



# Putting the Fight against Childhood Cancer on the Global Health Agenda

68th World Health Assembly, Geneva, May 18, 2015



## **Childhood Cancer Overview**

**Childhood cancer is a steadily growing and devastating global disease.** The human and economic costs of childhood cancer are staggering and significantly undermine development gains. Childhood cancer impoverishes families and pushes them deeper into poverty. It robs children and youth of their growing years, puts at risk their future well-being, and strikes at the heart of families and communities.

While there has been a substantial reduction in childhood mortality due to infectious diseases, deaths due to childhood cancer are increasing.

**Cancer is the leading Non-Communicable Disease (NCD)-related cause of death among children in all countries around the world!**



# “Every three minutes a child is diagnosed with cancer somewhere in the world.”



**Childhood cancer incidence has likewise increased;** this is well documented in developed countries. However, in low and middle income countries (“LMICs”) where a large proportion of the world’s children live, and where it is estimated that 85% of children with cancer are located, the lack of cancer registries leads to under-reporting and under-recording of the real burden of childhood cancer. Despite this limited data, the staggering fact is, **“Every three minutes a child is diagnosed with cancer somewhere in the world.”**



**Childhood cancer is often referred to as the “20th century medical miracle” due to tremendous increases in the five-year survival and cure rates.** However, these improvements have not substantially impacted low and middle income countries. **There is significant inequity and disparity in survival rates across countries and even within continents.** In LMICs, where access to health care is limited and very challenging, survival rates are as low as 10 to 20 percent (only 1 or 2 children out of 10 who are diagnosed with cancer and receive treatment will survive). Conversely, in High Income Countries (“HICs”), depending on the cancer type, survival rates can be as high as 80 to 90 percent (only 1 or 2 children diagnosed and treated for cancer will die).

Childhood cancer is a neglected and marginalized disease in most countries of the world—both rich and poor. Access to timely and affordable treatment, care and support for these children remains beyond the reach of too many families in resource-poor countries, while access to effective new therapies remains out of reach for too many children in developed countries.

**There is an urgent need to elevate attention on childhood cancer and create a collaborative, multi-stakeholder Global Platform and Program for coordinated actions against childhood cancer. There is a need for a consensus document spotlighting the urgency for creating a global essential medicines fund for childhood cancer and calling for national commitments to strengthen health systems, human capital and service capacities for childhood cancer care and follow up survivor care, ensuring availability and access to affordable essential medicines, embedding childhood cancer in universal health coverage and accelerating the development of new, less toxic, more targeted therapies.**



**“The future of our children should not rest solely on the shoulders of families and friends who have lost their beloved children, or on the kindness of strangers who feel their pain. We need our leaders to be accountable, to take bold and decisive steps to address the needs of kids with cancer, survivors and their families. They need to realize that the future of our nations depends on their willingness to invest in the health and well-being of our children NOW, before it becomes too late.”**

## Rationale

Cognizant of this, the Russian Federation, in partnership with the Federal Republic of Germany, the Republic of Ghana and the Republic of the Philippines and through the support of The International Society of Pediatric Oncology (SIOP) and Childhood Cancer International (CCI), **calls on the 68th World Health Assembly to address the human rights and needs of children with cancer, survivors and their families and to recognize the fight against childhood cancer as a top global child health priority.**

The international community, through various human rights instruments, has consistently underscored that children are especially vulnerable, and are entitled to a specific set of human rights that guarantee special care, assistance and protection. The UN Convention on the Rights of the Child (“UNCROC”), which is the most widely ratified international instrument, affirms at its core that “in all actions concerning children... [the] best interests of the child shall be a primary consideration.”

Article 24, recognizes the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health; it obliges States Parties to strive to ensure that no child is deprived of his or her right of access to health care services and to take appropriate measures to ensure such access. While the obligation rests with the State to act, UNCROC also declares that State Parties undertake to promote and encourage international co-operation with a view to achieving progressively the full realization of the right to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health.



## Scope and Coverage of Side Event

This side-event will bring together policy and opinion leaders from various countries, key stakeholders of various international development institutions and civil society organizations.



They will:

- Discuss and share progress in the implementation of best practice childhood cancer national models that contribute to improved access to care and reduced childhood cancer mortality;
- Engage and dialogue on the latest updates, emerging challenges and windows of opportunity identified by key development institutions (WHO, IARC, FDA, EMA);
- Develop shared agreements and actionable items which address priority childhood cancer issues and challenges, and
- Recommend realistic solutions to overcome barriers that limit access to affordable care and services for children with cancer and the survivors.



