

Partnerships for Dystonia in Europe

DYSTONIA EUROPE NEWS

Summer 2013

Happy 20th Anniversary
Special Greetings from former Presidents!



DE members gathered in Bol, Croatia in 2012.

www.dystonia-europe.org

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

Secretariat & Communication

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Monika Benson

Dear all,

It's with mixed feelings I write to you my very last President's message. After being elected President of EDF – European Dystonia Federation - in Vienna in 2007, my two terms of 3 years each will soon come to an end.

It was first after serious consideration, and good advice from people around me whom I value very much, that I put myself forward for the nomination to the EDF Board and the position as President. Looking back today I am very grateful that I was elected for this task. For the last six years I have been able to work for people with dystonia not only in Sweden but also in the other countries of Europe. I have experienced challenges but also inspiring encounters and I have met some amazing people – all thanks to dystonia.

When the opportunity was given to me a year and a half ago to lead the project of COMPASS I was fully committed to move the work within the field of dystonia in Europe even more forward, focussing on raising awareness across Europe, strengthening the relationships with sponsors,

promoting dystonia research, and reaching out to dystonia patients in countries still lacking dystonia support groups. It's my view that wherever you live in Europe as a dystonia patient you should not feel alone and you should have somewhere to turn to for support. Dystonia Europe has been to Lithuania, Russia and Czech Republic during the past year, to meet patients and physicians and to inspire and motivate them to create dystonia patient groups, which I hope to see being established in the near future.

A major makeover of the organisation took place two years ago when name, logo and colours were changed. I am very grateful for the valuable and professional input that was offered to us pro bono through a very prestigious public relations company in Sweden. The 'branding' brought new energy and inspiration to our organisation. At last year's Annual Conference and General Assembly in Bol, all participants were given Dystonia Europe t-shirts in orange or red, and the photo shoot by a professional photographer turned out to be a happy team-building session. We are a great team of 18 member groups from 16 countries with different languages and cultures but because of dystonia we are like one big family. And we need to be – by coming together we get stronger and our voice is better heard, and that is the only way we can make dystonia more known, as we move into the 3rd decade of our existence.

The selection of Dystonia Europe to be the grantholder of the 4 –year COST Action "The European Network for the Study of Dystonia Syndromes" brought more responsibilities for DE, but also the benefit of working even more closely with dystonia specialists from all over Europe. The goal of the project is to encourage networking among dystonia researchers to inspire to new research partnerships as well as training of the young medical profession in the challenging field of dystonia.

Nothing of this could have been accomplished if it weren't for all the wonderful people who have contributed to the creation of Dystonia Europe. First of all I would like to thank all the members of EDF who, at the GA back in 2007 believed in me and elected me the next president after Didi Jackson. I would like to thank the always supportive DE board for their fruitful guidance and clear views; our Communication Adviser Amanda Benson for her "young" and modern input, thinking and advice that took the look of DE to another level; our Executive Director Alistair Newton for his never-ending dedication and whose 20 years of experience in patient advocacy on the European level has contributed so much to establishing the reputation of

Dystonia Europe among other European organisations; our MSAB for their expert advice in medical matters; our sponsors and partners who value patient opinion and involvement for the benefit and well-being of dystonia patients all over Europe today and beyond.

Last but not least I want to thank my dear family: my four lovely daughters and my parents, who have had to listen to all my talk about dystonia, but all along have been there to support and encourage me throughout these years.

I wish my successor and Dystonia Europe all the best for the future, and I look forward to playing a part in its continued success.

*Monika Benson
President*



EDF members at the annual meeting 2010 in Malmö, Sweden.

Message from the Founder President



Alistair Newton and Tom Warner

As Dystonia Europe reaches its 20th Anniversary, I've been thinking of the many people who have been involved along the way, and the many events which we have organised or in which we've participated. So many colleagues – patients, clinicians, researchers, industry personnel and friends..... Without the input, hard work and goodwill of these many individuals, we would not have been able to contribute to the events nor would we be able to celebrate so much Achievement and so much Hope in our special Conference in 2013. Behind me too, all of this time, my dear wife Pat and our daughters Claire and Gill, have given me enormous support and have patiently endured my frequent absences from home to travel to meetings across Europe. They have even been forgiving of my constant activity on the work of Dystonia Europe while I am not travelling! I could not have continued without their love and understanding.

After several preparatory meetings, European Dystonia Federation was founded in Spoleto, Italy, in June 1993. There, I was elected as the first President, and the real work began! Vice Presidents Laura Latini from Italy, followed by Feli Justo Alonso from Spain and, later, Didi Jackson from Germany, plus other Board members, helped us progress from year to year. Finance, as always, was difficult. In the early days, there was no internet or email, and international communications were much more complicated than they are today! The national patient organisations of many other countries have joined us along the way, and we hope to achieve a total of 20 member organisations by the time of our 20th Anniversary General Assembly in September this year. I thank all of our Board members and members'

delegates over the years, especially another old friend – our current Vice-President Prof Maja Relja. Maja and I are the only two people left working still for Dystonia Europe, from the founding group in Spoleto in 1993.

Over our 20 years of life, European Dystonia Federation, now Dystonia Europe, has become a strong and credible partner for several organisations. Many eminent clinicians and researchers, and their organisations and networks across many countries, have given us their invaluable support in various aspects of our activities. We are extremely grateful to them all – particularly to the eminent dystonia specialists on our Medical and Scientific Advisory Board who have contributed so much to our efforts to promote research, and in many other ways. Of all these medical professionals, Professor Tom Warner in London must have special mention, as his ever-available and thoughtful advice and his friendship have been requested very often, and given generously each time during all of those 20 years. The tremendous contribution made by Tom and all our scientific advisers, for the benefit of all dystonia patients, has been very much appreciated.

The new Dystonia Europe Research Network, funded by the COST inter-governmental organisation, is chaired by another long-standing supporter and friend of Dystonia Europe, Professor Alberto Albanese. Dystonia Europe acts as Administrator and Grantholder of the Network. With this latest partnership, and so many other activities over 20 years, we have continued to work towards the achievement of our aims.

These aims are to be active in areas of opportunity at the international level which are just not available to dystonia 'stakeholders' which operate nationally, and to promote the longer-term interests of the patients.

And what can I say about our sponsorship partners? Only that so many people from "the industry" have been extremely supportive at different times and, without them we could have done very little. The industry is often criticised, but we all know that so many of our contacts do their best for us because – personally - they want to help us. That altruism combines well with the collaborative practical activities which make their support possible, and we are grateful for all of it.

In 2001, I retired as President, and was succeeded by Didi Jackson - while I remained closely involved as Executive Director. Before and after that changeover, she and I worked together closely and travelled to many conferences and meetings, where she proved to be an excellent ambassador for dystonia in Europe.

Didi introduced the David Marsden Award in 2003, and this has been a very successful promotional project for dystonia amongst young scientists. She was also deeply involved in the organisation of our successful international dystonia medical conference in her home city, Hamburg, in 2008 - where we welcomed 250 medical professionals from many countries. As Vice President and then as President, Didi contributed greatly to the continued development of our pan-European work. On her retirement from the Presidency, Didi was elected as a well-deserved Honorary Member of European Dystonia Federation.

The Hamburg conference led to our even greater success in Barcelona in 2011 where, in partnership with the Dystonia Coalition and Dystonia Medical Research Foundation, we created the 5th International Dystonia Symposium. This time, over 550 medical specialists from 39 countries attended and the event has been described as the 'turning point' for dystonia. Fundraising for an event like this, costing hundreds of

thousands of Euros just to 'break even', is always a big challenge and something of a risk. At exactly the right moment, we received a message from our good friends Greet Ruelens and Lieve Van Gorp of the Foundation for Dystonia Research (FDR), offering us a substantial grant to kick-off the funding, and giving us the confidence to begin the arrangements. Their generosity and insight contributed greatly to an event which has helped considerably to stimulate the growth of interest in dystonia in the scientific professions, bringing real benefits to dystonia patients in the long run.

In 2007, Monika Benson was elected as our President and is now about to retire from that position after a tremendously successful 6 years. It has been an enormous pleasure to work with her during that time, and to enjoy a partnership which has produced great change as well as great success. Monika's hard work, enthusiasm, vision and calm determination have provided the main push to modernise which has transformed an outmoded European Dystonia Federation into the new Dystonia Europe, and we are now in really good shape to face the next 20 years!

At this 20th General Assembly, I will retire from the job of Executive Director, and I am delighted that the Board has appointed Monika to the post as her many capabilities and enthusiasm are what it needs. However, it gives me great pleasure to know that I will not lose touch with DE. As a Board member, I will work specifically to continue the liaison with the European research network.

I have enjoyed so many wonderful experiences, and I greatly value the friendships and stimulating working relationships which I have been fortunate to have with so many people in the world of movement disorders over these 20 years. As I take a step back from the 'front line', I look forward to seeing the continued progress of Dystonia Europe and the success of its activities in the years ahead, and I offer all those friends and colleagues my grateful thanks and my warmest good wishes.

