



# 2021 ANNUAL REPORT




Meet Michael on page 3, a three-time survivor and recent candidate for public office.



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[WWW.CHILDRENSCANCERCAUSE.ORG](http://WWW.CHILDRENSCANCERCAUSE.ORG)



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

## **FOUNDED IN 1999**

Children's Cancer Cause is the 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://CHILDRENSCANCERCAUSE.ORG/OUR-MISSION)



**Together, we're giving  
children with cancer a**

**Voice.**

Dear Friends,

It would be an understatement to say we live in challenging times. As we entered the second year of the pandemic in 2021, we dealt with uncertainties as a country and community that we hadn't seen in our lifetimes.

But thanks to you, our voice continued to be heard among our nation's leaders in Washington. We continued to fight for meaningful change for children and survivors of childhood cancer.

At Children's Cancer Cause, we are committed to help foster the best pediatric cancer therapies, expand resources for research and special care, and address the unique needs and challenges of childhood cancer survivors.

We extend our deepest appreciation for the tremendous outpouring of support we received this past year.

In these pages, we look at some of the things we were able to do, together.

This community is strong and resilient. Thanks to you, we are more hopeful than ever.

Childhood cancer hasn't stopped and neither have we.

Thanks to you, our voice will never waver.

A handwritten signature in dark ink, appearing to read 'Steve Wosahla'.

Steve Wosahla  
Chief Executive Officer

# IMPROVING DRUG DEVELOPMENT

GIVING KIDS A VOICE IN THE PROCESS 

**"I feel like I have a responsibility to do whatever I can to help future patients."**

*- Childhood cancer survivor*

Children's Cancer Cause collaborated with Pfizer on a focus group in the spring of 2021, seeking patient input on how to make better medicines to treat children and young adults. Participating survivors were graduating high school seniors or college undergrads who recounted their experiences from treatment in childhood or younger teen years. Participants discussed their experiences with different types of formulations such as pills, liquids, or injections, sharing their preferences and the particular challenges they encountered.



**"Including the patient voice as part of the drug development process is critical to improving treatments. We thank these survivors for their courage in sharing so openly in the hopes it will help others as they manage their disease."**

*- Moderator Beth Silber, Children's Cancer Cause board member and parent of a childhood cancer survivor*

A core pillar of our mission is ensuring that the needs and perspectives of children with cancer and survivors are integrated into the highest deliberations on health care and cancer policy. This collaboration with Pfizer is one example of how we work day in and day out to fulfill our founding mission and march toward a future where every child with cancer can live a long and healthy life.



"Even if I live just a few more years, I want to make them count."

— Michael

## A THREE-TIME CANCER SURVIVOR

On his last day of school in 8th grade, Michael was diagnosed with Ewing's Sarcoma, turning summer vacation into grueling weeks of aggressive chemotherapy and invasive surgery.

Michael relapsed in high school and again in college, but he continues to beat the odds and maintain a positive spirit with determination to make a difference in the lives of others. In 2021, while still an undergrad at university, Michael took his passion for advocacy a step further by running for local public office in Washington state on a platform of "Children Come First."

We're proud to count this future leader among the alumni of our College Scholars Program, and we can't wait to see what he does next.



Michael is an alumni of the Children's Cancer Cause College Scholars Program. **Meet our 2021 scholars on page 8.**

*"Together we can change lives."*

[WWW.CHILDRENCANCERCAUSE.ORG/MICHAEL](http://WWW.CHILDRENCANCERCAUSE.ORG/MICHAEL)

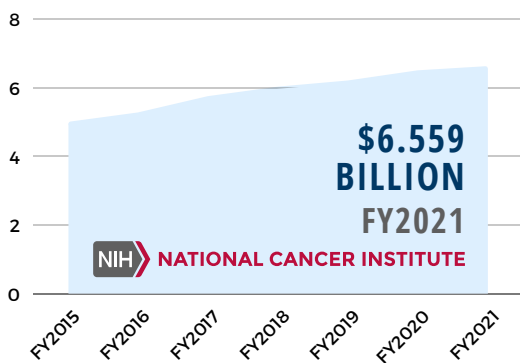


# Policy Progress

## FORGING A PATH FOR KEY LEGISLATION

In 2021, lawmakers demonstrated their continued commitment to children with cancer by supporting full funding for the Childhood Cancer STAR Act and the Childhood Cancer Data Initiative, support for the Kids First Pediatric Research Program, more resources for the FDA to effectively implement the RACE for Children Act, and record funding for the National Cancer Institute (NCI).

