



# ANNUAL REPORT

# 2020



IN LOVING MEMORY OF JACK OVERTON (2015-2020), PICTURED ABOVE

# OUR MISSION

**The 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.**



***"Steve's experience in the national cancer arena is well suited toward advancing our mission of ensuring that the needs and perspectives of children with cancer and survivors are integrated into the highest deliberations on health care and cancer policy."***

- Susan Weiner, Founder of Children's Cancer Cause

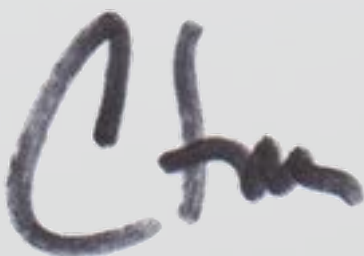
Dear Friends,

As the new CEO of Children's Cancer Cause, I'm humbled and honored to join this dedicated team as we work to tackle the significant and urgent challenges around survivorship care, healthcare inequities, and the development of safer, more effective drugs to treat children. My predecessor George Dahlman ushered in an era of growth and progress for Children's Cancer Cause - much of which we will share in this report - and we all wish him a very happy retirement.

2020 proved to be a year of unprecedented change around the world, which deeply impacted all of us, especially children with cancer, survivors, and the families we serve. What hasn't changed is our commitment to these children and their families -- and it never will, as long as we have you by our side.

Because of your support, we were able to accomplish so much in 2020. We launched a new survivorship program, awarded a record number of scholarships to childhood cancer survivors, and celebrated ambitious legislative achievements.

I'm looking forward to working with families and advocates around the country as we build on the strong foundation this community has created. Thank you for standing with us in this fight.

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

- Steve Wosahla, Chief Executive Officer



# NAVIGATING CHILDHOOD CANCER DURING A PANDEMIC

Our vision and many of our plans for 2020 took a sharp detour early in the year when the coronavirus pandemic hit like a tidal wave. Especially in those early days of the pandemic, the childhood cancer community was consumed by fear about what this novel disease might mean for children undergoing cancer treatment and to childhood cancer survivors with compromised immune systems.

As the year went on and we learned more about the virus, researchers were able to provide some comfort to worried families of children with cancer, as new data suggested that children receiving cancer treatment are not at increased risk of developing symptoms from COVID infection and seem to recover well even if they do develop more serious symptoms.

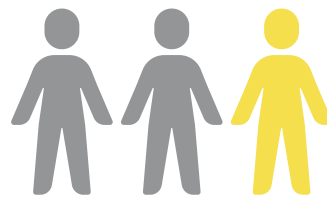
Researchers stress that there are still many unknowns, including long-term effects of COVID-19 on children, and that the research is based on very small numbers of children.

Many families felt crippled by anxiety, with some referencing COVID-19 as a PTSD trigger.

**40%** One study\* found that over 40 percent of childhood cancer survivors reported their current mental health to be worse now than before the pandemic.

\*<https://doi.org/10.1007/s00520-020-05824-z>

In order to represent our community's unique needs to policymakers during this pandemic, we conducted a survey of childhood cancer families. We learned that experiences regarding disruptions to treatment and access to care varied widely.



**67%**

*Two-thirds of the families we heard from reported experiencing a reduction in income as a result of COVID-19.*



We focused on bringing families and survivors trusted information and advice from experts amid a rapidly evolving public health crisis, along with policy updates from Congress and federal agencies on COVID-related issues of relevance to our community, such as potential impacts on clinical trials and access to telehealth services.

Through our work with coalitions such as One Voice Against Cancer (OVAC), the Cancer Leadership Council, and the Alliance for Childhood Cancer, we continue to pursue COVID-related policy needs on issues like restarting clinical trial research paused by the pandemic and prioritizing cancer survivors for vaccines.

With the world so laser-focused on COVID, it was especially challenging to capture lawmakers' attention on other issues in 2020. Advocates were unable to march down the National Mall and into Congressional offices to share our stories and plead our case for support. Fortunately, Children's Cancer Cause has a strong grassroots program, and empowering advocates to take action from home is something we've been doing for years.

We're proud of our community's ability to pivot and still ensure that our voices were heard loud and clear by policymakers, through virtual lobby days and year-long grassroots action. This report shares more on the hard-fought legislative wins for the childhood cancer community.

