

SUMMARY

01 EDSA AND OUR UKRAINIAN FRIENDS

06 WDSO 2022 EDSA POSTER CAMPAIGN

07 WDSO 2022 – EDSA MEMBERS' INITIATIVES

08 ICOD- Project

09 EU FUNDING OPPORTUNITIES

EDSA AND OUR UKRAINIAN FRIENDS

Dear EDSA members, Cora's letter is of yesterday and represents just a picture of that moment. The situation is changing all the time. Perhaps this evening we'll have different options, solutions.

Also Jarek's letter might be unclear here and there.

We are aware that both mails are just „letters“ and not articles. But we have decided to leave them as they are, in order to spread first-hand information all over Europe, hoping that this can support in some way our Ukrainian friends.

Dear EDSA members,

we would like to inform you about the following – what can EDSA do for Ukrainian families with a child with Down-Syndrome? Some of you have asked us if they can send money, clothes, food, medicine? Or if EDSA is collecting money.

The situation at the moment is that EDSA is in contact with board members of DS-Ukraine. They have sent us a list with things they need most (food, medicine). But at the moment it is not possible – or very difficult and dangerous – to transport goods over the Polish border into Ukraine.

In Poland we have Jarek Pieniak from Wroclaw, who was once EDSA board member as well and who is very much engaged in supporting families coming from Ukraine and who could buy food and medicine (though things are already lacking in South Poland as well). He could organize transport up to the Ukrainian border, but further transport might be difficult.

Another option is sending money to the bank account of DS Ukraine. But this might not be secure. And once the money is there, it is hard to say what can be bought as shops are empty and then how to distribute among the families? Dinka, Pat and Isidro are checking what kind of papers etc is needed for a money transfer, and how we can be sure that this money arrives at the right place.

Another fact is that EDSA as NGO cannot give money to single, private persons. We have to find different ways. That is why we are not collecting donations at the moment.

We believe that the best support might be to help those families who come over the borders and look for a place to stay.

DS associations in the different countries could help with finding accommodation, help them with medical care and with the burocratical stuff. Later then with finding them kindergarden/schools and other things they might need.

Right now we are in contact with some families who are on the way to Hungary, Romania, Czech Rep. More will follow. We will contact the associations in these

countries so that they can care for them. In Poland some families have already arrived and are looked after by a team of volunteers from DS associations.

In the long run a lot of support will be needed in Ukraine. Then EDSA could give financial support through DS Ukraine for therapists, learning material etc.

It is hard to know what is the right thing to do. We will keep you informed and will appeal to you if we know when a family with a child with DS travels to your country.

Best regards, Cora

Here is a letter from Jarek, who is in Poland coordinating support for families from Ukraine who have a child with Down-Syndrom.

Hi Friends,

here it goes some summary of today's situation:

SITUATION ON UKRAINE BORDER

- 1.Today Russians are doing everything to smash Ukraine.
- 2.They and their friends from Belarus push away Arabic refugees being in this country towards Ukraine/Polish border.
- 3.This situation makes a huge problem on the border slowing down people movement when the troops accelerate.
4. An hour ago there was information that generally the best way to escape from Ukraine is via Slovakia, Hungary, Romania now.
5. In Poland are now ca. 720 000 people from Ukraine and ca. 1 000 000 total out of Ukraine
6. It is said that we expect 5 000 000 refugees from Ukraine then in Poland 3 000 000.

UKRAINIAN SITUATION IN POLAND

- 1.There is massive scale support for Ukraine and people crossing the border
2. Due to this fact there are no goods in the shops, especially those easy to transport, to keep
- 3.There is no medicines, karimats, sleeping bags in the south part of Poland in distribution. You need to get out to very local places to buy something.
- 4.There is a shortage of petrol here as well. People from Ukraine escaping in that direction due to:
 - the most Ukrainian used to live and work here before the war
 - there are the biggest number families and friends
 - this is a road to Germany and far from Russia
 - everybody expects war between Russia and Poland (Nato)
5. In the cities alongside the border it is now humanitarian calamity due to massive number of the people, but they got stopover now there before they move forward.

