



PAISLEY, LEUKEMIA SURVIVOR

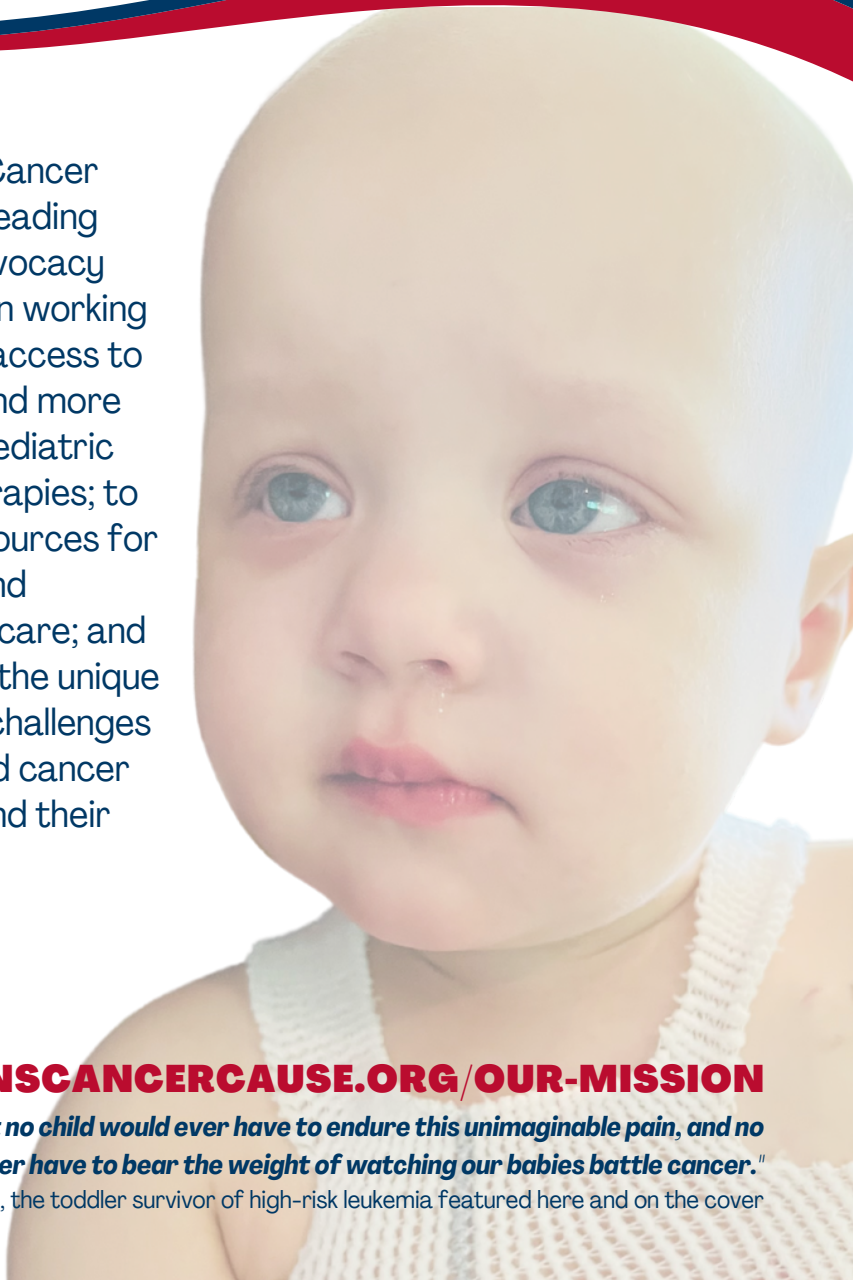
 children's
cancer cause

2022 ANNUAL
REPORT

PUBLISHED MARCH 2023

our **A LONG, HEALTHY LIFE FOR EVERY CHILD WITH CANCER** mission children's cancer cause

Children's Cancer Cause is a leading national advocacy organization working to achieve access to less toxic and more effective pediatric cancer therapies; to expand resources for research and specialized care; and to address the unique needs and challenges of childhood cancer survivors and their families.



