



OUR VISION: A LONG, HEALTHY LIFE
FOR EVERY CHILD WITH CANCER

ANNUAL REPORT 2023

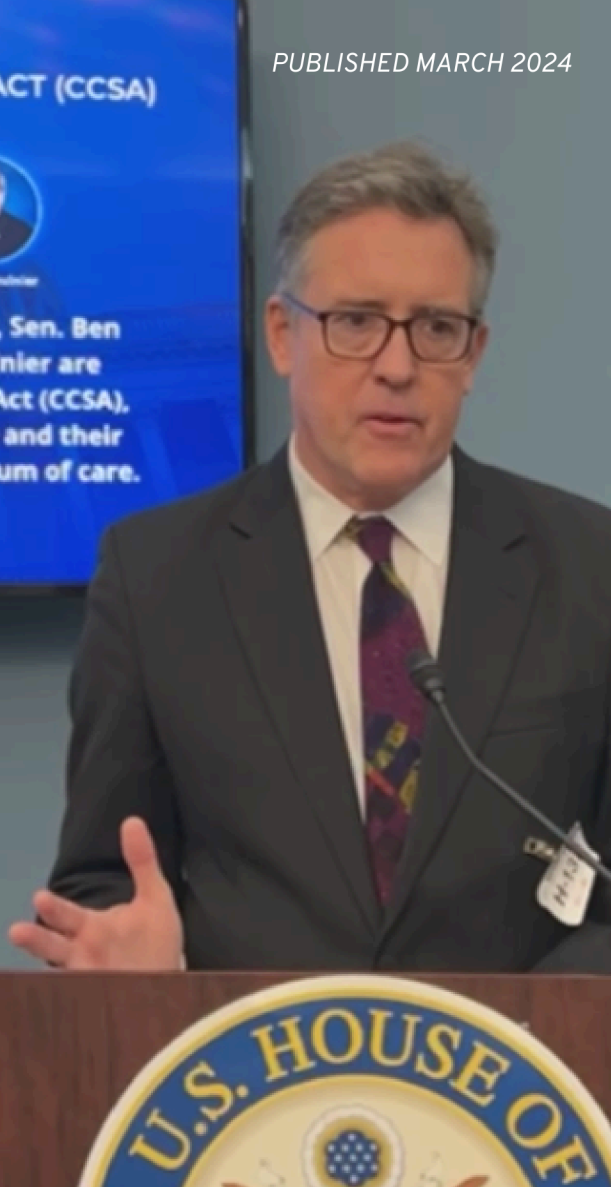


**ALEXIA,
NEUROBLASTOMA SURVIVOR**



**Our mission is
to champion
policies and
programs
that improve
the lives of
children
with cancer
and survivors.**

PUBLISHED MARCH 2024



FROM THE DESK OF THE CEO

As we enter our 25th year serving as national advocates for children with cancer, we thank you for standing with us. Your support enables us to do this life-saving work on behalf of the 15,000 kids being diagnosed this year and the 500,000 survivors of childhood cancer in this country.

2023 was a big year for legislative achievements. At Children's Cancer Cause, our policy work focuses on two main pillars: drug development and survivorship. We were successful in achieving the introduction of legislation on both fronts, which you'll read more about in this report.

Every day that we work together, we take one step closer to a future where every child with cancer can live a long and healthy life. Thank you for joining us in pursuing a brighter tomorrow. It's within our reach.

A handwritten signature in black ink, appearing to read "Steve Wosahla".

STEVE WOSAHLA
CHIEF EXECUTIVE OFFICER

P.S. Join our Kids Action Network to help push for policy progress in the coming year!

Founded in 1999, Children's Cancer Cause is a leading national advocacy organization dedicated to creating a brighter future for children with cancer, survivors, and their families.

CHILDREN'S CANCER CAUSE WITH OTHER CANCER ADVOCATES ON A TOUR OF NCI LABS, SEPT. 2023



LEGISLATIVE ACHIEVEMENTS

STAR ACT REAUTHORIZED FOR FIVE MORE YEARS

President Biden signed the *Childhood Cancer STAR (Survivorship, Treatment, Access, Research) Reauthorization Act* into law just days into the start of 2023. This was a major legislative victory 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 authorizes \$30 million annually through fiscal year 2028 to support and expand STAR programs

at the National Cancer Institute. These STAR programs are advancing childhood cancer research, enhancing surveillance, and supporting 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 workgroup, which was instrumental in drafting the survivorship provisions within the *STAR Reauthorization Act*.

