

### SUMMARY

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### EDSA WEBINAR..... MINUTES



#### 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.

For those who want to deepen the argument....

- Estimation of the number of people with Down syndrome in Europe

<https://www.nature.com/articles/s41431-020-00748-y>

Supplement: <https://go.downsyndromepopulation.org/europe-supplement>

- Estimates of the live births, natural losses, and elective terminations with Down syndrome in the United States

<https://onlinelibrary.wiley.com/doi/abs/10.1002/ajmg.a.37001>

- Estimation of the number of people with Down syndrome in the United States

<https://www.nature.com/articles/gim2016127>

## HORIZON 2020 PROGRAMME – IMPROVING COGNITION IN DOWN SYNDROME



### **New project, funded by the European Union's Horizon research and innovation programme: Improving Cognition in Down syndrome (the ICOD project)**

The ICOD project is ready to start: the first EU-funded project on an innovative pharmacological approach for the treatment of cognitive dysfunction in Down Syndrome

Down syndrome (DS) is the most common chromosomal abnormality in children leading to lifelong intellectual disability. Over one million people in the EU and US have DS, and its prevalence has increased in the last ten years. Thanks to significant advances in medical and social care, the life expectancy of individuals with DS has increased greatly, so that many of them reach even the age of 60-70.

DS causes lifelong cognitive dysfunction, which results in important negative consequences for these individuals, their families and society. Despite the heavier social burden and the greater medical needs linked to this intellectual disability, there isn't an approved therapy for DS-related cognitive dysfunction yet. Furthermore, though there are specific cognitive screening tests designed for individuals with DS, no official guidelines have been developed to assess their cognitive deficits or their impact on quality of life of DS individuals and their families. Further challenges to be met include the difficulty in dissecting age-related cognitive decline from the underlying intellectual disability, and the lack of international consensus on validated and accepted cognitive psychometric tools able to detect the potential clinical efficacy of a new drug both at preclinical and clinical levels.

The ICOD project (Improving COgnition in Down syndrome) aims to address these unmet clinical needs by bringing into humans a first-in-class new drug (AEF0217) that targets the CB1 receptor, whose hyperactivity has been recently linked to cognitive deficits in DS. AEF0217 belongs to a new pharmacological class, named "signalling specific inhibitors of the CB1 receptor (CB1-SSi)", which has been shown to reverse cognitive deficits in mouse models of DS.

The ICOD project will provide a clinical proof of concept for a new therapy to counter cognitive deficits in DS by performing first in humans (Phase I), as well as proof-of-principle clinical efficacy studies (Phase II) with AEF0217. The clinical efficacy of AEF0217 will be evaluated through an innovative psychometric approach where the same cognitive psychometric tools adopted at preclinical level will be used also in Phase I/II trials.

The European Consortium of the H2020 EU-funded ICOD project is led by IMIM (Rafael de la Torre, Barcelona, Spain) and AELIS FARMA (Pier Vincenzo Piazza, Bordeaux, France) in collaboration with Oasi Research Institute (Filippo Caraci, UniCT,

Catania & Oasi Troina, Italy), Institut Jérôme Lejeune (Sophie Durand, Paris, France), Centre Hospitalier Universitaire (Renaud Touraine, Saint-Etienne, France) and the Hospital Universitario de la Princesa (Diego Real de Asúa, SERMAS, Madrid, Spain).

The final goal of the ICOD project is to make available this innovative first-in-class drug for DS individuals 7 years after its clinical development, offering people with DS and their families a novel approach for the treatment of DS-related cognitive dysfunction.

The ICOD project has received the funding from the European Union's Horizon research and innovation programme under grant agreement n° 899986

<https://cordis.europa.eu/project/id/899986>

## WDSD 2021 EDSA MEMBERS CAMPAIGN



World Down Syndrome Day (WDSD) is a global awareness day recognized since 2012 by the UN, which takes place on 21 March every year. On WDSD 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.

