere perfection and virtuosity by the joy of emotional communication shared with the audience and the musicians.

Prof. Dr. med. Eckart Altenmüller, MD, MA
www.immm.hmtm-hannover.de



Eckart Altenmüller

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Sweden

The Swedish Dystonia Association Hosts a Workshop on Physiotherapy & Dystonia

In mid October SDF, the Swedish Dystonia Association, organised a workshop on physiotherapy for cervical dystonia. The target audience was physiotherapists within neurology rehabilitation and the project was collaboration between one of the main partners from the pharmaceutical industry and SDF. One of the goals of SDF is to support the specialist training of physiotherapists throughout Sweden. This will allow our organisation to recommend and refer patients to a local physiotherapist who has experience of dystonia.



Lena Zetterberg, Göran Olson, Ylva Åkerblom, Monika Benson and Anders Johansson

This was the second workshop of its kind and was held at Umeå University hospital, where it attracted participants from the major cities in Northern Sweden. The trainers were two physiotherapists specialised in Dystonia: Lena Zetterberg and Ylva Åkerblom from Uppsala University and neurologist Anders Johansson from Karolinska University Hospital. Anders started off the day by giving a good overview on dystonia, how it is diagnosed, and what treatments are available. Ylva and Lena explained the important role of the physiotherapist when treating a patient with cervical dystonia. The goal is to help and guide the dystonia patient through special exercises to be able to find relaxed positions, strengthen weak muscles, and

ultimately regain control. Being there and having cervical dystonia myself I was invited to be the "demo-patient". I was walking back and forth, standing still, turning my neck left and right so they could all see what cervical dystonia symptoms look like.

Since I am already fortunate enough to have specialised physiotherapy myself, I also shared my own experiences with the audience. For me physiotherapy treatment and training, as well as learning how to deal with dystonia, meant getting tools of my own to do something to help my muscular condition in between the injections. As long as there is no cure for dystonia, physiotherapy may be one of the methods to empower the patient to achieve a better quality of life and run less risk of social isolation and depression.

Göran Olsson, President of SDF and I were both very pleased with the event and the participants' evaluation of the workshop showed that they were very satisfied too. Now we are looking into how we can continue this successful workshop and take it to another region of Sweden to further educate physiotherapists on how to treat dystonia.

Monika Benson

United Kingdom

Dystonia Advocacy on the Web



*Paul King,
Executive Director, The Dystonia Society*

There has never been a better time to be a small patient organisation – the internet enables us to outreach, link together and drive change cheaply and effectively in ways that have never been possible before.

This is especially true for patient groups supporting people with dystonia because the nature of the condition means that the web is highly effective:

Poor awareness and misdiagnosis of dystonia make web outreach highly relevant.

- ✓ The symptoms are distinctive and easy to describe.
- ✓ People with dystonia are widely spread which limits the effectiveness of on-the-ground support but there are enough people with dystonia in each country to make web-

- ✓ based social networking lively and effective.
- ✓ Many people with dystonia are passionate about communicating with each other so forums are well used and informative.
- ✓ People with focal dystonia experiencing onset of symptoms are in an age group used to getting information on the web (although this is less true of blepharospasm).

This article is about some of the ways the internet can be harnessed – it has made a dramatic difference to our organisation in the last 2 years – in expected and unexpected ways. This is not to forget that the internet can never replace face to face and telephone communication and support – computers are not suitable for everyone especially the elderly and those whose dystonia prevents them using keyboards or looking at screens.

Background

The Dystonia Society is a well-established and strong organisation. It has 3000 committed and supportive members, a professional staff team and a brilliant group of volunteers. But it faced a couple of major problems:

- ✓ Despite a lot of good public relations work and the support of a well-known celebrity, awareness didn't seem to improve. Knowledge about dystonia among doctors generally is very poor and the average time to diagnosis was stuck at around 4 years
- ✓ The membership of the organisation had not grown for many years and the average age of members had risen to 65 years. We estimate there are at least 30,000 diagnosed with dystonia in the UK with whom we had lost touch

The internet has helped address these problems – they aren't yet solved but there are strong signs we are on a good track.

Outreach using Google Adwords / grants

Advertising on Google is a fantastic way of reaching out. The adverts only appear when particular search terms are put into Google and you only pay if someone clicks on your advert. Thus you can ensure that each person you bring to the website is interested in what you've got to tell them. In addition, Google generously provide grants of free advertising to charities. These are reasonably easy to get – and mean you can reach up to 200,000 new people per year free!

