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### LETTER OF THE PRESIDENT

Dear Friends

In the last years EDSA has grown; we are 34 members and 28 nations. This is a great result for all of us.

The mission of EDSA is to promote the development of a network of Down syndrome associations in all European countries, respecting the diversity of cultures and peoples, the common denominator being the improvement of the quality of life for persons with Down syndrome and for their families.

EDSA's goals are to:

- promote all actions and efforts which contribute to the welfare of persons with Down Syndrome according to the rights awarded to them by their own constitution, the Declaration of Human Rights and rights of persons with disabilities by the United Nations, and the European convention relating to the protection of fundamental rights and liberties.
- promote the well-being of persons with Down Syndrome in every possible way and area, and in every aspect of life: health, education, personality, autonomy and integration in the society according to the individual's aspirations and capabilities.
- encourage all scientific efforts towards advances and improvements in medical care, education, rehabilitation, vocational training, employment, leisure and independent living.
- further the interests of persons with Down Syndrome by securing all necessary resources, support and services to that end.
- create a bond among all persons with Down Syndrome, their families, friends and associations. (from Article 3 of the EDSA Bylaws)

For further information about EDSA's identity, mission, values, principles, objectives and priorities, refer to EDSA Identity Document

[http://www.edsa.eu/files/essentials/edsa\\_essentials\\_1\\_identity.pdf](http://www.edsa.eu/files/essentials/edsa_essentials_1_identity.pdf)

With the board we have selected our priorities for the next 3 years

1. Give to DS people same opportunities in Europe -> support to national actions/ training for lobbying
2. To exchange and share experiences, to know other realities -> share holidays, visit of professionals, visits of people with DS.. (e.g. give a message on the national magazines, database matching, European funding)
3. To share competencies (using our experts and offering the possibilities of flights paid by EDSA for experts)
4. To reach members in the country in which we are not present (letters, visits- actions with the old members)

I would like to point out to you the importance of sharing experience

and competencies.

Our newsletter is intended to go in this direction!

We want to use this instrument to know better each other and I need your help!

You can send us an introduction about your organization and your activities or suggest topics and links for our "Topic of the month" section.

I remind you that our newsletter is available also on Edsa web site!

I look forward to your contribution

Best regards

Anna Contardi  
*Edsa President*

### EUROPE DAY 9TH OF MAY 2015



Europe Day held on 9 May every year celebrates peace and unity in Europe. The date marks the anniversary of the historical 'Schuman declaration'. At a speech in Paris in 1950, Robert Schuman, the then French foreign minister, set out his idea for a new form of political cooperation in Europe, which would make war between Europe's nations unthinkable. Schuman's proposal is considered to be the beginning of what is now the European Union.

To celebrate Europe Day, the EU institutions open their doors to the public in May in Brussels, Luxembourg and Strasbourg. But also local EU offices in Europe organise a variety of activities and events for all ages. Have a look at the web site to see what's happening in your country !

<http://www.europarl.europa.eu/opendoors/en/in-your-country.html>

## NEWS FROM EDSA BOARD

Edsa Board is planning a meeting with MePs members of the Disability Intergroup in Brussels.

People with Down syndrome, coming from EU countries, will make their voices heard and the associations will have the opportunity to know the main achievements of the group at European level in the framework of a round table on "Inclusion of people with Down syndrome",

To be better prepared for the meeting, we kindly suggest you to read their objectives and activities in the following article.



### DISABILITY INTERGROUP OF THE EUROPEAN PARLIAMENT

#### OBJECTIVES AND ACTIVITIES

The Disability Intergroup, established in 1980, is one of the oldest Intergroup of the European Parliament and has traditionally been one of the largest, with around 100 Members, most active and visible. The overall objective of the disability Intergroup, rooted in the UN Convention on the rights of Persons with disabilities, is to promote the rights of persons with disabilities in and outside the EU through parliamentary work. Disability Intergroup members submit amendments, draft parliamentary questions and other parliamentary initiatives, participate as keynote speakers in European events on disability issues and raise the concerns of the European disability movement.

