



# pdate

European Dystonia Federation

No. 1 Summer 2005

News • Facts • Dates

*Dear Friends,*

We are pleased to introduce **EDF „Update“**, a quarterly newsletter, which will be distributed by Email with news on national groups, facts about new projects on Dystonia and dates of patient meetings and medical congresses. The idea is to keep you 'up-to-date' with EDF activities more frequently. To do this effectively, we need your input to give us regular news about interesting events and projects in your group.

## Project of Interest

At our Annual Meeting we would like each delegate to talk about an interesting project of your national group. You can show a video, slides or just talk for not more than 15 Minutes. This is not intended to be a description of your group or your whole year's programme. The idea is to share your experiences with one successful project. Please hand in your concept by Email by the **end of July**, so that we can plan the programme accordingly.



## Annual Meeting 2005 in Brussels

**The General Assembly 2005 will take place in the Club de la Fondation Universitaire in Brussels from the 23<sup>rd</sup> – 25<sup>th</sup> September. We hope that all national groups will be able to send at least one delegate to this Meeting. Member groups will be responsible for all travelling expenses for their delegate. There are several airlines offering cheap flights to Brussels, including Ryanair and SN Brussels (formerly Sabena).**

Delegates will have rooms reserved at the Club de la Fondation Universitaire or at a nearby Hotel. The EDF again will pay the cost of the Hotel accommodation for 2 nights, including lunch on Saturday, Dinner on both evenings and coffee breaks for **one** delegate of each national group. We will be delighted if more than one delegate from each group can come to Brussels, but, as you will appreciate, EDF does not have enough funding to pay any expenses for additional people. A fee has been carefully calculated and, including Saturday Lunch, Dinner on both evenings and Coffee Breaks, we will require a

payment of **60 Euro** for each additional participant. This does not include Hotel accommodation costs at 95 Euro per night (single) and 135 Euro per night (double).

We have again attached a **Registration Form** and kindly ask you to complete and send it back to the Secretariat by the **end of June**. This will assist us to make final arrangements. The official programme including detailed travel information, a map of Brussels, will be posted to you in due course.



## Membership Fee

Over the past few years, the annual EDF Membership Fee has been a nominal 10,00 Euro. At the General Assembly 2004 in Basel the EDF Board made a proposal to increase this fee to 100,00 Euro for each national group. At our General Assembly 2005 this proposal will be discussed again and voted on. Please make sure that your national Board comes to a decision on this subject before the EDF GA. Assuming that the proposal is agreed, it is hoped that payment of fees will be made by bank transfer, which is free of charge in the Eurozone. For member organisations who are not in the Eurozone, the fees will be accepted by the Treasurer in cash at the GA.

At the General Assembly of the **Swiss Dystonia Society** (Schweizerische Dystonie-Gesellschaft) in May 2005, Dr. Beate Westenberg retired as Chairwoman and the members elected Corinna Rogger as her successor.



**Corinna Rogger**

Corinna Rogger studied medicine in Bern and has been actively involved with Dystonia for many years. Her husband, a psychiatrist, is affected by Dystonia and delegates who attended the EDF Meeting in Basel in September 2004 will remember the interesting workshop 'Coping with Dystonia' with Dr. Urs and Corinna Rogger.

The **Austrian Dystonia Society** (Österreichische Dystonie-Gesellschaft) also has a new Chairman. Christa Hafenscher resigned after 10 years of chairmanship and is now honorary chairwoman.

Prof. h.c. Richard Schierl was elected as the new chairman. Richard Schierl is well known to most of the EDF member groups, as he has taken an active interest in all EDF activities. Dystonia has been part of his whole life, but despite those difficulties he always had a positive outlook and his numerous professional interests have inspired many patients affected by Dystonia.



**Richard Schierl**

The **Norwegian Dystonia Society** (Norsk Dystoniforening) has also elected a new Chairwoman.

Aud Engen has been vice chairwoman since 2004, but „switched“ position with Annar Hansen and took over the leadership this year. She has been a member of NDF since 2003 and has had blepharospasm since 2000. Aud works for the Norwegian oil company Norsk Hydro and is fond of travelling, especially to Greece.



**Aud Engen**

In October 2004 there were also changes on the Board of **ADDER**. The new Chairwoman is Ann Smith, who has been elected for a term of three years. The social secretary is Pauline Dawson.

