



## Dear Friends,

I always found it extremely difficult to write something of interest, something clever, something amusing, something about EDF in the Editorial of Update. But this time it is different, as my term as President of EDF will come to an end later this year, and someone else will take over this task. I feel happy and sad at the same time! Twelve years ago I joined the EDF Board as Treasurer, then as Vice President and, during the last six years, as President. It has been a wonderful period of my life, working with so many dedicated people from all parts of Europe and caring for people affected by Dystonia. I suppose I am twelve years older now and very grateful that my kind of Dystonia only affected my voice, but not my body. It is time to move on and although I will miss EDF and the work involved, I will always look back with pleasure, cherish the numerous events and achievements and hope that I will maybe also be remembered as someone who tried to get Dystonia the attention it deserves in Europe.

Didi Jackson, President

## 14th Annual Meeting in Vienna

Visiting Vienna is always special – the atmosphere, the buildings, the Viennese charm - EDF likes to be special and invites one delegate of each EDF member group to come and join them for the Annual Meeting at

**Hotel Ananas  
Rechte Wienzeile 93-95  
A-1050 Vienna  
from Friday, 21. September –  
Sunday, 23. September, 2007.**

We will of course see as much as possible of the sights of Vienna and you will certainly not be disappointed, as we have a few surprises planned.



But our main object will again be an interesting scientific meeting on topics of dystonia, e.g. a young

patient from Norway will talk about his DBS operation, Claire Centrella, President of Dystonia Medical Research Foundation, Chicago, will join us to tell us about projects in USA and a Workshop on 'Life with Dystonia' will involve all participants. These are just a few of the interesting topics at this year's meeting. The full programme will be sent out soon.

We hope that all national groups will be able to send a delegate to the Meeting and we are looking forward to receiving your Registration Form soon, so that we can plan all activities in good time.

## Membership Fee

**May we remind those national groups who have not paid the Membership Fee of EUR 100 for the Year 2006/7 to remit the sum to the EDF Account before the General Assembly 2007 (KBC Bank, IBAN: BE83735005085515, BIC: KREDBEBB).**

# News on National Groups

*In the following articles we report on the activities of some of the national group during European Dystonia Week 2006. We want to thank all those who invested a lot of time, work and initiative into these functions and hope it will motivate others to do something similar for European Dystonia Week 2007 from 17. - 24. November.*

## Austria



The ÖDG always tries to organise a special function for the European Dystonia Day. This year the 'Salzburger Gebietskrankenkasse' (SGKK) – a Health Insurance Co. – organised a public meeting on the afternoon of Friday, 24th November, 2006 giving information on Dystonia. The PR work of SGKK was excellent, placing advertisements in local papers, printing posters and handouts. Christa Hafenscher and I of course were really interested in this initiative, attended the meeting and were positively surprised. The Meeting was held in a Health Centre in Salzburg, where several neurologists, who were experts on Dystonia, one doctor, an expert on homoeopathic therapy, a pharmacist and a psychologist were present to answer any question on the subject of Dystonia. The Salzburg Dystonia Group was also represented with an Info-Stand and we were able to display ÖDG brochures and newsletters.

The public interest was very good. Not only Dystonia patients, but also people just interested in general approached the doctors with questions and matters

of concern. We were surprised that so many were also most interested in the work of the ÖDG and we were able to give plenty of advice. It was also very positive to see so many young people there, like the students of the Nursing School Salzburg. If all students would acquire more knowledge on Dystonia at such meetings we would not have to worry about the future.

We would like to thank the SGKK for their excellent initiative, which was a wonderful example of cooperation between a Health Insurance Co. and a Self-Help-Organisation for the benefit of patients – an initiative, which could or should be copied in other parts of the country!

We took the opportunity to visit a local hospital and the Umbrella Organisation of the Salzburg Self-Help-Groups on the same day to talk about the ÖDG. Exhausted, but very happy with this year's Dystonia Day we boarded the train back to Vienna.

**Richard Schierl**

## Belgische Zelfhulpgroep voor Dystonievpatiënten v.z.w.



The Belgian Dystonia Society concentrated its activities for European Dystonia Week in November 2006 on public awareness and organised a Meeting in Leuven, a town 20 km east of Brussels. We invited, of course, the members of the Belgian Dystonia Society, doctors (in particular general practitioners), physiotherapists, nurses and also medical students. We were very pleased that also a number of people attended who had not heard of Dystonia and the Belgian Dystonia Society.

