

SUMMARY

- 01
EU Funding - Next opportunities: The Europe for citizens Programs
- 02
News from projects run by partner EDSA-Members Aldo-cet (Romania)
- 04
A letter from Down Syndrome International
- 05
How to explain Down Syndrome to Children
- 06
Access on information as an improvement in quality of life
- 08
Contacts

EU FUNDING - NEXT OPPORTUNITIES



Europe for Citizens

THE EUROPE FOR CITIZENS PROGRAMME

General and specific objectives of the Europe for Citizens Programme

The general objectives are under the overall aim of bringing the EU and its citizens closer together:

- Contribute to citizen awareness of the EU, its history and diversity;
- Foster European citizenship, and improve conditions for civic and democratic participation at EU level.

The structure of the Europe for Citizens Programme, and types of grants the Programme is implemented through is via two strands:

- Strand 1: European remembrance: Raise awareness of remembrance, common history, values and the EU's aim.
- Strand 2: Democratic engagement and civic participation: Encourage democratic and civic participation between citizens at an EU level. Europe for Citizens.

Measures in this strand are:

Town Twinning
Town Networks
Civil Society Projects

Next deadlines:

Town-Twinning 1 September 2016
Town Networks 1 September 2016

**Applications must be submitted before the deadline of 11.00h (GMT). If the deadline for submission falls on a weekend, the 1st working day after a weekend will be considered the deadline day.*

Further information: http://eacea.ec.europa.eu/europe-for-citizens_en

NEWS FROM PROJECTS RUN BY PARTNER EDSA MEMBERS



ALDO-CET (Romania)

THE EUROPEAN PROJECT HEALTHY DS PROMOTES REDUCING OBESITY AMONG PEOPLE WITH DOWN SYNDROME



***HEALTHY DS** increases the ability of people with Down Syndrome, families, and professionals, in the prevention and reduction of obesity through the development of an innovative training programme, focused on promoting a healthy lifestyle and self-management.*

ALDO-CET Romania participates in the European Project HEALTHY DS focused on developing a training program aimed at people with Down Syndrome, families and professionals, with the aim of promoting a healthy lifestyle, self-management, reducing obesity, and increasing the quality of life for people with Down Syndrome.

During the project, running from September 2015 to September 2017, the Consortium will develop training materials and an online platform for implementing the training methodology. About 40 people with Down Syndrome, families, and professionals, will participate in the validation of the project results in each participating country, creating direct impact.

The Consortium consists of stakeholders who support people with Down Syndrome: ASINDOWN FOUNDATION Valencia (Spain) is the coordinating stakeholder, DRUŠTVO DOWNOV SINDROM SLOVENIJA, DDSS (Slovenia), ASSOCIAÇÃO PORTUGUESA DE PORTADORES DE TRISSOMIA 21, APPT21 (Portugal), DOWN EGYESÜLET (Hungary) and ASOCIATIA LANGDON DOWN OLTENIA CENTRUL EDUCATIONAL TEODORA, ALDO-CET (Romania). All are dedicated to supporting people with Down Syndrome. FUNDACIÓN LLUIS ALCANYIS of University of Valencia (Spain) is participating as a nutritional and physical activities expert, as well as the TECHNOLOGICAL INSTITUTE IAT (Germany) as an expert in the development of ICT Tools adapted for people with disabilities.

HEALTHY DS is a project funded by the European Commission through the ERASMUS+ 2015 Programme.

PARTICIPANTS IN THE EUROPEAN PROJECT HEALTHY DS MET IN ROMANIA

On the 12th and 13th of last April, the second meeting of the European Project HEALTHY DS took place in Romania, with the aim of increasing the ability of people with Down Syndrome, families, and professionals, to prevent and reduce obesity through the development of an innovative

training programme, focused on promoting a healthy lifestyle and self-management.

Two representatives of each member of the Consortium participated in this meeting.

The meeting took place in Craiova (Romania), where we dealt with issues as the development of the training programme progressed (details to follow). Theoretical contents, indoor and outdoor activities were specified, the virtual platform applied, media dissemination of support, such as on the web www.healthyds.eu which is already underway, leaflets, etc., all to ensure the validity of the material and the imminent launch.

On April the 13th we visited the ALDO-CET center which is based in Bailesti, where partners from different countries received a warm welcome and were able to participate in a day of activities, such as sport and adapted dance and music therapy sessions with both users and staff at the centre. We enjoyed a locally, healthy, Romanian meal later on. It was a great experience.

For centres, or people interested in this programme, stay tuned because the registration deadlines will soon be opened, to carry out the training programme in question. For more information contact your nearest stakeholder or via the website: www.healthyds.eu

HEALTHY DS is a project funded by the European Commission through the ERASMUS+ 2015 Programme.