**“THE COVID-19 CRISIS HAS CERTAINLY BROUGHT BACK THE FEELINGS OF ISOLATION AND HEALTH CONCERNS THAT WERE PREVALENT DURING MY DAUGHTER'S TREATMENT.”**





# LEGISLATIVE BUILDING BLOCKS

Much of our policy work in 2020 built on progress from prior years. When the RACE Act and the STAR Act were signed into law in 2017 and 2018, we knew the intricate work of implementation was just beginning...

## RACE FOR CHILDREN ACT:

Children's Cancer Cause continued to collaborate with stakeholders in 2020 around the Research to Accelerate Cures and Equity (RACE) for Children Act, which took full effect in August. This was an important milestone toward the ultimate goal of accelerating early pediatric evaluation of molecularly targeted cancer drugs and is a drug development issue that Children's Cancer Cause has been engaged around since our founding in 1999.

We are developing a policy agenda around drug development for a new round of legislation in this area during the 117th Congress.

## CHILDHOOD CANCER STAR ACT:

In July 2020, the Government Accountability Office released a report on barriers to care for childhood cancer survivors. This report, which is an outcome of the Survivorship, Treatment, Access and Research (STAR) Act that was championed by Children's Cancer Cause, creates growing government acknowledgement around the need for improvements in access and support for childhood cancer survivors.

We secured the third straight year of full funding for the STAR Act!

The barriers identified in this report - affordability, knowledge, and proximity - form much of our agenda at the Children's Cancer Cause as we craft policy solutions for childhood cancer survivors.

Our advocacy efforts also resulted in the Agency for Health Research & Quality (AHRQ) receiving funding for work on an assessment of childhood cancer survivorship programs and standards of care with a special focus on access and barriers.

*This AHRQ report was published in March 2021.*



# 1,386

*letters sent to  
Members of  
Congress  
through our  
2020 Legislative  
Action Center.*

*Thank you for  
using your voice  
to help create a  
better, brighter  
future for our kids.*

“ —

Dear Congress,

I am writing this from the hospital room where my 5-year-old son Jennings has just relapsed from AML. He was in remission after a bone marrow transplant 2.5 years ago.

Now that he has relapsed, his prognosis and options are limited.

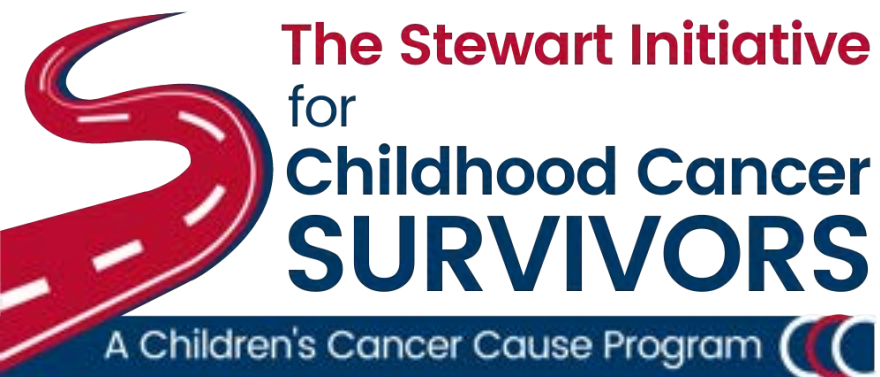
**We need better solutions.** |

— ”

# NEW! STEWART INITIATIVE FOR CHILDHOOD CANCER SURVIVORS

**WWW.CHILDHOODCANCERSURVIVORSHIP.ORG**

With generous support from the Stewart Family, Children's Cancer Cause is developing initiatives to address the medical and psychosocial care needs of pediatric cancer survivors. By delivering resources and interactive educational elements, we aim to empower the nation's 500,000 childhood cancer survivors to be strong self-advocates for their long-term care.



As part of this Initiative, Children's Cancer Cause partnered with MyLifeLine to launch a discussion board for young adult survivors of pediatric cancer who are post-treatment to connect directly with other young adult survivors of pediatric cancer.

This free online forum is a place to support one another with information, opinions, stories, and inspiration on topics like post-treatment challenges. You can find the discussion board at [childrenscause.mylifeline.org](http://childrenscause.mylifeline.org).

