

## News from the president

### Dear EDSA members,

I tried to get this letter and my easter wishes across to you in time, before Easter, not after. Now they come exactly on easter sunday. My apologies. Life is just so very busy. Here are some impressions of the last weeks. More dates on next edsa meetings etc. come towards the end of april.

spring collection of one of the best fashion storehouses together with promis from the fashion-, television and sportworld. 700 guests came to see the show in Zürichs most known Club, Kaufleuten (which was chosen from a british magazin as one of the top ten locations in Europe!) The fashionshow was a great event for everybody attending, and became extremely positive feedback in the medien. My gratulations to the organisers!

From the **USA** came Dennis McGuire, one of the autors of the book „Mental Wellness in Adults with DS“, who is an expert on mental health topics like depressions, grooves, selftalk etc. Also Karen Gaffney, a 31 year old lady with ds from Oregon talked to the audience. Karen doesnot need a manuskript or powerpoint, she is a very eloquent speaker and has an own foundation. Karen also showed a film about how she swam across the lake Tahoe 2009.



### World DS Day

It is not such a long time ago that you got my last letter. In the meantime we celebrated World Down-Syndorme Day and from some of you we heard over the EDSA Mailinglist what you have been organising in your country. The German DS InfoCenter offered again their postercampaign, this is an ongoing succes. We made far over 500 posters and they were then distributed by the families themselves in their own towns. The slogan we used was **Today is our day. I am part of it.** Besides that we had postcards, a flyer and our pin. In three big shoppingcenters in Nürnberg and Ansbach we organised exhibitions with big portraits of children and youngsters with DS. (Photo) And we gave away 1000 dvd's with our new informationfilm to schools and genetic counsellors. throughout Germany.

### WDS in Switzerland

One of the best events was surely the fashionshow in Zürich, Switzerland. 30 models with DS presented the new

### Nominations for DSi-Awards

On behalf of EDSA I collected names and dates of individuals and groups to nominate them for the DSi Awards. DSi was going to announce the awards from 2010 onwards every year on WDS. Unfortunately I havenot heard anything about this after the 21.march. Did you see the new website of DSi? It is worth a visit: [www.ds-int.org](http://www.ds-int.org) We are busy with the new edsa-site, this takes some time.

### DS Conference in Norway

I attended the DS Conference in Norway from 17-20 march. 460 participants, parents and professionals from all parts of the country came to Bergen. As we normally do not hear so much about what is going on in the north, I'll give you a short summary. The organisers of the conference, the Ups and Downs Ass. from Bergen with Nina Skauge as their leading lady managed to invite speakers from some nordic countries, from the States, Germany and Poland.

Though Karen has serious hipproblems and cannot walk very well, she is an excellent swimmer! Read more about Karen: [www.karengaffneyfoundation.com](http://www.karengaffneyfoundation.com)

From **Iceland** came Gudrun Stefansdottir, who works at the university in Reykjavik. She presented a project, that started 2007 as the first students with intellectual disabilities among them many with DS entered in a university-course, where they were educated to be childcareworkers, together with non disabled students. The students are together all the time. There is no extra class, or course, nor extra program, but students learn in tandem-system.

From **Sweden** came Professor Irene Johannson, very known in Skandinavia, especially in the field of speechdevelopment and signing. Her method: the Karlstadmodel is widely used in the nordic countries. The swedish psychologist Christina Renlund topic was the development of the

identity of children with ds and how we can help them in this process. Another lecture about speechdevelopment with focus on the more motoric problems children with DS might have and on stimulation of the mouth, tongue etc. based on the Castillo Morales therapy, was given by Sissel Tønneberg from Oslo together with Anne Regner from **Poland**.

I myself had the opportunity to speak about new projects, campaigns and what else is going on in the european DS-scene. This offers me also a possibility to talk about edsa. In a second talk my topic was „Managing life as an adult“ and how we can prepare our children for a life in the community.

Interesting for me was the concept of the Peder Morset Folgehøgskole, a residential adult college in north Norway, where students can spent one year after having left highschool and before they enter university or the workforce. Part of the students have a disability, some of them DS.

„Am I a teenager or do I have Down syndrome?“ Caroline Tidemand-Andersen from Oslo has worked with a group of 12 now young adults for over ten years, discussing with them all the life-questions youngsters have especially about their identity as a person with DS. Carolin has written a book with the same title, which was presented at the conference.

The premiere of a film about the transition from kindergarden into school was also on the program Two children had been followed during their last kindergarden- and first schoolyear. Preparations for the schoolstart, cooperation between staff from the different schools, therapeuts and families are shown in this film.

A lecture about the worksituation of adults with DS in Norway made clear that – even though Norway has mainstreaming in schools since many years – there is nearly no possibility to go on with inclusion once the person finishes school. Integration of the first workmarket is nearly not existent. That was the reason why Andrea Seeger from **Germany**, who works for a jobcoach service/workintegration com-

pagny and who gave many examples of good functioning workers with ds on the first market, became a lot questions after her presentation. [www.access-ifd.de](http://www.access-ifd.de)

Do you want to teach your child with ds english? Do it with Teddy! This is a method to teach english to small children or children with learning difficulties. „Learning english with Teddy“ becomes more and more popular in Norway and many children with DS are working with the Teddy materials. More on the website: [www.teddylanguage.no](http://www.teddylanguage.no)

Anne Stine Dolva from Lillehammer University who just finished a doctor-degree about integration of children with DS talked about social interaction between students with and without DS. While Sylvi Storvik from the Autisme Competencecenter in Oslo presented her researchproject about the doppel-diagnose of DS and autisme Ofcourse there were more lectures and some other cultural presentations, like a dance performance from the Oslo youngsters and a speech by a young lady with DS.

### Meeting with the DS-Ass. from Sweden, Denmark and Norway

I had also the possibility to talk to the representants from the swedish and the danish DS-Ass. both are EDSA members. Together with the norwegian we had a meeting where we discussed future cooperation. Especially interesting is the attempt to set up a scandinavian DS-journal.

This was a well organised, very informative congress.

### DS-Situation in Denmark

As many of you may have heard before, the situation for DS-children in Denmark is not particular positiv. 2008 only 20 babys were born, while 140 have been aborted. Denmarks doctors are trying hard to get their country DS-free.

**I wish you all nice easter days!  
Kind regards**

Cora Halder  
EDSA President



**Some pictures from the fashion- show in Zürich, because they are so nice!  
Photos: Conny Wenk  
[www.connywenk.com](http://www.connywenk.com)**