We focused on people searching symptoms such as “twisted neck”, “muscle spasm” or “eye twitch” (in all we advertise on several hundred different search terms). The results have been stunning – 125,000 each year click on our adverts and 25,000 of these research in detail – reading an average of 5 pages. Given that only 2000 people per year experience dystonia onset, this is a huge amount of information getting out to people who didn't previously know about dystonia. We are careful to discourage self-diagnosis – we emphasise that diagnosis must be done in consultation with a doctor and that final diagnosis of dystonia can only be made by a neurologist or ophthalmologist.

We now hear of a steady stream of people who've been diagnosed as a result of our adverts. Since we started advertising, the proportion of people first hearing about dystonia online has risen from 10% to 30%. Early signs are that diagnosis times may be falling – people diagnosed in 2011/12 are reporting waiting 3 years (1 year quicker than previously) but we'll need to wait a couple of years to see if this is a trend or a statistical blip.

Holding on to people

As a result of Google we now have a very lively website with more than 200,000 visitors per year. We need to stay in touch with as many as

possible. To achieve this we've completely changed our website to make it more friendly and accessible. This doesn't have to be expensive – there is excellent free open source software and lots of good inexpensive software designers. Changing our website, including setting up a forum, cost us only 5000 Euros. An alternative approach is to use one of the many companies who specialise in supporting charity websites – but in my opinion these are best avoided. They'll charge a lot more – and they are often quite inflexible if you want to make changes.

A forum is a great way for getting people to come back to the website – people with dystonia really want to share information and hear the experiences of others. In the first year, our forum had more than 8000 visitors. We had more than 1500 posts and the average visitor looked at more than 20 pages.

To build stronger links, we've set up an e-newsletter. To sign up, all you have to do is give us an email address. The mail can be managed through a free specialist such as Mailchimp – which enables you to track what people are reading. So far we have 850 sign ups growing by 40 per month and 85% of these are non-members. People with dystonia really read the information we send out – the readership level is 15 times better than the average for a non-profit e-newsletter.

Facebook

Facebook is perfect for dystonia. It enables two-way communication between our office and people with dystonia around the UK. We can use it to share articles, stories, news, fundraising events etc. We have 1350 likes so far – but an attention grabbing article can be shared many times and reach 3 to 4 times that number. Our weekly reach is usually between 3000 and 5000.

Facebook advertising is exceptional value for money. You can advertise to those who've listed dystonia as one of their interests but who may not be aware of your organisation. You only pay if they come to your page. Since we started advertising 3 months ago, we've got 500 new likes – at a total cost of 100 Euros. That is an absolute bargain when you think our membership was stuck at 3000 for 10 years!

Conclusion

The online project has exceeded all our expectations. We believe we are speeding diagnosis and, in one year, the number of people we reach through Facebook and newsletters each quarter has gone up from 3000 to 6-10,000. A third of those we reach online are below 35 – and, in the UK, this group is crucial for fundraising (running marathons, going on treks etc).

There have also been other unexpected benefits – calls to the helpline have gone up by nearly 70% and community fundraising is up around 40%. A strong online reach also enables us to collect huge amounts of information for almost no cost (using Google Documents). A recent survey on treatment was filled out by 1200 online – giving us an insight into what is going well (and not so well) that we've never had before.

Huge thanks to Google Grants, to the Medtronic Foundation who have supported this project from the start and to Ipsen UK who have also supported this project more recently. Without their support none of this would have been possible.

Paul King

Delegates gathered in Croatia from



Belgium and Holland



The British Isles



Switzerland and Germany



Scandinavia



Italy, France and Switzerland

Italy

Living with Musicians' Dystonia

At the beginning you just don't take it into account at all. It is like stumbling during a walk, slipping while you are deep in your thoughts. Then you start realising it happens again and again. When you begin to become aware of it, at first you feel puzzled, then concerned. From there on you will never stop any longer.

The first time was in 2000. I suddenly realised that in the opening cadenza of Schubert's Grande Sonata for piano 4 hands, which I had been playing since I was 16, the scales were uneven. Then I also began to slip in simple exercises on the five notes. The third finger could not stay on the keys any longer, but it began to bend by itself, with an autonomous and uncontrolled movement under the palm. I was unable to go on playing.

The more I persisted in practising, the more the finger became ungovernable, unintelligible, stranger, difficult to perceive, but capable of breaking those automatic movements that had always perfectly worked in 35 years of playing.