**MUCH OF THE EXCITING WORK IN SURVIVORSHIP IS NOT REACHING THE FOLKS WHO NEED IT MOST - SPECIFICALLY YOUNG ADULT SURVIVORS. OUR PURPOSE IN SPONSORING THE STEWART FAMILY SURVIVORSHIP INITIATIVE IS TO DEVELOP MORE EFFECTIVE WAYS TO DISSEMINATE LIFE-SAVING INFORMATION.**

*- Nancy and John Stewart*





“ —

OUR TEAM IS SO HONORED TO BE SELECTED FOR THIS YEAR'S CHAMPION'S PRIZE AND GRATEFUL FOR THE OPPORTUNITY MADE POSSIBLE THROUGH THIS GENEROUS DONATION TO SUPPORT PROGRAMS FOR OUR DIVERSE POPULATION OF SURVIVORS.

- Dr. Maria Monica Gramatges, Texas Children's

— ”

## SURVIVORSHIP CHAMPION'S PRIZE

Children's Cancer Cause was proud to name Texas Children's Cancer and Hematology Centers Long-Term Survivor Program as the 2020 recipient of the inaugural Survivorship Champion's Prize, in recognition of the Program's innovative work to provide comprehensive, integrated care for childhood cancer survivors.



The \$10,000 Survivorship Champion's Prize is a component of the Stewart Initiative and will be presented 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.



Thanks to the generosity of the Stewart family, three other top-scoring applicants were also recognized with smaller awards in special categories of distinction:

### FOR IMPACT:

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

### FOR SCALABILITY:

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

### FOR COLLABORATION:

Children's Wisconsin Next Steps Survivorship Program

Nominate an institution for the Champion's Prize here:

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



# COLLEGE SCHOLARS PROGRAM

To help more childhood cancer survivors in a challenging year, we vastly expanded our scholarship awards in 2020.

Our College Scholars Program typically awards two survivor students annually, but in 2020 we were thrilled to welcome seven survivors into the program!

## MEET OUR 2020 SCHOLARS

These survivors receive a financial scholarship to help with academic expenses and gain valuable cancer advocacy experience. Each member of our College Scholars Program completes a project of their choosing related to childhood cancer advocacy, with support and mentorship from the Children's Cancer Cause team.

# ABBY KAILI RYAN



Abby Snider of Winchester, Virginia, was diagnosed with high risk T-cell ALL at age 15.

She is studying public health at Shenandoah University, working towards her dream of becoming a pediatric oncology nurse.

*"I want to give back and help other children fight cancer." - Abby*



Kaili Wegener of McHenry, Illinois, was diagnosed with Hodgkin's Lymphoma at age 12. She is studying political science at Northwestern University.

She hopes to continue using her passion and skills for public policy to speak up for cancer survivors as she moves forward in her studies and future career.



Ryan McKinney was just five years old when he was diagnosed with a brain tumor. The native of Sullivan, Missouri, battled through late effects of treatment from his first diagnosis and from a second surgery when he was 14.

Ryan is studying Sports Management at Fontbonne University.

“ —

I CANNOT CHANGE WHAT HAPPENED TO ME,  
BUT I CAN MAKE THE EXPERIENCE BETTER  
FOR THE NEXT PERSON GOING THROUGH IT.

— Meaghan — ”

# MEAGHAN PATRICK



Meaghan Kilner of Potomac, Maryland, was diagnosed with Hodgkin's Lymphoma when she was 15 years old.

She is studying chemical engineering at Vanderbilt University.



Kentucky's Patrick McSweeney is a seven-time cancer survivor attending the University of Louisville. After suffering six relapses, Patrick received a second bone marrow transplant in May 2018 and has remained cancer-free ever since.

# MICHAEL



Michael Albrecht of Bothell, Washington, was diagnosed with Ewing's Sarcoma on the last day of 8th grade. At 17, he suffered a stage four recurrence and was given just a 15 percent chance of survival.

Michael is studying biochemistry at the University of Washington in Seattle.

# SEQUOIA



Sequoia White of Bulverde, Texas, was diagnosed with Non-Hodgkin's Lymphoma when she was fifteen.

She is pursuing a biology degree in Global Health at Baylor University — while still receiving maintenance chemotherapy.





# HIGHLIGHTS FROM THE HILL

A DECEMBER 2020 OMNIBUS PACKAGE INCLUDED:



## RECORD FUNDING FOR THE NIH

Congress granted \$42.9 billion for the National Institutes of Health (NIH) for FY2021. The NIH includes the National Cancer Institute (NCI), which supports the Children's Oncology Group.

The NCI received \$6.559 billion, a \$119.5 million increase over FY2020 levels.