Dr. W. Van Landegem, Neurologist and Member of our Medical Advisory Board, offered to talk on all aspects of Dystonia and we had asked him to make sure that everybody could understand it, not only medical experts. He certainly gave a most interesting talk, especially as he made sure to involve the audience

asking questions. It went on much longer than we had anticipated. In the end the manager of the Youth Hostel, where the Meeting was held, had to ask us to leave!



**Dr. W. Van Landegem**

We feel that our aim to promote public awareness has been successful. Everybody gained more knowledge about Dystonia and we were pleased that this Meeting motivated a number of patients to join the Belgian Dystonia Society.

**Herman De Craecker**

## Norway



My name is Stein Dølmo and I am the newly elected chairman of the Norwegian Dystonia Association (NDF).

I like to start with a short presentation of myself. I was born in 1959 and my Dystonia started 1997. I quote from my medical journal as follows: "The patient suffers from a serious and disabling cervical segmental dystonia with cranial components. He has a very severe laterocollis to the right, combined with torticollis to the left and a slight anterocollis. Severe damage to his teeth as a result of bruxism and involuntary movement in the jaws"

As a result of this, I have been unable to work since 2002. I live with my wife Gry, my daughters Stine and Ida and our two cats in Tolga. Tolga is a small town with about 1,800 inhabitants in the heart of southern Norway, near Røros, about midway between Oslo and Trondheim.

At an early stage, I received Botulinum Toxin treatment with limited success, combined with a large variety of other medication. The treatment, however, became less and less successful, which was the main reason that I had to retire from my job in 2002.

November 8th 2006 will forever be a turning point in my life and the life of my family. On that day I became the 17th Norwegian Dystonia patient to undergo Deep Brain Stimulation (DBS) Surgery. The surgery was successful and immediately after the stimulation centre was turned on one day after the surgery, a notable pain relief occurred. At present I am still having an intensive course of training by a physiotherapist. A lot of muscles are still not functioning correctly after 10 years of strange head, neck and face positions!

I have recently started to work again as an advisor to the local council, so far only part-time (50%), but I hope to increase the working hours in the course of 2007.

During the European Dystonia Week 2006 the Norwe-

gian Broadcasting Corporation (NRK) filmed my surgery and this was presented on the TV programme "Schrödingers Katt" on Nov. 23rd 2006. This is a popular science programme screened in prime time and always watched by a lot of viewers in Norway.

The programme's main focus, however, was on Gabriel Horseng, the first Norwegian affected by Dystonia to undergo successful DBS surgery. Gabriel had surgery in 2002 and is now a well-functioning family man with a wealth of resources and talents. The attention this TV programme received proved to be a very good and effective way of marketing the "Month of Dystonia" in Norway.

My main objective as new Chairman of NDF is to continue the good work that the organisation has been doing in past years. NDF has decided to concentrate on the following objectives and main projects in 2007:

- increase knowledge and improve treatment services and public information
- establish a National Centre for Movement Disorders
- establish a Dystonia Centre
- establish the post of a permanent Dystonia Contact. Our Dystonia Contact was appointed in October 2006 and our experience so far has been very positive. Our intention is to make this a permanent post, but that will require increased financial support.
- apply to the "Foundation for Health and Rehabilitation Organisation"
- focus on Dystonia among children and young people.

The Board of the Norwegian Dystonia Association now has a perfect selection of experienced people with a lot of routine in working with Dystonia objectives and young and vital people with an immense fighting spirit. It will be a pleasure, but also a major challenge to keep up the good work the organisation has been doing so far.

I am looking forward to continue the cooperation with the EDF and NDF will carry on participating in all EDF activities, as practised by our most experienced members for many years.

**Stein Dølmo**

Email: [sdoelmo@online.no](mailto:sdoelmo@online.no)

## ALDEC (Associació de Lluita contra la Distonia a Catalunya), Spain



On the 15th November, 2006 ALDEC organised the 2nd Dystonia Day to celebrate European Dystonia Week 2006. Ana Sánchez, President of ALDEC, invited healthcare professionals, social workers, medical students, Dystonia patients and their families and friends to a very interesting scientific meeting with important speakers, not only from Barcelona - like Dr.

Eduard Tolosa and Dr. M. Marti - but also Jean-Pierre Bleton from Paris, who gave a talk on Physiotherapy in Dystonia Treatment.

