

EUROPEAN DOWN SYNDROME ASSOCIATION

September 2018

SUMMARY

01

EDSA AGA - SAVE

THE DATE

02

NEWS FROM EDSA

04

WDSD GLASGOW

2018

09

EU OPPORTUNITIES

EDSA AGA - SAVE THE DATE - 26/28 OCTOBER 2018

Dear EDSA members,

I would like to inform you that the this year EDSA AGA (Annual General Assembly) will take place from 26-28 October 2018 in Madrid. Our host will be Down Espana.

Depending on the number of participants the meeting will be in the offices of Down Espana, or in a hotel not far from their premises.

Please let us know, if you are planning to come and with how many persons from your association you will take part. You can answer directly to halder.cora@t-online.de

A detailed program of the conference on Job Inclusion and the agenda of the AGA will be available as soon as possible. As well as some information about suitable accommodation.

These are the outline dates:

Friday, 26. October 2018 16.00 - 19.30 hrs. AGA, part 1 from 20.00 hrs. dinner/leisure/sightseeing

Saturday, 27. October 2018 9.00 hrs – 18.00 hrs conference on Job inclusion from 19.00 hrs. sightseeing/dinner/leisure

Sunday, 28. October 2018 9.00 hrs – 13.00 hrs AGA, part 2

I hope many of you will come to Madrid!

Best regards.

Cora



NEWS FROM EDSA

DOWN SENDROMU DERNEGI (TURKEY)

EVALUATION MEETING OF "MY VOICE MY COMMUNITY" PROJECT.

The Down Sendromu Dernegi (Turkey) held a meeting with the experts from Down Syndrome International to evaluate "My Voice My Community" Project. It is a project that empowers people with Down syndrome to speak up for themselves via self-advocacy sessions.

News about Project was seen on media at the same time.

http://www.haberturk.com/istanbul-haberleri/15839557-downsendromu-derneginden-oz-savunuculuk-egitimi





NEW SERIES OF BOOKLETS ON AUTONOMY



Publisher Erickson produces new series of booklets.

The series comes from the experiences of "Programmes for teaching autonomy" led by the AIPD (Italian Association for people with Down Syndrome).

Each book offers material, activities and exercises for **teaching the basics of autonomy** to children and adolescents with intellectual disabilities. All the books, which are **written using easy-to-understand language** and are **colour illustrated**, come with a **handy guide for educators and parents**.

As **Anna Contardi** affirms «We have been working at improving people's autonomy for 25 years. We have achieved excellent results. For example, we have managed to teach youngsters with serious intellectual disabilities, who are unable to read or write, to take public transport, handle money, take care of their personal hygiene, do housework and cook».

If you are interested in translating books into your language please contact the Erickson International office and they will be glad to help you. http://www.erickson.international/en/request-info/

For the moment the books that are already available in other languages are:

- "Friendship, love, sex: let's talk about it now" in Spanish
- Some in Turkish and Russian

Watch the presentation video for the series

Further information on the Erickson International website



WDSD 2018 GLASGOW

DOWN SYNDROME INTERNATIONAL (DSI) AWARD FOR ALBANIA





AWARDS CEREMONY AT THE WDSC IN GLASGOW DURING THE **GALA DINNER**

One of the awards was presented to Emanuela Zaimi from Albania. Emanuela is a mother of 3 children, the oldest one Arbi, a 7 years old boy was born with Down syndrome. Founder and CEO of Down Syndrome Albania Foundation. Board Member of European Down Syndrome Association and Member of the Albanian National Council for the Civil Society.

Emanuela has graduated PR and Publicity, in Ankara University, in Turkey. She hold a Master Degree in "Creation and Development of SMEs in Transition Countries" and from September 2018, she will start a Master Program on "EU studies and EU project Management" In Burgenland

The Photo shows Vanessa dos Santos, president of DSi (left), presenting the award to Emanuela.

"LACK OF KNOWLEDGE, POLITICAL WILL AND LACK OF MONEY"

In her speech Emanuela said: "I am deeply grateful to everyone who has a mark in the cause of people with Down syndrome in Albania. These five years of the existence of Down Syndrome Albania Foundation (DSA), have been both, a huge challenge and success for a newborn NGO like ours, in a country where there are a million problems and disability rights and needs are not a priority, due to the lack of knowledge, political will and lack of money.



BIG CHANGES DURING THE FIRST FIVE YEARS OF DS-ALBANIA

However, during these years, we managed to get everyone's attention for our cause in Albania. Five years ago, little was known and talked about our children in Albania. Many parents too were shy or feeling ashamed or scared to show and talk about their child. It is a different story now, a better reality ... I started this alone, but with the push of many other mothers. Today many of them are volunteers of DSA, sisters, and brothers too are and some of them are employees of DSA. We see the children of our center growing, developing, articulated and all are in mainstream kindergarten and schools.

BUT STILL A LOT WORK TO BE DONE

But, I will not be in peace until I see every child and adult with Down syndrome in Albania getting what their legitimate right is: acceptance in an inclusive community. I will not be in peace until I see that parents are not being worried anymore and asking the "one million dollar question – What will be with my child with Down syndrome when I will not be in this world?" I will not be in peace until I ensure a financial sustainability for our NGO. I need all this peace for my family as well.

