

Children's Cancer Research Fund®

Butterfly®

WINTER 2016 | VOL. 37 | NO. 1



conquering fear

NEW SARCOMA
BREAKTHROUGHS

THE IMPACT OF
YOUR DOLLAR

GREAT CYCLE
CHALLENGE

DAWN OF
A DREAM

CONQUERING FEAR

Every time Jill arrived at the hospital for her 8-year-old son Griffin's chemotherapy treatment, she posted signs and drawings on the blank hospital room walls. One sign in particular hung above Griffin's bed and his IV pole: "Griffin Strong," it said, with the scribbled signatures of his second-grade classmates. Another, posted across the room, roared "No Fear" above the hospital sink. These are the mottos that Griffin and his family have carried with them since the beginning of Griffin's journey with Ewing sarcoma.

And this winter, Griffin, his four siblings, Dallas (20), Hailey (17), Grace (11), and Reese (6), and his parents packed up his posters for what will hopefully be the last time. After over a year of chemotherapy treatments, surgery on his pelvis, high fevers, infections and a myriad of other ups and downs, Griffin wrapped up his final chemotherapy this winter.



Jill describes Griffin as "all boy"—from baseball to golf, he loves sports and running around. So when Griffin started complaining of leg pain, began limping and grabbed at his thigh constantly, she and Kurt, Griffin's father, knew something was wrong with their energetic child. Then, one night last February, Kurt says Griffin just lost it. The pain was too agonizing.

After seven hours of countless scans and X-rays at the doctor's office, Kurt received a devastating phone call: A baseball-sized tumor was embedded in Griffin's pelvis. Jill remembers Kurt pointing at Griffin and shaking his head as he was on the phone with the doctor.

"He didn't even need to say anything," says Jill. "I just knew. Nothing [was] going to be the same now."

A CT scan and a biopsy confirmed that the mass was Ewing sarcoma, a type of bone cancer that occurs most often in and around the bones and typically affects children and young adults. Griffin immediately began treatment at the University of Minnesota Masonic Children's Hospital.

Griffin says that when he found out he had cancer, all he knew was that he had to take medicine and that he did not like medicine. "It was also scary because I didn't know I had to get needles in my port."

Part of Griffin's treatment protocol involved chemotherapy infusions of six types of drugs, one being a trial treatment. Each treatment session for Griffin started with a terrifying needle insertion in his chest to access his port. The first time that the nurses accessed his port, it took nearly an hour because he was so afraid of the needles.

Kurt says he could not watch his son go through it. "At first, we really sold it to Griffin like it was a good thing because he wouldn't have to take medicine," he says. "He can't stand taking anything orally."

He and Jill both remember how little they knew about cancer before they went through Griffin's treatment. "People just gloss it over," says Jill. "The port access sounded like no big deal."

Then, during the first twelve weeks of chemotherapy treatments, Griffin started to see his hair on his pillow. "He loved his hair," says Jill. "He used to rock a side sweep, and there were times when he was maybe going to miss the bus because he was doing it. I had to talk him into shaving his head."

Along with a shaved head, Griffin had a scar across his side from the surgery to remove the tumor after the chemotherapy had shrunk it to about the size of a stick of gum. This was hopeful news for Griffin's family, as doctors initially thought Griffin would need an amputation to fully remove the tumor.

“Childhood cancer works overtime to destroy families. It does to children what even strong adults crumble beneath,” says Jill.

After the surgery, Jill heard the pitter-patter of footsteps across the upstairs. “Griffin yelled, ‘Hey! I’m walking! I’m walking normal!’” says Jill. She and Kurt ran upstairs to see that their son was finally able to walk normally again.

Then, in September 2015, the family received news that the tumor site was clean.

Griffin completed twenty-six weeks of post-surgery chemotherapy this winter in the hope that it will keep the cancer from recurring. But this process was not without its challenges. Right before Christmas and before Griffin’s last scheduled session of chemotherapy, for example, he was stricken with a high fever and mucositis, a condition that leaves painful sores and inflammation along the digestive tract. During one of his days in the hospital, as Griffin lay in the hospital bed, he asked his dad through tears why this was happening to him.

Despite the ups and downs, Griffin says God, his mom and his dad help him to be brave, along with his nurses, who have helped him master his port accesses. And as Griffin exits treatment, he has some advice for other kids going through sickness just like him. True to the motto he has kept with him through it all, he says, “Stay strong. You can do it.”

Connect with us on Facebook and learn more about Griffin’s journey at [Facebook.com/ChildrensCancerResearchFund](https://www.facebook.com/ChildrensCancerResearchFund)

What is a port access?