## Key Issues and Challenges

### Inequity of Survival Rates

Survival rates vary depending on factors such as the status of a country's health system, medical culture and socioeconomic conditions. Other reasons for the inequity include: lack of information about early signs and symptoms of childhood cancer, delayed diagnosis, misdiagnosis, absence/weak referral systems, difficult access to care and essential medicines and treatment, catastrophic costs of treatment and essential medicines and abandonment (i.e. discontinuance of treatment for a minimum of one month).

**Survival rates also vary depending on the type of cancer being treated, the availability of effective treatment and the access and availability to affordable childhood cancer essential medicines.**

**“Research reveals that treatment abandonment may account for a third of the survival gap between HIC and LMIC. Treatment abandonment is disproportionately higher in low- and middle-income countries (LMIC). It is often caused by factors related to difficulties in accessing care such as low socio-economic status, catastrophic /unaffordable costs of treatment, geographical distance and limitations of the healthcare system.”**

### Poor Access and Availability of Affordable Medicines

One of the major reasons for the poor survival of children with cancer in LMICs is the lack of a consistent supply of reliable and good quality medicines for curative, supportive and palliative care. The majority of medicines required to treat most types of childhood cancer are off-patent, generic medicines which are included in the World Health Organization's Essential Medicines List for Children (recently revised). However, since very few LMICs manufacture medicines, a multitude of challenges impede the availability and affordability of these drugs to children in LMICs. These include: 1) failure of adequate production to meet the needs of children worldwide; 2) inefficient importation procedures and weak distribution mechanisms and 3) lack of reliable and comparable quality available globally.

**There is strong evidence that with unhampered and continuous access to these essential medicines, at least 50% of children in the world who currently have no chance of survival, could have the chance for a cure.**

### Lag in Development of New, Less Toxic, More Targeted Therapies for Childhood Cancer

While there has been significant progress in drug development to treat the many types of adult cancers including precision medicines that offer new hope for less toxic therapy and more targeted therapy, development of childhood cancer drugs is seriously lagging behind.

In the USA, the Food and Drug Administration (“FDA”) has approved 109 new drugs to treat adult cancers since 1990. In sharp contrast during the same time period, only 2 drugs have been approved by the FDA to exclusively treat childhood cancer. This weak record of drug development for pediatric cancers underscores a huge gap and highlights the fact that children continue to be treated with drugs primarily developed in the 1950s-70s and with drugs that were developed to treat the many adult types of cancer that children simply don't get such as breast, prostate, lung and colon cancer. Research has shown that childhood cancers are biologically distinct from adult cancers, resulting in a need for drugs to be developed that are specific to children's treatment needs. (<http://www.medilexicon.com/drugs-list/cancer.php>)

### Long Term Late Effects

Given this dependence on drugs developed three decades ago to treat the majority of children with cancer in the world, **two-thirds of childhood cancer survivors suffer long-term late effects from treatment.** This includes: cognitive deficits leading to severe learning disabilities, endocrine dysfunction, heart and lung disease, loss of hearing and sight, infertility and sadly, secondary cancers. Recent research reveals that **by the time childhood cancer survivors are 45 years of age, more than 95% of them will face a chronic health problem; one-third of which are classified as severe to life-threatening.**

The hope and expectation of families around the world is that children with cancer will be treated successfully with innovative therapies, derived from current scientific insights that can avoid the harmful long term health problems survivors currently experience.

## Way Forward

The International Society of Pediatric Oncology (SIOP) and Childhood Cancer International (CCI) **are calling on the WHA, WHO and international development organizations, to propose and pursue coordinated global action in a) the provision of affordable essential childhood cancer medicines, timely and appropriate treatment, care and support for children/adolescents with cancer and survivors everywhere, b) the establishment of a Global Childhood Cancer Clinical Trials Network that would accelerate the development of less toxic and targeted therapies and c) mainstreaming childhood cancer in child and adolescent healthcare platforms and programs as well as healthcare systems strengthening interventions.**

Governments and partners at the national level are urged to join forces to ensure that childhood cancer is made a public child health priority with adequate resources and continuing support, integrated into all levels of the healthcare systems, so that premature deaths due to childhood cancer are minimized and risks to developmental growth and well being of children and adolescents are avoided.

