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EDSA – T21RS A NEW COLLABORATION

Edsa decided to accept the T21RS proposal to create an interface committee with T21RS members and EDSA representatives, to work on the following two objectives:

1 Inform parents and carers about progress made in research on Down Syndrome, exchange information about early intervention, cognitive stimulation and pharmacological treatment.

2 Start a lobbying campaign towards the EU Health directorate.

The committee will meet for the first time in Rome on June the 27th, but EDSA and T21RS have already sent a letter to Ruxandra Draghia-Akli, Director of the Health Directorate at the Research DG of the European Commission, asking to;

1 Create a permanent committee assembling international and European professional associations (such as T21RS for Down syndrome), parents associations, EU representatives and pharmaceutical industry representatives, to work on the future development of European research on genetic intellectual disabilities.

2 Define the thematic lines focusing on specific aspects of genetic intellectual disabilities, to be included in the next calls of H2020.

Here the full text of the letter sent:

*Ruxandra.DRAGHIA-AKLI, Director of the Health Directorate at the
Research DG of the European Commission
Carlos Moedas, Commissioner for Research, Innovation and
Science*

Catherine Berens, Head of the Neurosciences Sector

Dear Dr Draghia-Akli

On behalf of EDSA, the European Down Syndrome Association, which unites more than 40 European associations, and of T21RS, Trisomy 21 Research Society, which has more than 70 European academic members, we would like to draw your attention to research programmes on Down Syndrome in Europe.

Down Syndrome affects more than 500,000 people in Europe. It is more common than Cystic Fibrosis, Muscular Dystrophy and Huntington Disease combined.

The incidence of Down Syndrome in Europe is at least ten times higher than AIDS. Any improvement in the autonomy of people with Down Syndrome could greatly improve their way of life, and decrease the burden on their families.

Down Syndrome is caused by the trisomy of chromosome 21, and is a complex condition characterized by a number of phenotypic features, including a reduced neuron number, synaptic plasticity and mental retardation, early Alzheimer-like neurodegeneration, craniofacial dysmorphia, heart development defects, increased incidence of childhood leukaemia, and powerful suppression of the incidence of most solid tumours. Mouse test samples replicate a number of these phenotypes.

The last 10 years have seen tremendous advances in the comprehension of the links between the phenotypic features and the errors in gene dosage. The sequencing of chromosome 21, gene content of this chromosome, physiological description of various murine models with partial trisomy, transcriptome analyses of cells and tissues from individuals with trisomy 21 and the description of dysregulated pathways.

Using these new results, some research groups have started the development of therapeutic strategies targeting brain functional impairment, which have been assessed on murine models. Some of these strategies have produced a substantial improvement in cognitive capacities of the models. Clinical trials have been launched recently and at least one of them has already given positive results.

However an efficient assessment of the different possible targets and strategies requires a concerted programme, bringing together scientists from different fields of research with complementary expertise. The final objective will still be to assess the effectiveness of these treatments with clinical trials.

This programme will not be achieved by research carried out solely in individual countries. It will also be necessary to involve a large number of patients, and this will require collaboration between clinics from different countries.

A major funding effort in the US over the last ten years has been devoted to researching Down Syndrome, with 200 M\$ coming from federal organisations and 20 M\$ from private foundations. In comparison and during the same period of time Europe (Health programme in FP6, FP7, H2020 and private organisations) has founded smaller programmes for 15 M€.

We think that the time has come for Europe, through the H2020 Health Programme, to strongly support European scientists and clinicians willing to commit themselves to this type of research. The difficulties encountered by scientists working on other genetic intellectual disabilities are similar to those seen by Down Syndrome scientists. We would like to make two suggestions to try to improve this situation:

1 Create a permanent committee, uniting European professional associations, parents associations, EU representatives and pharmaceutical industry representatives, to work on the future development of European research on genetic intellectual disabilities.

2 Define the thematic lines focusing on specific aspects of genetic intellectual disabilities, to be included in the next calls of H2020.

We are ready to participate in a direct meeting or a video conference to discuss possibilities. We hope that such an interview will be compatible with your agenda.

