Dear Members of European Parliament

On behalf of EDSA, the European Down syndrome association, which represents more than 40 European Down syndrome associations, and of DSG2D, a network of the European college of Neuropharmacology on Down syndrome and other genetic developmental disorders, and of Trisomy 21 Research Society (T21RS), which has more than 70 European scientists as members, we would like to draw your attention to the need for research programs on Down syndrome in Europe.

Down syndrome concerns 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 carers and families.

Down syndrome, caused by the trisomy of chromosome 21, is a complex condition characterized by a number of phenotypic features, including reduced neurons (brain cells), synaptic plasticity and intellectual disabilities, as well as early Alzheimer-like neurodegeneration, craniofacial dysmorphia, heart development defects, and increased incidence of childhood leukemia. The syndrome is also associated with suppression of the incidence of most solid tumors. Mouse models replicate a number of these phenotypes.

The last 10 years have seen tremendous advances in the understanding of the links between the phenotypic features and the damaging effects due to three copies of chromosome 21. These new results have started paving the way for therapeutic strategies targeting brain functional impairment as well as common co-morbidities such as Alzheimer's disease in experimental models. For some of those therapies, **clinical trials have been launched recently** to test their efficacy in individuals with Down syndrome and at least one has already given positive results. However, future research for an efficient assessment of **possible therapeutic targets and strategies need a concerted research program** bringing together scientist, clinicians and expert caregivers from different fields of research and with complementary expertise.

This program will not be achieved by research supported by individual countries, as it will be necessary to involve a large number of people with Down syndrome, and this will require collaboration between different countries.

In **US** and for the last ten years a major funding effort has been devoted to research on Down syndrome with $200 M coming from federal organisations: (source: NIH website) and $20 M from private foundations.

In comparison and in the same period of time **Europe** (Health program in FP6, FP7, H2020 and private organizations) has funded smaller programs for less than 15 M€ . In the last years these H2020 programs have been focusing only on the cause of Down syndrome, e.g. meiotic errors or chromosome non-disjunction (6.6 M€) and social and education programs (3.56 M€). **None of these programs have focused on molecular aspects or development of pharmacological or other interventions, or on clinical trials.** National funding is very low or non-existent. The situation of European teams working on translational research oriented towards Down syndrome is becoming critical.

We think that the structure of the EU calls which put together programs on diseases with a high prevalence like diabetes, cancer, or cardiovascular diseases and projects on diseases with very low prevalence (i.e. rare diseases) do not permit a fair evaluation of the applications presented by EU researchers on Down syndrome, and more generally, on other individuals with genetic forms of intellectual disabilities, as these conditions are perceived to be neither common nor rare enough to qualify for most of the current EU funding calls. The criterion used for evaluation of applications appears to be the general impact, but those focused on intellectual disabilities may be judged to have less general impact if compared to programs targeting major diseases, despite the clear potential for significant impact upon the quality of life and abilities of these disadvantaged groups of individuals and their carers. Lifelong caring is necessary for many people with intellectual disabilities creating a major burden for families and a very high economic cost for each European country.

We think that the time has come for Europe, through the H2020 Health Program, to give a strong support to European scientists and clinicians willing to commit themselves to research on individuals with genetic intellectual disabilities such as those with Down syndrome.

We are asking your support to encourage EU commission to propose thematic lines focusing on specific aspects of genetic intellectual disabilities including Down syndrome in the next calls for 2018, 2019

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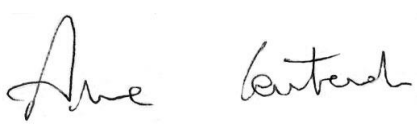
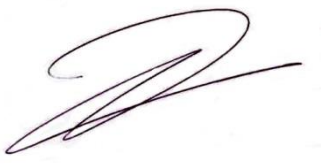
Jean Maurice Delabar

T21RS Past President
Chair of the committee for sponsoring

Marie Claude Potier

T21RS General Secretary
Chair of DSG2D ECNP network





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