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EDSA NEWSLETTER NOVEMBER 2016

EDSA ANNUAL GENERAL ASSEMBLY 2016



The Annual General Assembly 2016 of the EDSA (European Down Syndrome Association) was held in Zagreb (Croatia) on 19th November 2016. The Assembly was attended by 22 participants from 14 countries.

EDSA president Anna Contardi presented the activities and status since the last AGA in 2015.

A few important things from the report:

1. **World Down Syndrome Day 2016** – The topic, named “*My friends my community*”, includes 20 stories from 19 countries, published on the EDSA website
2. **On my own... at work (OMO)** project (Erasmus+) - EDSA participates as a partner in the OMO project which is led by AIPD, with the participation of APPT 21 and Down Espana
3. **Family Exchange Programme (FEP)** - one of the aim of the Programme is to build bridges between families who have a child or a relative with Down syndrome and are living in different countries, The dedicated website, www.edsafamily.com includes a platform called Family Exchange Programme (FEP)

4. **Communication:** mailing list, website, newsletter, Facebook
5. **Sharing competences** ->Experts (flight costs paid by EDSA)
– The project will continue in 2017. Up to now one third of the planned budget has been spent.
6. **EDSA – T21RS new collaboration** - EDSA decided to accept the Trisomy 21 Research Society proposal to create an interface committee between T21RS members and EDSA representatives. Actions towards EU Parliaments and MEPs were agreed (e.g. letter towards MEPs) .
7. **Poseidon Project** – The project is moving on and the developing phase is now close to the end. The final review will take place in Luxembourg in January, and in the meantime three applications have been prepared. The three apps resulting from the project are: routes, calendar and training (for money).

Treasure Budget report was given for the year 2015 and part of 2016.

Several issues were discussed and agreed:

1. WDS campaign for 2017 is “My voice my community”

We haven't decided to go to the EU Parliament yet because we don't know whether the MEPs will be held in Brussels or in Strasbourg. Last two years they were in Strasbourg. Strasbourg is very complicated to get to. First it is necessary to check the EU Parliament calendar for 2017 and then agree about the activities.

Ideas for the WDS 2017 – like the year stories on EDSA web site and a flash mob in each country on the same day.

BIH team informed us that they invited their contact working in the UN to go to the meeting organized by DSi and then inform them about the meeting. It was a very good idea for all members.

2. Educational webinars (web sessions)

It was agreed to organize Educational webinars (web sessions) on four topics:

1. Social enterprise
2. Self-advocacy
3. What was going on in research
4. Behavior problems

3. Operational secretary

Considering the difficult work of EDSA without a professional structure that could support the volunteers and in order to ensure continuity of its action and reach the objectives has decided to set up a small Secretariat at one member's headquarters, which could work as a permanent reference point. It was agreed with Cora Halder to take this role and an agreement has been prepared.



#MyVoiceMyCommunity - Enabling people with Down syndrome to speak up, be heard and influence government policy and action, in order to be fully included in the community

It is linked to #MyFriendsMyCommunity initiative that was successful last year and hopefully the strapline will be clearly illustrated by 2017.

Purpose and method of the campaign

The purpose of the campaign is to enable people with Down syndrome and those who advocate for them to speak up, be heard and influence government policy and action, to ensure that people with Down syndrome can be included, on a full and equal basis, in all aspects of society.

Working with Down syndrome advocacy organisations in our global network, the campaign will:

- Explain **why it is important** for people with Down syndrome and their advocates to speak up and influence local, national, regional and international policy makers.
- Explain **what are the key policies** that affect the lives of people with Down syndrome and how, if implemented, they can ensure full society inclusion.
- Explain **how advocates can get involved** – from media campaigns to direct political advocacy.
- Explain **how to empower people with Down syndrome** (and those supporting them) to advocate for themselves and provide accessible tools to facilitate this.

