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EDSA AND OUR UKRAINIAN FRIENDS



“A friend in need is a friend indeed,” says a well-known proverb.

Since the war started in Ukraine, I have the feeling that we have many friends in the whole world. For me personally, it was very important that EDSA shared an official statement of its position regarding the situation in our country. At that chaotic time, I needed a clear position of some people that were important to me.

Since the beginning of the war, every day brought many changes: Many people moved to the Western part of Ukraine and even more of them wanted to move abroad because of the safer situation for them and their children. There were a lot of worries and fears.

It has been very difficult to make the right decision not only for me but for two small children, considering that one of them has Down Syndrome. I couldn't dare to leave my home for a few days, because of the uncertainty. Since the first day of the war, we were in contact with Cora Halder due to some organizational issues of EDSA regarding the help to families with children with DS. But one day, Cora wrote me that I had to think about my own children and look for a safe place for them. She invited my children and me to her home in Germany and offered us her full support with registration and other official procedures, by sourcing an inclusive kindergarten for my little Ivanka. Only this invitation helped me to make a decision to leave my home near Kyiv, because I understood where we were going and where we could stay. We drove with a paid private car to the border.

Jakub Suchoski met us at the Polish border. That was organized by the two DS organizations in Poland in coordination with EDSA. We stayed in the house of his family for some days. Then we got bus tickets to Berlin, bought by Jarek Pieniak from DS-Razem in Wroclaw. Money came through EDSA, from other DS organizations.

We moved to Berlin and stayed there at Bernd and Nele Ronacher's place, friends of Cora and active in DS Berlin, as well as at Barbara's place. In each family, we had a lot of help, a warm atmosphere, and kind words of support. We became free train tickets from Berlin to Nürnberg And finally, we came to Cora. She has taken the lead in all paperwork and solving organizational issues. Now, we have a separate

cozy apartment, Ivanka visits a great inclusive kindergarten, and all needed official procedures are done. Cora's family members support us in all other life issues.

It's really great to have so many nice people with great hearts in different countries and cities, who understand our pain and needs, who give us their time, thoughts and empathy. I'm very thankful to all our friends from the different DS associations for their kind support.

Elena Bolshanina

Ukrainian Down Syndrome Organization



Dear Edsa Member,

Hope all is well!

The EDSA transfer of 4,000 euros was distributed to families who have not yet received financial assistance from other sources, as well as to those in difficult circumstances.

Thanks to you, we provided assistance in the amount of UAH 3,470 for 29 families. These are residents of Kherson city, Kherson, Mykolaiv and Vinnytsia regions. Also, part of the funds was directed to pay for fuel to volunteers involved in humanitarian aid.

Speaking of supporting these families, we want to point out how important it is. Especially for 16 families from Kherson and the region. Since the beginning of the war, food prices have risen, but in Kherson they have become 5-10 times higher than in other regions of Ukraine. The city has been under Russian occupation for

more than two months. The last two weeks there have been bad internet, tv, phone connection, only now we have now learned that the city is disconnected from Ukrainian radio, television, mobile and partly Internet channels. It was not easy to get in touch with those who asked for help before the transfer of funds, but the work of the banking system allowed them to receive the necessary support. And we thank you for this opportunity.

Here is a little more information on the current situation:

Our created questionnaire works. It has already been filled by more than 600 families who have children with Down Syndrome. Additionally, we also provide humanitarian aid and medicine.

Thanks to you we were able to support more than 450 families who needed support. Not only direct financial help, but online classes and psychological support helps people to overcome obstacles, difficult living conditions and stay strong. People feel that they are not alone and that brightens their day. All that wouldn't be possible without your support.

However, there are some updates. The economic situation in Ukraine gets worse, gas prices are drastically going up which leads to increased cost in basically all the necessities from food to clothes. Additionally, deteriorating situation doubles due to the fact that businesses are failing to find new clients, as ports in Odessa are blocked - we are unable to export what we can, therefore there are not enough jobs and the whole economy is feeling it.

Despite this situation, Ukrainians are trying to support each other, and we are not an exception. Currently, 150 families are waiting for a financial assistance (these families have sent all the necessary documents for payments). There are as well some other families who are in the process of providing documents. We are constantly looking for finances and are counting on you, on your financial support.

Thank you again for your help and support.

