

## News from the president

### Dear EDSA members,

Christmas is coming up and before that I want to give you some information about what is going on in the EDSA-world.

### Formalities

Boardmembers are busy with some boring timeconsuming but necessary formalities.

Isidro Moyano, our new treasurer f.i. has to change the EDSA bancaccount from Dublin to Prag.

Another formality is changing the official EDSA address, which up til now was at the private address of one of the former boardmembers in Belgium. Erik de Graaf, the general secretary is busy with this job.

### Payment of EDSA Fees 2008

Isidro has also just sent you the invoices for the 2008 memberfees, these should still be paid into the **irish account**. We hope everyone of you got the invoice and will make the effort to pay the fee as soon as possible.

### European DS-Conference in Sarajevo

Some ten days ago, you all got a first invitation to the international DS-Conference from Sevdija Kujovic, the president of the DS organisation in Bosnia&Herzegovina. The conference will take place from 2.-5. April 2009 in Sarajevo.

EDSA as an organisation, cannot give financial support, but some professionals from different EDSA member organisations are prepared to hold lectures, give seminars etc. and will be present in Sarajevo.

This is very important, as in B&H the situation for people with DS ist still not very good. An international conference with support from EDSA and with many

interested participants from abroad is very helpful to inform and encourage parents and professionals and it is an important tool to get the medien interested in this topic.

The bosnian DS organisation is very generous. They offer one participant from every EDSA-membergroup free hotel for three nights, including breakfast and lunch and some sightseeing in Sarajevo. We hope to see some of you in Sarajevo, this will also be a good occasion to have a boardmeeting.

### Website

Frank Buckley, from DownsEd (elected to vice president of EDSA) is pleased to host and maintain an updated web site for EDSA, but to keep it informative and useful, the content must come from members!!

We are preparing some basic information for the website at the moment:

1. The history of EDSA, plus the essentials will be part of the website.
2. Ofcourse there will be links to all your organisations websites.

3. In 2006 I collected dates from all members about their organisation and the situation of people with ds in their countries. 22 membergroups answered this questionnaire, a summary was than published published in „News and Update“. pdfs will be made from these articles and come up the website as well.

But at that time not all members have answered the questionnaire! I will try to collect the information from these organisations again!

Plus from our new members since 2006: Bosnia, Norway and from Razem the polish group in Wroclav.

4. To have an interesting and functioning website, it is necessary that all members will provide recent news

and updated information regularly. As long as text and photos are provided, DownsEd can take care of layout and web publishing.

Frank will contact you in the new year with information, how to handle the website

### Database of DS-literature

Since long we were planning to build up a database with DS-specific-literature in all european languages and have this information on the website.

So far it has only been a plan, but it is a great concern to me to get this database from the ground.

### So here comes your first homework!

Attached you will find a file, where you can fill in titles and information on DS-books in your language. There are three sections: books for families, books for professionals and magazines. If you have only one or two books as a recommendation, that is fine, if you have ten titles, that is ok too. I will collect this information so please send the forms back to me directly, you can use my E-Mail address: [halder.ds.infocenter@t-online.de](mailto:halder.ds.infocenter@t-online.de)

### The European Day of People with Disabilities 2008

On the occasion of the European Day of People with Disabilities 2008 (set at 3 December by the United Nations 1992) a conference was organised in Brussels by the European Commission of Employment, Social Affairs and Equal Opportunities in close cooperation with the EDF.

The main theme of the conference was „Acting locally for a society for all“. As a representant of EDSA, I attended this conference. So did our boardmember Pat Clarke, in his function as board-member of EDF.

### What is EDF?

EDF is the European umbrella organisation representing the interests of disabled citizens at EU level. EDF membership includes national umbrella organisations of people with disabilities from all EU/EEA countries, candidate countries and



Pat Clarke during his speech in Brussels

other European countries, as well as NGOs representing the different types of disabilities. More information is available at: [www.edf-feph.org](http://www.edf-feph.org) EDSA is member of EDF.

### Theme of the conference

The conference dealt with the topic how the UN Convention is put into practice on the local level. Different speakers presented projects. A main issue here is, how to involve people with disabilities in all decisions affecting them.

### People with DS should take part in these meetings

It is worrying me, that at such an occasion like this conference people with Down-syndrome or with another learning problem – although they are represented by people like me from EDSA, or from other organisation like Inklusion International, Mencap etc. – are not there on the spot themselves. We do have to train some of our young adults to be able to come along, to take part in these official meetings, to speak up for themselves and to be visible to the others.

Even among all these people with handicaps they seem to be a forgotten group.

I was glad, that Pat in his function as member of the EDF Executive Committee focussed in his concluding remarks on this issue as well.

### World-Down-Syndrome-Day 21.3.2009

2009 we will celebrate the World DS Day for the 4th. time.

There will be no international theme, as has been decided before. It is too difficult to find a motto, which is equal good and appropriate for all countries. So everyone, can think of an own theme.

To give you a suggestion ... My own organisation the German Down-Syndrom InfoCenter has decided on the motto: „Don't let me down!“

This will be the slogan for our do-it-yourself-poster campaign. Such a poster-action might be an idea for others as well. The dutch association and several other groups has been using this idea in the past years. If you are interested, we are happy to give more information.

Our main campaign this year: we will show a spot on so called Infoscreens, hanging in railway and subway stations in 20 german cities. On the day of 21. March the 10 second spot with the theme „Don't let me down!“ will be shown 100 times on ca. 400 screens.

### Season's greeting

And with this beautiful photo I wish everyone of you a very merry Christmas and a happy New Year!

Cora Halder  
EDSA President



Conny Wenk, the mother of Juliana and a professional photographer, gave us permission to use this photo in our Christmas mail ([www.connywenk.com](http://www.connywenk.com))