DS Int. thinks there is quite a lot to do about this. For example, we can bring in the 2030 UN SDG agenda for the conference and for the DSI's international part of the campaign.

We can also prepare some easy to read/understand, visual materials for people with DS.

We can also support national groups to adopt this theme and consider what are the policies in their countries, how they can be changed or implemented etc.

We can also bring in methods of campaigning such as media campaigns or direct political lobbying.

NEWS FROM EDSA MEMBERS

CENTER JANEZA LEVCA LJUBLJANA (SLOVENIA)

BE AN ARTIST - A CALL FOR THE 10TH INTERNATIONAL ARTS CONTEST »PLAY WITH ME« 2016/2017



In the framework of the annual **Festival »Play with me«** the **International Arts Contest »Play with me«** is traditionally held again this year.

The opening exhibition of the International Arts Contest “Play with me” will be held in Cankarjev dom, in January or February 2017 and will include the setting up of the received works, the opening of the exhibition and a varied animation program.

The exhibition will later move to different cities around Slovenia. Last year alone we received 6073 art works from Slovenian schools and institutions and from abroad.

We invite you to take part in the contest that is this year is dedicated to two subjects.

First being the traditional: **PLAY WITH ME** (you can play alone – with toys, dancing, doing sports, playing on the computer or you can play with friends – schoolmates, grandparents, teachers, animals, ... you can play at home, at a playground, in the woods, on the street, ...)

The second subject: **MY FAVOURITE 10** (My favourite 10 books, my favourite 10 animals, my favourite 10 colours ... Number 10 you may connect with our anniversary – the 10th International festival year “Play with me” ...)

You can enter the open call by filling in the [online application \(in Slovene\)](#) or mail us the information about the participants and their works to bodiumetnik@igrajsezmano.si and then send us the work by e-mail (more information in the attachment).

The hand-in deadline is the 12th of December 2016.

Contact and additional information:

- phone: **00386 1 2418 125** workdays between 12.00 and 14.00
- email: bodiumetnik@igrajsezmano.si

CROATIAN DOWN SYNDROME ASSOCIATION (CROATIA)

EDUCATIONAL FORUM

Employment of persons with down syndrome - challenges and good practices



Croatian Down Syndrome Association organized the educational forum “Employment of Persons with Down Syndrome - Challenges and Good Practices” on 18th November 2016 in Zagreb, capital of Croatia.

More than 90 participants attended the Educational forum. The participants were from Croatia mostly but also from Norway, France, Ireland, Turkey, Albania, Bosnia and Hercegovina, and Czech Republic.

Dinka Vukovic, president of the Croatian Down Syndrome Association opened the educational forum and gave an introduction of on the Down syndrome and on persons with Down syndrome in Croatia.

Every year more and more children with Down syndrome attended regular school, primary and secondary. That is the reason why Croatian Down Syndrome Association organized educational forum, so that they will soon be able to work and be employed. Parents from Croatian Down Syndrome Association through the last fifteen years learned from the other associations and countries in Europe and USA how to improve life and education for their children.

Anna Contardi, president of EDSA (European Down Syndrome Association) and Coordinator of the Italian Down Syndrome Association (Associazione Italiana Persone Down, AIPD) held a presentation on the topic “Employees with Down syndrome: it can be done - the Italian experience”.

Second presentation was held by Cora Halder from German Down-Syndrome InfoCenter on “Development of the job market for persons with Down syndrome in Germany: searching for the best solution”.

After presentations of Anna and Cora, Dinka spoke about law and good practice in Croatia.

The discussion after all the presentation was very fruitful and a lot of questions were asked and answers given to the participants.

Parents from Croatian Down Syndrome Association are grateful to Anna Contardi and Cora Halder for their presence and share of experiences of work and employment of persons with Down syndrome in their countries.

Presentations from Anna and Cora are recorded and they are on the Facebook site of EDSA, link <https://www.facebook.com/edsaofficial/>

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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