



Kids with Cancer Suffer as Inequity Gap Widens

Proposal seeks to repair inequitable access to early phase clinical trials in Canada

Toronto, ON, May 17, 2018 – Today over 23 leading pediatric oncologists and researchers, and 27 cancer organizations from across North America, are shedding light on the inequitable access to promising early phase clinical trials for Canadian children, adolescents and young adults (CAYA) with cancer and offering solutions to ensure no child gets left behind.

Authored by Advocacy for Canadian Childhood Oncology Research Network (Ac2orn), with assistance from C17 Council and Helena's Hope: Pathways to More Kids Surviving Cancer, the proposal "Improving Outcomes for Canadian Children, Adolescents, and Young Adults with Cancer: A proposal for a working relationship with Health Canada", provides actionable feedback from researchers and clinicians across the country.

"Currently, no coordinated system exists to allow Canadian children with cancer to access promising early phase clinical trials outside of their home province," said Dr. Jim Whitlock, Chair of C17 Council. "Families without treatment options in their home province are forced to advocate for early phase clinical trial access and often must pay extraordinary out of pocket costs, or they can die while they wait for funding appeals. No child should have to miss out on something that has a reasonable possibility of saving their life."

The proposal to the Federal Minister of Health contains two requests:

1. Establish a program that will facilitate equal access to promising phase 1 and 2 clinical trials for children, adolescents, and young adults (CAYA) with cancer, regardless of home province or financial means; and
2. Establish a collaborative working group with Health Canada for two-way conversations, with patient and family engagement, that identifies challenges and initiates solutions to move forward on improvements in CAYA cancers.

To read the full proposal, please visit: curesforourkids.com/media.html

"Ten years ago, after watching him run, jump, dance, sing, smile, and love, I watched my three year-old son Finn die," said Patrick Sullivan, Chairman at Ac2orn. "We are in a Golden Age of cancer research and are on the edge of a world where children like Finn will get to thrive and grow. But without innovation, our Canadian children are going to be left behind and where you live in Canada will impact if, when, and how you will benefit from the changes that are coming. This proposal to the Federal Government was developed to address the opportunity this Golden Age presents while recognizing where the challenges lie."

Helena's Hope has come together with Ac2orn and C17 for a coordinated Canadian effort, with a goal to continue to increase survival rates and improve quality of life through treatment and beyond for CAYA with cancer. Helena's Hope was founded in March 2017 when Helena Kirk, a 12 year-old leukemia survivor and founder of Helena's Hope, began advocating the Federal Government after watching too many of her friends die from cancer. Over 80 families from 7 Provinces have joined Helena's advocacy effort and are seeking endorsements of MPs and Federal Ministers to support the Ac2orn proposal. To date, Helena has met with Prime Minister Trudeau, Science Minister Kirsty

Duncan, MP Anita Vandenberg, former Health Minister Jane Philpott, and current Health Minister Ginette Petitpas Taylor.

“Now is the time!” said Helena Kirk, Founder of Helena’s Hope. “Canada is the best country in the world, but we are failing our childhood cancer families. Some of my strongest and bravest friends have died from cancer, like my best friend Jadyne who was, and still is, my biggest role model and idol. Jadyne was offered palliative care when a clinical trial that could have saved her life came too late. That’s not okay. We need to do better and the good news is better is very possible. I am hopeful that the government will help my friends who are still fighting, so they can become survivors like me.”

While in Ottawa, Helena gave a speech to the All-Party Women’s Caucus members, her speech can be found here: <https://youtu.be/rp99pz3JGWk>. Helena was recognized for her advocacy efforts in the House of Commons by MP Anita Vandenberg, Anita’s statement can be found here: <https://youtu.be/kaEXwsVilkk>.

For more information on Ac2orn, please visit curesforourkids.com. For more information on Helena’s Hope, please visit helenashope.com or Facebook page: [Helena’s Hope](#). For more information on C17, please visit c17.ca.

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About Advocacy for Canadian Childhood Oncology Research Network (Ac2orn)

Advocacy for Canadian Childhood Research Network, Ac2orn, is committed to advocating for translational research and effective treatments to realize the goal of curing childhood, adolescent, and young adult cancers (CAYA). Ac2orn is a national organization made up of CAYA cancer families and survivors who are dedicated to breaking down barriers and building bridges in the world of CAYA cancer research. Ac2orn was formed in 2014. For more information on Ac2orn, please visit curesforourkids.com.

About Helena’s Hope: Pathways to More Kids Surviving Cancer

Helena’s Hope was started by 12 year-old leukemia survivor and Helena’s Hope founder Helena Kirk with a goal to find pathways to more kids surviving cancer. Helena’s Hope is supported by over 80 Canadian childhood cancer families from 7 Provinces who are collaboratively advocating the government for increased funding and access to innovative treatments. For more information on Helena’s Hope, please visit helenashope.com or Facebook page: [Helena’s Hope](#).

About C17 Council

C17 is a non-profit organization in Canada that links all the pediatric oncology programs across Canada to improve health outcomes and quality of life for children and adolescents with cancer and serious blood disorders. C17 fosters, funds and supports multi-centre and translational research on cancer and serious blood disorders in children and adolescents in Canada through access to international academic cooperative group clinical trials, funding research grants and providing educational research and training opportunities to support health professionals in delivering pediatric hematology, oncology and BMT services across Canada. For more information, please visit c17.ca.

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