The problem was so paradoxically powerful to block you on the keyboard. I was so incredulous and powerless that I started confusing and breaking the connections between the fingers. I couldn't even play the simplest of Czerny's studies. It was impossible to play a C major scale as well.

For three years, the condition of my hand got worse day by day. The effort to control my third finger was huge. The more I wanted to raise it the heavier and slower in articulation it became. At last one day it began not to rise any more from the key and to bend tenaciously under the palm.

I have never felt any pain in the hand or finger, but the effort to practice was so heavy that the muscles of the forearm, back and shoulder were completely contracted and the suffering was unbearable.

I tried everything: traditional physiotherapy, acupuncture, Feldenkreis (the only method that gave me temporary relief), massages, many NSAIDs (Non Steroidal Anti-Inflammatory Drugs) and pranotherapy (an alternative medicine practice that consists in the imposition of hands on the diseased part of the body in order to allow the passage of prana ("vital breath") between the operator and the patient's body)! Nothing of these produced any results.

After that I undertook various neurological visits and had therapies. I did see hand surgeons. Doctors made different diagnosis: from carpal tunnel to Gehrig's disease, to "you must look inside yourself"... Two surgeons told me that it could be a third finger tendon instability at the metacarpophalangeal joint level. An operation could certainly work everything out. After many dramatic diagnoses, I thought I had found the solution and in 2003 I underwent the surgery. Unfortunately, after the operation, all my problems increased. Eventually I wasn't able to play at all.

In May 2005, I found out by chance that in Milan there was a conference on musicians' diseases. I attended it in order to see what my hand could be suffering from and that was the first time I heard of focal dystonia in my life. Nobody had ever spoken to me of this disease and did not even know of its existence. I remember watching a movie: a pianist performing Mozart's C major Sonata. Immediately, I recognised my hand watching his right hand at the beginning of the scales. It was me; it was what happened to my hand. Was I suffering from focal dystonia then? I listened to Professor Eckart Altenmueller's passionate speech and what he said was exactly what I was experiencing and living at that moment. I had probably found what the problem was.

In the following July, I went to the "Institute for Music physiology and Musician's Medicine" in Hanover. The diagnosis was immediate: focal dystonia, supposedly the same kind of illness Robert Schumann had.

In September I started rehabilitation with Professor Laurent Boullet who would work in collaboration with the Hanover Institute. First of all I made proprioception exercises, exercises at the piano to help the hand recover the intrinsic muscles, then exercises to establish again the relationships between fingers. I suddenly became aware of the fact that playing 2-3 is not at all the same of playing 3-2 and therefore I began to learn a new technique which follows the principles of a physiological approach to the keyboard (weight, rotation, articulation, use of flexors). One of the basic principles of this re-education is that, if movements are physiological, the brain immediately recognizes them and accepts them.

However, changing a neurological command is a very difficult and slow process. Every day for 5 years I have continuously worked with great concentration on my hand always trying to figure out how to develop the basic exercises. I started having injections of botulinum toxin in 2007 and after each injection I could work more easily for at least three months. The third finger was suddenly lighter and not "rowing against" the recovery of the hand.

Three years later, I was able to play short and simple pieces. At last, on May 19th 2012, exactly after seven years since my last appearance, I came back on stage, in Berlin, on the occasion of a concert organized by DDG (Deutsche Dystonie Gesellschaft)

I have not finished my job yet. I still have to completely recover, but the good thing is that I have started to give concerts again. Now I am also working on prevention so as to make musicians aware of the existence of this disease. The sooner you recognise it, the faster you may recover from it.

From this experience I have learnt to better know myself as a musician and to understand the correct movements, the dynamics of gesture and of posture, which are the basis of a good and effective technique.

Like many other diseases, which suddenly develop in an age when the future in front of you is still full of hopes and ambitions of success, my dystonia has had the power to make me see things in a new perspective. I even started to better appreciate music, to feel more deeply the wonder of it, to enjoy playing it like never before.

Cristina Frosini



Cristina Frosini and Massimiliano Baggio

London School of Economics and EFNA organise course on HTA – Health Technology Assessment

For three days in September, I attended the course in Health Technology Assessment (HTA) in London, to learn more about what patient organisations can do to be able to influence decision-makers regarding health care. The course is a joint initiative and a collaboration between the London School of Economics (LSE) and The European Federation of Neurological Associations (EFNA).

