

# CONTENTS

LETTERS FROM LEADERSHIP	3
A MIGHTY MESSAGE	5
RESEARCH	12
PROGRAM SUPPORT	24
FUNDRAISERS	35
FINANCIALS	50
BOARD & STAFF	53

0

Dear Friends of Children's Cancer Research Fund,

We are pleased to present our annual report for our fiscal year ending June 30, 2019. The theme of this year's report is "Mighty," and there are multiple ways that word applies to our mission.

First, mighty describes the young cancer patients who inspire our work every day. They are mighty strong, mighty brave and, occasionally, even mighty silly as they face their cancer treatment with an amazing balance of courage, grace and humor.

Mighty also describes the passionate and dedicated scientists whose work we support. They are mighty smart, and they are exploring mighty new technologies like gene editing, cellular therapies, and genomic sequencing to create more effective cures. Together, they are a force to be reckoned with.

Finally, mighty describes the hundreds of volunteers and hundreds of thousands of donors who make the work we do possible. Whether it's riding hundreds of miles for Great Cycle Challenge, creating a community fundraiser or volunteering to serve dinner to patients and families, each gift and each act of kindness has a mighty impact. We are grateful for all that you do.

One housekeeping note: we are changing our fiscal year to a calendar year as of Jan. 1, 2020. Making that change will allow us to more effectively administer the research grants that, we hope, will change the practice of medicine.

Thank you for being mighty with us as we bring hope and comfort to families.

Sincerely,

Matt Hedman Chair, Board of Directors

Jee O. Helly John O. Hallberg Chief Executive Officer

# **MOVING BOLD RESEARCH FORWARD**

Our organization's fundraising and outreach footprint has grown dramatically in the past few years. In response to that growth, we are changing how we direct our resources so we can increase the impact of our research funding.

This past year, a committee of our Board of Directors reached out to cancer researchers and clinicians around the country and gathered their ideas on how we could accelerate research progress and bring us closer to cures. We heard a clear need to act courageously and collaboratively to improve childhood cancer outcomes.

As a result, we've formed a Research Advisory Committee that includes leading physicians and scientists whose expertise and insights will guide our research granting. We've also determined the three research funding priorities listed below.

**EMERGING SCIENTISTS** — developing the research of the best and brightest researchers still early in their careers.

**RARE, LOW SURVIVAL RATE DISEASES** — discovering new therapies and cures for the rarest, deadliest and most difficult to treat of childhood cancers, with an emphasis on research and funding collaboration.

**SURVIVORSHIP** — investigating long-term complications of cancer treatment to improve the lives of the growing population of childhood cancer survivors.

In addition to funding research around the country, we will continue to provide meaningful support to the clinicians and researchers at the University of Minnesota. This group of talented and passionate scientists continues to explore bold new ideas that leverage scientific advancements, including cell and gene therapy and precision medicine.

Sincerely,

Matt Hedman Chair, Board of Directors

S. RF MIGHTY KIDS. & MIGHTY KIDS. RF MIGHTY KI

When a child is diagnosed with cancer, the child and the family face challenges they never knew existed, but they also find strength they didn't know they had. Cancer has a mighty fierce opponent in kids because these kids are mighty strong, and their stories are mighty powerful. And funds raised for childhood cancer awareness make a mighty big difference.

The fight against childhood cancer reveals and requires each of our unique strengths. Whether it be a researcher, doctor, supporter or child, we all have a mighty big role to play to achieve a world without childhood cancer.

### **MIGHTY RESEARCHERS**

Your support makes it possible for CCRF to fund promising researchers all over the country with big ideas about how to defeat and cure the most difficult-to-treat childhood cancers.

### **MIGHTY CREATIVE**

Our supporters are not short on creativity; this year, charity livestreams, ice cream trucks, golf tournaments and birthday fundraisers raised over \$2.6 million for childhood cancer research.

### **MIGHTY BRAVE**

This year, our outreach team connected with hundreds of families who bravely and selflessly shared their cancer journeys to inspire others to join us in the fight.

A special thank you to Physician's Nationwide and Michael B. Hoffman, CFP, for sponsoring our Mighty Stories.



GHTY KIDS. & MIGHTY K



# **BELLA, MIGHTY SMART.**

Bella knows far more about being a doctor than many adults, despite being only 6 years old. That's because since she was diagnosed with hepatoblastoma, Bella has played doctor to Jessie, her favorite doll. Jessie goes through every poke and procedure that Bella does; she even has her own ostomy bag (but Jessie's holds M&Ms). Bella can tell you all about port access, blood tests and PICC lines because they're all things she's experienced herself. Thankfully, as Bella's health improves, she has fewer of those things to deal with every day, but everything she's learned is sure to stick with her as she grows up and takes her cancer experience with her.

"We're finding so much joy in the little things — things that were taken away from us but now returned," said Tabitha, Bella's mom. "It's such an incredible feeling to be at the healing point on our journey."

# NATE, MIGHTY DETERMINED

Whether he's at his house on the couch or in a hospital bed, Nate feels most at home when he's playing his guitar. He's been able to keep playing through months of chemo and a major surgery that involved removing several ribs and shaving part of his spine to get rid of the osteosarcoma growing there. His long recovery from surgery involved painful physical therapy sessions to help Nate grow strong enough to walk again. Amazingly, Nate powered through every session with positivity and determination. Despite all he's been through — the nausea caused by chemo, the isolation from school and friends and the long recovery from a major surgery — Nate says he's not afraid to face the future.

"There are definitely things that are scary, and I understand my situation," Nate said, "but I just don't think moping around is going to do anything for me."





# MARIAH, MIGHTY UNSTOPPABLE.

When Mariah was 2 years old, a diagnosis of osteosarcoma put her life in danger. But after three months of chemotherapy, an amputation and six more months of chemotherapy, Mariah was declared cancer free. Now a college graduate with a degree in biology and psychology, Mariah has become a cancer researcher and is contributing to the field that saved her life. She's also mastering rock climbing, even as an amputee. Mariah has proven she's unstoppable, and her dedication to her work inspires us.

"I have never taken my life for granted, and I'm thankful for all the people along the way who have been, both directly and indirectly, part of it," Mariah said. "My treatment was part of a clinical trial, and without research, my protocol would not have existed. I want to give back and be part of the research that works on finding treatments for pediatric cancers."

RESEARCH | 12 CH. CC MIGHTY RESEARCH. 🦑 MIGHTY RESEARCH. 🦗 GHTY RESEARCH. 🦗 MIGHTY RESEARCH. 💱 MIGHTY RESEARCH. 🦗 MIGHTY RESEARCH. 🍬 MIGHTY RESEARCH. 👫 MIGHTY RESEARCH. 🍬 GHTY RESEARCH. 🦗 MIGHTY RESEARCH. 👫 MIGHTY RESEARCH. 🦗 MIGHTY RESEARCH. 🍬 MIGHTY RESEARCH. 👫 MIGHTY RESEARCH. 🍬

# **RESEARCH = HOPE**

Every week, 38 kids pass away from cancer. Childhood cancer researchers are doing everything they can to stop that, and they are making major progress. Discoveries are being made, and treatments are being developed at a faster pace than ever, meaning families have more reasons to hope. This year we asked childhood cancer researchers from the University of Minnesota, "What gives you hope?"