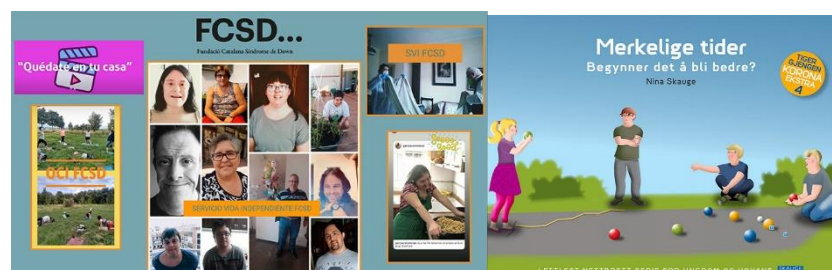
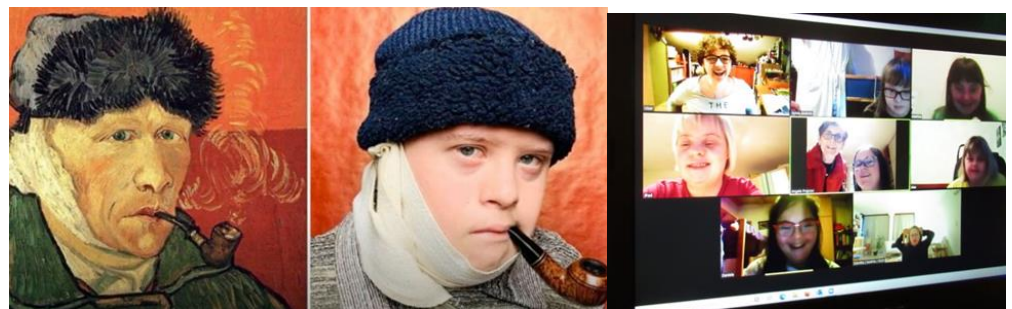
CONNECT for World Down Syndrome Day 2021  
The COVID-19 pandemic has forced many of us, individuals and organizations, to adapt the ways that we connect and communicate with each other. It has been a huge challenge and many people, particularly those with disabilities, have been left behind. It is important to find new ways of connecting that are accessible to everyone.

The focus of the EDSA campaign "CONNECT" was 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?

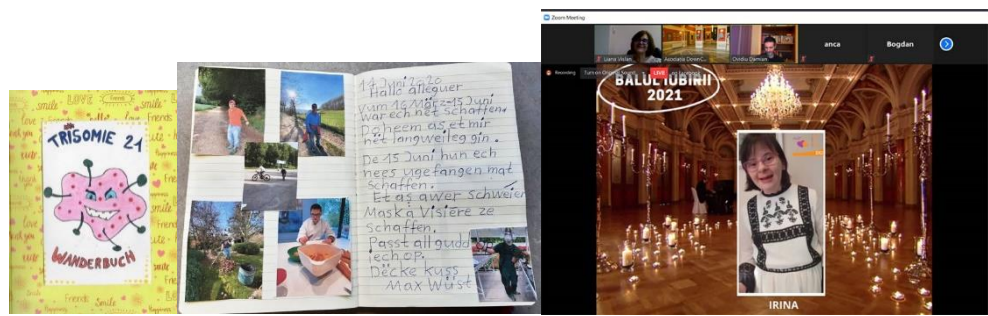
From 1st to 21st march we have showed good examples from all over Europe!

Here some pictures from Russia, Austria, Spain, Norway, Luxemburg, Romania, Netherlands, France, Ukraine, Switzerland (Italian speaking), Germany, Albania, Kosovo, Croatia, Slovakia, Czech Republic, Italy, Switzerland (French speaking), Spain, United Kingdom, Netherlands and Bosnia Herzegovina.

[Look at all the examples](#)





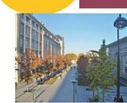


#### Come and share the Meeting for the 16th World Down Syndrome Day

RESERVATION REQUIRED: Individual registration: per half day

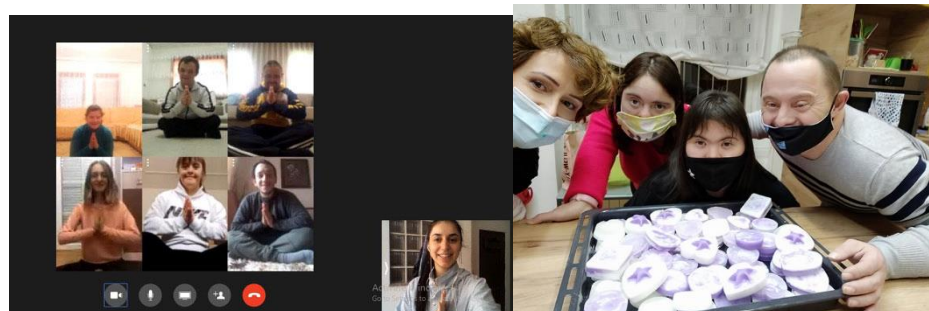
Free registration form on [www.afrt.fr](http://www.afrt.fr)  
To be completed before March 15, 2021 and to be sent by email to

[jacques0costils@hotmail.com](mailto:jacques0costils@hotmail.com) & [afrtassociation@gmail.com](mailto:afrtassociation@gmail.com)