Professor Panos Kanavos at LSE has, together with EFNA and professional patient advocate Jean Mossman, developed a program and created a "toolkit", that will help us laymen better understand and apply "Health Technology Assessment" (HTA). The course aims to provide representatives from various European patient organisations an opportunity to learn more about HTA to allow them to take a more active role in healthcare decisions on a political level in their home countries.

I assume that you, as I did, now ask yourself: what on earth is HTA? "Health Technology Assessment" is not what you first might read from the words. It has nothing to do with "technology" in the sense of i.e. evaluating electronic devices. HTA refers to the processes used in a society to be able to evaluate and determine where and how much of the financial resources should be allocated within a specific area. It could be whether to invest in using a new drug or new treatment, or to change the existing processes and working methods.

It quickly dawned on me, as for the 20 other participants, how complex the subject actually is. At times, the lectures were very emotional, especially when Jean Mossman showed a documentary about a cancer patient's struggle to get the decision-makers to accept a new cancer drug to be launched on the UK market.

The film raises the question of resource allocation and what it actually means. As with all expenditures of a society the resources for health care are regulated by the state budget. The limitations are the result of often quite lengthy and careful considerations by decision-makers on where the money will be spent most effectively. An example of such a difficult consideration is whether to prolong a cancer patient's life by 1-3 years with a new medication? Or instead, to save an infant from an inevitable early death by equipping the local neonatal unit with new equipment? These are difficult choices that healthcare decision-makers in the UK and throughout Europe must determine on a regular basis.

How do you decide who deserves to live and who shall die? To help their discussions the decision-makers have developed a system to measure individuals' quality of life. This system is called QALY and aims to consider as many factors as possible in order to get an overall idea of the individual's situation. It involves measuring pain, estimating the possibility to participate in social life, work capacity, being able to care for one's family, mobility and so on.

Life quality is faced against the cost of healthcare and what an individual is expected to contribute to society for the remaining part of his or her life. As you can imagine children and young people will often be rewarded by the system since they are expected to be healthy and productive members of society for many years to come. A cancer patient who is 60 + years of age and receives a disease-modifying drug will, in fact, face an inevitable darker future despite gaining an extra 1-3 years of life. There are many opinions about this system and there are certainly improvements that can be made, but for the time being this is what we have to work with.

It's very difficult to stay emotionally neutral when these issues are discussed, especially when it has to do with children, but Jean emphasized the fact that that's exactly how we need to act. To be as efficient as possible in our work as representatives of patient organisations, we must learn to put emotions aside and focus on professionalism in this context. It is very important to prepare carefully with plenty of good arguments, evidence and data, such as results from statistics and surveys.

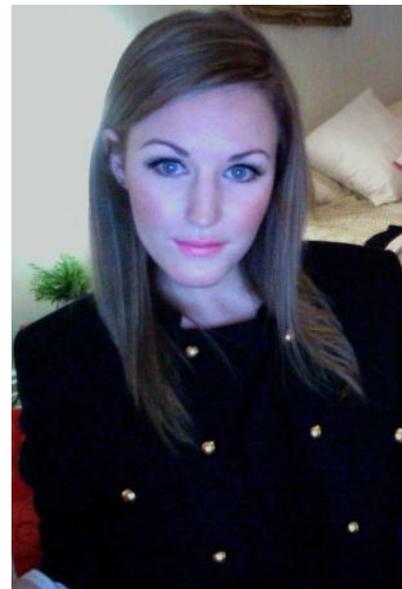
Panos and his team of graduate students from the LSE, as well as guest speakers from across Europe, did an exceptional job with their presentations, and all together we had many interesting discussions. But the course in general was on quite a high level and, even for me as an economist, could sometimes be difficult to keep up with. My biggest lesson from these three days was HOW MUCH MORE there actually is to learn. We encountered the tip of an iceberg; the iceberg itself is, in fact, enormous and affects each one of us in some way or another, today or later in life.

LSE and EFNA have tried to cover as much as possible during the course, but I cannot help but ask myself if they "served us more than we could chew"? At the time for evaluation of the course I raised two questions: the first one regarding the advanced level of the course and what they expected of us within our organisation, when we go back home to our countries?

The second question was about something that I felt was raised a lot in other contexts during the lectures, and that was measurability. As a health economist, Panos spoke often about the measurability of processes?

