



update

European Dystonia Federation

No. 2 Winter 2005/2006

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Dear Friends,

At the beginning of a New Year the members of the EDF Board send you their best wishes, in the hope that it will be a happy and peaceful year. The EDF will continue to support your national activities by spreading awareness and lobbying at the European level, while promoting international research and we thank you for sharing this task with us. We are proud to work with our friends across Europe and we look forward to the time when we will see real advances made in the understanding and treatment of dystonia.

Didi Jackson, President

12th Annual Meeting in Brussels

As Brussels has become the official 'home' of EDF we thought it would only be just to have the EDF Annual Meeting there. We were very fortunate to have the 'Club de la Fondation Universitaire' as our Meeting Place, due to Alistair Newton being a Club Member. And it proved to be a perfect venue: a wonderful old building, excellent meeting rooms and most of the delegates were also accommodated in the Club. This event is a real family gathering, as most of the delegates have known each other for many years. Newcomers are always welcome and soon integrated, the only occasional problem being the different languages, as the common language of EDF members is English. We are also very fortunate to have the support of members of our Medical Advisory Board and our Sponsors, who always find the time to attend the meeting.



Delegates of 15 National Groups attending the Meeting

The programme was again split up into scientific subjects and subjects of general interest. We really try hard to find subjects on dystonia which are new and interesting and that is not easy. Most of the scientific talks are published on the EDF Website.

We also made sure this time that delegates had the opportunity to talk about interesting projects or events of their own group and – limited to 15 Minutes for each talk by Annar Hansen as the timekeeper – we really were able to learn a lot from each other and go home with new ideas. We will surely continue doing similar projects at the next annual meeting.

Of course we also had some very lively social events, starting with a wonderful Dinner at a French Restaurant on Friday night. Not only the food was good, but also the entertainment, as it turned into a singing contest of typical national songs and we certainly have some talents among the delegates.

Saturday late afternoon – thanks to the wonderful organisation of Herman De Craecker and his wife Greta – we enjoyed a very informative bus tour and saw the sights of Brussels. We were even guided on foot to the famous Manneken Pis, before we finally had Dinner in a typical Belgian Restaurant on the Grande Place.



Dinner at 'Le Bretagne'

Our next **Annual Meeting** will again be at the 'Club de la Fondation Universitaire' in Brussels from the **22nd – 24th September 2006.**

We hope that you will keep the date free and be able to attend the meeting. More details in our Spring 'Update'.

General Assembly 2005 in Brussels

The General Assembly of the European Dystonia Federation is always the final and official part of the Annual Meeting, where amendments to the constitution, approval of the annual accounts, election of new members and nomination and revocation of officers of the EDF are voted on. The Minutes and Annual Accounts will be sent to each member organisation in due course.

At the General Assembly 2005 the positions of the Vice-President and the Treasurer came up for election.

Dr. Anthony Butler expressed his willingness to stand for another term of three years as Vice-President and was unanimously re-elected. Bert Gerrits resigned his position as Treasurer for personal reasons in Spring 2005. We'd like to thank him again for all the support which he has given the EDF for many years. Herman De Craecker, Board Member of the Belgian Dystonia Society, who was co-opted in the summer 2005 by the EDF Board as Acting Treasurer, was the only candidate for this position and was also officially elected by the delegates.

David Marsden Award 2005

The EDF introduced the Award in 2002 to encourage research into dystonia in all European countries, especially by young scientists. By naming it the David-Marsden-Award we wanted to honour Professor David Marsden and give credit to the enormous part he played in developing knowledge of and interest in dystonia.

In September 2005 the David-Marsden-Award, supported by an unrestricted educational grant from Allergan, was presented at the EFNS Congress in Athens for the second time. 12 papers by nine scientists were submitted for evaluation. All papers were of high scientific value. With the support and expert judgement of the EDF Medical Advisory Board, the EDF Managing Board decided to present the David-Marsden-Award 2005 to Dr. Victor Candia, Collegium Helveticum, Univ. and ETH Zürich, together with a cheque for € 2.500.

His Paper "**Effective Behavioral Treatment of Focal Hand Dystonia in Musicians alters Somatosensory Cortical Organization**" was received with great interest by the audience.

