Nate, fighting osteosarcoma, and his mom

# Children's Cancer Research Fund<sup>®</sup>

# JULY 1, 2019 - DECEMBER 31, 2019

# table of contents

- **3** OPENING LETTER
- 4 NATE'S STORY
- **5** RESEARCH HIGHLIGHTS
- 8 PROGRAM WINS
- 10 EVENT WINS
- 12 FINANCIALS
- 15 BOARD & LEADERSHIP

LEARN HOW WE

supported groundbreaking research & vital family support services this year

# opening letter

We are pleased to present this impact report for our shortened fiscal year, which was July 1 to December 31, 2019. Going forward, our fiscal year will align with the calendar year.

In just six months, you've helped us make great strides towards our goal of removing roadblocks that stand in the way of research breakthroughs.

This incredible progress heartens me as a leader, and it makes it all the more bittersweet to announce that:

#### I will be retiring as CEO of Children's Cancer Research Fund in June.

I feel confident that I'm leaving CCRF in a position of strength and poised for even greater impact.

In my 13 years at CCRF, I've been fortunate to hear so many family stories that have made me truly grateful to lead an organization with such an incredible mission. Several months ago, I saw a quote from a parent of a child with cancer who we've gotten to know over the past few years. During her daughter's cancer treatment, she found out that many researchers struggle to get funds to study her daughter's disease because many funding sources deem it "too rare" to invest in the research that would lead to better treatments and cures. She said, "All I could think was, 'Why? Why aren't we there yet? And I found out it's because researchers don't have the funding."

No parent should ever be told their child's disease is too rare or to hopeless to study, and no researcher with a great idea should be without the resources to make better treatments a reality.

Thank you for helping us fill critical funding gaps so that lifesaving work can move forward.

Sincerely,

John Hallberg, CEO





Seventeen-year-old Nate is most himself when he is playing his guitar. He's been playing since he was around 10 years old, and his favorite songs to play are all over the place – they range from heavy metal Metallica to ska punk band Sublime. What Nate most looks for in a good guitar song is a challenge. But last year, a different kind of challenge came creeping into Nate's life – he was diagnosed with osteosarcoma, an aggressive bone cancer. Doctors found the tumors on his ribs, creeping slowly toward his spine.

Nate has had a 10-hour surgery to remove several ribs and many rounds of chemotherapy to eradicate remaining cancer cells.

He was declared cancer-free in July 2019 and was easing back into normal life until extreme back pain forced him and his family to investigate what might be wrong.

In March, Nate's doctors confirmed what everyone feared most – the cancer had returned. This time, it was taking over his spinal column, causing immense pain and making it nearly impossible for Nate to walk. This development was heartbreaking for Nate's family, and their path forward is unclear.

Nate's incredible strength, even in the midst of his pain, has inspired everyone he's met since beginning his cancer journey. Even when people tell him he'd have every right to be angry and upset, he decides to stay positive however he can, using his music and humor to see him through. His oncologist, Dr. Emily Greengard, says that seeing Nate's maturity beyond his years inspires her every day.

"Nate is simply an incredible human," Dr. Greengard said. "If my son grows up to be as gracious and wonderful as Nate, I'll know I did a good job."



FOR KIDS LIKE NATE

## we invest in three research areas where we believe your gift can make the greatest impact

**EMERGING SCIENTISTS - HARD TO TREAT DISEASES** 

**SURVIVORSHIP** 



FROM THESE THREE AREAS







#### **EMERGING SCIENTISTS - XINGGUO LI**

Dr. Xingguo Li, PhD, at the University of Rochester in New York was confident he could target a newly discovered pathway that drives neuroblastoma, but as a researcher early in his career, he couldn't get the funding he needed to move his idea forward. A grant from CCRF allowed him to start developing a drug that may change the game for kids with neuroblastoma.

"The support from CCRF gives us the ability to stabilize the research team and move forward at a much faster pace." - Xingguo Li

#### HARD TO TREAT DISEASES - OSETEOSARCOMA

Osteosarcoma is one of the most aggressive forms of childhood cancer. Beau Webber, PhD, a researcher at the University of Minnesota, is working on a new immune-based therapy that targets osteosarcoma – and he isn't afraid to use the word "cure" to describe its potential.

