

**Mrs. Ursula von der Leyen**  
**President of the European Commission**

European Commission,  
B-1049 Brussels

Vienna, 15 September 2025

**Subject: EU4Patients – Operating Grants are essential to keep patient voices at the table**

*Open Letter from NGOs representing parents, patients and survivors of childhood cancer*

Dear President Von der Leyen,

The European Union has emerged as a leader in involving civil society in policymaking.

In recent years, it has been encouraging to see childhood cancer prioritised on the European political agenda through initiatives such as Europe's Beating Cancer Plan and the EU Cancer Mission. These efforts have opened the door for health organisations to step in and shape what matters most: the health, lives and wellbeing of real people.

That is the mission of Childhood Cancer International – Europe. We represent children, adolescents, and young adults with rare and life-threatening cancers, as well as their parents and families. They face toxic treatments, long hospital stays, and enormous uncertainty - always with their families by their side, hoping for survival and for a better future. Parents, patients and survivors, through their lived experience, play a vital role in raising awareness about the burden of the disease and the many challenges that remain.

Together with and for these patients, we have contributed to projects such as EU-CAYAS-NET, focused on improving survivorship and mental health. Through the European Reference Network for Paediatric Cancer (ERN PaedCan), we support families in accessing standard-of-care treatment across borders. More recently, we have been honoured to coordinate patient involvement in the EU

Health Technology Assessment (HTA) process – ensuring that new medicines and therapies are aligned with the real needs of real patients.

Not only do we work on projects, but we also provide a critical role in creating connections between patient organisations from the 27 Member States and beyond. We facilitate mutual learning, reinforce each other, and identify common challenges. **We carry those voices back to the European Commission to ensure tomorrow's policies truly reflect the needs of young patients and their families.**

We are proud to contribute. And we are committed to continuing this work.

But to do so - professionally, independently, and across borders - we need stable and sustained financial support. Not just project-based funding, but sustainable operating grants that allow organisations like ours to stay active, coordinated, and effective. Without them, the essential infrastructure of patient representation is at risk.

Today, even though the 2025 EU4Health Work Plan has been recently published, it makes no reference to operating grants, and there has been no further official communication about when – or if – a call for operating grants will follow. The lack of transparency around this delay raises serious concerns and leave patient organisations in a place of uncertainty. Without this framework, patient organisations like ours are left in limbo - unable to plan, hire or engage - while expectations and needs towards our commitment continue to grow. It not only puts our work at risk, but it undermines the EU's own goals for a resilient and inclusive European Health Union.

**CCI Europe believes that strong patient advocacy is a vital part of building effective, inclusive health systems.** Backing that advocacy with sustainable funding is how the EU can turn its values - unity, solidarity and democracy - into real action.

**We therefore urge you to ensure the immediate approval of the full-year operating grants for European civil society organisations, clarifying this uncertain and confusing situation as soon as possible.** A strong European Health Union needs strong patient representation - and those voices need support to be heard.

Sincerely,

**Signatories:**

1. Childhood Cancer International – Europe
2. Acreditar-Associação de Pais e Amigos de Crianças com Cancro
3. Association "Children with Oncohematological Diseases"
4. Association P.A.V.E.L.
5. Association Romande des familles d'Enfants atteints d'un Cancer
6. Barncancerfonden - The Childhood cancer fund
7. CanTeen Ireland
8. Childhood Cancer Foundation "CRAB"
9. Childhood Cancer Ireland
10. Dăruiește Aripă Association
11. Deutsche Leukämie-Forschungshilfe
12. Érintettek Parents' Association
13. Estonian Association of Parents of Children with Cancer
14. Federación Española de Familias de Cáncer Infantil (FEFCI) – representing 23 member organisations
15. Federazione Italiana Associazioni dei Genitori e Guariti Oncoematologia Pediatrica (FIAGOP) – representing 33 member associations
16. Flaga Parents Association of children with cancer
17. Fondation Kribskrank Kanner
18. Heart for kids with cancer
19. Imagine for Margo – Children without Cancer
20. KARKINAKI Awareness for Childhood and Adolescent Cancer
21. KickCancer
22. Krijesnica (Firefly)
23. Lithuanian Children's Cancer Association Paguoda
24. Monk Andrew's Charity Foundation
25. Panhellenic association of Childhood and Adolescence Cancer Survivors Kyttaro
26. POMÁHAME S ÚSMEVOM n.o.



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International – Europe**

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27. Saving Kids with Cancer Foundation
28. Sawera Health Foundation
29. Soleterre
30. Solving Kids' Cancer UK
31. Survivors Luxembourg
32. Survivors Österreich - Kinder-Krebs-Überlebenden-Initiative
33. Sylva
34. TABLETOCHKI Charity Foundation
35. Together Fighting Sarcoma Association
36. Udruzenje "Uvek sa decom"
37. Vereniging Kinderkanker Nederland
38. Zaporuka Charitable Foundation
39. Zoé4life
40. "Zvončica" Parent's organization of children with cancer and other rare diseases



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**Countries:**

- |                         |                    |
|-------------------------|--------------------|
| 1. Austria              | 15. Lithuania      |
| 2. Belgium              | 16. Luxembourg     |
| 3. Bosnia & Herzegovina | 17. Netherlands    |
| 4. Bulgaria             | 18. Poland         |
| 5. Croatia              | 19. Portugal       |
| 6. Estonia              | 20. Romania        |
| 7. Finland              | 21. Serbia         |
| 8. France               | 22. Slovakia       |
| 9. Georgia              | 23. Spain          |
| 10. Germany             | 24. Sweden         |
| 11. Greece              | 25. Switzerland    |
| 12. Hungary             | 26. Ukraine        |
| 13. Ireland             | 27. United Kingdom |
| 14. Italy               |                    |



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