Throughout its years of existence, the Disability Intergroup has been instrumental in the adoption of legislation favourable to persons with disabilities in areas such as transport, employment, research or structural funds. The Disability Intergroup members have submitted hundreds of amendments and spoke on numerous occasions in defence of disability rights in Europe.

The Disability Intergroup cooperates closely with the European Disability Forum (EDF), the umbrella organization representing the interests of over 80 million people with disabilities in Europe. EDF provides the Secretariat of the Disability Intergroup.

#### MAIN ACHIEVEMENTS OF THE DISABILITY INTERGROUP 2009-2014

- The Disability Intergroup is an informal, cross-party gathering of MEPs committed to promote equal rights and opportunities for persons with disabilities in and outside the EU through parliamentary work. Established in 1980, the Disability Intergroup is one of the oldest intergroups and also one of the largest ones, with over 100 members, from all political Groups and all EP Committees, and regularly attracting new members.

- There are 80 million persons with disabilities in the EU (16% of the whole population), a number likely to grow due to ageing population.
- The Disability intergroup organized 24 meetings throughout the legislature. Intergroup MEPs supported or participated in many other conferences, submitted hundreds of amendments in favour of disability rights and tabled written and oral questions.
- The Disability intergroup was instrumental in the adoption of EU legislation which made a real difference in the everyday lives of millions of persons with disabilities:
  - Improved regulations on the accessibility of transports in the EU and on passengers' rights in various transports modes.
  - A strong and ambitious EP position on the EU directive on the accessibility of public websites - a critical directive designed to end persons with disabilities' exclusion from the digital world.
  - The inclusion of non-discrimination and accessibility for persons with disabilities as a conditionality in the Structural Funds regulations, ensuring that the funds will contribute to enable persons with disabilities to participate in society and will support their transition from segregating institutions to life in the community.
  - The inclusion of a disability and accessibility clause in the revised public Procurement legislation and in the State Aids regulation.
  - The Inclusion of strong provisions on the implementation of the UN Convention on the Rights of Persons with Disabilities, to which the EU is a party, in the new EU instruments 2014-2019.
  - The inclusion in the EP resolution on the situation of fundamental rights in the EU of strong provisions on the realization of persons with disabilities' fundamental rights.
  - The Disability intergroup was instrumental in Parliament officially supporting a European Accessibility Act and the general non-discrimination directive.
- The Disability Intergroup contributes to ensuring that EU legislation and policies are designed and implemented together with persons with disabilities.
- The DI actively supported the organisation of the 3rd 'European Parliament of Persons with Disabilities', a high-level conference which brought together MEPS and more than 500 Europeans with disabilities from across Europe (December 2012).

### **WORLD DOWN SYNDROME DAY 2015**

GLOBAL VIDEO 2015 – DOWN SYNDROME INTERNATIONAL  
 “MY OPPORTUNITIES, MY CHOICES”

Down Syndrome International presents “My Opportunities, My Choices”, interviews with people with Down syndrome from 39 countries looking at their enjoyment of full and equal rights and the role of their families.

View the preview video:

[https://www.youtube.com/watch?v=BwlJ6ilQ1Bo&list=PLRtkPbCZe1o\\_IM0nwnbCOtODvFbPP1Ma1&index=1](https://www.youtube.com/watch?v=BwlJ6ilQ1Bo&list=PLRtkPbCZe1o_IM0nwnbCOtODvFbPP1Ma1&index=1)

Visit the DSI you tube channel to view all 39 individual videos in full  
[https://www.youtube.com/playlist?list=PLRtkPbCZe1o\\_IM0nwnbCOtODvFbPP1Ma1](https://www.youtube.com/playlist?list=PLRtkPbCZe1o_IM0nwnbCOtODvFbPP1Ma1)

## NEWS FROM EDSA MEMBERS

### WHAT WAS HELD IN OUR COUNTRY?

#### *ALDO-CET (ROMANIA)*

In Craiova, the capital of our region, the players of two very well-known football teams from the first division, wore T-shirts with the message “My Opportunities, My Choices”. Three children with Down syndrome accompanied the teams’ leaders and the main referee in match opening. During 5 minutes, the speaker talked about people with Down syndrome. The match was broadcasted on TV. The campaign T-shirts were offered to supporters at the stadium.