Alistair Newton

20 Years EDF European Dystonia Federation A wonderful Chapter in my Life with Dystonia



Didi Jackson

I am sitting here, thinking back on 20 years EDF. I know the name has recently changed to Dystonia Europe, but I grew up with EDF. 1993 was the year EDF went public and several countries in Europe, like I in Germany, also formed their Dystonia Society. Only the UK was well ahead and the Dystonia Society had decided to share their experiences with others. What a good idea! The inaugural meeting took place in a small place in Italy, called Spoleto, and 9 delegates from 9 European countries were delighted to travel to sunny Italy and find out about EDF. The idea of EDF was not only to have close contact to existing Dystonia Societies in Europe and assist new member countries to start, but also to spread the knowledge of Dystonia e.g. at the EU, inform WHO, have a European medical panel, apply for grants, establish close contact to DMRF (Dystonia Medical Research Foundation) and WEMOVE in USA. (Photo)

I remember that we all had plenty on our hands with our newly established national group, but Alistair Newton, who chaired the meeting, made

it interesting enough for us to support EDF. Well, a lot of work was ahead of those on the EDF Board and Alistair Newton, as President for so many years, was and still is the ideal person to take on these difficult tasks.

To keep up the personal contact with the national groups EDF invited one delegate of each national group once a year, not only to listen to medical talks, but to get to know each other, share experiences and just have a good time. I can tell you that over the years we did have wonderful meetings. I remember at one of our earlier meetings Alistair picked up the delegates in a VW bus from Heathrow Airport and drove them personally to the meeting place at Beaconsfield. Another time we nearly got lost in Kloster Eberbach in Eltville on the Rhine, as it got dark too quickly, and then our 10-Year-Celebration at the Caledonian Club in London with Bag Pipes and Haggis at Dinner and delegates in their national dress – at least the Norwegian delegate in a most colourful dress and the German delegate in Lederhosen complied.

This was the social part of EDF. The meetings of the Board of EDF – twice or three times a year – were really hard work. Over the years so many dedicated people only mentioning Laura Latini, Feli Justo Alonso as past vice-presidents and never to forget Ginger Butler held the flag of EDF high. We had good and successful times, but also difficult ones especially in finding sponsors to support us financially. At one stage we had our doubts whether we could carry on. But then came one of those moments I will never forget – out of the blue or 'from above' we received a life-saving donation from a Swiss person, who did not want to be named. Bless her or him, - what a wonderful feeling it was and how grateful we were to be able to continue our task to make Dystonia public in Europe!!!

Another important activity was to represent EDF at neurological congresses. Alistair and I spent many hours and days all over Europe and USA, displaying our brochures at an Info-Stand, talking to doctors and sponsors. What always upset us was that Dystonia was never a big topic at those meetings, and I always had a dream of organizing a European congress for doctors solely on Dystonia. At the end of my time as President of EDF I was able to realize this dream - with the support from the EDF Board and our medical advisory board. The 1st European Congress solely on Dystonia called 'Dystonia Europe' organized by a patient group took place in my hometown Hamburg in 2008 and much to the surprise of the experts over 250 doctors from all over Europe,

even from Ghana and Australia attended. It was a big success and we wish we could do it again.

My years on the EDF Board from 1995 – 2007 – some as Treasurer, some as Vice-President and six as President I will always cherish as an important chapter in my life, caring for others, getting to know people from all over the world, worrying, laughing and sometimes even crying. I am sure EDF – now Dystonia Europe - will carry on the valuable and important work! This is only possible, because dedicated people with Dystonia are willing to give their time to spread awareness and inspire doctors to find a cure for Dystonia.

Didi Jackson

Past President and Honorary Member



Founding meeting – Spoleto, Italy, June 1993.

Left to Right Back Row: Didi Jackson (Germany), Alistair Newton (UK), Feli Justo Alonso (Spain), Alan Leng (UK), Gunilla Noren (Sweden) Front Row: Tore Wirgenes (Norway), Jean-Marc Bildan (France), Laura Latini (Italy), Maja Relja (Croatia), Beppy Smitshoek (Netherlands)

Second International Congress on Treatment of Dystonia



From left: Professor Joachim Krauss, Professor Eckart Altenmüller and Professor Dirk Dressler

From May 8 to May 11 more than 500 dystonia experts from 45 countries met in Hannover, Germany for the Second International Congress on the Treatment of Dystonia (ICTD). The congress presented all different treatment options for dystonia bringing together neurologists, neurosurgeons, rehabilitation specialists, pediatricians, pharmacologists, neurophysiologists and various basic scientists. 'We believe in this format: A compact congress

dedicated to dystonia alone. All specialists in one room. This guarantees vivid discussions and direct interactions', said Dirk Dressler, together with Eckart Altenmueller and Joachim Krauss organizers of ICTD, all based in Hannover. For the first time ICTD was accompanied by the First International Conference on Rehabilitation of Dystonia. ICTD featured an intense 3 day program including plenary sessions, 9 workshops covering practical problems of botulinum toxin therapy, deep brain stimulation, physiotherapy, experimental therapies and a poster session. 4 industry sponsored lunch seminars and a busy industry exhibition presented the latest aspects of botulinum toxin therapy and deep brain stimulation. Patient groups including Dystonia Europe came for information and networking. Many working groups used Hannover for business meetings. 'We are proud to say that Hannover is now an established station on the international movement disorders circuit', says Dressler. The highlight of the meeting was Dr Stanley Fahn's keynote lecture on the development of the dystonia concept. This lecture will be made available as a free DVD through Merz Pharmaceuticals, Frankfurt/M.

Interview with Professor Dirk Dressler

DE: Professor Dressler, are you satisfied with the meeting?

Dressler: This was the second ICTD we organized here in Hannover. It all started four and a half years ago when I came to Hannover to take over the position as head of the movement disorders section. Hannover just had the right kind of collaborators: Eckart Altenmueller a world-famous expert in musician's dystonia, Joachim Krauss a prolific neurosurgeon and Hans Bigalke one of the fathers of botulinum toxin in Europe: the perfect place to be. Soon we developed the

idea to join forces and to set up a special meeting dedicated entirely to the treatment of dystonia. We wanted to get away from the congresses focused on methods: botulinum toxin therapy, DBS. We wanted to put the patient in the focus: all patients with dystonia, all therapies. We had learned that the often only right combination of treatments produces satisfactory results. Surprisingly, dystonia is still not well presented at international meetings. Usually it comes under 'related disorders' at Parkinson meetings. The number of patients and the tremendous work that is being done in the field merits a standalone congress of this size. We were absolutely sure about this and the feedback we received showed that we were right.

DE: Do these meetings make sense? Do they really help to advance the field?

Dressler: We are sure that these meetings are absolutely necessary. It is all about communication. The breakthroughs occur in the departments and in the labs. But it is at meetings like ours where these results are discussed and that research groups are interconnected. I see science as a large river: keep it flowing and it will bring you to new frontiers. What we have seen in the last years is that the field consolidated. We have established clinical centres. We train young doctors. We try technology and basic sciences. In this way the critical mass increases and a steady flow of knowledge and new insight is generated. Again, interconnecting therapies is very important. This is why we, for the first time, organized a special satellite congress on Rehabilitation of Dystonia.

DE: Where has the progress in dystonia treatment been during the last years?

Dressler: In botulinum toxin therapy we discovered new opportunities by high dose therapy allowing us to treat a much larger number of target muscles than a few years ago. We begin to discuss reduced interinjection intervals to minimize the time patients are suboptimally treated. We liaise with physiotherapists to enhance the results of botulinum toxin therapy. In DBS we explore new targets and we explore new subtypes of dystonia. The area of behavioural therapy is ever creative.

DE: Have you been satisfied with the input from the patient organisations?

Dressler: Patient organisations have played an important role in dystonia for many years. It all started in North America and later came to Europe. Patient organisations have a long history in the civil societies of the anglo-saxon world. In central Europe, especially in Germany, we still believe too much in governments and organized

welfare. So we need to develop the patient organisations further, especially in Europe.

Dystonia Europe has a unique historical opportunity to achieve this.

DE: We saw a lot of activities in musician's dystonia at the congress. Can this help patients with other dystonias as well?

Dressler: There has always been a two-way relationship between general dystonias and musician's dystonias. A lot that was first described in general dystonias was later studied in musician's dystonias. Why not try in general dystonias what has worked for musician's dystonias? Physiologically I always believed that task specific dystonias can teach us so much. As my teacher David Marsden used to say: The problem is that we just don't know to ask the right questions yet.

DE: Anything to add?

Dressler: Thank you to everybody who contributed. Thank you to everybody who participated. In the end the participants are the ones who generated the atmosphere of friendly and open exchange we wanted to provide.

DE: Professor Dressler, thank you very much for this interview.



Professor Dirk Dressler

Second International Congress On Treatment Of Dystonia



Heike Wolf

In 2010 the first International Congress On Treatment of Dystonia was held in Hannover, Germany with overwhelming response which mirrors the fact that dystonias are amongst the most common movement disorders and that there are still considerable unmet therapeutical needs. This is why, three years later, Prof. Dr. Joachim K. Krauss, Prof. Dr. Dirk Dressler and Prof. Dr. Eckart Altenmüller organised the Second International Congress On Treatment Of Dystonia which took place in the Hannover Congress Centrum from May 8 – 11, 2013. Invitations were extended to all who take care of people with dystonia, and a satellite event dealing with the rehabilitation of dystonia was added. Even patients were addressed in an afternoon symposium which was held in German. During the congress an industry exhibition was held and abstracts of the presentations were made available on posters. Patient advocacy organisations were also invited. Dystonia Europe was represented by Monika Benson and Alistair Newton and the Austrian and German dystonia associations worked their information stands side by side, passing out flyers and networking with doctors, physiotherapists and other specialists. Representatives of patient organisations from

other European countries also attended the conference, among them Annika Hagen, the newly elected president of the Norwegian Dystonia Association and Paul King, Executive Director of the Dystonia Society in the UK. The programme included presentations from early morning to late in the evening. Even lunch time was used for symposiums by the three leading manufacturers of botulinum toxin. They provided interesting insights into new studies conducted on their products concerning topics like pain management and better localisation techniques for the muscles affected by dystonia. The first day of the conference was exclusively dedicated to physiotherapy and chaired by physical therapists Teresa Jacobson Kimberley from the US, Heidrun Pickenbrock from Germany and Lena Zetterberg from Sweden. Monika Benson had teamed some of them up at the dystonia congress in Barcelona in 2011. They expressed their gratitude to her and also said that they were very excited for this opportunity to work together.



