# healing the whole child

Children's Cancer Research Fund 2016 Annual Report



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We can offer patients the most pioneering experimental treatments possible, yet at times this can seem at odds with providing the compassionate care that is so needed by children, their parents and the teams who helped them get well. Three years ago, we began asking how we could work with the whole child — body, mind, emotions and spirit — to create an experience that was truly transformative. Could that approach, we wondered, produce even more favorable clinical outcomes? We looked to Children's Cancer Research Fund to help us find the answers.

Building on the Bone and Marrow Transplant (BMT) program's reputation for leading the nation and world in transplant medicine for life-threatening diseases, we decided in 2014 to officially include integrative therapies in the care model on the BMT unit. Regardless of the family's ability to pay, all newly

diagnosed patients and their families were offered the opportunity to meet with the Integrative Nurse Clinician, Megan Voss, DNP, RN, as part of their pre-transplant work-up process. Voss is a graduate of the Doctorate of Nursing Practice (DNP) in Integrative Health and Healing (IHH), a first-in-the-nation program offered at the University of Minnesota.

Integrative therapies, including acupressure, guided imagery, aromatherapy, biofeedback, massage, music therapy, reiki and yoga have been found to diminish treatment and disease-related symptoms and strengthen the child's body, mind and spirit. Healing therapies, when used in addition to medications, help build resiliency in a way that medication alone cannot. Targeted for patients, parents and siblings, these programs introduce skills that help everyone cope better with illness and disruption to daily life.

The Pediatric BMT integrative therapies initiative has recently completed its start-up phase. By all measures, this program has been an astounding success. Most patient and families have elected to utilize integrative therapies, with reiki, massage and aromatherapy being most commonly used for managing pain, nausea, insomnia and anxiety. Music therapy is especially effective in children with epidermolysis bullosa (EB), who cannot receive hands-on therapies due to skin fragility.

As a result of the program's success, a second fulltime integrative therapies clinician will be hired to provide expanded therapy hours; music therapy

services will be increased; and massage therapist services will be added. Programs for families will be expanded to include workshops on yoga, creative arts, reiki and nutrition. The team will devote greater capacity and time to research, beginning with a study of topical essential oils for patients with EB.

Clinicians and staff are also at high risk for injury, compassion fatigue and burnout. An essential element of the program's next phase will be to create a culture of well-being that supports staff as well as patients. A room on the hospital's fourth floor has been dedicated as respite space for families; funding from CCRF will be used to renovate that space to increase privacy and improve aesthetics, using design elements to relax, calm and heal.

Healing therapies, when used in addition to medications, help build resiliency in a way that medication alone cannot.

> The BMT Integrative Therapies Program is another great example of how CCRF funding lays the foundation to create innovative, successful programs. The University of Minnesota Masonic Children's Hospital is committed to expanding the delivery of integrative therapies to all of their patients, transforming the practice of medicine to include the whole child and the whole family. Your support allows us to challenge the status quo, to create new innovative therapies and to push the boundaries of science and medicine with the ultimate goal of fulfilling our promise to ensure the fullest and healthiest lives possible for children seeking cures for life-threatening diseases. We are grateful for your generous support.

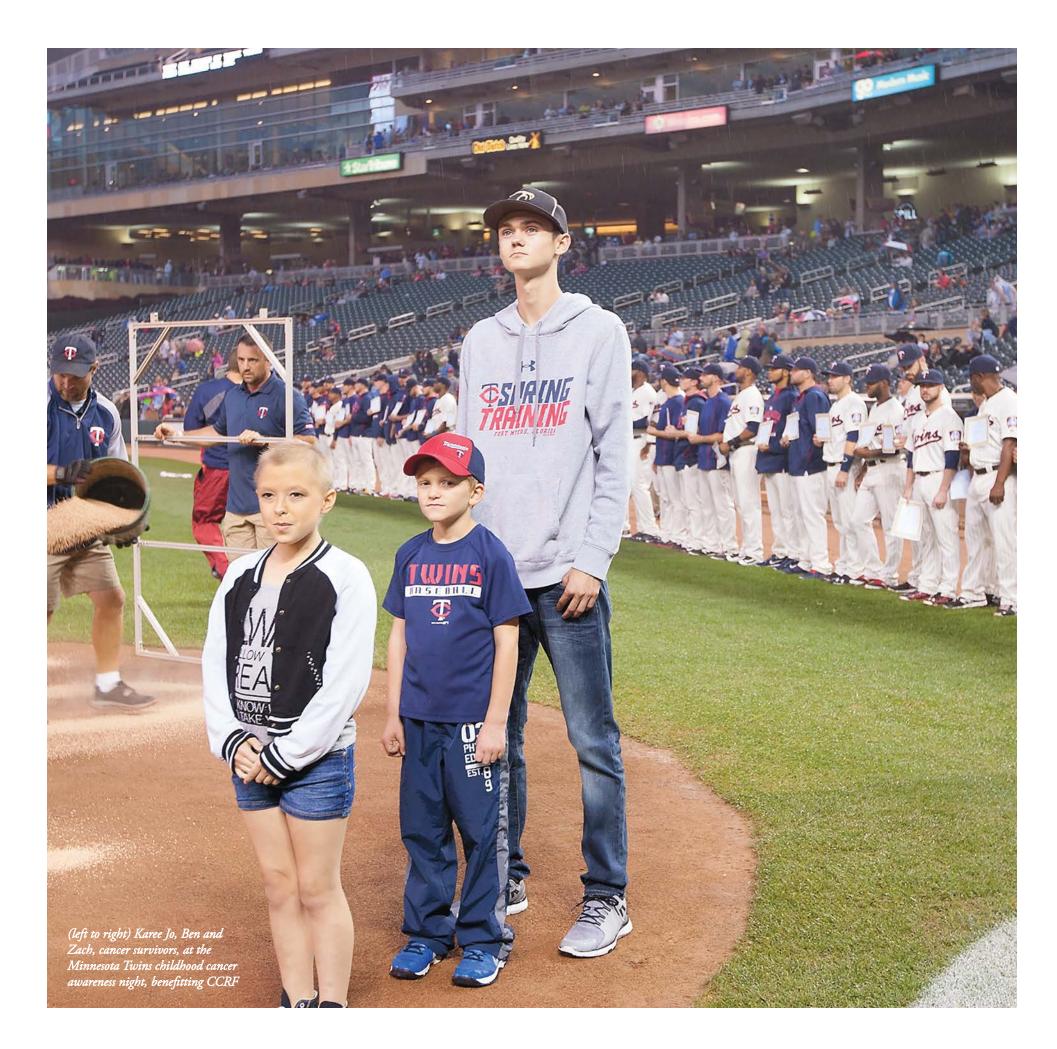
Sincerely,

logan G. Speitr John Wagner, M.D. Logan Spector, PhD

Enlique

Brenda Weigel, M.D.





We are pleased to present our annual report for our fiscal year ending June 30, 2016.

Our mission of understanding the whole cancer, treating the whole child and engaging the whole country - all to improve outcomes for young cancer patients - would not be possible without your commitment to our mission and your support of our work.

Thanks to major advances in technology, we are increasing our understanding of the genetics of cancer. By unlocking the genetic code of Ewing sarcoma, for example, Logan Spector, PhD, and his colleagues will eventually be able to understand the depth of cancer to its fullest. In the coming years, continued investments in bioinformatics will transform treatment for many types of cancer.

We are also improving the ways in which we treat the whole patient — body, mind and spirit. Megan Voss, DNP, RN and her team are bringing integrative therapies to patients at the University of Minnesota Masonic Children's Hospital. Through a variety of approaches, including massage, music, reiki and yoga, Voss is able to reduce patients' pain and anxiety during therapy — even if there isn't a cure.

Providing hope to children facing cancer is a team sport, so we are making our team bigger.

Providing hope to children facing cancer is a team sport, so we are making our team bigger. The nearly 8,600 fundraisers and 60,000 donors to Great Cycle Challenge made it possible for us to make grants to nine research institutions that are part of the Children's Oncology

Group. These grants will help support their Phase I clinical trials that provide the path to a new standard of care.

Thank you for your dedication to children across the nation. When we work together, a world without childhood cancer is possible.

Gratefully,

PAN.

Paul Perseke Chair, Board of Directors

John Hallberg Chief Executive Officer

HEALING THE WHOLE CHILD

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## HEALING THE WHOLE CHILD

We hope and work tirelessly for a tomorrow where childhood cancer is always curable or even nonexistent — a day when kids no longer must slog through days and months of toxic chemotherapies and radiation, risky surgeries and transplants. We yearn for a time when parents, siblings and friends no longer have to pack all of their present, past and future love into a few words of goodbye.

But today, as we search for the answers that will lead to better treatments, cures and even prevention, there's something we can all do to make the realities of childhood cancer a little bit easier.