[CHILDRENSCANCERCAUSE.ORG/OUR-MISSION](https://www.childrenscancercause.org/our-mission)

"I wish that no child would ever have to endure this unimaginable pain, and no family would ever have to bear the weight of watching our babies battle cancer."

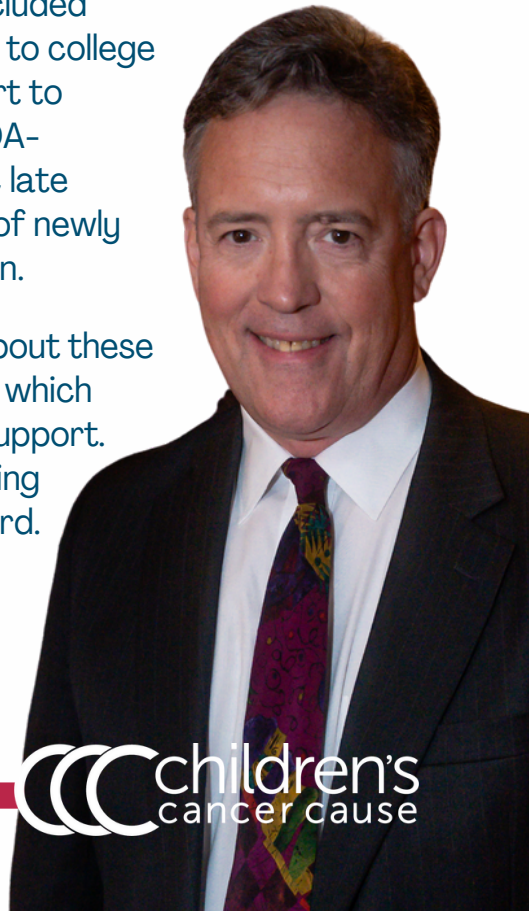
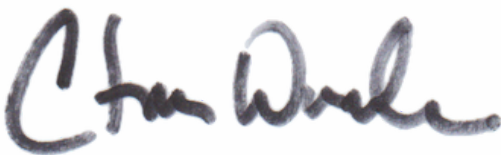
- Mom to Paisley, the toddler survivor of high-risk leukemia featured here and on the cover

A LETTER FROM CEO **STEVE WOSAHLA** 2022 PUT **SURVIVORSHIP** IN THE SPOTLIGHT

At Children's Cancer Cause, we're laser focused on a future where every child diagnosed with cancer can go on to live a long and healthy life. Our two foundational pillars are advancing policies to improve drug development and survivorship care. Survivorship has been a core pillar of our mission since our founding in 1999, and our work in 2022 demonstrates that our commitment to improving the lives of the more than 500,000 childhood cancer survivors in the U.S. is stronger than ever.

In 2022, our survivorship work included awarding academic scholarships to college students, providing direct support to survivorship clinics, hosting an FDA-approved conference on cardiac late effects, and drafting provisions of newly introduced survivorship legislation.

In this report, we share details about these achievements and more, none of which would be possible without your support. With you at our side, we're creating hope and driving progress forward.



GIVING A VOICE TO CHILDHOOD CANCER FAMILIES IMPACTED BY CARDIAC LATE EFFECTS



Pediatric cancer survivors and caregivers spoke to the Food and Drug Administration (FDA) in September 2022 about the “ticking time bomb” of cardiac late effects caused by harsh chemotherapy and radiation treatments. During this Externally-Led Patient-Focused Drug Development (EL-PFDD) meeting, hosted by Children’s Cancer Cause, survivors and families shared their experiences with treatment-induced cardiac late effects that may lead to a lifetime of health challenges, describing conditions ranging from heart failure to high blood pressure, chronic fatigue, and more.



The September 15th virtual meeting, *Reducing Cardiac Late Effects in Pediatric Cancer Survivors*, gave childhood cancer survivors, parents, and caregivers an opportunity to present to a wide range of stakeholders, including staff at the FDA and the National Cancer Institute (NCI), pediatric oncologists and other healthcare providers, and representatives from pharmaceutical companies.

Why this issue matters:

Anthracyclines and radiation therapy are the foundation of treatment for many pediatric cancer patients. But these therapies can lead to serious, chronic, and life-threatening cardiovascular complications that can increase with age and impact long-term well-being.