At the Annual Meeting 2005 of the EDF in Brussels Dr. Candia again gave a talk on his paper, - the full text is published on the EDF Website www.dystonia-europe.org



Dr. U. Tiesler (Allergan), Didi Jackson, Dr. V. Candia

Victor Candia

Collegium Helveticum,
Univ. and ETH Zürich



Victor Candia is German, but was born in Chile in 1966 and attended school there. From 1982 – 1989 he studied Classical Guitar at the University of Chile and from 1989 – 1992 at the Musikhochschule Trossingen in Germany. He also taught classical guitar at several other music schools in Germany.

In 1991 he himself developed Dystonia in his left hand and had to finish his career as a guitar player. He studied Psychology at the University of Konstanz, Germany from 1992 – 2000 and devoted all his time on research in Musicians with Dystonia.

In 2004 he finished his studies with a doctoral degree as Dr. of Natural Sciences with a thesis on Clinical Neuroscience and brain plasticity focusing on musicians with dystonia.

He has received various Awards like the First Award for Art and Science of the Fundació Ciència i Art, Terrassa, Catalonia in 2002 and has published numerous scientific papers especially on Hand Dystonia

In 2004 he took up a position at the Collegium Helveticum founded by the University and ETH Zürich, where he is working on interdisciplinary research projects including brain and emotions, as well as brain plasticity and focal dystonia.

European Dystonia Day 2005

The idea of a European Dystonia Day was started in November 2002 and it is quite remarkable how much effort has gone into these special events by most of the national groups since then – one of the unusual events last year was the Football Match organised by the Belgian Dystonia Society. We know it is not always possible for each national group to organise something on a specific date, but we would like to thank everybody for their tremendous support and hope you will keep it up in the coming years.

Here are some of the reports we received about activities for last year's European Dystonia Day:

ALDEC, Catalunya, Spain

European Dystonia Day was again an important event for ALDEC. One of our aims was to spread information among lecturers and teachers as well as students, physicians and nursing staff. On the 15th November we set up an information booth at the University Hospital and distributed a lot of leaflets on Dystonia especially to medical students and answered plenty of questions about causes and consequences of all forms of dystonia.



Ana Sánchez Sánchez and Members of ALDEC

On November 17th another information stand was set up at the Clinic Hospital of Barcelona. This was the day when patients received their botulinum toxin treatment. Most patients knew about dystonia, but we had an opportunity to tell them about ALDEC and also EDF and inform them about valuable information on the website.

An informative text about dystonia, ALDEC, EDF and the significance of the European Dystonia Day on November 15th was placed in one of the most renowned newspapers in Catalonia, "El Periodico de Cataluña". As a result we received many calls requesting further information.

We also produced a special leaflet about European Dystonia Day, the member groups of the European Dystonia Federation (EDF) and all activities and initiatives currently developed to further public awareness about the illness.

All these activities could only be carried out by a lot of involvement of ALDEC members, but we feel more than rewarded by the positive response of the general public, as well as many dystonia patients. We offer a special 'thank you' to those people who so generously assisted us.

ADDER - UK

Over the past few years ADDER has been unable to be active for European Dystonia Day, as the date has always coincided with other events. This year ADDER made up for it with some very exciting activities.

It started with a Meeting at the Post Graduate Lecture Theatre at York District Hospital. From 150 letters sent out about 30 people attended the meeting with talks by Dr. Phil Duffy, Neurologist at York District Hospital, Val Sharpe as coordinator of ADDER and Dr. Anthony Butler, who talked about Genetics of Dystonia.

On Saturday, 17th November an unusual event - a Fancy Dress, Karaoke and Disco - was organised at the Club

in Gateshead, which was enjoyed tremendously by a lot of members.

As it was near to Christmas the Meeting in Carlisle on Friday, 25th November took place in a church vestry. The weather forecast was for snow which restricted the number of people attending, since the area is very rural. Nevertheless everyone enjoyed the chat and the lovely buffet, which had been prepared by one of the members.

Again all these activities spread awareness of dystonia and have given support to people affected by this movement disorder, which is still largely unknown to the public and the general medical profession.

DDG, Germany

European Dystonia Day was celebrated in various ways by most of the 20 regional groups of the DDG. This year one of the main aims was to approach doctors and medical students in hospitals. Scientific Symposiums were organised in Rostock, Zwickau and Hamburg, where Prof. Christine Klein gave a talk on genetics and Dr. Dirk Dressler on 'Dystonia – One Name – 100 Faces'.

Another very effective way of telling people about Dystonia was the Info Stand in the main entrance hall

of one of the big hospitals in Hamburg, where members of the DDG approached visitors and handed out info material.