*We congratulate them all, wish them well and offer all the assistance they might need.*

## UK Dystonia Awareness Week 2005

Dystonia Awareness Week in the UK took place 8<sup>th</sup>-14<sup>th</sup> May and the Dystonia Society made every effort to promote awareness through its own efforts and those of its 3,000 members. The Society marked the week with the launch of a new national helpline number to provide a support and information service for dystonia sufferers, their carers and anyone else affected by this distressing condition.

The Society distributed over 250 Awareness Week Information Packs to members, medical professionals and service providers. The packs contained three new leaflets - a general one „Dystonia explained“, and others on blepharospasm and cervical dystonia - posters, stickers and ideas for fund-raising events to be held during the week. Also included was a new lapel badge featuring the Society's distinctive logo, developed last year to mark the charity's 20<sup>th</sup> anniversary, and nearly 1,000 of these have been distributed in the past month.

Amongst other things to mark Awareness Week members have held coffee



**Maria Pinto and her husband**

mornings, fashion and cosmetic sales, taken part in sponsored events of various kinds and put up displays and information stands in their localities. The spirit of the week was perhaps best summed up by Maria Pinto, a 68-year-

## New Office in Vienna

The **Austrian Dystonia Society** has a new 'home', a centre, where members can go for information or advice or just read, and where the regional group has its regular meetings. Opening hours are from Tuesday to Thursday from 12 – 3. p.m., as well as on Wednesday from 6.00 – 8.00 p.m. Whenever you are in Vienna you will always be welcome. Österreichische Dystonie Gesellschaft Obere Augartenstr. 26 – 28 Stiege 2, 1st Floor, Nr. 1 1020 Vienna AUSTRIA Tel./Fax +43 1 33 42 649 Email: [dystonie@aon.at](mailto:dystonie@aon.at)

old member from Dundee in Scotland, whose husband has dystonia. Despite being afraid of heights Maria bravely decided to undertake a sponsored parachute jump to raise funds for the Society. She said „I had my eyes tightly closed before the jump but had them wide open on the way down and thoroughly enjoyed the experience. I think my husband and son, David, were more anxious about it than I was!

The Medical Advisory Board of the EDF has two new members. The EDF Board has invited Professor Philippe Coubes and Professor Maja Relja to join the Medical Advisory Board and we are honoured that both have accepted.



**Philippe Coubes**

Professor Philippe Coubes is Head of Neurosurgery and the Research Unit of Movement Disorders of the Gui de Chauliac Center of the Montpellier University Hospital. He has received numerous international academic awards and is known worldwide for his achievements in neurosurgery especially on deep brain stimulation for patients with dystonia.

**Professor Philippe Coubes** is Head of Neurosurgery and the Research Unit of Movement Disorders of the Gui de Chauliac Center of the Montpellier University Hospital. He has received numerous international

**Professor Maja Relja** has been Professor of Neurology at the Medical School, University of Zagreb since 1990.

She is a member of numerous international medical societies with special interest in movement disorders. She is also founder of the Croatian Dystonia Society and has been an active member of the EDF for many years.



**Maja Relja**

We are grateful for their support in all medical matters.

neurological patient advocacy organisations to be fully involved in this Platform, and emphasising that this should be from the earliest meetings to decide the basis of the research to the assessment meetings where final decisions are made on individual projects. He especially made the point that (almost) all medical research should be aimed only at trying to answer the real needs of patients and that scientists (including physicians) should not make the common mistake of assuming that they know what these needs are. Surveys of medical and patient opinion on this topic have shown that medical assumptions are often quite different from the views of the patients.

Clearly, there are medical research projects which may not immediately seem to be based on patients' needs but are likely to bring benefits in due time. Also, there are some research projects which are of scientific interest only and these will often provide knowledge which will be useful in the overall picture. There must be some flexibility of approach, but Alistair asked the scientists present to be sure to take the principle into every new project and reinforced the statement that the involvement of patient advocates is very important at all stages. The presentation was well received and several questions were asked by the scientists.

In March 2005, Alistair attended another workshop at the Research Commission, this time a meeting for toxicologists to contribute to the Technology Platform. Many of the scientists present had totally the wrong idea and merely expected the 'Platform' to deliver more funding to them so that they could expand their 'empires' and do more research without too much external control. Alistair was able to remind them of the title of the workshop and the aims expressed by the organisers, which were to find ways of providing better medications to patients more efficiently and effectively. A number of the delegates accepted the criticism and began to consider the work in a different 'light'.

It is hoped that this initiative by the Commission and the positive response by EFNA and EDF will ensure that patients are fully involved in this important process.

