

## SUMMARY

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### **Coronavirus and Europeans with Down syndrome: news from EDSA members**



ASSOCIAÇÃO PORTUGUESA de  
PORTADORES DE TRISSOMIA 21

#### **PORTUGAL (Fernando Ferreira)**

Since 12th of March, the professionals are working from home and our kids (users) with ID are on online school so we spend some time working in the computer to help them out and we try to do online sessions with them and the parents.

Not all children accepted this routine change and are not so motivated for the intervention, but most have adapted very well to online support. At the national level, not all early intervention teams have been able to provide systematic support.

Parents are making a great effort to reconcile all tasks, child support, telework and household chores.

APPT21, has continued its work, responding to parents' requests. It will reopen on 18 May, gradually, only with urgent medical consultations and evaluations and we will gradually open to the rest of the departments.

## GERMANY (Cora Halder)

Perhaps this is helpful for the German situation: the text of Dr. Hammersen, the medical doctor, specialist for DS and the one we work with a lot just wrote to all speakers who were invited to Sarajevo Conference (now canceled) in this issue

*Since the German statistics about COVID 19 don't register Downs Syndrome (DS) as a separate entity in addition to COVID 19 there are only few anecdotal data about patients with DS and COVID 19. It has been speculated that in children with DS the clinical course and risk of COVID 19 might not be different from other airway infections; but there aren't enough data to draw any conclusions yet.*



## ROMANIA (Liana Maria Vislan)

During these days that completely change the way we live, the services of Asociatia Langdon Down Oltenia Central Educational Teodora, ALDO-CET, are psychically closed but they are open on-line.

Together with our members and friends, we learn that there are new ways to stay connected to each other. We all experiment how to use ICT tools that allow us to be close to our families and to those interested even from a distance. And we have enough time to work on the design of our website, Facebook and to open an YouTube channel.

Our group is accustomed with unforeseen situations! Over the time, we have learned to immediately find solutions to the unexpected and to build up a plan so that we remain a compact, united and cheerful group.

At the beginning of March, we banned the hugs and we started wearing disposable shoes in the center. The last face-to-face meeting was on the 10<sup>th</sup> of March and by mutual agreement, we decided to stay active at home.

It was difficult, because we had to face an avalanche of questions from our users with Down syndrome and to keep our presence of mind to maintain the emotional balance of all. We had to explain why we no longer see each other; for how long; how to be active at home, how to stay together virtually and not lose our friends. We remember this day because everyone was sad, worried, some cried and it seemed like no one wanted to go home ...

In 2016, our association has started the e-literacy of our users with Down syndrome and of their parents. Trainings in the use of ICT tools has become a practice in our activities. At that moment, it was very difficult to convince parents to participate in these courses and to make them believe in the training usefulness, but now we have at hand the saving solution.

We do not use the term "isolation" and yet, no matter how active we are, many of us have begun to feel the pressure of the same walls.

ALDO-CET decided to keep in touch daily with the users, and therefore many activities are developing on the electronic environment.

We designed the program "**Home Station 2020**", which has six components:

**COVID-19** - It is good to know what safety measures we should take to prevent coronavirus infection. People with Down syndrome can find out useful information about this virus by watching the video we made for this purpose.

**WDSD** - We have cancelled all the public events dedicated to World Down Syndrome Day, but we participated in EDSA Poster Campaign and we invited our people to wear colorful socks and to spread the word.

<https://www.sindrom-down.ro/ziua-mondiala-sindrom-down-2020/>

We also invited them to make their own flash mob at home, using the music proposed by AIPD for the European flash-mob initially planned. Here is a collection of some videoclips at home.

<https://www.facebook.com/InfoSindromDown/videos/pcb.506936036859925/202373804421161/?type=3&theater>

**THE VIDEOCLIP OF THE DAY** - ALDO-CET develops a collection of materials that exemplify activities that people with Down syndrome perform at home in order to continue their personal development, to practice their autonomy skills and to maintain their physical and mental health. Our professionals provide the private group with videos exemplifying specific elements of intervention, which people practice, as they can, at home. We invite the families to make a videoclip with a specific activity and then publish it. The joy of people is huge when they can see their own person in public posts and of course, they can have fun with what was good and what was not. We put together some videoclips with the same theme in one movie and that was a huge success.

Here are few examples.