6.Thanks to Tania and Ostap I am in touch with 11 families trying to come out of Ukraine. They want to go as far from Russians as possible.

7. Eliena who was supported in Warsaw wants now to escape to Leszno which is ca. 100 km north of Wrocław due to Russians. Warsaw seems too close for them.

8. In Poland there are still a lot of job opportunities. Helena, who is an English teacher, starts today to flee from Kharkov and got booked the work as an English teacher either in kindergarten or school.

... but they are the first.

SITUATION IN POLAND

1. Poland waits for Ukrainian. In my city used to live up to 300 000 Ukrainian before the war... and we may accept 50 000-100 000 more and then it will be full

2.The same situation will be soon in other places.

3. Polish government as EU countries are introducing some law simplifying status (not asylant but refugees), receiving health services, travel opportunities etc. free and access to work.

4. It will be full in Poland in 2 weeks time then....

5. We need to prepare Ukrainian people to go Western Europe

WHAT WE DO

1. There is no Polish wide DS-association.

2. We made a team with Małgosia (Gdańsk) and Andrzej (Wrocław) to start with. We add people from Warsaw, Poznań, Szczecin, Białystok, Dębica to cover as much as it is possible.

3. We planned to accommodate families as we with DS children...but we are just a few, and the financial status of our families for long term support is not good enough.

4. So it seems that we will be able to support up to 7-8 families with accommodation and for the rest we may support the DS children, with education when Ukrainian classes will be set up according to the new education bill.

5. We may be a center of redistribution of help to Ukraine and we are doing that by ourselves now.

GENERAL

I know that this is the first wave of people. Each next will be difficult, more difficult. Nobody thinks about what we should do next, giving as much emotions, strength to support the people of Ukraine now...but soon we will meet something that was out of our mind.

ACTION

Tomorrow I should collect all the people around and spread activities. Today is too much for me and I need to unload it. Up to Monday we should be ready with 2 trucks of help to send to Ukraine. We do not plan beyond but something must be done.

All the best, Jarek

EDSA statement on protection and safety of persons with Down Syndrome in Ukraine

Open letter to the Head of the European Institutions, European, Russian and Ukrainian Heads of State and NATO

26 February 2022

The European Down Syndrome Association (EDSA) calls for all parties to ensure the protection and safety of persons with Down Syndrome and other disabilities in Ukraine, by respecting:

- their obligations under the UN Convention on the Rights of Persons with Disabilities, in particular Article 11 on situations of risk and humanitarian emergencies
- the UN Security Council Resolution 2475 (2019) on Protection of Persons with Disabilities in Conflict
- International Humanitarian Law and the Humanitarian Principles.

In any situation of crisis or conflict, persons with Down Syndrome and other disabilities face disproportionate risk of abandonment, violence, death, and a lack of access to safety, relief, and recovery support. Women with disabilities are at increased risk of sexual violence and children with disabilities are more exposed to abuse and neglect. Crucial information on safety and evacuation is often inaccessible, and evacuation centres themselves are also rarely accessible, meaning that persons with Down Syndrome and other disabilities are too often left behind.

There are 2.7 million persons with disabilities registered in Ukraine. Our contacts in the country have confirmed that the situation for persons with disabilities is appalling. For example, shelters in Kiev are inaccessible, so people with disabilities are forced to stay at home, not knowing where they can go to be safe.

Persons with Down Syndrome and other disabilities living in institutions, are already cut off from their communities, risk being abandoned and forgotten.

We call on the political leadership and all humanitarian actors dealing with this crisis to ensure that persons with Down Syndrome and other disabilities:

- Have full access to all humanitarian aid
- Are protected from violence, abuse and ill treatment
- Are provided with accessible information about safety and assistance protocols, evacuation procedures and support

Page 1 of 2

- Have full access to all humanitarian aid
- Have full access to basic services including water and sanitation, social support, education, healthcare, transport and information
- Are accounted for and not abandoned: it is also essential that measures are in place which fully include people living in institutions or orphanages; and relocation and evacuation measures should not force more persons with disabilities to live in such institutions
- Are meaningfully involved in all humanitarian action, through their representative organisations

Along with persons with Down Syndrome particular attention must be paid to those who are most at risk – including women, children, blind and deafblind persons, persons with psychosocial and intellectual disabilities, and persons with high support needs.