CHILDHOOD CANCER SURVIVORS
HAVE A 15-FOLD
INCREASED RISK OF DEVELOPING
CONGESTIVE HEART FAILURE.

An infographic with a red background. At the top is a yellow graphic of a heart with an ECG line passing through it. Below the graphic, the text reads: 'CHILDHOOD CANCER SURVIVORS HAVE A 15-FOLD INCREASED RISK OF DEVELOPING CONGESTIVE HEART FAILURE.' The words '15-FOLD' and 'CONGESTIVE HEART FAILURE' are in a larger, bold, yellow font.

"The treatments that saved my life now seem to be slowly stealing it. On difficult days, I feel that survivorship is a progressive terminal illness."



Susan is a Hodgkin's lymphoma survivor with valve disease and breast cancer as a result of childhood radiation treatment.

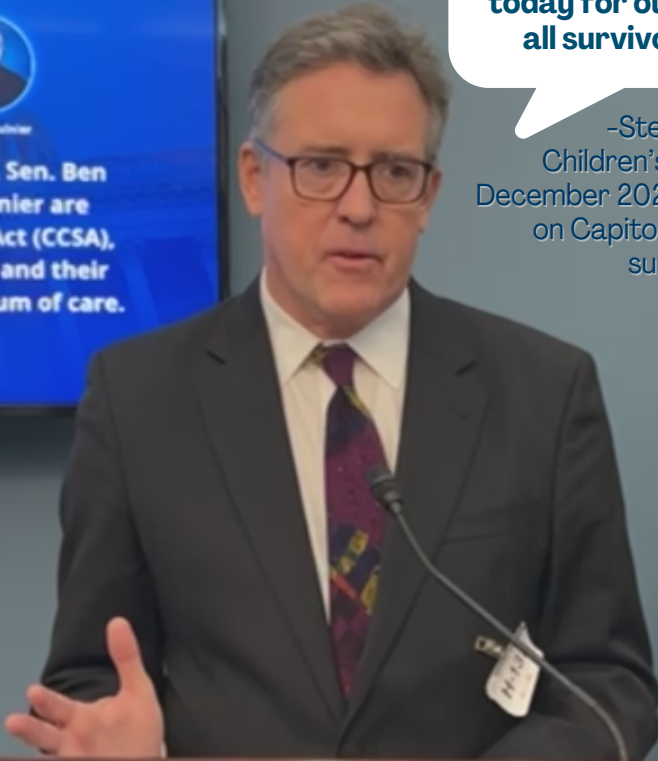
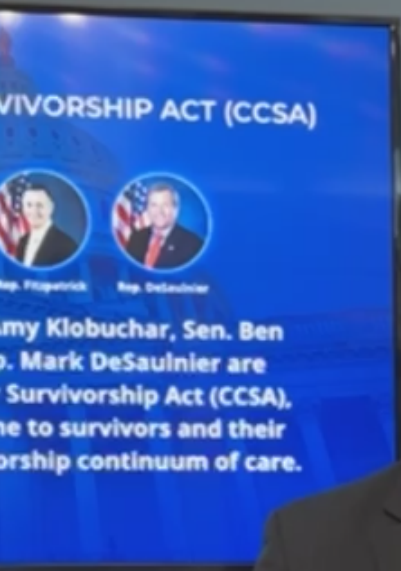
In total, over 150 people participated in the event livestream, which featured patient and family testimonials, panel discussions, research presentations, and interactive polling.



As a follow-up outcome from the meeting, Children's Cancer Cause submitted a Voice of the Patient report to the FDA in February 2023. Visit childhoodcancerpfdd.org for the public report and the event recording.

"Not only did we have a child battling cancer for the second time but she had heart failure. My greatest hope in sharing her story is that other families and children do not have to go through what Abby did for 11 of her 15 years on this earth."

This meeting was presented in collaboration with the American Academy of Pediatrics, the American Society of Clinical Oncology, the American Society of Pediatric Hematology/Oncology, The Andrew McDonough B+ Foundation, and Teen Cancer America.



