



The European Childhood Cancer Community Urgently Calls for the Release of the Proposal of the Revised EU Pharmaceutical legislation

[The European Society for Paediatric Oncology \(SIOP Europe\)](#), the single united European organisation representing healthcare professionals and researchers in paediatric oncology, and [Childhood Cancer International – Europe \(CCI Europe\)](#), the largest European patient organisation representing childhood cancer patients, parents and survivors, have been involved in the review and analysis of the EU Orphan and Paediatric Regulations since 2012.

With the current legislation, [only 16 new anticancer medicines with specific paediatric indication have been approved in comparison to over 150 anticancer medicines for adults](#). The lack of sufficient investment and the slow pace of innovation has stalled the progress in curing paediatric cancers, which remains the first cause of death by disease in children older than one year of age in Europe.

The publication of the proposal for revision of the EU Pharmaceutical legislation was already delayed several times. Most recently, it was announced for March 29th, 2023 and now it has been postponed again to April 26th 2023.

Hence, we are calling for an **urgent release** of the proposal for revision of the EU Pharmaceutical legislation. Among others, we are very concerned that the delayed publication may prevent the adoption of the new legislative package within the current EU policy term. As a result, any additional delay – even if it's only one day – is adding up to unnecessary risk for many young cancer patients placing high hopes in the revision of the EU Pharmaceutical legislation.

We urgently need this ambitious revision that will tackle inequalities and put the unmet medical needs of young cancer patients, survivors and their families at the centre of a European strategy for medicine development, which is in line with our goal to cure every child and adolescent with cancer across Europe and restore them to their full health.

We count on the European Commission's commitment for April 26th, 2023 to be the final date of the publication of the proposal for revision of the EU Pharmaceutical legislation.

ABOUT EUROPEAN CHILDHOOD CANCER ORGANISATIONS



Childhood Cancer International - Europe (CCI-E, or CCI Europe) represents childhood cancer parent and survivor groups as well as other childhood cancer organisations in Europe: 63 organisations in 34 European countries are members of CCI-E. CCI Europe works together with all relevant stakeholders for the same aim: help children and adolescents with cancer to be cured, with no - or as few as possible - long term health problems/late effects. (www.ccieurope.eu)



The European Society for Paediatric Oncology (SIOPE, or SIOP Europe) is the single united European organisation representing all professionals working in the field of childhood cancers. With more than 2,500 members across 35 countries, SIOP Europe is leading the way to ensure the best possible care and outcomes for all children and adolescents with cancer in Europe. (www.siope.eu)