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BREAKING NEWS



COVID-19 and Down syndrome

Wednesday, 15 December 2021, 17.00 CET, per Zoom

Speakers: Bianca Streng and Regina Lamberts

Registration: https://us02web.zoom.us/webinar/register/4116387816755/WN_h8rn2v5KTr6mMI5ynsxvpw

Individuals with Down syndrome are at risk for severe COVID-19 disease resulting in a higher hospitalization rate and increased mortality. The older population in particular are at highest risks. The increased risk of severe COVID has a major impact on day to day life, resulting in restrictions and in some cases voluntary quarantine in order to avoid being infected.

Vaccination is important to protect this high risk group, but the impaired immune system in persons with Down syndrome might affect the effectivity of COVID-19 vaccines. Until now, the immune response to COVID-19 has not been investigated in people with Down syndrome.

In this webinar we will give a brief overview of the immune system in Down syndrome and of course, show the first results of the PRIDE study about the antibody response after COVID-19 vaccination in adults with Down syndrome. Besides this we will highlight the experiences of people with Down syndrome in this uncertain times, how did they cope with the COVID -19 pandemic and restrictions? The PRIDE study is supported by ZonMw, the medical branch of the Netherlands Organization of Scientific Research (NWO).

Biography



Regina Lamberts

Regina Lamberts is the Director of 'Stichting Down Syndroom', the Dutch Down Syndrome Foundation, member of the EDSA. Regina is a psychologist and, in addition to being a director, she is also an expert in the field of Down syndrome. From the start of the pandemic, Regina has collected information about corona and Down Syndrome. The Down Syndrome Foundation is at the center of the Downs community with regard to providing information on this subject.



Bianca Streng

Bianca Streng is a Medical Doctor and PhD candidate working in the respirator viral research group led by Louis Bont at the Wilhelmina's Children's Hospital (WKZ) of the University Medical Center Utrecht, the Netherlands. Under supervision of Dr. Joanne Wildenbeest, she has led the PRIDE consortium investigating the immune response of individuals with Down syndrome after COVID-19 vaccination, including premature aging of the cellular immune system.

EDSA AGA 2021



EUROPEAN DOWN SYNDROME ASSOCIATION

To all edsa members,

by clicking on the following link

https://drive.google.com/file/d/1N5O_iTAbF5B_WKQvluTMRtmduycwovmU/view?usp=sharing

you can read the minutes of the last aga!!

GOOD NEWS

France's First Public Official with Down Syndrome Helps Everyone See Disability Differently



In the town of Arras in northern France, the country's first ever appointed official with Down syndrome is leading from the front, changing hearts and minds and bringing a new perspective on mental disability.

In 2020, Éléonore Laloux was appointed municipal councilor of Arras under the mayor Frédéric Leturque, for which she has received continual praise for her colorful nature, her insatiable desire to make people smile, and for promoting the inclusivity of disabled persons in society.

On October 15th, Ms. Laloux was awarded membership of the National Order of Merit, the second highest civilian honor roll in the country.

"Inclusion isn't something that we just think about; it's not a generous act. It's our duty," Mayor Leturque [told the Christian Science Monitor](#). "Éléonore has helped the entire town progress in terms of how we see disability."

Along with holding down a part-time job at a hospital, a packed volunteer schedule, and a board position on Down Up, a nonprofit her father launched to support community members with Down syndrome and their families, Laloux has made numerous adjustments to everyday community features in Arras to support disabled people; not exclusively those with Down syndrome, but other forms as well.

Arras' famous town center, town hall, and belfry are a UNESCO Heritage Site, and for those who can't ascend to the top, Laloux organized and commissioned the creation of a virtual tour.

Down below, crosswalk lights now sound off verbal instructions for those who can't hear or see. She has also scheduled an "includathon" for next summer, an event to inspire disabled people and the community at large through sports and culture.

"I'm a very committed and dynamic person, and I like to be out working with people," said Ms. Laloux, who in 2014 wrote a book which roughly translates to *Down Syndrome, So What?!*

Perhaps unsurprisingly, this upbeat attitude has made her a very popular figure in town and country, and [she has made numerous television and other public appearances](#), including alongside many national politicians and cabinet members. But her appointment is by no means a gimmick to gain support from sensitive constituents; she's made some brilliant changes in civil life.

