

2015 CHILDHOOD CANCER SURVIVOR WEEK: ACT NOW... DO MORE

1. Why is there a need to have an International Childhood Cancer Survivors Week (ICCSW) during the month of June?

In the early 1950s, less than 10 % of childhood cancer patients survived. **Today, for certain kinds of childhood cancers, especially in more developed and high resource countries, 80–90% of children/adolescents diagnosed with cancer become long-term survivors.** In other resource constrained countries, early diagnosis, available and affordable essential medicines, timely and appropriate treatment, supportive networks of care (e.g. parents organizations, cancer support groups) have also improved childhood cancer survivorship from a **low 5 - 10% to 20- 30% or in some cases, all the way up to 60%. Nevertheless, huge inequities exist across countries and even in the same continents.**

The journey of childhood cancer does not end after the final treatments have been given and the announcement that a child/adolescent is now cancer free. Along with the impressive gains in survival have come “late effects,” which may impair some of the survivors’ health and quality of life. Research reveals that as many as two thirds of childhood cancer survivors suffer long-term late effects from treatments. These late effects include complications, disabilities or adverse outcomes that are the result of the disease process, the treatment or both. Patterns of late effects have emerged among subgroups of childhood cancer survivors that have contributed to the categorization of childhood cancer as a chronic disease with implications for continuing care. By the time survivors are 45 years of age, more than 95% of them will have a chronic health problem.

Thus, **childhood cancer survivors need a lot of continued support and care.** They and their families need assistance to proactively prepare for, and successfully overcome, health and other emerging challenges (e.g., finding meaning again and enjoying life free of cancer; staying healthy and living productive lives; effectively re-integrating back into the community [education, livelihood] and more). **They need to be well informed and well prepared to navigate the next part of their journey—the new normal and life beyond childhood cancer.**

Survivors of childhood cancer can be found all over the world. With this growing number of survivors and the continuing challenges that they face, it is imperative that the world hears their needs and concerns; recognizes what we can do for/with them and how we can become part of their journey as they resume their lives and work to shape a better future.

On February 15, 2015 (International Childhood Cancer Day), the **ACT NOW Global Campaign** was launched calling on all sectors and various stakeholders to join forces and consolidate initiatives to spotlight the need for childhood cancer to become a global child health priority.

This June, as part of the ACT NOW call for solidarity, let us collectively honor and stand with our childhood cancer survivors. But even as we honor them, let us commit and urge governments, development institutions, civil society organizations and resource institutions to ACT NOW and DO MORE for childhood cancer survivors and their families.

This must be accomplished through:

- **More targeted, less toxic, less damaging childhood cancer treatments;**

While there has been significant progress in drug development for many types of adult cancers, development of childhood cancer drugs is lagging behind. In the USA, since January 2000, the FDA has approved 109 new drugs for adult cancer. In sharp contrast, only 2 drugs have been approved since 1990 to exclusively treat childhood cancer (i.e., chlofarabine to treat acute lymphoblastic leukemia and Unituxin to treat high-risk neuroblastoma). This weak record of drug development for pediatric cancers underscores a huge inequity in attention and focus. It also highlights the fact that children continue to be treated with drugs developed in the 1950s, '60s and '70s. <http://www.medilexicon.com/drugs-list/cancer.php>.

- **Optimal information and education campaigns to:**

- **increase awareness of late effects and their implications for long-term health and well being of childhood cancer survivors and their families;**
- **Address stigma and discrimination against childhood cancer survivors.**

In some cultures, survivors have the extra burden of stigma and discrimination associated with having had childhood cancer. They are viewed as “genetically defective,” “inferior,” “damaged” or even “infectious.” (See accompanying primer on Myths and Misconceptions about Childhood Cancer Survivors).

- **Reinforce and strengthen public programs, services and health insurance coverage for childhood cancer survivors;**

- **Enhance training on survivor needs, late effects and their management for both specialty care professionals and primary care medical practitioners;**

We know from international research and studies that there is no uniform care plan applicable to all survivors. Just like treating childhood cancers differ; caring for the survivors also requires individual plans best suited for each child/adolescent. These should be age appropriate and take into consideration the type of childhood cancer diagnosed, the treatment protocol(s) followed and the associated long-term risk factors.

Nevertheless, appropriate follow up care programs and strategies will help complete the triumph of successful childhood cancer treatments and extend the horizon of success to beyond the 5-year survival, to a life free of disability and disease; a life full of possibilities.