INNOVATION IN PEDIATRIC DRUGS ACT OF 2023

The *Innovation in Pediatric Drugs Act of 2023* (H.R. 6664) is a bipartisan bill introduced in the House of Representatives in December of 2023 that would strengthen the development of childhood cancer drugs.

For the past several years, Children's Cancer Cause has advocated that the Food and Drug Administration (FDA) have the same authority to penalize companies who fail to complete required studies for pediatric drugs as they currently have for studies of adult drugs. This bill strives to achieve that equity.

The biology of cancer in children is different from cancer in adults. Drugs to treat children must be developed that are tailored for children.

This bill is an important step to ensure that required studies are completed for children as they are currently done for adults.





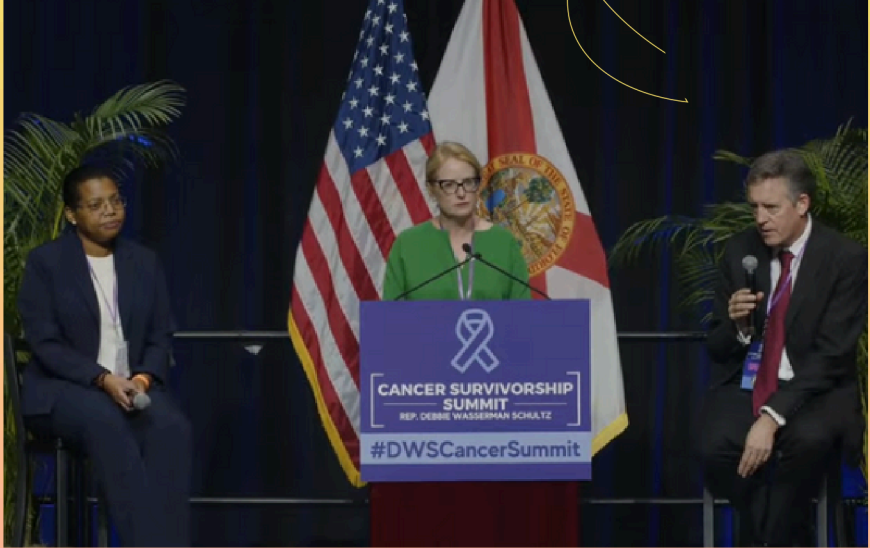
A STRONG, CLEAR, UNIFIED VOICE

In support of our policy and legislative work, we participated in the White House’s Childhood Cancer Forum (pictured above) and in lobby days on Capitol Hill. These meetings with legislative offices, alongside our coalition partners and grassroots advocates, rallied bipartisan support for our priorities. We also presented at the inaugural Cancer Survivorship Summit hosted by Congresswoman Debbie Wasserman Schultz (pictured on page 5).



*Dear Congress,
I am a cancer mom. My daughter is alive today because of the leaps in childhood cancer research made in just the last few years. No parent should have to see their child face death so closely. Please help!*

Hundreds of grassroots advocates around the country sent messages to Congress through our Legislative Action Center in 2023, and our Kids Action Network continues to grow in numbers and strength.



COMPREHENSIVE CANCER SURVIVORSHIP ACT

Reintroduced in both the House and Senate in the summer of 2023, the *Comprehensive Cancer Survivorship Act* (H.R. 4362/S.2213) addresses care planning, transition, navigation, reimbursement, quality, and the entire continuum of care.

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 of all ages. The bill has two childhood cancer provisions that Children's Cancer Cause helped draft and provided technical feedback on.

Since our founding, Children's Cancer Cause has made survivorship a key pillar of our work toward our vision of a long, healthy life for every child with cancer.

We have long advocated the creation of standards of care for survivorship care planning. The *Comprehensive Cancer Survivorship Act* would take important steps to help further this goal.

MEET OUR 2023 COLLEGE SCHOLARS

These ten students have demonstrated a strong commitment to cancer volunteerism and advocacy. Each of these inspiring young cancer survivors receives a financial scholarship and undertakes a volunteer project related to cancer advocacy.



