



News from the president

Dear EDSA members,

It is already some time ago that I sent around a letter with general news about edsa related activities. Before you are all off on holiday I would like to get across the latest news.

Our general secretary Erik de Graaf represented EDSA at the annual meeting of EDF last month in Athens. He reported about it on 13th. may in a mail via the EDSA-List.

Webpage: www.edsa.eu

Frank Buckley from the Educational Trust and his colleague Howard Hurd have set up the EDSA-website. First information is available now about the EDSA-mission, its values and goals. You can read the bylaws (sorry, still only in dutch language, the english translation will follow). You will also find a short summary about EDSA's history, the EDSA publications and the names of the present boardmembers.

There is a list of all EDSA members with links to their website, as far as known, and part of the members are linked to an article with their profile. These articles has been written 2006 after a small survey I did among the members and were then published in the magazin Down Syndrome News and Update.

In case people want more information about EDSA the contactaddresses of Erik and myself are on the website.

One of the next steps will be to insert the database on ds-literature. Some members have already sent back the special forms, with which we collected titles of recommended books and journals concerning DS in their language. If you have any interesting news you would like to place on the website, please send this information to me: halder.ds.infocenter@t-online.de

The screenshot shows the EDSA website homepage with a navigation menu (home, about, publications, members, join, contact) and a 'Latest news' section. Below it is a news article titled 'Spain / Balearic Islands ASNIMO (Asociation Sindrome de Down de Baleares)'. The article includes details like 'Internet: www.asnimo.com', 'Founded: 20 November 1976', 'President: Juan Perera Mezquida', and 'Members: 382'. It also lists 'Main goals' and 'Services'.

or to Erik: erikdegraaf@downsyndroom.nl and we will try to get it on the page.

One part of the webpage is thought as a forum, where people can communicate topics of interest, which fills the website with more life!

Please, donot forget to pay your membershipfee!

DS- organisations in Iceland and Croatia interested in EDSA

During the last months we have been in contact with DS-organisations from different countries, who are not yet in EDSA, but are interested to become member.

One is Félag áhugafólks um Downs-heilkenni, the DS-organisation of Iceland. I became a very interesting and positiv report about the situation of children and youngsters with DS in this northern country. Inclusion from playschool to upper secondary school is normal and since 2007 people with disabilities also have a right to an university education! Financial, and social support are very well organised and the medical care is good. Iceland has applied for EDSA membership and this will be on the agenda at the next annual meeting in Dublin.

Another organisation applying for membership is the Croatian Down Syndrome Association (HZDS - Hrvatska zajednica za Down sindrom), established April 2005, as a roof organization of eight local-county associations.

Sharing knowledge

I am also in contact with ds-groups in Slovenia and Estonia. Some of our own german publications have recently been translated into slovenian language. Most of us are not in the position of giving financial support to others, but we can share our knowledge and make our publications available, which is a great help as well. And an important mission of EDSA.

Visit to Bulgaria

Some months ago we heard via the EDSA Maillinglist about the situation of children with Down syndrome in Bulgaria, especially through an article in the Times, with the title: Exposing Europe's guilty secret: the incarcerated children of Bulgaria", which shocked us all. In the meantime first contacts were laid

by Liana Vizlan, our boardmember from Romania and Erik in the netherlands has been making posters from bulgarian children for World-DS-Day.

Just last month the parents organisation was founded and I got in contact with the chairman of this new group, Valentina Nikolova, who has invited me to come to Sofia for a first seminar with parents, professionals and students in july.

DS-Conferences

Different EDSA-members are organising national conferences:

- 25. - 27. september 2009
Austrian DS Conference in Salzburg
Info: www.down-syndrom.at
- 18. - 20. march 2010
Norwegian DS Conference in Bergen
Info: www.upsanddowns-hordaland.no
- 2. Congreso Iberoamericano
29. april - 2. mai 2010 in Granada
Info: www.granada2010down.org

10th. World Down Syndrome Conference in Dublin

It is only two more months that the 10th. World DS-Conference will be held in Dublin. It is not only an excellent possibility to inform ourselves about research and good practises in the DS-field, it is also an opportunity to meet up with old friends and getting to know parents and professionals from all over the world. I was so fortunate to be able to attend the last 5 worldconferences and have benefitted a lot from each of them. So I am looking forward to Dublin and hope to meet as many EDSA members there as possible.

The conference website: www.wdsc2009.com

The Annual EDSA meeting will be hold during the World Conference! In July Erik de Graaf will send you the invitation for the annual general meeting and the agenda. If there are any matters you want to be discussed, please let us know.

**I wish you all a nice summer!
Kind regards**

**Cora Halder
EDSA President**



Conny Wenk, a photographer from Germany makes beautiful fotos of children and youngsters with DS. If you are interested, you can find her 365 projekt: <http://kidswithalittleextra.blogspot.com/> and more pictures on her website: www.connywenk.com