All these activities again helped to spread awareness and the number of new members, gained by this publicity, showed how important it is to take this message to the public.

NDF, Norway

This year the Norwegian Dystonia Society concentrated their activities for European Dystonia Week on advertising in national newspapers and articles in Health Magazines on personal stories of people affected by Dystonia. The Health Magazine "Better Health" published a very informative article about a young woman – Oddhild – with severe generalised dystonia, who had deep brain stimulation and is now able to lead an almost normal life again.

This advertisement was placed twice in a weekly paper in Norway, which aroused a lot of interest and many enquiries to the Norwegian Dystonia Society.



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What is Dystonia?

Dystonia is a neurological **movement disorder** characterized by involuntary **muscle contractions**, which force certain parts of the body into abnormal, sometimes painful, movements or postures.

Dystonia can affect **any part of the body** including the arms and legs, trunk, neck, eyelids, face, or vocal cords.

10 Years – ÖDG, Austria

The Österreichische Dystonie Gesellschaft (ÖDG) celebrated their 10th Anniversary on the 14th and 15th October 2005 in Vienna and Didi Jackson, EDF President, was the guest of Honour. There is a long story behind this, as Didi – then Chairwoman of the German Dystonia Society – assisted Christa Hafenscher, founder and President of the ÖDG, in many ways in forming the ÖDG in 1995 and ever since has kept close contact. Didi, of course, was also there to represent the EDF and had plenty of opportunity to do so.

Viennese people have so much charm and their events are always very special. The official event started on Friday night with a wonderful reception in the Vienna Town Hall – an enormous and beautiful old building. A Representative of the Mayor of Vienna, Christa Hafenscher and Richard Schierl, now President of the ÖDG, and Didi addressed the audience and special members of the ÖDG received a pewter badge from the Mayor of Vienna. It is hard to describe the special atmosphere of this remarkable event.

Next day the celebration carried on in their new Meeting Place "Maria Frühwirt". This is a beautiful old building, where several Self-Help-Groups have their offices and meeting rooms. The ÖDG had invited all their members, doctors who had supported them from the start, politicians and sponsors, who were all interviewed by a radio moderator. It was livened up by musicians and two charming singers, who kept the audience happy with popular songs like "Moon River" – some even danced – and at the end of the day everybody enjoyed the wonderful choir of about 30 young singers, who came specially by bus from Bratislava.

Everybody was happy, drinking coffee and wine, eating cake and sandwiches and Christa Hafenscher and Richard Schierl always present with their special charm. The EDF Board takes this opportunity to congratulate Christa Hafenscher, Richard Schierl and all ÖDG members on their achievements to spread awareness of dystonia. Their approach is unique and personal and it



Didi Jackson, Richard Schierl, Christa Hafenscher
with the new ÖDG Cap

is successful. National Newspapers and a Health Magazine have written numerous articles on dystonia and they had interviews on radio and TV stations. They never give up till they succeed to tell the public about dystonia.

Last but not least congratulations to Christa Hafenscher: The Mayor of Vienna presented her with the “Reward of Humanity 2005” for her remarkable achievements for people affected by dystonia.

EDF Activities

Reimbursement for Botulinum-Toxin-Therapy

The EDF was approached by several national groups about the increasing problems of reimbursement for Botulinum-Toxin-Therapy. We developed a questionnaire to collect specific data in order to assess the position across all the countries of our member groups. We are grateful to everybody who took part in this survey - only 3 of the 19 groups did not return the questionnaire. Here is a summary of the results which Alistair Newton commented on at the General Assembly 2005 in Brussels.

Botulinum Toxin Therapy is acknowledged for the treatment of dystonia in all European countries, but only officially approved by the national Health Authorities for Cervical Dystonia and Blepharospasm. For all other forms of dystonia reimbursement is not automatically assured, depending on the health system of each country. In the UK, for instance, treatment for all kinds of dystonia is reimbursed by the National Health Service. Scandinavian countries also have free treatment or limit the patient's cost to a maximum amount per year (in Finland a maximum of € 606). In other countries treatment is free only when carried out in hospitals, not when done by a neurologist or other

specialist in his surgery – this applies for instance to Austria.