Through a consensus paper and a global commitment to work together to effectively address childhood cancer challenges and reduce the burden of childhood cancer, we can take a huge stride forward in saving more lives and building better futures for children/adolescents with cancer and the survivors.

Carefully implemented childhood cancer programs in LMICs have documented improvements in survival rates of 30% within less than a decade. Studies have shown that simple interventions like education, training of healthcare workers or organizing parent groups are cost efficient and very effective strategies that can yield a significant return on investment by lessening abandonment and/or increasing the cost effectiveness thresholds of treatments. Twinning programs or sustained partnership with centers of excellence in developed countries or other middle income countries with advanced capacities, along with a modest investment of funding, mentoring, training, and support for key personnel in the LMIC center, have also been shown to effectively complement top-down efforts to improve national healthcare coverage and national cancer control efforts for children.

Contrary to the perception that treatment of childhood cancers is not cost effective, recent research in LMICs in Africa and Central America reveal that investments in making available affordable essential medicines is extremely cost-effective for highly curable and common cancers like acute lymphoblastic leukemia and Burkitt's lymphoma. Moreover, other recent studies have revealed that enhancing childhood cancer care is an opportunity for horizontal strengthening of an integrated health care system. Children with cancer should suffer less and survive more. Working together, parent organizations, professional societies, governments, institutions dedicated to global development, academic institutions, industry, civil society organizations and individuals of good-will, can make a difference for children who otherwise would have no hope for a future.

**“The majority of children with potentially curable cancers can get cured even in low-resource settings, and all children with advanced cancer can benefit from pain relief and palliative care. Children’s rights cannot be fulfilled and protected unless preventing and treating cancers is included as a priority within national cancer control programmes.**

**Together with NGOs such as Childhood Cancer International and SIOP, WHO is strongly committed to supporting national efforts to control childhood cancers in low- and middle-income countries and to reach all children in need, wherever they are excluded and left behind. If we overcome the barriers that have kept these children from the services that they need and that are theirs by right, then more will grow up healthy and realize their full potential. ”**

**Dr. Oleg Chestnov, Assistant Director-General, Noncommunicable Diseases and Mental Health  
World Health Organization**

## About SIOP

Established in 1969, the International Society of Pediatric Oncology (SIOP), with over 1500 healthcare members, is the leading provider organization concerned with the issues of children and young people who have cancer. The society envisions that “no child should die of cancer.” To realize this vision, SIOP’s mission are to:

- 1) ensure that each child and young adult with cancer has access to state-of-the-art treatment and care;
- 2) ensure that all involved in childhood cancer worldwide, have access to the latest progress through meetings, networking, and continuing professional development;
- 3) support those caring for children and young adults with cancer to provide the best curative and palliative therapies; and,
- 4) advocate for appropriate long-term follow-up for children and young adults after treatment for cancer.

Prof. Giorgio Perilongo is the President of SIOP. SIOP is governed by a board of directors and has its headquarters in Geneva, Switzerland. [www.siop-online.org](http://www.siop-online.org)

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## About CCI

Founded in 1994, Childhood Cancer International [(CCI) formerly known as International Childhood Cancer Confederation of Parents Organizations] is the largest organization of its kind representing children and adolescents with cancer, the survivors, families of children with cancer and childhood cancer support organizations. CCI believes children and adolescents with cancer everywhere deserve the best possible treatment and care. Through its network of 177 grassroots organizations and national coalitions in 90 countries, CCI undertakes initiatives in five key areas:

- 1) Access to Care (Strengthening support and access to care for children and adolescents with cancer, the survivors and families of children with cancer);
- 2) Awareness Building (Intensifying awareness for early and accurate diagnosis of childhood cancer);
- 3) Advocacy (Driving policy change and health reforms on childhood cancer);
- 4) Capacity Development (Escalating dialogue and enhancing capacities on childhood cancer; conducting meetings, trainings, learning sessions and convening regional and annual international conferences; and
- 5) Partnership Building and Networking (Expanding partnerships and alliances; creating more supportive and favorable environments for children and adolescents with cancer, the survivors and families of children with cancer).

Carmen Auste is the Chair of CCI. CCI headoffice is located in the Netherlands with a governing board representing all six continents. [www.icccpo.org](http://www.icccpo.org)

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Superman on and off the screen, said, "So many of our dreams at first seem impossible, then they seem improbable, and then, when we summon the will, they soon become inevitable."