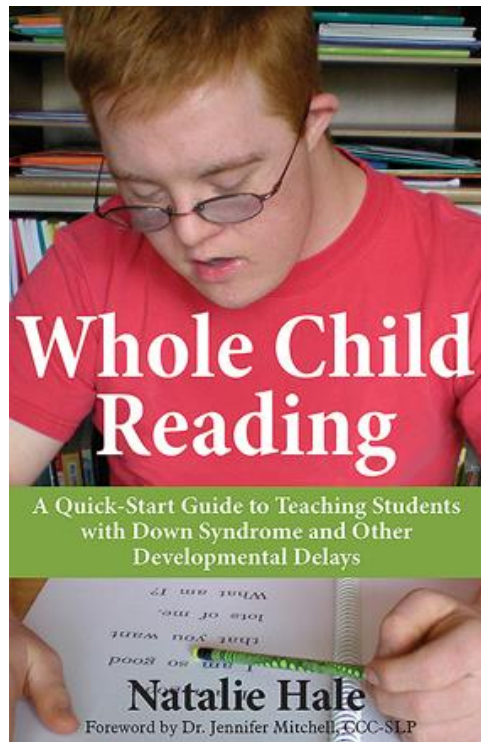
One such accomplishment is opening Arras to a Dutch method of civil society called "the Nudge" a sort of "c'mon then," to the community to get them to treat it better. Nothing could better represent this than putting small imitation basketball hoops over public trash bins.

She's continued her activism on behalf of those with Down syndrome, with her "Friends of Eléonore," foundation, even during public life, and argues vociferously against those with a limited understanding of the capabilities of disabled persons.

BOOKS REVIEW

Whole Child Reading:

A Quick-Start Guide to Teaching Students with Down Syndrome and Other Developmental Delays



Discover the keys to teaching children and adults with Down syndrome and other developmental disabilities how to read for meaning. Written for today's busy parents and teachers, this easy-to-use guide explains how to “go in through the heart” to hook beginning and struggling readers with high-interest, individualized materials—flashcards, personal books, and modified trade books. The simple strategies described are designed to “teach to the brain” and are based on research about how we learn most easily and naturally.

The methods in the book can be adapted for learners of any age who are reading at a third grade level or below. One of the main strategies is “Fast Flash,” which involves making flash cards of the words the child is learning and then showing them to him or her as quickly as possible. Another strategy is “Sandwich Style,” a motivating method of alternating fun reading activities with less-fun, but equally important ones.

The crux of the instructional method described in **Whole Child Reading** is to teach the child to sight read for content before focusing on phonetics. The book emphasizes providing new or struggling readers with books that are intensely interesting to them about topics they love in order to get them excited about reading. With the help of plentiful illustrations, author Natalie Hale explains how best to motivate new readers using a combination of home-made and adapted materials.

Whether or not you have any formal teaching experience, you can easily work the reading activities described in **Whole Child Reading** into your child's routine at

home. If you have at least five minutes a day to spend on reading, you have enough time to get started using **Whole Child Reading!**

Written by Natalie Hale

[Natalie Hale](#) is the mother of an adult son with Down syndrome. A national speaker on the topic of teaching reading to learners with Down syndrome for the last 24 years, she founded Special Reads for Special Needs in 2000. She lives in Los Angeles and continues to travel, speak, and teach across the United States and abroad.

SURVEY



The InCARE project will contribute to the design of a coherent and coordinated approach to the development of national long-term care policy and care services at local and regional level, by establishing socially innovative and participatory decision-making processes.



Join the survey: https://lse.eu.qualtrics.com/jfe/form/SV_6nc3RoO51iB0Bng

The InCARE project aims to promote participatory, innovative and integrated approaches to long-term care (LTC) policy and service development. InCARE emphasizes four key aspects for system sustainability and innovation capacity:

- Multi-stakeholder cooperation;
- Community engagement;
- Evidence based decision-making;
- Capacity building through mutual learning.

We propose social innovation in LTC should reflect the aspirations and needs of older people with functional or cognitive impairment and their caregivers, while emphasizing the role of local communities and service providers to shape care

service delivery in innovative ways, facilitated by national policy-level support for adapting, adopting and enhancing these initiatives.