*The chart below shows NCI funding growth over the past several years (in billions).*



Much of our legislative energy in 2021 was focused on the day-to-day policy work involved in laying the foundation for an impactful, action-oriented 2022, including two mammoth pieces of pending legislation: reauthorization of the Prescription Drug User Fee Act (PDUFA) and a "2.0" version of the 21st Century Cures Act.

In other Capitol Hill news, we continued to push ahead toward crafting a Center for Medicare and Medicaid demonstration program to develop standards of care based on Children's Oncology Group guidelines for survivors with a focus on scalable models across the United States.

Learn more about our CAST Model: [childrenscancercause.org/cast-model](https://childrenscancercause.org/cast-model)

Our policy work to improve survivor care aligns with three Agency for Healthcare Research and Quality (AHRQ) reports released in 2021. We engaged closely with AHRQ to secure and formulate the three reports, submitting comments and feedback throughout the year with specific recommendations, including our demonstration program proposal.

This progress is made possible in large part due to our network of grassroots advocates spanning all 50 states. Thank you!

**\$30  
MILLION**

3rd year of full funding for the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act

**\$50  
MILLION**

2nd year of full funding for the Childhood Cancer Data Initiative (CCDI)

"I'll always have to deal with frustrations related to long-term survivorship and challenges in healthcare, employment, mental health, and more.

"That's why I'm rooting for the STAR Act and for Children's Cancer Cause's survivorship initiatives to be fully supported, funded and expanded, so others don't have to go through the same thing.

"I'm optimistic that future adult survivors of pediatric cancer will have a much easier time thriving throughout their lives."

— Rachel  
BRAIN TUMOR SURVIVOR

Rachel authored a twelve-part guest blog series in 2021:

[CHILDRENSCANCERCAUSE.ORG/RACHEL](https://CHILDRENSCANCERCAUSE.ORG/RACHEL)



## EMPOWERING SURVIVORS TO BE FUTURE LEADERS

Our College Scholars Program has awarded 18 childhood cancer survivors with scholarships to help make their dream careers possible. We are especially proud that the program is empowering these promising young cancer survivors with the tools and leadership experience to be strong advocates and leaders in their communities.

Alumni of the Children's Cancer Cause College Scholars Program have gone on to become medical students studying pediatric oncology, clinical trial researchers, and candidates for local public office.

**"I'm really grateful for the chance to work on clinical trials, as I know how important they can be for patients with chronic disease, including cancer,"** says Amelia, a 2019 Scholar and survivor of Hodgkin's lymphoma. She's now a Clinical Research Coordinator with the University of Colorado, putting her Masters of Public Health degree to good use.



### THE SURVIVORSHIP CHAMPION'S PRIZE IS IMPROVING CARE, EDUCATION, AND RESEARCH.

2021 was the second year that we awarded the Survivorship Champion's Prize to recognize excellence in providing long-term care for childhood cancer survivors. Meet the 2021 award-winning institutions on page 8.

On page 7, we share an update on the first class of Prize recipients from 2020.





**"We're grateful to Children's Cancer Cause and for the award that has allowed us to provide a variety of supports to pediatric cancer survivors in these especially trying times."**

*- LITE Program for Pediatric Cancer Survivors at Rutgers Cancer Institute of New Jersey*

**Here are a few ways that programs recognized in 2020 are utilizing Prize funds to make a real difference in the lives of survivors:**

**TOP PRIZE WINNER IN 2020:**

**Texas Children's Cancer and Hematology Centers Long-Term Survivor Program**

- Conducting a clinician survey to improve Passport for Care;
- Launching a new survivorship podcast;
- Purchasing educational materials for survivors; and
- Establishing a new research internship!  
*Learn more about the internship below.*

**The HEROS Clinic for Childhood Cancer Survivorship at Yale School of Medicine**

- Purchasing iPads to better identify patient's needs; and
- Providing additional resources to survivors who have chronic conditions related to their cancer therapy (i.e. exercise bands, cookbooks, and mindfulness apps).

**LITE Program for Pediatric Cancer Survivors at Rutgers Cancer Institute of New Jersey**

- Helping fund the LITE Program's survivor education program;
- Reaching underserved survivors; and
- Surveying survivors to address concerns about COVID vaccines.

**Children's Wisconsin Next Steps Survivorship Program**

- Expanding research efforts, including a team research retreat; and
- Securing the technology needed to conduct electronic surveys of survivors.