"I don't throw that word around, and I definitely don't use it lightly. But it's hard to overstate the potential here. It's realistic to have that as our goal – there's a real chance for a remarkable cure." - Beau Webber

#### SURVIVORSHIP - SYSTEMS TO ADDRESS LATE EFFECTS

Karim Sadak, MD, MPH, MSE, knows that many health issues childhood cancer survivors face are preventable if they get the treatment they need right away. His team at the University of Minnesota is enrolling survivors in a study to find out how to help survivors, doctors and health systems communicate more efficiently to address late effects so that they don't slip through the cracks.

"We're working to make sure that a cure stays a cure forever. We need to have systems in place to deliver care that is accessible, long-term, and evidence based so we know they are getting the best care possible." - Karim Sadak your gifts also fund critical family support programs that improve the lives of kids, their families and caregivers



**HIGHLIGHTS FROM THIS YEAR** 







#### MOMCOLOGY — 2 RETREATS FUNDED

Your dollars sponsor retreats by Momcology, our program partner that provides cancer caregivers ways to connect and know that they are not alone.

"I love using what I've been through to educate and help other parents who are where I was a few years ago." - Andrea, Momcology retreat leader

#### **BIG DREAMS TOUR** — 4 HOSPITALS VISITED

Musician James Orrigo travels across the country to visit the hospital rooms of kids fighting cancer. He uses his guitar and "magic music box" to help them use their imagination to create a personalized song and music video to escape the cancer world for a little while.

"The goal is to bring the patient's imagination to life through music, animation and recording. The kids, staff and families are all involved and the results are special and long lasting." - James Orrigo

#### C.C. BEAR — 129 BEARS DELIVERED

C.C. Bear is a cuddly teddy bear for any child impacted by cancer. Families can request bears online for free thanks to generous donor support.

"We received our bears and the kids really love them. Our daughter was just diagnosed with a brain tumor. Our family is used to doing everything together, so the boys have been feeling really left out. We really appreciate that you offer the bears for the siblings, too – they were very excited to have something to hold onto." - Krystal this year we gathered to advocate for our mission, raised critical funds and celebrated how far we've come

# event wins



### \$112,000 RAISED

#### TIME TO FLY - 9.28.19

New activities at CCRF's annual walk included a family resource fair, food trucks and inflatable activities for kids. Dedicated teams like Jack Attack, who has been participating in Time to Fly for ten years to support Jack's fight with brain cancer, raised over \$112,000 to fund cancer research and services that help families and survivors.







## \$73,142 RAISED

#### **MONARCH CIRCLE** — 12.15.19

Hosted by Jill and Jon Halper, the inaugural Monarch Circle celebrated a shared vision while honoring the legacy of Jon's parents Sharon and Joel Waller, whose Benefactors Circle began more than 29 years ago and raised \$3.4 million for childhood cancer research. Parents Michelle and Kristy, both mothers of leukemia survivors, shared stories of the enormous impact research can have on families like theirs.

## \$730,884 RAISED

#### KS95 FOR KID'S RADIOTHON — 12.15.19

KS95 aired stories of kids fighting cancer, including Allison, who passed away in January from cancer, to inspire supporters in the Twin Cities to fund better, safer treatments for kids with even the most aggressive of cancers.

### \$94,804 RAISED

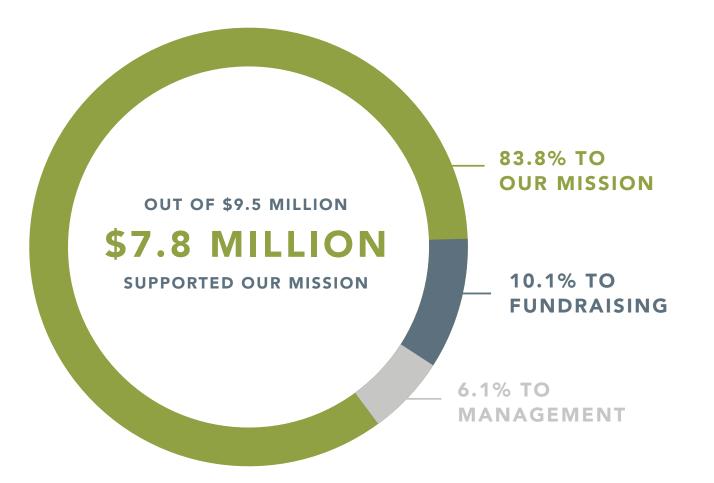
#### KS95'S "CLOUDS CHOIR" FOR A CAUSE - 12.15.19

Thousands gathered at the Mall of America to sing Zach Sobiech's hit song, "Clouds" and raise funds for better treatments for osteosarcoma, the disease that took Zach in 2013 at the age of 18. The director and cast of the upcoming movie based on Zach's life, also titled "Clouds," joined Zach's real-life family onstage.