We can help families and children heal, even if a child can't be cured.

#### MIND, BODY AND SPIRIT

Sleepless nights, tears over needle pokes, feeling clouded with queasiness: these are just some of the scary and painful things cancer treatment causes.

Doctors and nurses know all too well the pain, anxiety and distress that accompany cancer. That's why, with support from Children's Cancer Research Fund donors, the University of Minnesota Masonic Children's Hospital is tending to its patients' minds, bodies and spirits with integrative therapies.

In conjunction with a child or teen's medical plan, integrative therapies help address a patient's wellbeing beyond basic treatment, working to alleviate pain and emotional exhaustion.

The integrative therapy team uses aromatherapy, guided imagery, massage therapy, music therapy and other techniques to fill the gaps where pills, needles and injections can't help.

"Delivered at its best, integrative therapy allows for partnership in care in the context of a patient's mind, body, spirit and community, no matter his or her age," said Lynn Gershan, MD, CM, and integrative therapy practitioner.

Through integrative therapy, the team teaches patients, staff and caregivers how to handle various kinds of suffering from treatment. Applications could include anything from symptom management to spiritual

growth, helping patients cultivate resiliency and develop coping skills to handle the psychological reactions which accompany cancer diagnosis, treatment and life afterward.

"Integrative nursing acknowledges human beings as whole [mind, body and spirit], and those dimensions can't be separated," said Megan Voss, DNP, RN. "It acknowledges that as a nurse, you can be an intervention and help in a way drugs cannot."

Patients light up when Voss-a vibrant nursing professional-enters their hospital rooms. Much of her work happens on the blood and marrow transplant unit, where she works with kids and teens who are receiving stem cell transplants. "Most children and parents are scared and in a state of shock as they take in an overwhelming amount of information to prepare them for the life-sustaining, difficult procedure," she said.

When a child or teen is admitted to the hospital for a stem cell transplant, he or she undergoes one week of intense chemotherapy and sometimes additional radiation. Isolated for a minimum of 30 days or until their immune systems show signs of recovery, transplant recipients often suffer from mouth sores, pain, nausea, vomiting, fatigue, sadness and anxiety.

Though medications are critical to helping resolve physical symptoms, they simply aren't enough. That's where Voss and the integrative therapy team step in, with their toolboxes in tow.

Some of these tools are tactile, like oils and musical instruments; others are skills, like massage and healing touch training; underlying them all is the drive to be connected, authentic and caring with their patients. Depending on the patient, they might use all of these tools, or just a few.

"When I introduce these children and their families to our integrative therapy program, time and time again I see a familiar look of relief and excitement," Voss said. "Patients and families find comfort in knowing the health care team is invested in their entire well-being."



## INTEGRATIVE THERAPIES TEAM



LYNN GERSHAN MD, CM

Medical Director of Pediatric Integrative Health and Well-being



MEGAN VOSS DNP, RN Integrative Therapies Program Manager



BECKY PAULY DC, FICPA

Integrative Health and Well-being Program Manager



GRETA YATES MA, MT-BC Music Therapist

Cattaleya, EB survivor, with her mom

### HEALING THE WHOLE CHILD

When Voss first began her work a couple years ago, she was surprised to find that teenage boys and young men were the most excited about integrative therapies.

This was the case for two young adults in particular: Roozie and Alex.

#### ROOZIE: CREATING A BETTER DAY, TODAY

Roozie, 21, was smart, loyal and reliable — the kind of guy who friends would go to when they had problems they needed solved, including relationship problems. He was the only member of the family who could figure out the PlayStation<sup>®</sup> joystick or TV remote; his mother, Farideh Amiri, would often call him when she needed help but he was out of the house. When his sister, Raha (25), was feeling sick and needed a ride in the middle of the night, Roozie was there.

Roozie, short for Roozbeh, means "better day" in Farsi. "Wherever he was, [and wherever] he is, it will be a better day there," Farideh said. He'd go above and beyond for friends, giving of himself for others, she said.

You'd often see Roozie wearing old sweatshirts — he was particularly fond " of an Aeropostale zip-up — that he hung onto for years. Almost every one of them had holes in his sleeves for thumbs. He loved math and science and would bore his sister Raha by explaining the mechanics of a refrigerator. Roozie aced the math portion of the ACT, graduated high school and entered the University of Minnesota's College of Science and Engineering to study mechanical engineering.

He did all this while fighting childhood cancer — four different types over the course of 12 years.

At age 10, Roozie was diagnosed with medulloblastoma, a type of brain tumor. When he turned 14, he was diagnosed with lymphoma. Then, at age 15, he received a bone marrow transplant (BMT) to treat MDS, an early form of leukemia. The transplant lasted for nearly 5 years; however, the MDS returned and Roozie received another BMT at the University of Minnesota Masonic Children's Hospital. In June of 2015, the MDS returned as AML leukemia. In October 2015, he passed away.

Throughout the four cancers, he endured brain surgery, chemotherapy, radiation, bone marrow transplants, painful shingles, graft-versus-host disease and more. He once told his mom he thought he was born to suffer, though he was and always remained extremely positive throughout his life.

At points during his treatment, he couldn't relax. He couldn't sleep. And none of his pain medications seemed to be helping.

"Megan came in and started massage therapy from head to foot," said Farideh. "I left the hospital room and when I came back, there he was, asleep."

"Only Megan could come and calm him down," said Abi Assadi, Roozie's father. "Several times he'd want the doctors out, and he'd say, "Only Megan."

Farideh describes Voss in one word: Peace. "Working with her gives peace," she said. And it wasn't just for Roozie, Voss also gave Farideh peace knowing her son had a moment of relief.

## *Farideh describes Voss in one word: Peace. "Working with her gives peace," she said.*

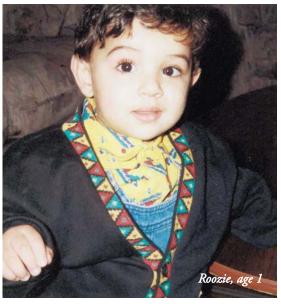
In addition to massage therapy, Voss provided Roozie with essential oils to help with relaxation, nausea and sleeping. He'd keep the oils open by his bed to help him sleep at night and temper nausea. She also taught him breathing exercises to help him get through any pain. "He wanted [Voss' help] every day and every hour," said Abi.

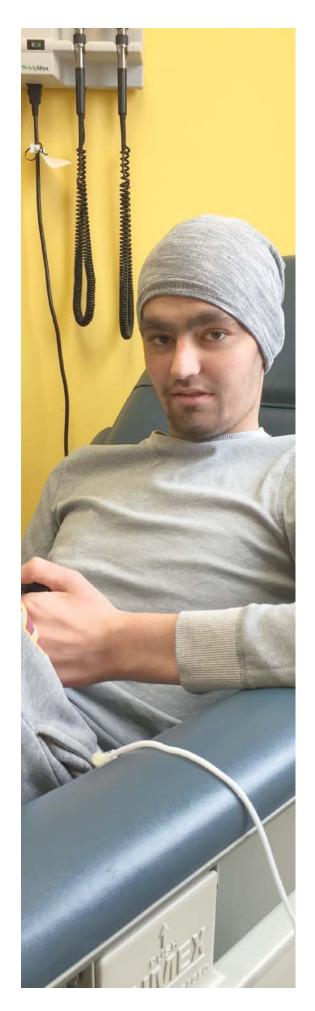
Roozie's family said he also healed from intentional conversation with Voss. "That was the only time he would actually relax," said Abi. "He actually connected with her. He would talk about life with her."

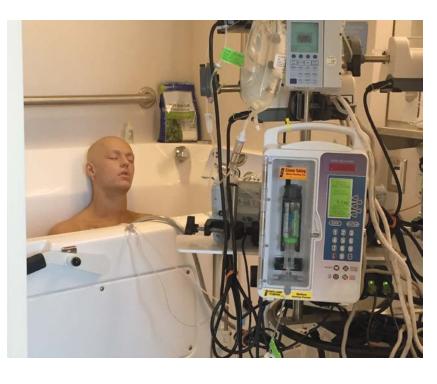
Today, though the pain of loss makes it difficult to talk about Roozie, his family is grateful for Voss' influence in his life and in theirs by making his last days better in the face of immense pain and loss.













#### ALEX: EASING THE PAIN OF TRANSPLANT

"I begged for Megan to come in every day," Alex told us, with his sister Kirsten and mother Nancy nearby.

While most of his friends are headed off to college, Alex is fighting his latest post-stem cell transplant symptom: a knocked-down immune system and painful shingles that spread over his back, abdomen, head, face and mouth - one of the worst cases his care team has ever seen.