**Children's Cancer Cause Survivorship Research Internship**

The Texas Children's Long-Term Survivor Program has established this new internship in our name to support a student research project. The results from their research will be presented as abstracts for national meetings and will be used as pilot data to support future research funding. This internship will provide program-wide benefits for local survivorship research and help draw students to the field of oncology and survivorship. Our Champion's Prize funds will go toward the intern's stipend and have been allocated to fund the internship for several years.



# 8 Congratulations 2021 COLLEGE SCHOLARS



We welcomed seven new survivors into our College Scholars Program in 2021, each of whom received a financial scholarship to help with academic expenses and the opportunity to gain valuable cancer advocacy experience with mentorship from the Children's Cancer Cause team.



Molly is passionate about spreading thyroid cancer awareness on campus:

**"When caught early, thyroid cancer is very treatable."**

Molly



Caleb's experience as a military kid and rhabdomyosarcoma survivor inspired his passion for connecting childhood cancer military families through a dedicated social network.

Caleb



Moira's love of art helped her get through treatment for leukemia when she was 15. She created a special design for our Awareness Month campaign in September.

Moira



Brain tumor survivor Victoria is pursuing a degree in neuroscience. For her College Scholars project, Victoria produced a ten-episode podcast series aimed at inspiring other adolescent cancer patients.

Victoria



Emily was diagnosed with Wilms' tumor at age four. She dreams of one day starting her own nonprofit to help cancer families in Oklahoma.

Emily



Hodgkin's lymphoma survivor Kirstie plans to become a pediatric oncologist after graduating medical school.


Kirstie



Leukemia survivor Darren celebrated two years in remission at the end of 2021. He is studying oncology nursing and is involved in a service organization on campus focused on spreading awareness about the lack of ethnic bone marrow donors.

Darren

»» **"Children shouldn't have to wait months and years for a donor match."**

A portrait of a young woman with long, wavy brown hair, smiling and resting her chin on her hand. She is wearing a light blue t-shirt. The background is white with a red horizontal bar below the logo.

"I have surpassed all expectations set for me and I refuse to stop now.

Brain cancer may have knocked me down but I have always gotten back up -

*stronger than I was before."*

MEET VICTORIA

[CHILDRENSCANCERCAUSE.ORG/VICTORIA](http://CHILDRENSCANCERCAUSE.ORG/VICTORIA)

# Partnerships Promote Progress

**We firmly believe that collaboration with other stakeholders is the key to making big strides in our collective fight against childhood cancer.**

- We are proud to be a **CureFest** sponsor, helping to bring hundreds of families together for this multi-day gathering in D.C.
- We work with policy partners as an active member of the **Cancer Leadership Council, One Voice Against Cancer**, and the **Alliance for Childhood Cancer** - leading a survivorship work group at the Alliance in 2021.
- We were a founding member of the **Coalition Against Childhood Cancer (CAC2)** in 2013 and have staff at the table on the CAC2 Board of Directors and on working groups.
- Our Founder Susan Weiner serves on the **ACCELERATE** Steering Committee. ACCELERATE is an international forum that brings global stakeholders together to accelerate innovative cancer therapies.

**Day in and day out, we work with these trusted partners and many others to ensure that our collective voice is strong, clear, and unified. Together, we're achieving a brighter future for children with cancer.**

*Pictured: CureFest 2021's Childhood Cancer Shoe Memorial Ceremony*



We are honored to receive this prestigious award from the Children's Cancer Cause as we have been impressed with their advocacy and commitment to childhood cancer survivors. Our clinical and research teams are committed to working together to improve the overall physical and mental health of survivors. We know the end of cancer therapy is only the beginning of the survivor's lifetime health journey.

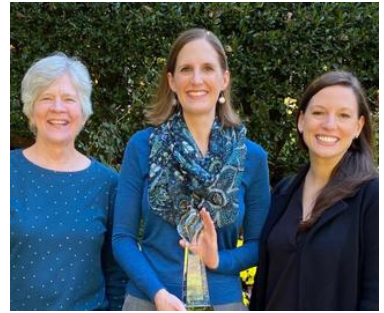
- DR. KAREN EFFINGER, AFLAC CANCER AND BLOOD DISORDERS CENTER

## 2021 Survivorship Champion's Prize

Congratulations to top Prize winner:

**Aflac Cancer and Blood Disorders Center  
of Children's Healthcare of Atlanta**

The \$10,000 Prize is awarded annually to an institution making significant advances in programs and services to provide life-long health maintenance for childhood cancer survivors.