From the Hannover Conference

They all gave presentations illustrating therapy approaches for different kinds of dystonia including also musician's dystonia. Involuntary muscle contractions cause wrong sequences of movements which have to be erased and

relearned. The necessity of physical therapy for most dystonia patients was stressed and a lot of emphasis was put on the need to find better ways of evaluating the patient's progress. In a workshop "pioneering dystonia physiotherapist" Jean Pierre Bleton demonstrated some of his techniques when treating cervical dystonia and with the help of some invited patients the attending therapists could get an idea of his work and methods.

It is impossible to sum up the great variety of presentations about the treatment of dystonia given during the following three days. However, it illustrates how big this field of science has become and how much need there still is for further research. An interesting new impulse is the development of non-invasive cerebellar stimulation for treatment of focal dystonia. So far effects only last for about three days but the research appears very promising. We also heard that researchers are developing a new kind of Botulinum Toxin A2 which is designed to be more potent and longer lasting than the kinds now

used for therapy. I personally found the presentations about animal research very interesting and I was glad to hear that there is a tendency to reduce the use of animals when manufacturing Botulinum Toxins. There were also lectures about genetic research, Deep Brain Stimulation and the problematic diagnosis of psychogenic dystonia. Large emphasis was put on the treatment of different forms of musician's dystonia. A very special highlight was the speech by Professor Segawa about dopa-responsive dystonia.

The Second International Congress On Treatment Of Dystonia brought together experts from all over the world determined to collaborate in order to improve the lives of patients with dystonia. We would like to thank the congress organisers and the participants of this event for their ongoing commitment and wish them a lot of success in their fields.

Heike Wolf

Board member of DDG, Germany

First International Conference on Rehabilitation of Dystonia



Anniken Hagen

On May 8, the first conference in history exclusively on physiotherapy and rehabilitation of dystonia, was held in Hannover, Germany. Studies and research results were presented.

Unfortunately there are varying quality in the studies that have been published, and not all studies are evidence-based. Personally, I missed more practical and concrete solutions of physical therapy and effective techniques. Fortunately, it was offered with a patient demonstration in one of the workshops. Here, specific treatment principles were demonstrated.

Physiotherapy in cervical dystonia

Physical therapy plays an important role for focal dystonias. Abnormal postures of cervical dystonia vary according to the muscles involved. One of the physiotherapy options widely promoted is relearning normal posture by controlling muscular strength. Jean Pierre Bleton is probably one of the most well-known and experienced physiotherapists in Europe, in terms of functional treatment of dystonias. He has prepared a series of exercises for the treatment of dystonia, including cervical dystonia and writer's cramp.

The exercises focus selectively on the underperforming muscles. The head is strictly maintained in the opposite position to the dystonic posture in order to contract the corrective muscles and not cause an overflow to the dystonic muscles. The position of the eyes plays an important role. Directing the line of sight to the side opposite of the cervical dystonia reduces the spasm and promotes correction. Recent studies have shown a longer duration of clinical benefit and a lower dosage of botulinum toxin at reinjection.

Jean Pierre Bleton showed his techniques during a patient demonstration. The patient sat in front of a mirror, while J-P Bleton was standing behind the patient. The communication during the patient demonstration occurred partly through the mirror and partly through an interpreter because of language challenges (German patient). By using slight touches on the face and on the head of the patient, J-P Bleton was directing the patient into different movement pattern. J-P Bleton's motto is "turn the face, don't turn the neck». As I said before, the position of the eyes plays an important role. It was really exciting to see Jean-Pierre Bleton practice his methods!

Recent studies have shown that daily repetition of exercises such as J-P Bleton describes, combined with botulinum toxin, may help the patient to need lower dosage of botulinum toxin for optimal treatment results.

Physiotherapy in writer's cramp / hand dystonia

Writer's cramp is a task-specific form of dystonia with abnormal movements and postures of the hand and arm during writing. The ability to regulate and adjust grip force according to visual and proprioceptive information seems to be affected in both symptomatic hands. Therefore, the current physiotherapy programmes are established with the aim to improve independence and precision of fingers and wrist movement. A better adjustment of the finger pressure and force on the pen is obtained by modifying the pen grip. In a pilot study, the

magnetoencephalography (MEG) somatosensory map of the cortex controlling the dystonic hand, is "normalised" for the patients who had recovered to near-normal handwriting after rehabilitation. Nevertheless, the beneficial effects of physiotherapy vary from one clinical feature to another.

A pilot study shows excellent results of handwriting which is almost normal with active rehabilitation and by changing the grip of the pen. Nevertheless, the beneficial effects of physical therapy varies, depending on which muscles are involved and the severity of wrong position of wrist and fingers.

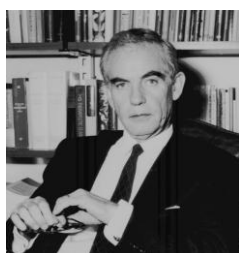
Research on physical therapy in the treatment.

Physiotherapist Teresa Kimberley has conducted exciting research on how physical therapy affects brain activity. There has been significant scientific advances in Neurophysiology involving greater knowledge of focal dystonia. Research on rehabilitation of dystonia is still only in its infancy. Clinically there are still confusion about effective techniques and the mechanisms of benefit. To improve our understanding of rehabilitation and apply scientific principles for functional treatment of focal dystonias, it is important to understand the changes that occur in the brain.

Physiotherapist Lena Zetterberg has evaluated several studies on the effect of physiotherapy in cervical dystonia. There is currently insufficient scientific evidence to determine the effects of physical therapy in the treatment of cervical dystonia. Large, well designed, randomized controlled trials with cervical dystonia are needed, before the outcomes can be confirmed. Research into cervical dystonia and physical therapy has only been going on for the last ten years with a few published studies. More studies with reliable designs are needed to develop and confirm the effects of present and new rehabilitation strategies for cervical dystonia.

Anniken Hagen, Physiotherapist and Chairwoman of the Norwegian Dystonia Association.

The David Marsden Award 2013



Prof: David Marsden

The **David Marsden Award** was presented for the first time in 2003 by the European Dystonia Federation (now - Dystonia Europe), and in 2005, 2007, 2009 and 2011. Professor David Marsden (1938 – 1998) was one of the leading neurologists in Europe and DE wishes to honor the enormous part he played in developing knowledge of and interest in dystonia.

The **Award of €10,000** is intended to encourage research into dystonia in all European countries, especially by young scientists.

We congratulate this year's winner, Dr Katja Lohmann, of the Institute of Neurogenetics at the University of Luebeck, Germany, for her paper entitled: ***Whispering dysphonia (DYT4 dystonia) is caused by a mutation in the TUBB4 gene.***



Katja Lohmann

The Adjudication Panel of our medical and Scientific Advisory Board assessed this paper to be the best of those submitted for the Award, and Dr Lohmann will present her research during our 20th Anniversary Conference in Edinburgh, on 6 September 2013.

Dystonia Europe is grateful for the support provided for this Award by Ipsen

Dystonia Europe Award for the best Rehabilitation Poster

The award was given to Jean Pierre Bleton from Sainte-Anne Hospital in Paris, France, for his poster: *"Impaired force control in writer's cramp showing a bilateral deficit in sensorimotor integration"*. Jean Pierre Bleton's many years of dedicated work to improve the lives of people with dystonia, has contributed to the development within the field of rehabilitation /physiotherapy for dystonia.



Monika Benson and Jean Pierre Bleton

Dystonia Europe President Monika Benson presented the award to Jean Pierre Bleton who commented that prize will further support the research of his team in Paris.

Monika Benson

Dystonia Europe at Global Neuro Summit in Milan

Dystonia Europe President Monika Benson and Executive Director Alistair Newton were invited to the Global Neuro Summit being held beginning of March in Milan. The 2-day-conference included a programme with speakers from both the US and Europe. 500 participants took part of various presentations and some of the highlights included:

- Relevance of 3-month injection intervals
Patients' expectations and satisfaction with botulinum toxin therapy
- How to improve patients' satisfaction with botulinum toxin therapy
- The benefits of ultrasound-guided injections

Interactive workshops: exchange on botulinum toxin experiences and relevance and use of clinical scales in daily practice.



Christina Frosini and Alistair Newton



There was also the opportunity to meet up with Cristina Frosini. Cristina is a music professor and pianist in Milan. She has musician's dystonia and in the last issue of DE News she shared her story. She very much wants to help out to raise awareness of dystonia.

Monika Benson

Dystonia Europe in Czech Republic

In mid May, Dystonia Europe Executive Director, Alistair Newton, and President, Monika Benson travelled to Prague. They had been invited by Dana Okparaigwe of Ipsen Pharma in Czech Republic, and she had made all the arrangements.

