

EUROPEAN DOWN SYNDROME ASSOCIATION

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BREAKING NEWS

A VALUEABLE NETWORK!!



Isaac and Samuel of Down Espana (Vigo), together with their tutor Eva, met Leo Messi, FC Barcelona's football player, during their internship within the project "A Valueable Network" at Melià Milano Hotel (Italy)!







EDSA AGA IN MADRID

EDSA Annual General Assembly 2018 in Madrid



32 representatives of 24 different DS-Associations from 20 European countries met in the premises of Down Spain last weekend (26-28 October) for their annual meeting. It was nice to meet all these dedicated people who work so hard in their organizations to improve the situation of children, youngsters and adults with DS. Among the delegates were some who participate for the first time, as their organizations have just lately become an EDSA member. Therefore they had the opportunity to introduce their organization through a talk and a PowerPoint presentation. This time there were presentations from Iceland, Poland, Hungary and from the Italian-speaking part of Switzerland. It is always very interesting for all members to see and hear what others are doing and you get to know projects and activities which might be interesting for your own country as well.

Change in the board

As is the rule the presidents report and the financial reports were on the agenda. There was a change in the board: Lars Brustad from the Norwegian DS Network wishes to step back as Board member out of personal reasons. Karianne Abrahamsson also from Norway was nominated and elected by the AGA as his successor.

Further activities

Other important issues on the agenda were the further activities of EDSA, especially actions regarding the WDSD 2019 and the "Invite an expert"project that has not very often been used during the past 5 years. It was discussed how this project, which really is helpful, can be better promoted.

EDSA needs a new strategic plan for the next few years. There was not enough time to talk this matter in the AGA, but ideas were collected. The next board meeting will address this subject.

The first part of the AGA-meeting was on Friday, the second part on Sunday. The Saturday was dedicated to the seminar on Job Inclusion (separate article)



Traditionally, the annual meeting also includes a joint evening. Our host Down Spain organized a flamenco lesson for the delegates and afterwards a dinner, accompanied by flamenco dance and music.

The minutes of the AGA can be found in the restricted area of Edsa website.

SURVEY OF EDSA MEMBERS ABOUT JOB INCLUSION



A questionnaire was sent to all EDSA members prior to the AGA. Currently there are 40 DS organizations from 33 different countries. The questionnaire was compiled by Anna Contardi (AIPD, Rome) and contained 11 questions on inclusion in the first labour market.

20 associations from 17 countries answered the questions.

The countries that were involved: Albania, Austria, Germany, Spain, Hungary, Czech Republic, Italy, Denmark, Netherlands, Ukraine, Portugal, Croatia, Romania, Iceland, Turkey, Scotland and Slovenia. Most of the respondents confirmed that these are often estimated figures because there is no exact data on the subject.

Some associations – from Sweden, Norway and Switzerland – replied that there was so little data available in their country that they could not provide any information.

Results

The first question asked to indicate where adults with DS go after leaving school: Do they stay at home, visit an activity centre, work in a workshop or inclusion company or are they active in the primary labour market?

Only a very small percentage have a job in a regular company, around 2%. The highest figures here came from Italy (13%), Portugal and Germany (10%), Spain (5%) and Austria (4%). However, in most countries there is no job opportunity at all and the majority of adults with DS remain at home



without any employment. Only in the Netherlands, Austria and Germany do almost all adults with DS work and are not at home.

The second question was: Is there a law that promotes the integration of people with DS in the workplace (including a more general disability law)?

With the exception of one country (Slovenia), everyone answered yes.

3. How does the state promote labour inclusion?

The most frequently mentioned measure was that there was a salary subsidy or that the companies received other financial support. That may be tax benefits or there may be no fine to pay if you do not employ people with disabilities. In most countries the rule applies that a company of a certain size is obliged to hire one or more disabled persons, if this is not done, a fine must be paid.

- 4. Does a worker with DS who works in the open market receive the same salary as his colleagues? Approximately half agreed, the others answered no.
- 5. Does an employee with DS in a sheltered workshop receive a salary equal to the minimum wage?

No for 73% and yes for 27%.

6. Are people with DS employed full time, part-time or just a few hours?

Most of them work part-time (between 20 and 25 hours). Occasionally, people with DS have a full-time job. Four countries replied that if the adults work anything at all, it is less than 15 hours a week.

