EUROPEAN DOWN SYNDROME ASSOCIATION

August 2024

INDEX

SAVE THE DATE

EDSA AGA 2024

Dear EDSA members,

I am happy to inform you that the next EDSA AGA will take place from 25 - 27 October 2024 in Lisbon, Portugal.

Our EDSA member PAIS21 will host our annual meeting.

1. Here the **info-package** about Lisbon. You will find the location of the AGA and how to get there. You might start looking for a hotel in that area.

2. Here the **preliminary programme**. We might keep the same time frame for AGA and Seminar like last year. Some details can still be changed!

3. **The topic of the Seminar this year will be „SPORT".**

How sport for people with DS is organised in the different European countries? Good ideas and practical experiences etc. Sport and Inclusion.

You can already start preparing a presentation!

Now that we have decided on the dates and destination of the next assembly, you can start looking for the best flights!

Best regards

Cora

EDSA WEBINAR

THE DUAL DIAGNOSIS OF DOWN SYNDROME AND AUTISM

Date: Friday, 13 September 2024 17.00– 18.00 CET
Speaker: Noemi Spinazzi
Translation: To be announced
Registration: To be announced

Autism occurs more frequently in children with Down syndrome than in the general population, but it is often missed or diagnosed late.

This presentation will discuss common presenting signs and symptoms of autism in children with Down syndrome, measures that are used to assess for co-occurring autism in children with Down syndrome, and therapeutic supports that can help children with a dual diagnosis thrive.

Biography

Noemi Spinazzi, MD is a primary care physician at UCSF Benioff Children’s Hospital Oakland and an associate professor at the UCSF School of Medicine. She founded a specialized clinic serving patients with Trisomy 21. She is also the director of the developmental and behavioural paediatrics resident rotation at UCSF Benioff Children’s Hospital Oakland. Dr Spinazzi has participated in multiple research endeavours focused on developmental disabilities and equitable care. She was recognized by UCSF by being awarded the Chancellor’s Diversity Award for Disability Service in 2022.

She was born and raised in Milan, Italy and moved to the United States when she was 15 years old. She received her medical degree from the University of Pennsylvania in Philadelphia, Pennsylvania. She completed her residency at UCSF Benioff Children’s Hospital Oakland, where she was the Chief Resident.

ŽIVOT SA DOWN SINDROMOM FEDERACIJE BOSNE I HERCEGOVINE

The Association Life with Down Syndrome of the Federation of Bosnia and Herzegovina was founded in 2006 by families of children with Down Syndrome. The association is located in Sarajevo, Bosnia and Herzegovina.

Very soon after its foundation, the association identified key barriers in society that hindered the inclusion of people with Down syndrome, and based on that, determined strategic directions of work and action. Primarily, the association works to promote the human rights of people with Down syndrome, reduce prejudices towards them through public advocacy activities, information and education of parents, educators, teachers, medical workers and other experts who follow the development and teach people with Down syndrome.

The focus of the Association's activities is the right of children to early intervention and family empowerment. The message we are sending is Happy family - happy child and this program includes several different activities: informing and advising parents in the area of their children's rights; educational workshops on various topics: development of children with Down syndrome, techniques in speech development, preservation of mental health, etc. In the field of inclusive education, in addition to teacher training, the association advocates harmonizing legal regulations with the UN Convention on the Rights of Persons with Disabilities, which actually strengthens the education system in order to provide an adequate response to the needs of children in their education.

After completing their education, what we want for young people with Down syndrome is to start their careers as part of the open labor market, but, as you can imagine, is very hard in Bosnia and Herzegovina. Therefore, the Association advocates for the improvement of the mediation and employment system for people with disabilities and their employment in the open labor market. We successfully cooperate with labor institutions and employers and we can already record of successful employment of young people with Down syndrome in public institutions and the open labor market. Still, it is part of the system, and for every young person with DS we need to find an employer, prepare that company and close follow-up of every person integration in company's process. However, we are still the pioneers in this area and continue to operate in it, which demands all pour resources.

A very important part of a healthy lifestyle is engagement in cultural and sports activities, because socialization and a quality cultural life of people with Down syndrome, as well as physical activity, contribute especially to their cognitive development. Therefore, these are two important directions of activity of the Association. We advocate accessibility and inclusion in culture and sports, we promote the possibilities of young people in creating inclusive performances and successful sports results.

The association has established cooperation with relevant state ministries and institutions as well as organizations of persons with disabilities, and we are often participating in the development of strategies and laws that regulate the rights of persons with disabilities, as our goal is to harmonize them with international documents.

The association is an active member of the European Association for Down Syndrome (EDSA) and the International Down Syndrome Organization (DSI).

You can find more information about the association at www.downsy.ba

The photo we are sending is from one of our campaings. This particular campaign was about the right to vote. The campaign, which we will repeat in every election year, consisted of a programme for young people with Down syndrome so that they can understand why elections and politics are important, to learn more about plans of different parties. Also, part of this programme was to meet politicans from different parties, where people with DS had the opportunity to ask them what precisiley their political party has done and plan to do to improve the inclusion of people with disabilities.

The campaign name was „Moj glas je bitan“ – „My vote is important“ and „We build society of equal opportunities“.

NEWS FROM EDSA MEMBERS

Hello from Ukraine!

Hello from the forest camp for families who have children with Down Syndrome. Summer is the best time for rest, to recuperate, it's time for ReStart.