Similarly, I raised the question about this program. The HTA course has been held for several years, but have we actually seen any measureable results and improvements? According to Panos and EFNA, no such measurement has been performed yet. The course was rewarding and I feel privileged to have been able to attend. But my advice as a business economist would be to simplify the content of the course and set up some parameters to measure the effectiveness of this initiative. Economics is about conserving resources, doing the most with what you've got, and as we all know, there is not much money in our nonprofit organisations. There is no shying away from the fact that this is a fairly lavish initiative. Therefore, I ask the rhetorical question: is this really where the money does the most good?

Amanda Benson



*Amanda Benson,
Swedish Dystonia Association*

Patient Link Workshop Brussels

On 15 – 17 November leaders of patient organisations were invited by the Medtronic Foundation to attend the latest in the biennial series of Patient Link Workshops in Brussels. Several national patient organisations were present, representing a variety of conditions such as Parkinson's, MS and Dystonia. Countries represented included Norway, Finland, Denmark, England, Ireland, Germany, France, Spain, Italy and Switzerland. There were also a few delegates present from pan-European umbrella organisations, including Dystonia Europe.

There was an interesting programme, with two main topics.

The first: How does the European lobby work?
The second topic: Use of social media by patient organizations.

There were several interesting speakers making presentations on these two topics in greater depth.



Nicola Bedlington European Patients' Forum, David Bowe former member of European Parliament, Jessica Cole parliamentary assistant to an MEP, Mihaela Militaru, adviser to an MEP, answering questions on European Patient Advocacy.

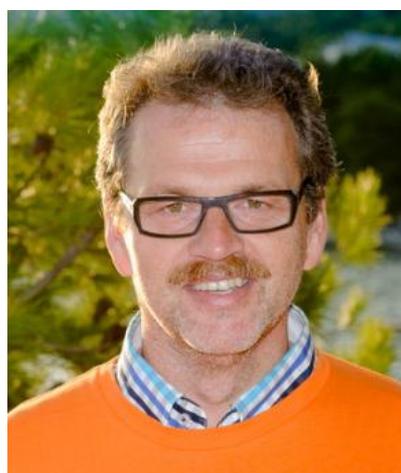
Lobbyist David Bowe explained how the European Commission, the European Parliament and the European Council interact with one another, and with citizens and organisations which wish to influence them. He explained how the patient organisations can lobby in the most effective way. Set a clear and realistic lobbying

goal. Bring useful information to the European officials and politicians by providing possible solutions to the problems you are highlighting. Aim your efforts only at the European officials and politicians who are actually involved in the issue you want to talk about.

Several social media experts explained the different aspects of the use of these communication tools. Paul King of the Dystonia Society gave a wonderful presentation on how small patient organisations can use the Internet effectively and at little cost. By using Google optimisation, The Dystonia Society was able to increase its ability to attract undiagnosed patients in the UK. People were also reconnected. By using the Internet thoughtfully, a patient organisation can build a long term relationship with various stakeholders.

In addition to the programmed sessions, the Workshop offered the opportunity to network with speakers and patient leaders from other fields, as well as to talk with representatives of sister-organisations to discuss possible collaboration.

I am looking forward to the next meeting.



*Robert Scholten
Chairman Dutch Dystonia Association*

20th Anniversary of Dystonia Europe 1993-2013, Edinburgh, Scotland

6-8 September 2013 Dystonia Europe will be celebrating its 20th anniversary. Plans are already being made for this very special event to bring Dystonia Europe stakeholders together.

Other details will be published as soon as possible. Throughout the year of 2013 DE will participate in different activities to raise awareness of dystonia

Dystonia Europe on Facebook

We use Facebook as a tool for communication; to spread information and spark conversation. Get the most recent updates and a chance to connect with others. The page has a little more than 230 followers and you will find it on www.facebook.com/dystonia.europe

Like us on Facebook today!

Dystonia Europe's new website

Right before Christmas the new website was launched at: <http://dystonia-europe.org/>

David Marsden Award — 2013

We are delighted to announce that the amount of the Award for 2013 has been increased to €10,000, with the generous support of Ipsen Pharma.

The award was introduced by Dystonia Europe in 2003 and is presented every two years to stimulate research on dystonia, especially by young scientists in Europe.

Professor David Marsden (1938 – 1998) was one of the leading neurologists in Europe and Dystonia Europe wishes to honour the enormous part he played in developing knowledge of and interest in dystonia.