The main question of course was “What action can be taken if reimbursement is refused?” There is no clear answer to this, because each country has different legislation. The best advice is to inform the Health Authority and insurance companies comprehensively about dystonia, supply information material and scientific articles. Each case of dystonia is different, the symptoms vary in location and extent, and it is important to point out that the Botulinum-Toxin therapy is often the only successful treatment. Get the Insurance Companies on your side and hope for their goodwill.

So far the attempts of national Dystonia Societies to get global approval for all forms of dystonia from their national Health Authorities have not been successful and it would be futile for EDF to attempt to raise the matter in Brussels, as the EU so far has no direct control over national health policy at this level. The pharmaceutical companies are in constant contact with the national health authorities to improve the situation and the EDF will of course also endeavour to achieve improvement wherever possible.

New EDF Website Portal

The Website of EDF has a new ‘look’, thanks to the wonderful work of Annar Hansen, the EDF Webmaster, and we hope you will find it more informative and easier to use. We also now have a **Forum** for ‘Members only’, which can only be opened with a password. **Members can obtain the password from their national group.**

This Forum is intended for communications among our members, questions, interesting events, photos – anything that is of interest to all members of national dystonia groups in Europe. Please feel free to use it.

Stem Cells and Patients – The Big Debate

EFNA Conference, Brussels – 15/16 December 2005

Because stem cell research involves so many religious and ethical questions, the information available to the public is often taken from only one angle or another. This has made it difficult for patients to hear the basic facts and then ask questions before deciding what their own views are.

EFNA, the European Federation of Neurological Associations, won a large grant (€500,000) from the European Commission, and raised further substantial funding, to host a ‘conference with a difference’ on stem cells and their potential for patients. This was not the usual series of presentations from scientists, politicians or religious leaders on their own views of this sensitive issue. It was organized as a television debate, with pre-recorded video, live interviews and an experienced moderator who walked among the audience and invited them to ask questions and argue with the experts. The clear aim was to give the basic scientific information about stem cells, alongside the views of political, religious and ethical leaders, then find out what patients actually thought about this important area of research. Electronic keypad voting was used to find out the views of the audience on several of the most important issues.

500 people (more than 60% of them patients, carers and patient group leaders) attended this meeting held in Brussels in December 2005. EDF, through its very active membership of EFNA, and the work of Executive Director, Alistair Newton, was deeply involved in the organisation, and the EDF Board members attended the conference, as part of their regular Board meeting. A number of representatives of EDF member groups also attended (invitations were sent to all EDF member groups).

As the facts emerged, it was clear that stem cell research has considerable potential in many areas of medicine, including neurology. Although it was agreed that we must be careful not to raise too much hope in terms of ‘magical’ treatments, the huge majority of experts and patients also wanted to allow research to develop further, as the prospects are so good for real benefits to patients in the future.

The event was a great success and the European Commission has already acknowledged that it shows an exciting new way of finding out what European citizens actually want to happen in important areas of their lives.

AMN

News

Denmark:

Ulla Balsler Poulsen, who is the founder and was chairwoman of the **Danish Dystonia Society** for over 10 years, has retired and we thank her for all the support she has given to EDF and wish her well. Harry Nonboe is the new chairman and also the contact for EDF. We hope we will be able to welcome him officially at the General Assembly in Brussels in September.

The new address is: Dansk Dystoniforening, Harry Nonboe, Solbakken 18, DK 7500 Holstebro, Tel. +45 97405065.

UK:

THE DYSTONIA SOCIETY has moved to a new office. Camelford House is fully accessible to visitors with disabilities and less than five minutes walk from Vauxhall Tube Station and several bus routes. They always look forward to meeting members in their new office.

Address: 1st Floor, Camelford House, 89 Albert Embankment, London SE1 7TP, Tel. +44 845 458 6211, Fax: +44 845 458 6311, Helpline: +44 845 458 6322.

ADDER also has a new office and Val Sharpe is the new coordinator. Address: Lead Road, Greenside, Ryton, Tyne & Wear, NE40 4JU, UK. Tel/Fax: +44191413 9500. Email: valsharp@btconnect.com.

Austria:

We congratulate Prof. h.c. Richard Schierl, Chairman of the **Austrian Dystonia Society** and Gabriela, who got married on the 5th December 2005 in Vienna. They have known each other for almost 12 years, organising interesting trips to many parts of Europe. Gabi supports his activities for the ÖDG whole-heartedly. Good luck to you both!!!



Just married!

EUROPEAN DYSTONIA FEDERATION

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Didi Jackson & Alistair Newton