

## News from the president

### Dear EDSA members,

Two weeks ago I had the pleasure to invite the EDSA-board to Nürnberg for an extensive meeting: Friday evening, Saturday and Sunday morning. To all of us this was a very welcome opportunity, because this gave us enough time to discuss EDSA-matters. In this letter I will inform you about some of the topics we discussed.

### Member fees

One topic we are concerned about is the fact that some EDSA-members have not paid their fees for 2008, even after having been reminded by Isidro Moyano, our treasurer. We cannot longer tolerate this. any longer. These members will receive a letter from me as the president, with a last request. We regret this very much, but EDSA can no longer accept members, who do not pay their membership fees.

### EDSA must become more attractive for the members

A better and functioning website is our main goal, which will provide members the possibility to communicate ideas, problems, questions etc., is our main goal for the future. More contact among members especially through partnerships in EU-projects is a next important step. I myself wish more responsibility from those countries, who have long stable organisations for the new associations in Southern and Eastern Europe. This could be support through transfer of knowledge, sharing information or forwarding good practices, etc. It must be also clear that none of our member-organisations do have financial resources to support others with funds. More the contrary, they are mostly struggling for money themselves.

From my point of view and from the experience of many years working in the



Boardmembers from left: Anna Contardi, Pat Clarke, Liana Vizlan, Juan Perera, Cecile Dupas. On this side of the table: Cora Halder, Jacqueline London and Isidro Moyano.

field, I can confirm that there are many positive points for being an EDSA-member. The contact to other professionals and organisations have been very beneficial for my work, for my personal development and often helpful for the education of my own daughter. It was decided to set up a paper – working title is: What can EDSA do for you? – to be distributed among members and members-to-be.

### Mailinglist not very effective

During the last year I experienced how difficult it is to stay in contact with all the EDSA-members. Questions or enquiries sent over the EDSA-mailinglist receive very few reactions and if they do, then mostly from the same few people. So this does not seem the best way, to get things off the ground, to find solutions or discuss topics. We hope that with an interactive website communication will be more successful.

I have also noticed that once people from different organisations got to know each other personally, contacts get more frequent and efficient. So this might be another good reason to try to attend the annual EDSA-member meeting (AGM), an European conference or other international meetings.

### Suggestion to all members

One suggestion for member organisations is to place the EDSA-logo on their websites, easily visible, to show that you are a member. Some organisations have done this already. A short English text as an introduction to EDSA and the logo could be send over the mailinglist. You can translate this text into your own language. You might also like to show this newsletter and the link to the EDSA-Website.

### EDSA-website

I am very aware that the EDSA-website has not really been succesful and must apologise for that. It is very hard, nearly impossible, to find volunteers who can handle such a job in the long run. At the board meeting we have discussed different options and are working out a new solution.

### World DS Day

With the World DS Day coming up soon I would like to remember you to send information about your campaigns, activities, etc. to: [wdsd@downsyndrome-singapore.org](mailto:wdsd@downsyndrome-singapore.org) sothat this can be placed on the official wdsd-website: [www.worlddownsyndromeday.org/](http://www.worlddownsyndromeday.org/) It is also helpful for your own publicity work around the 21.3 You can refer journalists etc. to this page – if there is a lot of information here, from many

places around the world, it would underline the importance of the WDS.

### DSi-Awards

Down Syndrome International (DSi) will announce awards in the voluntary, professional and scientific categories to coincide with World Down Syndrome Day on 21st March each year. As a member organisation EDSA was asked to come forwards with nominations. I have been collecting suggestions of EDSA board members and sent them to DSi. Awards will be presented on 23th march at the Langdon Down Center in Teddington, UK. On this occasion the new website of DSi will be launched as well. So have a look there: [www.ds-int.org](http://www.ds-int.org)

### Medical aspects in adults with Down syndrome

Until now EDSA has produced a few publications, the EDSA essentials (Identity Document, Health Care Guidelines, Orientation for Families and the Code of Ethics ). We are planning a next one, which will be available via the website. This time the focus will be on adults with Down syndrome, as we are all aware how important it is to disseminate more knowledge especial on medical aspects. In some countries some information on this topic is already available. We have started with the preparation of this document and hope to be able to present it autum 2010.

### Don't be afraid of EU-Projects

We have discussed the cooperation among EDSA-members in the context of EU-projects. Some of our members have already been involved in EU-projects, others have not. It seems that the fear for the paperwork, the financial management and the unsureness about the workload of these projects is the reason that most organisations do not even want to try it. I do understand that, I was skeptical myself. But ... once you start to deal with it more seriously, you will soon find out that the paperwork is not that bad and can be done in relatively short time, and having done it once, you will notice that the forms to fill in are more or less the same for every project. The main work ofcourse has the promoter, the initiator who has to write the proposal,

find the partners, prepare the budget, coordinate it all, etc. But for a start you could easily be one of the partners in a small, clearly arranged project and find out how it works!

The international team of APID in Rom has a lot of experience in this field and has come up with different proposals to EDSA members in the past. One problem with frequently occurs is that partners have to react quickly as there is only a 4-6 weeks period of time between the announcement of the programm and the final date of submission.

Spending some time on EU-projects and the way they work beforehand seems like a good idea!



### Project: Yes, we can!

There are several European projects going on at the moment, where EDSA members are involved. One is the „Yes, we can“ in the framework of the Grundtvig Programme. The aim of this project is to evaluate the mathematic skills of adults with DS and find a proper methode and material to help them developing more competences in the areas needed. DS-groups from Czech Republic, Austria and Germany are among the 6 partners. Once our website will function we can present ongoing projects and via that way also find partners for new projects.

### Projectproposal: Networking

Anna Contardi came up to the board meeting in Nürnberg with a proposal in her pocket (prepared by her colleagues in Rom) and could convince most of the other boardmembers to sign up for this project, which focuses on international networking. In the meantime the project has been submitted and we are waiting for an answer from Brussels, whether it was accepted or not.

### Situation in Bulgaria

The president of the new ds-organisation informed us, that under pressure of regulations from Brussels institutions or orphanages in Bulgaria are closing



From left: Erik de Graaf, Jacqueline London and Cora Halder

down, without having a solution for the children. In the country people are not willing to adopt these children. It is tried to bring these children abroad via adoption organisations. EDSA-board members are very concerned about the situation in Bulgaria and especially about the practices of some of these adoption organisations. Pat will bring up this matter to EDF.

### Aimee represents EDSA in the EDF Youth Committee!

Aimee Richardson from Ireland has been selected to join the EDF Youth Committee as EDSA's representative. The EDF, the European Disability Forum is an independent European non-governmental organisation (ENGO) that represents the interests of 65 million disabled people in the European Union and stands for their rights. EDF is the only European platform of disabled people, which is run by disabled people or the families of disabled people unable to represent themselves. Aimee is the first person with an intellectual disability to be selected for this committee! So this is really a substantial progress!

### DS-Conferences

Next international DS-Conference, which will include meetings with all Scandinavian DS-organisations is the Norwegian DS Conference in Bergen 18. - 20. march 2010  
Info: [www.upsanddowns-hordaland.no](http://www.upsanddowns-hordaland.no)

### Kind regards

Cora Halder  
EDSA President