In collaboration with the Association of Innovative Pharmaceutical Industry of the Czech Republic, patients and physicians had been invited to a meeting on dystonia in the Chamber of Deputies in the national Parliament. The theme of the meeting was "Living with Dystonia". After a welcome and a short introduction by Patricia Kotalíková, Professor Petr Kanovsky of the Neurological Clinic of Olomouc gave an overview of dystonia – the various forms, treatment options and research initiatives.

Then followed a presentation by Monika Benson who told her story of Living with Dystonia. She explained how one of the key factors to her recovery was her involvement in patient advocacy work. She presented the work of the Swedish Dystonia Association as an example of the importance of a national dystonia group and what they can do.

Alistair Newton went on to present the work of Dystonia Europe and how being united on the European level and international collaboration can increase awareness and stimulate research.

After the Question and Answer session refreshments were served while networking. A few patients and neurologists discussed the possibility of forming a dystonia patient group. Any readers who are interested in more information about the group in Czech Republic should contact the Dystonia Europe Secretariat at sec@dystonia-europe.org and your information will be forwarded to the contact person in Czech Republic.

Monika Benson



AMADYS board of directors

Dystonia Europe at AMADYS GA and Annual Meeting 2013 in Marseille

Dystonia Europe President Monika Benson was invited by AMADYS (the French Dystonia Association) to attend their General Assembly and Annual Conference in Marseille, on the last weekend of May. About 130 people attended the one-day meeting that included very high quality presentations on dystonia, treatment and research.

This year AMADYS is supporting two research projects through the Breughel Prize. The winners - Professor Pierre Burbaud from Bordeaux and Doctor Sabine Meunier from Paris, presented their research.

DE was included in the morning session where Monika Benson presented the work and plans of the organisation. In 2014 it has been proposed by AMADYS President Stéphanie Fréhel, that the DE Annual conference and General Assembly should be held in Paris.

Stéphanie Fréhel was re-elected President for a new period, and Professor Marie Vidailhet was elected president of the AMADYS Scientific Advisory Board.

Congratulations to AMADYS for a very well organised and very interesting meeting.

Monika Benson

EPF 10th Anniversary Conference “Towards active patients’ involvement in healthcare”



Robert Scholten

On behalf of Dystonia Europe I attended the EPF, European Patients Forum, 10th Anniversary Conference on May 23rd in Dublin. The conference was a collaboration between the European Patient forum (EPF), the European Federation of Neurological Associations (EFNA) and the Neurological Alliance of Ireland. The theme of the conference was patients’ involvement in healthcare.

Tonio Borg, EU Commissioner for Health, talked about the important role of patient organisations on the EU level as well as on a national level. Tonio Borg: “The patient should be the beginning and the end of all the discussions on healthcare in Europe”. Then followed several patient groups’ presentations on good practices. The European

Cancer Patient Coalition showed how cancer became a European healthcare priority. EMSP, The European Multiple Sclerosis Platform, talked

about early advocacy successes in neurology. The Neurological Alliance of Ireland gave a presentation on Patient Advocacy for Neurological Services in Ireland. GAMIAN, Global Alliance on Mental Illness Advocacy Networks, presented their work and efforts on Mental Health issues at the European level.

In the afternoon there was a plenary debate on how other patient groups can replicate the successes of other patient organisations. What are the opportunities and barriers? Where does solidarity play a key role?

There were also presentations on the work of EUPATI - European Academy on Therapeutic Innovation, and EPRN - the European Patient Research Network (EPRN).



EU Commissioner for Health Tonio Borg

The following day I attended, on behalf of DE, an EFNA meeting on their future position and strategy. It was concluded that there has to be a strong neurological focus in all of their work. For more information on the various presentations please go to the following link: <http://www.eu-patient.eu/Events/EPF-10th-anniversary-celebration-and-Annual-General-Meeting/Presentations-conference/>

Robert Scholten

President of the Dutch Dystonia Association

Dystonia Europe at DDG 20th Anniversary

The last weekend of July the German Dystonia Association (DDG – Deutsche Dystonie Gesellschaft) celebrated its 20th Anniversary. President Ute Kühn was pleased to welcome the 250 participants who had come from all over Germany, for the one-day-conference at the Bucerius Law School in Hamburg. There were also representatives of dystonia patient organisations from other European countries, among them Richard Schierl, President of the Austrian Dystonia Association, and Hanspeter Itschner, President of the Swiss Dystonia Association. Dystonia Europe was represented by President Monika Benson.

All participants were given a booklet "Faces of Dystonia" (that you can read more about on page 26) together with a CD with music from the Musicians Dystonia awareness event in Berlin 2012, and a special brochure of Anniversary Greetings.

The programme included presentations on both dystonia treatment and research. Among the speakers were professor Dirk Dressler and former President of DDG and EDF (now Dystonia Europe) Didi Jackson.

Dystonia Europe wishes DDG Happy Anniversary and all the best in their future work for dystonia patients and their families in Germany.

Monika Benson



Monika Benson, Ute Kühn and Didi Jackson

4th Biennial Workshop on Dystonia: “Circuits and Pathways in Dystonia and Parkinsonism”, May 31 - June 1, 2013, Monte Porzio Catone (Rome)

Workshop Summary



Antonio Pisani

The fourth biennial workshop on dystonia, entitled “Circuits and Pathways in Dystonia and Parkinsonism”, held on May 31st and June 1st 2013, focused on clinical and scientific aspects of

the relationship between dystonia and Parkinson’s disease (PD). Several clinical and experimental observations suggest that dystonia and PD may exhibit common clinical and pathogenic aspects.

Primary dystonia may be linked to genetic mutations, whereas secondary forms of dystonia may be a clinical feature of different neurological diseases, such as Parkinson’s disease (PD), even as a result of side effects of PD pharmacological treatment.

The aim of this round of the biennial workshop was to provide a complete overview of these potential interactions, highlighting the role of the underlying circuits and pathways.

During the first two sessions, the pathophysiology of dystonia (focal and generalized) was considered, and possible similarities with PD were discussed. Cardinal clinical features, age of onset, neuroimaging and neurophysiological data were considered. A complex picture emerged, mostly based on the interpretation of the aspects mentioned. For instance, focal dystonia may represent the early sign of a generalized form, but it may also remain focal forever. Similarly, dopaminergic abnormalities described both in imaging studies and in post-mortem samples have been often linked to generalized dystonia. However, the discovery of the GNAL mutation which is linked to dopamine signalling, and has clinical features that do not necessarily resemble a generalized form, need to be taken into consideration.

Another issue of debate was the possible role of cerebellum vs. basal ganglia in the pathogenesis of dystonia. Also in this case, the recent report of a novel gene mutation in a large population of patients with cervical dystonia suggests caution (Charlesworth et al., 2012). Indeed, the implication of an ion channel, with predominant expression in the striatum, provides insights in novel, alternative mechanisms in the pathogenesis of cervical, and probably more in general, focal dystonia.

These new genetic discoveries during the past few months generated interest and enthusiasm and promoted discussion on the potential functional roles of the gene products. Interpreting these novel mutations is challenging, although it was tempting to speculate that some similarities with monogenic forms of PD may be found. This consideration emerged by analyzing the link between PD-related genes (i.e. parkin, PINK1, DJ1) and the common appearance of dystonia as presenting symptom.

It is definitely too early to attempt to link together the novel dystonia gene mutations, such as GNAL and ANO3, but interesting parallels were proposed and discussed. In this respect, Dopa-responsive dystonia (DRD) which presents with clinical features that include both dystonia and Parkinsonism represents a paradigmatic example of inherited dopaminergic dysfunction. The contribution of neuroimaging and clinical neurophysiology was important, to discuss the potential circuit abnormalities observed in both focal and generalized dystonia.

In the third session, the speakers discussed the pathogenic aspects of levodopa-induced dyskinesias (LID) and dystonia. Evidence was provided that in non-human primates, but also in rodents, dystonia may appear as an early manifestation of LID, although species differences have to be taken into consideration. In this context, besides the well-established role of dopaminergic pathways, the contribution of serotonergic and noradrenergic pathways was described, both in primate and rodent models of LID. The issue of species differences is a major, crucial element, especially when considering the differential innervations/connections between intralaminar thalamic nuclei and neuronal subtypes in the basal ganglia.

The last session debated on cellular and molecular aspects of dystonia. The speakers discussed novel evidence obtained from both non-human primates and rodents.



Antonio Pisani

Some controversies emerged regarding the relevance of the cerebellum compared to the basal ganglia, but, again, a note of caution should be used when dealing with distinct species.

Novel interactors of TorsinA were identified and presented. Lastly, new potential therapeutic strategies were considered, involving both dopamine-mediated signaling as well as negative allosteric modulators of metabotropic glutamate receptors.

The meeting was successful in terms of scientific quality and participation. Registrations for the first day were 110, whereas the second day we had 95 attendees. Many of these were young medical students, PhD students, and post-docs, all of them involved in neuroscience disciplines.

Prof. Antonio Pisani

DystonieNet: A Dutch approach for optimizing the treatment of cervical dystonia.

DystonieNET

Cervical dystonia (spasmodic torticollis) involves abnormal postures and/or involuntary movements of the head and is the most common form of dystonia in Western Europe. The first line of treatment is injections of the affected neck muscles with botulinum toxin (BTX). In addition, many patients in the Netherlands are referred for physical therapy. However, BTX treatment is still not optimal and evidence towards the effects of physical therapy is lacking.

About two years ago an initiative was started to optimize the care for cervical dystonia patients in the Netherlands, called DystonieNet.