Dahlia, Stewart Scholar

Leukemia survivor studying biology at Wesleyan University

Dahlia, a native of Chevy Chase, Maryland, was diagnosed with Acute Myeloid Leukemia (AML) during her senior year of high school.

Dahlia received the 2023 Stewart Scholarship, presented to a survivor who demonstrates exceptional potential to make a positive difference in the world. It is named in honor of John and Nancy Stewart, founders of our Stewart Initiative for Childhood Cancer Survivors.

"I'm so grateful for this scholarship and for the opportunity to raise awareness around childhood cancer."

-Dahlia



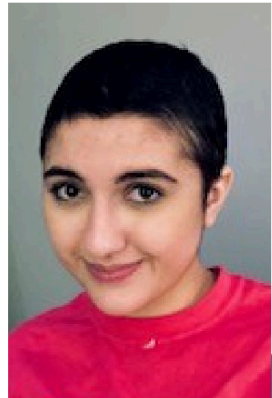
Morgan

Leukemia survivor studying biology at St. Norbert College



Isaac

Leukemia survivor studying business at Messiah University



Liliana

Lymphoma survivor studying psychology at Univ. of Kansas

"I've dreamed since I was a child that I would become an oncologist and help people like my doctors helped me."

-Morgan



Kevin

Non Hodgkins lymphoma survivor studying cellular biology at NYU



Hannah

Osteosarcoma survivor studying business at the University of Hartford



Kendal

Rhabdomyosarcoma survivor studying biological sciences at UC Santa Barbara

"I want to be an example to other survivors, proving that we can all rise above our circumstances with resilience and distinction to achieve a greater good."

-Maurquez

Scan the QR code to read about their stories and learn about their projects:



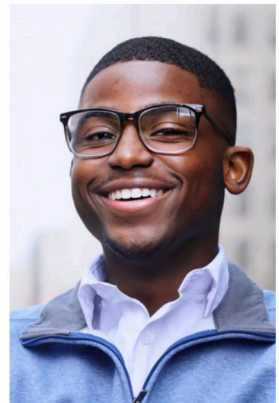
Christin

Wilms tumor survivor studying biology at the University of Chicago



Caeleigh

Leukemia survivor studying nursing at James Madison University

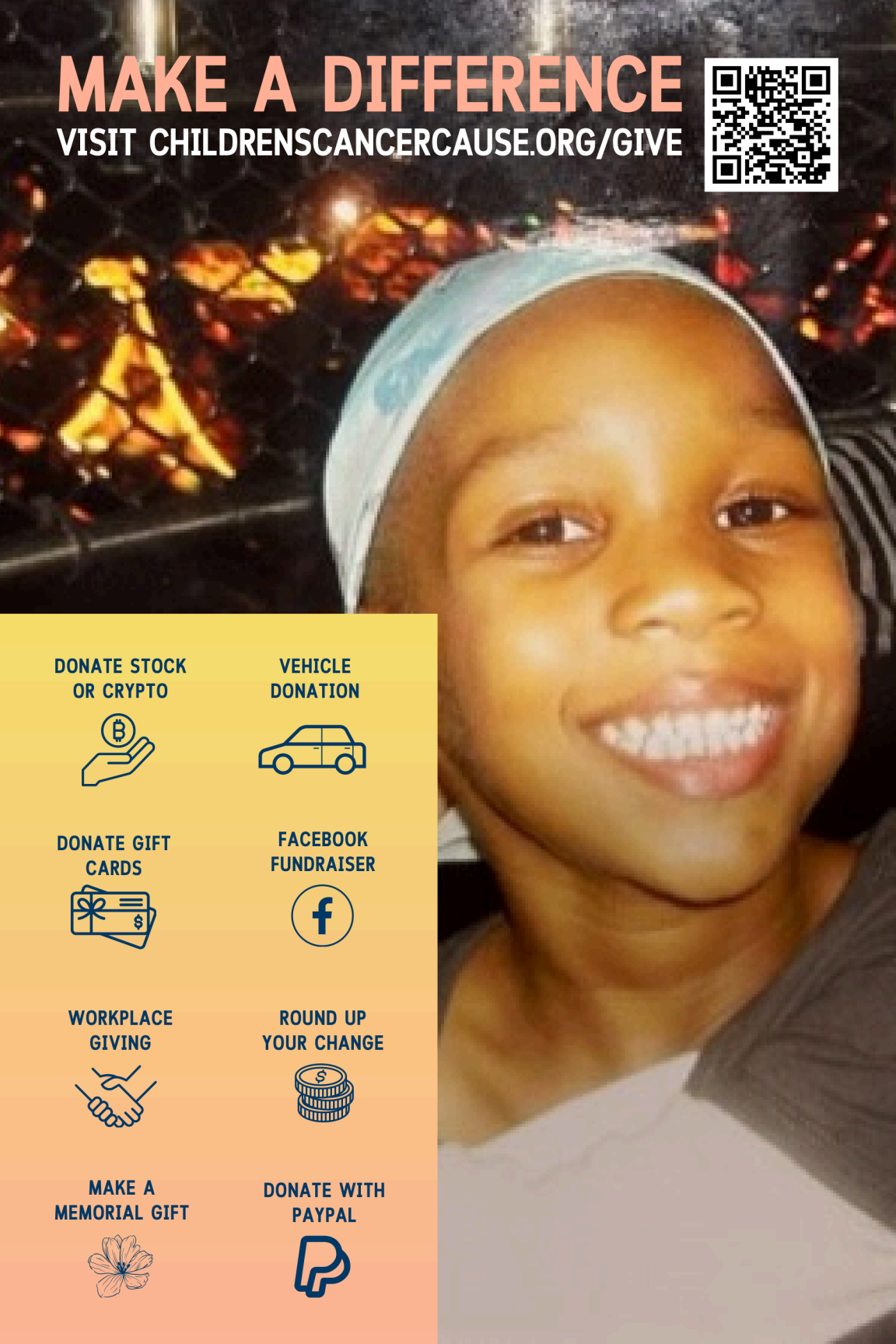


Maurquez

Leukemia survivor studying social justice at Stanford University

MAKE A DIFFERENCE

VISIT CHILDRENCANCERCAUSE.ORG/GIVE



**DONATE STOCK
OR CRYPTO**



**VEHICLE
DONATION**



**DONATE GIFT
CARDS**



**FACEBOOK
FUNDRAISER**



**WORKPLACE
GIVING**



**ROUND UP
YOUR CHANGE**



**MAKE A
MEMORIAL GIFT**



**DONATE WITH
PAYPAL**



SURVIVORS MAKING A COMMUNITY IMPACT

Each of our College Scholars completes a childhood cancer volunteer project with mentorship and support from our team. Francesca and Isaac are two of these inspiring young leaders making a difference in their local communities.



Isaac hosted a blood drive at his local church in the summer of 2023.

"Most of the donors were first-time donors, which was so exciting," said Isaac's family. "This was the first time that our church had hosted a blood drive, and they hope to do it once or twice per year from this point forward."

Isaac's sister was so inspired by the success that she hosted a blood drive, too!

