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WDSO 2020 POSTER CAMPAIGN ON EDSA WEB SITE

[Dead line: 20 February 2020](#)**World Down Syndrome Day 2020**

On the occasion of World Down-Syndrome Day 2020, we will have our poster campaign on the EDSA website like in the years before.

The theme of WDSO 2020 and of our poster campaign is: „We Decide“

– All people with Down syndrome should have full participation in decision making about matters relating to or affecting their lives. Effective and meaningful participation is a core human rights principle supported by the United Nations Convention on the Rights of Persons with Disabilities (CRPD) –

More general information about the „We Decide“ campaign:

<https://www.worlddownsyndromeday2.org/event/call-to-action-2020>

Information about the poster campaign on the EDSA website

We are aware that the topic „We Decide“ is hard to show in a photo. It covers daily decisions like what clothes to wear or what to eat as well as decisions about friendship, where and how to live, about work up to having an own voice in political issues.

Examples: choosing clothes in a shop / at a mirror clothes to wear, choosing tv channels with the remote, simulating a voting box, shopping with a list at the supermarket, ordering a meal in a restaurant, reading a holiday brochure, cooking with a recipe book, putting jewellery on, choosing some music on an ipod etc.

We need two things from every member:

- 1. Photo > good quality, landscape format, space enough for the slogan**
- 2. short text> about what the photo shows, in your own language and in english**

We prepared an easy frame. Look at our draft-examples in the attachments. And send us a photo that fits this format, together with a short text. I am collecting your contributions from now.

Like in the years before we start showing the first photo on march 1st.

And then every day up to 21st march. That means: altogether I need 21 photos with text. Have a look on the campaign in the years before on the edsa website <http://www.edsa.eu/category/world-down-syndrome-day/>

Questions? halder.cora@t-online.de

Photo and text please as soon as possible to: halder.cora@t-online.de

Not via this mailing-list!!

I am eagerly waiting your contribution! Kind regards, Cora



Who will be elected into the new municipal council? Who will be the next mayor in our city? Andrea wants to cast her vote like all other citizens and informs herself in advance, so that she can have a say. Her decision counts.



Andrea loves to decide for herself what she wants to eat and where she buys the ingredients. Sometimes these are also things that are not quite so common in her own family. Nevertheless, she decides herself what she needs!

DOWN SYNDROME CONFERENCE



T21RS meeting in Barcelona June 2019

The third International Conference of T21RS – a great success

The third International Conference of T21RS held last June in Barcelona gathered a total of 429 participants from 36 countries, scientists, families, and industry representatives. The most represented countries were Spain, USA, France, Italy, United Kingdom, and Brazil, but we had attendees from many other countries. The program was tight over the four days, with plenary sessions, parallel scientific sessions, poster sessions and updates on the T21 society.

167 posters were presented, among which 65 teams had the opportunity to present their results in a short talk or a nano symposium. There were 4 plenary lectures, 3 satellite symposia, 14 symposia (70 talks), a session devote to Industry, another one to Education Session and a Science and Society Symposium.

The meeting was organized by the 11 members of the Organizing Committee, 12 PhD/Postdoc volunteers and 9 volunteers with Down syndrome, 10 members of the Program Committee, and the support of the 11 members of the executive board. The technical secretariat managed more than 7.300 emails and we had the support of 19 companies/institutions.

Scientific sessions

This event will help further progress in all areas of Down syndrome research and will help to address the challenges we face in the field.

Beside the scientific sessions which focused on specific areas of research, including clinical and pre-clinical studies, daily plenary lectures gave a more in-depth look into a range of topics :

- Stylianos Antonarakis (University of Geneva, CH) talked about the genetics of human chromosome 21.
- Wieland Huttner (Max Planck Institute, GER) discussed how the morphology of basal progenitor cells influences neocortex development.
- Li-Huei Tsai (Massachusetts Institute of Technology, USA) spoke about the potential for using g-waves to modify the pathology of Alzheimer's disease.
- André Strydom (King's College London, UK) gave an update on the results obtained from the LonDownS Consortium, an association based in London of scientists working on Down syndrome from a molecular, clinical, and genetic point of view.

During a session on the ethics of using different types of models, a panel of scientists discussed the pros and cons of mouse models versus induced pluripotent stem cells (iPSCs), defending their preferred models, and a sparking discussion between them and the audience.

Scientists meet people with Down Syndrome and their families

In addition to the science, events like 'Family Day' and 'Meet the Scientist' put scientists together with people with Down syndrome and their families, thus enabling both communities to know each other better. As one of the pre-meeting events, the European Molecular Biology Laboratory (EMBL), the Center for Genomic Regulation (CRG) and the Barcelona Beta Brain Research Center (BBRC) centers opened their lab doors to conference attendees to exhibit their state-of-the-art equipment and facilities, and share updates on their current projects.

Social program

Finally, the social program also offered a wide range of entertainment. Quim Vilamajó presented his art project '**I am able**', where he passionately talked about his experience of living with Down syndrome; the Compañía Nacional de Teatro Manantial de Ilusión (Chile) performed 'Romeo and Juliet' in a capturing wheel of colours and music; the band 'Els Cracs d'Andí' offered a concert from the terrace of the Mirabè Restaurant just before the conference Gala Dinner

At the opening of the congress, Quim Vilamajó, a young man with Down syndrome, presented with amazing self-confidence and joy **I am able**, the artistic project that he is working on together with his father. Through videos and photographs, Quim reflects upon living with a disability such as Down syndrome and calls into question about our own disabilities.