A LETTER FROM DOWN SYNDROME INTERNATIONAL



Dear national organisation representatives,

Down Syndrome International understands that research conducted by Roche into improving cognitive functioning in people with Down syndrome has been completed (CLEMATIS trial). Given the lack of efficacy seen, Roche has decided to discontinue the ongoing clinical trial in children (6-11 years old).

The invaluable information about Down syndrome gathered by Roche during the CLEMATIS trial from families across the world will be shared by Roche, to inform any future research in this field. Roche has issued the following statement:

“The CLEMATIS trial was a Phase II study investigating the efficacy and safety of basmisanil (RG1662) in adults and adolescents with Down Syndrome. It was a 26 week, multi-centre, randomized, double-blind, three arm, parallel-group, placebo-controlled study.

This phase II study didn't meet its primary and secondary objectives in improving in cognition and function. There was no difference observed between adults (18-30 years old) and adolescent (12-17 years old) in the study. In addition, there was no significant difference between those who took the drug and those that took the placebo.

Given the lack of efficacy seen in the CLEMATIS trial, Roche has decided to discontinue the ongoing clinical trial (WP28760) in children (6-11 years old) with Down Syndrome. This pediatric study is not being discontinued for safety reasons, as basmisanil was well tolerated and no relevant safety signals were observed with basmisanil, when compared to placebo and previous trials.

We are disappointed by the lack of efficacy seen in the CLEMATIS trial. We have learnt a lot from people with Down Syndrome and their families over the past few years, and are very grateful for their willingness to participate in this clinical trial programme.

We are committed to sharing our findings with the community, and the results of the CLEMATIS trial will be presented at an upcoming medical congress as well as being posted on clinicaltrials.gov.”

Regards

Andrew Boys

Director

Down Syndrome International

HOW TO EXPLAIN DOWN SYNDROME TO CHILDREN



TEDI, Vanguardia en síndrome de Down, a Mexican association has made a video to explain 'What is Down Syndrome?'

Click on the link to watch the video:

<https://www.youtube.com/watch?v=TEXcnUF3qZY>

ACCESS TO INFORMATION AS AN IMPROVEMENT IN QUALITY OF LIFE

Access to information and its understanding is a fundamental right; the informed citizen can only knowingly take decisions concerning his/her life, achieving equitable personal and social development.

Unfortunately, essential information doesn't always reach those with limited reading, writing and comprehension abilities.

The ability to read provides great confidence, allows expansion of horizons and control of one's own life.

Through reading individuals can share ideas, thoughts and experiences, and grow as human beings (from the IFLA Guidelines).

Learning to read gives access to a world of knowledge, the ability to resolve problems, develop thinking, and to discover new worlds through books, newspapers and the computer.

People with writing or reading difficulties have problems of a different nature: mental health difficulties, or a disability limiting their ability to read (Dyslexia), poor education, or they speak a different 1st language.

Texts sent to these people must be easy to read and understand, but producing "easy reading" text introduces a number of variables which relate to the ability of this group, or the subject matter. Similarly, topics can vary according to the kind of information required, but normally they are the same ones used by everyone in daily life:

- Daily News.
- Consumer Information.
- Rights and Obligations.
- Access to Public Services.
- Information on Leisure Time.
- Public Transportation .

Therefore, it isn't possible to establish a universal set of rules for writing, suitable for all people with reading and comprehension difficulties. However, general principles that characterize "easy reading" material exist, as follows:

- Use of clear and concise language;
- Clear and coherent text structure, with a sole principal idea for each sentence;
- Avoid technical terms, abbreviations and acronyms;
- Avoid, as far as possible, abstract concepts. Should it be impossible to avoid them, they must be illustrated with examples;
- Use illustrations and photographs that are only strictly connected to the text.

Writing in simple and consistent language doesn't mean writing in a childish way, considering it often involves adult readers. The key point is to maintain a linear sequence, and avoid unnecessary sentences or ideas.

A document that is easy to read is therefore a document containing the most important information only, written and introduced in a direct way, so it can be understood by the majority of people.

When discussing an easy reading text it's important to consider the audience; it's also advisable to consult people with intellectual disabilities throughout the process up to the final version, in order to adjust the text according to their feedback.

Inclusion Europe – Lifelong learning Project (Pathways 2) ANFFAS
Easy Reading Multimedis Srl

Universidad de Zaragoza – Gruppo Edi (grupo-edi.com/lectura_facil)

Make it easy – A Guide to Preparing Easy to Read Information – Accessible Information Working Group 2011

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

phone: 0039 06 3723909

e-mail: internazionale@aipd.it

THE STAFF

Michela Cinti

Federica Girard

Carlotta Leonori

Paola Vulterini