RCH. Y

RCH. Y

RCH. 🍾

RCH. 🦗

GHTY RESEARCH. 🍬 MIGHTY RESEARCH. 👫 MIGHTY RESEARCH. 🦗 MIGHTY MIGHTY RESEARCH. 🌳 MIGHTY RESEARCH. 👫 MIGHTY RESEARCH. 🦗 RESEARCH. 🍬 MIGHTY RESEARCH. 🗣 MIGHTY RESEARCH. 🍬 MIGHTY RESEARCH. 🏾 MIGHTY RESEARCH. 💱 MIGHTY RESEARCH. 🥓 RESEARCH. 🍬 MIGHTY RESEARCH. 👫 MIGHTY RESEARCH. 🍫 МІРИТУ ВЕРЕЛЬРИ 🎭 МІРИТУ ВЕРЕЛЬРИ СС МІРИТУ ВЕРЕЛЬРИ 🦕

### COLLABORATION

"Pediatric cancer is relatively rare, so it requires the entire world to work together to find cures for these various types of cancers in children. No longer are we the individual investigator working in individual laboratories at the University of Minnesota alone. There are no walls; we're one great big laboratory. When we're working together, we can also find discoveries more quickly." — John Wagner, MD

#### INNOVATION

"Right now, the most exciting research we're doing is in the field of cancer immunotherapy, which I really do think is the cure for cancer. We're seeing miraculous therapies coming out using what are called CAR-T cell therapies." — Branden Moriarity, PhD

#### **SURVIVORSHIP**

4

"What gives me the most hope is having the opportunity to see these children as they're finishing therapy, as they're starting school, as they're moving through college, as they're getting married and seeing how well they're doing." — Lucie Turcotte, MD, MPH

"We've come a long way. Today, our goal is not cure at any cost. It's cure, but with the best quality of life possible." — Karim Thomas Sadak, MD, MPH, MSE

#### DEDICATION

"I'm always impressed with my patients because all of my patients are on clinical trials, and the patients and their parents will say, 'We want to be part of this because we want to make things better for the next person who goes through this.' And that's amazing." — Heather Stefanski MD, PhD

"I am hopeful because I have seen firsthand how our local community partners and interested families are so strongly committed to funding research, and they believe that our work will help patients soon." — David Largaespada, PhD

# HOW YOUR DONATION HELPS

Children's Cancer Research Fund makes it a priority to fund researchers who study rare, hard-to-treat cancers that seldom receive government funding. Without philanthropic support, many of these scientists would not be able to explore their bold ideas that have great potential to yield better, safer treatments and cures for children with the rarest, most stubborn types of cancer. Your donation helps ensure that these children and their families never have to give up hope.

# **RARE DISEASES**

Though hepatoblastoma is rare (like most childhood cancers), the word "rare" loses its meaning when the disease takes over the lives of kids and their families. According to the latest research, infants and toddlers have the highest incidence rates, and the 5-year survival rate for hepatoblastoma has plateaued at about 65%.

"Although hepatoblastoma research is very important to the families affected by it, sometimes reviewers from the National Institutes of Health, the government agency that grants funding to certain research projects, just do not see the need to study such a rare cancer," said researcher Logan Spector, PhD, who is CCRF's chief medical advisor.

## HOW YOUR DONATION HELPS

Despite the lack of federal grants, CCRF-funded researchers Erin Marcotte, MPH, PhD; Jenny Poynter, MPH, PhD; and Spector do see the importance of researching rare diseases, and they have joined forces to press forward with enough data to study hepatoblastoma. Recently, CCRF helped fund Spector and Marcotte's work to launch the first genome-wide study for hepatoblastoma, which includes 1,060 samples from kids with the deadly liver cancer — the largest number of samples ever pooled. By fall 2019 they hope to compare each data set to see what genes are most responsible for making the disease fatal to children.

"Without CCRF funds, we would not have been able to conduct this important research," said Marcotte. "We know that this research is critical for all families affected by hepatoblastoma, and we are so thankful to CCRF for its support of this work." Connor, cancer survivor





# **DIFFICULT-TO-TREAT CANCERS**

More children die of brain tumors than of any other kind of childhood cancer, so the need for better treatments and cures is urgent. But brain tumors are extremely difficult to study because there are over 100 types, all of which need their own special kind of treatment.

For families like Connor's, help can't come fast enough. In the summer of 2018, doctors found a tumor the size of a large egg on 2-year-old Connor's brain. Today's treatments, which include aggressive chemotherapy and radiation, have had some effect — Connor's tumor is no longer growing, but it isn't shrinking either. His parents, Bernadette and Kevin, are clinging to hope — and for them, research equals hope.

#### **HOW YOUR DONATION HELPS**

Dr. Moertel and Dr. Olin, leading brain cancer researchers at the University of Minnesota, are pursuing a bold new research project that aims to "turn off" a specific protein called CD200, to allow a groundbreaking tumor vaccine to destroy cancer cells. With funding from CCRF, this project has the potential to be a huge step forward in the world of brain tumor research and bring hope to families like Connor's.

"Every once in a while, in the field of cancer therapy, these huge steps happen that make a big difference for a lot of people," Dr. Moertel said.

"We really think this has the promise to do that, and support from CCRF will help us get it done as quickly as possible."

READ MORE ABOUT RESEARCH PROJECTS: ChildrensCancer.org/Research



Jacob's cancer has a 40% chance of relapse, and that reality always looms in the back of his mom, Nicole's, mind when she thinks about her son's future. New cell and gene therapy treatments could reduce the risk of relapse for kids like Jacob.

# CELL, GENE AND IMMUNOTHERAPY

For kids like Jacob, a bone marrow transplant is often a risky but necessary treatment to keep cancer at bay. But it can also cause severe side effects. A combination of his bone marrow transplant and damage caused by chemo means his immune system may never be 100%. He has to be extra careful when sharing supplies at school or playing with his friends — and being careful is a lot to ask of a 6-year-old boy. But researchers are working on a solution.

Today, researchers are focused on making BMTs safer and more effective so kids like Jacob don't have to endure the many setbacks that today's BMTs can cause.

Cell, gene and immunotherapy (CGI) have incredible potential to completely change how cancer is treated. These direct, precise therapies can deliver drugs that destroy disease while leaving normal cells unharmed, replace damaged tissue, enable self-healing and reprogram the body to function better.

### THE POTENTIAL OF CGI TREATMENTS

- T cells could be directed to bind to cancer cells and kill them.
- Doctors could deploy viruses to penetrate deep into tumors to deliver a genetic payload that destroys cancerous cells.
- + Reduce or eliminate the need for chemotherapy as a cancer treatment.
- + Give patients an alternative option to the often risky blood or marrow transplant.

# A BRIGHTER FUTURE WITH CGI

CGI has the potential to be the biggest leap forward in childhood cancer treatment since the first successful bone marrow transplant at the University of Minnesota 50 years ago. It could mean the birth of precision medicine that targets disease and leaves normal cells unharmed with benefits such as:

- Reduced health care costs that would result from dealing with complications of and late effects from current treatments.
- + Decreased risk of second cancers in survivors.
- + Allowing the patient's immune system to remain intact, decreasing recovery times and risk of infection.

Current treatments mean that, in their journey toward becoming cancer-free, kids like Jacob are always at risk of infection or relapse. As we explore the new frontier of cell, gene and immunotherapy, we give kids like Jacob and his family hope that cancer treatment soon will be a series of steps forward, always moving toward renewed and lasting health.

