

that up to 50% of people with degenerative cervical myelopathy who receive treatment report no improvement in their symptoms because of the irreversible damage by the time the disease is diagnosed and treated.³ Raising awareness about this disease is crucial to reduce diagnostic delays and improve outcomes.

A not-for-profit charity has established incubator groups targeting diagnosis, assessment, and rehabilitation. The organisation, which includes surgical and non-surgical experts from across the globe, is working to improve awareness and outcomes. The charity is also synthesising practice guidelines to aid in diagnosis, and contributing to the Enhanced Recovery After Surgery project. We invite the global medical and research community to join us in this urgent mission.

We declare no competing interests. The authors would like to thank the other members of the Myelopathy.org Perioperative Incubator Group: Benjamin Davies, Aditya Vedantam, Justin M Lantz, Joshua Plener, Rana Dhillon, Carlo Ammendolia, Sukhvinder Kalsi-Ryan, Vishal Kumar, Annalena Paus, Rohil Chauhan, Marije de Jong, Maryse Fortin, Timothy Boerger and Nicky Wilson.

**Jay John Wardropper,
Andreas K Demetriades,
David B Anderson
jjw90@cam.ac.uk*

School of Clinical Medicine, University of Cambridge, Cambridge CB2 0SP, UK (JJW); Sydney Musculoskeletal Health, Faculty of Medicine and Health, The University of Sydney, Sydney, NSW, Australia (DBA); Department of Neurosurgery, New Royal Infirmary, Edinburgh, UK (AKD)

- 1 Grodzinski B, Stubbs DJ, Davies BM. Most degenerative cervical myelopathy remains undiagnosed, particularly amongst the elderly: modelling the prevalence of degenerative cervical myelopathy in the United Kingdom. *J Neurol* 2023; **270**: 311–19.
- 2 Behrbalk E, Salame K, Regev GJ, Keynan O, Boszczyk B, Lidar Z. Delayed diagnosis of cervical spondylotic myelopathy by primary care physicians. *Neurosurg Focus* 2013; **35**: E1.
- 3 Pope DH, Mowforth OD, Davies BM, Kotter MRN. Diagnostic delays lead to greater disability in degenerative cervical myelopathy and represent a health inequality. *Spine* 2020; **45**: 368–77.

Paediatric neurology in Ukraine: a call for help

In Ukraine, before the war, neurological care for children was provided by approximately 700 paediatric neurologists (one per 8400 children). The responsibilities of paediatric neurologists in Ukraine are diverse and include neurorehabilitation for children with acquired CNS injury and psychiatric care for pre-school aged children. Substantial challenges were identified during a 2021 visit of the Training Advisory Board of the European Paediatric Neurology Society to Ukraine.¹ This evaluation noted that physicians trained as paediatricians or neurologists received only 5 months of further specialist training, compared with 2.0–3.5 years in other European countries. The evaluation also noted little involvement of trainees in daily clinical practice and reduced access to up-to-date genetic and metabolic diagnostics and novel therapeutics, such as emergency antiseizure medications, drugs, and gene therapies available in other European countries.²

The situation has changed markedly since the start of the Russia–Ukraine war in 2022. By July, 2024, almost 7 million Ukrainian refugees (about 15% of the population and mostly mothers and children) were living outside Ukraine, and almost 4 million people were displaced within Ukrainian borders. The number of paediatric neurologists in Ukraine is now around 300. The shortage of specialists is particularly bad in regions close to the front line. The length of paediatric neurology training is now reduced to 3 months. The constant risk of missile attacks causes fear and anxiety, reducing parents' desire to leave home and seek highly specialised care in tertiary centres. These circumstances have resulted in delayed diagnosis of neurological conditions. The number of children requiring rehabilitation for CNS injuries has increased due to war-related trauma. There are very few child psychiatrists in Ukraine;

therefore, the management of post-traumatic stress disorder in children is now done by paediatric neurology services. We need urgent help to deliver comprehensive services for children with post-traumatic stress disorder.

We call on national governments and medical societies in Europe to support children with neurological disorders in Ukraine. Once the war ends, the country must develop and fund a training programme for paediatric neurologists that is in accordance with the standards set by the European Paediatric Neurology Society syllabus. We call for help to establish systems and funding to ensure that children in Ukraine can access therapies regarded as standard of care elsewhere in Europe. Also, paediatric neurologists in Ukraine need support in managing mental ill health in children with neurological diseases.³

AN is a representative of the Association of Child Neurologists of Ukraine at the European Paediatric Neurology Society Committee of National Advisors. KR has received consulting fees from Roche for the Operetta 2 Study, payment or honoraria from Merck for lectures, and is Preseicent of the European Paediatric Neurology Society. SMZ is Vice President of the European Brain Council, a member of the Scottish Palestinian Health Partnership, past President of the European Paediatric Neurology Society, and a member of Child Health Advocates 4 Palestine. DC is Chair of the Education and Training Committee of the European Paediatric Neurology Society. AJ is Chair of the Advocacy and Collaboration Committee of the European Paediatric Neurology Society. CEC-B is Vice Chair of OneNeurology and past Chair of the Education and Training Committee of the European Paediatric Neurology Society. All other authors declare no competing interests.

**Alla Nechai, Oxana Nazar,
Kevin Rostasy, Sameer M Zuberi,
Dana Craiu, Anna Jansen,
Coriene E Catsman-Berrevoots
allanechay@ukr.net*

Department of Neurology, Kyiv City Children Clinical Hospital No1, 04209 Kyiv, Ukraine (AN); Department of Pediatrics, Pediatric Neurology and Medical Rehabilitation, Shupik National Healthcare University of Ukraine, Kyiv, Ukraine (ON); Department of Pediatric Neurology, Vestische Kinder und Jugendklinik, Witten/Herdecke University, Datteln, Germany (KR); Paediatric Neuroscience Research Group, Royal Hospital for Children, University of Glasgow, Glasgow, UK

For more on Myelopathy.org see <https://myelopathy.org/>

For the European Paediatric Neurology Society syllabus see <https://www.epns.info/education-and-training/european-syllabus/>

(SMZ); Pediatric Neurology Clinic, Al Obregia Hospital, Carol Davila University of Medicine, Bucharest, Romania (DC); Division of Pediatric Neurology, University Hospital Antwerp, Antwerp, Belgium (AJ); Department of Paediatric Neurology, Erasmus Medical Center/Sophia Children Hospital, Rotterdam, Netherlands (CEC-B)

- 1 Catsman-Berrevvoets 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†*

marie-claude.potier@icm-institute.org

†Members, affiliations, and declarations of interest are listed in the appendix. ICM Institute for Brain and Spinal Cord, Hôpital de la Pitié Salpêtrière, Paris 75013, France; INSERM, Paris, France; Centre National de la Recherche Scientifique, Paris, France; Assistance Publique Hôpitaux de Paris, Paris, France; Sorbonne Université, Paris, France

- 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