

# 'Mobilising public support to improve development of and access to better and kinder drugs for children with cancer - a grass roots NGO/Parent led movement'



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## Introduction

Cancer remains the primary cause of death by disease of children and adolescents in Europe. Overall, 6000 children and young people under 24 still die of cancer every year (1).

Investment into childhood cancer research lags far behind that for adults with less than 3 new drugs being approved specifically for children in the last 60 years.

However a few basic changes to European law and the Paediatric medicines regulation could transform the situation and utilise advances that have been made in biological science for the benefit of children with cancer.



*"We strongly support replacing the class waiver system with one that looks at the mechanism of action of the drug, and feel that this would substantially increase the number of paediatric trials for potentially very important drugs for childhood cancers"*

## Objectives

**Unite2Cure** is a network of groups and individuals from across Europe, which is calling for better treatment and better access to treatment for children and young people with cancer.

The movement, which is parent/NGO led aims to unite parents/carers, survivors, charities, health professionals, researchers and other industry experts in a campaign to save more young lives.

**We are working towards a specific set of reforms to be made to the Paediatric Medicines regulation without delay.** Pharmaceutical companies consider the adult population their key customer base. Childhood cancers have been neglected as they are made up of a series of predominantly rare illnesses, virtually none of which offer a lucrative market for commercially developed drugs (2).



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## Call to action

The lives of children depend on laws for paediatric medicine in Europe being amended. We therefore propose:

1. No waivers if the mechanism of action of an adult drug is relevant to a childhood condition.
2. Support for a European database of molecular targets in paediatric cancer.
3. Facilities for the EMA to encourage collaboration between drug companies.
4. A 'lifecycle' approach in which early clinical trials are conducted before PIP's (Paediatric Investigation Plans) are submitted and plans can be revised in the light of evolving data.
5. PIPs that show significant promise to be carried forward even if the corresponding adult trial is abandoned.
6. Encourage the voluntary development of specific paediatric drugs by pharma.
7. Flexible ages of entry to adult trials based on biology and considerations of safety

## What can you do?

1. Ask your MEP to support the vote to reform
2. Raise awareness of the need to increase research and funding into childhood cancer
3. Visit our website and learn more
4. Become an ambassador for Unite 2 Cure



## References

Vassal, G. et al., (2014). Challenges for Children and Adolescents With Cancer in Europe: The SIOPE-Europe Agenda Paediatric Blood Cancer. 61(9):1551-7. Viewed 18/07/15 at: <http://www.ncbi.nlm.nih.gov/pubmed/24706509>

Saint-Raymond, A., Herold, R., (2012). Medicines for paediatric oncology: can we overcome the failure to deliver? Expert Reviews. Clinical Pharmacology. 5(5), 493-495. Viewed 18/07/15 at: [http://www.researchgate.net/publication/232809972\\_Medicines\\_for\\_pediatriac\\_oncology\\_Can\\_we\\_overcome\\_the\\_failure\\_to\\_deliver](http://www.researchgate.net/publication/232809972_Medicines_for_pediatriac_oncology_Can_we_overcome_the_failure_to_deliver)

Samira Essiaf, European Society for Paediatric Oncology (SIOPE), Chief Executive Officer, Belgium: **"We should all work together towards a future where no child dies of cancer and survivors live to the fullest.**