

EUROPEAN DOWN SYNDROME ASSOCIATION

December 2018

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BREAKING NEWS

An invitation from Down Syndrome International to all Edsa members.

Dear organisation representative Representing European Down Syndrome Association (EDSA)

World Down Syndrome Day, Thursday 21 March 2019, is just over 3 months away. There are many ways you can get involved in DSi's WDSD activities. This is the first email in a short series, each focusing on 1 DSi activity, beginning with:

WDSD awards

The WDSD awards are announced on 21 March in the year before the next World Down Syndrome Congress (Dubai 2020). Awardees are then invited to receive their awards at WDSC, should they be attending, or have the award collected on their behalf and the opportunity to send a video message.

Please note we have changed the criteria for the 2019 awards so that it is no longer required for nominators or nominees to be members of DSi.

There is a short window between now and 31 January 2019 to get your nominations in.

We very much welcome any nominations for people or organisations which have made a substantial positive difference to the lives of people with Down syndrome.

Nominees can be people with Down syndrome, volunteers, NGO or issued based professionals (e.g. teachers, doctors, employers), researchers or organisations.

Nominators will be asked to complete a form and this, together with references, will enable the DSi Board to select awardees.

But please note that DSi reserves the right to award only some or if appropriate none of the nominees.



To learn more and request a nomination form, please visit the:

WDSD website awards page

Regards
Andrew Boys
Executive Director
Down Syndrome International

EUROPEAN DAY OF PERSONS WITH DISABILITIES

A letter written by Cora Halder, EDSA secretariat, on her visit to Brussels and her participation in the conference on the 3 December, European Day of Persons with Disabilities.

"The yearly Conference to this special day took place on 3-4 December 2018 in the premises of the EU Commission.

I travelled with my daughter Andrea, after Pat Clarke asked me to let Andrea participate as an EDSA representative. He himself is on the EDF board and participating in that position. And nobody directly from EDSA was going to Brussels. So we decided to apply for participation and were accepted.

I would like to share with you some observations, thoughts and experiences





Participants

Persons with Down Syndrome are in fact hardly represented at these conferences. Besides Andrea there were two young adults from Ireland. There are also only few other persons with a cognitive impairment taking part in events like these. Blind and deaf persons or persons with a physical disability are much more numerous and they are also among the speakers. It is important that in the future more self- advocates with Down Syndrome participate in these meetings.

Down Syndrome – not so bad after all?

Andrea has been invited to this event on two former occasions, so has a bit of experience. She is always very impressed of the many different people, she meets there and would say: "Something which crosses my mind all day, is that there are so many people with severe disabilities, that it seems to me that Down-Syndrome is not so bad after all".

It's all about accessibility, but ... English knowledge is a must!

Again Andrea made the experience how important it is to speak and understand English – not only to follow the speeches but also during the coffee breaks and the dinner the common language is English. If you want to get into contact with others and talk with them, you simply need this language - so she decided to improve her English knowledge for future events!

Of course there is simultaneous translation of all speeches, also into German language. But not only are the topics complicated, also the used terminology is not easy to understand and it all is much too fast for a person with Down Syndrome.

I heard that the speakers had been asked to give their talks in easy language. The only one, who managed to do that was the mayor of Salzburg (reporting about the accessibility measures in her city) and Helen Stevens, Member of the EU Parliament, who spoke in sign language, what was translated in verbal language. But it was a structured talk, not so fast, short sentences and easy to follow.

Information beforehand would be helpful

Best would be for a person with Down Syndrome, to get a short summary of the speeches and topics some time **before** the conference, in easy language and have then the possibility to read and discuss the content beforehand at home with an assistant, a teacher, a parent or even discuss the topics with a group of other young adults in a kind of political session. Then the event would be much better accessible for persons with language limitations. (We became an overview of the program in easy English language two days before the event.)