# financial information

FISCAL YEAR: JULY 1, 2019 - DECEMBER 31, 2019

**GRAPH OF EXPENSE RATIOS AS OF 12/31/19** 



#### **SUPPORT & REVENUE**

TOTAL SUPPORT AND REVENUE	\$9,499,433
Other	\$48,716
Investment Income	\$269,696
Cause Marketing	\$102,395
Donated Goods and Services	\$4,503,509
Direct Expenses	\$(89,419)
Events	\$2,108,804
General Contributions	\$2,555,732

#### THE DIFFERENCE BETWEEN OUR SUPPORT & REVENUE AND EXPENSES

#### NET ASSETS

Change in net assets	\$126,086
Net assets, beginning of year	\$4,743,240
Net assets, end of year	\$4,869,326

#### **EXPENSES**

TOTAL EXPENSES		\$9,373,347
Management & General	6.1%	\$568,049
Fundraising	10.1%	\$950,826
SUPPORTING SERVICES	16.2%	
Patient & Family Services	1.6%	\$146,651
Education & Awareness	68.6%	\$6,431,335
Research	13.6%	\$1,276,486
MISSION - PROGRAM SERVICES	83.8%	

#### ASSETS

Cash & Cash Equivalents	\$3,915,500
Investments	\$3,576,248
Pledge Receivables, Net	\$1,486,193
Property & Equipment, Net	\$240,989
Other Assets	\$188,391

#### TOTAL ASSETS

\$9,407,321

#### LIABILITIES

TOTAL LIABILITIES	\$4,537,995
Grants Payable, Net	\$3,994,208
Other Liabilities	\$85,559
Accrued Payroll & Related	\$217,974
Accounts Payable	\$240,254

#### **NET ASSETS**

#### WITHOUT DONOR RESTRICTIONS

TOTAL NET ASSETS	\$0 /07 221
TOTAL NET ASSETS	\$4,869,326
WITH DONOR RESTRICTIONS	\$1,200,987
Board Designated	\$2,999,586
Operating	\$668,753

### & LIABILITIES \$9,407,321

# board & staff leadership

#### **CHAIRPERSON**

Matt Hedman

### SECRETARY AND VICE CHAIR ELECT

Susan Doherty

### VICE CHAIR

Michelle Johnson

#### **TREASURER** Dan Bartholet

#### IMMEDIATE PAST CHAIR

Charlie R. Manzoni, Jr.

#### **BOARD MEMBERS**

Ingrid Culp Peter Dorow Barb Farrell John Golden Carol Grannis Jon Halper Meghan Harris Molly Kinsella Dawn Lamm Kris Larson Pete Leacock Beth Monsrud Barry Morgan David Royal Dan Seeman Greg Soukup Carmen Thiede Chris Toppin

#### NATIONAL ADVISORY COUNCIL

Souheil Badran Suzanne Boda Jessica Kenyon Cari Erickson Streich R.J. Shook

#### RESEARCH ADVISORY COMMITTEE

Logan Spector, PhD *- Chair* Oren Becher, MD Lisa Diller, MD Abbie Miller, MD Sabine Mueller, MD, PhD Jake Petersburg, PhD Leo Wang, MD, PhD Jason Yustein, MD, PhD

#### **STAFF LEADERSHIP**

John Hallberg *Chief Executive Officer* 

Tamara Andrews Human Resources Manager

Kenna Dooley Director, Development & Donor Relations

Laura Grant Director, Events & Partnerships

Darla Nemec Director, Finance & Operations

HaiVy Thompson VP of Mission & Marketing

# thank you for supporting our mission!

Every week, 38 kids pass away from cancer. We want to stop this, so we support the brightest and boldest minds whose groundbreaking research is leading to better treatments and cures. We also fund vital family support services and advocate for childhood cancer education and awareness.