The Canadian Initiative

Improving Outcomes for Canadian Children, Adolescents, and Young Adults with Cancer:

A proposal for a working relationship with Health Canada

June 1, 2018

Supporters/Signatories:

For more information, please contact Patrick Sullivan (patrick@ac2orn.com) or Antonia Palmer (antonia@ac2orn.com).
My Journey to This Place
Four Central Pillars: One Advocates Perspective
1. Do Not Confuse How With Why* 

Act, Think & Communicate from the INSIDE OUT!

WHY - Your Purpose
Your motivation? What do you believe?

HOW - Your Process
Specific actions taken to realize your Why

WHAT - Your Result
What do you do? The result of Why. Proof

With credit to Simon Simek-Start With Why
2. Success Complicates Progress

WHAT PEOPLE THINK IT LOOKS LIKE

WHAT IT REALLY LOOKS LIKE
3. Apart Will Not Work

International Collaboration

Advocates/
Patients

Regulators

Industry/Pharma

Clinicians/
Scientists

Payors
4. We Need To Start With Why
Why

ALL-HR
Phoebe

Post-Transplant
Eric

AML
Zach

Rare Pediatric Cancers
Mateo

Brain Tumors
Derek

Ewing Sarcoma
Brenden

Osteosarcoma
Katie

Neuroblastoma
Oscar, Erik,

Rhabdomyosarcoma
Sean

Dr. Stefan Pfister, DFKZ, Heidelberg
Overview
Despite gains in childhood, adolescent and young adult (CAYA) cancer research and treatment, Canadian children continue to die. This will improve only if our health care system identifies and implements innovative models of care for CAYA with cancer. We have a plan that has been built over time and on the basis of collaboration: a plan for a coordinated Canadian effort to ensure that survival rates continue to increase, quality of life continues to improve through treatment and beyond, that research capacity is strengthened, and that Canada continues to lead in CAYA oncology.

Our plan starts with two initiatives:

1. **Enabling equitable access to early phase cancer clinical trials**

   Currently, no coordinated system exists to allow Canadian children with cancer to access promising treatments outside of their home province or outside of Canada. Families without treatment options in their home province are forced to advocate for early phase clinical trial access and must often pay extraordinary out of pocket costs. The Canadian healthcare system needs to support families and help them access potentially life-saving clinical trials for their children – no matter where they live. Therefore, we need new ways to effectively reallocate resources from futile “standard” treatment to promising and effective new treatments. We are proposing a program to address these problems.

2. **CAYA Oncology Patient Engagement Collaborative**

   We are asking a Health Canada Secretariat to create a collaborative Working Group to address health system issues related to CAYA cancer. This Working Group will be a forum to create a Report to discuss the allocation of an additional federal commitment to solve problems such as inadequate supports for pediatric oncology research, the lack of a formalized CAYA cancer drug discovery program, the need for a clinical trial pipeline and potential opportunities to incentivize industry to support CAYA oncology. Together with Health Canada, we would like to meaningfully address these and many other issues.

Ac2orn, Advocacy for Canadian Childhood Oncology Research Network, was founded in 2012 as a national
December Health Canada Meeting

1. Terry Fox Profile

2. Use of Off-Label Drugs in Context of Clinical Trials

3. Accelerate
Never Underestimate What This Community Can Offer

“The pediatric oncology research community through extensive collaboration worldwide has been at the forefront of exploiting next-generation sequencing technologies to gain better insight into tumour biology” Implementation of mechanism of action biology-driven early drug development for children with cancer” Working Group 1 Accelerate
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Take-A-Ways

1. Canadians Need Your Help and Canadians Want to Help You

2. Sustained Success is Complicated

1. We All Control Different Parts of the Puzzle

1. Always Start With Why

1. Advocates Can Work From The Outside or from the Inside

1. Success Will Only Come From Working Together

1. We Can Lead

1. We Should Lead