An IV access port is a device used to give treatments and take blood. The port is a small container that is placed under the child’s skin, usually in his or her upper chest. To access a port, doctors and nurses stick a needle into the child’s chest, like pushing a tack into a bulletin board. Read more about how Griffin overcame his fear of ports on page 4.



OVERCOMING THE PORT ACCESS



Written by Jill Dahmen

Access. When I used to hear that word, I would think of a secret little route to get onto the highway quicker.

Access. It's like a special privilege, right? When a doctor gives me their cell phone number and tells me that I have access to them 24/7, I feel pretty privileged. We all want access.

When cancer struck our family and chose our then 7-year-old son, Griffin, as its victim, my husband and I quickly realized that we were not in control of anything any longer. The extreme assault of tests, scans and needles that came at Griffin caught us all off guard, specifically the IV. When we heard the words from Griffin's oncologist that they were "going to place a port" — hit pause for a moment please, that verbiage right there is deceiving — it sounded so gentle and unassuming.

They were going to "place a port access in his chest so that they wouldn't need to use an IV going forward," and we thought this was going to be a good thing. We told Griffin how great this port was. We told him how there would be no more needle sticks in his arm for an IV. We sold him on this port big time!

The problem was that neither Kurt nor I knew a darn thing about cancer or accessing ports. No, there would be no more needle sticks in the arm. Those were now replaced with needle sticks in Griff's chest. The sheer terror that would come over this child when he saw those needles that

needed to go into his chest was like nothing I have ever seen before. It would take us hours to get him "accessed."

He would scream in fear. He would beg us, through tears, to give him more time. His body would literally come off of the table with superhuman strength. We, as his parents, felt heartbroken, defeated, angry, helpless... exhausted.

Griffin wouldn't succumb either. No length of time would allow for his mind to accept those needles going into his chest. We literally had to pin him down. Myself on one side, Kurt on the other and my dad on Griff's feet with tears streaming down each of our faces. We felt like monsters, torturing our son.

Griffin would continue to cry after the access, but his tears were full of sadness—not anger, not fear, but sadness. He would tell us that he was sorry and ask forgiveness for his behavior. This happened weekly for months. Then one day, Griffin needed to be de-accessed. I was exhausted simply anticipating the event. Griffin's nurse that day was Andrew. Andrew invested time in our son. He built a relationship with Griffin that involved a foundation of trust. It didn't happen immediately. It took many months in fact, but it happened. That particular afternoon, Griffin would lie in his hospital bed and find courage deep from within.

Courage, not to be confused with "not being afraid," but rather, being afraid and facing that fear head on. Griffin dug his chin down into his neck so that he could stare down those stinkin' needles that had such a grip on him. He would then say to Andrew with a slow, calm conviction in his voice, "Tell me when YOU'RE ready, and then I'll count to three." This time was different. There were no tears. There was a confidence in his tone. He viewed his nurse as his teammate—together, they were going to do this.

As I watched this unfold I found myself holding back tears. Somehow I thought that if I didn't draw attention to Andrew accessing Griffin's port and the fact that he wasn't crying, fighting or screaming, we could pull a fast one and get it over with before Griffin realized that he was being accessed. Quickly, something became clear to me. Griffin knew exactly what was happening! Griffin and Andrew were speaking unspoken words to each other. It was like they were dancing together. Each move was in response to the other person's move.

Andrew brought a calm peace into that situation that we hadn't previously experienced. He did for Griffin what Kurt and I had been unable to do countless times before. I knew my job was to hold Griffin's hand, be quiet and marvel both at Andrew's care and Griffin's courage. That day, I learned that my job as a mother doesn't require me to have all the answers.

YOUR DONATIONS WILL HELP KIDS LIKE GRIFFIN

Predicting Ewing Sarcoma

Children's Cancer Research Fund supports Logan Spector, PhD, who is currently a co-investigator on an National Institutes of Health grant called *Genetic Risk Factors for Ewing Sarcoma*. The research he's doing could help doctors detect Ewing sarcoma early on, increasing patients' chances of survival or prevent it entirely. In collaboration with the University of Utah, the investigators are collecting DNA from Ewing sarcoma patients worldwide through the Children's Oncology Group to find genetic markers for the disease. The information they have acquired so far is immense, but thanks to a new supplement from Gabriella Miller Kids First Pediatric Program, the amount of data is about to get far larger.

Instead of one million genetic variants across the genome, which they initially anticipated gathering, they will have three billion base pairs (i.e., a DNA "letter"). Each genome is about 100 gigabytes of data, meaning that the entire dataset would fill about 1,600 iPhones. As soon as the data is ready in the spring, they will begin the massive effort of combing through nearly one thousand whole genomes to identify the specific variants that cause Ewing sarcoma.

