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## EDSA AGA 2022



Dear EDSA members,

The 12th November 2022 we had our annual meeting (AGA)

1. The [minutes](#) of the meeting.
2. The „ALL IN ONE“ [presentation](#), that Dinka prepared. It includes the complete AGA with all the files, like the financial documents and all the presentations from our members.
3. And the [letter](#) from Tetiana Pavluk, vice president of DS UKraine with an update of the situation for the families with a child with DS in Ukraine. This letter was read during the AGA.

It was a very interesting meeting and we thank all the 30 present members, representing 27 DS Associations from 22 European countries.

Next year we plan to organize a presence-meeting and hope to see many of you again.

Best regards

Cora

## FEW NEWS FROM SELECTED SCIENTIFIC PAPERS ON TRISOMY 21

**Jacqueline London, Emeritus professor Paris-Cité, AFRT Founder and vice-president**

### **A) Four papers related to cognitive abilities**

- 1) The team of S. Vicari in Roma published in « Frontiers in Psychiatry » a paper on parental perspectives on the quality of life (QoL) of their children with Down syndrom/ trisomy 21. The team used the Adaptative Behavior Assessment System II (ABASII) to investigate 75 children (5-12 years) with a questionnaire to parent/primary caregiver with eleven skill areas organized into 3 general domains : conceptual, practical and social. The main result was that the emotional functioning was the the domain with the highest level of QoL. Moreover low levels of QoL was correlated with low levels of analogical reasoning, worse adaptative skills, more ritualistic/sameness behavior and more autistic symptoms. One important point was that there was no difference between parental education and employment. The authors conclude that understanding cognitive and behavioral factors related to various degrees of QoL in children with T21 is crucial for the development of effective strategies to promote the improvement of QoL in these patients.
- 2) The team of S. Vicari published also in « J. Clin. Med 2022 » a general study on gender clinical characteristics in 715 children and adolescents with their first diagnostic of ADHD (Autism). The main result was that girls show more ADHD features and lower IQ while boys showed more prominent internalizing problems and obsessive-compulsive symptoms. Is it true for persons with T21 was not assayed.
- 3) The team of Egil Nygaard (Norway) published a paper in « Brain Sci, 2021) about the prediction of expressive development in children with DS and controls. The aim was a better knowledge for planning appropriate expressive vocabulary interventions especially adapted for the language profile for children with DS. Both home literacy environment, receptive vocabulary and auditory memory and oral motor skills were significant predictors of expressive vocabulary development were shown to be good predictors for children with DS.
- 4) The NIH (National Institute of health) validate a new Toolbox Cognitive Battery in intellectual disability (Dr Hessl : drhessl@ucdavis.edu) validated for children and young adults with Intellectual disabilities (ID) with mental age (years and more)

## **B) About pharmacologic interventions,**

**1) Florenza Stagni and Renata Bartesaghi published a very well documented review** in « Frontiers in cellular Neuroscience, May 2022 ». The review summarizes :

- a) Current knowledge about pharmacological interventions in the embryonic and neonatal periods in mouse models of DS and their improvement in brain development and training performance.
- b) Current knowledge on the timeline of neurogenesis and dentritic alterations in T21 in order to better determine the time of an eventual treatment in persons with T21 either in the prenatal or neonatal period.
- c) Identification of the respective/cumulative roles of the most important triplicated chromosome 21 genes which are responsible for these alterations
- d) Although studies with animal models (mice, rats, drosophyla, c. elegans) represent a fundamental step for the development of therapies in human diseases, cerebral organoids derived from hiPSCs represent the best approximation of a whole brain and a powerful tool to study the biology of DS and potential treatments.

### **2) The Perseus pediatric study on the efficiency of EGCG**

The multicentric study for innocuity and efficiency of EGCG (inhibitor of the DYRK1A protein) is currently performed in children with DS 6-12 months. Results are ongoing

### **3) New molecules as DYRK1a inhibitors**

A new generation of DYRK1A inhibitors (leucettine 41, Man Rose therapeutics, Roscoff, France) have been tested for cognitive improvements in mice. On-going clinical trials and results are expected 2023-2024

### **4) AEF 0217 : a new path for the treatment of cognitive impairment in DS**

The product acts selectively on certain subtypes of cells with hyperactivity of the CB1 receptors and modulate their cellular activities. The research is supported by UE H ICOD.

