

EUROPEAN DOWN SYNDROME ASSOCIATION

September 2023

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Annual General Assembly (AGA) 2023 in Madrid

We are happy to invite our members this year to a face-to-face annual meeting, which will take place in Madrid from **27 to 29 October 2023** and will be organised by Down España.

Annual General Assembly / AGA

Every year EDSA holds its annual meeting, the Annual General Assembly, called AGA. All members are invited to take part in the meeting, to inform themselves about EDSA's program, financial status, to discuss plans for the future, take part in board elections etc. At the same time it is an ideal possibility to get to know each other better, to exchange experiences, share ideas and prepare joint projects. Members have the opportunity to introduce themselves and their work.

Conference

Combined with the official meeting a day seminar is organised around a special topic. Speakers are invited, workshops, films and talks are on the programme as well as visits to interesting work or living locations. Conference topics in the last years were u.a. School inclusion, Job inclusion, autonomy and independent living. Speakers with Down syndrome were occasionally invited as well. In the future the focus will be on more participation of persons with Down syndrome.

In the past years, the AGA has taken place several times in Rome and Madrid, as well as in Lisbon, Zagreb and Dublin. In 2020, 2021 and 2022 we had to switch to an online mode, due to the Covid pandemic.

This year we can finally invite to a face-to-face annual meeting again. All EDSA members are welcome to participate in Madrid from 27 to 29 October 2023. The meeting will be organised by Down España.

More information about the meeting and the conference will follow soon.



NEWS FROM EDSA MEMBERS

ASOCIAȚIA OBȘTEASCĂ PRIETENA MEA - MOLDAVIAN DOWN SINDROME ASSOCIATION

(The newest Edsa members!!)



Dear Edsa Members,

I am glad to share with you one of our recent projects.

We organized the first summer camp for parents who have children with Down Syndrome.

It was a great experience and we hope to have more and more editions.

Here a short presentation about it.

Thank you for your time and greatest regards from Moldova!

Ludmila ADAMCIUC,

President,

A.O. Prietena Mea





SPOLOČNOSŤ DOWNOVHO SYNDRÓMU NA SLOVENSKU - SLOVAKIA DS



30TH ANNIVERSARY OF THE SLOVAKIAN DS

Dear Edsa Members,

this year we celebrated the 30th anniversary of the existence of our organization. But the path was not always easy.

Regardless of the anniversary of the group of people, every year in every community is a reason for celebration. Especially in the communities of families, who have to fight with their full strength every year. The Down Syndrome Association in Slovakia is no exception. We are also happy for every year that we manage to continue to help and support families where a child was born with an extra chromosome, help spread awareness or share information with the general public.

The Down Syndrome Association was created as an initiative of parents of children with Down syndrome, initially for the purpose of community meetings and rehabilitation stays, later sports and educational, publishing and charitable activities were added. We must not forget to mention the effort for inclusion or active employment of people with DS. Behind the creation and running of the company is a group of volunteers (especially parents and siblings of people with Trisomy 21) who dedicate their personal free time to activities aimed at children and youngsters with Down syndrome, either in the form of volunteering at youth, family or sports stays, or by working on social networks or publishing activities (this year our magazine Slnečnica /Sunflower/ celebrated its 27th anniversary). In addition to the magazine, we have also published several books publications.

We celebrated our anniversary appropriately on the 20th of May on the ship Harmónia in Bratislava. It was a day full of fun, dancing, singing, and all this in a beautiful environment and in the best company of friends and sympathizers or supporters, many of whom stood behind us from the very beginning. We are very grateful to each of them and look forward to the next years of cooperation, which are undoubtedly ahead of us.

Best regards, Martina Sulova, Spoločnosť Downovho syndrómu na Slovensku





GOOD NEWS

ANES KUJOVIC FROM SARAJEVO IS THE FIRST UN VOLUNTEER WITH DOWN SYNDROME IN THE WORLD



Anes Kujović from Sarajevo is the first person with Down syndrome in the world who became a United Nations Volunteer as part of the Regional Programme on Local Democracy in the Western Balkans 2 (ReLOaD2) and thus gained the opportunity to attain work experience.

In the premises of the Municipality of Centar Sarajevo, where hundreds of employees are busy completing their daily duties, hides his inspiring life story.

The life path of 21-year-old Anes was not the same as that of his peers. From early childhood he walked through a world that often did not understand his unique abilities. He was born with Down syndrome, which greatly influenced his upbringing and life circumstances, from schooling, adolescence, to acceptance in society. But every obstacle was a new step towards success for him.

With a determined spirit and with the great support of his family and friends, he managed to fight for his place in the community. Today, Anes sits in the Department for Education, Culture and Sports in the Municipality of Centar Sarajevo, where he performs administrative tasks as a UN volunteer – the first in the world with Down syndrome.

Every new working day for Anes is a new victory and a reminder that he managed to break barriers, doubts and misconceptions of people.

Anes got the opportunity for his first internship through the Regional Programme on Local Democracy in the Western Balkans 2 (ReLOaD2), which is funded by the European Union and implemented by the United Nations Development Programme (UNDP). In order to promote diversity and inclusiveness in all spheres of society, ReLOaD2 has provided the opportunity for internships to all young people from the area of this municipality and 12 other partner local governments, regardless of their abilities or disabilities.



To the delight of the Kujović family, Anes became the first UN volunteer with Down syndrome in the world. In addition to the internship, by participating in the ReLOaD2 project, Anes got the opportunity to further develop his skills through various educations, as well as the mentoring support of Faris Bečić, a young man who is also engaged within ReLOaD2 and who monitors his progress and attitude towards work.

The specific tasks in which Anes is involved together with Faris are administrative tasks such as opening cases, scanning and printing documentation, archiving documentation, holding meetings with parties and civil society organizations, recording incoming projects through public calls and the like.