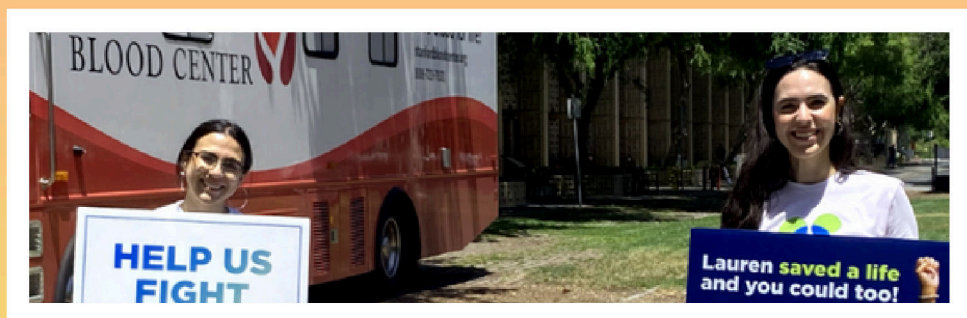


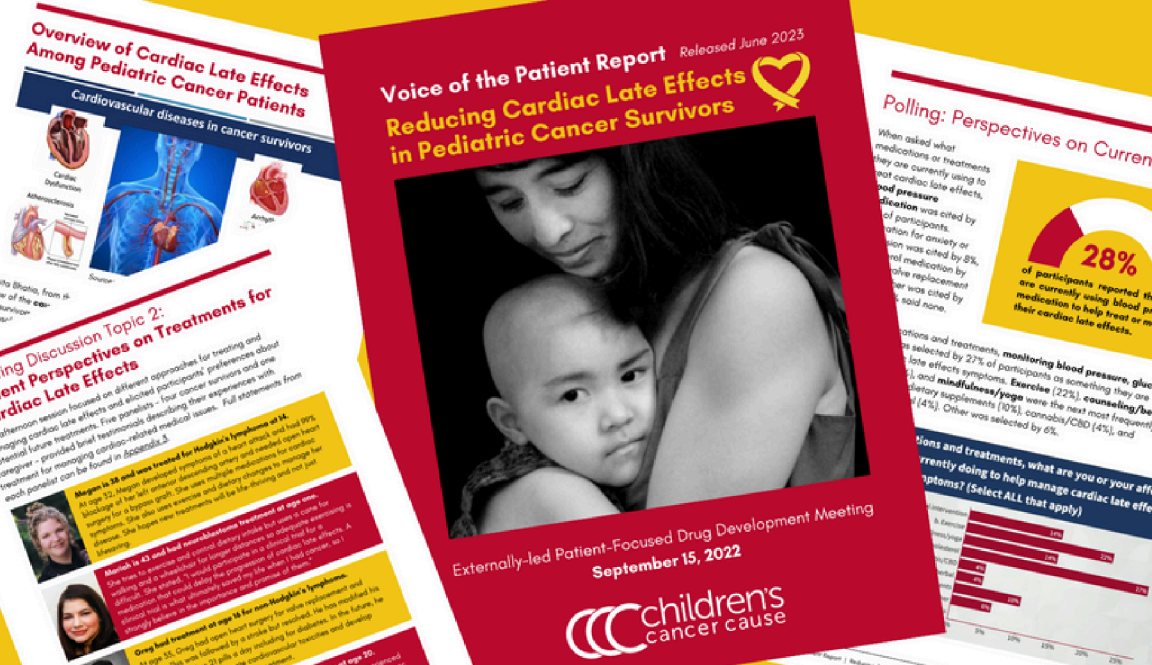
"So many times during my experience with cancer, my life was saved by a stranger."

FRANCESCA, STEWART SCHOLAR & MED STUDENT

Francesca organized a campus bone marrow drive at Stanford University. The event was a big success, enrolling approximately 45 new potential donors from diverse ethnic backgrounds into the national marrow registry.

"Thank you so much for this opportunity to share with others the importance of signing up for the match, educate them on racial disparities in cancer treatments, and inform my campus about pediatric cancers. I am honored to be part of this community and want to offer any support I can in the coming years!"





“A TICKING TIME BOMB”



VOICE OF THE PATIENT REPORT EMPHASIZES BURDEN OF LIFELONG CARDIAC LATE EFFECTS IN PEDIATRIC CANCER SURVIVORS

This report, submitted to the FDA in the spring of 2023, stems from our Externally-Led Patient-Focused Drug Development meeting on reducing cardiac late effects in pediatric cancer survivors. The report is available at the QR code or this URL:



WWW.CHILDHOODCANCERPFDD.ORG

The report includes survivor stories about challenges with everyday activities due to shortness of breath, racing heartbeat, fatigue, depression, and anxiety, in addition to testimony from parents whose children survived their cancer but later died from cardiac complications caused by the harsh, toxic treatments.