Kind Regards,
Pavliuk Tetiana

Ukrainian Down Syndrome Organization's Vice President

EU FUNDING OPPORTUNITIES

Call for proposals for NGOs launched to support mental health of Ukrainian refugees



A € 2 million call for proposals for non-governmental organisations has been launched on 20 April to support mental health of displaced people from Ukraine. Proposals will implement best practices to improve mental health and psychological wellbeing in migrants and refugee populations, with a special focus on Ukrainian displaced people. Deadline to submit proposals is 31 May. More information on the [Funding and Tenders Portal](#).

This action is funded under the [EU4Health](#) Programme and will be complemented by an agreement with the International Federation of Red Cross Societies to provide mental health services in the form of psychological first aid, triage, psychological trauma support and counselling to refugees in their own languages. Commissioner for Health and Food Safety, Stella **Kyriakides**, said: *“Russia's brutal aggression in Ukraine has laid bare the horrors and scars of war. It has forced millions of innocent people, many of them children and vulnerable, to flee the only homes, lives and livelihoods they have ever known for a path of uncertainty. We must offer essential mental and psychological support to all those who need it. With this additional funding, we will ensure that this assistance is quickly provided on the ground with the help of our partner organisations. It is also a tangible example of our commitment to supporting Ukrainian refugees as they start to rebuild their lives.”*

NEWS FROM EDSA MEMBERS

DOWN SYNDROME CZ

DownSyndrom.cz



A Czech family created this video specially for this year's WSDS "Inclusion means ..." campaign!

Inclusion means there is no difference in the way people look at you.

Main character of this video is Tonda. The video was made only by his friends from scout unit.

They look at him in the same way as they look at each other.

<https://www.facebook.com/edsachannel/videos/1214357712671618>



Brain Train: Smart actions that might boost cognition and prevent Alzheimer’s disease in people with Down syndrome

The 27th of April this webinar was held and the speaker was Dr. Skotko, the Emma Campbell Endowed Chair on Down Syndrome at Massachusetts General Hospital.

It wasn’t a presentation about supplements or nutraceuticals. Instead, Dr. Skotko provided a set of actions that caregivers can take that might improve the long-term wellness for their loved one with Down syndrome.

As unfortunately the webinar could not be recorded, so it is not available on you tube, here are some useful materials for both those who participated and those who could not attend.

You can find a handout of his talk:

<https://protect2.fireeye.com/v1/url?k=31323334-501d5122-313273af-454445555731-43d9b6cdf96b1ffd&q=1&e=2ee5e353-78cd-4015-9b97-1d4d5beb3304&u=https%3A%2F%2Fdrive.google.com%2Ffile%2Fd%2F1-zgKM097AbmZMLRnjTlx8w89qHtMgkbQ%2Fview%3Fusp%3Dsharing>

and a link where you can access all of his in-depth videos:

https://vimeo.com/ondemand/downsyndromebraintrain?fbclid=IwAR21nEfEkBuxX38H1phkiA68twoCScZLZSMIDjcWyyxOx_gfKltL_fRs2Xo

Read more: www.downsyndromebraintrain.com

OPPORTUNITIES FOR EDSA MEMBERS



Dear Edsa Members,

I am a violin teacher with nearly 15 years of experience. For more than two years I had the chance to teach violin to children with down syndrome, first came Cosmin and then Yannick. Those two years have been life changing for both of my students and I. My enthusiasm toward teaching violin to down syndrome children even brought me to publish (in print as well as online) a piece in the UK based world reference string instruments magazine, The Strad. Here is the link to the article: <https://www.thestrاد.com/debate/opinion-to-speak-plainly/14103.article>

At first it might seem unlikely that a person with down syndrome learns how to play violin - probably the most difficult music instrument - but they do, and do it well. Not only have I seen my students learning how to read music, play and memorise a dozen different songs but I have seen their aggressiveness and sometimes restless temperament disappearing totally. Their parents told me how their children can focus and communicate better, do better at school and feel less frustration overall. Moreover, I am teaching online, which in many ways is even better for children with down syndrome as they feel safe and well in their home; an environment they know well.

I am working with a small music school in London, the Hope Music Academy (<https://hopemusicacademy.co.uk/>). I am writing to you because I would like to teach and nurture the talent of more children with down syndrome and I was wondering if it was something we could work on together.

Let me know if you would like to set up a zoom meeting to discuss it further.

I look forward to hearing from you,

Jacqueline

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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