Working with Congresswoman Debbie Wasserman Schultz and the other bill sponsors, **we're making an incredible step today for our population and all survivors in America.**

-Steve Wosahla, CEO of Children's Cancer Cause at a December 2022 press conference on Capitol Hill announcing new survivorship legislation

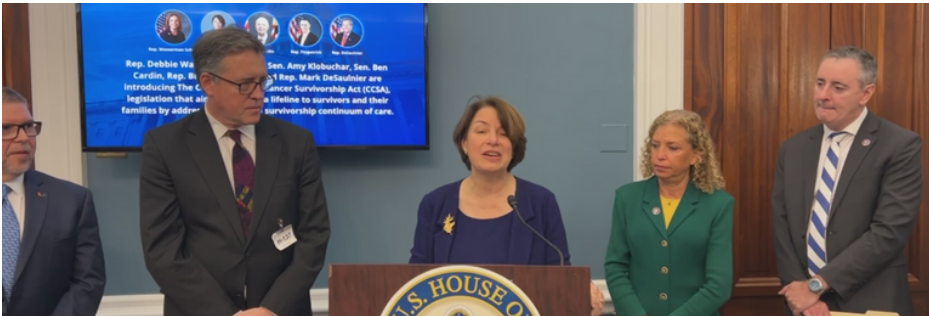
INTRODUCTION OF THE COMPREHENSIVE CANCER SURVIVORSHIP ACT

In December 2022, we celebrated the introduction of The Comprehensive Cancer Survivorship Act, landmark legislation that aims to provide a lifeline to survivors and their families by addressing the entire survivorship continuum of care.



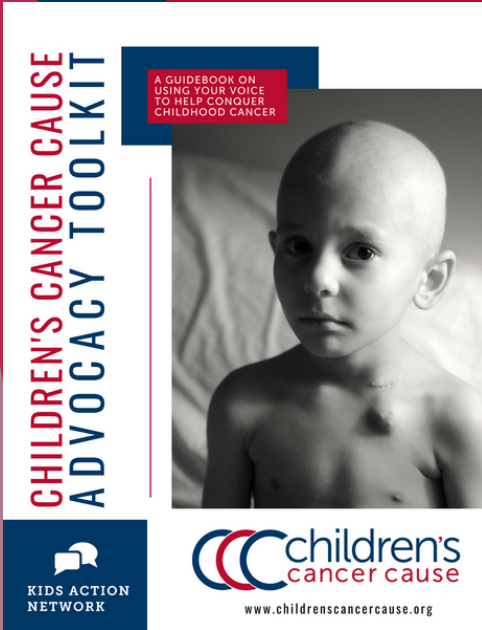
For years, Children’s Cancer Cause has worked closely with Capitol Hill staff on drafting this legislation and helping to ensure pediatric cancer survivor provisions were included in its bipartisan introduction.

The Comprehensive Cancer Survivorship Act addresses care planning, transition, navigation, reimbursement, quality, and much more. It aims to address gaps in survivorship care and develop desperately needed standards to improve the overall patient-centered quality of care and navigation needs of the nation’s 18 million cancer survivors, including over 500,000 survivors of childhood cancer.



Learn more: childhoodcancersurvivorship.org/ccsa

EMPOWERING ADVOCATES



ADVOCACY TOOLKIT

Our free digital publication, **updated with new content in 2022**, provides the tools to become an informed, effective advocate for kids with cancer and childhood cancer survivors.

Download your copy at
childrenscancercause.org/toolkit

OUTREACH TO CONGRESS

1,638

messages sent to Congress in 2022 through our grassroots action center.

366

first-time advocates, including Jessica, the mom of cover girl Paisley, both pictured here.

Become an advocate at
childrenscancercause.org/kan



A VICTORY FOR KIDS: PASSAGE OF THE STAR REAUTHORIZATION ACT



Just before the end of the 117th legislative session in December 2022, both chambers of Congress passed the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Reauthorization Act, legislation that will impact the future of pediatric cancer research and the delivery of care for the rest of this decade and beyond.



Reauthorizing this landmark legislation for five more years enables STAR Act programs to continue making a life-saving impact for children with cancer and survivors. Children's Cancer Cause helped draft the original legislation - at the time, the largest childhood cancer legislation ever enacted - and chaired the Alliance for Childhood Cancer's survivorship work group, which was instrumental in drafting the survivorship provisions of the STAR Reauthorization Act.