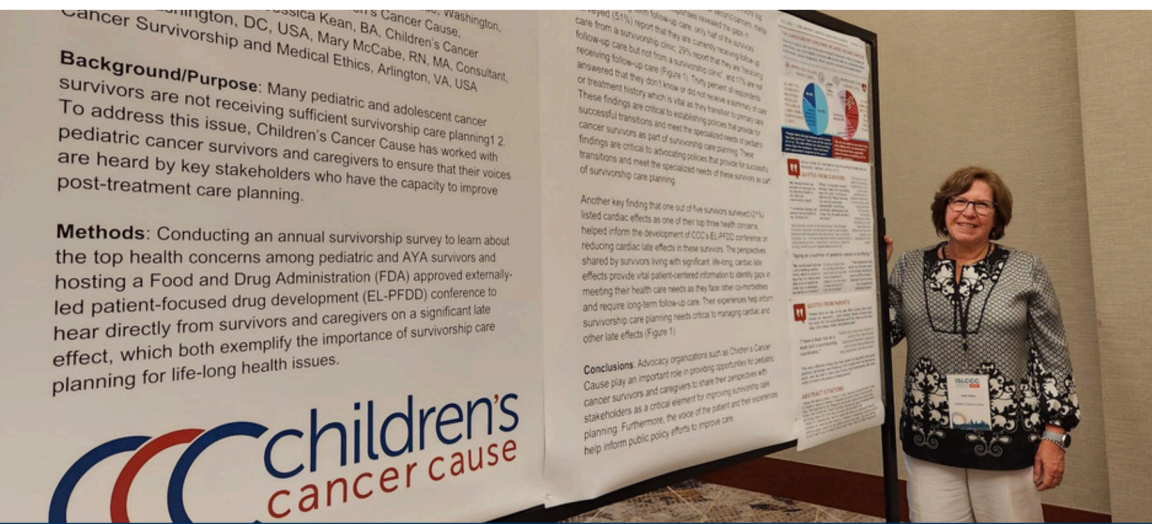
“We hope that this Voice of the Patient report will impact the way we think about this population’s needs, encourage future research, and advance successful new treatments as survivors transition into adulthood and face a lifetime of significant health challenges.”

-Steve Wosahla, CEO
Children’s Cancer Cause

GIVING SURVIVORS A VOICE

Children’s Cancer Cause was proud to present a poster at the International Symposium on Late Complications After Childhood Cancer (ISLCCC) in Atlanta, Georgia. The June 2023 symposium showcased cutting-edge research findings and valuable insights gained from real-world clinical practice, with the aim of fostering research collaborations and enhancing survivorship care on a global scale.

Our abstract - *Elevating the Voice of the Survivor to Improve Survivorship Care Planning* – emphasized the role of advocacy organizations like ours in improving survivorship care planning and informing public policy efforts by providing opportunities for childhood cancer survivors and caregivers to share their perspectives with stakeholders.



Our annual survey of survivors helps ensure that we are best representing their unique needs and perspectives in our program planning and in our policy work on Capitol Hill.



“Transitioning into **my first year of college** and trying to **manage survivorship care** with no care plan in place **feels impossible.**”

“**Doctors aren’t trained** to handle our cases.”

LACK OF CARE PLANS

Over half of survivors we surveyed reported that they **do not** have a Survivorship Care Plan to share with future providers to help manage their long-term care and health risks.

KNOWLEDGE GAPS

35% of survivors surveyed reported that in the last year, their non-oncology doctors **“rarely or never”** seemed up-to-date about the care their patient has received from cancer specialists.



SURVIVORSHIP CHAMPION'S PRIZE

In October, we named the Childhood, Adolescent and Young Adult (AYA) Cancer Survivorship Program at City of Hope as the recipient of the 2023 Survivorship Champion's Prize, in recognition of their multidisciplinary approach to improving the quality of health and well-being of survivors.

Since its inception in 2020, the Survivorship Champion's Prize has awarded \$85,000 to a total of thirteen prestigious survivorship programs across the country, enabling these institutions to address disparities in access to care, enhance and expand healthcare transition programs, improve technology, and purchase tablets and books for clinic patients.

"We are honored to be the recipients of this year's Survivorship Champion's Prize, which will enable us to develop a comprehensive, scalable database to engage survivors throughout their survivorship journeys."

-Dr. Rusha Bhandari, City of Hope

The Survivorship Champion's Prize is a component of the Stewart Initiative for Childhood Cancer Survivors, an educational program of the Children's Cancer Cause.



HONORING PEDIATRIC ONCOLOGY TRAILBLAZERS

In recognition of their extraordinary leadership in combatting childhood cancer, Steven Joffe, MD, MPH, and Vickie Buenger, PhD, received special awards from Children's Cancer Cause at our signature event of the year in New York City.

Dr. Steven Joffe, a pediatric oncologist with specialty in the ethical complexities of childhood cancer research, received the 8th annual **Leonard M. Rosen Memorial Research Award**. The Rosen Award honors an individual who has made outstanding contributions in the fight against childhood cancer and pays tribute to late Children's Cancer Cause chairman and founding board member Leonard Rosen.