In the Netherlands there are about 8.000 cervical dystonia patients. Most of these patients are treated with BTX injections and additional physical therapy. The success of BTX treatment depends on many factors like proper identification and injection of the affected muscles, determination of the right doses BTX. Experiences from third line outpatient clinics teach us that there is still room for improvement. An important problem towards physical therapy is that the evidence of effectiveness is lacking. Besides, most physical therapists are not familiar with cervical dystonia and interdisciplinary partnerships of neurologists and physical therapists are uncommon in the Netherlands.

DystonieNet

To overcome these problems, the neurology departments of four Dutch university hospitals (University Medical Center Groningen, Academic Medical Center Amsterdam, Leiden University Medical Center, St.Radboud Medical Center Nijmegen) and the physical therapy department

of the Amsterdam University of Applied Sciences initiated DystonieNet.

The main goal of DystonieNet is more collaboration between specialised neurologists and physical therapists in local networks on education, research and treatment of cervical dystonia. By collaborating in local networks, neurologists can refer patients to specially trained physical therapists who are familiar with cervical dystonia. Already 53 neurologists from 39 hospitals across the country participate and 127 physical therapists are willing to work in DystonieNet.



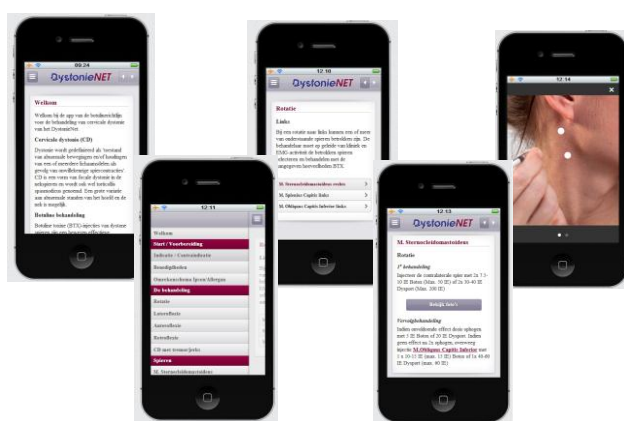
Participating hospitals in the Netherlands

BTX treatment guideline

To optimize the Dutch BTX treatment, an evidence based BTX treatment guideline was developed in 2012 which is currently being implemented via the DystonieNet (the Dutch version of the guideline is downloadable from www.dystonienet.nl). It will also be translated into English, this version is expected in December 2013. Based on the guideline, a special training course is given twice a year for neurologists and nurses treating cervical dystonia patients with BTX. The Dutch guideline comes with an application for Iphone, Ipad and Android platforms that is easy to use in the outpatient clinics. The application will be available for free in the App Store and Android Play Store in the summer of 2013. The English version will follow shortly after that.

Physical therapy treatment guideline

Due to a lack of evidence towards the effects of physical therapy in cervical dystonia, it was not possible to create an evidence based treatment guideline. Based on recent literature, a new standardized physical therapy program was developed together with experienced physical therapists and neurologists.



The (cost) effectiveness of this standardized physical therapy program is currently being studied in 100 patients in the Netherlands. The results from this study will form the basis for a best evidence treatment guideline. This study will be finished in 2015 and the treatment guideline is expected in 2016. After that, special training courses will be given to physical therapists participating in DystonieNet.

Future directions

For now, the main focus of DystonieNet will be on the BTX and physical therapy treatment of cervical dystonia. In the (near) future we also want to involve other disciplines like occupational therapists and psychologists. Additionally, other forms of dystonia will also be included in DystonieNet.

Another future goal of DystonieNet is international collaboration. Translation, adaption and implementation of guidelines on a European scale will combine knowledge and give uniformity of treatments among healthcare providers throughout Europe. By doing so, we want to create the best possible treatment for all dystonia patients.

If you have any questions about DystonieNet please contact Joost van den Dool, physiotherapist and coordinator of DystonieNet, [email; j.vandendool@amc.uva.nl](mailto:j.vandendool@amc.uva.nl)

On behalf of
Prof dr Marina AJ de Koning-Tijssen,
chair DystonieNet
Prof dr Bob van Hilten, dr Bart van den
Warrenburg & dr Hans Koelman,
members DystonieNet

*Joost van den Dool, Physiotherapist and
coordinator of DystonieNet*



Joost van den Dool

Dystonia Europe research Network



This Network is funded by COST (www.cost.eu) with a grant of €400,000 over 4 years. The grant may be applied only for activities to create the network, and not for the resulting research.

We are now well into the second year of the COST grant period, and a Steering Committee meeting was held during July at the COST offices in Brussels. The main topics were:

- the detail of the proposals to create a genetic registry for research purposes
- the proposed formal agreement between the network and Dystonia Europe, to confirm the working relationship and arrangements for administration of funding external to the COST grant.

DE already has a formal agreement with COST, on behalf of the Network, to administer the COST grant, but also holds funding which has been provided by an industry sponsor and further applications for support are under way.

In the autumn of 2013, a second training school for young scientists will be held, this time in London, at the Institute of Neurology. The opportunity will be taken also to hold a Steering Committee meeting, and the annual meeting of the Management Committee, plus some Working Group meetings. The Network also supports Short-term Scientific Missions for individual young scientists, who wish to work on projects in the laboratories of institutions in other countries. Grants are provided to selected applicants, to support travel and living costs during the missions.

The COST grant period continues until April 2016.

Alistair Newton

OTHER RESEARCH NEWS

St. Jude Medical receives CE Mark approval for deep brain stimulation in treating dystonia

St. Jude Medical has received regulatory approval for the use of deep brain stimulation (DBS) for managing primary and secondary dystonia. "This approval represents a significant milestone for St. Jude Medical as we continue to develop therapies to treat a broad range of neurological conditions," said Eric S. Fain, M.D., president of Implantable Electronic Systems Division. St. Jude Medical develops medical technology, is headquartered in St. Paul, Minn., and has four major focus areas that include cardiac rhythm management, atrial fibrillation, cardiovascular and neuromodulation. For more information, please visit sjm.com.

Research agreement between Ipsen and Harvard Medical School

In mid July Ipsen announced that they have initiated a research and development collaboration with Harvard Medical School on novel engineered botulinum toxins. Ipsen will fund Harvard research for at least three years with the aim to discover, evaluate and develop novel engineered recombinant botulinum toxins for the treatment of serious neurologic diseases. For more information:

<http://www.ipсен.com/sites/default/files/communes-presses/PR%20Harvard%20Ipsen.pdf>

France

Development and training of local networks in France



Stéphanie Frehel

AMADYS is the French national association of patients with dystonia. It organizes activities throughout the country, thanks to its local network of 70 local representatives. But it is important to develop the local network because it still lacks delegates in many large cities of France. To respond to needs of patients in all regions of France, AMADYS implemented, with financial support from IPSEN, a project to better train and develop local networks. Local representatives of AMADYS are essential intermediaries to conduct all actions with patients.

This project was born from the interviews which were conducted in early 2012 with the local network. Responses showed a strong demand for more support in their mission.

The project consists of three major steps:

The creation of a training package for local delegates. This is a case that contains all the tools necessary to perform their mission:

- A booklet presenting the association
- A manual for the delegate describing any actions that may be taking place in different parts of the country: meetings for members, meetings with specialists of dystonia, continuity in treatment centers, organization of events for the benefit of AMADYS, etc ... This manual also describes how people can connect to a restricted area of our website and find all the information for request for financial support.
- Brochures by type of dystonia. These booklets have been produced in collaboration with physiotherapists and specialists of dystonia, with 10 questions and answers
- The DVD on the rehabilitation of cervical dystonia
- A T-shirt for each event for AMADYS
- Membership applications to give to patients
- Posters

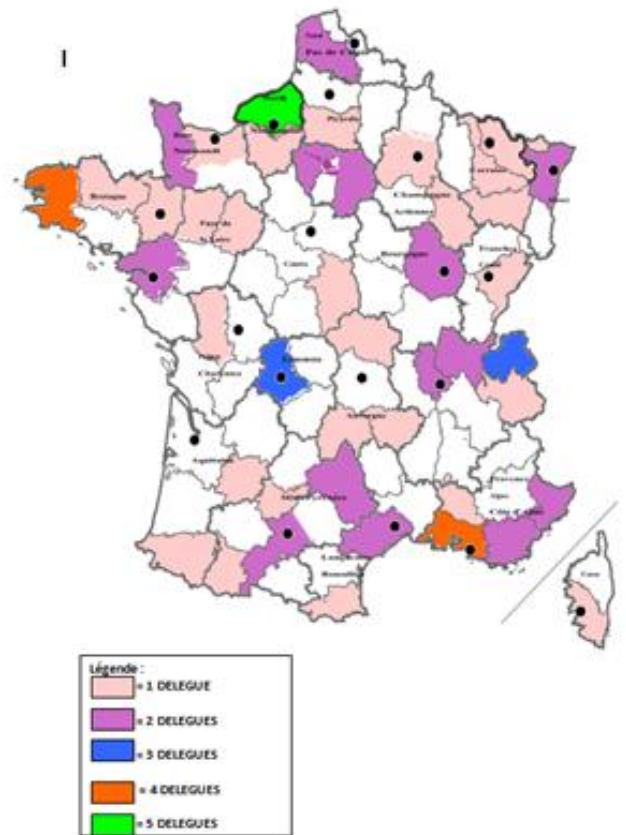
A large national meeting in Paris in November 2012 where we could invite all local networks (accommodation and travel). Nearly 50% of the delegates made the trip. This meeting took place in three stages:

- Presentation of the new strategy
- Sharing of experiences among delegates who were able to explain the difficulties encountered in the course of their mission
- Intervention of a journalist consultant who presented some methods to interest the media on dystonia

A campaign to recruit new local representatives: we identified the places in France where we had a lot of members but no local representative. Meetings were then held in large cities by Emmanuel Bassi, coordinator of the local network in the Board of Directors, with local members to introduce them to the mission of a local representative.

