The nonprofit organization formerly named Children's Cause for Cancer Advocacy.
2019 was an especially exciting year for us at Children’s Cancer Cause as we celebrated our 20th anniversary. For the past two decades, we have been a strong, clear voice to our nation’s leaders in Washington, fighting for meaningful change for kids, survivors, and families.

A long-term presence in Washington as a trusted, steady voice really matters. Much of the policy progress from 2019 (which we'll share in more detail in this report) is built on achievements from prior years. These legislative wins take many years to bring to fruition and are a testament to the collective power of a passionate community of families and advocates working hand-in-hand with organizations like ours.

We couldn’t do this without you. Thank you for supporting our work, sharing your story, and speaking up to Congress about issues that improve the lives of children with cancer, their families, and the nation’s 500,000 childhood cancer survivors.

Thank you,

George Dahlman
Chief Executive Officer
OUR VISION
A LONG, HEALTHY LIFE FOR EVERY CHILD WITH CANCER.
Our name changed in 2019, but our mission, vision, values, and depth of commitment to this cause remains the same.

We changed our name to Children's Cancer Cause because friends, supporters, and Capitol Hill staff told us over the years that our old name was a real mouthful.

We took that feedback to heart and embraced the opportunity to grow and improve in our 20th year, while remaining committed to our founding principle that advocacy is our purpose.

We take pride in our reputation as a trusted and credible voice in national debates on research, treatments, healthcare, and survivorship. We work to give those affected by childhood cancer the knowledge and skills to become effective advocates.

Thank you for making 20 years of policy progress possible, and for your continued support of the Children's Cancer Cause.
2019 began with the longest government shutdown in U.S. history, causing significant disruptions to federal agencies - including the FDA and its ability to expedite lifesaving therapies to patients in need.

Once the government reopened, the policy landscape for the childhood cancer community improved dramatically when the Administration announced an investment of $50 million annually for the next decade for childhood cancer, a commitment that shaped into the Childhood Cancer Data Initiative (CCDI). CCDI is intended to facilitate access to the broadest possible collection of childhood cancer data. The first year of funding for CCDI was secured at the end of 2019, empowering CCDI to move ahead with its ambitious slate of plans related to data collection and accessibility.

In April, we celebrated the President signing the ACE Kids Act into law, as part of the Medicaid Services Investment and Accountability Act of 2019. The Advancing Care for Exceptional Kids Act will improve care for approximately two million children with medical complexities in the Medicaid program. The Children’s Cause joined the nation’s leading children’s hospitals, along with the Children’s Hospital Association, in supporting this legislation.

An uncertainty in research funding loomed over the policy landscape for much of the year. But as 2019 came to a close, we got terrific news: A $1.4 trillion spending deal secured record funding for the NIH and included funding for implementation of the Childhood Cancer Cancer STAR Act.

7% increase in NIH funding.
In October, we in the childhood cancer community found ourselves in crisis mode, as the alarming news hit that pediatric hospitals around the country were facing a shortage of the chemotherapy drug vincristine - an essential component in the treatment of most childhood cancers.

Families and advocates acted quickly, coming together to speak up for kids who rely on vincristine as part of their treatment protocol.

Our collective voices had an impact: sole supplier Pfizer expedited shipments to hospitals in need, and Teva Pharmaceuticals announced that they are re-introducing vincristine to their supply line.

The drug shortage issue is complicated, with multiple factors and no simple solution. Preventing future shortages will require a multi-faceted approach.

The Alliance for Childhood Cancer convened a working group on this issue, and Children’s Cancer Cause will continue to work with this and other coalitions in the pursuit of solutions that ensure families in the future are not faced with devastating shortages of drugs needed to treat their child’s cancer.

An action-packed Awareness Month in September was headlined by introduction of legislation to permanently reauthorize the Creating Hope Act.

1,356 LETTERS SENT TO MEMBERS OF CONGRESS THROUGH OUR 2019 LEGISLATIVE ACTION CENTER
Amelia was an 18-year-old college freshman when she found herself thrust into the world of cancer with a diagnosis of Hodgkin’s lymphoma. For her advocacy project, Amelia launched a new student organization for "Survivors and Thrivers" — those who have survived serious childhood illnesses like cancer and those who are managing chronic diseases like diabetes. Amelia’s organization is both a support group and an advocacy network that works to tackle policies around medical leave, student accessibility, and student health resources — finding solutions to the same problems that plagued her as a patient, student, and survivor.

Children’s Cancer Cause offers an annual opportunity for childhood cancer survivors to gain valuable cancer advocacy experience and receive $2,000 college scholarships. This program helps survivors achieve their academic dreams and includes a requirement of completing a childhood cancer advocacy project of the scholar’s choice.