"Our team at the Cancer Survivor Program at the Aflac Cancer and Blood Disorders Center of Children's is looking forward to using the award funds to start the process of expanding SurvivorLink™ into a mobile application," said Dr. Ann Mertens, Research Director. "The SurvivorLink™ platform offers survivors and their families access to educational materials and their survivor care plans to support them in their health journey and transition to adult care."

Three additional top-scoring applicants were also recognized with \$5,000 awards in special categories of distinction:

### FOR IMPACT:

**Treatment After Cancer  
and Late Effects  
program at Louisiana  
State University Health  
Sciences Center**

*New Orleans, Louisiana*

### FOR SCALABILITY:

**Valley Children's  
Hospital Childhood  
Cancer Survivorship  
Program**

*Madera, California*

### FOR COLLABORATION:

**After Cancer Treatment  
Survivorship Program at  
Children's Hospital of  
Orange County**

*Orange, California*

**Nominate an institution for the Champion's Prize:**

**[WWW.CHILDHOODCANCERSURVIVORSHIP.ORG/CHAMPIONS-PRIZE](http://WWW.CHILDHOODCANCERSURVIVORSHIP.ORG/CHAMPIONS-PRIZE)**

# Listening to Survivors

Children's Cancer Cause conducts an annual survey of childhood cancer survivors to ensure that we are best representing their unique needs in our programs and in our policy work on Capitol Hill. Here's what we heard in 2021:



## **Relapse and secondary cancers are top concerns:**

One out of every two pediatric cancer survivors we surveyed in 2021 expressed a fear of relapse as one of their top three health concerns. More than half shared concerns about a secondary cancer diagnosis.



## **Survivors are seeking more education about risks:**

Over 70 percent of those we surveyed expressed an interest in learning more about the risks of late effects. Other top issues of interest include disability rights and legal protections, self-care, and financial rights and responsibilities.



## **Provider knowledge gaps pose risk to survivors:**

One out of three survivors reported feeling that their general practitioner or other non-oncology doctors are 'rarely' or 'never' informed and up-to-date about their cancer history.



## **Increase in anxiety, depression since 2020:**

Over 60% of childhood cancer survivors we surveyed in 2021 reported an increase in mental health problems over the course of the COVID-19 pandemic.



**“Cancer may have stolen my childhood, but that doesn't mean I have to let it define my adulthood. I get to choose what I want to be known for.”**

# Conversations WITH children's cancer cause

We launched a new video series in 2021, where we dive into timely and relevant topics with pediatric oncology experts and community leaders. Our "Conversations Series" features a new discussion every month, broken down into brief, easy-to-share topical episodes.



Browse our library of episodes:

[www.childrenscancercause.org/conversations](http://www.childrenscancercause.org/conversations)

"I'm not a researcher. My experience is not as a physician. But I'm experienced in what it feels like to be told three times: your child doesn't have the drug she needs to survive.

**That's an unthinkable statement to ever give any patient anywhere."**

- Laura Bray, Angels for Change  
December 2021 Conversations Series



# Rosen Award

Representative Jackie Speier (CA-14) was named the 2021 recipient of the Leonard M. Rosen Memorial Research Award, presented annually to an individual who has made an outstanding contribution to childhood cancer policy and advocacy.



Congresswoman Speier serves as co-chair of the bipartisan Congressional Childhood Cancer Caucus, a group of House members instrumental in the passage of several significant pieces of childhood cancer legislation in recent years. Rep. Speier has served in Congress since 2008, representing California's 14th Congressional District.

In the Congresswoman's honor, Children's Cancer Cause designated the \$10,000 award funds to the Children's Brain Tumor Foundation in recognition of their excellence in the field of brain tumor survivorship.

**"Just over a decade ago, pediatric cancer patients did not have a voice in Washington. Today, not only do they have a voice, they are a force to be reckoned with."**

- Representative Jackie Speier

**The annual Rosen Award pays tribute to late Children's Cancer Cause chairman and founding board member Leonard Rosen and his many years of service on the Board of Directors.**