We invite submission of papers for The David Marsden Award 2013. More information about application procedure on our website: <http://dystonia-europe.org/activities/awards/>

If you have any questions please contact the Secretariat at sec@dystonia-europe.org

Over 1000 cervical dystonia patients worldwide in one survey

The International Cervical Dystonia Patient Survey was promoted all over the world and on-line until December 31st. Some weeks before Christmas the goal was reached and 1000 cervical dystonia patients worldwide had answered the questions about their expectation on treatment and the relationship with their neurologist. The results of the survey will be published in full later this year, following the completion of the survey and analysis of all data collected.

Thank you again for your help and support with promoting the survey within your country.

12 January - DE board meeting, Brussels, Belgium

9 March - Global Neuro Summit 2013, Milan, Italy

8 May – Pre-congress Rehabilitation and Physiotherapy in Dystonia, Hannover, Germany

9- 11 May 2nd International Conference on Treatment of Dystonia, Hannover, Germany

31 May-1 June – The 4th Workshop on dystonia: Circuits and Pathways in Dystonia and Parkinsonism, Rome, Italy

16-20 June 17th International Congress of Parkinson's Disease and Movement Disorders, Sydney, Australia

5-8 September Dystonia Europe 20th Anniversary and General Assembly 2013, COST Training School, Edinburgh, Scotland

21-26 September World Congress of Neurology in co-operation with EFNS, and presentation of David Marsden Award 2013



SECOND INTERNATIONAL CONGRESS ON TREATMENT OF DYSTONIA

2013

For all who take care of people with dystonia

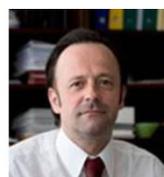
**Second International Congress on Treatment of Dystonia together with
first International Conference on Rehabilitation of Dystonia, May 8-11, 2013 Hannover, Germany.**

Dystonias are amongst the most common movement disorders. Botulinum toxin and deep brain stimulation have revolutionized their therapy. However, there are still considerable unmet therapeutical needs. This was the reason to organise the First International Congress on Treatment of Dystonia in the year 2010. The response was overwhelming: More than 450 participants from over 45 countries came to Hannover for an intense 3 day program.

With this encouragement we are now calling for the second congress of this series. With 3 years in between we believe there is now ample new data to discuss. For the first time we are able to reach out to rehabilitation: The First International Conference on Rehabilitation of Dystonia will be incorporated as a pre-meeting satellite event.

We hope that this meeting will continue to serve as an open platform for all of us who want to collaborate for improving the future of patients with dystonias.

Information and registration at: www.treatment-of-dystonia.org



From left: E. Altenmueller, D. Dressler and J.K. Krauss

Partners

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, EFNS – European Federation of Neurological Societies, EBC – European Brain Council.

And also: Allergan, Ipsen Pharma, Merz, Medtronic, Medtronic Foundation

Members

Dystonia Europe has member organisations from the following countries:

Austria, Belgium, Croatia, Denmark, France, Germany, Ireland, Italy, The Netherlands, Norway, Poland, Portugal, Spain, Sweden, Switzerland and the UK

Donations & Support

All the work and activities of Dystonia Europe is funded by membership fees, individual donations, various grants and organisational 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!

Board of Directors

Dystonia Europe is governed by a volunteer Board of Directors.



*Monika Benson, President.
Sweden*

Monika was elected president of EDF, now Dystonia Europe, in 2007. She was re-elected for a second term in 2010. 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.



*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,
Web-master & 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 the Dystonia Europe website and the Newsletter.



*Alistair Newton, Executive Director.
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 has been our Executive Director since 2001. Alistair also co-founded EFNA – 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 EBC- the European Brain Council, and has been a board member and Treasurer ever since. Alistair has had cervical dystonia for 30 years.



*Amanda Benson, Communication
Advisor, Sweden*

Amanda Benson is a communication and social media consultant with a business degree from Lund University in Sweden. She runs her own business – B|Social Sustainability and Social Media Consulting and advises DE on various communication matters.

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Secretariat & Communication

Secretariat

Dystonia Europe
37 Square de Meeus, 4th Floor,
B-1000 Brussels, Belgium
www.dystonia-europe.org

Executive Director
Alistair Newton
Tel: +44 773 662 5450
E-mail: alistair@newton1.co.uk

Communication

Web-master & Newsletter
Sölvi E. G. Engeland, Norway
E-mail: g-engela@online.no

Communication Advisor
Amanda Benson, Sweden
E-mail: benson.social@gmail.com
www.bensonsocial.com

Photos from Croatia:

Stephan Röhl
E-mail: info@stephan-roehl.de
www.stephan-roehl.de

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