# REACHING MORE MILESTONES: THE IMPORTANCE OF SURVIVORSHIP CARE

Lucie Turcotte, MD, MPH, MS, loves hearing about school, dating, graduations, weddings ... everything "normal" in a childhood cancer survivor's life. As a survivorship doctor and researcher at the University of Minnesota, she meets children and families at their absolute low points — sometimes when they are potentially facing death. "Seeing them celebrate the milestones they feared would not come is almost indescribable," Turcotte said.

She also sees that regrowing hair and rising energy after the completion of treatment creates many misconceptions about survivors. Just because cancer treatment is over doesn't mean that a patient isn't still dealing with the aftermath.

"People do not understand the physical, mental and emotional struggles many survivors might be dealing with," Lucie said. These struggles, called late effects, compose a long list ranging from heart disease to infertility to secondary cancers and extreme anxiety. Many, if left unchecked, can become fatal.

"The reality is that two-thirds of childhood cancer survivors will develop long-term complications from their prior treatments," said Karim Thomas Sadak, MD, MPH, MSE, and director of the University of Minnesota's Childhood Cancer Survivor Program (CCSP), which is supported by Children's Cancer Research Fund.

The CCSP provides specialized health care and education to cancer survivors, including late effects screening and health care plans. The program is typically introduced to patients before they transfer from the oncology team to the survivorship team.

But a meager 20% of survivors in the United States receive the survivor-focused care they need, and the CCSP aims to increase that number.

"It breaks our hearts to meet a survivor who now has life-threatening health conditions directly related to their prior treatments, and we could have helped catch them before they became serious, or even better, prevented them altogether," said Sadak. He sees that many adolescents and young adults lack the self-efficacy and self-management skills necessary to keep up with their health care. Everything from navigating insurance to scheduling appointments can become daunting roadblocks for survivors.

The gap is also affected by holes in essential information regarding the patient's diagnosis, treatment and health. In fact, research shows many long-term survivors cannot fully or accurately describe their previous cancer treatments or long-term health risks.

"When we lose a patient to follow-up in the CCSP," said Sadak, "we lose an opportunity to make their life healthier and better in so many ways. The right education may help prevent the scenario where survivors stop seeing the specialists that they so desperately may need."

For him, the ideal survivorship scenario looks like this: open communication among everyone involved, including survivors, oncologists and nurses. Everyone is well-informed and everyone is trusting. Sadak and Turcotte agree that a team approach is imperative for all concerned parties to be aware of risks and how to lower them.

Turcotte believes more overlap between a patient's primary oncology team and the survivorship team early on could create a feeling of continuity for survivors, and it could help the teams fill gaps in diagnosis and treatment information.

Turcotte also speculates that the preparation beforehand and a face-to-face annual one-hour visit with a survivor might not be enough to develop a full picture of a survivor's case.

As a result, the survivorship team is developing alternative strategies to help survivors understand their health and develop plans that empower survivors to care for themselves and stay healthy in the long term.

That includes developing a mobile health app-based intervention that will help providers stay connected with childhood cancer survivors via text messages and updated contact information and deliver education through interactive, fun approaches specifically geared to adolescents and young adults.

Additionally, with help from CCRF, Sadak and Turcotte are working on several other projects to improve survivorship care, including studying the connection between childhood cancer and secondary breast cancer and developing outdoor physical activity interventions to improve the health and quality of life for survivors.

"CCRF donors provide the funding that allows us to create ways to never let a survivor slip through the cracks or get lost in the health care system," said Sadak. "Together, we can make sure that children with cancer live their lives to the fullest and don't just survive; they thrive."

### GOGGLES, HEALING PROTEINS, AND CANCER ATLASES:

# EMERGING SCIENTISTS CHANGE THE CHILDHOOD CANCER LANDSCAPE

Grant applications from cancer researchers have increased more than 50 percent in the past five years, according to a recent National Cancer Institute (NCI) report. While the wealth of incoming ideas is exciting, more applications and limited funding means many lifesaving ideas never make it to the lab. "If discouraged researchers leave the field, we will squander the tremendous momentum and innovation alive in the research community today," said the NCI.

Your donations keep the momentum going for up-and-coming researchers through our Emerging Scientist Awards. Our \$100,000 grants will help 11 researchers transform their fresh approaches into potentially lifesaving realities for children nationwide. Here's a sample of some of the promising new work underway.





JIE CHEN NGUYEN, MD, MS AT THE CHILDREN'S HOSPITAL OF PHILADELPHIA

# CREATING MORE ACCURATE IMAGING FOR CHILDREN WITH DEADLY BONE CANCERS.

#### THE PROBLEM

Before surgeons remove tumors, radiologists use scans and imaging to tell them where the tumor resides in a child. The "x-ray vision" helps surgeons remove an entire cancer mass so it does not have time to spread. Though current imaging helps doctors see bone cancers like osteosarcoma and Ewing sarcoma, the technology is primarily made for soft tissue cancers. As such, surgeons can be 2-3 cm off from the margin when removing bone cancers. For a young child, the inaccuracy could determine whether he or she lives or dies, because the cancer can spread throughout the body.

### HOW HER RESEARCH WILL HELP

With the Emerging Scientist Award, Dr. Nguyen (working with Dr. Arkader) will have the funding to use a "better set of goggles for seeing the margins," as she puts it. Using a more precise MRI "pulse" technology, she will eliminate a lot of the guesswork involved with determining bone cancer margins.

# "We can start doing lifesaving work right away," she said, starting with at least 12 patients.

Once the new technology has been proven to work on a small scale, her hope is that it will become a standard of care for all children facing bone cancer.



# RAUSHAN KURMASHEVA, PHD AT THE UNIVERSITY OF TEXAS HEALTH SCIENCE CENTER AT SAN ANTONIO

# DECREASING THE TOXIC EFFECTS OF EWING SARCOMA TREATMENT WITH DNA REPAIR.

### THE PROBLEM

The survival rate of children whose Ewing sarcoma cancer has spread is nothing short of heart-breaking, and only 20% of children with this cancer live for 5 years after the cancer returns. "Current therapies for children with relapsed or metastatic Ewing sarcoma are not effective," said Dr. Kurmasheva. Recently, she and her colleagues published a study on a powerful therapy regimen using PARP1 inhibitor and DNA damaging agent, which worked well in mice with Ewing sarcoma tumors. But currently, the drug combination is too toxic and that is a critical problem that needs to be urgently addressed.

### HOW HER RESEARCH WILL HELP

Dr. Kurmasheva found that two proteins (called PARP1 and MGMT) work together to repair damaged DNA. Using the Emerging Scientist Award, she is aiming to discover a drug that will help these proteins prevent her new therapy from being too toxic. The funding will also help them understand the mechanisms behind the proteins function. If successful, she and her team can create a new lifesaving treatment for Ewing sarcoma patients who have no other options. Using proteins to repair damaged DNA could also apply to many other cancers. "CCRF generously honored me with this award, which provides an opportunity and valuable support to test my discovery," she said.



## NATALIE COLLINS, MD, PHD AT DANA-FABER CANCER INSTITUTE

# CREATING MORE ACCURATE IMAGING FOR CHILDREN WITH DEADLY BONE CANCERS.

### THE PROBLEM

Immunotherapy, harnessing a patient's own immune system to treat their cancer, could be the next chapter in childhood cancer treatment. Unfortunately, personalized medicine is not a reality for most children yet, as most immunotherapy research focuses on adult cancers. Little is known about how the genetic changes that occur in childhood cancer interact with the immune system.

