

News from the president

Dear EDSA members,

Just for eastern I would like to send around a next letter with some general news about edsa related activities in the last two months.

Meeting in Brussels with EU-specialist and follow-up

17, March 2009 EDSA-boardmembers Jacqueline London, Frank Buckley and Erik de Graaf together with Dr. Delabar from the Univ. Paris Diderot had a meeting in Brussels with Dr. Patrik Kolar, head of Unit „Genomics and Systems Biology“ (Research Directorate of the European Commission) to discuss possible ways to support research on DS in the future. A report of that meeting has been sent around by Erik de Graaf via the EDSA-List to all members on 31. march

As a follow up, it has been decided that EDSA will prepare a document, to be presented in Brussels by september(!), with the main ds-research areas from the families point of view and from scientists/professionals and institutions from all over Europe. The purpose of this document is to make the responsible authorities in Brussels more aware about the needs of people with DS and which topics research should focus on. It is not a request for specific projects.

To get the opinion of families and professionals we need the help of you, of all the EDSA members! Frank Buckley prepares a questionnaire which you, as a leader or coordinator of your association should send on to some of your own representative memberfamilies and try to get answers back from them in short time. If we all participate, we get a broad idea of which topics families think research is important.



Sevdjia Kusovic, president of the bosnian DS-association and organiser of the conference in Sarajevo

You can find more information about this project in Franks mail, sent via the EDSA List on 3. April. You will also find there a ppt about research funding in Europe.

European DS-Conference in Sarajevo

From 2. - 5. april the ds-organisation Downsy in Sarajevo, organised the first DS Conference in Bosnia Herzegovina! The conference was a great succes, so it really has been worth all the efforts, and all the hours work Sevdjia Kusovic, the Downsy-president and her team had spent in the preparations. About 160 parents and professionals attended the conference, politicians were present at the opening ceremony, and there was a lot of attention from the medien.

Heute ist mein Tag – Today is my day!
The German DS InfoCenter used this 2 meter high banner to attract attention to their informationstands.

On the programme were many speakers from Bosnia, but also some from Croatia and Slovenia. Besides that, Sevdjia had managed to get 10 speakers from the edsa-member countries. They travelled to Sarajevo to share their knowledge and experience with the bosnian parents and professionals.

I want to thank all these speakers for their willingness to come. This kind of commitment is in my opinion one of the main tasks of EDSA. We all have to congratulate Sevdjia Kusovic and her team for having the courage to organise such an international conference only three years after their organisation was founded and make it into such a succesful event.

Fotos of the conference:
www.mijnalbum.nl/Album=LDMETE33



This is Nicolina, she is 14 years old, visits a regular school and has an orange belt in karate. We met her in Sarajevo, where she showed us bosnian folksdancing

Very succesful Do-it-yourself-Poster-Campaign for World Down Syndrome Day!

Erik de Graaf, our general secretary, together with his son David, has made more then 150 posters for the international market! Many EDSA members send him photographs of children and youngsters with Down-Syndrom. The pictures came among others, from Iceland, Portugal, Albania, Belgian and Croatia. All Edsa-posters are shown at this adress:
www.mijnalbum.nl/Album=88WTAUU8

Great interest found the poster-campaign in Poland. A „poster-factory“ was founded by Jaroslaw Pieniak in Wroclaw, They took also care of the romanian posters. The „moving“ polish poster gallery can be seen here:
www.stowarzyszenie-razem.org/galeria/

The posters of the german campaign can be viewed:
www.ds-infocenter.de/MEDIA/WDS09/Galerie%2009/index.html

You can inform yourself about WDS09-actions worldwide here:
www.worlddownsyndromeday.org/events.htm

And a very nice spot from Italy is here: www.aipd.it/cms/index.php

EDSA-boardmeeting in Sarajevo

While in Sarajevo we also held an open EDSA board meeting, that means that besides the actual boardmembers representants of edsa membergroups who attend the conference were invited as well. Together we were about 18 delegates from 11 different countries. The minutes of the meeting will be sent via the EDSA list by Erik de Graaf in the coming days.

All EDSA members and speakers became a very warm welcome, all of us were waited at the airport, taken to a nice hotel in the city of Sarajevo, situated very convenient to the conference venue and to the interesting old part of the town. After the conference we were invited to a bosnian evening with typical food and music, where some of us even dared to share in the folksdancing.

Webpage: www.edsa.eu

Frank Buckley from the Educational Trust and his colleague Howard Hurd are preparing the EDSA-website, now coming up soon! Startpage is already there.

Payment of EDSA Fees 2008

May I remind you again, that still half of the members didnot pay the 2008 membershipfee, after Isidro Moyano, the EDSA- treasurer sent out the invoices at the end of last year. I would appreciate it, if all members could settle this in the next weeks so that Isidro doesnot have to sent out reminders.

Database of DS-literature

For our database on the website I am still collecting the titles of books and journals concerning Down Syndrome in your language, that you can recommend to other parents, professionals, students.

Special forms to fill out have been sent via the EDSA List earlier. Please send the forms back to my mail-address:
halder.ds.infocenter@t-online.de

10th. World Down Syndrome Conference in Dublin

Registration, programm and all other information is available on the website:
www.wdsc2009.com

The Annual EDSA meeting will be hold during the World Conference!

I wish you all a happy easter!
Kind regards

Cora Halder
EDSA President