Bečić explains that mentoring support within the ReLOaD2 programme is crucial during the transition to work for people with disabilities. The process of mentoring, as he says, enables the monitoring of a person in the process of work, development and growth of skills, as well as the attitude towards work and the way of solving simple and complex tasks. In the course of working with Anes, he says that he is building an incredible relationship full of sensibility.

Anes regularly receives compensation for volunteering. He calls it a "salary" from which he plans, as he says, to pass the driving test and buy a car.

"The internship brought enormous changes to Anes. His self-confidence has increased, he has developed critical thinking and is much more responsible towards work than he was towards schoolwork. He is happy because he is really building a friendly relationship with his work colleagues who are the center of his daily stories", said Anes' mother Sevdija.

Anes is one of the extremely rare people with Down syndrome in Bosnia and Herzegovina who has achieved the right to work, one of the fundamental human rights. Although many people like him can make a great contribution to the development of the community, and be useful both for themselves and for society, systematic support for the employment of people with Down syndrome has not yet been developed in Bosnia and Herzegovina.

"This responsibility belongs primarily to the institutions, which should encourage others to accept differences by their example. In this regard, it is necessary to develop policies and services for inclusive employment, because the goal is not only to hire them, but to maintain long-term employment," said Anes' mother, Sevdija Kujović.

The Municipality of Centar Sarajevo hopes that other institutions will follow their example and work on programs to empower young people with disabilities. So far, ReLOaD2 has provided internships in cities and municipalities for 22 young people throughout Bosnia and Herzegovina, including four people with disabilities.

From Sarajevo Times, 29th July 2023



EU FUNDING OPPORTUNITIES



ERASMUS KA1. YOUTH PARTICIPATION INITIATIVES

(Projects starting between 1 January and 31 May 2024)

Deadline for submission: 4th of October 2023

ABSTRACT

Youth Participation Activities are informal learning activities which encourage, promote and facilitate the participation of young people in the democratic life of Europe at local, regional, national and European level. They aim to enable young people to experience exchanges, cooperation, cultural and civic action, helping them to strengthen their personal, social, citizenship and digital competences and to become active European citizens.

OBJECTIVES

- To provide opportunities for young people to engage and learn to participate in civil society (by providing pathways to engagement in their daily lives but also in democratic life, aiming at civic, economic, social, cultural and political participation of young people from all backgrounds, with particular attention to those with fewer opportunities)
- Raising young people's awareness of common European values and fundamental rights and contributing to the process of European integration, including by contributing to one or more European youth objectives;
- Developing young people's digital competences and media literacy (in particular critical thinking and ability to evaluate and work with information) in order to increase young people's resilience to disinformation and fake news and propaganda, as well as their ability to participate in democratic life
- Bringing young people and policy-makers together at local, regional, national and transnational level and/or contributing to the EU dialogue with young people.

ELIGIBLE ACTIONS

<u>Activities</u> supported may take the form of (or a combination of):

workshops, debates, role-plays, simulations, use of digital tools (e.g. digital democracy tools), awareness-raising campaigns, training courses, meetings and other forms of online or offline interaction between young people and policy-makers, consultations, information events, etc.



As a concrete <u>outcome</u>, young people should make their voices heard (through the formulation of positions, proposals and recommendations), especially on how youth policies should be shaped and implemented in Europe.

Where relevant, the integration of digital activities (e.g. webinars, hackathons, e-participation, etc.) and/or training on the use of digital democracy tools in the activities to be implemented is strongly encouraged.

If the project plans to implement mobility and/or physical events, a timetable of such activities must be attached to the application form.

TARGET GROUP

Young people aged between 13 and 30 years resident in the country of the participating organisations and policy-makers relevant to the issues addressed by the project.

Read more



NEWS FROM THE PROJECTS WITH EDSA MEMBERS IN THE CONSORTIUM

THE VALUEABLE NETWORK

The <u>Valueable Network</u> – a European Network working on inclusive employment for persons with intellectual disabilities in the hospitality industry – is launching a new online course on "Health and Safety at Work". This is produced within the Erasmus+funded Project "Value-able safety at work" and will be available in 8 different languages: English, Spanish, Italian, Hungarian, Portuguese, Croatian, German, and Turkish. Because the work place must be a safe place! Check out the course promotional videos which are already publicly available via the Valueable Network social media profiles (Instagram, Facebook).

Are you an (aspiring) employee with an intellectual disability or a social worker in charge of facilitating job placements for persons with intellectual disabilities? Then this is your chance! You can easily register for **FREE** with your email address on https://safetywork.valueablenetwork.eu. Get to be amongst the testing team and contribute to the development of the course by providing your feedback on user experience and satisfaction.

Choose your language and take the modules at your own speed — asking for assistance if needed. The learning material contains PPT slides, visual cues and clear video explanations of the core concepts related to health and safety at work. Topics range from how to deal with different risks and hazards present in the workplace, to explanations about your rights and duties as an employee. At the end of the course, there is a short assessment with questions about the different lessons you have covered. If you answer correctly, you will receive a **certificate as an "expert"** on safety and health at work.

Project partners are now in the piloting phase of this E-Learning course. Stay tuned for upcoming Multiplier Events in the 7 European partner countries, which will take place at the end of September, where the finalised version of the E-learning tool will be presented and discussed.

EDSA members that are partners of the Valueable network:

Associazione Italiana Persone Down (IT)

Associacao Portuguesa de Portadores de Trissomia 21 (PT)

Down España. (ES)

Down Alapitvany (HU)

Down Sendromu Dernegi (TR)

Hrvatska zajednica za down sindrom (HR)

and ...

EDSA itself!







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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