Helena's Hope
PATHWAYS TO MORE KIDS SURVIVING CANCER

BRIEFING NOTE

Nation-wide consensus of childhood, adolescent and young adult funding priorities, supported by:

Children's Cancer & Blood Disorders

Coast to Coast Against Cancer Foundation

Childhood Cancer Canada

Mamma Warriors

Childhood Cancer Survivor Canada – in it together

Ac2orn – Advocacy for Canadian Childhood Oncology Research Network

AYA Canada

OPACC – Ontario Parents Advocating for Children with Cancer

leucan – Association for Children with Cancer

Leukemia & Lymphoma Society of Canada

Fondation Charles-Bruneau

Canadian Cancer Society

Lymphoma Canada | Lymphome Canada

neuroblastomacanada

LSTN – Life-Saving Therapies Network – Better Therapies, Faster Access

Canada's Children's Hospital Foundations

SickKids

la fondation de l'hôpital de montréal pour enfants – the montreal children's hospital foundation

Fondation CHU Sainte-Justine Foundation

BC Children's Hospital Foundation

IWK Foundation

CHEO Foundation Fondation

Jim Pattison Children's Hospital Foundation

McMaster Children's Hospital Foundation

The Children's Hospital Foundation of Manitoba

Children's Health Foundation

Stollery Children's Hospital Foundation

Janeway Children's Hospital Foundation

Kids with Cancer Society

childcan – Facing Childhood Cancer Together

Team Finn – Run Jump Bounce Dance Sing Love Smile Ride

Northern Ontario Families of Children with Cancer

Phoebe Rose Rocks Foundation

Le Fonds de Sarah des Cèdres – Sarah's Fund for Cedars

Tears Mean Love

Ottawa Regional Cancer Foundation – Fondation du cancer de la région d'Ottawa

miracle marnie

Candlelighters Simcoe – parents of children with cancer

OncoHeroes Biosciences

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Briefing Note: Helena's Hope Response to the Liberal Party of Canada's Pediatric Cancer Research Platform

Issue:

- In its election platform, the Liberal Party of Canada committed $30 million to Pediatric Cancer Research.
- Helena's Hope, a National Advocacy Group representing families impacted by childhood cancer, is proposing key considerations for long-term planning. We endeavour to work collaboratively in the development and delivery of this life-saving work.

Key Considerations for Implementing Long-Term Plans for Pediatric Cancer in Canada:

1. **Establish a National Childhood, Adolescent, and Young Adult (CAYA) Cancers Steering Committee to work collaboratively and be accountable for overall steering and oversight.**
   - Determine membership and terms of reference for National CAYA Cancers Steering Committee Team, CAYA Cancers Access to Treatment Pilot Program Development Team and formal links to international leadership initiatives, such as Accelerate.
   - The current Pediatric Cancer Stakeholder Roundtable could fill the preliminary functions of the National CAYA Cancers Steering Committee.

2. **Development of a National Childhood, Adolescent and Young Adults Cancer (CAYA) Strategy:**
   - Unlike many other jurisdictions, Canada has never had a cohesive, national childhood cancer strategy. Such a strategy is urgently needed and must also include adolescent, young adult cancers and be culturally safe.
   - A national strategy would determine benchmarks, priorities and targets for improvements.
   - One area of particular interest is in improvement for access to care and patient outcomes for cancers that have low or zero prognosis for remission and survival.
   - The strategy could also address topics such as setting research priorities, ethics approval, equalization of access to treatments and inclusive of Indigenous populations.
   - A National Strategy must also include the development of a CAYA Cancer Survivorship Plan. Our children face many and significant lifelong after-effects from toxic treatments even after they survive cancer.
   - The strategy needs to include formal engagement and partnerships with patients and families across Canada, including representation on important committees and research boards.

3. **Fast, Fair and Safe Access to Trials and New Treatments**
   - Helena's Hope, as a national patient advocacy group, has the mission to find more pathways for kids to survive cancer and lead long and health lives. This includes overcoming equity barriers such as: where a child lives in Canada, or how much money their family can access quickly, should not determine if a child lives or dies.
   - Helena's Hope proposes a 4-year pilot program, concurrent to the National Strategic Plan work, to improve access to new and emerging trials and treatments for young Canadian cancer patients where standard treatments fails and there is potentially life-saving treatment available.
   - The pilot would be designed and guided by a CAYA Cancers Access to Treatment Pilot Program Development Team that will work collaboratively to design and oversee the pilot.
   - We are interested in evaluating both the health outcomes of the children, the economic benefits (costs/savings) of the pilot and the new systems' ability to ensure fast, fair and safe access.

