

Date: July 18, 2024 Barcelona, Spain

Dear Member of the European Parliament,

Congratulations on your recent election to the European Parliament!

In anticipation of the forthcoming Multiannual Financial Framework (MFF), and more specifically, Framework Programme 10 (2028-2034), we want to draw your attention to the crucial matter of children's and adolescents' health in the EU and urge you to address the unique needs of this population in the upcoming MFF negotiations.

Children are not small adults; they have unique needs that have been underrepresented in the Framework Programmes. To date only two calls have specifically targeted children under Horizon Europe¹ in Cluster 1 (Health). In children's hospitals, we encounter **significant health disparities between children in the EU due to inequitable access to healthcare**, ², ³ affecting both regions and populations. The development of diagnostics, medicines and medical technologies for children's healthcare is lagging due to insufficient investments and market failures. In Europe up to 69% of medications administered to children in hospital are used without being designed for them, ⁴ leading to unnecessary suffering.

Investment in research and innovation is crucial to overcoming these challenges and helping correct these market failures. It also offers a unique window of opportunity to strengthen the foundation for a healthy life course for new generations and their parents. We call for strategic allocations towards research, innovation, and policy development in four pivotal domains:

- 1. Tailor early interventions and healthcare services to meet the distinctive requirements of children and adolescents across Europe, with an emphasis on paediatric chronic diseases and palliative care, rare diseases and mental health.
- 2. Implement coordinated strategies to optimise the utilisation of paediatric orphan medicinal products through harmonising regulatory procedures and providing appropriate incentives.
- 3. Accelerate advancements in paediatric health by nurturing collaborative endeavours among stakeholders within the EU and prioritising funding for research initiatives. Additionally, urgent measures must be taken to guarantee continued access to high-risk medical devices for children through the enactment of responsive EU regulations.
- 4. Tailor innovative biomedical research methodologies and technologies to accommodate the unique biologic nuances of the paediatric population. This strategic adaptation will catalyse an increase in paediatric clinical trials, fostering the development of transformative medical interventions and precision medicine for children throughout the EU.

We cordially invite you to engage in a dialogue with ECHO at your earliest convenience regarding the paramount importance of children's health and access to care in the European Union. We look forward to working with you and your colleagues on relevant committees to ensure future funding and legislation address the health challenges children and young people in Europe face.

Sincerely,

Manuel del Castillo Rey

ECHO President

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Ruben Diaz ECHO Executive Director

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The European Children's Hospital Organisation (ECHO) is a growing organisation representing 16 of the leading children's hospitals in 12 EU countries. ECHO advocates for children's health and their access to the best quality care through the collaborative efforts of children's hospitals.

ECHO Members

Astrid Lindgren Children's Hospital, Karolinska University Hospital, Stockholm, Sweden; Children's Clinical University Hospital, Riga, Latvia; Children's Health Ireland, Dublin, Ireland; Children's Memorial Health Institute, Warsaw, Poland; Comprehensive Center of Pediatrics, Medical University of Vienna, Vienna, Austria; Dr. von Hauner Children's Hospital, LMU, Munich, Germany; Erasmus MC—Sophia Children's Hospital, Rotterdam, Netherlands; Great Ormond Street Hospital for Children, London, United Kingdom; HUS New Children's Hospital, Helsinki, Finland; Mary Elizabeth's Hospital Rigshospitalet for Children, Teens and Expecting Families, Copenhagen, Denmark; Meyer Children's Hospital, Florence, Italy; Necker-Enfants Malades Universitary Hospital AP-HP, Paris, France, Ohmatdyt National Specialized Children's Hospital, Kyiv, Ukraine; Oslo University Hospital, Division of Paediatrics, Oslo, Norway; Sant Joan de Déu Barcelona Children's Hospital, Barcelona, Spain; Schneider Children's Medical Center of Israel, Petach-Tikva, Israel

¹ Towards a holistic support to children and adolescents' health and care provisions in an increasingly digital society (HORIZON-HLTH-2024-STAYHLTH-01-02-two-stage), and Access to health and care services for people in vulnerable situations (HORIZON-HLTH-2024-CARE-04-04-two-stage).

² Botta et al. (2022), EUROCARE-6 Working Group. <u>Long-term survival and cure fraction estimates for childhood cancer in Europe (EUROCARE-6): results from a population-based study</u>. Lancet Oncol.

³ OECD/European Union (2022), "Coping with COVID-19: Young people's health in an age of disruption", in Health at a Glance: Europe 2022: State of Health in the EU Cycle, OECD Publishina, Paris.

⁴European Commission, Directorate-General for Health and Food Safety, Marjolein et al. <u>Study on off-label use of medicinal products in the European Union – Report,</u> Publications Office, 2019.