### HOW HER RESEARCH WILL HELP

Dr. Collins hopes to learn more about the complexity of children's tumor environment and immune system. "If we can identify the cells in the tumor environment and learn what their roles are, we can better design drugs and therapies to harness the immune response and treat the tumor," said Dr. Collins. With her Emerging Scientist Award, she plans to look at the individual cells inside tumors from children who were diagnosed with sarcomas that harbor fusion oncoproteins. Using layers of data, her team will develop the first "atlases" to see what's happening in the tumor environment.

"We believe, by looking at individual cells, that we will be able to characterize both cancer cells and immune cells that are present and how these change from person to person and from disease to disease," she said. "Without CCRF, these atlases would not exist."

### **GRACIE'S STORY**

# THE HEALING POWER OF MUSIC THERAPY

Seventeen-year-old Gracie has always been an athlete. Her coaches and teammates recognized her as a hard worker, and she was usually among the first to finish the difficult running drills that kept her in shape to play basketball. But when she started slipping from the front of the pack to trailing her teammates, she had an inkling that something bigger might be at play.

"At first I was worried that I was just out of shape, so I kept pushing myself," Gracie said. "But then I was having a hard time catching my breath during games, and I was wearing out really quickly, which didn't feel normal."

When she developed a golf-ball-sized lump on the side of her neck, she thought it was time to see her doctor, who told her it was likely just a virus but to keep an eye on it in case anything changed. Three days later she had two golf-ball-sized lumps on the other side of her neck. Not long after, she was diagnosed with Hodgkin's lymphoma.

What came next was a roller coaster of difficult treatments, procedures, good news and bad news. Gracie started treatment right away, undergoing multiple rounds of chemotherapy and radiation and taking oral chemo pills regularly. It appeared the treatment was working, and she was declared in remission — until a devastating relapse sent her back to the starting line.

It became clear that Gracie's best option to beat her cancer was a stem cell transplant, an often risky procedure that would require months in the hospital to recover. That also would mean months away from her friends and her usual activities, feeling sick and knowing a long road to recovery was ahead.

But just before that daunting procedure, Gracie met Greta, a music therapist at the University of Minnesota. Greta told Gracie she could try a music therapy session, just to see if she'd be interested. Children's Cancer Research Fund helps provide funding for the music therapy program, which is laying the groundwork for expansion.

"I figured I'd give it a shot," Gracie said. "I have a music background, and I play a few instruments, but I typically don't like to play in front of other people because it makes me nervous. But I tried it out anyways."

Gracie, cancer survivor, with Greta

.1



The first time Greta visited Gracie, she brought a ukulele, an instrument Gracie had been hoping to learn for a long time. Greta taught Gracie a few beginner chords, and in almost no time she was hooked. Despite the exhaustion and nausea that Gracie battled after her transplant, she practiced her three chords until her fingers were blistered.

"When you're recovering from a transplant, they are very careful about any ways you can get an infection because you have no immune system at all," Gracie said. "With just those three chords, I played so much over the weekend that my ukulele had to be taken away because they wanted my fingers to heal."

It's difficult for Gracie to explain exactly how music therapy helped her through her long hospital stay, but she knows it did. Some days she was so sick that she couldn't get out of bed and walk to the couch without vomiting, so she mostly stayed in bed — unless Greta was there.

# "For some reason, I would completely forget I was sick for the hour that she was there," Gracie said.

"She would make little deals with me, like if I got out of bed and walked to the couch, she would teach me a new chord. Even just getting out of bed was a huge deal for me. I don't think I ever got sick while Greta was there, and I felt sick every day for months."

Gracie says the incredible benefits of music therapy didn't end when she left the hospital; she uses the songs she learned on the ukulele to escape when she's sad or not feeling well.



She remembers how it helped her get out of bed when she was feeling her worst. Even today, music helps her look on the bright side, even in moments that seem dark. She also wrote an essay called "Listen to the Healing Happen" to explain how much music therapy helped her, and it recently won the local Rotary Club's annual essay contest.

Today, Gracie is in remission and busy preparing her college applications. Her grades are great, and she's keeping her options open, but she's seriously considering attending the University of Minnesota, possibly to become a music therapist.

"It sounds crazy, but my time at the U of M was such a positive experience for me, and I loved my time with Greta so much that I've been thinking about music therapy as a profession," Gracie said.

"Greta helped me so much, and I want to do that for other people."

As she moves forward from her time fighting cancer, Gracie looks back with an emotion some may think is strange for someone in her situation: thankfulness.

"Everyone laughs when I say this, but I think if I could go back, I would not change a single thing," she said. "It doesn't mean I didn't struggle, but I'm thankful for the people I've met and the experience I learned, like how to advocate for myself, or how to look for the positives in a dark situation. I'm thankful for cancer because it changed me in a positive way."

# CCRF EXPANDS BIG DREAMS TOUR

James Orrigo has never heard of an idea he thinks is too silly to bring to life. This past year he's written songs about Ninja Turtle attacks, Mario Kart races and more — all with the help of kids fighting cancer.

All those silly ideas are part of James's "Big Dreams" tour sponsored by CCRF. He brings his guitar, along with a portable recording studio, into each child's hospital room and helps them write a song and animate a music video that expresses the child's own creative ideas, and the sillier the better.



This year James took his talents to 11 hospitals across the country and also partnered with high schools for his "Bridging Room Project" that aims to bridge the gap between the hospital room and the classroom. As part of his project, James takes the music videos he creates with the children and directs students on how to bring the songs to life.

This past May, James brought the students of Stillwater Area High School together with Wyatt, a 6-year-old cancer survivor who wrote a song about Ninja Turtles. For his video, Wyatt wanted to help the Ninja Turtles defeat their nemesis, Shredder.

Students at Stillwater Area High School created costumes and props, played characters in the video, and sang the song that James and Wyatt wrote together.

While shooting the video, Wyatt rode in a Lamborghini, fought alongside his favorite Ninja Turtles and, ultimately, saved the world!

The students at Stillwater Area High School cheered Wyatt on all afternoon; he even got to throw a pizza in Shredder's face!

A big thank-you to James and all the students of Stillwater Area High School for bringing Wyatt's incredible imagination to life.



### ADVOCACY

# HEART-TO-HEART TOPICS IN PARTNERSHIP WITH MOMCOLOGY

Children's Cancer Research Fund is proud to partner with family support programs like Momcology, a national support network for parents and caregivers of children with cancer. Momcology's online support groups allow parents to seek advice, affirmation and comfort from one another, even when they can't leave their child's side in the hospital. With your help, CCRF funds restorative retreats and in-hospital programs that help parents from across the country connect in person.



This year, CCRF and Momcology strengthened our partnership by starting online conversations called "Heart to Heart" conversations, so caregivers can discuss some of the issues and experiences only those who have gone through it understand. The caregivers' responses are then turned into meaningful content that raises awareness about what families face while going through childhood cancer. By combining CCRF's authentic storytelling capabilities with the many voices and experiences from within the Momcology network, we are eager to provide a new platform to amplify caregivers' voices to the public to both accelerate research and raise awareness. Here is one of our most popular collaborative blog posts:

# HEART TO HEART

# **6 WAYS CANCER CHANGES YOUR PERSPECTIVE**

When your child is diagnosed with cancer, it changes the lens through which you view the world. Things look and feel different, and certain things matter far more or far less than they used to. With the help of our partner, Momcology, a national peer support and community building foundation, we asked a group of pediatric cancer families, "What do you see differently since becoming a cancer parent?" Their insightful answers are below.