Radio Oltenia Craiova was the voice that told what Down syndrome is, what means to have Down syndrome and how people with Down syndrome play an important role in our lives and communities, by an interview of one hour during lunch time.

One student in high school and one of our ladies with Down syndrome

composed the lyrics of the Romanian Anthem of Down Syndrome Associative Movement. Together with a dancer with DS they form “IRI’s 47”. They launched the Anthem during 2 national events organised on the stage of National Children Palace and “Masca” Theatre in Bucharest.



Internet European Flash Mob – we prepared a photo according to the agreed EDSA instructions and translated the text in Romanian language. We post it on our Facebook and invited general public and friends to send it to president Juncker, to our Romanian Presidency, Parliament, Chief Senator, Chief Deputy, regional and local authorities. On my personal account 38 people shared and delivered the photo.

A young girl with glasses, wearing a white sweater, is smiling and holding a small Romanian flag. She is standing in front of a bookshelf. The image is part of a campaign poster with text in Romanian.

**În Europa suntem aproximativ 300.000 de persoane cu sindrom Down.**

**Dați-ne posibilitatea să colaborăm cu dumneavoastră și să fim recunoscuți drept cetățeni europeni la fel ca toți ceilalți.**

**Noi vrem să învățăm la școala de lângă casă, să muncim și să avem o viață independentă.**

**Permiteți-ne să ne cunoaștem! Ascultați-ne vocea! Aveți încredere în noi!**

„Nu vă ghidați după fața mea, ci apreciați-mi competențele” Joao Miguel, un portughez cu sindrom Down

4 adults with Down syndrome answered the agreed global questions and made a film for the 2015 Global Video Event. 2 of them are in the published movie.



#### *DOWNSYNDROM CZ (CZECH REPUBLIC)*

On the occasion of the 10th World Down Syndrome Day in 2015, a new Czech specific website ([www.dends.cz](http://www.dends.cz)) was launched as an initiative by the Down syndrome association from the city of Brno, called Úsměvy (Smiles). This website including a version in English gathers information about the celebration events for the WSD held in several Czech and Slovak cities, as well as in the Hungarian town of Nyíregyháza, which hosted a meeting of representatives of DS associations from the 4 countries of the Visegrad Group (Czech Republic, Slovakia, Poland and Hungary).

The different events from cities around the Czech Republic joined together symbolically at 2:13 in the afternoon and 21:03 in the evening, when hundreds of balloons with hand-written wishes and messages were released by the participants of the events from several Czech cities.

In Brno the Down syndrome association Úsměvy (Smiles) in cooperation with Aldente Theatre organised an event called Who's afraid of Down syndrome?, title inspired on Who's afraid of Virginia Woolf? by Edward Albee.

A new kind of event was live broadcasting of videoclips about Down syndrome and live interviews with participants from Aldente Theatre through You Tube channels.

In Prague the WSD event organised by DownSyndrom CZ started with a group of families following a route from the Prague Smart Guide (which was worked out within the Tourists Not by Chance project), starting on the Republic Square in the city centre and ending on the Petřín hill, where they released lots of balloons.

At the astronomical observatory on the Petrín hill the participants attended a short presentation about the Planet number 213.



## WHO IS AFRAID OF DS?

The whole country celebrates the World Down Syndrome Day

**Saturday, 21 March 2015**

**Watch!**

16:30, 18:30 a 20:30

Live internet broadcasting on Youtube channel

### Release a wish for people with DS!

2:13 PM a 21:03

Released wishes in the form of balloons (by air), toy boats (by water), lighting a candle (wishes in our thoughts) for people with Down syndrome

### What kind of event can you join in your town or city?

Find out on the web page

[www.denDS.cz](http://www.denDS.cz)

Under the auspices of Bc. Matěj Hollan, Deputy Mayor of Brno and Bc. Roman Cělý, DiS., Deputy Governor of South Moravia

### DS INFOCENTER (GERMANY)

#### Postercampaign

In 2014 we have produced a book titled "Einfach Sontje" in English "Simply Sontje".

We took this title as motto for our yearly world-ds-day do-it-yourself-poster campaign.