Research into Sarcomas Gets Help from Man's Best Friend

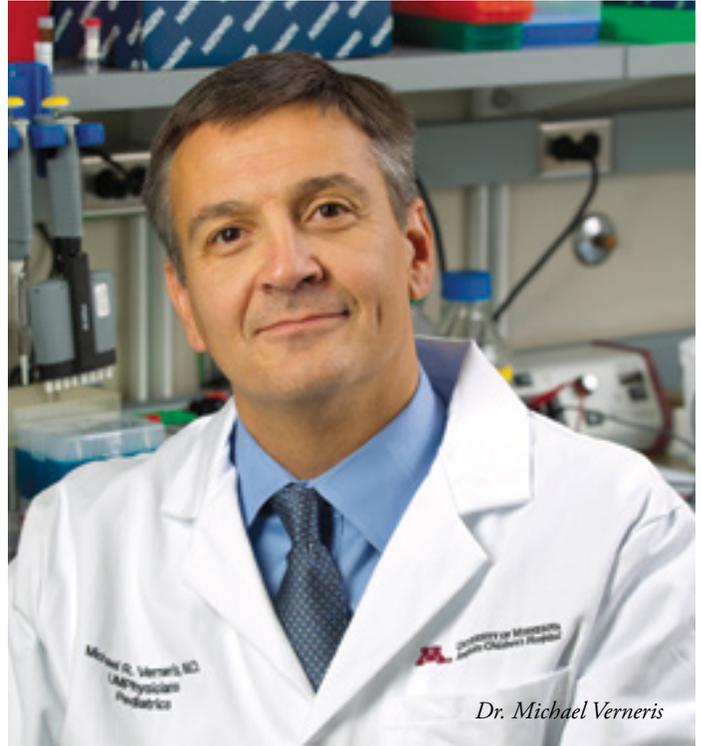
"Sarcoma is a tragic disease," says Michael Verneris, MD, professor, Pediatric Blood and Marrow Transplantation, University of Minnesota. "It is heart-wrenching to explain to a patient or family that the cancer has recurred."

A cure does not yet exist for relapsed sarcomas in children, yet Dr. Verneris is energized by the results that he and his colleagues are seeing in the laboratory and in studies involving pet dogs with hemangiosarcoma. Like Ewing sarcoma, osteosarcoma and rhabdomyosarcoma in children, hemangiosarcoma in dogs is difficult to treat because it is aggressive and progresses rapidly.

"Our interest was piqued when Dan Vallera, a professor in the Department of Therapeutic Radiology, told me about a compound he made to test in adult cancers," says Dr. Verneris. Vallera specializes in the design and development of new anti-cancer drugs. "I asked him to try some in pediatric sarcoma cell lines, and it was highly effective. It was a very early 'aha' moment for us, and I realized we had something here."

Researchers recently tested this compound in dogs, resulting in significant improvement in the expected survival of dogs with hemangiosarcoma. "We are really excited about it and are charging ahead with additional studies in mice, comparing two different compounds," Dr. Verneris adds.

The compounds are targeted immune toxins that recognize cancer cells to destroy them. These drugs are made up of a growth factor—a substance



Dr. Michael Verneris

"We hope the results of these studies will help us soon bring these therapies to children with sarcoma," Dr. Verneris says.

that stimulates the growth of cells and tumors needed to survive—along with a toxin or a poison. As the growth factor binds to the cancer cell, it takes the toxin along with it, selectively killing the cancer.

In the lab, Kristy Pilbeam, MD, a University of Minnesota fellow funded by Children's Cancer Research Fund, is working on this project. She is determining how these compounds develop and is testing new drugs. Additionally, she is engineering tumor cells so that researchers can follow the response of the tumors in the treatment in living animals.

"Once we establish effective targeted tumor reduction in the lab, our goal is to move this therapy into a clinical trial," says Dr. Pilbeam. "Even more exciting is the potential this project has for further development. If successful, these targeted therapies could be used as a potential first-line treatment along with traditional chemotherapy to improve cure rates for pediatric sarcoma and other cancers."

"It's a super exciting time," Dr. Verneris added. "The landscape for sarcomas is changing. I hope our research will help children and adults with no other options."

DEFEATING “THIS BEAST”



At midnight on the second anniversary of Jennie Nichols’ osteosarcoma diagnosis, her mother, Kelly, sat at the computer and hit the Zach Sobiech Osteosarcoma Fund donate button as her eyes filled with tears.