Yours sincerely,

The President of EDSA



ABOUT T21RS

Trisomy 21 Research Society (T21RS) is the first non-profit scientific organization of researchers studying Down Syndrome, founded to promote basic and applied research on Down Syndrome, stimulate translational research, and apply new scientific knowledge to develop improved treatments and cures.

Main Aims:

- **To facilitate the permanent interaction** between researchers studying Down syndrome via our website, scientific meetings, publications in journals, and the two-yearly T21RS International Conference.
- To establish common protocols both for basic research (scientific studies on mice studies and stem cells) and translational research (for clinical trials with biomarkers, cognitive paradigms, etc.)
- **To support the education and training of young researchers** at all stages of their careers, including undergraduates, graduates and postdoctoral fellows who are interested in Down Syndrome, by providing training programmes and grants to young scientists.
- To **promote research** on Down syndrome.
- To explain (recent) findings in Down Syndrome studies to **the general public, and to inform legislators** and other policymakers about new scientific knowledge, recent developments and their implications for public policy and society.
- To **promote the interaction between scientists and patient associations, foundations and pharmaceutical industries.**

In Celebration of Down Syndrome



The Museum of disABILITY History presents

“In Celebration of Down Syndrome”

**Exhibit runs through to the end of 2016
3826 Main Street, Buffalo NY 14226**

“In Celebration of Down Syndrome,” an addition to the Museum of disABILITY History, recognizes individuals who have Down Syndrome in a fascinating new exhibit. The exhibit explores medical history, myths and facts, as well as success stories and popular culture.

Exhibit highlights include:

Vibrant multimedia and Hollywood memorabilia.

Stunning photography of Eva Snoijink: Select photos from her book, *Downs Upside: A Positive View of Down’s Syndrome*.

Stories of individuals living in Western New York who have Down Syndrome.

[Kelly’s Hollywood](#), an inspirational documentary about a young woman who has Down Syndrome and fulfills her dream is available to view as part of the exhibit.
Medical history of Down Syndrome.

Myths and facts – you may be surprised to learn something new.

Hollywood popular culture: Celebrity actors and advocates are featured in our pop culture panel exhibit, including [Lauren Potter](#), Christopher Burke, [Jamie Brewer](#), and model [Madeline Stuart](#).

“The Unspoken Voice,” an art exhibit showcasing the talent of Bailey Bastine, a young artist from East Aurora, NY, who has Down Syndrome.

The Museum of disABILITY History is proud to host “In Celebration of Down Syndrome” as a special exhibit open to the public.

To view photos from the grand opening event, [click here](#).

“In Celebration of Down Syndrome” was created with the assistance of [Down Syndrome Parents Group of WNY](#) and [NYS Council on the Humanities](#).

Special thanks to Gail Williamson, founder of [Down Syndrome in Arts & Media](#) and talent agent for the Diversity Department of [Kazarian/Measures/Ruskin & Associates](#), who contributed photos of the pop culture panel exhibit.

THE MEDICINE OF A SMILE

Pope Francis denounces the social mentality that marginalizes sick and disabled people •



June 13, 2016

The Gospel reading was dramatized by a group of people with intellectual disabilities for the first time in St Peter’s Square, so the text might also be understood by those with cognitive impairments.

This took place on Sunday June the 12th, during the morning Mass when Pope Francis celebrated the occasion of the Jubilee of the Sick and Disabled.

In his homily, the Pope firmly denounced the existing mentality that idealizes the “care for one’s body” and obscures “anything imperfect”, since “it threatens the happiness and serenity of the privileged few and endangers the dominant model”.

However, the Pope pointed out that, “the world does not become better because only apparently ‘perfect’ people live there – I say ‘perfect’ rather than ‘false’ – but when human solidarity, mutual acceptance and respect increase”.

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[The Pope’s homily](#)

From *L’Osservatore Romano*, June 13, 2016

UPCOMING EVENTS WITH EDSA MEMBERS INVOLVED

POSEIDON PROJECT **POSEIDON**

Poseidon will hold its last workshop meeting outside London (Teddington) between September 23rd and 25th.

CROATIAN-SLOVENIAN CONFERENCE



The conference will be held in Zagreb and in Ljubljana on the 16th and 17th of NOVEMBER 2016.

The main theme will be “Working opportunities for people with Down Syndrome”.

We will give you more information on attending the conference at the earliest possible stage.

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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