This is the third summer for Ukrainians stolen by wide-scale war. Summer 2024 with total problems in energy sector, just few hours electricity supply in apartments in July. Heat has broken all temperature records…

Camp became the lifeline for families with children in these challenging circumstances. 3 one-by-one groups for a total of 138 – it has been possible as a result of our European friends' support.

«Forum RGOW - Religion & Gesellschaft in Ost und West» from Switzerland, Spain Down Syndrome Association, «Abilis» from Finland.

What is the main reason to participate for families? Fun outdoors for children, communication and psychological support for parents, changing anxious routine for everyone.

Ukrainian Down Syndrome Organisation has been managing vacation camp for families for the second summer. The demand for this service is huge. It looks like all troubles fell on their heads – the war, displacement, energy sector collapse. And they care their children with Down Syndrome inside all of these. How should they stay on the feet? We're looking for answers together in the ReStart Camp, because there aren't ready ones.

And we thank for support great European family since all our sources are focused on fighting with Russian aggressors!

WORLD DOWN SYNDROME CONGRESS – BRISBANE

9 – 12 July 2024 Brisbane, Australia,

By Down Syndrome International

A three-yearly Congress for people with Down syndrome, families, advocates, professionals and researchers to meet, and share knowledge, insight and experience with others from different countries and environments around the world.

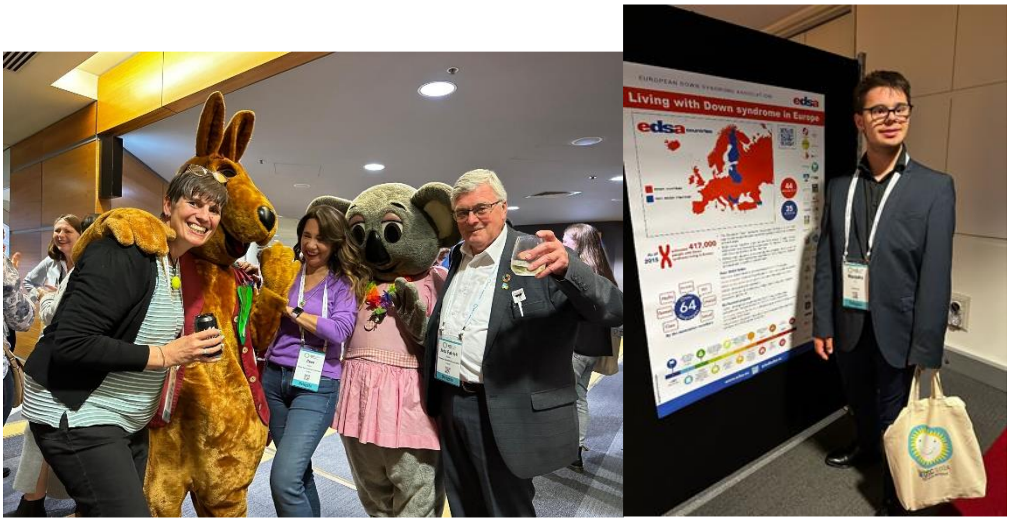
The Congress included:

- a Health Professionals and Researchers Day Meeting, where health professionals and researchers shared latest updates a research.
- 'Health and therapeutic advances' as one of the five streams that ran through the main programme, over three days.

The WDSC was an unmatched opportunity for people with Down syndrome, families, advocates, professionals and researchers to meet, and share knowledge, insight and experience with others from different countries and environments around the world. Those who attended once rarely miss it again!

Down Syndrome International (DSI) are responsible for the World Down Syndrome Congress. DSI are committed to organising the World Down Syndrome Congress (WDSC) in different locations around the world every 3 years. Edsa attended the Congress!!!!

More information



EU FUNDING OPPORTUNITIES

CITIZENS, EQUALITY, RIGHTS AND VALUES PROGRAMME (CERV)

Promote civil society organisations' awareness of, capacity building and implementation of the EU Charter of Fundamental Rights (CERV-2024-CHAR-LITI)

Deadline date: 18 September 2024 17:00:00 Brussels time

Scope: Promoting rights and values by empowering the civic space

In line with the Charter Strategy and following up to the Charter Report 2022 on a thriving civic space for upholding fundamental rights in the EU, as well as the findings of the 2023 seminars and concluding conference, projects under this priority should promote rights and values by empowering civil society actors to work together at the local, regional and national levels on the fields covered by the programme. Projects should also help creating a channel of communication with the EU level to report on the state of the civic space in their countries and voice their concerns.

More specifically, projects could create a systematic and comprehensive monitoring system to regularly and consistently monitor the environment in which civil society organisations work in the national contexts, building on the Fundamental Rights Agency indicators about the shrinking civic space and of internal organisations' data, and in particular of breaches of civil society organisations and human rights defenders' fundamental rights.

Projects could also support and enhance the protection of civil society organisations, their members and human rights defenders working to protect and promote EU values under attack, including by facilitating access to dedicated support services. As such, they could also contribute to strengthening the resilience of civil society actors against attacks, including cyber threats, and their capacity to fully exploit the possibilities of the converged media to carry out effective, visible and impactful advocacy activities in the digital environment.

Transnational partnerships with mutual learning possibilities for partners in several EU Member States are particularly encouraged to apply, as well as networks of relevant actors at national level such as National Human Rights Institutions (NHRIs), equality bodies, Ombuds-institutions, and the national Charter Focal Points.

Read more

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

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THE STAFF

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