# TOLERANCE FOR DRAMA OR LOW-IMPORTANCE ISSUES DROPS TO ZERO

When you're a parent of a child with cancer, time and energy become hugely valuable resources. You don't have the space in your brain to contribute to drama or harbor negative feelings about people or issues that, in your new normal, just don't matter. Know that it's your right to cut sources of unnecessary drama out of your life; you have bigger fish to fry.

"I see anything that takes from what I have to give to my children cannot be part of my life. I have no energy for drama or negative experiences that are optional." — Les Lee

"We are in the middle of a huge drama with my in-laws ... They aren't respecting our home or our family, and we had to set some tough boundaries this week. It comes with some guilt, but this helped me realize we did the right thing." — Susan

#### HOW YOU EXPERIENCE EMPATHY CHANGES

For some parents, this means deeper empathy for everyone you come in contact with because you never know what someone else may be going through. For others, it means a sudden lack of patience for stories about other kids' minor bumps or scrapes. Whichever one of these you are, or if you're a little bit of both, know that it's OK to decide for yourself how much of someone else's situation you are able to handle. "I'm just not empathetic to normal kid sickness/injuries. When Facebook friends complain of a stomach ache or sore throat, I'm thinking, please ... Not exactly proud of this, but give me a break!" — Chrissy

"I was the opposite. I asked my family and friends to share the normal stuff because they quit doing so. They didn't feel comfortable complaining to me about petty stuff. But I also limited how often or when I could be a good listener; that was key! It was OK for me to NOT expose myself to it as well." — Mindy

"I have developed much deeper empathy toward others, and I have discovered, in a deep way, that giving of yourself really helps fill you up. I am a 100% changed person. I see past the small stuff now; I have a completely altered perspective." — Julie

### YOU LEARN TO LET LITTLE THINGS BE LITTLE

Cancer is a big deal, and it has a way of making so many other things feel so much smaller. Household tasks, minor arguments, none of those things matter as much as they did before. That realization gives you the freedom to spend time doing things you love with the people who matter most.

"Little things just don't matter. Let your kids do weird things with their hair and clothes and whatever else." — Jenny

"It's a lot easier to let the little stuff go and not let it bother me. Laundry can wait; my house doesn't have to look perfect all the time. I'd rather take my extra 30 minutes spending that quality time with my family than worrying about everything else." — Heather

"I took my older, non-cancer son out of school for his birthday, and my husband took the day off, and we went to the aquarium. I would never have let my child miss school unless sick before. I celebrate more now." — Vanya

#### YOU CHANGE YOUR EXPECTATIONS FOR YOUR CHILD

When your child has cancer, the child is often asked to adjust to situations that are far beyond their age or maturity level. Plus, it's hard to expect a child to behave like their peers do when they are feeling sick or in pain, so you allow tantrums, bend the rules, modify expectations. The rules of parenting that may have seemed clear before are blurred, and you adjust along the way.

"I have more patience for my child. I am able to sit back and let him have his meltdowns and not react like I used to. I can understand he's just a kid, and he's allowed big emotions like me; he just can't control them, and that's okay." — Melissa "I am a rule follower, so letting go of my perceived rules for what a kid should or shouldn't do at his age is a big thing that shifted for me. That PG-13 movie he wanted to watch while he's going through chemo transported him into that world away from the hospital bed." — Mel

#### YOU VIEW STATISTICS, RISKS AND THE WORD "RARE" DIFFERENTLY

When the thing that only happens to one of every 285 children per year happens to your child, statistics that used to comfort you now scare you. You've won the bad-luck lottery too many times to count, and you now know that things you thought would be part of your normal life aren't guaranteed. Just because something is "rare" doesn't mean it can't happen to you or your family.

"Risks, statistics — when you've been the one to draw the short straw, that one in however many that is comforting to others is scary to you. I've lost my innocence and am so aware of the reality that anything can happen, and there are no guarantees. It's a heavy weight to walk with." — Ashley

"Rare has a different meaning to me now. When it's your son, 'rare' just doesn't matter anymore." — Kelly

### **GRATITUDE CAN COME FROM UNEXPECTED PLACES**

The things you appreciate now might have slid right past you before cancer was a part of your child's life. You might even come to appreciate things you rolled your eyes at before. Cancer has a way of turning some of us into optimists, holding on tight to every happy moment.

"There is so much joy in chaos. By chaos I mean the busy schedules of sports and school activities that I used to dread attending that now I'd give my right arm to be at!" — Amanda

"I have the gift of perspective; I see the positive side of almost anything. I am grateful, and I am not afraid to express my appreciation. I try not to take anything for granted." — Ash

"The small things don't matter, and even the big things aren't that big anymore. Perspective is amazing. I know how little I can live with and who really will be there for you and what is important. Life really is too short not to be happy. I feel like I am a walking bumper sticker now." — Nadine

"I am more grateful for the small things in life! A note from your son or text from your daughter who is two hours away in college means everything. Cherish the time you have with your family and friends!" — Susan

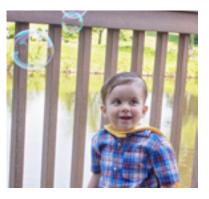
### **EDUCATION & AWARENESS**

# CONNOR'S INSTAGRAM TAKEOVER

Every day in the United States, 43 families hear the words, "Your child has cancer." But many of those families didn't know anything about the realities of childhood cancer until it happened to them. Part of our mission is to raise awareness of childhood cancer through the powerful stories that these incredible families share with us. Our goal is to reach millions of people with these stories that honor the struggle and celebrate the hope that these families experience. Below is an Instagram takeover featuring Connor, written by his mom, Bernadette.



"Meet Connor. This is him being silly while trying on hats at Target. Little did we know that he had a tumor the size of an extra-large egg on his brain and that he would be diagnosed with brain cancer (anaplastic astrocytoma, a grade III glioma) just days after this photo was taken."



"June 2018: Connor has had two brain surgeries thus far, one biopsy and one partial resection (removal). He's been blessed to have amazing surgeons and has bounced back quickly post surgery. This moment was captured just days after his partial resection, a major brain surgery."



"Connor had his port placed and started a 16-month chemotherapy treatment plan on July 11, not long after his hair started falling out in clumps, so we decided to have a very special haircut one night before bed. Connor wasn't fazed in the least; he's such a happy boy!"



"Connor's such a silly boy. Here he is playing in a box on Christmas morning. We were enjoying Christmas at home before heading to the hospital the next morning for monthly inpatient chemo."



"When Connor is feeling well and his counts are good, he enjoys spending time at the park with his friends. He's one joyful little boy!"



# FORBES/SHOOK EVENT RAISES \$1 MILLION FOR BRAIN TUMOR RESEARCH

Children's Cancer Research Fund was selected as the philanthropy partner for the 2019 Forbes/SHOOK Top Advisors Summit in Las Vegas in February. The event, a gathering of the nation's top wealth advisors, raised \$1 million to enable a clinical trial for a new, potentially lifesaving therapy for children with brain tumors, including glioblastoma, one of the deadliest childhood cancers.

During the summit, attendees heard from two families whose lives have been affected by brain tumors — Lindsay and Zach Mertz, whose daughter, Maddison, passed away in 2017, and Bernadette and Kevin Long, whose son, Connor, is currently in treatment for brain cancer. They also heard from Christopher Moertel, MD, researcher at the Masonic Cancer Center, University of Minnesota, whose work with Michael Olin, PhD, has led to the clinical trial that could significantly improve treatments not only for brain tumors but also for many other cancers, including breast, ovarian, prostate and melanoma.