Since being signed into law in 2018, the STAR Act has delivered over \$120 million to boost childhood cancer research and bolster data collection, with another \$30 million secured for Fiscal Year 2023. This reauthorization ensures that progress into promising research will continue and expand in the coming years.

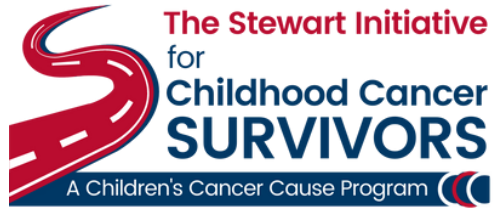
2022 COLLEGE SCHOLARS

Children's Cancer Cause welcomed eight students into the 2022 class of our College Scholars Program. These survivors receive a financial scholarship to help with academic expenses and gain valuable leadership experience by undertaking a volunteer project related to childhood cancer advocacy.



STEWART SCHOLAR FRANCESCA

Francesca was diagnosed with thyroid cancer when she was 15 years old. She's studying at Stanford University School of Medicine with plans to become a pediatric oncologist.



The Stewart Scholarship is named in honor of John and Nancy Stewart, founders of our Stewart Initiative for Childhood Cancer Survivors.



GOLD SCHOLAR CARLY

"Cancer is one of the biggest obstacles a person can face. I am who I am today because of my past," says brain tumor survivor Carly, now studying at Belmont University. For her volunteer project, Carly created a database of college scholarships available to cancer survivors in Connecticut, to help others achieve their college dreams.



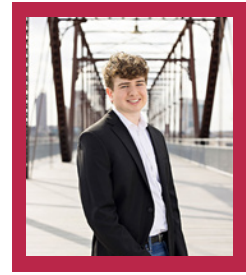
GOLD SCHOLAR ANDREW

Andrew was diagnosed with osteosarcoma when he was seven years old, undergoing a complicated limb salvage surgery and a full year of learning to walk again. He is studying mechanical engineering at Northeastern University and gives motivational speeches.

SILVER SCHOLAR CONNOR

Connor was diagnosed with a brainstem glioma when he was three years old. He was given just six months to live. Today, he is studying architecture at Texas Tech.

“Cancer allowed me to see people and the world from a different perspective. Perhaps that’s why I want to be an architect. I am always looking for ways to make something better.”



SILVER SCHOLAR BRENNAN

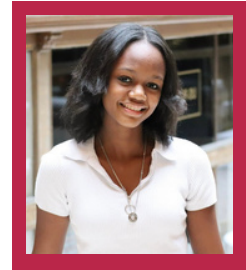
Brennan was diagnosed with a rare type of Hodgkin's lymphoma when he was 14. Despite spending his freshman year battling cancer, the honor student served as Class President and is now studying molecular biology at the University of Michigan.



BRONZE SCHOLAR SHAMARI

Shamari was diagnosed with osteosarcoma when she was 13. Today, she studies International Affairs at GWU and is working on a peer tutor program.

“It was a long journey, a stressful one, and a very, very scary one. But it’s a journey that I’m proud of and one that I think was necessary for me to take to grow into the person I am today.”



BRONZE SCHOLAR PRESTON

Preston was diagnosed with Hodgkin's lymphoma at age five, which had spread from his neck to his chest and down to his liver. He's attending Purdue University.

“I was forced to mature almost overnight, and I quickly realized that an optimistic look on life - even when the world is on fire - can make these situations bearable.”



BRONZE SCHOLAR SPENCER

Spencer is a two-time survivor of Ewing's Sarcoma, diagnosed with cancer in the soft tissue above his right eye when he was four years old. Today, he is studying engineering at Arizona State.



GIVING SURVIVORS A VOICE

Teen, young adult, and adult survivors of childhood cancers participated in our annual survey of survivor needs in the summer of 2022. We're using their insights to ensure that we are best representing the unique needs of childhood cancer survivors in our program planning and in our policy work on Capitol Hill.

Here's some of what we heard:

Relapse or recurrence

was named by almost half of the survivors we surveyed as one of their top three health concerns.