InCARE includes two main types of activities, built around the structure of a Theory of Change process:

1. **Formative research** tasks in support of policy processes (creation of knowledge base; policy toolkit; participatory decision-making)
2. The design, implementation and evaluation of **socially innovative long-term care service pilots** in 3 European countries: Austria, North Macedonia and Spain.

InCARE will provide proof of concept for a road-map to inclusive LTC system development, promote multi-stakeholder national and international partnerships and support LTC policy processes and reforms.

Read more: <https://incare.euro.centre.org/about/>

EMOTIONAL WELLBEING



Emotional wellbeing is about how we think and feel and how we cope with life events. It is also about how we deal with our own emotions as well as those of others.

We have produced a range of resources to help parents, supporters and people who have Down's syndrome to support emotional wellbeing.

We hope the resources will help people who have Down's syndrome to feel good about themselves and give them ways of coping when life is challenging.

<https://www.downs-syndrome.org.uk/about-downs-syndrome/health-and-wellbeing/emotional-wellbeing/>

EU FUNDING OPPORTUNITIES

Erasmus+ Programme Guide



The Erasmus+ Programme Guide is essential to understanding Erasmus+. It provides participating organisations and individuals a comprehensive list of opportunities supported by the programme.

The 2022 Programme Guide is available as an [online version](#), with a more user-friendly, accessible format to make it easier to find information, as well as a [PDF version](#).

What is it?

The [Erasmus+ Programme Guide \(version 1 of 24/11/2021\)](#) is an integral part of the [2022 Erasmus+ Call for Proposals](#), published on 24/11/2021.

Organisations and institutions seeking funding in the framework of this call must comply with the conditions for participation and funding expressed in this Guide.

The document provides information on

- the priorities of the programme
- the actions supported
- the funding available for different actions
- detailed information on participation

How to apply?

Organisations are invited to submit applications online to the [National Agency](#) in the relevant country, via the [Erasmus+ forms website](#), or to the [European Education and Culture Executive Agency](#).

For actions managed by the European Education and Culture Executive Agency (EACEA), the relevant documents by action are open for submission on the [Funding and Tender Opportunities Portal](#).

Individuals seeking to apply should contact their organisation, institution, or educational establishment.

Where to find out more?

Organisations seeking further information on the process can contact their [National Agency](#), [National Office](#) or the [European Education and Culture Executive Agency](#) in Brussels.

NEWS FROM EDSA MEMBERS

UKRAINIAN DOWN SYNDROME ORGANIZATION



Ukrainian Down Syndrome Organization with the support of the Ukrainian Cultural Foundation conducted an information campaign "Music is important. Music is possible." Its purpose is to inform society about the capabilities and talents of children with Down syndrome.

An experimental music art-therapeutic online group worked as part of the information campaign. It involved 16 children – those are children with Down syndrome and their siblings. The youngest member of the group is 4 years old, the oldest ones are 14. Classes were joined by children from different regions of Ukraine (except Kyiv and the region): Ternopil, Nikopol (Dnipropetrovsk region), Arbusynka (Mykolaiv region) and Poltava. Psychologist Yulia Holovata, correctional teacher Olga Lisnenko, music teachers Valeria Brovko-Divyna and Yulia Myronchuk worked with the children.

In addition, as part of the campaign, Valeria Brovko-Divina, a music teacher at Down Syndrome Organization, wrote pedagogical recommendations for music lessons for children with Down syndrome. Psychologist Yuliya Holovata and correctional teacher Olga Lisnenko were consultants during the writing of the manual.

This guide will be useful for both music teachers and those who want to do music with children with the syndrome. It is written in accessible, simple language, so no special education is required to use it. These materials are valuable primarily because they have been written by teachers who have been working with children with Down syndrome for more than 10 years. They summarized all their experience and included it in this manual. Equally important is the fact that professionals have experience of the online work, so the manual is relevant in today's environment. The manual is in free access!