[jacques0costils@hotmail.com](mailto:jacques0costils@hotmail.com)  
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**CONFERENCIAS DOWN**

Conversaciones sobre  
**Síndrome de Down y Coronavirus**

**NUEVA FECHA** Viernes 27 de marzo de 2020 • 19:00 a 20:00 h.  
Aforo máximo: 500 personas

Dr. José María Borrel  
Asesor médico de Down España

accede gratis a la videoconferencia en  
<https://zoom.us/j/164019888>  
ID de la reunión: 164019888

**DOWN** España

**Sharing Positive Support**  
online session:  
for parents/carers and professionals

**Ik ben Rixt**

**Geed bezig!**

**#thuisblijven**

**STICHTING Down syndrome**





Just in case our/your European project is approved, how to manage it? A guide



Open Project Management  
Methodology



### Open Project Management Methodology

OpenPM<sup>2</sup> is a **project management methodology designed by the European Commission**. Its purpose is to enable project teams to manage their projects effectively, and to deliver solutions and benefits to their organisations and stakeholders. While OpenPM<sup>2</sup> is suitable for any type of project, it is ideal for projects related to the public sector, or EU programmes and grants.

OpenPM<sup>2</sup> is a **free version of the PM<sup>2</sup>** developed by the Commission in 2007. It incorporates elements from globally accepted best practices, standards and methodologies. OpenPM<sup>2</sup> gives open access to the PM<sup>2</sup>, widening the circle of beneficiaries across Europe and enriching the methodology with additional good practices and examples. It aims to improve project management competency in the EU.

#### What OpenPM<sup>2</sup> offers now:

- PM<sup>2</sup> Guide - Open Edition - **new version published in October 2018!**
- PM<sup>2</sup> Templates
- PM<sup>2</sup> Online resources (wiki)
- A Project Support Network (PSN) - a network/community of PM<sup>2</sup> users that can support each other in rolling-out PM<sup>2</sup> in their organisations, and with using the PM<sup>2</sup> methodology in their projects.

#### Coming soon:

- Establishment of an OpenPM<sup>2</sup> Project Support Network, a network of local Project Support Offices
- Publication of the remaining PM<sup>2</sup> publications

#### Our solution at a glance

Read the [OpenPM<sup>2</sup> leaflet](#).

Look at the [OpenPM<sup>2</sup> infographic](#).

Read the [presentation The PM<sup>2</sup> Story](#).

### **Get started**

Download the [PM<sup>2</sup> Guide](#) (latest version 3.0 published in October 2018).

Download the latest [Open Artefacts/Templates](#) to be used for your projects.

Visit the [OpenPM<sup>2</sup> wiki](#) (EU Login registration required, [click here for the tutorial](#)).

[Download the Project Management Methodology Overview](#) (currently available in 11 languages).

### **Any questions?**

Please contact the OpenPM<sup>2</sup> team through the form [here](#).

Contact the [Interoperability Unit](#) at DG Informatics (please use the subject line 'OPM<sup>2</sup>').

### **More detailed information**

Join the [OpenPM<sup>2</sup> community](#) on Joinup.

Read more about the [Sharing and reuse of IT solutions](#).

### **Who is already using this solution?**

The **European Commission, the European Council, EU External Action Services, the Committee of the Regions, ECB, EIB, SRB, CVRIA, CEFEFOP, OP, ESM, ESMA** and **over 20 EU Agencies** located all over the EU Member States. The methodology is also used by many consortia and hundreds of contractors involved in EU projects.

Source: European Commission





### ERASMUS PLUS 2021-2027 – PROGRAMME GUIDE

#### 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 2021 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**.

[Read the Programme Guide](#)

[Download the PDF](#)

#### What is it?

The [Erasmus+ Programme Guide](#) (version 1 of 25/03/2021) is an integral part of the [2021 Erasmus+ Call for Proposals](#), published on 25/03/2021.

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.

#### Which language versions are available?

The Programme Guide is currently being translated. Translations will be published here as soon as they become available.

In the case of conflicting meanings between language versions, the English version prevails.

#### 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](#).

The 2021 online application forms and related documents are currently being prepared. Depending on the actions concerned, these will be made available on the websites of either the [National Agencies](#) or the European Education and Culture Executive Agency.

For actions managed by the European Education and Culture Executive Agency (EACEA), the relevant documents by action will be published and opened for submission on the [Funding and Tender Opportunities Portal](#) on 14/04/2021.

**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.

Source: European Commission

## 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

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