The Meeting was well attended and Ana Sanchez has to be congratulated on her achievement to promote awareness and understanding of dystonia amongst the public and the medical profession.

## Switzerland



The Swiss Dystonia Association SDG/ASD lacked the personal resources to observe Dystonia Day 2006 in November, but we have been able to spend a successful Dystonia Afternoon 2007, participating in the 5th «Parkinson's Disease and Movement Disorders Symposium» in Zurich on 22nd March.

The idea of organizing a small scale conference on dystonia for the members of our MAB, which came up at our last AGM in May 2006, developed in the course of the subsequent months into a 'merger' with the tradition of the «Symposium» held regularly at the Department of Neurology in the University Hospital of Zurich. This year, the first half of the afternoon was devoted entirely to dystonia, and the second part, on «Emotions and Movement Disorders», had quite something to offer to listeners interested in dystonia as well.

The three presentations on dystonia covered the «Pathophysiology of Dystonia» (Prof. Joseph Classen, Würzburg, who could be invited with the support of our anonymous 'good fairy' donator), «Genetics of Dystonia» (PD Dr. Hans Jung, Zurich), and «Therapy of Dystonia» (Dr. Daniel Waldvogel, Lucerne). The doctors attending were thus given an excellent 'tour d'horizon' of the tricky triple character of dystonia (interacting disorders of the GABAergic, sensor, and motor systems, to put it in a very amateurish way) as well as possible causes and ways to tackle it, and of

course we, though far from understanding all the niceties e.g. of metabolism, learnt a lot, too.

Moreover, and even more important perhaps, the SDG/ASD was mentioned in the invitation as cooperating partner and was consequently made known, along with our main objectives, to everyone who received it. We were assigned a large table and movable wall in a prominent place in the reception area, and the four of us present (Anette Mook, Vice President, Hanspeter Itschner, Webmaster, Sabine Gygli, Writer's Cramp Study, and me) were made welcome with interest and respect for our work on behalf of the patients.

Warm thanks are owed to Dr. David Benninger (responsible for the Swiss Writer's Cramp Research Project together with Dr. Victor Candia, EDF's David Marsden Award Winner of 2005, and Prof. Peter Fuhr), who worked with me on the preparations as representative of the organizers of the Symposium, Prof. Claudio Bassetti and Dr. Daniel Waldvogel. Both they and we have decided that we want to carry on with our cooperation to perhaps establish another tradition. Though next year we'll put out tasty Leckerli rather than dry paper on the SDG/ASD table in order to attract even more attention!

**Barbara Gygli Dill**

## ADDER (Action for Dystonia, Diagnosis, Education and Research), UK



### European Dystonia Awareness Week 2006 and the Neurological Alliance.

ADDER has been working with a number of other neurological charities for over a year in order to set up a local Neurological Alliance to facilitate better care for thousands of patients with long-term neurological conditions across parts of the North East of England. More than 100 people attended the launch of the Tees Valley, Durham and North Yorkshire Neurological Alliance, which aims to give patients a stronger voice across with a range of conditions including Acquired Head Injury, Brain Tumour, Dystonia, Epilepsy, Motor Neurone Disease, Multiple Sclerosis, Parkinson's Disease and Stroke.

The working partnership - thought to be one of the largest of its kind in the UK - draws on expertise from health, social care and voluntary sectors with charities working on behalf of people with neurological conditions, families and carers. Their first step to breaking down some of the communication barriers was a major conference at Darlington Football Club on Tuesday, 21st November 2006.



Guestspeakers included the local Health Trust's Chair Glenys Marriott, the Chief of Neurosciences Dr Phil Kane, Ms Jan Douglas, Middlesbrough

Council's Executive Director of Social Care and Mary Baker MBE, President of EFNA (European Federation of Neurological Associations) and Vice-President of EBC (European Brain Council).

Glenys Marriott, who formed the Alliance Steering Group, said: "This is an exciting initiative; one which we hope will really make an impact and difference to the lives of people living with a neurological condition. By working consistently together through the Alliance, patients will have a stronger voice which, in turn, will provide a legacy for patient care in the future and I'd like to thank everyone who supported the event".