Today we witness full scale conflict on European soil. With the escalation of the situation in Ukraine, the European Down Syndrome Association urgently reminds states of their responsibilities to ensure the protection and safety of all.

EDSA continues to monitor the situation, by remaining in contact with our members in the effected regions.

For more information please contact: info@edsa.eu

M. Sc. Dinka Vukovic
EDSA President
edsa.eu@gmail.com
www.edsa.eu
<https://www.facebook.com/edsachannel>
Mobile +385 91 153 9698

WDSO 2022 EDSA POSTER CAMPAIGN

World Down Syndrome Day 2022: Inclusion means ...



Since 2016 we prepare for the EDSA website a poster campaign to celebrate the World Down Syndrome Day. We collect among our members a picture and a text according the WDSO-slogan.

We always start the campaign on March 1st and show poster every day up to March 21st.

The slogans in the last years were: "My friends, my community (2016), "My voice counts" (2017), "Leave no one behind" (2019), "We decide" (2020) and "Connect" (2021).

If you want to have a look at those posters you can find them on EDSAs website: <http://www.edsa.eu/category/world-down-syndrome-day/>

In this year the slogan is "**Inclusion means**". The contributions of 23 associations came in time. Thank you all very much for your participation.

On March 1st we will start with the Ukrainian poster. As we received it, we lived in a better world. Sadly things have changed since then. The statement to the picture is: **Inclusion means that there will be a place for you in the team.** Here the football team is meant.

BUT ... the Ukrainian DS Association will also keep their place in the EDSA team!

WDSD 2022 – EDSA MEMBERS' INITIATIVES



17th colloquium on Trisomie 21

Paris, March 19 2022 – 17th colloquium on Trisomie 21 for the 16th World Down Syndrome Day

The french organization AFRT and the national and local associations organize a one day conference in Paris on March 19 2022, in person (Université de Paris, site des Grands Moulins Amphitheatre 3B) and in videoconference.

Topics

Health and Research : New tools in genetics for intellectual disability ; obesity and environment ; immunology-COVID19 and trisomy 21 ; treatments for intellectual disability.

Inclusion and day living : two round tables

Round table A : Tools for communication : values and risks

Round table B : living at your home without being alone

An important place will be given to the inclusion process with a presentation by Denis Piveteau (State consellor) and some presentations of livings (« Bon secours »Arras, « AppartAsoi »

The program as well as the online register forms are available on the AFRT website : <http://www.afrt.fr> or by mel : afrt@univ-paris-diderot.fr

[View program \(PDF, French\)](#)

ICOD- Project – Improving Cognition in Down syndrome



On the occasion of the World Down Syndrome Day and in the framework of the H2020 EU-funded ICOD (Improving Cognition in Down Syndrome) project, the partner members organize the first ICOD symposium in collaboration with the Italian Task force for DS.

The objective of the event is to offer people with DS and their families the most recent and innovative approaches in the diagnosis and treatment of cognitive deficits in DS.

The symposium will be held in Troina from March 20th to 21st, 2022 and will be aimed at sharing knowledge about innovative therapeutic approaches in the management of cognitive deficits in Down syndrome.

The event will be run in a mixed modality a combination of in-person (in compliance with anti-Covid regulations) and online participants (Zoom platform).

The first ICOD symposium was conceived to give a response to the unmet needs of DS families on the topic of cognitive dysfunction. Considering the great impact that these deficits have on the daily life of people with DS and their families, it is particularly relevant for our consortium, led by Prof. Rafael De La Torre, to focus on this topic on March 21, World Down Syndrome Day.