## THE CLINICAL TREATMENT ACT

The 2020 end-of-year package included The Clinical Treatment Act, legislation we have supported for years. This new law requires Medicaid to cover routine care costs associated with enrollment in approved clinical trials for those with life-threatening conditions.



## CHILDHOOD CANCER DATA INITIATIVE

Congress included \$50 million to fully fund the Childhood Cancer Data Initiative (CCDI) for fiscal year 2021. CCDI focuses on the critical need to collect, analyze, and share data to address the burden of cancer in children, adolescents, and young adults.



## CREATING HOPE ACT

The package included a four-year extension of the Creating Hope Act, which was originally enacted in 2012 but was expiring in 2020. The Creating Hope Act incentivizes pharmaceutical companies to develop drugs for rare pediatric diseases when it is cost-prohibitive.

## & MORE



- The year-end package included a provision to reduce the medical expense deduction floor, allowing individuals to deduct unreimbursed medical expenses that exceed 7.5% of adjusted gross income.
- The Department of Defense's Peer Reviewed Cancer Research Program received a \$5 million funding increase and again included Pediatric and AYA cancers as a priority research topic.



**"I cannot leave  
the cancer world  
behind me and  
just move on.**

**I have been  
exposed to too much  
and seen things I  
never knew existed.**

**I want to  
give back  
and help  
other  
children  
fight  
cancer."**

**MEET ABBY**

**[childrenscancercause.org/abby](http://childrenscancercause.org/abby)**

In a typical year, we gather in the fall in New York City for our signature fundraising event, headlined by the presentation of the Rosen Award. We are grateful to our faithful donors for adapting with us in response to the pandemic and supporting a special virtual event in 2020.

# ROSEN AWARD

In November, we presented the 5th Annual Leonard M. Rosen Memorial Research Award to Gilles Vassal, MD, PhD, founder and chairman of ACCELERATE.

ACCELERATE is a unique global platform, working to advance innovation in cancer drug development for children and adolescents.

As the foremost pediatric oncologist in Europe, Dr. Vassal has held multiple leadership positions in pediatric oncology professional societies and is currently Professor of Pediatric Oncology at Gustave Roussy, a comprehensive cancer center in France.



"This award honors the legacy of my grandfather and is granted annually to an individual who has made an outstanding contribution to childhood cancer policy and advocacy.

Congratulations, Dr. Vassal. On behalf of pediatric cancer survivors and patients worldwide, thank you for your dedication to fighting childhood cancer."

**- Ben Rosen,  
childhood cancer survivor**



# FINANCIAL REPORT

## FISCAL YEAR 2019-2020

### REVENUE

Contributions	\$841,618
Interest & Investments	\$55,197
Total	<b>\$896,815</b>

### EXPENSES

Programs	\$603,808
Administrative	\$75,465
Fundraising	\$142,709
Total	<b>\$821,982</b>

### ASSETS & LIABILITIES

Beginning of Year	\$1,547,144
End of Year	<b>\$1,753,935</b>

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

More than 75 cents of every dollar raised supports our programs and services on behalf of children with cancer and survivors.



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

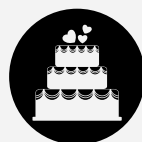


# WAYS TO GIVE



Globally, it is estimated that there will be 13.7 million children diagnosed with cancer in the next 30 years.

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



mark a special occasion



donate spare change



join our scholar boosters

## CHILDRENSCANCERCAUSE.ORG/GIVE



sponsor an event



Amazon Smile



donate a vehicle



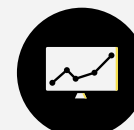
workplace giving



honor or memorialize



monthly giving



donate stock

Text GIVE to 202-516-7644

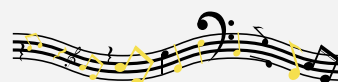
Venmo: @childrenscancercause

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



We offer a wide variety of ways for donors to support our work, including the new frontier of virtual events, such as those shown on this page from 2020.

Learn about our 2021 events at:



[childrenscancercause.org/jazzinjune](http://childrenscancercause.org/jazzinjune)



[childrenscancercause.org/nyevent](http://childrenscancercause.org/nyevent)



## **BOARD OF DIRECTORS**

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## **COMMITTED TO EQUALITY**

Children's Cancer Cause works to create a future where **every child** with cancer can live a long and healthy life.

As public policy advocates, we renew our commitment to addressing disparities in access to health care, improving minorities' quality of care, and fighting discrimination at every level. We are hopeful that a renewed national focus on civil rights will bring greater equality and justice to the minority families we serve.



EST 1999



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