

News from the president

Dear EDSA members,

It will try to give a short overview about some EDSA-related facts, that happened in the last few months, since I wrote my last letter to you in June. Some of these points you might have already read in the minutes of the edsa annual meeting send to you by Erik our secretary.

One year presidency

Now it is nearly one year ago, that I was elected to EDSA's president. I had to learn, that it is not easy to actually „do“ something on an European scale. Due to the fact that things need to be discussed with many others and this takes time. Mails get lost, computers crash, people are on holiday, abroad, or just have no time to react. So perhaps I feel a bit disappointed, not being able to work in the same speed as usually in my own organisation.

Anyway, I try to keep in touch with many of you and fortunately there is more contact among the EDSA-members as before, there is some more news and information going through the EDSA-maillist. We now do have an EDSA-webpage, though not yet functioning as well as it should. We have Paola in Rom busy with finding funds for an European project, with networking as main objective. 12 EDSA-members have shown their interest being partner in such a project; The moment Paola finds the right thing, all interested associations will be informed and invited to prepare the necessary papers.

Welcome to new members

I would like to welcome our new members. The Croatian DS Association „Hrvatske zajednice za DS“ from Zagreb became member after the general assembly in Dublin approved their application. And both DS-organisations from Israel and Maroc became affiliate



Posterexample from Bulgaria's awareness-campaign
The ds-parentsgroup has just prepared a first posterserie to make people aware of children with ds.

members of EDSA.

On the „waitinglist“ are DS-Iceland and the new founded DS-associations of Kosovo and Bulgaria. These groups will apply, but have to wait for the next annual meeting as only then, membership can be obtained.

Kosovo

If you are interested to see what the new ds-group in Pristina is busy with, you might visit their website: <http://www.downsyndromekosova.org/> The page is partly translated into English.

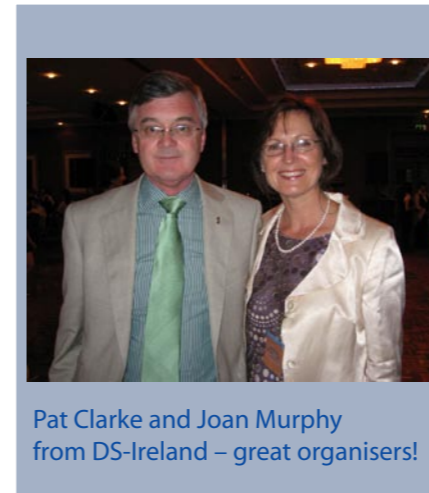
Visit to Bulgaria

My visit to Sofia, Bulgaria has been an impressive experience. I got a very warm welcome from the president of the organisation, Valentina Nikolova. She had organised a two day seminar for parents, professionals and students. Both days were held in the university of Sofia and very well attended. My lectures were in English, but there was a very competent young lady as translator.

I had also the possibility to visit the

DS-medical clinic in the hospital, a place where newborn babies are looked after, have their medical cheques and parents get information. Though the overall situation for children and adults with Down syndrome in Bulgaria is still very very bad, – f.e. many newborns are left behind in hospitals and then moved on to institutions – can we notice first succes in medical and therapeutic care.

Valentina has also managed to get the topic Down syndrome into a television program, informing about achievements of people with Down syndrome nowadays ... if they get the chance. After the program she became a lot of phonecalls of grateful families who thanked her for this positive perspective. But also dramatic calls from families, who, realising that the future of children with ds might be brighter as they had expected, now want to have their children back, which they left directly after birth. But some of them, don't even know where the children are! You understand that this is a country that needs our support urgently.



Pat Clarke and Joan Murphy from DS-Ireland – great organisers!

DS-Conferences

Dublin

The World DS-Conference seems already long ago. A very well organised, very interesting and motivating event. And we have to thank DS Ireland for all the enormous work they did. It surely was not an easy job in midst of the global finance crisis.

It was nice to meet edsa people from different places in Europe but time is always too short to talk with everybody. The programme was so tight that there was not even enough time for both the edsa board and the annual meeting. Unfortunately we had to rush through the agenda.

There was a very informativ abstract book available during the conference for all participants. It might be worth for those who could not attend the conference and who would like the abstractbook to inform with the DS Ireland if there are rest copies, that can be ordered.

The synode with the adults with Down Syndrome has been a very succesful and moving event. To give people with DS an own voice and to listen to what they have to say, should be high up on our priority lists. It is a must on all future conferences, regional, national and international!

Salzburg, Austria

Another well organised and good conference was the one in Salzburg, Austria which took place in the end of September. Over 600 participants came to Salzburg. As EDSA-president I had the honour to hold the openingsspeech.

DS-Conferences to come

● Bergen, Norway

18. - 20. march 2010

Info: www.upsanddowns-hordaland.no

● Granada, Spain

29. april - 2. mai 2010

Info: www.granada2010down.org

Patient-Partner Workshop

Jacqueline London, our vicepresident, attended as representative of EDSA the North-Western European regional Patient-Partner Workshop which took place in London on 12-13 October 2009 with the title "Defining the needs and means for more partnership between Patients, Patient Organisations and Other Stakeholders in Clinical Trials".

Jacqueline wrote: „Firstly the meeting was very well organized at a general level without pointing out any specific disease and gathering 14 representatives of patients organizations (POs) and 12 of pharmaceutical firms and 35 specific members of policy officers in various European Research Network either in UK, in Brussels or in Netherlands. There were main lectures but also round tables and even exercises in order to find out best practices.

The purpose of the meeting was to find out the best ways for the patients to have access to new medication through trials and for the companies/stakeholders to find out how they can better cooperate with POs“. These kinds of meetings are also a good possibility of getting to know other professionals and to build up useful contacts.

Jacqueline wrote, that it was really worthwhile to attend the meeting and she encouraged a lot, that an EDSA representative attend the Eastern Europe countries meeting, which will take place 30 November-1 December 2009 in Zagreb.

DS/Fashion-Project

In an E-Mail I wrote to you about the DS-fashion project, we are developing in Germany together with an expert in the field. In the meantime we are collecting the necessary dates and have a questionnaire on-line in German, English and Spanish language.

I have also send the link with a short

text about the project to Frank Buckley in Portsmouth to have it on the EDSA-website as well.

http://www.peyman-amin.de/downsyndromumfrage09/index_en.html

Feel free to inform about the project on your own websites with a link to the questionnaire. We are hoping for as many reactions as possible.

The idea is to design nice fashionable clothes, fitting persons with Down syndrome and offer them through a webshop.

Thanks a lot to the people of Asnimo who translated the questionnaire into Spanish.

Representant in EDF Youth Committee

Aimee Richardson, a young lady from DS Ireland has been nominated to represent EDSA in the EDF Youth Committee. Aimee has excellent communications skills and has done media training. She has strong opinions on education and community living. In case, Aimee will make it, this would be the first time that a person with an intellectual disability would serve on an EDF committee.

We wish Aimee all the best!

Next EDSA-Board meeting in february 2010 in Nürnberg

I am looking forward to the 12-14 February 2010. At that date there will be an EDSA board meeting in Nürnberg, hosted by my own organisation the German DS InfoCenter. This time we will work together from Friday till Sunday midday – a meeting with enough time to discuss all the topics properly, I hope. We will set up a paper with the main goals for EDSA in the next few years and define next concrete steps. All of you will be informed about that directly after the meeting. I am delighted that 10 out of 11 boardmembers are able to attend and will come to Nürnberg.

**I wish you all a good, healthy time!
Kind regards**

Cora Halder
EDSA President