- 7. Are there any support measures for job integration? There are no such measures in Romania, Croatia and Turkey. In the other countries there is both private and state support, with private integration services being more widespread.
- 8. Does your association also offer support in job searching and job assistance?

Eleven organizations confirmed this, eight do not offer this service.

9. If YES, with which of these interventions?

The answers were: with vocational orientation and training courses, searching for interested companies and their sensitization, between suitable candidates and employers, job coaching, informing entrepreneurs and their staff.

10. Which method is most frequently used to promote vocational integration?



"Training on the job" was mentioned seven (7) times. Five (5) countries indicated that young people first received a more general vocational training and four (4) times specific vocational training was mentioned.

11. What is the main obstacle to the employment of people with DS in your country?

The biggest obstacle was: too little support (9), prejudices among employers, in the world of work in general (5), lack of state support/legislation (4) insufficient preparation of young people with DS (4), resistance of families (4)

EU OPPORTUNITIES



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.

PDF versions of the 2019 Programme Guide are currently available in all official EU languages. An online version of the Guide will be soon available via this page.

Download the PDF

About

What is it?

The Erasmus+ Programme Guide is an integral part of the 2019 Erasmus+ Call for Proposals.

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 available in the following languages:

<u>bg</u> <u>da</u> <u>de</u> <u>et</u> <u>el</u> <u>en</u> <u>fr</u> lv CS <u>lt</u> <u>hr</u> <u>hu</u> <u>mt</u> nl pl pt ro sk sl fi SV

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 Education, Audiovisual and Culture Executive Agency.

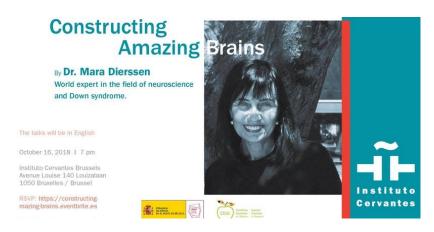
The 2019 online application forms and related documents are currently being prepared. Depending on the actions concerned, these will be made available on the websites of either the National Agencies or the Education, Audiovisual and Culture Executive Agency.

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 Education, Audiovisual and Culture Executive Agency in Brussels.





CONSTRUCTING AMAZING BRAINS

By Dr Mara Dierssen – world expert in the field of neuroscience and Down syndrome

 Instituto Cervantes, CEBE (Científicos Españoles en Bélgica) and the Cultural and Scientific Section of the Embassy of Spain in Belgium invite you to the talk by Dr. Mara Dierssen

Down syndrome is a complex condition that results from having a third copy of human chromosome 21. People with the syndrome experience problems with learning and memory that affect many aspects of their lives.In DS individuals and trisomic mice models early intervention results in only limited and temporary cognitive improvements. Our previous work in trisomic mice suggested that this is probably due to an inability to translate the temporary changes in synaptic efficiency after exposure to enriched environments, into stable structural changes. Several molecular mevchanisms may account for these alterations but not all are good therapeutic targets. I will discuss the experimental arguments that make one of the triplicated genes in DS a good pharmacological target for boosting plasticity: Dyrk1A a candidate gene closely implicated in various DS features.

Dr Mara Dierssen is a world expert in the field of neuroscience and her contributions have been published in more than 160 peer-reviewed papers (h index 45). Dr. Dierssen has received several awards for her work in intellectual disability including Ramón Trias Fargas, Jaime Blanco, Trifermed Social Impact of Healthcare Award, or Sisley-Lejeune awards and the National Science Culture Award from the Generalitat de Catalunya. Dr. Dierssen is president of the Trisomy 21 Research Society, and pastpresident of the Spanish Society of Neuroscience, and the International Behavioral and Neural Genetics Society, she served as executive committee member of the Federation of European Neuroscience Societies (FENS). She is member of Editorial Boards (Genes Brain and Behavior, Frontiers in Behavioral Neuroscience, Amino Acids, Frontiers in Genetics among other) and very active in organizing international research conferences. She serves as evaluator of different Scientific Committees and Boards (ERC, Spanish National Evaluation Agency, Panel Expert for EU). She is member of the Academia Europaea and of the European DANA Allianze for the Brain.

Further information of the organizer can be found here.



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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