Questions to the scientists

During the three days of the conference, Quim and the Trisomy 21 Research Society shared through their social networks (#Iamableproject, @quimvilamajo, @culturaccio, @T21RSBarcelona) six videos in which Quim shared his reflections and addressed questions to the scientists:

- 1) What makes people with Down syndrome different?,
- 2) Why do some people with Down syndrome express themselves better than others?,
- 3) Will we ever have the tools to solve things for ourselves?,
- 4) Why people with Down syndrome talk to themselves?,
- 5) Why do things affect me so much and I get sad?, and
- 6) Why is it so difficult for people with Down syndrome to see the positive side of things?

To date, the videos have reached almost 10,000 views and have contributed to spread the commendable goal of the **I am able** project: to break down barriers and

prejudices about people with “disabilities” and to influence about the role they can play in this complex, difficult and competitive world.

A Special Issue of the journal Brain Sciences

A Special Issue of the journal **Brain Sciences** about Research on Down Syndrome on the direction of Alberto Costa will be through soon. The group of Alberto will have a chapter titled “On the Design of Broad-Based Neuropsychological Test Batteries to Assess the Cognitive Abilities of Individuals with Down Syndrome in the Context of Clinical Trials”.

The next T21RS Conference will be organized at Irvine, California, in May 2021.

Report: Jacqueline London

NEWS FROM EDSA MEMBERS

COORDOWN – ITALY



Hello,

CoorDown would like to hear the opinions of people with Down syndrome in your association!

What do people with Down syndrome think about various topics? What kind of schools do they attend? Do they have jobs? Do many people with Down syndrome have a driver's license? What do they want out of life? How do they feel about a range of things?

The "It's My Say" survey about the thoughts and needs of people with Down syndrome is now live!

This global survey is open to anyone from any country who has Down syndrome. The survey is available in 6 languages with the support of a voice reader. A version with AAC symbols is also available. The responses will help to provide an up-to-date insight into the experiences and the perspectives of people with Down syndrome about school, work and social life. We intend to use the results to better represent the interests of people with Down syndrome and to foster self-advocacy.

**You can access the online survey here <http://itsmysay.coordown.it/>
Please also [share this link](#) with your community and ask people with Down syndrome to complete the survey!**

It should take no more than 15 minutes to complete. All responses are anonymous.

The survey closes on 29 February.

The more people who respond and share their experiences, the more powerful our voice will be!

Thanks in advance for your participation!

Martina

DOWN SENDROMU DERNEĞİ



SELF-ADVOCATES WITH DOWN SYNDROME BEGAN TO STUDY AGAINST POVERTY AND SOCIAL

EXCLUSION



Turkey Down Syndrome Association's "Voice +1" self-advocacy group established in 2018 with 10 youngsters from four cities in Turkey. After full year hard work, the members of the group accomplished lots of successful activities to create awareness to Down Syndrome. Now the members pioneering new self-advocacy groups in their cities and inspire other cities.

4 weeks ago, new self-advocacy groups began their trainings to become self-advocates in Ankara, Eskişehir, İstanbul, İzmir, Tokat and Adıyaman. Previous members are helping new ones and sharing their experiences with new members while refreshing their own knowledge.

The self-advocacy teams reached a consensus about working on poverty and social exclusion. They will learn what means being poor, what is social exclusion and which people lives under the risk of social exclusion or poverty. After that, they will decide what they can do to create awareness or to help these people and which tools can be used.

Last year the previous self- advocacy group were visited a nursing home and they cooked for poor people and shared their meal. Now they will guide new self- advocacy groups. We are curious which activities they will decide in 2020.



EU FUNDING OPPORTUNITIES



SPORT

Erasmus+ activities in the field of sport aim to support actions that increase capacity and professionalism, improve management skills, and increase the quality of implementation of EU projects, as well as the creation of links between sport organisations.

In particular, these activities should aim at:

- addressing cross-border threats to the integrity of sport
- promoting and supporting good governance in sport and the parallel careers of athletes
- promoting voluntary activities, social inclusion and equal opportunities in sport
- increasing awareness of the health benefits of physical activity
- increasing participation in sport.

The programme funds collaborative partnerships and non-profit sporting events, and supports actions that aim to strengthen data for policy making and promote dialogue with stakeholders.

At systemic level, actions in this area should contribute to the development of the European dimension in sport; from an individual perspective, projects supported by Erasmus+ should lead to increased levels of participation in sport and the promotion of physical activity.

For all actions in the field of sport, the application is directly managed by EACEA, the Education, Audiovisual and Culture Executive Agency.

Go to the [ERASMUS+ SPORT INFORMATION PAGE](#)

The Erasmus+ Programme Guide 2020 information, objectives and application modalities.

DEADLINE: 2 APRIL 2020 12.00 NOON,

Application forms

The facsimile templates of the application forms valid for the 2020 deadline are available on the page of the European website of the Programme.

https://eacea.ec.europa.eu/erasmus-plus/funding/sports_2020_en

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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