<https://www.youtube.com/watch?v=LLq6S860A6I>

<https://www.youtube.com/watch?v=QoPaCvHRB-Y>

<https://www.youtube.com/watch?v=QFiZyiEqjrk>

The general public can find all the topics and videoclips on the association's webpage or Facebook page:

<https://www.sindrom-down.ro/videoclipul-zilei/>

<https://www.facebook.com/InfoSindromDown/>

**THE PHONE RINGS** - we encourage and support our people with Down syndrome and their parents to call someone from the association every day. We organized a private discussion group on two communication channels, and every Sunday afternoon we organize a video call, to which we invite all the people and parents. Of course, at the time and the date proposed by us, some are available, others are not, but this is exactly what keeps the desire to see each other again and to use the phone.

**THEME OF THE DAY** - every day we give a work theme online. It is aimed at our users, but often the help of parents is needed in order to solve it. And even if some fail to perform the exercises, we all know that we will discuss these topics when we resume our work at the center. These topics are correlated with the e-learning platforms we have developed, which can be accessed by visiting the association's website:

[www.sindrom-down.ro](http://www.sindrom-down.ro)

We now work on healthy lifestyles and obesity prevention, and those interested can find the whole course by accessing:

<http://www.sindrom-down.ro/proiecte/>

<http://www.healthyds.eu/index.php?r=website/welcome&lang=ro>

and online games

<http://www.healthyds.eu/index.php?r=site/shoppingGame&unit=1>

Our people also have fun with the ICT tools developed in the framework of DS LEISURE project and we made available a public guide <https://www.youtube.com/watch?v=V619wOgmX5M&feature=share>

## What is happening around Europe

1. **Employment for all awards**, by the European Association of Service providers for People with Disabilities



[Employment for all awards booklet](#)

2. **1st of May**, International Workers day: **Two European campaigns** to claim the right to work of people with Down syndrome and of all people with intellectual disabilities.

- a. **#iwantwork, BY THE VALUEABLE NETWORK**







## b. EXPERTS IN OVERCOMING

On 1st of May, with the occasion of the INTERNATIONAL WORKERS DAY, ALDO-CET launched the "EXPERT IN OVERCOMING" campaign. The campaign was proposed by ASINDOWN SPAIN with the participation of 17 entities from different places and countries in Europe. Each participant develops the campaign in its own way.

ALDO-CET aims to bring to the attention of Romanian society the rights of people with intellectual disabilities and the social inclusion of adults with Down syndrome after the health crisis caused by COVID 19.

This is a poster campaign in which we present a legal provision versus the real situation in the country, supported by a photo of one of our users and one foreign user.

People with functional diversity are fighters for life. Since they were born, they overcome barriers, trying to grow and evolve at the pace required by society, because they want to live in a society without bias, on equal terms with others.

THEY ARE EXPERTS IN OVERCOMING!



<https://www.sindrom-down.ro/expert-in-depasire/>

Oamenii cu sindrom Down cer un rol activ în depășirea dificultăților sociale pe care le va prezenta "noua lume" după coronavirus.

**EXPERT ÎN DEPĂȘIRE**

Oamenii cu sindrom Down sunt experți în a da strălucire vieții, în motivație și în improvizatie. Ei își doresc să aibă o viață activă și să muncească.



## News from Down Syndrome International

Want to know more about COVID – 19 and Down syndrome in the world?  
Click on the link of Down syndrome International about COVID 19?

<https://www.ds-int.org/pages/category/coronavirus-information-updates>

## Funding opportunities from the European Commission

### CALL FOR PROPOSALS VP/2019/016

Call for proposals to promote and protect the rights of persons with disabilities

<https://ec.europa.eu/social/main.jsp?catId=629&langId=en&callId=596&furtherCalls=yes>

The **objectives** of this call are to:

- promote the collection, exchange and dissemination of innovative good practice for the promotion and protection of the rights of persons with disabilities and for their active inclusion and full participation in the society taking into account socio economic trends such as the ageing of the population and digitalisation.
- **fill in data gaps** related to the situation of persons with disabilities in specific areas such as for example on deinstitutionalization and independent living, social protection, education, accessibility markets or assistive technology service delivery.

The types of **activities** that may be funded under this call for proposals include:

- **studies**, researches, analyses, surveys, evaluations, collection of data and statistics; development of common methodologies and, where appropriate,

indicators or benchmarks; elaboration and publication of guides, reports and educational material;

- **mutual learning**, peer reviews, workshops, experts' meetings and conferences;

- **training activities**, train-the-trainer events and the development of online training tools or other training modules;

- **awareness-raising and dissemination** activities, such as the identification of, and exchanges concerning, good practices, innovative approaches and experiences; media campaigns; compilation and publication of materials to disseminate information about the Programme and its results; the development, operation and maintenance of systems and tools using information and communication technologies. Proposed actions should be creative and propose innovative measures whilst building on existing good practice where relevant. The instrument or combination of instruments proposed should be adequate to address the issues at stake and be targeted to achieve the objectives set.

## 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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