"Every time I get tired, the fear creeps in that it's because I'm relapsing."

Mental health, fertility, and second cancers were other top-ranking health concerns.

"I have so much grief over not being able to have children."



Survivors expressed frustration about the concept that being post-treatment (or "cured") means that a cancer survivor's health problems are over.

"The journey never truly ends."



30% of respondents don't know or did not receive a **summary of care or treatment history.**

15% of those with a Survivorship Care Plan haven't looked at it "in a while," "rarely," or "never."



"It's important to realize that life doesn't go back to being rainbows and butterflies; it's actually living with a constant fear that the cancer will return."

-Hodgkin's survivor

SURVIVORSHIP CHAMPION'S PRIZE



2022 Prize Awarded to Phoenix Children's Hospital Survivorship Program

The \$10,000 Champion's Prize is awarded annually to a group, program, or institution making significant advances in programs and services to provide life-long health maintenance for survivors of pediatric cancers. In 2022, Phoenix Children's Hospital's Survivorship Program was selected for this award in recognition of their patient-centric research and impressive multidisciplinary care model.

Additional recognition awards of \$5,000 were awarded to:

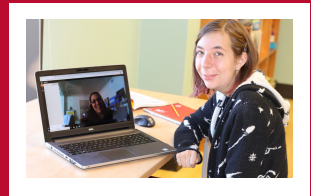


COLLABORATION

David B. Perini, Jr. Quality of Life Clinic, Dana Farber Cancer Boston Children's Cancer and Blood Disorders Center
(Boston, MA)



PROGRAM IMPACT
St. Jude Transition Oncology Program
(Memphis, TN)



SCALABILITY

ASK Childhood Cancer Foundation
(Richmond, VA)

COMMUNITY & CONNECTION



A foundational principle of Children's Cancer Cause is our commitment to collaboration and teamwork with other stakeholders in the cancer community. It's in the best interest of the children and families we serve to prioritize collaboration and work together with other organizations and coalitions that share our mission.

We are founding members of the Coalition Against Childhood Cancer (CAC2) and the Alliance for Childhood Cancer, and today we have staff on work groups and task forces at both coalitions. We are also active members of the Cancer Leadership Council and the One Voice Against Cancer coalition.



Photo, left: Together with CAC2 Members after attending a Cancer Moonshot forum at the White House.

Our Founder Susan Weiner serves on the ACCELERATE steering committee, taking an active role in global efforts to accelerate innovative cancer therapies.

We also support community programs and events like CureFest, which we sponsor annually in order to help bring childhood cancer families and advocates together in DC.

We can achieve much more together than we can alone.

ROSEN AWARD

In recognition of his lifetime commitment to advancing research in childhood cancer, Children's Cancer Cause presented the 2022 Leonard M. Rosen Memorial Research Award to Malcolm Smith, MD, PhD, Associate Branch Chief for Pediatric Oncology at the National Cancer Institute's Cancer Therapy Evaluation Program (CTEP), at a reception in New York City in November 2022.



The Rosen Award, now in its seventh year, honors an individual who has made outstanding contributions in the fight against childhood cancer, the leading cause of death by disease among children in the United States. Dr. Smith's work has furthered scientific understanding of the unique biology of pediatric cancers and the challenges associated with the care and treatment of the 16,000 children diagnosed with cancer each year in the U.S.



"Dr. Smith has been responsible for building the national architecture of programs for childhood cancer research at NCI over the past 25 years, and he's done it with crystal clear thought leadership and analysis."

- Children's Cancer Cause founder Susan L. Weiner, PhD, pictured here with board chair Adam Rosen and Malcolm Smith



