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- 1 Catsman-Berreoets CE, Craiu D. Evaluation of the paediatric neurology training in the republic of Ukraine. 2021. <https://www.epns.info/wp-content/uploads/2022/02/2021-TAB-Visit-to-Ukraine.pdf> (accessed Feb 24, 2025).
- 2 Craiu D, Haataja L, Hollody K, et al. The training and organization of paediatric neurology in Europe: special report of the European Paediatric Neurology Society and Committee of National Advisors. *Eur J Paediatr Neurol* 2020; **28**: 6–15.
- 3 Pinchuk I, Leventhal BL, Ladyk-Bryzghalova A, et al. The Lancet Psychiatry Commission on mental health in Ukraine. *Lancet Psychiatry* 2024; **11**: 910–33.

Advocating for increased awareness and research on Down syndrome

World Down Syndrome Day, observed annually on March 21 and recognised by the UN since 2012, aims to raise awareness of Down syndrome to help people better understand and support those with the condition. As members of the executive board of the Trisomy 21 Research Society (T21RS)—the only

international society dedicated to Down syndrome research, which was founded a decade ago and now has more than 680 members worldwide—we advocate for greater recognition of the people with Down syndrome, aim to enhance health care, and address the burden of co-occurring conditions through research.

Ongoing research is essential to improving the quality of life of individuals with Down syndrome by addressing increased risk of comorbidities, enabling their early diagnosis, and developing tailored interventions. Individuals with Down syndrome are at high risk for Alzheimer's disease, but have not been included in clinical trials for approved Alzheimer's disease immunotherapies yet.¹ Therefore, it is unknown to what extent such treatments will prove to be safe and effective in those with Down syndrome. Research on Down syndrome enriches our knowledge, promotes social inclusion, and informs policies on education and employment. As life expectancy for individuals with Down syndrome increases, continued research will ensure better ageing care. Insights gained from research on accelerated ageing in individuals with Down

syndrome could also have broader applications for understanding ageing processes, diseases, and treatments that will benefit all populations. Down syndrome research is indispensable, yet currently insufficient.

T21RS aims to foster collaboration among Down syndrome researchers globally through online platforms, international meetings, and conferences (figure) by establishing standardised protocols for basic and translational research; supporting education and training for young researchers through education programmes and pilot grants; by communicating research findings to the public and policy makers; and by strengthening connections between scientists, industry, patient associations, foundations, and society at large.

Marie-Claude Potier is President of the Trisomy 21 Research Society.

**Marie-Claude Potier on behalf of the Trisomy 21 Research Society executive board†*

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- 1 Fortea J, McGlinchey E, Espinosa JM, Rafii MS. Addressing challenges in health care and research for people with Down syndrome. *Lancet* 2024; **403**: 1830–33.

See Online for appendix

For more on T21RS see <https://www.t21rs.org/>



Figure: Trisomy 21 Research Society conference in Rome, June, 2024