Isha was diagnosed with Pre-B Acute Lymphoblastic Leukemia in 7th grade. Middle school is hard for everyone but it’s especially challenging when you’re singled out with a cancer diagnosis, as Isha discovered. To combat social isolation faced by pre-teens and teens with cancer, Isha is creating an online community for 10-18 year old patients and survivors. Isha’s advocacy project aims to connect kids with survivors who can act as mentors in their journey.

AMELIA CORL

Isha KUNNATH
We were a founding member of the Coalition Against Childhood Cancer (CAC2) in 2013 and today have staff at the table on the CAC2 Board of Directors.

We work with policy partners as an active member of the Alliance for Childhood Cancer, the Cancer Leadership Council, and One Voice Against Cancer.

Our Founder Susan Weiner is one of four representatives from the United States serving on the ACCELERATE Steering Committee. ACCELERATE is a new international approach to accelerating innovative cancer therapies.

Day in and day out, we work with these coalitions - and others - to ensure that our collective voice is strong, clear, and unified.

At the Children's Cancer Cause, we take pride in being a team player because we know that cooperation and collaboration with other organizations and coalitions is in the best interests of the children and families we serve - and that matters more than who takes credit.

“No matter how we found ourselves part of this 'club,' and no matter what our talents or background, we each have something to contribute.”
- George Dahlman, CEO
At our 2019 New York event, we presented the 4th Annual Leonard M. Rosen Memorial Research Award to David Poplack, MD, Director of Global HOPE, in recognition and support of his life-saving work around the world.

ROSEN AWARD

At our 2019 New York event, we presented the 4th Annual Leonard M. Rosen Memorial Research Award to David Poplack, MD, Director of Global HOPE, in recognition and support of his life-saving work around the world.

Dr. Poplack is a pioneer in the field of childhood cancer and one of our community’s premier thought leaders. He served as Director of Texas Children’s Cancer Center for 25 years, where he grew that institution into one of the nation’s top pediatric cancer centers. To survivors and their families, Dr. Poplack is best known as the developer of Passport for Care, an online tool that helps survivors manage their long-term care.

"Dr. Poplack’s new role tackling childhood cancer in the developing world has been a passion for him. And as usual, he’s been one step ahead of the curve in terms of what problems are needed to solve."

- Dr. Michael Link

We gather in New York City every fall for our signature fundraising event of the year, headlined by the presentation of the Rosen Award. We are grateful to our faithful donors in the New York area for their unwavering support year after year.
"This has become the go-to organization for people interested in childhood cancer advocacy. Children's Cancer Cause has done a wonderful job in developing landmark legislation and training people how to become advocates."

- Dr. David Poplack
GuideStar is the world’s leading provider of information about nonprofit organizations. The Platinum level recognition demonstrates our deep commitment to nonprofit transparency and accountability.

Our most recent audited financials & IRS Form 990 are available at childrenscancercause.org/governance

Children’s Cancer Cause is a participant in the Federal government’s official workplace giving program, the Combined Federal Campaign (CFC).

Our CFC # is 71422

More than 75 cents of every dollar we spent in 2019 supported our programs and services on behalf of children with cancer and survivors.

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<td>Interest &amp;</td>
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<td>Administrative</td>
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Most of our revenue comes from individual donors whose generosity makes our live-saving work on behalf of children with cancer possible.

Beyond our signature fundraising event in New York City, we offer a wide variety of ways for donors to support our work:

childrenscancercause.org/give

AmazonSmile • donate your change • birthdays/special occasions

VEHICLE DONATION:
Selling a vehicle takes time, money, and a lot of effort. But donating your vehicle is hassle-free and lets you make a lasting impact. We accept all kinds of vehicles including cars, trucks, SUVs, RVs, boats, motorcycles, and even airplanes.

Find out how it works: childrenscancercause.org/vehicledonation

SCHOLAR BOOSTERS:
Our College Scholars Program provides scholarships for childhood cancer survivors.

For as little as $10 a month, you can become a Scholar Booster and help us provide this financial support: childrenscancercause.org/scholarboosters

JAZZ IN JUNE:
The photos on this page are from our 2019 Jazz in June event, in Washington, DC. Jazz in June is an annual event that brings together friends, supporters, and fans of great music.

