



Monday, 4<sup>th</sup> of December 2017

Dear Mr. Andriukaitis,

We are the proud parents and representatives of beautiful, funny, noisy children. Some of them live in our hearts, some of them survived cancer after a long and toxic treatment.

When a child is diagnosed with cancer, people often comfort parents by invoking progress made in cancer treatments.

**The scandal is that in Europe, curing cancer is making progress, except for children.**

Recently, after the publication by the European Commission of the 10-year review report of the Paediatric Medicines Regulation, we heard you commenting: *"It's of my biggest concern that the development in childhood cancer drugs has not been as effective as in adult oncology"*.

**Paediatric cancer is a public health issue and the first cause of death by disease for children in Europe.**

Some cancers benefit from an excellent cure rate, others are well below 50%. And yet, the treatments for those have hardly changed over the last 15 years. **No access to innovation means no hope.**

Many people think: *"we don't know the long-term side effects of new drugs..."*. Well, we do know that today, one child out of five is not cured and that two-third of the survivors will go through life with long-term side effects caused by their treatment, such as cardiac problems, secondary cancers, cognitive delays, blindness, amputations, fertility problems...

The Paediatric Medicines Regulation mandates industry to perform clinical trials in children for new drugs to be authorised for adults: it was a revolution for many children but NOT for children with cancer. This shortfall on paediatric cancer was clearly identified in the European Commission's recent report on the Regulation.

We cannot accept that industries be authorised to avoid developing a drug that could benefit some paediatric cancers thanks to biological similarities with adult cancers. We know many examples of lost opportunities for our children in the last 10 years.

Mandatory tests of drugs, based on a shared molecular profile of the tumour between adults and children, is already happening in the US with the RACE for children Act voted this summer by Congress. Why can't we do the same in Europe?

We are so disappointed that the report does not propose immediate action... **If we do nothing today, children will continue to die.**

Dear Commissioner, we are calling upon you to order an executable work plan to start improving the Regulation as soon as possible.

**Now, let's act upon this! Together.**

#Unite2Cure, #ChildhoodCancerInternational

Acreditar (Portugal), Adolescenti e cancro (Italy), Association "Children with onco-hematologic diseases" (Bulgaria), Association Aïda (France), Association Cassandra (France), Association Laurette Fugain (France), Barncancerfonden (Sweden), Barncancerfonden Mellan Sverige (Sweden), Barncancerfonden Norra (Sweden), Barncancerfonden Östra (Sweden), Barncancerfonden Södra (Sweden), Barncancerfonden Stockholm/Gotland (Sweden), Barncancerfonden Västra (Sweden), Bethany's Wish (United Kingdom), Charitable Foundation Zaporuka (Ukraine), Childhood Cancer Foundation (Ireland), Christopher's Smile (United Kingdom), Create for Chloé (United Kingdom), Deutsche Kinderkrebsstiftung (Germany), Érintettek Egyesület (Hungary), Federación Española de Padres de NIÑOS CON CÁNCER (Spain), Fédération Enfants Cancers Santé (France), FIAGOP (Italy), Fondazione Soletterre (Italy), Fondatioun Kriibskrank Kanner (Luxembourg), Grace Kelly Ladybird Trust (United Kingdom), Imagine for Margo (France), KickCancer (Belgium), Kytтары - Adult Survivors from Childhood and Adolescence Cancer (Greece), Association Hubert Gouin "Enfance & Cancer" (France), L'Etoile de Martin (France), Österreichische Kinder-Krebs-Hilfe (Austria), Paguoda (Lithuania), PORT - Paediatric Oncology Reference Team (United Kingdom), Princesse Margot (France), SMILE n.o. - Pomáhame s úsmevom (Slovakia), Solving Kids Cancer (United Kingdom), Tuki (Belgium), Udruženje - Srce za djecu koja boluju od raka u FBiH (Bosnia), VOKK - Vereniging Ouders, Kinderen en Kanker (Netherlands), Zoe4life (Switzerland).