



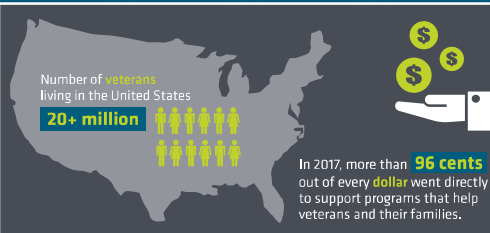

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CFC #11322



A Powerful Advocate for Children with Cancer

Even though survivors of childhood cancer have overcome great obstacles, 95 percent of them will suffer from significant long-term health effects that can occur months or even years after their cancer treatment has ended. Known as late effects, these issues affect both the body – like organ function and growth and development – and mind – like memory, mood, and learning. This can drastically influence the survivor's quality of life into adulthood.

Research from the National Cancer Institute has revealed three main factors that determine the risk level for late effects: the patient, the tumor, and the treatment.

Insofar as treatment goes, there are options such as surgery, chemotherapy, radiation therapy, and stem cell transplant, among others. These treatment options are where the medical community has already and can continue to make a great impact with regard to late effects and improving the quality of life for childhood cancer survivors.

This is a major focus point for Children's Cause for Cancer Advocacy (CCCA), a nonprofit dedicated to policy and advocacy for childhood cancer.

Just this summer, the organization achieved a major victory with the passage of the Childhood Cancer Survivorship, Treatment, Access and Research (STAR) Act.

"Passage of the STAR Act was a huge accomplishment and the culmination of many years' worth of research, relationship-building, and hard work," says Jess Kean, communications director at Children's Cause for Cancer Advocacy. "This is the most comprehensive childhood cancer legislation ever taken up by Congress, and it was passed with unanimous bipartisan support in both chambers. The STAR Act will create better, less-toxic therapies for the 16,000 kids diagnosed with cancer every year."

Specifically, the STAR Act authorizes \$30 million in annual funding from 2019-2023 for grants that support programs and research centered on childhood cancer.

Even after this success, CCCA is still working at full steam toward other policy changes. In 2019, the organization will focus some of its efforts on healthcare access issues.

"There's a big need to alleviate some of the crushing financial burdens that a childhood cancer diagnosis can have on a family," Kean



Zack is a cancer survivor.

says. "We've been surveying families and gathering research around issues of health insurance access barriers and reimbursement challenges that face childhood cancer families, and now we're looking at what some of the solutions might be and how we can achieve progress in that arena."

CCCA estimates that the average cost of a hospital stay in the United States for a child with cancer is \$40,000 and approximately one third of American kids who have cancer are covered by Medicaid.

The organization is supporting two pieces of legislation – the Accelerating Kids' Access to Care Act and the Advancing Care for Exceptional Kids Act – that will improve care for the children who are enrolled in Medicaid by helping to alleviate coverage issues and reduce hurdles in receiving timely care.

"Legislation typically takes years to advance into law – and even longer to start changing things in the real world," Kean says.

She has been working at CCCA for more than a decade and knows the process well. Unfortunately, when it comes to CCCA's important and time-sensitive advocacy work, you'd rather measure success over months and not years.

"When you're working with kids who don't have the luxury of time – that progress can feel agonizingly slow," Kean says. "But it's happening, and it's saving lives." •

Story by Tara Shubuck
CFC #71422

PHOTO COURTESY OF CHILDREN'S CAUSE FOR CANCER ADVOCACY