Jennie’s osteosarcoma journey began in 2013 when she was just 12 years old. Strong-willed, she was involved in all of the decisions regarding her treatment from day one until she passed away on June 20, 2015.

“Jennie got an iPad for Christmas, and we were in the hospital. The doctors were throwing out treatment options, and she was on her iPad researching everything,” says Kelly. “She wasn’t playing Angry Birds. She was learning about her options.”

Having gone through eight chemotherapy treatments, surgeries and immunotherapy by Jennie’s side, Kelly, her husband Michael and their son Graham, know all too well that osteosarcoma is “a beast.” After enduring all these treatments and therapies, Jennie was out of options.

“I told her we weren’t going to stop looking for options, and Jennie didn’t want to give up either,” says Kelly. Jennie was willing to have her pelvis removed in order to live. “She said, ‘I can do that. I can take the pain,’” Kelly recalls.

In total, Jennie attended five days of seventh grade because she was constantly in treatment. “She didn’t even get to take a basic biology class,”

says Kelly. Instead, she was learning about the complicated medical terms and procedures that her life depended on.

Before her daughter passed away, Kelly promised Jennie she would not just raise awareness about osteosarcoma, she was going to work tirelessly to change how osteosarcoma is treated and find a cure. As part of that promise, she made a donation that brought the Zach Sobiech Osteosarcoma Fund to exactly \$1 million, a milestone that is already changing osteosarcoma research.

“I wanted this donation to be a big moment,”
Kelly explains. “I wanted resurgence in
osteosarcoma research.”

That donation is not all Kelly is doing to create change for her daughter. This spring, she plans to start a Great Cycle Challenge team in her hometown in Kansas to continue her mission of beating osteosarcoma once and for all by raising more money for continued research.

The multidisciplinary approach to defeat osteosarcoma at the University of Minnesota drew Kelly to the Zach Sobiech Osteosarcoma Fund. Currently, four research projects are underway, bringing together a diverse team across many areas of science, including epidemiology, genomics, molecular biology and veterinary medicine.

“I never felt like we gave up on Jennie. I feel like science gave up on Jennie. The University of Minnesota research team gave me a shot of hope that there are people behind this who really, really care, not just about the research, but about those who are affected by this beast,” she says.

Researchers are using a collaborative, comparative oncology approach to help advance the study of osteosarcoma, and preliminary results highlight the power of this approach. You can read more about their progress at ChildrensCancer.org.

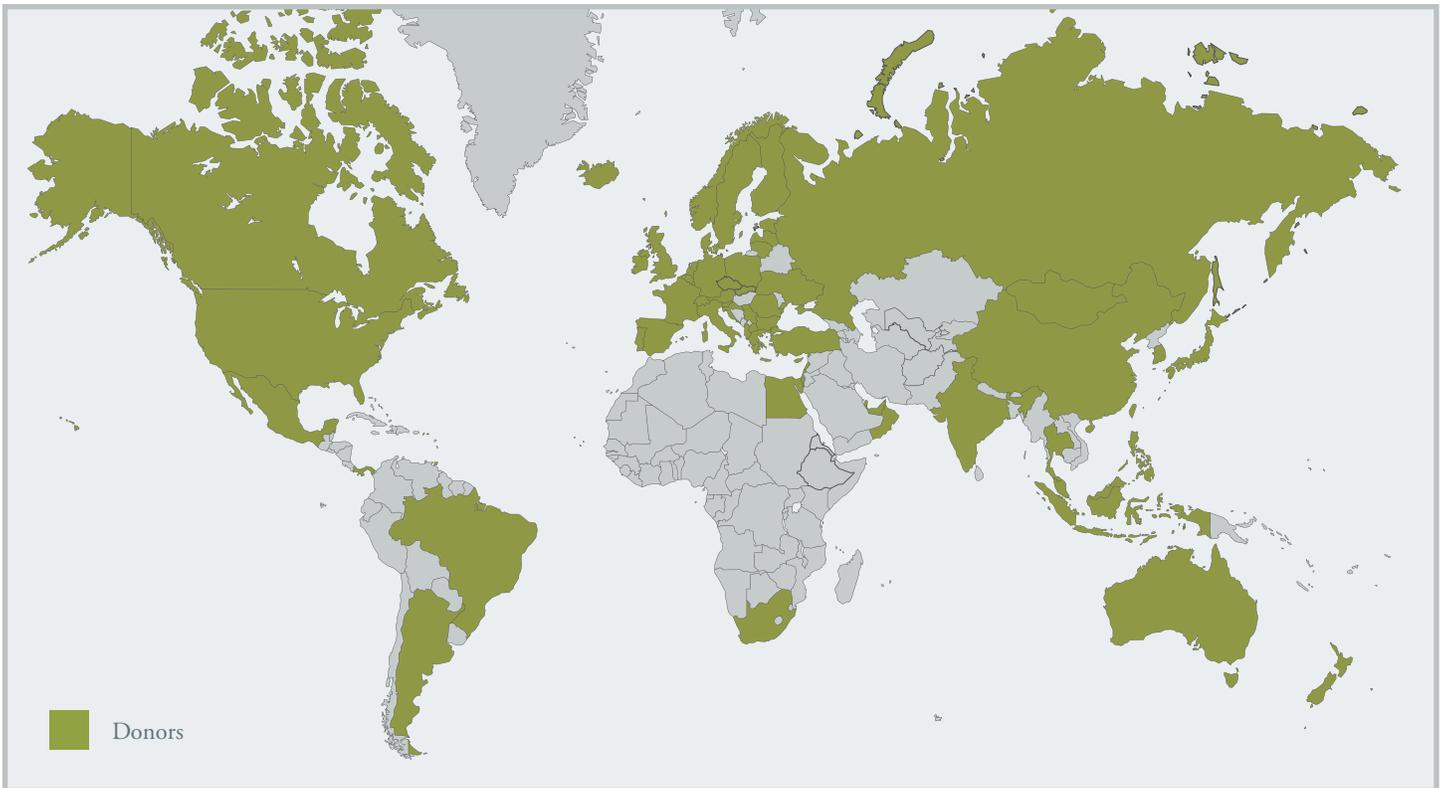
With the additional funding provided by the Nichols family and many other donors, researchers can keep the momentum going, building on their initial findings and moving into pre-clinical studies, which may lead to new drugs and other therapies.

