



WHY CHILDREN and ADOLESCENTS with CANCER DESERVE OUR ATTENTION

1. Because all children have the right to enjoy childhood and life.

194 governments across the world have signed the UN Convention on the Rights of the Child (UNCRC). The UNCRC is a legal undertaking and a promise to all children, regardless of gender, ethnicity, nationality, religion, language, culture and economic background, to promote, defend and protect their rights.

Two rights strongly affirmed by the UNCRC are: Every child has the right to life, survival and development (Article 6) and Every child has the right to the best possible health. (Article 24)

For children with cancer, survival rates in high-income countries differ radically from those in low- and middle-income countries. This has led to a situation in which the place of birth and location of treatment determine whether a child with cancer survives or not.

The world should WORK TOGETHER in solidarity, to ensure that children/adolescents everywhere in the world have access to quality and affordable childhood cancer care and are ensured of the best possible treatment, psychosocial support and assistance.

2. Because children/adolescents with cancer are among the most vulnerable and helpless.

Treatment for childhood cancers last longer than other childhood diseases (e.g. up to 3 years for leukemia) and requires more time in hospitals and medical facilities. Despite these, childhood cancer is often given lower priority and allocated lesser resources in national budgets and development plans. This is true even in high income countries.

We need to secure the necessary political will and ask that our governments make available sustainable health financing and supportive investments in health infrastructure for children/adolescents with cancer.

3. Because every child deserves the chance to fight cancer and to live.

Early diagnosis is one of the primary factors related to childhood cancer survival and better health outcomes.

At present, too many children/adolescents with cancer experience major delays in diagnosis or are misdiagnosed, allowing the malignancy to spread and reducing their chance of a cure. Those whose diagnosis are completely missed, die without ever being seen by an appropriate health professional or being given the treatment that could have saved their life or given them the chance at a cure .

Delayed diagnosis and advanced stage of the cancer create the need for more aggressive therapy for childhood cancers, which results in adverse toxicity and increased costs. It oftentimes is also a factor for

increasing incidence of treatment abandonment (i.e. discontinuance of treatment for 4 weeks or longer, which then leads to relapse and death from progressive cancer).

We need to ask our governments to strengthen our health systems and build the capacities of our health professionals and community health volunteers so as to ensure the timely diagnosis and start of appropriate treatment for children /adolescents with cancer.

4. Because childhood cancer is still a neglected, marginalized public health issue.

While childhood cancer is considered a modern-day medical miracle, studies have shown that patient survival has plateaued over the last years especially for more difficult to treat childhood cancer diseases. These indicate the need for innovative treatments with new mechanisms of action to control these diseases.

We need to urge policy makers, political leaders and the scientific community, to make childhood cancer research and development a global and national priority. They need to invest in innovations to improve therapy and treatment processes, making it less toxic, risky and hazardous for children/ adolescents with cancer. These less toxic therapies will also prevent long-term side effects and health problems for survivors of childhood cancer.

5. Because children are the future of every nation. Healthy children are the bedrock of a vital and productive society with a prosperous and sustainable future

Children/adolescents who survive childhood cancer, by and large, live long and productive lives contributing to society so much more than the cost of their childhood cancer care and treatment. Each child/adolescent who survives cancer has a projected contribution to their community and society as a whole of 71 years.

Recent studies have revealed that 2/3 of childhood cancer survivors have late-occurring side effects due to the treatments they received. In addition, survivors may face numerous challenges such as difficulty finding jobs, stigma and discrimination, and the fear of cancer recurrence.

The effects of cancer don't simply end when treatment does.

We need to advocate that survivorship programs be established and /or strengthened in our countries. Integrated and wholistic support and nurturing should be given to each child/adolescent survivor. This is vital in safeguarding their future and ensuring that their potentials are harnessed and developed to the fullest.

6. Because children with cancer should not suffer unnecessarily. Pain management and palliative care in children is often not adequately addressed due to misconceptions or erroneous beliefs (e.g. children cannot tell you where they hurt, children become accustomed to pain or painful procedures, or children tolerate pain better than adults).

The FACTS ARE: a) Children, as young as 3 years old, are able to express and identify pain with proper use of pain assessment scales; b) Children exposed to repeated painful procedures often experience increasing anxiety and perception of pain with each subsequent procedure; c) Younger children experience higher levels of pain during procedures than older children.

Untreated pain not only affects the child/adolescent in pain, but also their family. Studies show that parents of children with cancer described the experience of seeing their child in pain as unbearable. They felt helpless in responding to it and believed that the health staff was often unprepared as well. Parents were also concerned that their child's pain was not taken seriously. Survivors often speak of these same feelings and experiences. Evidence is clear that many children with cancer, and especially those at the end of life, suffer substantially due to inadequate pain management and palliative care interventions.

We need to advocate and demand that our country and health facilities has adequate programs for pediatric pain management and palliative care .

- 7. Because no family should lose their child to cancer simply because they are poor.** Despite some progress, societies are still failing children/adolescents with cancer and their families. This is most severely experienced in low income countries and among the poorest communities where catastrophic costs of childhood cancer pushes already disadvantaged families deeper into poverty.

Studies and anecdotal reports from families of children/adolescents with cancer, show that even in high and middle income countries, where there is access to health insurance, there is a “tsunami” like effect on household finances.

There is a need to transform the financing landscape for childhood cancer and to foster innovative financing mechanisms and models to make costs of childhood cancer treatment more affordable .

- 8. Because children/adolescents are our responsibility.** Across cultures and religions, children are recognized as gifts, blessing and priceless treasures. As part of our stewardship role, we need to promote, protect and defend the rights and needs of children/adolescents with cancer, from the community level to the global arena. One death is too many.

No child/adolescent should face the cancer journey alone. They need all the attention, support and care we can provide and harness. They deserve our encouragement and inspiration that they can triumph over this adversity and conquer childhood cancer.

We need to ACT NOW and DO MORE for children/adolescents with cancer and the survivors.