The conference, which drew together a panel of speakers looking at where we are now, what happens next and the future, provided some thought-provoking debate. Mary Baker added: "If you are to move forward none of these illnesses should be versus one another. It's about the common principles, dignity of the patients, the needs of the carers, of the informa-

tion, of the very local support, but also keeping an eye on the bigger issues we know we have got to influence. We need to focus on the needs not the wants and I think you will find the needs are very common whatever the illness. Distress is not enough - this does not form part of your alliance, but you've got to address the costs of these illnesses - the cost to the NHS, the cost to the patient and their families - the cost if treated badly - and that is incredibly high."

Dr Anthony Butler, Vice-President of EDF, who has since been elected Chairman of this local Neurological Alliance added: "The publicity surrounding conditions such as Multiple Sclerosis and Parkinson's Disease often overshadows the lesser known but equally debilitating conditions such as Dystonia or Myasthenia Gravis. However, there are huge similarities in the difficulties patients face trying to manage their condition and maintain a quality of life. We want to inform and educate those who commission and provide services on the long-term impact of neurological conditions and secure the highest standard of services while improving access to care, information and equipment."

The event was planned to coincide with European Dystonia Awareness Week and the local publicity surrounding its inception did manage to make more people aware of dystonia and the fact that the vast majority of European countries were involved. In particular the involvement of Mary Baker was of great significance in that it showed how we all are part of the European neurological scene.

If anyone of you would like more information on the Neurological Alliance in the UK or indeed how this event was planned, log onto the website at [www.neurologicalalliancencortheast.org.uk](http://www.neurologicalalliancencortheast.org.uk)

Finally to round off the week, ADDER itself had planned to hold its Annual General Meeting during European Dystonia Awareness Week. They had a very successful meeting on Saturday, 25th November in Gateshead, at which Mr Alistair Jenkins, the Consultant Neurosurgeon from Newcastle General Hospital was the main speaker.

He has performed over 200 Deep Brain Stimulation operations on Parkinson's Disease patients, but so far only 5 on people with dystonia. Fortunately four of them were able to be present at the meeting and were able to describe their conditions before and after the operation. We will keep you all informed of the results of these operations in future editions of 'Update'.

## DAVID-MARSDEN-AWARD 2007

The David-Marsden-Award was presented for the first time in 2003 by the European Dystonia Federation. Professor David Marsden (1935 – 1998) was one of the leading neurologists in Europe, and the Federation wanted to honour the enormous part he played in developing knowledge of and interest in Dystonia. The Award is intended to encourage research into Dystonia in all European countries, especially by young scientists.

The Medical Advisory Board and the Board of the EDF have evaluated 8 papers submitted for the David-Marsden-Award 2007 on the basis of originality, clinical and scientific content, experimental design, clarity of presentation and most important significance in the field of dystonia.

All papers were of high value and we congratulate

**Mirta Fiorio, PhD**  
**Dept. of Neurological and Vision Science,**  
**University of Verona**

on being chosen as Winner of the David-Marsden-Award 2007 for her Paper  
*'Defective temporal processing of sensory stimuli in DYT1 mutation carriers: a new endophenotype of dystonia?'*

The Award of EUR 2.500 will be presented to Mirta Fiori by Didi Jackson at the EFNS Congress in August 2007 in Brussels. She will also come to the Annual General Meeting of the EDF in Vienna to give a talk on her paper to the delegates.

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## European Dystonia Week

EDF started European Dystonia Day in 2002 and proclaimed 15th November as the special date. The idea was to create public awareness throughout Europe and most national groups joined in with various activities. It certainly achieved a lot more understanding of dystonia among the public and the medical profession. In the following years EDF left the date more open and called it European Dystonia Week, so that national groups could find a date which suited them. As you read in the foregoing articles there are a number of countries which are still very active and organise various functions and activities. Other groups, like TDS, UK, have always organised their Dystonia Day activities in May each year. In our opinion it would be a pity if we don't keep up this initiative, but we would like to discuss new ideas and/or different dates at the Annual Meeting in Vienna.

**Please bring up this subject at your next Board Meeting and give us your thoughts on this subject at the Meeting in Vienna. We want to keep you involved! Only by working together we will be able to keep European Dystonia Week as lively as before.**

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## ADDER

ADDER moved Office - the new address is:  
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Bensham, Tyne & Wear, NE8 4QL  
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Val Sharpe is no longer their delegate.  
Please now contact Ann Smith, ADDER Chairwoman.

### EUROPEAN DYSTONIA FEDERATION

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### Update Editors

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