An 18-year-old non-Hodgkin lymphoma survivor, Alex has had to overcome many other complications. He almost lost his life last fall after the transplant, leaving his family terrified. "I don't think we were ever prepared for what we went through," said Kirsten.

"I admire his strength," said Kirsten. "He's never had a pity party or used the cancer card. He's been through hell, and I'm just really grateful he's here."

> First diagnosed with cancer in October 2014, Alex has relapsed twice with two different types of non-Hodgkin lymphoma and has contracted graft-versushost disease. With that came a slew of painful and exhausting symptoms — so much so that he doesn't remember whole chapters of his recovery process and relies on his sister, Kirsten, for the chronological details.

On the bone and marrow transplant floor, Alex met Voss and Greta Yates, MA, MT-BC and a music therapist. Alex said integrative therapies have been a huge help in managing his pain and neuropathy.

"My hands and feet would just sting. With [Megan], it would hurt much less," Alex said. She would massage his hands and feet with essential oils, helping him manage the stinging in his feet. She also taught him how to use Epsom salt in his baths to help with bone achiness. "I live in the bathtub with Epsom salt," Alex said. "I do it every day, sometimes two or three times a day." Once, Nancy found Alex asleep and snoring in the bath tub because he was so relaxed. "We have 15.5 gallon containers in the garage full of Epsom now," said Nancy. The baths also help Alex manage the pain from the shingles.

Additionally, Voss showed Alex how to use essential oils on his joints — a technique that came in handy when he was learning how to walk again posttransplant. His joints would lock painfully, and the oils would help ease the discomfort.

This school year, Alex is continuing chemotherapy and is on steroids to fight graft-versus-host disease. He has three classes left before graduation and will be Skyping into the classroom for his lessons. What he misses most is being with his friends and being included when his friends go out. "My friends say, 'Oh, I didn't think you could go do that,' after they do it," says Alex. For a guy who loves fishing, hunting and anything outdoors, this has been especially difficult.

"I admire his strength," said Kirsten. "He's never had a pity party or used the cancer card. He's been through hell, and

> For these two young men, integrative therapy was vital to their healing. Voss and the integrative therapy team have seen many successes in healing like what Roozie and Alex experienced,

I'm just really grateful he's here."

especially on the blood and marrow transplant floor.

Next, the integrative therapy team is initiating studies that demonstrate the efficacy of integrative therapies. Although studies show that symptoms of post-traumatic stress and anxiety decreased when patients used these therapies, "adding to the evidence base for pediatric integrative therapies is critical," said Gershan.

"The more the practitioner explores this side of medicine, the better a doctor, nurse, social worker, pharmacist or any other kind of provider you will become," said John Wagner, MD, of the University of Minnesota Masonic Children's Hospital and Children's Cancer Research Fund Co-Chief Medical Advisor.

Blythe Brenden is a catalytic philanthropist, community leader and founder of the Blythe Brenden-Mann Foundation. Dedicated to medical research, integrative health and more, the foundation invests in the expertise of organizations like Children's Cancer Research Fund to find workable solutions to complex problems by working collaboratively. One of her sources of inspiration comes from an African proverb: "If you want to go fast, go it alone. If you want to go far, go together." Children's Cancer Research Fund is grateful for her dedication and passion for integrative therapies and healing children.

"I want 'integrative therapy' to be 'health.' I want everyone to have a sense of how important it is — that it's just how medicine is done. In order for it to transform, it's going to take dollars; it's going to take people believing in it ... everybody has to speak the same language."

Blythe Brenden, Blythe Brenden-Mann Foundation and long-time supporter of Children's Cancer Research Fund.



Thanks to support from donors like you, the integrative therapy team has been able to:

- Create a DVD teaching parents and family members how to use integrative therapies with their children.
- Train staff including nurses, social workers, chaplains and doctors — in Yoga Calm, a program designed specifically for children, helping them connect their minds and bodies and build resiliency, self-regulation, positive thinking and cognitive flexibility. CCRF funding helped provide yoga mats and DVDs to share with families.
- Expand music therapy services, including funding a music therapist on the BMT floor of the University of Minnesota Masonic Children's Hospital.

## With your continued support, the integrative therapy team will be able to:

- Initiate studies demonstrating the efficacy of integrative therapies.
- Educate and train hospital staff to create a culture of well-being.
- Expand support for patients by creating two full-time integrative therapy positions.
- Create workshops for families, including creative arts and yoga.
- Create a healing space for families to retreat to when they are physically, emotionally and mentally exhausted.



#### THE INTEGRATIVE THERAPY TOOLBOX

*Acupoint therapy:* Includes acupressure/acupuncture, Shoni-Shin and laser therapy. According to the principles of traditional Chinese medicine, this promotes the body's natural healing ability and helps improve function by helping regulate flow of energy throughout the body.

*Aromatherapy:* Promotes physical and psychological well-being through the therapeutic use of essential oils.

*Biofeedback therapy:* Uses sensors to measure physiologic responses such as breathing, heart rate or skin temperature. Through this, the patient learns to recognize and regulate changes in the body and develop ways to relax and find calmness to reduce physical and emotional symptoms.

*Breathwork:* Focuses on breath techniques to increase blood flow to the brain and body. This leads to decreased muscle tension and increased relaxation.

*Energy therapy:* A variety of techniques, such as reiki, Healing Touch or Tui na, that use subtle energy and light touch to promote rest and relaxation and reduce pain, upset stomach and feelings of worry or sadness.

*Guided imagery:* Uses creative imagination to imagine a place that promotes rest, relaxation and healing. A health-care provider, family member or CD can be a helpful guide during this process.

*Massage:* Uses gentle movements to relax soft tissues to promote relaxation and healing.

*Music Therapy:* The clinical and evidenced-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional.

*Nutrition Consultation:* Suggests food choices tailored to your child's needs that help children and families maintain good nutrition.

*Self-hypnosis:* Focuses the use of imagination to achieve a specific goal.

*Yoga:* Provides physical and emotional healing through breath control, simple meditation and the adoption of specific bodily postures.

Zuzanna, EB patient, enjoying music therapy

#### YOUR DOLLAR COULD BE THE DOLLAR THAT UNCOVERS A CURE.

With only 4 percent of federal cancer funding dedicated to childhood cancer, promising new ideas may never see the lab, and funding gaps can slow down or halt potentially lifesaving projects.

And, grant writing to get that small portion of government funding can take up more than half of a researcher's time in a year. That means less time in the lab and snail-pace results.

But every dollar you give is more than a dollar; it's the catalyst that helps researchers secure an additional \$18 in funding from the government and private foundations. With more funding, doctors can advance new ideas more quickly and build compelling cases for their research, giving them better opportunities to win multimillion-dollar grants from the National Institutes of Health and National Cancer Institute.

This means your dollar is giving kids better treatment options sooner. Thank you.

Your donation helps families around the world.

Over 300,000 children and teens are diagnosed with cancer each year around the world. Childhood cancer doesn't discriminate; it is truly a global crisis.

But thanks to you, we can reach children and teens everywhere.

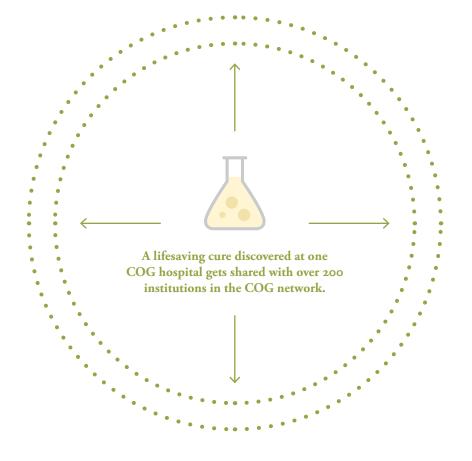
#### HERE'S HOW:

We fund research that's shared with over 200 institutions through the Children's Oncology Group. When researchers collaborate and share their findings, discoveries come more quickly and efficiently.

We've helped train over 90 former fellows who are leading the field in childhood cancer treatment around the globe.

Your donations help researchers travel to conferences to collaborate with other bright minds in their field.

Source: WHO's International Agency for Research on Cancer (IARC)



**RESEARCH HIGHLIGHTS** 

## **RESEARCH HIGHLIGHTS**

From using a child's own cells to fight cancer to creating next generation leukemia therapies, you're helping turn researcher's ideas into lifesaving realities. Here are some of the projects you helped fund this past year.

#### NATIONAL CLINICAL TRIALS RESEARCH

Children's Cancer Research Fund awarded nine hospitals around the United States with grants of \$20,000 each to fund early phase and clinical trials research.

The grants, done in partnership with Momcology, allow doctors and researchers to open up more clinical trials in their areas, enroll more patients in the trials and test the effectiveness of new technologies and procedures in cancer treatment.