Join the Nichols family this June to kick cancer’s butt through Great Cycle Challenge. Learn more about how you can be the catalyst for a cure on page 8.



ZACH SOBIECH
OSTEOSARCOMA FUND
REACHES \$1,000,000

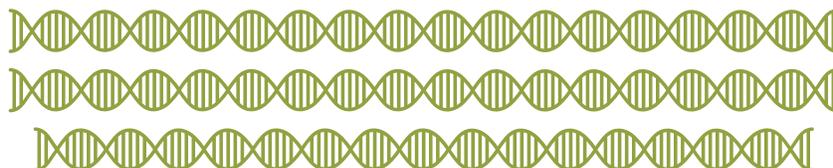
The fund's donors are from all over the world.



Four osteosarcoma research projects have already been funded.



200 osteosarcoma genes have been discovered.



These discoveries and more have been shared with researchers all around the world.
Thank you for your support.



Ride to Fight Kids' Cancer! Join Great Cycle Challenge

It may still be cold out, but it is never too early to start thinking about registering for Great Cycle Challenge! Whether you are a cycle enthusiast or recreational biker, join us in June to fight kids' cancer! Your participation supports important research that results in better therapies and treatments aimed at discovering a cure for childhood cancer.

Nearly four out of five children who are diagnosed with cancer can be successfully treated today because of past research, but cancer is still the leading cause of death by disease among children. Let's change that.

Get involved by visiting GreatCycleChallenge.com where you can register and set your personal challenge. It is a fun and easy virtual event. You can participate in it from anywhere in the USA. A toolkit full of resources will help you share your challenge with friends and family. Ask them to support your challenge by pledging dollars to help fight childhood cancer. Ride solo or in a team outdoors, at the gym or on a stationary bike—it all works.

You can download the free app to your iPhone or Android to track your miles the whole month of June. Feel good about reaching those fitness goals while also benefitting childhood cancer research.

Last year, 12,588 participants pedaled 1,046,286 miles, raising \$1,668,748! Whether you have a personal connection to childhood cancer or are just committed to your health and well-being, we would love to have you join this event. Let's all come together to kick cancer's butt!

Thanks to the generosity of Great Cycle Challenge participants, teams and supporters, funds raised during the event will help researchers find better treatments and a cure for childhood cancers.



BUTTERFLY AWARDS



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

(from left to right)

Juanita: Volunteer

Juanita has been a dedicated office volunteer for five years, working at Children's Cancer Research Fund each Thursday morning to help with mailings, assemble butterfly pin cards and complete additional tasks as needed. Her expert assistance is appreciated by everyone on the staff. Juanita is a delight to have in the office. She always greets each staff member with a friendly "hello" and updates on her job at Walgreens, her family and her cherished pets. In addition to Children's Cancer Research Fund, Juanita also volunteers for several other local nonprofits.