### **5) Pulsative GnRH treatment (Lille and Lausanne)**

Persons with DS show olfactory and cognitive impairments and reproductive maturation deficits. GnRH neurons project to neurons involved in cognitive deficits in the T65Dn mice (models for studying DS). A pilot study was performed in Lausanne on 6 young men with DS. Pulsative GnRH in persons with DS improves brain connectivity and function. The study in mice and in person with DS was published by the team of Lille and Lausanne in Science, 377, 1064, 2022.

## NEWS FROM THE PROJECTS WITH EDSA MEMBERS IN THE PARTERSHIP

### DOWN WITHOUT BARRIERS



This project was unded by the European Commission, under the Erasmus + Ka1 Mobility programme.

Direcția de Asistență Socială și Medicală from Cluj-Napoca (Romania) is the promoter organisation

Partners: Municipality of Fyli (Greece), Down Sendromu Derneği (Turkey) and Associazione Italiana Persone Down (Italy).

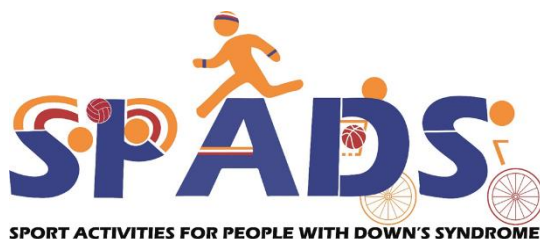
The theme of the project is leisure time of people with Down syndrome.

The overall aim is to offer educators, young people with Down syndrome and volunteers a training and an exchange of experience abroad.

The partners involved in the project published a guide on how to work with young people with Down syndrome!

Check it out here <http://dasmclujnapoca.ro/.../dasm-publica-ghidul-de.../>

## SPADS (SPORTS ACTIVITIES FOR PEOPLE WITH DOWN'S SYNDROME)



### In Rome the final conference of the project



The final conference of the ERASMUS+SPORT project called "Sports activities for people with Down's Syndrome (SPADS)", proposed and coordinated by ASD Running of Matera (Italy), was held on December 1<sup>st</sup>, in the Aula Magna of the Roma TRE University.

The 24-month project started in January 2021 and saw the work of a consortium made up of 8 partners from 5 European countries: the Italian Association of People with Down syndrome (AIPD), the Italian Federation of Paralympic Intellectual Relational Sports (FISDIR), the University of Jaen (Spain), ASNIMO Foundation (Balearic Islands-Spain), Hungarian Down Foundation (Hungary), ALDO-CET (Romania) and DSA (United Kingdom).

Sports activities for people with Down's Syndrome (SPADS) is a project of "Collaborative Partnerships" which had the main objective of encouraging social inclusion and equal opportunities in sports, through greater participation in sports activities by adolescents and young people with Down syndrome (DS).

The aim of the project was to start a sustainable and continuous learning path that connected educators, social workers, sports instructors of sports clubs, residential structures, associations, NGOs, foundations aimed at involving Down people in sports.

Many sports have been practiced: athletics, swimming, football, basketball, colpbol, rowing, etc. aimed at children and young people with Down syndrome who attend European facilities.

The specific objectives were:

- strengthening the use of sport as a tool for social inclusion;
- raising awareness of the potential of sport in improving the living conditions of people with DS;
- training educators and sports volunteers;
- implementating programs for the promotion of sporting activities for subjects with DS
- increase stakeholder knowledge of EU, national, regional and local policies and best practices in related to inclusion through sport.