- **Ensure national cancer control plans include a component on childhood cancer survivorship;**

- **Expand and scale up research on the nature, extent, implications and interventions to avoid or minimize impact of emerging treatment challenges and subsequent late effects on the survivors' health and overall well-being.**

2. What is International Childhood Cancer Survivors Week (ICCSW)?

International Childhood Cancer Survivors Week is a joyful celebration of life. It commemorates the courage and bravery of children/adolescents with cancer and their families who have fought and triumphed over cancer. It is held for a one week period during different weeks around the world.

It is time for everyone to appreciate that:

The **C-word** is no longer a death sentence.

There is a **new meaning to the C-word: Celebration** of Life and **Continuation** of Life beyond Childhood Cancer.

It is also a time for retracing the childhood cancer journey and understanding the issues and challenges that unfold during survivorship. ICCSW will capture the stories of the multitude of lives touched and changed forever; dreams broken or goals achieved; friendships created and extended families established throughout the lengthy and difficult time of combating cancer together.

ICCSW is also an opportunity to create awareness among the general public of the realities of childhood cancer, but more than that, it is a shout-out to showcase that childhood cancer is indeed curable. **Childhood cancer can be beaten. This devastating disease can be overcome with early diagnosis, timely and appropriate treatments, increased availability and better access to affordable essential medicines, adequate, quality care and sufficient support for the children/adolescents with cancer and their families.**

ICCSW is a declaration of support to help make possible new and brighter beginnings for childhood cancer survivors. It is an invitation to understand better and learn how to be there for survivors and their families as they face this new chapter in their lives—Being a Survivor!

Together, the presence of childhood cancer survivors proves: **There is LIFE after cancer. There is a new and meaningful journey of possibilities beyond cancer.**

Let us all continue to **STAND UP, SPEAK OUT** and be **PARTNERS** with childhood cancer survivors and their families. **TOGETHER** let us actively **ENCOURAGE** and **SUPPORT** their **SURVIVOR JOURNEYS**, enabling and empowering them to embrace this new and meaningful chapter in their young lives.

TOGETHER, WE STAND STRONGER.

3. Who is behind International Childhood Cancer Survivors Week (ICCSW)?

Childhood Cancer International (formerly known as The International Confederation of Childhood Cancer Parent Organizations) is convening this event in collaboration with the CCI Survivors Network, the International Society of Pediatric Oncology (SIOP) and the Union for International Cancer Control (UICC). For the past 21 years, CCI has consistently encouraged everyone to **STAND UP and SPEAK OUT** for children/adolescents with cancer, their families and the survivors.

Childhood Cancer International (CCI) is a network of more than 177 childhood cancer national coalitions and grassroots organizations as well as childhood cancer support organizations, in more than 90 countries and 6 continents around the world. CCI is the largest organization of its kind catalyzing action and support for children/adolescents with cancer and the survivors and families of children with cancer. It envisions a world where all children/adolescents with cancer receive the best possible treatment and care.

The **CCI Survivors Network (CCISN)** is the survivor arm of Childhood Cancer International. CCISN aims to bring together and connect childhood cancer survivors and organizations to **INFORM, INSPIRE, ENERGIZE** and **INITIATE** change on important issues faced by childhood cancer survivors. It also provides guidance and assistance in the establishment of childhood cancer survivor groups and survivor mentoring programs worldwide. It seeks to strengthen the voice of survivors and survivor groups and to further expand the network of childhood cancer survivor groups around the world through the sharing of resources, experiences and information.

The **American Childhood Cancer Organization (ACCO)** is comprised of the national office based in the Washington D.C. region and 39 local groups located across the United States. Founded in 1970, ACCO is the largest childhood cancer grassroots organization advocating for the voice of childhood cancer patients, survivors and their families in the U.S. and is the U.S. based member of Childhood Cancer International, representing America in the global fight against childhood cancer. ACCO is also the largest publisher and distributor of childhood cancer educational resources in the U.S.

Established in 1969, the **International Society of Pediatric Oncology (SIOP)**, with over 1500 healthcare members, is the lead medical society concerned with the issues of children and young people who have cancer. The society envisions that “no child should die of cancer.” SIOP is a vibrant medical association with strong presence in more than 100 countries around the world, and with membership which includes physicians, nurses, researchers, scientists, public health specialists and other health care professionals.

The **Union for International Cancer Control (UICC)** is a membership organization that exists to help the global health community accelerate the fight against cancer. Founded in 1933 and based in Geneva, Switzerland, UICC has a growing membership of more than 800 organizations across 155 countries that include the world’s major cancer societies, ministries of health, research institutes and patient groups.