Through this project, we already have **some good results**:

- Local representatives are all very satisfied with the case that contains the necessary tools for their mission
- We were able to recruit 10 new delegates from the beginning of 2013 in the South and in Britain
- The number of meetings organized by local networks has increased by 12%. They bring together patients and inform them about dystonia.
- Thanks to the November 2012 meeting, we identified a psychologist from the local representatives, who agreed to volunteer for AMADYS. So, when local networks have difficulties with some patients who require more support, our new psychologist supports them



There is still much work to do to re-engage the local network and other meetings to motivate members in this direction are planned by the end of 2013. But these initial results are very encouraging and respond across the whole country to the needs of patients who want closer relationships.

Stéphanie Frehel
President of AMADYS



Training Package

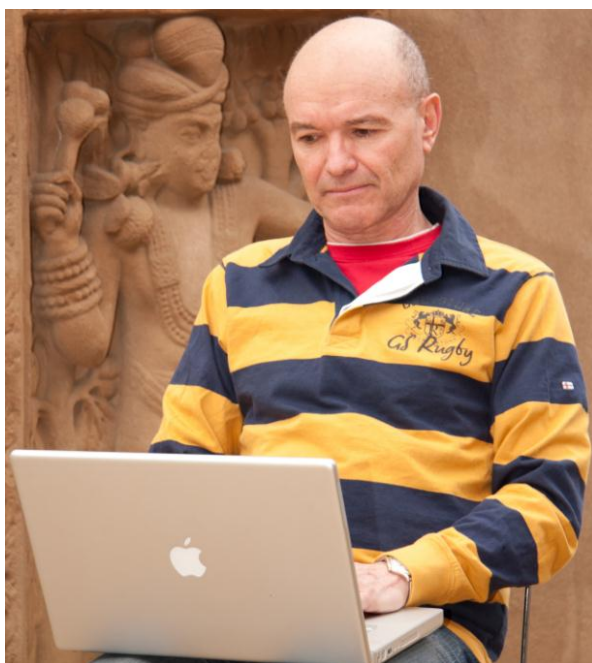
Germany

Dystonia has many Faces

The Berlin patient support group of the German Dystonia Association (DDG - Deutsche Dystonie Gesellschaft e.V.) published in February 2013 a booklet named "Dystonie hat viele Gesichter – Dystonia has many faces" in order to raise awareness of dystonia and to help patients cope with this movement disorder. We had financial support from three large German public health insurance companies for the project. 1.000 copies were printed and we are passing them out for free at various occasions and by mailorder.

The booklet consists of 76 pages and offers 13 testimonials by patients suffering from different kinds of dystonia. They share their stories on how the diagnosis changed and influenced their lives, what amends they had to make, and how they were able to come to terms with the disease, which we would like to call our "uninvited guest".

Some stories are very short, others several pages long. We did not want to cut anybody short, so we edited only when absolutely necessary. The voices you hear are original and authentic. Here are a few summaries from some of the testimonials to give you an idea of the content of our booklet:



Tilmann Tückardt

Tilmann Tückardt, born in 1957, is a Communication Scientist. He was diagnosed with blepharospasm in 2009 and received botulinum toxin treatment combined with muscle relaxants. He also tried many alternative therapies and psychotherapy. Tilmann had to give up his work as a communication consultant and his social contacts were compromised. He finds support in the Berlin dystonia patient support group, as well as from his spouse and his housemates. He discovered he had to apply a rhythm to life, and to let work wait until the medication kicks in, as well as to reduce stress in general. He concludes that even though dystonia has caused him new boundaries in life and forced him to change some of his lifestyle habits, he feels he is living a fulfilled life.



Ria Burrer

Ria Burrer, born in 1959, is a management assistant. She has generalised dystonia which started when she was a little child. Her strange walk was interpreted as a temporary fad. She was made to practise her handwriting for hours in order to improve it. In art class she was also very frustrated. In spite of her problems she successfully trained to become a management assistant. In order to be able to keep up Ria developed her own kind of shorthand writing and learned to store contents in her head. But her handwriting and typing became more difficult with time, and she developed torticollis as well. Ria had three children when she finally started seeing neurologists. Yet she still had a long way to go until

she got the right diagnosis based on a gene test. One doctor assumed she was an alcoholic. Ria was relieved to learn that she had not imagined her symptoms. In an attempt to run away from her problems she took up jogging, but she fell repeatedly and suffered several injuries. Nordic Walking also proved to be difficult. Ria notes that she can walk backwards without difficulty. She managed to work part time, but the neck pain progressed and became unbearable. She tried rehabilitation and different forms of therapy and finally she was granted disability benefits.

Ria stresses that she receives tremendous support from her husband, family and many friends. But she still has great difficulties to drink and dine in public places because she cannot control tremor, not even with medication. Nevertheless she refuses to go into hiding. Instead, she has developed strategies like ordering Latte Macchiato instead of Cappuccino and asking for a straw. She talks openly about her handicap to new people she meets and she enjoys the beauty of life.



Helga Leverenz

Helga Leverenz was working as a dramatic advisor for theatres when she started consulting several ophtalmologists because her eyes had started to blink uncontrollably. She found it increasingly difficult to complete her work which involved a lot of reading. She also saw non-medical practitioners who always promised quick healing.

Eventually she received the correct diagnosis, which was, of course blepharospasm. Her whole face had started grimacing. In spite of the support of her husband, she could no longer fulfill her highly demanding tasks like appearing in public, reading and observing.

Helga had no problem obtaining disability benefits but she was still far away from receiving the right therapy even though botulinum toxin injections were applied. The effect of the injections never lasted longer than four weeks and Helga was considered to be resistant to therapy. Psychotherapy also failed: the therapist wanted to heal the disease while Helga was hoping to learn a way to cope with it.

Nevertheless Helga did not withdraw from public, enjoying her favorite hobbies like concerts, theatre and cinema by the side of her devoted husband. She was also able to maintain her friendships. She discovered the library for blind and visually impaired people and started to listen to books on CD. She travelled a lot with her husband preferring quiet places but she also insisted to go to places all by herself relying only on a cell phone for emergency help.

15 years after her diagnosis she consulted Professor Reichel in Zwickau who changed the injection plan and included the upper eye lids. Helga felt like being reborn; she could finally read again. Sadly though, her husband died the same year. But Helga is very glad that she is now able to lead a self-determined life, doing sports three times a week, traveling and enjoying her hobbies.

“Being active“, Helga says, “is the key to living a fulfilled life in spite of age and handicap. It enables us to discover new things, stabilizes ralationships with other people, shows new possibilities. It adds change and confirmation, admits the feeling of being wanted and needed and prevents loneliness.”

Heike Wolf, Board Member DDG, Germany

Norway

Physio Pilates at Norwegian Dystonia Association meetings



From left: Merete Avery and Anniken Hagen

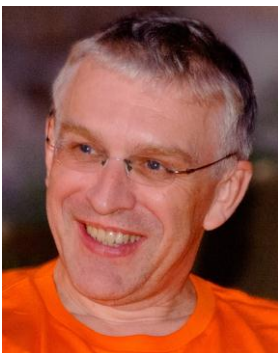
At the last national meetings, arranged by the Norwegian Dystonia Association, there were Physio Pilates classes offered for those who wanted to attend.

Physical therapist Anniken Hansen Hagen, who is also a Physio Pilates instructor, has firsthand knowledge about Dystonia since she has the diagnosis herself. Anniken has also attended a workshop held by the Swedish Dystonia Association on “Physical treatment for those affected by Cervical Dystonia” in 2012 in Umeå. Pilates is a physical fitness system developed in the early 20th century by Joseph Pilates. Physio Pilates are Pilates exercises especially developed for people with different diagnosis or disabilities who need more adjusted exercise routines. The classes have been very popular and are fully booked every time they are organised. The Norwegian Dystonia Association intends to continue giving these classes at its meetings.

Merete Avery, Board Member of the Norwegian Dystonia Association

United Kingdom

The Dystonia Society Helpline



Paul King

Dystonia is a condition with limited awareness so the newly diagnosed have a steep learning curve. In addition, the pre-diagnosis period is often long and, even after diagnosis, it can take several months to establish a stable treatment regime –

this gap between symptom onset and effective treatment often causes intense distress. Further, it is increasingly understood that dystonia can cause depression and anxiety both directly and as a result of symptoms. In turn, stress and anxiety can greatly worsen symptoms.

Accessible sources of information are therefore important – as is the opportunity to express concerns and so relieve stress and anxiety. While the vast majority of medical professionals provide good care, time constraints together with unequal status of patient and doctor inevitably constrain communication with patients at least to an extent.

A helpline provides a cost-effective method of filling this gap. The widespread usage of the TDS helpline and extremely positive outcome reports demonstrate this. The cost per caller is less than one fifth of one botulinum toxin injection.

What does a dystonia helpline do?