4. **Research Funding for Pediatric Cancer (Remainder of budget)**
   - Investments in Pediatric Cancer Research that would align with the research priority setting work within the new National Strategy (see #2 above).
   - Patients, survivors and parents must play meaningful roles in determining research priorities, in research review boards and research committees. This would likely include exploring, selecting and adopting new approaches to patient advocate involvement that have been. successfully employed in other jurisdictions and for other diseases.

Stats and Facts:

Despite gains in childhood cancer research and treatment, kids and young adults continue to die.

- Cancer is the number one cause of death by disease among children.[i]
- The average age at diagnosis is 8 overall (ages 0 to 19).[ii]
- There are 70 potential life years lost on average when a child dies of cancer compared to 15 potential life years lost for adults.[iii]
- More than 95% of childhood cancer survivors will have a significant health related issue by the time they are 45 years of age; these health-related issues are side-effects of either the cancer or more commonly, the result of its treatment. Of those, 1/3 will suffer severe and chronic side effects. [iv]
- On average, about 17% of children die within 5 years of diagnosis. Among those children that survive to five years from diagnosis, 18% will die within 30 years of diagnosis.[v]
- Childhood cancer threatens every aspect of the family's life and the possibility of a future, which is why optimal cancer treatment must include psychosocial care.[vi]
- Thirty leading Pediatric Oncologists/Researchers, 31 cancer organizations and 150 families from coast to coast have advocated for a coordinated Canadian effort to ensure we continue to increase survival rates and improve quality of life through treatment and beyond for young Canadians with cancer. The advocacy proposal given in April 2018 to the Minister of Health can be viewed at www.HelenasHope.com.
- Only 7 drugs have been approved by Health Canada in the last 35 years for childhood cancers.
- The drugs Terry Fox received in treating his osteosarcoma are the same ones Helena's friend Emma received 40 years later for the same cancer. The results were the same for both Young Canadian athletes: they relapsed and died. In other words, no meaningful progress has been made in improving outcomes of osteosarcoma since Terry Fox was diagnosed.
- Most of the drugs given to cancer kids in Canada are used off-label. Current Health Canada drug approval regulations do not require evidence to support labeling for those patients under 18 years of age. Moving forward, inclusion of kids in new treatment labeling is important.
- In 2012, Emily Whitehead was the first patient to receive CAR T-Cell immunotherapy for leukemia. She was 6 years old and did not have any other treatment options available to her. Emily is still in remission from her disease and her experience paved the way for other children and adults to receive this therapy. Approximately 50% of children with previously incurable childhood B-lineage ALL can now be cured with CAR T-cell therapy.
- Parents in Helena's Hope are concerned that Canadian children seem to have access to fewer clinicals in recent years and some promising trials that are open in other G7 countries are not opening in Canada.
- Parents are also concerned about the lack of cohesive support for their survivor children as they tackle long-term effects of their treatments that include necessary physical, psycho-social and emotional supports.

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

Helena's Hope, was Founded by 14-year-old leukemia survivor Helena Kirk when she was 12. Helena's Hope's goal is to find pathways for more kids to survive cancer and lead long and healthy lives. Helena's Hope is supported by over 150 Canadian childhood cancer families from 9 Provinces who are collaboratively advocating the government for increased funding, comprehensive strategies and access to innovative treatments.

For more information on Helena's Hope, please visit HelenasHope.com or Facebook page: Helena's Hope or Email: HelenasHopeInfo@gmail.com

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[i] Childhood Cancer Canada

[ii] NCI, SEER Age-Specific Rates and Counts for Cancer Sites by Single Year of Age at Diagnosis, Table 28.13 http://seer.cancer.gov/csr/1975_2012/results_single/sect_28_table.13_2pgs.pdf

[iii] National Cancer Institute, SEER Cancer Statistics Review 1973-1997 (NCI 2000) http://jnci.oxfordjournals.org/content/93/5/341.full

[iv] St. Jude Children's Research Hospital, (JAMA. 2013:309 [22]: 2371-2381) http://jama.jamanetwork.com/article.aspx?articleid=1696100

[v] Journal of the National Cancer Institute "Cause-Specific Late Mortality Among 5 Year Survivors" http://jnci.oxfordjournals.org/content/100/19/1368.full

[vi] Institute of Medicine, 2008 – Cancer Care for the Whole Patient