



News from the president

Dear EDSA members,

This is the first letter I write to you in my second period of presidency. Of course I feel honoured that you trust me to do this job for another three years, though at the same time I know, how hard it is, to please everyone's expectations. I will do my best.

EU-Funding, and how it works. Trainingcourse in Rome

Oktober 2011 we met in Rom for the trainingcourse on EU-funding. Paola Vulterini and the colleagues from AIPD in Rom organised a truly very interesting and challenging three-days session. We were 14 participants from 9 EDSA membercountries. After these intensive days we all do understand a lot more about the EU-fundingprogrammes and we are quite confident now to apply for a project. Hopefully all of us will put this new knowledge into practice soon. Thank you Paola, Carlotta, Anna and Maria Giulia! You did a great job.



New boardmembers: Dinka (Croatia), Tania (Ukrainia), Jarek (Poland)

New EDSA Board

Erik de Graaf from the Netherlands, Li-ana Vizlan (Romania) and Jacqueline London (France) left the board. We thank them all for the time and energy they invested in the edsa work. We welcome our new boardmembers: Dinka Vukovic from the Croatian DS Ass, Tania Mykhailenko from DS Ukrainia and Jarek Pieniak from Razem, Wroclaw in Poland. You will find some more information about them on the edsa website.

Another important fact is that Cecile Dupas is our new general secretary. She took over from Erik. And Anna Conardi became new vicepresident. Jacqueline London will now concentrate

more on building up or reviving the scientific committee, which might support EDSA- activities.

New EDSA members

We also welcome two new members: the Hungarian Down Syndrome Ass. and Down Sendromu Dernegi from Turkey.

EDSA website

EDSA website can now be visited via two adresses: www.edsa.eu and www.down-syndrome.eu New on the website are f.i. presentations from Kosovo, Czech Republic and Spain. Some of you have not yet send me a list of recommended DS-literature in your language. I would also be happy with interesting facts, scientific news, conferences, publications from your country. Textes should be in correct english, if you send photos then it should be in good quality.

Non-invasive bloodtest

During the meeting in Rom we discussed the new non-invasive bloodtest. It is a fact that this test will be on the market from 2012. We decided that EDSA members should act in their countries upon the quality of information around the testing procedure. Especially in Germany the new bloodtest is quite an issue in the media. Reason why we – the German Down-Syndrom InfoCenter will make it to our main action-topic at the next World DS Day.

World Down Syndrome Day

A most pleasant recent news was the fact that on november 9th the United Nations (UN) officially recognised and endorsed World Down Syndrome Day, 21st March. Recognition will help to safeguard the rights of individuals with Down-Syndrome across the world, particularly in the developing nations. EDSA welcomes this decision very much. Our campaigns around WSD will be more recognised. The status of a world-day means more seriousness, higher acceptance and media will be more interested in our concerns.

Activities and Campaigns around World Down-Syndrome Day 2012

I am interested to hear about campaigns and activities EDSA members plan to organise in their countries. If you tell about it via the mailinglist it can be an inspiration for others. We in Germany will focus on the bloodtest-issue with new informationmaterial for all gynecologists and genetic counselors. It will be distributed nationwide. On the other side we will offer again a do-it-your-self-postercampaign with a positiv message, and we bring out again the stamps and the pins.

DS-Conference in east or south-east Europe

There are some plans to organise a DS-Conference for parents and professionals in east and south-east Europe. Some of the EDSA members are discussing possibilities. We should support this idea as there is really a big need for information in these countries. There will be soon some more news via the mailinglist.

Upcoming national Down-Syndrome conferences 2012

France, Metz, 16. - 18. march
Belgium, Gent: 25, 26 march
Norway, Sarpsborg: 22.-24 march
Austria, Salzburg: 28. - 30. september

More information on the websites of the organisations.
(via edsa.eu/members)

EDF Conference in Denmark

On 5-6 March 2012 there will be a Danish Presidency conference entitled "Accessibility and participation – full inclusion of people with disability in society" which will take place in Copenhagen. Cecile Dupas will participate as representant for EDSA.

CapeTown, South Africa World DSConference 2012

August 2012 the 11th World DS Conference will take place in Capetown, South Africa. I do hope that some of you can be present there, even though this is an expensive event for us europeans. I am interested to hear, who of you will attend and who will give a presentation? I am pleased that our film „Down-Syndrome and I“ has been accepted. This means that I will travel to SA. The conference will be held from 15-17 august. A medical symposium is organised on 14 august, the day before the conference started. There will also be a special session for adults with DS. All information on the website: www.wdsc2012.org.za



EDSA-Logo

I will send to all of you via the mailinglist the EDSA Logo again. Please place it on your website. First it shows that your organisation is member in an international organisation. Secondly we can make EDSA more visible that way.

Merry Christmas and a Happy NewYear!

Only a few more days and we can celebrate Christmas. I wish you all some peaceful and relaxing days, time to enjoy family and friends and able to regenerate new power for the work waiting for us in the nex year!

New important book



Neurocognitive Rehabilitation of Down Syndrome: Early Years

by Jean-Adolphe Rondal, Juan Perera, Donna Spiker.

Juan Perera presented this new book in Rom. It has been published after the International Conference on Early Intervention in Palma de Mallorca, 2008. This book describes how early cognitive intervention in children with Down syndrome can be carried out, and can reduce, or compensate for, the major deficits characteristic of the condition. This comprehensive account relates the neurocognitive approach to the major therapeutic endeavors in the neighboring fields of neurogenetics, experimental environmental enrichment, molecular genetics, pharmacology, pediatrics and cardiology for infants with Down syndrome. Neurocognitive Rehabilitation of Down Syndrome provides the guidance required to establish effective rehabilitation programs, and is essential reading for developmental clinicians, pediatricians, neuropsychologists and other health professionals.

Cora Halder