Vickie Buenger received a **Special Achievement Award** for her dedication to children with cancer and her leadership in establishing the Coalition Against Childhood Cancer (CAC2).

When Dr. Buenger's daughter Erin died in 2009 of neuroblastoma, Vickie helped launch CAC2 to coalesce childhood cancer foundations and individual advocates to increase community collaboration around support, education, research, and advocacy.

"There's obviously a ton more work to be done, but [in the past 50 years] we've come an incredibly long way. And a critical reason for that is because of advocacy groups like Children's Cancer Cause. Thousands of kids are alive or living better lives because of everything you do."

-Dr. Steven Joffe

BOARD OF DIRECTORS



Board Chair Adam Rosen with 2023 Stewart Scholar Dahlia

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VALUES

Children's Cancer Cause believes every child with cancer deserves safe, effective, accessible, and affordable care of the highest quality.



Adam Rosen and Dr. Michael Link



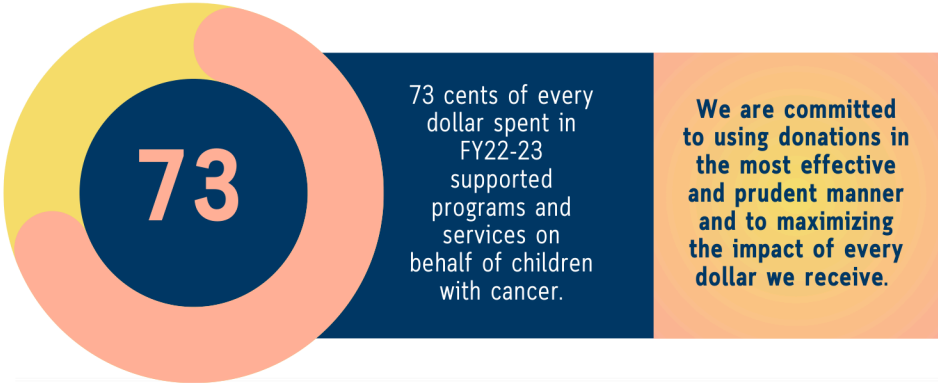
Susan Weiner and Susan Scherr

We value efficient, innovative research progress, evidence-based standards for treatment and care, and collaboration with the cancer community. We are committed to reducing disparities in access to treatment and care for underserved populations.

FINANCIAL REPORT

FISCAL YEAR
2022-2023

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, 2023

	Without Donor Restrictions	With Donor Restrictions	Total
REVENUE			
Contributions and grants:			
Cash and other financial asset contributions and grants	\$ 663,374	\$ 40,000	\$ 703,374
In-kind contributions	17,866	-	17,866
Investment return	103,391	-	103,391
Net assets released from restrictions	188,456	(188,456)	-
Total Revenue	<u>\$ 973,087</u>	<u>\$ (148,456)</u>	<u>\$ 824,631</u>
EXPENSES			
Program services	\$ 815,817	\$ -	\$ 815,817
Management and general	124,542	-	124,542
Fundraising	178,929	-	178,929
Total Expenses	<u>\$ 1,119,288</u>	<u>\$ -</u>	<u>\$ 1,119,288</u>
CHANGE IN NET ASSETS	\$ (146,201)	\$ (148,456)	\$ (294,657)
NET ASSETS, BEGINNING OF YEAR, RESTATED	<u>1,111,154</u>	<u>354,981</u>	<u>1,466,135</u>
NET ASSETS, END OF YEAR	<u>\$ 964,953</u>	<u>\$ 206,525</u>	<u>\$ 1,171,478</u>



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.

YOUR SUPPORT HELPS US SHINE A
SPOTLIGHT ON KIDS LIKE SAVANNAH.
THANK YOU.



Savannah was diagnosed with acute myeloid leukemia when she was just two years old. In 2023, she celebrated her 16th birthday!

“I know I will never be able to take anyone’s pain away, but **I hope my story will be able to guide others.**”

-Liliana

Thanks to the support of donors like you, Liliana received a Children's Cancer Cause scholarship in 2023, bringing her closer to her goal of becoming a child therapist to help other kids through challenging circumstances.





Alexia

Alexia, pictured here and on the cover, was diagnosed with stage 3 neuroblastoma when she was 14 months old. "She's in remission and doing well," says her mom.

     @CHILDRENSCAUSE

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