**[WWW.CHILDRENSCANCERCAUSE.ORG/ROSEN-AWARD](http://WWW.CHILDRENSCANCERCAUSE.ORG/ROSEN-AWARD)**



# FINANCIAL REPORT

## FISCAL YEAR 2020-2021

### REVENUE

Contributions	\$996,581
Interest & Investments	\$73,851

**Total**                **\$1,070,432**

### EXPENSES

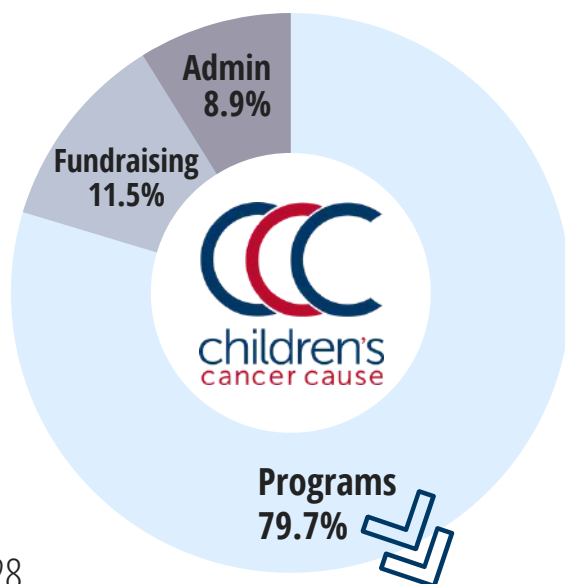
Programs	\$719,532
Administrative	\$80,070
Fundraising	\$103,644

**Total**                **\$903,246**

### ASSETS & LIABILITIES

Beginning of Year	\$1,605,428
<b>End of Year</b>	<b>\$1,990,452</b>

**80 cents of every dollar spent supports our programs and services on behalf of children with cancer and survivors.**



Major programs include advocacy training, community education, survivorship projects and scholarships, public policy, and grassroots advocacy.



Our most recent audited financials and IRS Form 990 are available at [childrenscancercause.org/governance](https://childrenscancercause.org/governance)



# Thank You

Most of our revenue comes from individual donors whose generosity makes our life-saving work on behalf of children with cancer possible.

We offer a wide variety of ways for donors to support our work, including non-monetary giving opportunities like donating an old vehicle. Learn more about all the ways to give at:

[childrenscancercause.org/give](https://childrenscancercause.org/give)



*Pictured: The team at the Treatment After Cancer and Late Effects (TACLE) Center at LSU Health Sciences Center, recipients of our 2021 Survivorship Champion's Impact Award*

## A NEW WAY TO GIVE

When you donate crypto, you receive a tax deduction for the fair market value and avoid the capital gains tax: [childrenscancercause.org/crypto](https://childrenscancercause.org/crypto)

## WE GATHER TOGETHER

Our annual in-person fundraising events were once again forced to go virtual in 2021. We very much look forward to gathering in person in 2022:

- June 16 in Washington, DC: Jazz in June, an evening of incredible jazz music from The Eric Byrd Trio (*pictured below*);
- November 3 in New York City: Children's Cancer Cause's signature event of the year, a reception to recognize and celebrate childhood cancer champions.



Learn more about these events:

- [childrenscancercause.org/jazzinjune](https://childrenscancercause.org/jazzinjune)
- [childrenscancercause.org/nyevent](https://childrenscancercause.org/nyevent)

**"Childhood cancer didn't stop for the pandemic and neither can our work. Over the past year, more than 16,000 American families were told that their child has cancer. Our mission is to ensure that each of those children can go on to live a long and healthy life."**

- New York Event  
Co-Chairs,  
Susan and Stephen Scherr  
Lynn Bayard



# BOARD OF DIRECTORS



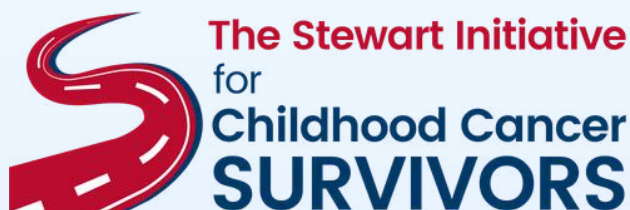
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## REMEMBERING JOHN STEWART, A CHAMPION FOR SURVIVORS

The Children's Cancer Cause family mourns the loss of John Stewart, a long-time board member and devoted public servant who passed away in 2021. John found our cause after his three-year-old granddaughter, Sylvie Stewart, died in 2000 of a brain tumor after a valiant 18-month struggle.

John's activism on behalf of all children with cancer culminated in the creation of the Stewart Initiative for Childhood Cancer Survivors, a unique effort that highlights model programs as a way of improving quality care for survivors on a national scale.



***"John's contributions to the Children's Cause have been truly remarkable. We are honored and thankful to have had him fighting along with us for the past twenty years."***

**- Susan L. Weiner, Founder of Children's Cancer Cause**



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