For details on our June 18, 2020 event at The Hamilton in Washington, DC, visit: childrenscancercause.org/jazzinjune
<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
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<tr>
<td>1999</td>
<td>Founded as Children’s Cause, Inc. by Susan L. Weiner with a mission to give a national voice to childhood cancer patients, survivors, and families.</td>
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<tr>
<td>1999</td>
<td>Helped found the Alliance for Childhood Cancer. Children’s Cancer Cause staff co-chaired the Alliance during its formative years.</td>
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<td>2000</td>
<td>Conducted a series of focus groups to gather data on the needs of adolescent and young adult survivors of childhood cancer.</td>
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<td>2001</td>
<td>Held the first of six regional advocacy conferences for childhood cancer survivors.</td>
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<td>2003</td>
<td>Focused the agenda on new therapies for children and high-quality care for survivors.</td>
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<tr>
<td>2004</td>
<td>Created the first in a series of national childhood cancer advocacy workshops, establishing grassroots advocacy training as a core aspect of our mission.</td>
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<td>2005</td>
<td>Provided testimony to Congress on reducing barriers to new childhood cancer drug development and strengthening NCI pediatric research capacity.</td>
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<tr>
<td>2006</td>
<td>Provided testimony to President’s Cancer Panel on the needs of childhood cancer survivors.</td>
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<tr>
<td>2007</td>
<td>Lobbied Congress to reauthorize FDA laws to encourage and require research on drugs for children.</td>
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<td>2008</td>
<td>Organized the first Capitol Hill lobby day for childhood cancer advocates.</td>
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<td>2008</td>
<td>Developed, advocated for childhood cancer care standards during creation of Affordable Care Act.</td>
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<td>2010</td>
<td>Helped draft the Caroline Pryce Walker Conquer Childhood Cancer Act, expanding opportunities for childhood cancer research and surveillance.</td>
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<td>2011</td>
<td>Introduced the bipartisan Pediatric, Adolescent and Young Adult Cancer Survivorship Research and Quality of Life Act, based on a 2003 Institute of Medicine report.</td>
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<tr>
<td>2011</td>
<td>Held the first reception on Capitol Hill highlighting childhood cancer needs for Members and staff.</td>
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Helped secure permanent reauthorization of FDA’s pediatric cancer review committee; coordinated childhood cancer groups to help make pediatric research laws permanent and require FDA to assess the impact of pediatric research laws on pediatric cancer therapies.

Organized a policy training workshop for regional nonprofit leaders on how to be effective advocates on national issues.

Worked with national leaders on challenges in drug development and recommendations for a public-private partnership to develop drugs for children with cancer.

Hosted a Capitol Hill briefing on barriers to care facing childhood cancer patients and survivors.

Awarded inaugural college scholarships to students who commit to undertake community or campus-based cancer advocacy projects.

Issued formal report on Chemotherapy-Induced Hearing Loss in Pediatrics to FDA, the outcome of an externally-led Patient Focused Drug Development workshop.

Created an intensive workshop for national nonprofit leaders on legislative issues related to childhood cancer and strategies for advancing policy change.

Reintroduced Childhood Cancer Survivors’ Quality of Life Act and hosted a Capitol Hill reception to honor Childhood Cancer Caucus.

Collaborated with national groups to create a comprehensive landscape report "Translating Discovery into Cures for Children with Cancer."

Launched the Kids Action Network, an online membership group of highly engaged advocates.

Helped secure passage of the RACE for Children Act, authorizing FDA to require pediatric testing of adult cancer drugs.

Partnered with national coalitions to secure passage of the STAR Act, the most sweeping childhood cancer legislation ever introduced.

Utilized data from two research surveys to inform policy work around the financial impact of a childhood cancer diagnosis.

Your support during our 20 years of fighting for children with cancer, survivors, and their families has made it possible to make significant progress and dream even bigger as we look toward the future.
For 20 years, we have been at the forefront of health care and cancer policy deliberations at the Federal level. In 2019, we took a big leap into new territory by launching a state advocacy program offering resources and coordination to advocates working on childhood cancer issues in their state capitals.

Parent advocate Lynn Schaeber, a member of our Advisory Board, paved the way for this type of legislation with Peyton’s Law, which was signed into law in 2017 in Maryland. Her daughter Peyton used remote classroom technology - paid for by her classmates - during treatment. These new state grants will enable many more homebound students like Peyton stay engaged in their classrooms and with their peers during treatment and recovery.

A NEW FRONTIER: STATE ADVOCACY

A SUCCESS STORY IN PENNSYLVANIA:

The Pennsylvania Assembly passed legislation in 2019 making telepresence technology available to critically ill or injured students so they can continue to participate in classroom activities through the use of mobile robotic devices.
Our work is far from done.

We are grateful for your continued commitment to help us achieve a brighter future for every child with cancer.