With more resources and opportunities, doctors are improving the chances for survival and quality of life for more children with cancer. Many of today's treatment protocols were developed 30 to 40 years ago; clinical trials are crucial to helping researchers identify innovative new therapies and treatments.

All nine hospitals are members of the Children's Oncology Group Phase I & Pilot Consortium, which was formed to ensure more rapid development of new therapies for childhood cancer patients. This group serves as a national and international model for new drug development in pediatric oncology.

#### The following hospitals received these grants:

Ann and Robert H. Lurie Children's Hospital of Chicago Children's Healthcare of Atlanta — Egleston Children's Hospital of Colorado Children's Hospital of Los Angeles Children's Hospital of Philadelphia Children's National Medical Center Dana-Farber Cancer Institute Seattle Children's Hospital St. Jude Children's Research Hospital



Thanks to the efforts of all Great Cycle Challenge riders, here is just the beginning of what will be funded with the over \$3 million raised from this year's event:

#### Ann and Robert H. Lurie

Children's Hospital of Chicago Chicago, IL Grant support will fund key personnel who are dedicated to early-phase clinical trials. Having expert personnel in place will allow researchers to pursue a wide range of studies.

#### Children's Healthcare of Atlanta – Egleston

Atlanta, GA This grant will provide much-needed relief for families who are traveling great distances to participate in clinical trials and who have travel and lodging expenses.

#### Children's Hospital of Colorado

Aurora, CO Funding will help hire and train specialized staff to carry out clinical trials and allow more children and teens to enter into trials. Caring for patients in early-phase trials requires significant time and expertise.

#### Children's Hospital of Los Angeles

Los Angeles, CA Grant support will help the hospital enroll more children in clinical trials, opening innovative treatments to patients who would not have had the opportunity otherwise.

#### Children's Hospital of Philadelphia

Philadelphia, PA This grant will test the effectiveness of a new blood draw/microsampling device called The Mitra. If successful, this device could improve the patient experience during clinical trials by decreasing the amount of time patients and families are required to be in the clinic and by decreasing required blood volume, all while preserving the goal to evaluate the safety of new drugs in children.

#### **Children's National Health System**

*Washington*, *DC* This grant will underwrite software and sample analysis/imaging tools to help doctors evaluate and adjust patient care in trials, provide funding for community outreach to recruit patients for trials and support an oncology fellow.

#### Dana-Farber Cancer Institute

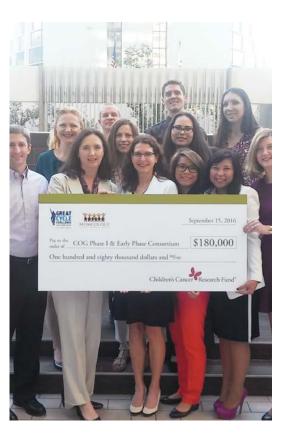
Boston, MA Grant support will fill current funding gaps such as repeat pre-screenings like blood work and scans prior to clinical trials, which can't be billed to insurance. Also, funding will help support early phase clinical trials by maintaining expert research staff.

#### St. Jude Children's Research Hospital

Memphis, TN The grant will support the work of a clinical research nurse to abstract and submit required data and assist with the management of patients on these studies allowing the team to recruit more patients for clinical trials.

#### Seattle Children's Hospital

Seattle, WA Funding will support clinical trials focused on new therapies that target molecular and immunologic pathways, thereby reducing late effects.





#### USING A PERSON'S OWN IMMUNE SYSTEM TO FIGHT CANCER

When the immune system fails, cancer is allowed to grow and thrive. Branden Moriarity, PhD, and Martin Felices, PhD, think we can do better for cancer patients by isolating their own immune cells, expanding and reactivating them in the laboratory and using the cells to fight a child's existing cancer. This treatment, called immunotherapy, has fewer side effects than either chemotherapy or radiation, and studies show that immunotherapy patients stay in remission longer.

#### How your donations help:

Currently, scientists use a special cell called a T cell to fight cancer, but Moriarity and Felices believe that natural killer (NK) cells could be more effective. With funding from CCRF, they plan to use a new technology to alter the genetic code of human NK cells to enhance their ability to expand, survive and kill cancer cells.

#### USING TINY PARTICLES TO DELIVER DRUGS DIRECTLY TO CANCER CELLS

Thanks to donors like you, Peter Gordon, MD, PhD, has already discovered how to deliver drugs to leukemia cells using nanoparticles. Typically, these tiny particles are about 20-100 nanometers in size. To put that in perspective, a sheet of newspaper is about 100,000 nanometers thick. This novel delivery system may help cancer drugs be more effective while making patients less sick because the targeted treatment avoids healthy cells and directly activates the drug in cancer cells.

#### How your donations help:

Gordon will further test his nanoparticle delivery system on Ewing sarcoma and neuroblastoma cells with a drug used to treat many childhood cancers. If successful, Gordon's idea could benefit patients with a variety of cancers around the world.

#### HELPING YOUNG ADULTS MAKE DECISIONS ABOUT LIFE AND DEATH

Twenty-five percent of adolescents and young adults (AYA) who need bone marrow transplants (BMT) will not survive. And less than a quarter of these patients' families have a plan called advance directives in place for quality-of-life decisions. Currently, advance directives are only legally binding - and thus only offered — for patients over the age of 18. But AYA patients with long histories of illness have preferences and wishes about their medical care if they are dying. Angela Smith, MD, MS, and Jennifer Needle, MD, MPH, are exploring interventions that will help AYA patients have a voice in their end-of-life decisions should they become unable to communicate them to a doctor or family member.

#### How your donations will help:

Researchers plan to test and evaluate a program called FAmily-CEntered (FACE) Advance Care Planning intervention to explore the unique needs, perspectives and decision-making processes of AYA BMT patients.

#### THE NEXT GENERATION OF LEUKEMIA THERAPY

Children with B cell leukemia are more likely to get infections because they don't have the protection of B cells, which are part of the immune system. Currently, a treatment called hematopoietic cell transplantation (HCT) is used for children with this type of leukemia. Though effective in some patients, HCT preparation is highly toxic, and when children relapse, it is associated with a poor outcome. Mark Osborn, PhD, is working on an innovative solution that could have an immediate impact on childhood leukemia.

#### How your donations help:

Today, scientists can engineer a special immune system cell called a T cell to "seek and destroy" a certain protein on B cells that causes the disease. Now that Osborn knows these special T cells can target the proteins, he's fine-tuning the control of the T cells so they don't cause potentially fatal side effects. He is testing an "on" and "off" switch on the T cell that will let it target the cancer while allowing the child's immune system to recover and function once the tumor is eradicated.

## **RESEARCH HIGHLIGHTS**

#### EARLY LEUKEMIA DETECTION IN NEWBORNS

Leukemia is one of the most common childhood cancers, representing approximately one-third of all cancer diagnoses among children under the age of 14. Studies show that acute lymphoblastic leukemia (ALL), the most common type of leukemia in children, begins in the womb. Researchers discovered a genetic error that is present at birth in some children who later develop ALL. It is not clear how many children have this error at birth, and whether it can be used to identify children who will develop ALL.

#### How your donations help:

Erin Marcotte, PhD, and Heather Nelson, PhD, will test a new method using advanced genetic sequencing to detect this genetic error. This will help researchers determine whether the genetic error is an accurate predictor of leukemia, helping doctors detect ALL early and increase a child's chance of survival.

#### ELIMINATING DEADLY GRAFT-VERSUS-HOST DISEASE

When a child gets a stem cell transplant, he or she can be at risk for the lifethreatening graft-versus-host disease (GVHD). This disease develops when the donor's immune cells mistakenly attack the child's normal cells. Nearly half of patients with severe GVHD will die. But thanks to donors like you, we're able to fund two projects that could eliminate this fatal disease once and for all.

#### How your donations help:

Oftentimes, GVHD attacks a child's digestive system, which causes side effects like abdominal pain or cramps, nausea and vomiting. Bruce Blazar, MD, will test two methods to prevent the disease in the digestive system. He has developed a new therapy that changes the environment in the digestive system and significantly reduces GVHD. Blazar plans to build up the immune-controlling environment before transplant. He will do this by using a special protein to stimulate the parts of the immune system that help prevent bacteria and food proteins from hurting the patient. Another way he plans to defeat GVHD is by taking the parts of the donor's immune system that prevent disease and multiplying and enhancing them so they can be even more effective in a patient.

Lucie Turcotte, MD, MPH, MS, will examine whether an association exists between donor obesity and GVHD. Both obesity and GVHD are classified as chronic inflammatory diseases, and many transplant donors are obese. To test her theory that there may be a connection, she'll perform genetic studies on donor blood cells, examining whether specific genetic changes increase risk for GVHD, and measure donor inflammatory status and correlate with recipient GVHD outcomes. If she finds a correlation, this will help doctors select donors who will not put the patient at risk for GVHD, thus reducing GVHD for children everywhere.

