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BREAKING NEWS FROM EDSA

EDSA-Webinar with Frank Buckley, Gert de Graaf.

Date: **Wednesday, 17 March 2021**, 17.00 h. CET, per Zoom

Registration:

https://us02web.zoom.us/webinar/register/WN_oHqR1IP6RICCISQYsh008A

Estimation of the number of people with Down Syndrome in Europe

How many people with Down Syndrome live in Europe as a whole, and how many in the different European countries? What is their **age distribution**? How have changes in survival rates influenced the numbers alive? What is the **effect of prenatal testing** and **selective terminations** on the number of live births of children with Down Syndrome? Is the number of people with Down Syndrome alive **decreasing** due to selective terminations? And, how do individual European countries compare?

In their study „**Estimation of the number of people with Down syndrome in Europe**“ the authors **Gert de Graaf** (Netherlands), **Frank Buckley** (UK) and **Brian Skotko** (USA) worked on data from 1901 until 2015.

They have stitched together registries across Europe to calculate a country-by-country estimate of the number of people with Down syndrome, the number of selective pregnancy termination because of Down syndrome, and the impact of such terminations on birth prevalence and population prevalence.

In our webinar Frank Buckley will give a talk on these very interesting and important issues. Both he and Gert de Graaf will answer questions after the webinar.



Frank Buckley is the CEO of Down Syndrome Educational International, UK and Down Syndrome Education USA. Since 2007, Frank has prioritized scientific research that promises to deliver near term benefits, and expanded global information and training services.



Gert de Graaf is the scientific and educational officer of the Dutch Down Syndrome Foundation in The Netherlands. His main research interests are the epidemiology of Down Syndrome and inclusive education.

More Information:

<http://www.edsa.eu/estimation-of-the-number-of-people-with-down-syndrome-in-europe/>

and

<https://rdcu.be/b9w27>

WDSO 2021

EDSA MEMBERS CAMPAIGN

EVERYONE NEEDS TO CONTRIBUTE

World Down Syndrome Day (WDSO) is a global awareness day recognized since 2012 by the UN, which takes place on 21 March every year. On WDSO people with Down syndrome, their families, friends and advocates, work to raise awareness of what Down syndrome is, what it means to have Down syndrome, and how persons with Down syndrome play a vital role in lives and communities.

CONNECT for World Down Syndrome Day 2021

The COVID-19 pandemic has forced many of us, individuals and organizations, to adapt the ways that we connect and communicate with each other. It has been a huge challenge and many people, particularly those with disabilities, have been left behind. It is important to find new ways of connecting that are accessible to everyone.

The focus of the EDSA campaign "CONNECT" is on how we can enable people with Down Syndrome to stay in contact with others, how they can participate and stay connected to the world, especially in this pandemic time. What can we do or what did we do to facilitate them, to take part in activities and not be separated or left alone? From 1st to 21st march we show good examples from all over Europe!



Read more: <http://www.edsa.eu/category/world-down-syndrome-day/world-down-syndrome-day-2021/>

if you have not yet done so, please send your contribution to halder.cora@t-online.de as soon as possible!!!!

EDSA MEMBER EVENT

REMINDER!!!!

Come and share the Meeting for the 16th World Down Syndrome Day

RESERVATION REQUIRED :
Individual registration: per half day

Free registration form on www.afrt.fr
To be completed before March 15, 2021 and to be sent by email to :

jacques0costils@hotmail.com &
afrtassociation@gmail.com



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AFRT (FRANCE)

A workshop in Paris, organized by AFRT. March 21st 2021 will be the 16th Down Syndrome day!

AFRT organizes a workshop devoted to some health and research issues related to trisomy 21, in particular in connection with the covid crisis.

It will be handled by videoconference. The language is French (but questions formulated in English will be accepted). The registration is free but compulsory to get an access code.

L'AFRT présente le
Colloque de la 16^{ème} Journée Mondiale de la Trisomie 21
19 et 20 mars 2021
Par VISIO-CONFÉRENCES

Santé et recherche



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Université de Paris,
Site Denis-Diderot



[PROGRAMME](#)

[REGISTRATION](#)

NEWS COVID 19 AND PEOPLE WITH DOWN SYNDROME

INTERNATIONAL STUDY FINDS INCREASED COVID-19 MORTALITY AMONG ADULTS WITH DOWN SYNDROME



Findings support prioritizing vaccines for those with the genetic disorder

Contact: info@t21rs.org

Research by the Trisomy 21 Research society (T21RS) have found increased COVID-19 mortality among adults with Down Syndrome compared to the general population, supporting the need to prioritize vaccination for those with the genetic disorder.