There were summaries in easy language, after the speeches, hanging out in the foyer. But difficult to concentrate there during the breaks. But now we found these texts also on the website of the Commission, so at least after the conference we can discuss some topics.

EDF Youth Commission

There were two talks of self- advocates of the EDF Youth Commission. Very eloquent speakers, both women. The Youth Committee is the voice of young people with disabilities inside EDF. The Committee has 8 members, they have different disabilities, but all have studied, some even hold a degree. A person with a disability like Down-Syndrome (some cognitive, perhaps also language difficulties) is not in this group. I think it is an absolutely must that in the future a person with Down-Syndrome should be part of this Committee. I know we have discussed this lately in Madrid. And we had some ideas around this issue. After this Brussels experience I am even more convinced how urgent this is. It made me sad, to realize, how little our persons with DS are present in Brussels.

2022 a new Youth Committee will be elected and it must be one of our goals to get a person with DS in this position.

Petition on the right to vote

Andrea was proud that she could sign the petition about the right to vote of persons with disabilities.

She has been voting already several times in Germany and for her this is a real big thing. Her comment: "It makes you feel important, when you can have your say. My vote counts, like all others".

More information

There is a lot of information available in the internet about the conference. F.i. you can follow the whole program with all the speeches etc. here:

https://ec.europa.eu/social/main.jsp?langld=en&catld=88&eventsld=135 2&furtherEvents=yes

Also a document called: What the speakers talked about in easy language!

Cora Halder "









NEWS FROM EDSA MEMBERS

From DOWN SENDROMU DERNEGI (TURKEY)





"Nothing about us, without us!"

This means that people with Down syndrome should have a say and be involved in any decisions being made about them.

We run "My Voice My Society" project in order to empower people with Down syndrome to speak up for their rights, wishes and futures and to become self-advocates. This is the video of their training processes and self advocacy activities.

This video was shared by many people in the social media.

Video link: https://www.youtube.com/watch?v=pXd-QdUJ9ls&feature=youtu.be





EU OPPORTUNITIES



ERASMUS + FORWARD-LOOKING COOPERATION PROJECTS

Forward-Looking Cooperation Projects (FLCPs) are trans-national cooperation projects aiming to identify, test, develop or assess innovative policy approaches that have the potential of becoming mainstreamed and giving input for improving education and training systems.

They provide in-depth knowledge on target group(s), learning, teaching or training situations and effective methodologies and tools that help policies to develop, as well as conclusions relevant for policy makers in education and training at all levels.

Forward-Looking Cooperation Projects aim at promoting innovation emerging from representative stakeholders in the field ("bottom-up approach").

Forward-Looking Cooperation Projects are implemented by key stakeholders with a proven record of excellence and state of the art knowledge, the capacity to innovate or reach a systemic impact through their activities and the potential to drive the policy agenda in the fields of education and training.

What does it support:

The projects should lead to proven results in at least one of the following areas:

- (i) Development and/or improvement of innovative actions in the fields of education and training in line with the call priorities;
- (ii) Improved evidence and understanding on target group(s), learning and teaching situations and effective methodologies and tools that can inspire and stimulate innovation at system level;
- (iii) Evidence of potential long-term impact on education and training systems through the mainstreaming of advanced and innovative policy approaches developed by the projects;
- (iv) European added-value through reinforced trans-national cooperation and mutual learning among major stakeholders.



Related Action(s):

Key Action 3: Support for policy reform

Erasmus+ -Key Action 3 - Initiatives for policy innovation

Erasmus+ Key Action 3: Support for policy reform - Initiatives for policy innovation - European policy experimentations

Forward-Looking Cooperation Projects

STATUS	DEADLINE	CALL REFERENCE
OPEN	19/03/2019 - 12:00 (CET, Brussels time)	EACEA/36/2018



MAKE THIS NEWSLETTER REALLY YOURS!

Have you got any news that we could publish in EDSA newsletter? Please send us any information you would like to announce and we shall be happy to disseminate it all over Europe!

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