Marcia Niedorf: Care Partners

A Care Partners volunteer since 2010, Marcia has made a tremendous difference in the lives of her assigned families with her steadfast care and attention to their needs. As a family volunteer, Marcia provides everyday support to families whose children are being treated for cancer or are undergoing a blood or marrow transplant at the University of Minnesota Masonic Children's Hospital. Because many of these families are far from home or have other children, Marcia's help—from doing laundry to grocery shopping to spending time with the kids and their parents—is invaluable. Marcia was first introduced to the program by Debbie Dworsky, former board chair of Children's Cancer Research Fund.

Joggers for Julian: Community

John Golden and Emily Eaton lost their three-year-old son, Julian, to acute lymphoblastic leukemia just two weeks after he was diagnosed and his treatment began. To honor Julian and to support research that would

spare parents and children from the same devastating experience, they started a Time to Fly team called Joggers for Julian. Since 2011, the team has raised \$70,000 for childhood cancer research, and they represent one of the largest teams at each year's run/walk event. John also serves on Children's Cancer Research Fund's Board of Directors.

Mark Osborn, PhD: Medical

Dr. Osborn, assistant professor in the Department of Pediatrics, Division of Blood and Marrow Transplantation, at the University of Minnesota, is focused on developing gene and cellular therapies that will increase the efficacy of transplants and decrease the harmful side effects. His cutting-edge research on gene editing, precisely targeting the cancer-causing gene mutation and replacing it with a corrected functional copy, holds tremendous potential for changing the practice of medicine. In addition, Dr. Osborn is an active member of the American and European Societies for Gene and Cellular Therapy.

Kaskaid Hospitality (CRAVE Restaurants): Corporate

Accepted by Zach Sussman

For five years, Kaskaid Hospitality has provided valuable support and awareness opportunities. CRAVE Restaurants cater the monthly Care Partners Dinner Program at the University of Minnesota Masonic Children's Hospital, giving patients and families a break from their routines and access to free meals. In addition, with the CRAVE Cares program, the organization has donated a portion of its restaurant sales during the month of September, which is Childhood Cancer Awareness Month. New this year, CRAVE guests can round up their purchases on their credit card receipts after dining. Patrons simply round up the check to the nearest dollar and the funding supports Children's Cancer Research Fund. Thanks to Kaskaid's committed partnership, more than 9,000 meals have been served, and nearly \$16,000 has been raised for childhood cancer research.



IRA Rollover for 2015 and Beyond

At the end of December, Congress extended the IRA Charitable Rollover and permanently put it in place for donors.

How It Works

If you are 70½ or older, you can give up to \$100,000 directly from your IRA to charities, such as Children's Cancer Research Fund.

The transfer generates neither taxable income nor a tax deduction, so you still benefit even if you do not itemize your tax deductions.

If you have not taken your required minimum distribution for the year, your IRA Charitable Rollover gift can satisfy all or part of that requirement.

The transfer may be made in addition to any other charitable giving you have planned.

If you have already made a qualifying gift in 2015, contact your financial advisor to make sure your gift is properly reported on your 2015 income tax return. If you are interested in this unique opportunity to help create a world without childhood cancer or if you have any questions, please contact Amy Polski Larson at 952-224-8486.

What is an IRA, and how can you use it to support childhood cancer research?

IRA stands for Individual Retirement Account. It is essentially a savings account with tax breaks, making it an ideal way to put away cash for your retirement. Under the current law, those who are 70½ or older can take money from their IRA and make a donation to Children's Cancer Research Fund.



35TH ANNUAL
**STRONGER
TOGETHER**

DAWN OF A DREAM

This year marked the 35th Annual Dawn of a Dream! Guests gathered in the decorated halls of the Historic 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." Because of our incredible donors, Dawn of a Dream raised nearly \$1.28 million, allowing researchers at the University of Minnesota to continue making life-changing discoveries in the pursuit of better treatments and cures.

Thank you to co-chairs Helenbeth Reynolds and Marci Weiner and their committee for putting together a great event. The evening began with a dinner and silent auction, including such exclusive items as a Dove Mountain golf experience in Arizona, a stay at a private condominium in Maui and a private wine tasting and dinner for eight at the home of David Hardten, MD, and his wife, Christine.

Throughout the program, researchers, donors, patients and their families shared what "Stronger Together" means to them. Children's Cancer Research Fund's chief medical adviser, Dr. John Wagner, said, "Too many stories do not have happy endings. So our job is not done. We need your help to do what others often say is impossible. We've done it before, so we'll do it again." Jearlyn Steele, the program emcee, shared the story of a leukemia survivor named Caiah. With her beautiful rendition of Rachel Platten's *Fight Song*, Caiah, along with Jearlyn and The Remnant gospel choir, brought the tearful audience to its feet. Equally moving was Isaac's story. Isaac is a 12-year-old battling Ewing sarcoma, and his story made an impact on many researchers, like Dr. Michael Verneris, who shared his new research on sarcomas.