Families sent us a picture of their child and we placed it in our layout and sent it back to them. They can print it out as a postcard, a poster, hang it out in shops, churches or schools etc. or distribute it per mail. This year we made over 600 Posters!



### Car sticker

We developed a car sticker with the slogan. “Down-Syndrome simply a bit more inside” and printed and distributed about 15.000 sticker.



### Award for sensitive counseling

Parents of babies with DS could mention us the names of pediatricians who did a real good job, in the way they had told them the DS diagnose. These doctors received a special award from us. They broke the news very sensitive, gave up-to-date information about DS and a positive perspective.

We also gave away a number of our very informative First Information Maps to children hospitals. Parents could order this map and bring it personally to their birth clinic. They took along their child with DS and had a talk to the staff.



### **Conference: Education**

We organized a conference around the topic lifelong learning. We had several speakers who presented us learning possibilities and new methods for younger and older children as well as for adults. The results from a large study done by the university in Hamburg with 1200 persons with DS, testing the attention and concentration were presented as well.

An interesting talk was from representatives from the Maynooth University in Ireland. They reported about a project with students with intellectual disability, among them some with DS, who were enrolled in regular university courses.

### *DOWN SENDROMU DERNEGI (TURKEY)*

down sendromu dernegi's president talked about ds in un world down syndrome conference in new york on march 21st  
the turkish association has also organised:

- a party in istanbul for 700 families.
- a seminar about ds for 280 people in ankara.
- fun activities in ankara, tokat and kastamonu



## APPT21 (Portugal)

### Activities

We were officially born in 1990; October 1st. as a nonprofit organization. We are celebrating our 25th anniversary. Our team includes more than 130 professionals. Multi-disciplinary team of professionals with a nationwide organizational structure: over 20 branches and partnerships with other institutions and schools. The institution has an annual budget of about 2,5 million €. No membership fees are envisaged. We sell educational softwares and undertake institutional marketing. We get some support from the Social Security Fund - about 8.000 Euros a month for 70 children between 0-6 years old in Yearly Intervention Program-Main revenues are private donations and sponsorships. The main institutional goal is to promote awareness and disseminate knowledge to pursuit the ideal of inclusion and human ethics. These are some of our activities:

- Each and every year we promote awareness workshops and training for parents, teachers, pediatricians, decision makers in schools and communities.
- We organize an annual meeting, usually in October, to present our work to the national community and discuss the state of the art concerning health, education, independent living and job inclusion.
- The institution includes an Investigation and Development Department which works closely with the Differences Development Centre. We have been engaged in educational software development and educational resources for teachers and parents. We have also several investigations currently in progress concerning the use of multimedia in learning/teaching and development assessment processes.
- We have been involved since 2010 in the development of European Projects. Presently we are involved in the project "On my own... at work", together with Italian and Spanish partners.
- Our institution provides training and expertise in developmental disabilities, namely Down Syndrome, to Centro de Atención Integral para la Discapacidad, Santo Domingo, Dominican Republic.



## 10TH EUROPEAN DOWN SYNDROME CONGRESS

BUILDING BRIDGES

5-6-7 AUGUST 2016, ISTANBUL



Down Syndrome Association of Turkey is happy to invite you to the 10th European Down Syndrome Congress in 2016 in İstanbul, Turkey. The Congress will be a central meeting point for families and professionals working on the subject of Down syndrome all over the world. Thanks to the strategic geographic position of İstanbul, participants not only from Europe but also from Middle East and Asia region will find it very easy to travel to this central location.

With its enchanting location spreading over two continents, İstanbul represents the unique feature of Turkey for serving as a bridge between different cultures. This feature will be the major asset of the European Down Syndrome Congress 2016 in bringing together people for a better future for individuals with DS. It will provide the perfect platform for introducing and discussing regional problems along with priority issues of global importance regarding DS.

Like these two continents reaching out to meet, we seek ways to connect people with each other.

For the congress the theme is "Building Bridges For a Better Future". The motto is "We add +1 value to life."

Web site **edsc2016.org** will be opened soon.

For any further information please contact **fulyaekmen@gmail.com**

### 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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