A dystonia helpline provides information and support to people affected by dystonia – primarily the newly diagnosed, those whose treatment regime has not stabilised and those whose dystonia has worsened. Examples of the types of call include:

- Someone who's just been diagnosed who didn't get all the information they need from the consultant.
- Someone whose treatment has stopped working or who is disappointed by the initial results of botulinum toxin.
- Someone who is struggling to cope due to the pain or psychological impact of dystonia.

Staff provide information about dystonia, treatment options and processes, lists of available treatment centres, coping strategies etc. They also listen empathically to the caller's experiences and enable them to vent their emotions. Doctors frequently tell people with dystonia to call the helpline to discuss their concerns as this limits the appointment length. The helpline therefore also provides a significant hidden productivity benefit to the health service.

The helpline is provided by paid staff experienced in providing telephone support. They are not medically qualified but require a specialised knowledge of many types of dystonia. Such expertise can take time to develop so careful thought therefore needs to go into training staff for a new helpline – and they will need ongoing supervision and access to medical advisers thereafter. In the view of the Dystonia Society (TDS), this is not a service that can safely be provided by volunteers. The work has a long training period and requires detailed knowledge. It is emotionally intense with 42% of calls dealing with mental health and/or pain issues – it is unfair to put volunteers in the situation of handling such calls.

What a helpline does not do

It is very important to be clear about the limits of the service for legal, insurance and safety reasons. In particular, the helpline is:

- Not a medical advice service. The staff are not qualified and cannot give advice or recommend treatments, doctors or treatment centres.
- Not a counselling service. Support should be limited solely to issues relating to dystonia. Also emotional support should be limited to listening empathically and staff must not get drawn into providing the types of therapeutic support that require a mental health expert.
- Short term. Most callers use the service only 2-3 times. Some callers do find it reassuring to touch base with the service from time to time and this is OK. However, if such calls start to be too frequent, the caller needs to be referred to a mental health (or other) helpline.
- Not an emergency service. If people with dystonia require urgent treatment or psychological support, then they need to contact the appropriate emergency services. The TDS helpline is open 10-4 on working days and we do not guarantee to answer calls. However, the service does need to be delivered to a service standard and we aim to call back every caller within 1 working day.

The benefits of a helpline

Quantitative feedback

Below are the latest results of our outcome monitoring (% of respondents reporting outcome – N.B. sample still quite small as we have only recently started this kind of monitoring):

I now have a better understanding of my condition	54%
I'm now more aware of treatment options and next steps	51%
I have more information on coping strategies	46%
It was helpful to express my feelings	77%
I feel less isolated in coping with my condition	57%
Found the helpline helpful	17%
Found the helpline very helpful	83%

It is important to note the high percentages of those reporting the benefit of expressing emotions / feeling less isolated. Online resources are valuable but they cannot replace the one-to-one human contact provided by a helpline.

Qualitative feedback

We get hundreds of positive comments about the helpline. Below are some examples all received in the last week:

- It was the first time anyone had listened and helped me to understand this
- condition. I was then better equipped to explain how this condition affects me when visiting specialists
- I have nothing but heartfelt praise for the helpline. The literature has helped me cope with dystonia.
- I feel less isolated in coping with my condition as the Dystonia Society Helpline understand the condition better than the doctors do.
- Knowing there's someone there who's sympathetic & understanding is a source of great comfort & I found the experience boosted my morale.
- It was very helpful to talk to someone who understood my problems, making me feel more less.

Statistics

TDS provides staff to answer 1,200 callers per year, and a total of 3,000 calls. In terms of the whole UK population, this equates to an expected 20 callers and 50 calls per million of the UK population. This takes 8 days of staff time every week (2 days' time of a manager and 6 days' time of other staff)

We have reviewed the activity of our helpline over a five year period and we estimate that we support approximately 65% of people in the UK who have been diagnosed with primary dystonia.

This estimate takes into account that people call at different stages in the development of their condition.

The cost of staff for 8 person-days per week is £77,000 (£89,000) per year, or £65 (£75) per caller and £25 (£29) per call.

Content of calls

An analysis of 331 calls shows the following topics mentioned in the call record:

		% calls
Botulinum		38%
Medication		25%
DBS		8%
Other therapy		7%
Pain		24%
Mental health / mood		22%
Side Effects		6%
Clinic		15%
Diagnosis		7%
Benefits		14%
Employment		6%

Paul King, The Dystonia Society, UK

Sweden – Nigeria

The Face of Dystonia

Edu Wealth Ochulor was born in Nigeria, but now is married to a Swedish woman and lives in Sweden with his wife and daughter. He is a member of the Swedish Dystonia Society and is active internationally in a number of roles – including those as a businessman, motivational speaker, educator and dystonia awareness activist.

During his childhood and young adulthood, despite visits to medical specialists in different disciplines and in many different countries, he did not receive a diagnosis of dystonia for 26 years. His life is now based in Sweden, but he has determined to – somehow – improve the situation for people with dystonia, especially in the country of his birth - Nigeria. He hopes that later he will be able to extend the project to other countries in Africa. The project is called “The Face of Dystonia”, and Edu has registered an organisation of that name as a non-profit association in Sweden.

Nigeria is the most populous black nation on earth with over 170 million citizens, which means that every sixth African is from Nigeria. Prevalence studies of dystonia are generally acknowledged to be based on imperfect data and it is broadly assumed that there is considerable under-recording of cases. There have been no such studies in Nigeria but, based on fairly recent medical estimates in the UK of around 860 cases per million of the population, it is possible that over 200,000 people in Nigeria are suffering from some kind of Dystonia. It is also suggested that many of these are likely to be secondary Dystonia cases because of lack of medical attention or due to the poor medical infrastructure.

Edu intends to start the project by creating awareness of dystonia among health care practitioners. This will be achieved by organizing conferences in different cities in Nigeria. The aim of these conferences will be to provide much more information to healthcare specialists on dystonia symptoms, and on the possibilities for management of the illness. He then intends to work with hospitals and their medical staff by revisiting patient records where there is a high probability of patients being affected by Dystonia. The number of records intended to be reviewed is considerable, with a commendably short timescale, and there are plans for follow-up with those patients who might benefit from clinical review and possible treatment.

Edu intends to begin work on this project during 2013. More information can be found on his websites at:

www.ewealtho.com

www.thefaceofdystonia.com



Edu Wealth Ochulor

Russia

Against all odds

Strong people are not those who are well and happy. Strong people are those, who are well and happy no matter what.



Soboleva Marina, Novosibirsk

I was born in 1979 in the Soviet town Novosibirsk. My mother had had prolonged labour delivering me which resulted in hypoxia (a condition in which the body as a whole or a region of the body is deprived of adequate oxygen) Doctors' forecast for the future development of the baby was rather grim, but my parents were happy to have a child in the family and were ready to face the challenge.

When I was 4 years old my mother began to worry that my speech sounded indistinctive and was lacking many sounds. She took me to a speech therapist and I had to do special exercises every day. My speech improved and in due time I started school. My studies went well although it took me a lot of effort. I spent from 6 to 9 hours doing homework, but I was a hard-working girl and never gave up.

Then my father got addicted to alcohol and it was a disaster to our family. I worried and worried about it. As a teenager I often had headaches, lived in constant tension and two fingers of my left hand were twitching. My mother took me to a neurologist and he diagnosed me with

vegetovascular dystonia, asthenoneurotic syndrome and residual disorder, and he recommended paying no attention to my twitching fingers.

Having to pass school exams and coping with problems in the family caused a lot of stress and my fingers twitched even more. My mother took me to the local neurologist and she prescribed vascular medicines.

I entered the University. The entering exams provided many stressful situations but I had managed to cope. I was even able to be much less nervous during the finals each semester. It may be hard to believe but I found it rather easy to study at university. I liked the subjects and was especially interested in reading books on psychology and educational science.

After graduating from university my mother found me a job. I started to work as a warehouse clerk for the same company my mother had been working for. At first I considered the position temporary, but after a while I got used to it and the various tasks, and I decided to keep the job.

My life – at last! – was complete and I was content and happy, but then my father died. This event affected my health: the whole left hand was twitching. I had difficulties with many manual activities, even the simplest. For example I got lots of minor injuries while cooking and cutting. It was not easy to get to work by public transport, as I could not hold on to the railing or carry a bag with my left hand. Often I could not sleep very well because of the twitching of my hand. At the time I was dating a young man, named AG, and I was worrying that the twitching of my hand could have a negative influence our relationship.

The local neurologist referred me to the City Center of Extrapyrimal Disorders (based on City clinic №1). They diagnosed consequences of polyneuropathy, secondary tortion dystonia with neck, body and arms muscles involved. Doctors prescribed clonazepam and baclosan and while taking these medicines I was feeling better. But they had to increase the dosages again and again.

During my regular consultation I asked the doctor how long I would have to take medicines and whether they could cause addiction? The answer was not very encouraging: I was going to take drugs for the rest of my life. On my way home I was crying and the same thoughts tortured me again: "Why me? Why did it happen to me? I'm so young and already suffering from an incurable disease".

But I was ready to fight for my health. I arranged to see the main neurologist of the city and he suggested trying Botulinum toxin A type treatment. He also recommended getting disability group (a disabled status allows to get Botulinum toxin free of charge). According to tests, my condition allowed me to get a disability group approval but I did not want it. I was still so young and in love, I had my job and I just did not want to feel like a disabled person. But the main reason, I think, was that I knew very little about my disease and about Botulinum toxin.