Thanks to donors like you, we're able to fund two projects that could eliminate graft-versushost disease once and for all.



Harrison, leukemia survivor, with his dad



Through endowed chairs, donors provide a consistent stream of funding to keep research moving forward and to help recruit and retain the brightest minds in the field of pediatric cancer research. Your donations help fund the groundbreaking work of these talented chair holders at the University of Minnesota.

#### BRUCE R. BLAZAR, MD Children's Cancer Research Fund Land Grant Chair

Bruce R. Blazar, MD, is the associate vice president of clinical research for the Academic Health Center, vice dean for clinical investigation for the School of Medicine, and Regents professor in the Department of Pediatrics Division of Blood and Marrow Transplantation. He was named Children's Cancer Research Fund Land Grant Chair in 2013. Blazar's research focuses on improving bone marrow transplant outcomes, preventing and treating graft-versus-host disease, stimulating the immune system to fight tumor cells and developing therapies that speed immune recovery and prevent immune complications.

#### DAVID A. LARGAESPADA, PHD Hedberg Family/Children's Cancer Research Fund Chair in Pediatric Brain Tumor Research

David A. Largaespada, PhD, is a professor in the Department of Pediatrics, Division of Pediatric Hematology/ Oncology and an associate director of basic sciences at the Masonic Cancer Center. He was named holder of the Hedberg Family/Children's Cancer Research Fund Chair in Pediatric Brain Tumor Research in 2014. Largaespada's research is focused on cancer genetics and finding targeted customized therapies based on the specific genetic makeup of a patient's cancer. As chair holder, he investigates the genetic basis of tumor development and continues efforts to create effective vaccine approaches for tumors of the nervous system.

#### LOGAN G. SPECTOR, PHD

Suzanne Holmes Hodder/Children's Cancer Research Fund Chair in Pediatric Cancer Research

Logan Spector, PhD, is the director of the Division of Pediatric Epidemiology and Clinical Research in the Department of Pediatrics and co-chief medical advisor for Children's Cancer Research Fund. He was named chair holder in 2015. Spector is focused on the causes of childhood leukemia, hepatoblastoma and bone sarcomas. Over the past year, he's led studies investigating the genetic basis of osteosarcoma to help diagnose the disease earlier and to identify new targets for therapy. In addition, he has analyzed and released preliminary results of the largest study to date to examine the risk of childhood cancer in children conceived by in vitro fertilization.

#### JOHN E. WAGNER, JR., MD,

Hageboeck Family/Children's Cancer Research Fund Chair in Pediatric Oncology

John E. Wagner, Jr., MD, is the director of the Division of Blood and Marrow Transplantation in the Department of Pediatrics and co-chief medical advisor for Children's Cancer Research Fund. Based on his substantial contribution to the treatment of children with cancer, Wagner holds two endowed chairs: the CCRF/Hageboeck Family Endowed Chair in Pediatric Oncology and the McKnight Presidential Chair in Childhood Cancer Research. Wagner is best known for his work in umbilical cord blood transplantation and exploring novel strategies for hematopoietic stem cell expansion, the isolation and expansion of regulatory T cells and the generation of thymic progenitors from umbilical cord blood. He has also developed treatment strategies for Fanconi anemia and epidermolysis bullosa, transforming survival expectations and the quality of life for many patients.

## BRENDA J. WEIGEL, MD

Brenda J. Weigel, MD, is director of the Division of Pediatric Hematology/Oncology in the Department of Pediatrics and co-chief medical advisor for Children's Cancer Research Fund. She was named chair holder in 2004. Weigel focuses on advancing new therapies for patients — particularly ones that harness the immune system's role in fighting cancer — translating promising therapies into clinical trials for children and helping accelerate the work of new faculty members.

Lehman Family/Children's Cancer Research Fund Chair in Pediatric Cancer Research

### UNLOCKING THE DOOR TO EWING SARCOMA

The answers to a deadly childhood bone cancer could be locked in a database holding 1,600 iPhones' worth of data. And thanks to a gift from a Children's Cancer Research Fund donor, scientists will be able to unlock and analyze the data, potentially discovering the genetic markers that cause Ewing sarcoma. Once doctors find this information, they may be able to detect and prevent the cancer entirely.

"If the answer is in any dataset, it is in this one," says Logan Spector, PhD. "It will take a few years to wade through all the data ... Ewing sarcoma is complex, but we should have a much clearer picture of it by the end of our analysis. It won't be hard to surpass what we know now, which is nearly nothing."

Spector has been working with colleagues from the University of Utah on a project called "Genetic Risk Factors for Ewing Sarcoma," studying the make-up of a bone cancer that has a survival rate of less than 60 percent for teens ages 15-19. "The survival rate hasn't budged in 20 years," says Spector.

Then, a funding breakthrough emerged when the National Institutes of Health started the Gabriella Miller Kids First Pediatric Research Program (GMKF), which pays for whole-genome sequenc-ing of patients with childhood cancers or birth defects, as well as their parents. Whole-genome sequencing focuses on all of the DNA in a child's genome rather than just pieces of it, which makes the analyses more complete. Spector's Ewing sarcoma project was one of the first chosen to participate in the program.

Originally, he was going to have to work with 1,000,000 gene variants, but, with help from GMKF, he now has all 3,000,000,000 DNA letters in each participant's genome.

"Instead of a dot painting, we're getting the richest detail imaginable," says Spector. "Very few cancer researchers have high-quality whole genomes on hundreds of patients and their parents. Most researchers have to start with the 'dot painting' approach to investigating the genome and slowly work toward filling in the picture. We're getting the whole picture at once."

Getting the best data possible is a good thing, but when it's in an unsorted pile, time and expertise are needed. Spector was essentially left with a mound of 3 billion puzzle pieces to sift through.

"Though I have a clear vision of what I wish to examine in the data, I have none of the programming skills needed to actually handle it. Without Children's Cancer Research Fund's help, I'd be spending a year and a half just trying to get the funding to put together a team," he says.

CCRF support has allowed Spector to hire Spencer Kelley, a developer and researcher, to put the puzzle together with the help of supercomputers. Nathan Pankratz, PhD, and associate professor in the Department of Laboratory Medicine and Pathology, supervises the work. "What's most exciting about the project is looking at the entire genome for the first time in a way we haven't been able to do before, and with higher accuracy. Our supercomputers are working harder than ever before, and we can come to the answers sooner," says Pankratz.

"Without Children's Cancer Research Fund's help, I'd be spending a year and a half just trying to get the funding to put together a team," Spector says.

> According to Spector, this important data analysis could even lead to prevention of Ewing sarcoma. "There's no way to tell ahead of time what genes or cellular processes will be implicated by our analysis, but it's conceivable some of them will be targets of prevention," he says. "There's a very tight window of a few years for developing Ewing sarcoma. If we could identify children at risk and offer them a preventative agent, we could perhaps steer them through adolescence disease free, after which the danger will have passed."

For now, Spector thinks identifying children at high risk and following them intensively for early tumor development is the more easily obtainable goal — a goal that could save lives.



As a Children's Cancer Research Fund donor, you're helping train the next generation of childhood cancer researchers.

With fewer doctors choosing academic career paths in hematology/oncology, your support is needed more than ever before. Incidence rates of childhood cancer are increasing around the globe, and we need more bold and brilliant researchers tackling these life-threatening diseases.

The ideas are there.

For 36 years, Children's Cancer Research Fund has helped young doctors foster connections with mentors, so their ideas can come to fruition and become potentially lifesaving therapies and treatments for kids with cancer.

Thanks to support from donors like you, over 90 fellows have successfully gone through the Pediatric Hematology/Oncology and Blood and Marrow Transplant Fellowship Program at the University of Minnesota. Your dollars are utilized by the brightest minds, making the biggest impact for kids around the globe.

One of these bright minds is Lucie Turcotte, MD, MPH, MS pediatric hematologist/oncologist. Recently awarded a grant from CCRF to explore a potential link between obesity in stem cell transplant donors and a heightened risk of graft-versushost disease, she says, "The fellowship program was great. It allowed me to work closely with several accomplished researchers from a range of backgrounds ... the breadth of research experiences ... helped me to focus on the areas I wanted to pursue going forward. Essentially all the work I am doing now comes from my work as a fellow." You can also read about her focus on survivorship research on page 31.

### PATIENT AND FAMILY SUPPORT

Childhood cancer patients and families often have care needs that extend beyond medical treatment. Emotional support, an engaged community and assistance with the needs of everyday life are just a few resources that help support individuals actively battling cancer.

Children's Cancer Research Fund provides funding and access to a variety of programs that help families connect to important resources to improve their lives in the face of difficult circumstances both during and after treatment.

