
Children's Cause for Cancer Advocacy

Childhood Cancer's Impact

Cancer is the leading cause of death by disease among U.S. children between infancy and age 15. More than 15,700 new cases of pediatric cancer are diagnosed each year. Since the causes of most childhood cancers are currently unknown, the disease cannot be prevented. According to the National Cancer Institute (NCI), the incidence of cancer in children has increased over the past 30 years, yet the combined five-year survival rate for all childhood cancers has improved from 50% in the 1970s to 80% today. This increase is largely attributable to improvements in treatments and to the high proportion of children participating in clinical research studies. However, for many childhood cancers, the current survival rate is 0%. Some pediatric brain tumors, for example, are terminal upon diagnosis with no new protocols developed in 30 years.

Access to targeted, safer, and more effective therapies for children is critical to saving and improving the lives of children. There are now almost 380,000 childhood cancer survivors who face serious, long-term effects from their treatments. Two-thirds will experience at least one late effect caused by their treatment, with one-fourth facing medical problems that are serious or life-threatening. Late effects can include second cancers, fertility issues, neurocognitive disabilities and strokes.

A Leader on Capitol Hill in Promoting Childhood Cancer Policy Priorities

The Children's Cause for Cancer Advocacy was founded in 1999 to ensure the needs and perspectives of children with cancer and survivors are integrated into federal deliberations on health care and cancer policy. The Children's Cause is different from other childhood cancer organizations because our area of expertise is federal policy. Federally funded clinical trials are a lifeline for the majority of children with cancer. Our guiding principle is ensuring that all children with cancer and survivors have access to the critical treatments and follow-up care they need, regardless of income, location, or insurance status. Our in-depth analysis of Congressional legislation and cancer policy at federal agencies has resulted in the imprint of CCCA's work on major federal laws and regulations affecting the development of therapies; funding and design of research and care; and attention to the needs of survivors. We focus on creating better policies and regulations because we know that's the key to a better future for our kids.

The Children's Cause develops and maintains active contact with Congressional offices and key personnel at the Food and Drug Administration (FDA), the National Cancer Institute (NCI) and the National Institutes of Health (NIH). We also stay connected with broad contacts in the nonprofit cancer community. We filter all new and potentially relevant Congressional legislation and administrative action through the perspectives of children with cancer. We work with Congressional staff to modify or add provisions favorable to our children. We structure the introduction of new legislation about childhood cancer with Congressional champions. We address draft agency regulations by submitting formal written comments and oral comments in open public meetings. And finally, we train and educate new advocates to increase policymakers' and public understanding of the needs of children with cancer.

Building a Network of Passionate Advocates through Education and Training

There has never been a greater need for advocates to be involved in public policy debates to ensure the needs of childhood cancer survivors are heeded. Federal budget pressures put corresponding pressure on the public investment

in pediatric cancer research, with the budget outlook likely very challenging for years to come. At the same time, the health care system is changing rapidly, with implications for where children with cancer will be treated, how clinical trials will be conducted and financed, how care will be paid for, and what financial burden families will bear for high quality cancer care. Effective advocacy can positively influence the individual's access to care, the pediatric cancer research and development system, and the health delivery system.

In response to this need, CCCA has built a network of over 10,000 consisting of parents with children who are battling cancer or are survivors, young adult survivors, advocates, researchers, federal policymakers, and donors. We communicate with our network through events, trainings, newsletters, social media, and action alerts on issues such as federal research funding, drug shortages and development, surveillance findings, and survivorship. By providing advocates with skills, information, and background, the Children's Cause is playing a key role in expanding and strengthening the childhood cancer advocacy effort. Childhood cancer patients, families, and friends bring their own powerful personal cancer experience to the advocacy effort, and Children's Cause is committed to offering advocates critical tools and information to make them even more effective. Armed with those tools, advocates will be able to advance the cause of children with cancer in Congress, federal agencies, state legislatures, and all other local, state and federal policy forums considering the needs of children with cancer.

18 Years of Policy Progress

Since our founding in 1999, Children's Cause for Cancer Advocacy has:

- Collaborated with Congressional staff and other stakeholders to draft the Caroline Pryce Walker Conquer Childhood Cancer Reauthorization Act, which was introduced in 2013. Fought for funding for the original Caroline Pryce Walker program during its initial authorization period.
- Developed strong principles of quality health care for children with cancer and advanced those principles during the Congressional debate on the Affordable Care Act. Children's Cause principles included elimination of pre-existing conditions exclusions and lifetime caps and annual limits on coverage; prohibiting excessive waiting periods for care, especially for clinical trials; and increasing the age for dependent coverage.
- Advanced provisions in the 2012 FDA Safety and Innovation Act (FDASIA) to speed the development of treatments for children with cancer through incentives for companies, to reauthorize the pediatric subcommittee of the Oncologic Drugs Advisory Committee on a permanent basis, and to increase the focus on pediatric rare diseases, especially cancer.
- Championed a definition of essential health benefits that reflected the special needs of children with cancer and survivors, as part of the standard-setting process that occurred during Affordable Care Act implementation.
- Helped organize Childhood Action Days to take advantage of advocates traveling to Capitol Hill and those who could advocate in their own communities. The 2014 results were: 1) 184 visits to Members of Congress by teams of childhood cancer survivors and families and 2) delivery of 1,100 online messages to Representatives and Senators, 3) a concurrent social media campaign through which over 1700 people tweeted the core campaign messages to their Congressional representatives.
- Convened five in-depth workshops on research and care for patients and survivors.
- Developed and disseminated a range of educational materials including an advocacy tool kit for survivors, a brochure for social workers, and initiated a new blog.
- Launched an advocacy training program, composed of in-person workshops and monthly conference calls and/or webinars.