Investigators found that adults with Down syndrome were roughly three times more likely to die from COVID-19 than the general population. This increased risk was especially apparent after the fifth decade of life: A 40-year-old with Down syndrome had a similar risk of dying from COVID-19 as someone 30 years older in the general population. However, as in the general population, the risk of death in younger people

and children with Down syndrome was considerably lower than in older adults. The results of the study were published this week in *The Lancet's EClinical Medicine* (<https://www.sciencedirect.com/science/article/pii/S2589537021000493>).

“Our results, which are based on more than 1,000 COVID-19 patients with DS, show that individuals with DS often have more severe symptoms at hospitalization and experience high rates of lung complications associated with increased mortality. These results have implications for preventive and clinical management of COVID-19 patients with DS and emphasize the need to prioritize individuals with DS for vaccination” says Dr Anke Huels , of Emory University, first author on this paper.

Professor André Strydom , of King's College London and the president of T21RS, says that this international collaboration involved many members of the society and collected data from several countries. “The results informed the decision of the CDC in the US to include Down syndrome as a ‘high-risk medical condition,’ which will

prioritize them for vaccination. Similar decisions have been made in the United Kingdom and Spain and we hope that other countries will soon follow”.

The T21RS’s clinical committee developed the survey under the leadership of professor Stephanie Sherman, PhD of Emory University and Professor Alberto Costa of Case Western Reserve University. Other members of the T21RS COVID-19 Initiative leadership team included Mara Dierssen, of the Barcelona Institute of Science and Technology.

To collect data for the study, T21RS COVID-19 Initiative launched an international survey of clinicians and caregivers of individuals with Down syndrome infected with COVID-19 between April and October, 2020. Survey respondents were mainly from Europe, the United States, Latin America and India. (The survey was available in English, Spanish, French, Italian, Portuguese, German, Bengali, Hindi and Mandarin).

The study was funded by Down Syndrome Affiliates in Action, Down Syndrome Medical Interest Group-USA, GiGi’s Playhouse, Jerome Lejeune Foundation, LuMind IDSC Foundation, The Matthew Foundation, National Down Syndrome Society, National Task Group on Intellectual Disabilities and Dementia Practices, and also supported by stakeholder representatives from Global Down Syndrome Foundation (USA), DSA (UK), DSMIG (UK), DSMIG (USA), DSRF-UK, DSI, DSE international, Trisomie21-France, Down España, National Down Syndrome Congress (NDSC), Down Madrid, Fundació Catalana Síndrome de Down (Spain), EDSA, Royal College of Psychiatrists, CoorDown (Italy), Associazione Italiana Persone Down (AIPD; Italy),

AFRT (France), Fundación Iberoamericana Down 21 (Spain), FIADOWN (Latin America), Federação Brasileira das Associações de Síndrome de Down (Brazil) and the European Down Syndrome Association.

The study included data from a large hospital survey in the UK (ISARIC-4C). Survey data was collected between April-Oct. 2020.

THE NEW ERASMUS PLUS PROGRAMME



The Erasmus+ programme has been one of the most successful flagship programmes of the EU and has supported more than 10 million people to have a life changing experience abroad. The new Erasmus+ programme for 2021-2027 aims to reach out to more and a broader range of young people and ensure that learners across Europe can more easily benefit from the mobility opportunities the programme offers.

This is where the new [Erasmus+ App](#) comes into play!

The first release of the new App that already includes a number of the planned features is now available to download to your mobile phone from the Google Play and App Store or online at erasmusapp.eu. Many more features are still to come later in 2021.

Digitalising your journey

The Erasmus+ App will guide participants through their mobility journeys step-by-step, allowing them to

- complete all of the different administrative processes associated with their mobility digitally
- access special deals and offers in the host community
- help them to connect with others by taking part in events, social activities and volunteering

The importance of digitalisation in education has never been as apparent as during this past year. Learning and training mobility brings Europeans closer together and fosters innovation in education. Despite the difficult challenges caused by the pandemic, learning exchanges continued throughout 2020 largely thanks to digital technologies bringing people together when physical interactions were difficult.

The Erasmus+ App is revolutionising the planning, administration and support services for mobile students and other learners in Europe, making participation easier regardless of their personal or academic background.

The objective is to boost mobility in line with the vision for the [European Education Area](#). It is also a core component of the [European Student Card Initiative](#).

Read more: https://eacea.ec.europa.eu/sites/eacea-site/files/the_new_erasmus_key_action_1_and_2.pdf

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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THE STAFF

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