I was still dating AG and after a while I got pregnant. I caught a flu during the first month of the pregnancy. My health was worsening rapidly. The whole upper part of my body twitched, I could not keep my head, hands, sometimes even legs steady. I could fell asleep only when my mother was holding my legs and AG was holding my hands. It was impossible to eat without help. I had to give up my job. I was consulting lots of doctors and specialists and they talked about different diseases: Kozhevnikov syndrome, localization-related epilepsy, muscle dystonia,

consequences of perinatal pathology with hyperkinetic syndrome. They prescribed loads of various medicines: Clonazepam, Tramadol, Baclosan, Phenazepam, Depakene, Carbamazepine, Mydocalm. I was taking them but I did not feel better and doctors were constantly increasing the dosage.

I was offered to terminate my pregnancy more than once but I could not bear the thought. My condition was getting worse: the upper part of the body twitched, I was not able to sleep, to eat, it was even difficult to get to the toilet. I was also deeply depressed because I understood that the medicines I was taking must have affected my unborn baby. But my health was so poor that I could not stop taking the drugs. My son was born with a caesarean after 38 weeks of pregnancy. The big dosages of medicine I had been taking had damaged his health and he had to be hospitalised for a month. I was transferred into the Neurology department. My blood was so full of drugs that I was subject to plasmapheresis three times. Finally I returned home but my health was very poor and life seemed useless.

My husband had been very unhappy seeing how much I suffered. Therefore he arranged for me to see the neurologist with great experience: M.D. Shperling Larisa. After examining me she prescribed Botulinum toxin A treatment. She did not promise to cure me, but she gave me a spark of hope. I went through all the necessary official steps and got disability group approval. The first set of botulinum toxin injections was given to me in spring 2008. Already three weeks later I felt a little better – for the first time in 18 months! My muscles relaxed a bit, my head almost stopped twisting. But the most important result was my newly obtained belief that there was help. After five months I got the second set of Botulinum toxin injections which allowed me to take my baby for a walk and to go to the local clinic by myself.

Today I have 2nd disability group and my health problems are lifelong. But nevertheless, I feel that I am a really happy person. I am loved by my family and my friends whom I love dearly too. When my son was two and a half years old I found a job. Nowadays I can work 8 hours a day. I don't have time to brood about my disability: my days are filled with my job, home, country house, my beloved family. And I am really grateful for all this happiness and I owe it to Dr Shperling and to the Botulinum toxin treatment. Depending on my health condition I get the injections every 3-4 month. I would like to tell everybody: don't let grass grow under your feet! Think positively!

Even if life is difficult and you are in pain – think about your family and try to make their life better! If they become happier, you will be happier too!

I also understood another very important thing: the disease can kill, but the same disease can also make a person stronger than he or she was before. I would very much prefer to be a healthy person, but I have to accept I am not. So instead I should turn my disease into a source of strength, and I will never give up! Be strong and healthy!

Soboleva Marina, Novosibirsk

Other News

Dystonia Stories” – personal stories for our 20th Anniversary!



The 20th Anniversary Dystonia Awareness Campaign was launched beginning of the year. Dystonia Stories consist of short video clips featuring interviews with dystonia patients, neurologists and researchers and their different views on dystonia. The clips can be viewed at the

DE website, the DE Youtube channel and the DE Facebook page. Watch and share these clips! The more visible we can make dystonia, 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 better understood, and are more likely to get support for their research.

I encourage you to participate in the campaign by sharing and spreading the information as widely as you can.

Monika Benson

EFNA Spring Events

European Parliament Events - May 7 and 8



*Heather Clarke, Bea De Schepper, Donna Walsh, MEP
Nessa Childers and EFNA President Audrey Craven*

On May 7, EFNA opened a document in the European Parliament for signing by MEPs - 'Putting Neurology Patients First: A pledge to support essential investment in neuroscience research and to protect the interests of neurology patients'.

20 MEPs signed on the day and pledged to support EFNA's work in striving to implement the key tasks - photos can be viewed on the EFNA

Flickr Page.

EFNA will continue to build this support network during Year of the Brain 2014 and in advance of the EU Elections.

On May 8, EFNA Members held an Information Day in the Parliament to distribute leaflets on the various conditions and supports available to patients. The base outside the main restaurant ensured lots of passing traffic throughout the day and high visibility for both EFNA and its Member Groups.

A number of MEPs dropped by to meet the EFNA Members, which included the European Multiple Sclerosis Platform, International Brain Tumour Alliance, Euro-Ataxia, Dystonia Europe, European Alliance for Restless Legs Syndrome and the European Huntington Disease Association.

World Congress of Neurology 2013 in Vienna

To build on this initiative, EFNA will invite its Members to exhibit at a Patient Corner to be organised at the World Congress of Neurology [WCN] in Vienna, September 2013.

The 'Patient Corner' will take over 18 square metres of the Exhibition Centre and will involve EFNA and its Member Groups distributing information and hosting a number of mini-events.

WCN will also see a joint EFNA/EFNS Session entitled 'Making the Case for Neurology' which will explore approaches to advocacy internationally and the annual EFNA General Assembly.

EFNA partners with the European Patients Forum to mark EMOB - May 23

The European Patients' Forum (EPF) celebrated its 10th Anniversary with a major conference in Dublin under the Irish EU Presidency and welcomed Commissioner Tonio Borg as a special guest. To mark European Month of the Brain, the Conference was organised jointly with EFNA and championed neurological disorders.

The need for a neurology strategy in all countries was one of the core issues emerging from the discussions. Effective partnerships are needed among patients' organisations to tackle serious and long term conditions. Moreover people affected by brain disorders require equitable

access to high quality, appropriate, care, treatment and support for full participation and inclusion in society.

“Brain disorders will affect 1 in 3 citizens and cost the EU economy almost €800 Billion annually. So, this conference and its emphasis on the brain is timely in highlighting that all patients share similar concerns and illustrating the value of sharing expertise from within”, said Audrey Craven, President of EFNA.

“The conclusions of this conference taken from the patient perspective, will be taken forward and incorporated into the high-level EU/IE Presidency Conference ‘Healthy Brain: Healthy Europe’.”

EPF Executive Director Nicola Bedlington said, “This Conference – marking 10 years of EPF – was a huge milestone. It reflected our strong bond with the Irish patient community and through working with EFNA and NAI, it demonstrated our commitment to solidarity and genuine partnership. It was a great springboard for concerted action, and EPF will take forward the recommendations of the meeting in close collaboration with our members and allies.”

Healthy Brain: Healthy Europe - May 27/28

EFNA played a key role in this conference - attended by high level representatives of the key stakeholder groupings in the field of brain disorders such as policy, industry, medical/research, patients, etc.

The EFNA President, Audrey Craven served on the Scientific Steering Committee for both this event and the earlier conference entitled: European Brain Research – Successes and Challenges, held in Brussels on May 14.

Encouragingly, the central role of patients and the need for active engagement with patient representatives were recurring themes across all sessions. Consensus was also reached on the

need to incentivise brain research in Europe, to continue public-private partnership and to promote a personalised medicine approach.

John Golding, President of the European Multiple Sclerosis Platform and Pedro Montellano of GAMIAN Europe spoke from the patient perspective during the conference. Mr Montellano used his speaking slot to present the conclusions and recommendations from the European Patients Forum/EFNA conference.

In advance of the conference, both men – along with EFNA President, Audrey Craven – met with keynote speaker Patrick Kennedy (Member of the US Senate and Founder of OneMind4Research) to present the impact of living with a brain disorder.

The conclusions and recommendations of this conference will be made available by EFNA once finalised and they will then work on implementing these during the upcoming Year of the Brain 2014.

From EFNA e-News Issue 3 June 2013,
www.efna.net



2013

5 September, Dystonia Europe Board meeting, Edinburgh, Scotland

6-7 September, Dystonia Europe 20th Anniversary Conference, Edinburgh, Scotland

8 September, Dystonia Europe Board meeting, Edinburgh, Scotland

8-10 September, Grenoble Symposium on Deep Brain Symposium, Grenoble, France

21-26 September, World Congress of Neurology in co-operation with EFNS, Vienna, Austria

1 October, Dystonia Patient Meeting, Bucharest, Romania

16-17 October, 5th Annual Dystonia Coalition meeting, Atlanta, USA

11-14 November, European Association of Neurosurgical Societies Annual Meeting 2013, Tel Aviv, Israel

20 November, COST Steering Committee Meeting, London, UK

21 November, COST Management Committee Meeting, London, UK

22-24 November, Dystonia Training School 2013, London, UK

8-11 December, XX WFN World Congress of Parkinson's Disease and Related Disorders, Geneva, Switzerland

2014

31 May – 3 June, EFNS-ENS Joint Congress, Istanbul, Turkey

8-12 June, 18th MDS International Congress of Parkinson's Disease and Movement Disorders, Stockholm, Sweden

September, Dystonia Europe 21st Annual Conference & General Assembly, Paris France

2015

14-17 January, Toxins 2015, Lisbon, Portugal



**DYSTONIA
EUROPE**

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

Dystonia Training School

Institute of Neurology in London

22-24 November 2013

Grants for travel and subsistence – apply now!

For information, application of grants and registration go to

www.euro-dystonia.org or contact: sec@dystonia-europe.org

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:

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Thank you for supporting Dystonia Europe!

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Medical and Scientific Advisory Board

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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.

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.

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, EFNS – European Federation of Neurological Societies, EBC – European Brain Council, Boston Scientific, Medtronic Foundation,



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