"Cancer is the biggest killer of children after accidents, so we all need to battle this together," said RJ Shook, founder of SHOOK Research.

"I promised a two-year-old boy, Connor, that we'd fight this together, and I would do anything I can to help him and others."

Thanks to SHOOK Research, the Mertz and Long families and everyone else who helped make this incredible event possible.

TO LEARN MORE ABOUT THE CLINICAL TRIAL VISIT: ChildrensCancer.org/shook.

### IZZY'S COMMUNITY FUNDRAISER

## **SQUEEZING LIFE'S LEMONS**

When Amanda and Jeremy's daughter, Izzy, was diagnosed with a rare form of cancer at only a year old, they felt all the emotions every cancer parent feels — anxiety, fear and despair.

But they decided they wouldn't let those feelings hold them back from also feeling hope — hope that Izzy could beat her cancer and hope that researchers could find better, safer treatments for kids like her. They decided that no matter what terrible sour lemons life gave them — a cancer diagnosis, a devastating relapse or weeks in the hospital — they would make lemonade.

Amanda and Jeremy started a fundraiser called Izzy Makes Lemonade to raise money for Children's Cancer Research Fund. They rallied their family and friends around their cause, selling T-shirts with a bright yellow lemon to symbolize how they were making the most of every moment during Izzy's fight. They encouraged those who purchased shirts to post pictures of themselves on social media on the one-year anniversary of



her diagnosis and include Izzy's hashtags (#izzysfightforward, #izzymakeslemonade, #squeezinglifeslemons, #fightchildhoodcancer) so that instead of dwelling on the day, the family would have something to look forward to.

When that day arrived, their social media pages were flooded with pictures of Izzy's loved ones and their words of encouragement. With the support of many, Izzy's family far surpassed their \$1,000 goal and raised \$5,000 for CCRF, which they delivered on the one-year anniversary of Izzy's diagnosis. And the shirts were so popular that the family reopened the campaign and raised another \$600.

## "We believe every dollar raised helps other kids like her and families like ours and that sharing facts and stats about childhood cancer can make a difference."

"Izzy's strength has inspired us in ways we didn't know we could be inspired and moved us to rally the troops to raise money for the organizations that supported our family," Amanda said.

"The past year has taught us a lot about how brave Izzy is, how amazing her prayer warriors are and how, when life gives you lemons, you really can make lemonade."



## AUGUST 18, 2018 140 GOLF INVITATIONAL

2018 was a milestone year for the 15th Annual 140 Invitational hosted by longtime CCRF partner Lube-Tech. What started as a casual game of golf between friends and co-workers turned into one of the Twin Cities' most profitable charity golf tournaments.

Participants raised over \$320,000 for childhood cancer research and family support services, bringing the event's 15-year total to over \$2.1 million.

The passion for helping children facing cancer and their families was obvious. Before the event, participants had already begun fundraising for the Fund-a-Need project to support CCRF's partner, Momcology, which offers retreats for fellow cancer moms to connect, support and encourage other moms whose children are facing cancer. Mindy Dykes, whose son, Connor, is still facing the late effects of the cancer treatment he received as a baby, spoke about the healing those retreats provide for parents.

"The retreat allowed me to heal through the hurt, bring purpose to this pain and validate that I wasn't crazy," Mindy said.

Funds raised from this year's event also will support the work of Dr. David Largaespada, a researcher at the University of Minnesota who has discovered a potential cancer-causing gene in several childhood tumors that arise from nerve cells.

Thank you to our dedicated partners at Lube-Tech as well as the supporters and volunteers who made this day possible.





# DATE FOR LIFE

At the 11th annual Date for Life, Minnesota's most eligible bachelors and bachelorettes met for cocktails, live music and a lively date package auction that raised over \$115,000 for childhood cancer research.

The event was created by Lynn Poferl and Sara Darling in memory of Lynn's daughter, Katie, who passed away from cancer at the age of 20. The energetic and lighthearted singles mixer and auction honors Katie's spirited personality and her strength during her battle with cancer.

Even in the midst of a Minnesota snowstorm, this year's Date for Life was a success. The evening featured stories of hope and resilience as well as a live performance from Caiah, a cancer survivor. Caiah stole the show singing her rendition of "A Million Dreams" from the musical "The Greatest Showman."

Thank you to Lynn, Sara and the team of dedicated volunteers who make this event possible and who share a passion for childhood cancer research and awareness. In its 11 years, Date for Life has raised more than \$700,000 to fuel promising research.



# SEPTEMBER 29, 2018

Thanks to everyone who attended or supported the 16th annual Time to Fly. The event marked exciting milestones for many survivors, including our Time to Fly ambassadors, Danny, Emerson and Brooklyn.

Danny is feeling great and started high school this year; Emerson attended her first concert ever, a trip to see Taylor Swift; and Brooklyn started kindergarten by saying she wants to be a scientist when she grows up.

We also heard from Dr. Karim Sadak and Dr. Jakub Tolar. Dr. Sadak spoke about the importance of research for kids currently in treatment as well as childhood cancer survivors. Dr. Tolar, dean of the University of Minnesota Medical School, emphasized the impact we can all make on moving research and care forward.

Time to Fly raises critical funding for kids facing cancer. Thanks to their dedication, event supporters raised \$130,347, increasing the 16-year total to \$2.48 million.



SEPTEMBER 6, 2018

## THANKS TO YOU

Valued donors, dedicated researchers and fundraisers came together in September for our Thanks to You event, but 5-year-old Brooklyn stole the show.

Guests were delighted to see an energetic and healthy Brooklyn handing out party favors and chatting with guests, especially considering she finally finished cancer treatment for the high-risk acute lymphoblastic leukemia she's been battling since she was only 2 years old. Brooklyn's mom, Michelle, spoke about her family's journey through cancer and the worry and fear they still feel as they navigate reentry into a new, cancer-free life.

Attendees also heard from researchers who are working to discover the causes of certain childhood cancers using biological data that many researchers consider the next major weapon against childhood cancer.

We offer a special thanks to all our valued supporters in attendance for their continued dedication to our cause.



# BENEFACTORS CIRCLE

On May 19, the Benefactors Circle, a dedicated group of CCRF supporters founded by Sharon and Joel Waller, gathered and celebrated for the 29th year. The Waller's son and daughter-in-law, Jon and Jill Halper, have generously co-sponsored the group's annual dinner at Café Lurcat Bar in Minneapolis. The group raised over \$100,000 this year to push its 29-year-total over \$3.4 million.

We thank our dedicated Benefactors Circle members and the Waller family for their unwavering commitment.



# KS95 FOR KIDS

In its 20th year, the KS95 for Kids Radiothon raised \$603,870. This event, which benefits Children's Cancer Research Fund and Gillette Children's Specialty Healthcare, supports groundbreaking research that means more days at home instead of at the hospital for kids like Liam, Izzy, Bella, Wyatt, Benjamin and Nolan, our inspirational ambassadors who are fighting cancer.

The finale of the all-day fundraiser was the 6th Annual "Clouds" Choir for a Cause, which nearly 7,000 people attended in the Mall of America Rotunda. "Clouds" is the song Zach Sobiech wrote to say goodbye to his family and friends before he passed away from cancer in 2013. At this year's event, a major revelation was in store for Zach's family: surprise guest Justin Baldoni announced from the stage that he will direct a major motion picture based on Zach's story. The movie is expected to open in theaters in 2020.