#### CARE PARTNERS

Care Partners volunteers provide nonmedical support to families of pediatric hematology/oncology and blood or marrow transplant patients receiving care at the University of Minnesota Masonic Children's Hospital. Last year, 67 individuals supplied 5,429 hours as Family, Unit, and Clinic volunteers for patients and families. Volunteers assist in a variety of ways, including giving caregivers breaks throughout the day; providing transportation; picking up groceries and special food requests; providing notary services; distributing books, magazines and local newspapers; delivering welcome bags to all new patients; and supporting playroom and bedside activities for patients and siblings. Care Partners also hosts the Picnic of Hope each year for patients and families.

#### DINNER PROGRAM

Once a month, the Care Partners dinner program provides food, beverages and a short break from the hospital room for patients, family members and caregivers at the University of Minnesota Masonic Children's Hospital. During the past fiscal year, volunteers from local organizations and companies served over 2,000 meals catered by CRAVE Catering and Chick-fil-A of Apple Valley, MN. They set up and cleaned up the dining area and helped patients safely navigate with their meals and medical equipment with friendly and welcoming smiles.

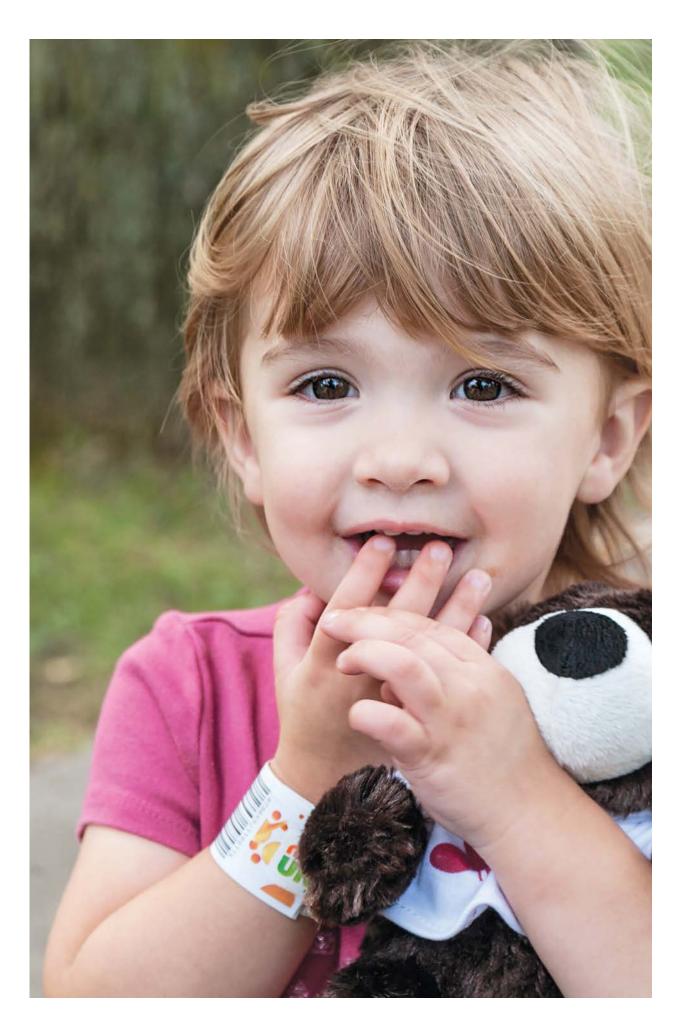
#### SIBSHOPS

Care Partners sponsors Sibshops, a monthly workshop providing brothers and sisters of children with special health-care needs with a fun opportunity to gain peer support and education within a recreational context. Child Family Life Specialists work with siblings individually and in group settings to provide coping and adjustment support for the many changes that take place during critical-care treatment for their brothers or sisters.

#### MOMCOLOGY

Children's Cancer Research Fund helps to support Momcology, a non-profit peer support organization established for mothers and primary caregivers of children diagnosed with cancer. Momcology serves thousands of families around the world by connecting parents whose children have been given the same diagnosis and are on similar treatment protocols. Members of Momcology support each other through personal experience in a safe and compassionate environment. In addition to online support, Momcology hosts restorative retreats around the country, offering moms the opportunity to connect in person, explore new ideas in self-care, learn to rediscover themselves and relax — and in doing so, begin to heal.

> "This was an unforgettable weekend spent with the most beautiful women that I am forever connected to. It was so difficult to convince myself to go, as I had not been away from my family since my child's diagnosis. I am so happy that I had the honor of experiencing love, honesty, stories, laughter and time. Time seems to escape us when we are going through something this painful. However, this retreat gave me a restart button. It made me realize that I am not alone in my journey. I will always treasure this memory." — Cat, retreat attendee



#### **BEADS OF COURAGE**

Care Partners funds the Beads of Courage program, an innovative therapeutic art program that lets cancer patients document their journeys with cancer. The program is designed to support and strengthen children and families coping with serious illnesses. Patients tell their stories by using colorful beads, which represent their courage and the milestones they've achieved along the treatment path.

#### C.C. BEAR

Cuddly C.C. Bear (Cure Cancer Bear) has been busy getting to those who need him most. Hundreds of children diagnosed with cancer and other lifethreatening diseases as well as their siblings have been comforted by our lovable donor-supported teddy bear. He can be found in homes, classrooms, hospitals and wherever he may be in tow! To request bears or learn more, please visit ChildrensCancer.org/CCBear.

#### FLAG DAY ICE CREAM SOCIAL IN MEMORY OF SUZANNE HOLMES HODDER

In June 2016, patients at the University of Minnesota Masonic Children's Hospital were treated to Kemps ice cream, music and face painting as part of the annual Flag Day Ice Cream Social in memory of Suzanne Holmes Hodder. Sue was a long-time supporter of Children's Cancer Research Fund who passed away in 2011. She loved all things patriotic, and the Flag Day Ice Cream Social honors her love of patriotism and children.



Graduation: It's a much-anticipated milestone that marks a new life ahead. For the many children who've overcome childhood cancer, the transition starts when they celebrate the end of treatment and look ahead to life as a survivor. Although patients may show no evidence of disease, the late effects of cancer are far from "cured."

Long-term complications of childhood cancer treatment, known as late effects, can be caused by treatments like chemotherapy, radiation, surgeries and bone marrow or stem cell transplants. Common late effects vary by person, from second cancers to lung and heart issues or fertility problems. They can also impair cognitive function and cause anxiety or depression.

"We've come a long way. Today, it's not cure at any cost. It's cure, but with the best quality of life possible," Sadak says.

> "Cure alone isn't good enough," says Karim Thomas Sadak, MD, MPH, MSE, of the University of Minnesota's Childhood Cancer Survivor Program (CCSP), which is supported by Children's Cancer Research Fund. They see approximately 300 survivors each year in their clinics.

"We've come a long way. Today, it's not cure at any cost. It's cure, but with the best quality of life possible," he says.

Lucie Turcotte, MD, MPH, MS, agrees. "We're thinking beyond this year or the next year, and toward a long and productive life," she says.

As a leading researcher in CCSP, she notes that the dual functionality of research and clinical practices backed by the university allows changes to be brought quickly and directly to the clinical front. Through data gathered by research, they can determine if a cancer is genetic and tailor a combination of therapies and target risks for each patient. They can also reduce the amount of radiation and cut down on chemotherapies associated with second-cancer risk.

Survivors themselves, some well into mid-adulthood, contribute to research on late effects by completing an annual survey. The national Childhood Cancer Study, initially funded by CCRF, has collected histories of survivors from 1970 and beyond.

"It's exciting to know that we can make changes just by observing," says Turcotte, noting that data from the study is informing current CCRF-funded research on the impact of donor characteristics on bone marrow transplant recipients.

The CCSP ensures that every visit is guided by a Survivor Care Plan unique to each patient. The plan includes a summary of prior treatment, a comprehensive list of late effects and a detailed

> plan for the survivor's health care future. The plan keeps the care team and family on the same page, from assessing medical factors to covering one of the most common survivor concerns: evaluating and supporting the family's well-being.

Knowing how to stay healthy as a survivor is critical, so education is a big part of the care delivered by the CCSP. Along with

providing guidance on logistical factors, such as insurance coverage specific to a survivor and his or her family's situation, the program empowers survivors to take responsibility for their health as they grow older. A highlight of the year is the CCSP annual spring Survivor Conference, funded by CCRF and attended by more than 250 survivors and families.

"We have a lifelong opportunity to make a difference in the quality of life of a childhood cancer survivor," says Sadak.

Along with disease surveillance to prevent or catch late effects, Sadak envisions long-term relationships with survivors as partnerships so that no one slips through the cracks. CCRF's focus on childhood cancer and survivors means that your donation funds research that benefits families fighting childhood cancer - before and after treatment.

#### **BUTTERFLY AWARDS**

Each year, Children's Cancer Research Fund presents Butterfly Awards to individuals, organizations and teams who have contributed significant time, service and resources to ending childhood cancer. We're truly thankful for the passion and commitment shared by these award recipients.

#### THE DYKES FAMILY AMBASSADOR

During the 29th Annual Dawn of a Dream gala, the Dykes family first shared the story of Connor's battle with cancer. Diagnosed with a brain tumor at just six weeks old, he survived an emergency surgery to remove the tumor, chemotherapy and a bone marrow transplant. Today, though Connor lives with developmental disabilities, partial blindness and seizures as a result of his cancer treatment, his love of golf and Minecraft shine through. He even rode 135 miles and helped his team raise over \$15,480 for CCRF during the past two years through the Great Cycle Challenge. His parents, David and Mindy, continue to share their story to raise awareness and inspire advocacy for childhood cancer research. In addition, David brings our mascot, C.C. Bear, to life at special events, and Joselyn, Connor's big sister, volunteers her time with the organization as well. Mindy also works at CCRF as a community outreach coordinator, supporting cancer families and helping them share their stories.

#### JOANN SCHULTZ CARE PARTNERS

JoAnn has provided wonderful support for children and families since 2009 as a Care Partners volunteer at the University of Minnesota Masonic Children's Hospital. Over the years, her kindness has touched families through the many areas of support that Care Partners offers. She has served as a family volunteer, special events volunteer and Sibshops volunteer, and she helps get meals to families during monthly dinners at the hospital. JoAnn's warm presence and generous spirit represent the best of the Care Partners program as she helps to ease the burden for families who are confronted by profound challenges.

#### PUNCH NEAPOLITAN PIZZA CORPORATE PARTNER

Since 2009, Punch has been a proud supporter of childhood cancer research, contributing more than \$86,000 to CCRF. Each September, they honor Childhood Cancer Awareness Month by donating 10 percent of pizza sales and helping raise awareness for the cause with staff and customers at their nine restaurants. In addition, they've donated proceeds from store grand opening events and continue to provide prizes to help raise money at CCRF events.

#### THE LAURA LEAGUE COMMUNITY PARTNER

The Laura League has raised over \$58,000 for osteosarcoma research through their annual participation at Time to Fly and ongoing fundraising efforts. The team was formed in 2014 to honor Laura Goering's battle with bone cancer – and in that first year, they became the largest team ever at Time to Fly, with 240 participants! Known for her bubbly personality and sense of humor, Laura also served as CCRF ambassador at Macy's Glamorama in 2012. Her parents, John and Mary, and her brother, Alex, continue The Laura League in her memory after she passed away in September 2014.

#### LOGAN SPECTOR, PHD MEDICAL

Logan Spector, PhD joined the University of Minnesota in 2002 as a post-doctoral fellow in cancer epidemiology. He is now a professor and director of the division of epidemiology and clinical research and holds the Suzanne Holmes Hodder Chair in Pediatric Research. He also serves as a cochief medical advisor for CCRF. Dr. Spector has been the principal investigator of four grants from the National Institutes of Health totaling over \$10 million, and author of over 100 peer-reviewed papers examining the causes of childhood cancer. He also leads a grant program that has trained nearly two dozen PhD students and post-doctoral fellows who now conduct childhood cancer research around the nation. As his colleague, David Largaespada, PhD says, "Dr. Spector is a generous, thoughtful and creative researcher—a real joy to work with. He has a broad vision for helping sarcoma patients and their families and is relentlessly working to understand why kids get cancer - and what we can do about it."





### EDUCATION AND AWARENESS

Providing education and raising awareness about childhood cancer are key elements of Children's Cancer Research Fund's mission. Our goal is to share information that inspires advocacy, collaboration and, ultimately, cures for cancer. We are proud to support the following education and awareness initiatives that reach millions of people, including childhood cancer families, doctors, researchers and the general public.

- Research news, patient stories, volunteer opportunities and more are communicated via our website, blog, emails, social media activities, newsletter, mailings and events such as the KS95 for Kids® Radiothon and Great Cycle Challenge USA.
- Je Education and awareness, through pro-bono advertisements are made possible thanks to support from MNI Targeted Media and Media Services Advertising.
- The Cancer Survivorship Conference, an annual event that provides valuable information to cancer survivors and their caretakers.

- > The Mark E. Nesbit Lectureship in Pediatric Oncology and the Norma K.C. Ramsay, MD, Distinguished Visiting Professor Lectureship Series bring nationally and internationally recognized childhood cancer experts to the Twin Cities to speak on current clinical and research issues. The Nesbit Lectureship celebrated its 25th anniversary this year.
- On Facebook, our mission was shared with more than 62,146 fans this fiscal year. Each fan has an average of 156 friends, meaning our message could have reached a population larger than that of New York City.

We are grateful to have generous donors not only across the United States, but also around the world. Thank you for your commitment to our cause!



Donors

EVENTS

#### GREAT CYCLE CHALLENGE JUNE 2016

In June 2016, more than 26,000 people from across the country came together to fight childhood cancer. Participants rode 2.8 million miles and raised more than \$3 million for Children's Cancer Research Fund with the support of their families, friends and community.

Many riders chose to ride on behalf of or in memory of someone they know or lost, such as top fundraiser Arden Virnig, who totaled over 900 miles in memory of his daughter, Mary, who passed away from gangioneuroblastoma in 2010. During Great Cycle Challenge 2015, Arden pedaled on a tandem bike with one empty seat to symbolize his daughter's absence. This year, he carried the warrior stick that Mary held onto throughout her fight with cancer.

"I know these kids have put up a huge battle. I just hope we can somehow make that easier, better. There has to be a way," he said.

#### **Fun Facts:**

- Ver 58,858 donations were made to fight childhood cancer.
- > There were rides recorded in 29 countries!
- 251 kids took on the challenge to fight childhood cancer.
- 6,614 riders took part in the challenge in memory of a loved one affected by cancer.
- Cancer took rider Sabrina Reiswig's leg 28 years ago, but she logged an incredible 200 miles!
- Vour oldest rider was 80 years young, and she clocked an impressive 102 miles.
- Billy Gogesch rode an incredible 1,813 miles as part of a much larger challenge, riding from Nevada to Ohio to attend his high school reunion.

Visit GreatCycleChallenge.com to register for Great Cycle Challenge 2017.







#### 35TH ANNUAL DAWN OF A DREAM NOVEMBER 7, 2015

2015 marked the 35th Annual Dawn of a Dream. Guests gathered in the decorated halls of The Depot in Minneapolis to celebrate the rich history and the bright future of fighting childhood cancer. The strength of families, children and doctors who battle childhood cancer and genetic diseases together truly encapsulated the night's theme, "Stronger Together." During the evening's exciting festivities, Macy's was honored with our Dream Maker Award for its decades of support of Children's Cancer Research Fund. In 23 years, Macy's raised nearly \$5.5 million to defeat childhood cancer. This year's Dawn of a Dream also featured the highest bid ever for a liveauction item: a trip for four to William Randolph Hearst's private California estate, Wyntoon - a generous gift from Erin Hearst. In its 35th year, the gala raised nearly \$1.28 million. Guests celebrated the successful evening by dancing the night away to the music of The Power of 10. Thank you to all of our guests, sponsors, donors and volunteers for making it a night to remember!

#### EVENTS



#### 17TH ANNUAL KS95 FOR KID'S® RADIOTHON DECEMBER 11, 2015

Each year, children affected by cancer, traumatic injuries and disabilities inspire the hearts of thousands by sharing their stories on the radio. This one-day event raised over \$500,000 for Children's Cancer Research Fund and Gillette Children's Specialty Healthcare. The broadcast, held at Mall of America, also featured fun contests and live interviews. In addition, KS95 *Clouds* Choir for a Cause brought together approximately 5,500 people who filled the mall's rotunda to sing along with holiday songs and Zach Sobiech's *Clouds*, carrying on Zach's story of hope.





#### TIME TO FLY JUNE 25, 2016

More than 1,000 fundraisers joined volunteers, vendors, sponsors and spectators for Time to Fly 2016 at Phalen Park in St. Paul, Minnesota. Children and families walked, ran and celebrated during the sunny morning to support childhood cancer research, raising nearly \$200,000 to benefit childhood cancer research at the Masonic Cancer Center at the University of Minnesota.

Congratulations to the outstanding 2016 team and individual award recipients:

**Top Team Fundraisers:** Jack Attack (\$20,852) Joggers for Julian (\$17,255) The Laura League (\$9,370)

#### **Top Individual Fundraisers:**

John Golden (\$11,860) Marj Groseth (\$9,060) Rebecca Dahlquist (\$6,340)

Visit ChildrensCancer.org/TimetoFly to learn more about next year's event, and check back this spring to register.

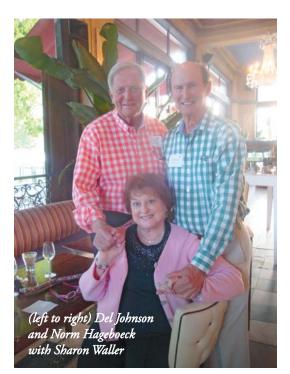


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### EVENTS



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Visit ChildrensCancer.org/TimetoFly to learn more about next year's event, and check back this spring to register.

#### 140 INVITATIONAL AUGUST 15, 2015

The 12th Annual 140 Invitational Golf tournament was held at Troy Burne Golf Club on Saturday, August 15, 2015 with a full deck of golfers and dinner guests. The event raised more than \$225,000! Thank you to presenting sponsor Lubrication Technologies, Inc. as well as platinum sponsors Ames Construction,



Harold Roitenberg, Soltex, Inc. and all our titanium, igniter, hole and table sponsors, as well as golfers, guests and the 140 Invitational committee members.

#### BENEFACTORS CIRCLE DINNER MAY 22, 2016

The Benefactors Circle members enjoyed a wonderful dinner hosted by founders Sharon and Joel Waller along with their son and daughter-in-law, Jon and Jill Halper, on May 22 at Café Lurcat in Minneapolis.

Starting with a small group of dedicated friends and family in honor of Sharon's daughter, Jo Beth, the Circle was born in the spring of 1991. Each year, members donate at least \$1,000 to the Benefactors Circle and receive an invitation to the annual dinner. Research funded by donations from the Benefactors Circle – more than \$3 million since 1991 – has gone on to support childhood cancer research. The money raised is earmarked for funding efforts to improve recovery and reduce infection risks for kids who have received a stem cell transplant.

Our Benefactors Circle members are the catalyst for a cure. They demonstrate what we can do if we stand together.

#### DATE FOR LIFE

In February 2016, ARIA was filled with electric energy as some of the Twin Cities' most eligible bachelors and bachelorettes gathered to be auctioned off in a live bidding format during the 8th annual Date for Life.

Jack Tomczak, from *Up and At 'Em* on News Talk AM 1130, and auctioneer Karen Sorbo introduced the bachelors and bachelorettes. It's Just Lunch, the premier matchmaking service for busy professionals, hosted this year's event.

Date for Life is held in memory of Katie Jurek, who passed away from osteosarcoma in 2007. Nearly \$70,000 was raised this year, with a record 600 people attending. Thank you to *Minnesota Monthly*, Media Bridge Advertising and Spark Starter for promoting the event.

#### COMMUNITY FUNDRAISERS

A special thanks to the organizers and participants of the following events that generously named Children's Cancer Research Fund as a beneficiary. The following list represents the collective effort of dedicated individuals who raised funds for childhood cancer research. We're grateful to have such wonderful partners in the fight against childhood cancer.

Angellfest

Brad Hank American Family Insurance Agency & Friends

Concert for the Cure, Chisholm, MN Emma's Hope Walk, Pepin, WI Friends of CCRF Golf Tournament John Goodman Dinner Event



## REMEMBERING NORMA ANGELL

Norma and her husband Charlie started a fundraiser called Angellfest in honor of their beautiful daughter Marissa, who passed away from brain cancer in 2009. They set a goal to raise \$100,000 in 10 years, but it took only four to reach it. With their strong commitment to raising awareness for childhood cancer, Norma and Charlie set a new goal of \$250,000. In 2014, she was the recipient of a Butterfly award for this amazing community fundraiser.

With great sadness, we share that Norma Angell, an influential fundraiser and friend of Children's Cancer Research Fund, passed away from complications of brain cancer last February. We are forever grateful for the incredible work she and her family have done for our organization.

## THANK YOU TO OUR PARTNERS

Thank you to our partners AmazonSmile, CRAVE, I See Me!, Macy's, Minnesota Twins, Punch Pizza, Valleyfair and Zen Box Izakaya, for their generous support of Children's Cancer Research Fund.

CCRF supporters could donate 0.5 percent of the price of their eligible purchases through AmazonSmile.

CCRF was a charity partner of the CRAVE CARES program, in conjunction with Round Up America, for the month of September.

I See Me! donated 10 percent of sales to CCRF during the month of September!

Macy's included Children's Cancer Research Fund in their Fashion Pass campaign, raising nearly \$400,000 to support children's cancer research.

Major League Baseball went gold for kids in September. During Childhood Cancer Awareness Month, the Minnesota Twins honored kids and families during their pre-game ceremony and also made matching gifts.

Each September, Punch Pizza donates 10 percent of pizza sales from all Twin Cities metro area locations to honor Childhood Cancer Awareness Month. Since 2009, Punch has contributed over \$86,000.

The Valleyfair Cares program raised over \$45,000 for Children's Cancer Research Fund in 2015 through the sales of specially priced admission and raffle tickets. Thank you to Hubbard Broadcasting for the promotional support they provided for this event and to Park Chrysler Jeep for donating a 2015 Jeep Renegade to serve as the raffle prize.

During Childhood Cancer Awareness Month, Mill City Zen Box Izakaya featured delicious bowls of ramen and ramen burgers from celebrated chefs around the country. The proceeds benefited CCRF.

#### 2016 MISSION PARTNER

Thank you to Lubrication Technologies, Inc. for their continued generous support as a Mission Partner, the highest designation given to corporate partners. In addition to committing significant financial resources to childhood cancer research funding and in-kind services, they have generously contributed through the organization of events, like the annual 140 Invitational Golf tournament, and by volunteering their time at the monthly Care Partner's Dinner Program.



#### COMMUNITY HEALTH CHARITIES

The mission of Community Health Charities (CHC) is to unite caring donors in the workplace with our nation's most trusted health charities. Our alliance with Community Health Charities helps individuals give, help and connect with their most important health causes. By providing resources to medical research, CHC is able to directly impact and improve the lives of those affected by chronic illness.



FINANCIALS

#### FINANCIAL INFORMATION

July 1, 2015 through June 30, 2016

We're committed to sharing transparent and complete financial information with our donors and the community. Included in this report is a snapshot of our performance during the 2016 fiscal year. To see more details and audited financial documents, visit ChildrensCancer.org/Financials

#### STATEMENT OF ACTIVITIES

Year ended June 30, 2016

#### SUPPORT AND REVENUE

General Contributions	\$5,246,886
Events	5,230,231
Direct Expenses	(312,059)
Donated Goods and Services	2,750,467
Cause Marketing	470,779
Investment Income	109,228
Other	78,250
Total revenues and gains	13,573,782

#### EXPENSE

Program Services	
Research	\$4,428,805
Education & Awareness	5,463,126
Patient & Family Services	408,967
Supporting Services	
Fundraising	2,477,595
Management & General	492,422
Total Expenses	13,270,915
Change in net assets	\$302,867
Net assets, beginning of year	\$3,887,395
Net assets, end of year	\$4,190,262

Research \$4,428,805

Patient and family services \$408,967

> Education and awareness, including research fellowships \$5,463,126

(Includes \$2,750,467 of donated goods and services)



77% PROGRAM SUPPORT

19% FUNDRAISING

4% MANAGEMENT

# \$13.5 million

Total amount raised in fiscal year 2016

## STATEMENT OF FINANCIAL POSITION

### Year ended June 30, 2016

ASSETS	FY 2016	FY 2015
Cash & Cash Equivalents	\$3,602,218	\$3,721,042
Investments	2,145,071	1,962,800
Pledge Receivables, Net	985,653	886,297
Property & Equipment, Net	206,224	56,585
Other Assets	250,874	277,642
Total Assets	7,190,040	6,904,366

#### LIABILITIES

Accounts Payable	\$603,488	\$419,875
Accrued Payroll & Related	268,860	247,139
Other Liabilities	180,510	149,994
Grants Payable, Net	1,946,920	2,199,963
Total Liabilities	2,999,778	3,016,971

#### NET ASSETS

Unrestricted Operating	\$1,351,304	\$1,091,935
Board Designated	2,577,671	2,572,915
Temporarily Restricted	61,287	222,545
Permanently Restricted	200,000	-
Total Net Assets	4,190,262	3,887,395
Total Liabilities & Net Assets	\$7,190,040	\$6,904,366

DONORS

\_\_\_\_\_

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Lifetime Pacesetters have reached a cumulative lifetime giving total of \$100,000, with founding members achieving that distinction as of December 31, 2006.

Angie and Ted Erickson

Italic: Founding Lifetime Pacesetters \* Deceased <sup>B</sup> 2016 Benefactors Circle Member

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