The scientific event was designed to ensure whole sessions dedicated to families and associations who will have the opportunity to interact directly with both the scientists involved in the ICOD project and with other researchers working in this field.

[See the program of the symposium \(PDF\)](#)

More information about the project: <https://www.icod-project.eu/>

EU FUNDING OPPORTUNITIES



European Youth Together

The **European Youth Together** action targets youth organisations at grass-root level which want to establish **partnerships across borders**, i.e. which aim at adding a European dimension to their activities and at linking these activities to EU youth policies, most notably **the EU Youth Strategy 2019-2027**.

The European Youth Together action consists of two parts (two sub-actions).

1. The **first sub-action** targets youth organisations at grassroots level which want to establish partnerships across borders, i.e. which aim at adding a European dimension to their activities. The purpose is to encourage new applications from organisations that are not already well established at European level.
2. The **second sub-action** is the large-scale partnerships action. It targets youth organisations, which have the capacity to work together in large-scale partnerships.

Specific Objectives

- The promotion and development of more transnational structured cooperation, online and offline, between different youth organisations to build or strengthen partnerships focusing on solidarity and inclusive democratic participation
- The implementation of EU Frameworks and initiatives
- To encourage young people to participate in the democratic process and in society by organising trainings, showcasing commonalities among young Europeans and encouraging discussion and debate on their connection to

the EU, its values and democratic foundations, including by providing a meaningful voice to youth in the framework of the Covid-19 recovery process

- Promote participation of under-represented groups of young people in politics, youth organisations and other civil society organisations by engaging vulnerable and socioeconomic disadvantaged youth.
- New ways to empower youth organisations in dealing with the Covid-19 pandemic and its aftermath
- The reinforcement of the European dimension of the activities of youth organisations, including activities on how to live better together after the pandemic and helping to design sustainable future ways of living transnationally.

Who can apply

- NGOs (including European Youth NGOs) working in the field of Youth;
- Public authorities at national, regional or local level;
- legally established and located in an EU Member State or third country associated to the Programme.

Eligible participating organisations

Any organisation, public or private, with its affiliated entities (if any), working with or for young people outside formal settings established in an EU Member State or third country associated to the Programme.

Public or private companies (small, medium or large enterprise (including social enterprises) may be included.

For sub-action 1: Minimum of 4 partners from at least 4 EU Member States and third countries associated to the Programme. At least half of the organisations in the consortia should not have been recipients of EU funds from the Erasmus+ Programme in Key Actions 3 – European Youth Together projects in the previous 2 years.

For sub-action 2: It targets organisations, which would propose projects involving at least 5 partners from 5 EU Member States and third countries associated to the Programme, which have the capacity to mobilise young people in partnerships covering different countries and regions within the EU Member States and third countries associated to the Programme.

Eligible activities

- Mobility activities for young people should form a key component of European Youth Together projects. This mobility should offer cross-border exchanges and non-formal or informal training opportunities for young people from across Europe (East, West, North and South) that can be prepared and supported through online fora to contribute to the objectives of this action;
- All the activities should contribute to broadening the outreach towards youth, reaching young people both within and beyond youth organisations including youth with fewer opportunities, to ensure a diversity of voices is heard.

Project duration: 2 years for both sub-actions. The activities must take place in the EU Member States and third countries associated to the Programme.

Budget: This action follows a lump sum funding model.

Sub-Action 1: Maximum EU grant per project is EUR 150,000.

Sub-Action 2: The minimum grant per project is EUR 150,000 and the maximum cannot exceed EUR 500,000.

Where to apply

To the European Education and Culture Executive Agency (EACEA).

The same organisation can submit only one application by the deadline.

[Call ID: ERASMUS-YOUTH-2022-YOUTH-TOG-1](#)

[Call ID: ERASMUS-YOUTH-2022-YOUTH-TOG-2](#)

Deadline: 22 March 2022, 17.00 (Brussels time).

Find out more [here](#).

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

phone: 0039 06 3723909

e-mail: internazionale@aipd.it

THE STAFF

Carlotta Leonori

Paola Vulterini