## EDF Activities

### European Commission – European Technology Platforms – „Developing Innovative Medicines for Europe“

**In the autumn of 2004, a meeting of scientists was held at the Research Commission in Brussels, to lay the framework for this particular Technology Platform. Our Executive Director, Alistair Newton, was invited by the Commission to make the case for patient involvement in this project.**

'Technology Platforms' are a fairly recent initiative of the Commission on a variety of topics and the Platform on Innovative Medicines is intended to improve various aspects of the work of the European pharmaceutical industry:

- To focus on avoiding bottlenecks in development of new medicines – scientific bottlenecks, regulatory bottlenecks, bottlenecks in delivery of medicines to patients, bottlenecks in patient compliance with the doctor's instructions, etc.
- To reduce the time it takes to bring a new medicine to the end user – the patient
- To avoid interfering with good market competition
- To bring some useful benefit to 'public health'
- To boost economic growth – biopharmaceutical companies form an important sector of the European economy
- To assist in the hoped-for recovery of a pre-eminent position for European biopharmaceutical research and development.

Since he was representing EFNA (European Federation of Neurological Associations) as well as EDF, Alistair made a presentation expressing the wish of

## Conference on Stem Cell Research and Therapies

**BRUSSELS – 15<sup>th</sup>/16<sup>th</sup> DECEMBER 2005**

A real Opportunity for all Citizens to debate the Issues

Through EDF's involvement with EFNA (an umbrella organisation for pan-European patient federations in the field of brain disorders) we will be centrally involved in organising a two-day conference of an estimated 500 participants, with the support of EU Directorate-General Research, to provide the latest scientific information on the research on, and therapeutic use of Stem Cells in severe disorders. This will take place in Brussels from lunchtime 15<sup>th</sup> to lunchtime 16<sup>th</sup> December 2005.

The goal of this conference is to promote a real dialogue on stem cell therapy between science and society. The understanding of most of the European population on the topic of stem cell research and its potential is limited. They need help to focus on research priorities, ethical questions and the role of society's institutions. The conference will use lay language in the form of a television debate and there will be ample opportunity to pose questions to experts in this very sensitive field of research.

You are encouraged to send a delegate to this conference, which will be one of

the most important and interesting of its kind. Registration will be free and lunch and coffees will be provided, but you will need to cover travel and 1 night's accommodation. The working language will be English, with simultaneous translation into major EU languages.

A special website for the conference is being created and its www address will be announced shortly. Contact may be made through the EFNA Secretariat: EFNA Office, Dept of Pharmacology, University of Florence, Viale Pieraccini 6, I-50134 Firenze, Italy, Tel: 0039 055 4362098, [www.efna.net](http://www.efna.net)

## Contact Corner

Who would like to contact Audrone Tamuliene, who lives in Lithuania, near Vilnius? She is the mother of Liucija, who is 14 years old and has torsion dystonia. As she does not know of any other children with dystonia in her own country, she would very much like to have contact with children with dystonia in other parts of Europe. She speaks good English and Russian and you can contact her via eMail [audronet@delfi.lt](mailto:audronet@delfi.lt) or write to her: Audrone Tamuliene, Ragaines 61 A, Siauliai, Lithuania.

*If anyone has a particular wish – such as corresponding with someone from France to improve their French, find out about skiing in Norway or a holiday in Croatia etc., please write to us and we will put it into the Contact Corner in our next Update.*



## European Dystonia Week 2005

Please note that **European Dystonia Week 2005** is from the **12<sup>th</sup> – 20<sup>th</sup> November 2005**.



Each national group is free to choose the date which is most suitable for their Dystonia Action, which could be one afternoon or a whole weekend.

Public awareness is what we want to help you to create and we would be happy if all European Dystonia Federation Member Groups will support this initiative.

### EUROPEAN DYSTONIA FEDERATION

Secretariat: 69 East King Street,  
Helensburgh, G84 7RE, UK  
Tel/Fax: +44 1436 678799  
Email: [mail@dystonia-europe.org](mailto:mail@dystonia-europe.org)  
Internet: [www.dystonia-europe.org](http://www.dystonia-europe.org)

#### Members:

Austria, Belgium, Croatia, Denmark, Finland, France, Germany, Ireland, Italy, Netherlands, Norway, Portugal, Spain, Sweden, Switzerland, United Kingdom

#### Update Editors:

Didi Jackson & Alistair Newton