Macy's was honored with the Dream Maker Award for its decades of support to Children's Cancer Research Fund. In twenty-three years, Macy's raised nearly \$5.5 million to defeat childhood cancer. Macy's continues its nationwide support for Children's Cancer Research Fund with the Fashion Pass campaign, which raised \$400,000 in 2015.

This year's Dawn of a Dream also featured the highest bid ever for a live auction item: a trip for four to William Randolph Hearst's private estate, Wynton, a generous gift from Erin Hearst.

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!



Past Dawn of a Dream Chairs



Bill Marzolf



Caiah and Jearlyn performing Fight Song

Ryan, Shannon & Fish's KS95^{94.5} For Kids Radiothon

Ryan, Shannon & Fish's KS95 for Kids Radiothon is an annual on-air fundraiser that benefits two local charities, Gillette Children's Specialty Healthcare and Children's Cancer Research Fund. This year, over \$500,000 was raised!

Meet some of the kids who were a part of this year's KS95 for Kids Radiothon!



(shown left to right, top to bottom)

Ben, age 14, anaplastic large cell lymphoma. Ben is a Boy Scout and has collected many badges.

Casey, age 16, osteosarcoma. Casey is a big sports fan and continues to be involved with his football team.

Dexter, age 8, neuroblastoma. Dexter loves Star Wars and Marvel.

Griffin, age 8, Ewing sarcoma. Griffin is a huge football fan and loves the Minnesota Gophers.

Isaac, age 11, Ewing sarcoma. Isaac loves the show Criminal Minds and wants to be a forensic anthropologist when he grows up.

Karee Jo, age 10, pleuropulmonary blastoma. Karee Jo loves to shadow at her local veterinary clinic.

Sydney, age 13, Burkitt's lymphoma. Sydney loves cheerleading and is known among her family and friends as "Sydney the Cancer Slayer"!

To hear their stories, visit KS95forKids.com.

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Third Annual Largest Clouds Choir for a Cause

Approximately 5,500 people, including school choirs, families and groups gathered to sing along to holiday songs and Zach Sobiech's *Clouds*, carrying on Zach's story of hope.

Beloved Nurse Coordinator Retires After Thirty-Three Years

“The best thing that I ever did was to apply to work on the Bone Marrow Transplantation Unit,” says Pat Fidler, a University of Minnesota pediatric Bone Marrow Transplant nurse coordinator, as she reflects on her a thirty-three-year career span as a nurse with this program. She retired on New Year’s Eve in 2015.

As the outpatient nurse coordinator, Pat helped patients and families transition from their local hospital or clinic to the Masonic Children’s Hospital and prepared them for the bone marrow transplant process and recovery. She continued as a team member for their follow-up post-transplant.

Many bone marrow candidates she worked with were affected by childhood cancer. Pat’s job was to make sure that they were informed, and she assisted with their care throughout their transplant journey. As a contact person who worked with Children’s Cancer Research Fund researchers Drs. Verneris, MacMillan and Wagner, she enjoyed her work. Pat first started her career in 1968 on the ninth floor of St. Mary’s Hospital, which is now the Journey Clinic, Center for Children with Cancer and Blood Disorders. She did not start out in pediatric care right away. Back then, she worked on the adult Med-Surg floor. After listening to early transplant doctors speak in 1982, she decided that she wanted to work with bone marrow transplant patients, so she took a nursing job at University of Minnesota.

“I arrived on BMT twelve years after the first transplants and learned a lot,” she says. “I learned from the physicians who were at the forefront of transplants. It was tremendous.”



Since then, Pat has experienced how things have changed due to progress in research and changes in treatments and therapies. When she first started in transplants, people stayed in hospitals for sixty to eighty days. Now, many of them are out of the hospital in half that time.

As she thinks about her past patients, Pat recounts her favorite parts of the job. “I loved sending them home and seeing them to the front door of their house. I loved hearing what makes them happy to be home again, how things were going and that they were achieving more and more normalcy during the first year after transplant.”



Picnic of Hope

On a crisp autumn day, C.C. Bear gathered with families to celebrate the twentieth annual Picnic of Hope. This event, sponsored by our Care Partners program, is an annual gathering that invites volunteers, doctors, cancer survivors, patients and family members to come together. Hosted at Highland Park this year, the kids enjoyed fun activities, including dancing with C.C. Bear, balancing-board activities and playground fun. As always, the Children’s Cancer Research Fund mascot was a crowd favorite as he joined everyone in games and dancing. Smiles truly were the common denominator on the beautiful fall day.