During the final conference, the 3 main final results obtained were illustrated:

- fact-finding survey on the current situation, aimed at families
- Guidelines “Sport for Down”, containing best practices
- e-learning platform for sports educators and volunteers, with which over 300 people have been trained

On the occasion of the final conference organized by AIPD as part of the international day of people with disabilities, the athletes Giulia Pertile (athletics), Arianna Sacripante (synchronized swimming) and the Italian national team of basketball with Down syndrome -who recently won, for the third time in a row, the title of World Champion- brought their testimony with their stories of sport and inclusion FIDSIR

To follow the project's activities on the Facebook page:

<https://www.facebook.com/profile.php?id=100064031984983>

## SAVE THE DATE



### **18th JMT21-2023 March 17<sup>th</sup> and 18<sup>th</sup>, 2023 in Bourg-en-Bresse (near Lyon and Geneva)**

*Friday March 17<sup>th</sup> from 4 p.m. to 7 p.m.: University site*

Presentations for medical students (1st year), health professionals and families.

- AFRT: Trisomy 21 "History and new perspectives in research" (Jacqueline London, Paris)
- Trisomy 21 today and tomorrow: Dr Michel Till (ST Luc hospital, Lyon)
- Interventions by persons with Trisomy 21: they will present themselves with their own means.
- Friendship meeting

*Saturday March 18<sup>th</sup> from 9 a.m. to 6 p.m.: Alimentec site*

Morning: Research and Health

- 9:15-9:30 a.m.: Opening speeches
- 9:30-9:45 a.m.: Research tools for pharmacological leads (J.London)
- 9:45 a.m. to 11:15 a.m.: Current pharmacological leads
- A) Inhibitors of the Dyrk1a protein: Nathalie Janel (Professor Paris-Cité)
- B) The AEF 0217 molecule that regulates cannabinoid CB1 receptors in the brain: Pier Vincenzo Piazza (CEO Aelis Farma, Bordeaux)
- C) GNRH treatment: Nelly Pitteloud (Professor, Lausanne)
- D) General discussion

- 11.30am-12.30pm

Trisomy 21 and behavioral disorders: how to overcome over-disabilities: Caroline Demily (Professor, Pôle ADIS and CRMR GénoPsy, Lyon)

Afternoon: daily life

"Not For me but WITH ME"

- A) "Easy Reading": General presentation and concrete experiences

B) Inclusive/participatory housing

Presentation on the "Cap'Soleil" inclusive residence in Bourg-en-Bresse and intervention of the social landlord DynaCité

Other interventions are ongoing

C) Training and jobs

Concrete examples of jobs in the open market and interventions of persons with trisomy 21 presenting their jobs

## NEWS FROM DOWN SYNDROME INTERNATIONAL



### World Down Syndrome Day 2023



Down Syndrome International is calling for a commitment to **With US Not For Us**. This message is fundamental to a human rights-based approach to disability. More information on the Dsi website: <https://www.ds-int.org/Blog/with-us-not-for-us-world-down-syndrome-day-2023>



## NEWS FROM EDSA MEMBERS

ASSOCIAZIONE ITALIANA PERSONE DOWN (ITALY)



"NOT ONE LESS." HOW DO PEOPLE WITH DOWN SYNDROME LIVE? AIPD - CENSIS SURVEY

Who are people with Down syndrome and their families, how do they live, what support do they have and, above all, what do they not have? Censis and AIPD have tried to answer these and other questions with the survey "Non uno di meno. La presa in carico delle persone con sindrome di Down per il perseguimento del migliore stato di salute e la loro piena integrazione sociale" ("Not one less. Taking charge of people with Down's syndrome for the pursuit of the best state of health and their full social integration"), conducted by Censis (Italian Institute of Socio-Economic Research) together with AIPD.

[Here](#) is a summary of the research

## EU COMMISSION FUNDING OPPORTUNITIES



### **The Erasmus+ Programme Guide 2023**

The essential guide to understanding Erasmus+

#### **About the 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.

It is an integral part of the 2023 Erasmus+ Call for Proposals.

#### **Who should read it**

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

Read more <https://erasmus-plus.ec.europa.eu/erasmus-programme-guide>

## **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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