BOARD OF DIRECTORS

ADAM L. ROSEN, JD, CHAIR
LARRY HAUSNER, VICE-CHAIR
WYLIE D. CHEN, TREASURER
SUSAN SCHERR, SECRETARY

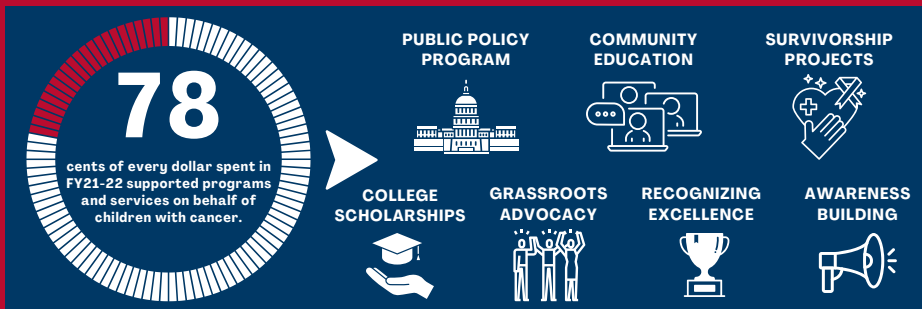
LYNN BAYARD, JD
 MARK J. CORNFELD, MD, MPH
 LEANN JACKSON
 MICHAEL LINK, MD



MARY MCCABE, RN, MA
 JENNIFER NIEDERMEYER
 GREG REAMAN, MD
 LORI SALLEY RING
 BETH SILBER, MPA
 NANCY STEWART
 DANIEL S. WECHSLER, MD, PHD
 JASON T. YUSTEIN, MD, PHD
SUSAN L. WEINER, PHD, FOUNDER

FINANCIAL REPORT FISCAL YEAR 2021-2022

Our work is supported by corporate and foundation grants, and by caring friends and families. **Our most recent audited financials and IRS Form 990 are available at childrenscancercause.org/governance.**



FOR THE YEAR ENDED JUNE 30, 2022

| | Without Donor Restrictions | With Donor Restrictions | Total |
|---|----------------------------|-------------------------|---------------------|
| REVENUE | | | |
| Contributions and grants | | | |
| Cash and other financial asset contributions and grants | \$ 603,716 | \$ 11,315 | \$ 615,031 |
| In-kind contributions | 51,022 | - | 51,022 |
| Investment return | (169,664) | - | (169,664) |
| Net assets released from restrictions | 164,395 | (164,395) | - |
| Total Revenue | \$ 649,469 | \$ (153,080) | \$ 496,389 |
| EXPENSES | | | |
| Program services | \$ 767,294 | \$ - | \$ 767,294 |
| Management and general | 76,335 | - | 76,335 |
| Fundraising | 139,469 | - | 139,469 |
| Total Expenses | \$ 983,098 | \$ - | \$ 983,098 |
| CHANGE IN NET ASSETS | \$ (333,629) | \$ (153,080) | \$ (486,709) |
| NET ASSETS, BEGINNING OF YEAR | 1,482,391 | 508,061 | 1,990,452 |
| NET ASSETS, END OF YEAR | \$ 1,148,762 | \$ 354,981 | \$ 1,503,743 |

Platinum
Transparency
2022

Candid.

Candid is the leading provider of information about nonprofits. The Platinum level recognition is the highest possible and demonstrates Children's Cancer Cause's deep commitment to nonprofit transparency and accountability.



give your own way

We offer a wide variety of ways to support our work, including:

**DONATE STOCK
OR CRYPTO**



**VEHICLE
DONATION**



**DONATE GIFT
CARDS**



**FACEBOOK
FUNDRAISER**



**WORKPLACE
GIVING**



**ROUND UP
YOUR CHANGE**



**MAKE A
MEMORIAL GIFT**



**PAYPAL OR
VENMO**



CHILDRENSCANCERCAUSE.ORG/GIVE

thank you



FOR YOUR
SUPPORT OF
KIDS LIKE
SPENCER.

Spencer was diagnosed with Ewing's Sarcoma when he was four years old. A relapse at age six required the complete removal of one eye. This inspired an interest in engineering, specifically vision prosthetics. He hopes to one day help create an artificial eye that works for him and for others.

Thanks to the support of donors like you, Spencer received a Children's Cancer Cause scholarship in 2022, bringing him one step closer to his goals.



I know that I am just one person, but one person can truly start a trend.





ALEXIA, NEUROBLASTOMA SURVIVOR

     @CHILDRENSCAUSE

INFO@CHILDRENSCAUSE.ORG | 202.552.7392

1325 G ST. NW, SUITE 540 | WASHINGTON, D.C. 20005

CHILDRENSCANCERCAUSE.ORG