From left: Norm and Diana Hageboeck, and Betsy and Ellie Schill

COMMUNITY HIGHLIGHTS

Diana Hageboeck honored with Katharine Phelps Lifetime Achievement Award

This past November, Diana Hageboeck, co-founder of Children's Cancer Research Fund, was the 2015 recipient of the Junior League of Minneapolis's Katharine Phelps Lifetime Achievement Award. Celebrating her outstanding leadership throughout her lifetime, the award recognized how Diana has used her talents and resources to advocate for families facing the devastating disease of childhood cancer. Diana is known in the community as a catalyst for funding groundbreaking research. Congratulations, Diana!

Team Kendal Kidz Concert

This annual concert raised more than \$25,000 for ongoing research. The event is held in memory of Kendal, who lost her fight to acute myelogenous leukemia. Team Kendal Kidz is dedicated to giving kids with cancer smiles for today and hope for tomorrow. Thank you, Team Kendal, for your ongoing efforts and endless support.

Angellfest

With a record turnout of attendees, this year's sixth annual Angellfest fundraiser raised more than \$18,000. This fundraiser for the Marissa Angell Brain Tumor Fund was held in memory of Marissa Angell. Thank you, Charlie and Norma, for your efforts in putting this event together in honor of Marissa!

Swing Fore! Hope Golf Tournament

Over one-hundred golfers gathered for the second annual Swing Fore! Hope Golf Tournament, sponsored by Soltex, Lubrication Technologies and the Bame Foundation. Together, they raised \$36,500. Thank you Swing Fore! Hope golfers!

Meg's Christmas Party

After Meg graduated from college, she and her friends gathered each holiday season to celebrate and exchange gifts. Ten years ago, she decided to change the focus of her New York City holiday party by asking guests to make a gift to charity. For the last seven years, Meg, her family and her friends have raised over \$31,000 for Children's Cancer Research Fund. Thank you!

Special thank you to these amazing community fundraisers:

- Birmingham Seaholm Volleyball Team
- Brad Hank American Family Insurance Agency and Friends
- Edina HS Senior Women's Car Wash
- Emma's Hope Walk
- KnockOut 5K
- Linda's Photography Lambs & Bunnies
- Miss Daisy Memorial Benefit
- Mounds View HS "Mustang Managers"
- Nicholas Cisewski Memorial Golf Tournament
- Rachel's 5K
- Taylor and Hudson County Market

Check out ChildrensCancer.org to get more details about our community fundraisers.



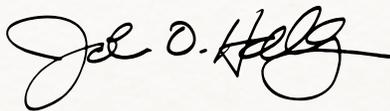
Swing Fore! Hope

IN THIS ISSUE

This past fall, I spoke at a gathering of Children's Cancer Research Fund supporters about the legacy that they had created. In preparing my comments, I looked up the origins of the word "legacy." The word goes back to the fourteenth century and means "a body of persons sent on a mission."

I cannot think of a better way to describe what you will read about in this issue than that—a body of persons sent on a mission. From the clinicians and researchers who are looking for new ways to improve the cure rates in sarcoma to 8-year-old Griffin, who overcame his fear of treatment, to the Nichols family, who found a meaningful way to honor their daughter, and, finally, to our founder Diana Hageboeck, whose lasting legacy was recognized through the Katharine Phelps Lifetime Achievement Award—they are all persons sent on a mission. Together, a world without childhood cancer is possible. Through our unwavering determination and commitment to groundbreaking research, we will find a cure.

Thank you for being a part of this legacy.



John Hallberg, CEO

thank you to
our mission partner:



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about us

Children's Cancer Research Fund is a national organization dedicated to eradicating childhood cancer by funding pioneering efforts in the prevention, diagnosis, treatment and cure of childhood cancers at the University of Minnesota, a leader in pediatric cancer research and other diseases. Many discoveries funded by Children's Cancer Research Fund have revolutionized the way childhood cancer is treated worldwide. We also provide education and support quality-of-life programs for patients and families.

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raise. walk. cure.

Phalen Park, St. Paul, MN | June 25, 2016

Fundraise for Children's Cancer Research Fund! Join our 10K run & 5K run, 5K walk and kids' 1K fun run! Early bird registration is open until March 1. Walkers sign up for FREE during early bird registration. Raise funds on a team or as an individual. Can't make it to the run? Try the new virtual participation option! Visit us at ChildrensCancer.org/TimeToFly for event info and registration.

Thank you to our presenting sponsor:

