

## **News from the president**

### EUROPEAN DOWN SYNDROME ASSOCIATION









#### Dear EDSA members,

## EDSA-Website finally online! www.edsa.eu

Finally! It took some time to design a new edsa-page and there were some technical obstacles to overcome before we could go online, but now it is finally there!

You can find it under: www.edsa.eu

Ofcourse you will notice, that it is not-complete – websites never are!
There is f.i. still a lot of information missing on the media site. Those of you, who cannot find books and films in your specific language, have not sent me this information, I have tried to collect since a year. You might like to catch up now, because it just doesnot make a good impression, if your association/country has nothing to contribute.

Besides literature or films on DS, you might have short news, important seminars, new books, nice projects etc, which you would like to inform about. We can place that information on the website. Please send us text and pictures.

The page "research" has no information on it so far. Jacqueline London, our vice president, has promised to collect interesting dates, but we are glad about everyone, who can contribute.

I also assume that there are more european projects running at the moment, where EDSA-members might be involved. Please forward also this information.

We need your input to develop the EDSA-page further and to make it into an interesting and informativ one. Contributions from all EDSA-members are welcome!

# Annual General Assembly Rom, 23rd. and 24th October

The EDSA Annual General Assembly (AGA) will be held in Rome, Italy on saturday, 23 October, whole day and on sunday, 24 October 2010 until midday. The location will be the Hotel Villa Aurelia, Via Leone XIII, 459 in Rome.

It is the first time that we will organise the meeting as an event on it self and not somewhere built in in the programm of a conference, like we did before f.i. last year in Dublin.

We have experienced at several occasions, that often there was no time enough to discuss all the topics, nor to share experiences or to learn about each others organisations and the projects we are busy with.

In the meeting in Rome we will have time for all that. The suggestion came from Anna Contardi of AIPD. It is also her team who has found the location. Rooms will be available in the Hotel Villa Aurelia. You have to contact Claudia from AIPD who is responsible for the hotelreservation. Her e-mail: aipd@aipd.it

You will receive the AGA-agenda from Erik de Graaf, EDSA-secretary, at least two weeks before the assembly. We expect from every attending EDSA-member a **short** (10-15 minutes) presentation about your organisation, your projects, the present situation of people with ds in your country.

Many of you have already confirmed that they will attend the AGA. I am looking forward to welcome representatives from all our member associations.

#### **EDSA-board meeting**

The day before the AGA the EDSAboardmembers are invited to a board meeting. Agenda and details will be sent to you in the beginning of october.

#### **EDSA membership in DSi**

EDSA as an organisation is member in Down-Syndrom International (DSi). The manager of this worldwide DS-Association is Andrew Boys.

In the last months I had some contact with Andrew on the following matter:

DSi has decided to change the Articles of Association and Membership structure of their organisation. They needed to bring in new Articles of Association to comply with changes in UK law. They also changed the structure so that their trustees will be the members and others, like EDSA, will become affiliate members.

In order to pass a special resolution, I have signed the nessecary forms, so that from now on EDSA is an affiliate member of DSi.

#### **Nominations for DSi-Awards**

Another topic I was dealing with in the meantime were the DSi Awards. You might remember that on behalf of EDSA I collected names and dates of individuals and groups to nominate them for the DSi Awards.

The award-winners have now been announced and I was very pleased to get the message that DSi made 3 awards to EDSA nominees this year.

Ofcourse DSi could not present awards to all nominees, but we can nominate these candidates in 2011 again.

#### Accepted for the award

- for a person with DS: Yta Strikwerda,
   a young lady from the Netherlands
- for a volunteer: Jaroslav Pieniak from Wroclav, Poland
- for an organisation: Laufclub 21, a running-club for adults with Down Syndrome from Germany.

All the award-winners will be published on the DSi website: www.ds-int.org In addition they are also invited to formally receive the awards at the 11th World Down Syndrome Congress in Cape Town, South Africa in August 2012, if they are planning to attend this event.

#### **EDSA-membership for Kosova**

The DS Association of Kosova has officially applied for the EDSA-membership. This will be on the agenda at the AGA in Rome. A representant from



Kosova will be there to introduce this new organisation.

#### **DS Conference in Kosova**

October 28th and 29th 2010 the first Balkan- DS-Conference: "Early intervention for children with additional educational needs" will be organised in Pristina/Kosova.

The main objectives are to establish a regional network of professionals, to build partnerships and sustainable communication and to strengthen the concept of the importance of early intervention for children with disabilities as a basic human right, consistent with European Union and international standards.

Guests from Albania, Croatia, Bulgaria, Greece, Makedonia, Kosova, Montenegro, Serbia Slovenia and Bosnia & Hercegovina will attend. It is the first time that such a conference takes place in the Balkan region, bringing together parents and professionals from these different countries.

I am very happy to be able to attend the conference as a representant of EDSA.

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#### **Medical guidelines for adults**

The EDSA-board is preparing a new document: guidelines about medical aspects in adults with Down syndrome. A first draft has been sent around to boardmembers and I am still collecting suggestions and additions. As soon as we have the text ready we will add it to the other guidelines and edsa docu-

ments on the website. We will not produce paper-version of the documents any longer, as this is too costly. Textes will be available as pdf and might be translated in your own language.

The good thing with a website: textes can be easily changed, so we can add new findings and knowledge and stay up-to-date.

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#### Yo tambien / ME TOO

I suppose that in the meantime everyone of you has seen the spanish film, Yo tambien". If not, you should!

Just last week the film was launched in the german cinemas and becomes a lot of positive reactions in the media. We wish this film a broad audience. In addition it is an important film for parents. Both actors Lola Dueñas and Pablo Pineda are fantastic in their roles as Laura and Daniel.



I wish you all still a nice summer. Kind regards

> Cora Halder EDSA President

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