"We are constantly amazed by how many hearts Zach's story has touched," said Laura Sobiech, Zach's mom. "Our family is excited about this astounding opportunity to share Zach's story with a new audience and to raise awareness about childhood cancer."



### APRIL 27, 2019

## DREAM 2019 BIG CHANGES BIG REWARDS

Children's Cancer Research Fund's signature event for the past 38 years has been called Dawn of a Dream. This event began as the government was cutting funding for childhood cancer research, and many research projects were grinding to a halt.

Thirty-eight years later, much has changed. More children than ever are surviving cancer, and researchers are on the brink of lifesaving discoveries. In this new era of hope, CCRF re-imagined its signature event, now called Dream, because our dream of a world without childhood cancer isn't just dawning; it is within reach. The event moved to the Armory in downtown Minneapolis and added a concert element to engage guests and celebrate how far we've come.

Dream 2019 was a huge success. Andy Grammer brought down the house with an incredible concert at the Armory, and event co-chairs Betsy Hageboeck-Schill and Julie Speetzen delivered on their promise of an unforgettable evening filled with inspiration and hope.

This year's event raised nearly \$1.3 million, funding seven new research projects with groundbreaking potential.



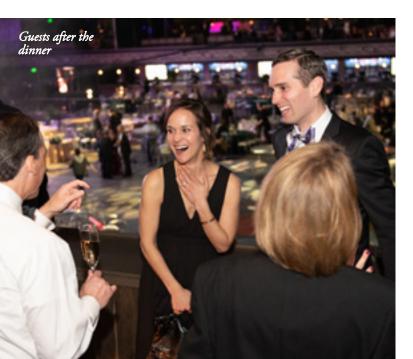
## THE SEVEN RESEARCH PROJECTS WILL COVER A WIDE RANGE OF TOPICS, INCLUDING:

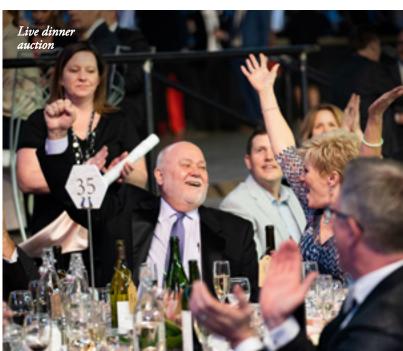
- + Immune therapy to reduce skin blistering in patients with epidermolysis bullosa.
- + Targeted therapies to inhibit expression of genes that cause osteosarcoma.
- + Genetic pathways involved in hepatoblastoma risk and survival.
- + Health impacts of platinum-based chemotherapy used to treat pediatric germ cell tumors.
- + Identify, isolate and kill chemoresistant leukemia cells that contribute to relapse.
- + Understanding the genetics of Ewing sarcoma using pluripotent stem cell technology.
- + Targeting multiple checkpoints to fight brain tumors.



### READ MORE ABOUT THE 7 DREAM FUNDED PROJECTS: Dream.ChildrensCancer.org







#### **JUNE 2019**

## GREAT CYCLE CHALLENGE

This year's Great Cycle Challenge (GCC) broke all the event's records worldwide. The 80,331 dedicated riders raised more than \$8.4 million for childhood cancer research.

New this year was the GCC Champions program in which 100 cyclists were selected to serve as ambassadors for the event. Our champions were passionate advocates for our mission, hosting group rides in their areas and helping bring together riders in their communities. We can't thank our participants and their sponsors enough for their passion and determination to create a world without childhood cancer.

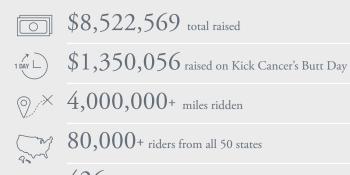
## **KICK CANCER'S BUTT DAY**

Our most successful day of Great Cycle Challenge was Kick Cancer's Butt Day when riders received a total of \$1,350,056 in donations, smashing the record for the largest fundraising day in the event's history.

In fact, at its peak, the GCC website was processing three donations per second. To top it all off, a generous group of donors offered to match donations that day up to \$900,000.

Thanks to all of our generous supporters - your gifts are making a real difference for kids fighting cancer.

### BY THE NUMBERS



426 group rides held



## **REMEMBERING NATHALIA**

The inspiration for many of this year's riders came from our dear friend Nathalia, who bravely advocated for cancer research throughout her journey with osteosarcoma.

Nat passed away on April 19 at age 15. Her passing broke our hearts, but her incredible wisdom and love for others, especially her mom, Katy, and her sister, Gabi, will never be forgotten.

Ever since Nat's diagnosis in 2016, she made it her mission to advocate for more research and better treatments for kids like her. While undergoing treatment, Nat served as an ambassador for Great Cycle Challenge where she and her family graciously let thousands of riders into their lives to inspire them with her story of strength. Nat shared how she preferred to talk about her cancer not as a fight but as a journey and how she hoped to use her story to make that journey easier for every other child with cancer.

Nat never missed an opportunity to give back to the people and places who cared for her during her nearly three years of cancer treatment. She always had a passion for art and design; creative art projects always brightened her long hospital stays. In March 2019 Nat asked GCC riders across the country to donate art supplies to local hospitals in her name, and that request brought smiles to other kids like her. GCC riders did not disappoint; they donated thousands of art supplies in Nat's honor, which CCRF distributed to hospitals throughout the country.

Read more about the research Nat & her team funded on the next page.



TO DONATE TO CCRF IN NAT'S HONOR, VISIT: ChildrensCancer.org/Nat.

> TO PARTICIPATE IN GCC NEXT YEAR VISIT: GreatCycleChallenge.com.



GCC riders in Rhode Island

## A CURE IN THE MAKING

To show support for Nat and her family, GCC started Team Nat, which quickly grew to over 3,000 members who raised nearly \$1.3 million for an osteosarcoma research project led by researchers Beau Webber, PhD, and Branden Moriarity, PhD.

Inspired by Nat's bravery and strength, members of Team Nat hopped on their bikes every day and pedaled farther than they thought they could.

In talking about a project to develop new treatments for osteosarcoma, Webber uses a word he doesn't typically get to say: "cure."

"I don't throw that word [cure] around, and I definitely don't use it lightly," Webber said. "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."

Webber and Moriarity are studying ways to engineer immune cells to attack and kill osteosarcoma cells. Osteosarcoma has proven to be a tricky cancer to treat with new immune-based therapies. But over the past five to 10 years, a boom in understanding the genetics of osteosarcoma and in the technology used to treat cancer have come together in what researchers believe could be the perfect storm.

This project aims to develop an engineered immune cell therapy that is highly effective at targeting and killing osteosarcoma. This is how it works: specific immune cells are engineered with a receptor, programming them to recognize osteosarcoma cells, which are usually good at escaping detection by the body's natural immune system. Once the immune cells can recognize the cancer cells, they can kill them all, leaving no trace. Patients and families will no longer have to worry that the surgeon wasn't able to remove the whole tumor or that the chemotherapy wasn't powerful enough to kill every cancer cell.

If all goes well and this research results in a clinical trial, the impact could be enormous. The kinds of treatments Nat underwent, including chemotherapy, radiation and surgery, leave patients with long-term side effects, and many times the treatments are not effective enough to completely destroy the cancer and prevent relapse. But future treatments resulting from this research could have almost no lasting side effects and be more effective than we've ever seen in treating this disease.