Link for the manual — <http://downsyndrome.org.ua/wp-content/uploads/2017/10/Znajomstvo-ditej-iz-sindromom-Dauna-z-muzikuvannyam.pdf>

The project "Music is important. Music is possible" is the information campaign, so special attention was paid to informing the public about the possibilities and talents of people with Down syndrome to make music, and take it seriously. In order to convey these messages to as many people as possible, the project actively collaborated with the media – TV episodes, radio broadcasts, articles in online

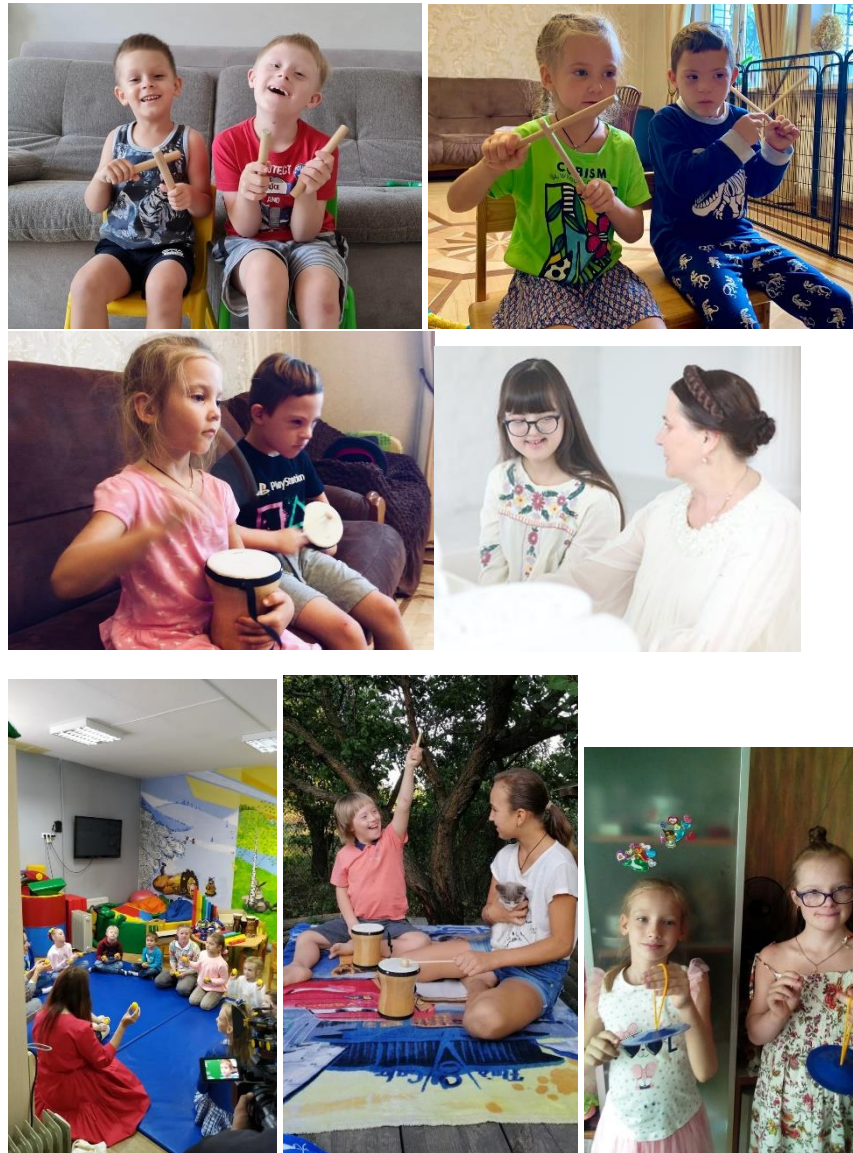
publications, interviews. In addition, 2 social videos were created. One of them has already been viewed on social media by more than 300,000 people, and the other has been broadcast on 25 TV channels, including both central and regional ones.

Link for the video [Facebook](#) / [YouTube](#).

Another channel for spreading important messages was [social posters](#), which could be seen by over than 1 million residents of 26 Ukrainian cities.

Group classes, interaction with the media, the process of creating a social video, stories of children and adolescents with Down syndrome, who are engaged in music, – such topics were actively covered on our social media pages – Facebook and Instagram. After all, it was important to convey to the whole society that children with Down syndrome have the creative potential and all the talents to make music. That they are like other children in their ability to make music. The creators of the project can confidently say that during its implementation they discovered a lot of new things and, judging by the comments and feedback of those who followed the project, they also made their discoveries.

The global goal of such projects is to overcome all the prejudices in society about the abilities of children with Down syndrome.



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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