GETTING THE DSI AWARD IS VERY MOTIVATING

The World Down Syndrome Day Award from Down Syndrome International to me and my staff is a motivation to "Don't Stay Calm, Keep Working" so the extra Chromosome feels safe and great in Albania, in Europe, and in the whole world. Thanks to all of the organizations that nominated me, most of which are from the EDSA family, where DSA belongs, although not an EU member country yet.



GERMAN YOUNGSTERS TAKING PART IN THE WDSC 2018 IN GLASGOW



CONGRESS DELEGATES WITH DOWN SYNDROME

Attending a World DS Conference is a big event for every person with DS. But the whole program is in english language, this means that it will be hard to follow, what is going on.

LANGUAGE BARRIER

Young people from different european countries, who were participating in the conference had none or just little knowledge of the english language. In order to be able to follow the Youth Program they needed a translator.

FINANCIAL SUPPORT FOR TRANSLATORS

Therefor the EDSA-board decided to give some financial support to translators, who were accompanying young adults to the WDSC in Glasgow. This was an offer from EDSA to their members. The DS Associations from Germany and France took advantage of this offer. The conditions were to write a short report about their experiences and send some photos.

WORLD DOWN SYNDROME CONGRESS 2018 IN GLASGOW

Andrea (32 years old), Michaela (26 years old) and Daniel (21 years old) from Germany took part in the World Down syndrome Congress in Glasgow. Together with a translator they attended the special programme for delegates with Down syndrome.



THE GATHERING



It started with The Gathering on the 24th July. They got to know many other delegates with Down syndrome from all over the world, spent an afternoon in a Scottish transport museum and took part in a block printing workshop, which was a lot of fun. They also were chosen to carry a flag at the Opening Ceremony on Wednesday, which was a fantastic experience.

INTERESTING WORKSHOPS ABOUT HUMAN RIGHTS AND INDEPENDENT LIVING



The next three days they attended workshops which dealt with the community the delegates live in, their human rights and speaking up. Extremely important human rights to the three delegates from Germany are to be respected and treated the same as everybody else, get the opportunity of a paid job, get support to live independently and be an active part of the community.

Andrea, Michaela and Daniel also learnt how to speak up for themselves and heard many self-advocates talking about living independently, which was very important to them. The presentations of the self-advocates were an inspiration to all of us. In interactive workshops they got to know the Scottish culture through listening and talking to Scottish piping players and learning a typical Scottish dance.



HIGHLIGHTS: SCOTTISH NIGHT AND THE GALA DINNER



Andrea, Michaela and Daniel also attended the Scottish family night and the Gala Dinner in the Hilton Hotel, where the families could come together and shared experiences. They enjoyed dancing and spending time with their new friends they have made during the congress.

SEE YOU IN DUBAI 2020!

It was a wonderful positive atmosphere during the whole congress and an enriching experience for everyone who took part in the World Down syndrome Congress in Glasgow. If it is possible, Andrea, Michaela and Daniel would love to attend the next one in Dubai in 2020.



EU OPPORTUNITIES

CALL FOR PROPOSALS FOR THE ESTABLISHMENT OF GRANT AGREEMENTS FOR THE COFINANCING OF COMMUNICATION ACTIONS IN SUPPORT OF THE 2019 EUROPEAN ELECTIONS



The EU Parliament finances communication activities on the 2019 European elections.

The call is open until the 17th of September.

The European Parliament has launched a call for communication actions in support of the European elections to be held in Europe from 23-26 May 2019. The aim is to support initiatives aimed at providing citizens with objective and real information in the run-up to the next European elections and at encouraging their participation in the electoral process.

The call aims to fund actions and products - both online and offline - that contribute to stimulating debate and citizens' involvement in the European democratic process. This may be the case:

- Events such as debates, round tables, meetings with citizens to give citizens and/or representatives of civil society the opportunity to discuss issues directly linked to the 2019 European elections.
- large-scale events such as festivals, fairs, concerts, sporting events, including in their programme an activity to inform participants about the European elections.
- structured activities such as information stands, door-to-door propaganda, marches, rallies, flash mobs aimed at increasing the visibility of the European election campaign and informing citizens and/or participants about the elections.
- information sessions, presentations, workshops organised in schools (for first time voters), universities and organisations to inform and raise awareness of the European elections.
- Online discussion groups, forums and other social media activities providing an opportunity for members and/or followers to discuss and exchange views on issues related to the European elections.
- dedicated video channels, websites, apps, web tools and social media accounts producing original content directly related to the European election campaign.



The call is open only to non-profit bodies and organisations established in one of the EU Member States and legally constituted and registered for at least one year at the time of submission of the application.

More info: http://www.europarl.europa.eu/contracts-and-grants/en/20150201PVL00100/Grants.

Call for proposals:

http://www.europarl.europa.eu/pdf/grants/Call for proposals Events 2018 COMM-SUBV-2018-E.pdf



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!

CONTACTS

phone: 0039 06 3723909 e-mail: internazionale@aipd.it

THE STAFF

Carlotta Leonori Paola Vulterini Claudia Galieti