"Because this treatment uses immune cells instead of chemotherapy or radiation, the side effects are much less severe," Webber said. "It's likely that all the patient would experience would be a strong immune reaction while the immune cells are doing their job, and then it's done. The cancer is gone."



## SEVERITY OF SIDE EFFECTS







This kind of leap forward has already been seen in many adult cancers and childhood blood cancers, and Dr. Webber sees the potential for their effectiveness in solid tumors.

"The goal of these kinds of therapies is cure, and the history backs this up," Webber said. "Trials of this kind in GI cancer and breast cancer have had 80-90% response rates for patients who had exhausted every other option. That's the kind of success we could be looking at here."

The funding this project received form Team Nat will likely take it from initiating the project to planning for clinical manufacturing and initiating a clinical trial. By that time, Webber and Moriarity hope to have enough data and publications to apply for large government grants that could fund a clinical trial, bringing new treatments from the lab to kids who are fighting osteosarcoma today. Webber stresses that this kind of leap forward would not have been possible without funding from Team Nat.

"It is really difficult to get funding to start projects like this one because a lot of other funding sources tend to lean toward research that yields incremental, safe advances.

But what philanthropy from sources like Team Nat does is jump-start research that has a better chance to make a huge impact," Webber said.

"This is an opportunity to swing for the fences and do something that is really transformative. It's so enabling and so exciting to get to roll up our sleeves and get started."

# FISCAL YEAR 2019: JULY 1, 2018 - JUNE 30, 2019 FINANCIAL INFORMATION

## STATEMENT OF ACTIVITIES —

## **SUPPORT & REVENUE**

General contributions	\$4,583,356
Events	12,472,150
Direct expenses	(446,002)
Donated goods and services	6,249,708
Cause marketing	164,701
Investment income	362,531
Other	75,889
TOTAL REVENUES AND GAINS	\$23,462,333

## **EXPENSES**

MISSION - PROGRAM SERVICES

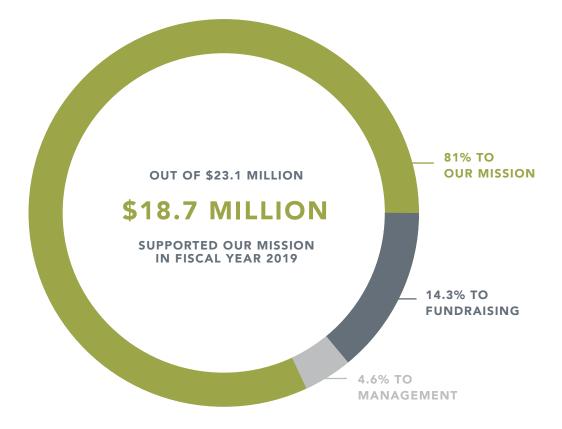
Research	6,685,512
Education & awareness	11,570,748
Patient & family services	466,120
SUPPORTING SERVICES	
Fundraising	3,311,844
Management & general	1,067,799
TOTAL EXPENSES	\$23,102,023

Expenses as percentages

 $\rightarrow$ 

## **NET ASSETS**

Change in net assets	\$360,310
Net assets, beginning of year	\$4,382,930
Net assets, end of year	\$4,743,240



## **EXPENSE RATIOS**

Research	28.9%
Education & awareness	50.1%
Patient & family services	2.0%
SUPPORTING SERVICES	19%
SUPPORTING SERVICES Fundraising	<b>19%</b> 14.3%

## STATEMENT OF FINANCIAL POSITION

AS OF JUNE 30, 2019

## **ASSETS**

Cash & cash equivalents	\$8,488,222
Investments	3,254,379
Pledge receivables, net	1,743,471
Property & equipment	275,261
Other assets	162,674
TOTAL ASSETS	\$13,924,007

## LIABILITIES

Accounts payables	\$1,243,584
Accrued payroll & related	313,516
Other liabilities	197,929
Grants payable, net	7,425,738
TOTAL LIABILITIES	\$9,180,767

## **NET ASSETS**

WITHOUT DONOR RESTRICTIONS

Operating	1,152,045
Board designated	2,729,890
WITH DONOR RESTRICTIONS	861,305
TOTAL NET ASSETS	\$4,743,240

## TOTAL NET ASSETS & LIABILITIES

\$13,924,007

TO SEE MORE DETAIL & AUDITED FINANCIAL DOCUMENTS VISIT:

ChildrensCancer.org/Financials

## **BOARD OF DIRECTORS**

CHAIRPERSON Matt Hedman

#### VICE CHAIRPERSON Stacy Anderson

TREASURER Dan Bartholet

SECRETARY Susan Doherty

#### CORPORATE RESOURCE Keith Nelsen

DEVELOPMENT Michelle Johnson

IMMEDIATE PAST CHAIR Charles R. Manzoni, Jr.

#### BOARD MEMBERS

Ingrid Culp Peter Dorow Scott Erickson Barb Farrell John Golden Carol Grannis Jon Halper Meghan Harris Dawn Lamm Pete Leacock Barry Morgan David Royal Dan Seeman Greg Soukup Carmen Thiede

## NATIONAL

ADVISORY COUNCIL Souheil Badran Suzanne Boda Cari Erickson Streich R.J. Shook

#### CHIEF MEDICAL

ADVISORS EMERITUS Mark Nesbit, Jr., MD Norma Ramsay, MD

HONORARY DIRECTORS Diana & Norm Hageboeck

#### LIFE ADVISORS

Jan Humphrey Del Johnson Deb Nesbit Jane Ramsland Cal Simmons Sharon Waller

NATIONAL HONORARY CHAIRS Tom & Melissa Lehman

CCRF LEADERSHIP John Hallberg *Chief Executive Officer* 

Darla Nemec Director, Finance and Operations

HaiVy Thompson Director, Marketing and Community Engagement

Kenna Dooley Director, Development and Donor Relations

Laura Grant Director, Events and Partnerships

Tamara Andrews *Human Resources Manager*  AIGHIY RESEARCH. & MIGHIY CURES. RF MIGHIY KIDS. & MIGHIY RESEARCH. A Search. & Mighty Cures. RF Mighty Kids. & Mighty Research. A Aighty Research. & Mighty Cures. RF Mighty Kids. & Mighty Research. A Search. & Mighty Cures. RF Mighty Kids. & Mighty Research. & Mighty Aighty Research. & Mighty Cures. RF Mighty Kids. & Mighty Research. A

## A MIGHTY MISSION FOR LASTING IMPACT

Every week 38 children pass away from cancer. We want to stop that, so we provide national support to the brightest scientists whose ideas are making the greatest impact for children with cancer. We also support vital family services across the country and advocate for childhood cancer education and awareness to surround families with community and, ultimately, hope.

With only 4% of federal cancer funding dedicated to childhood cancer, support from CCRF is crucial to finding safer, more effective therapies for kids battling cancer.

Thank you for joining the fight against childhood cancer. You have given us, and families everywhere, another reason to hope.

SEARCH. & MIGHTY CURES. RF MIGHTY KIDS. & MIGHTY RESEARCH. & MIGHTY Aighty Research. & Mighty Cures. RF Mighty Kids. & Mighty Research. & Search. & Mighty Cures. RF Mighty Kids. & Mighty Research. & Mighty Aighty Research. & Mighty Cures. RF Mighty Kids. & Mighty Research. & Search. & Mighty Cures. RF Mighty Kids. & Mighty Research. & Mighty Search. & Mighty Cures. RF Mighty Kids. & Mighty Research. & Mighty

