



Children's Cancer Research Fund®

# Butterfly®

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tough beyond her years

NEW LEUKEMIA  
BREAKTHROUGHS

BUTTERFLY  
AWARDS

GREAT CYCLE  
CHALLENGE

DAWN OF  
A DREAM

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## TOUGH BEYOND HER YEARS

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Three-year-old Brooklyn wears colorful, patterned leggings and never leaves home without slipping on at least one purple item of clothing (in addition to her bright purple shoes).

Along with reading *Five Little Monkeys Jumping on the Bed*, watching *Frozen* and playing with her kitchen set, she also thinks chemo shots, sedation and blood draws are just part of growing up.

Since being diagnosed with acute lymphoblastic leukemia in November 2015, Brooklyn's treatments and therapies have become second nature to her: She tells nurses which arm to wrap the big rubber band around when she has blood draws. And she intimately knows every step of accessing her port to her central line for infusions.

Her intense battle with cancer started when she was 2 years old. Worn out and weary, Brooklyn wanted to be carried more, often complained of leg pain in between playing and requested to "go right to bed" each evening after daycare.

Not assuming the worst, her parents Grant and Michelle watched and waited for the resolution of what they thought were growing pains or a virus.

For two weeks, Brooklyn continued to feel drained, and her legs ached so much one day that they were shaking uncontrollably. Her parents knew they had to take her to the pediatrician to perform blood tests and X-rays. The whirlwind began the next morning when the doctor called to tell them to pick Brooklyn up from daycare immediately, pack an overnight bag and bring her to the hospital. As they sat waiting on the floor for

children with blood disorders, they noticed pamphlets about childhood cancer on the front desk.

"I asked the doctors why we were there," says Grant. "They weren't telling us what was going on, so I just asked them to tell us what they were thinking. And they told us there was a really good chance that Brooklyn had leukemia."

Not long after their arrival, Brooklyn was officially diagnosed.

"I just cried. I could barely talk," said Michelle, who was pregnant with their second child. The threat of early labor due to stress added more anxiety to the life-altering news. It seemed absolutely impossible.

Brooklyn began the first stage of treatment, which included many painful spinal taps, bone marrow biopsies and toxic chemotherapies. "After [the first stage], you don't even recognize your kid," said Grant.

She gained weight on her small frame fast, lost all movement in her legs due to excruciating pain from the treatment, and had to relearn to crawl, stand and then walk with physical therapy. Cancer treatment plagued Brooklyn's tiny body with mouth sores, mood swings, unbearable muscle pain and tingling in her nerves, which caused her to cry out during diaper changes.

Signing treatment consent forms time and time again was a constant reminder to Grant and Michelle that Brooklyn's treatment could cause long-term damage to her heart, liver and more, even causing other types of cancer. "You're so focused on what's going on ... there's no difference between one day and the next," said Grant.

Her parents hoped this initial, brutal phase of treatment would put Brooklyn into remission so she would remain on the standard-risk protocol, the less difficult of two paths. If she didn't end up in remission, she would move up to high-risk and have to endure a series of therapies that would be far more trying.

At points during her treatment, Brooklyn's blood counts were dangerously low, and she needed blood and platelet transfusions to keep her going. Grant and Michelle recall that after one transfusion, Brooklyn fell asleep and started singing the ABCs in perfect tune. The heartbreaking contrast between childhood and cancer was never clearer than in those moments.

In December 2015, the first phase of Brooklyn's treatment wrapped up. Her family members held their breath for the news: Would their toddler take the expected, easier path of treatment? Or would she have to endure a more trying road to recovery? During the first traumatic and painful month of treatment, Brooklyn's parents welcomed their second child, Thomas, into their family — adding an extra layer of stress and joy to





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their lives. Not only did they have sleepless nights from a child in pain battling cancer, they also had a newborn to care for.

Grant and Michelle juggled frequent wake-up calls, ranging from a hungry newborn to a nearly unrecognizable toddler who also demanded food in the wee hours of the morning. High-dose steroids caused Brooklyn to feel ravenously hungry every few hours, including in the middle of the night. “It got to the point when you didn’t know if it was 5 a.m. or 5 p.m.,” said Grant.

The day before Christmas Eve, just over a week after the birth of Thomas, the results came back clear: Brooklyn was in remission.

Or so they were told. After they held very small Christmas and New Year’s celebrations and toasted to Brooklyn’s remission with friends and family, the oncologist told them a second review of bone marrow results showed Brooklyn was not in remission after all. “To hear that news was like hearing the diagnosis all over again,” Michelle said. Brooklyn immediately moved up to a high-risk treatment plan with a harsher protocol.

On the new protocol, Brooklyn reacted severely to one of the chemo drugs. Seconds after an infusion began, she coughed, her throat began closing and she screamed to her mom, who was holding newborn Thomas in her arms, “Something’s happening, Momma! What’s happening? I can’t breathe! I can’t breathe!” Michelle handed baby Thomas to a nurse and instructed Brooklyn to hug her daddy and take deep breaths. A nurse immediately drew the drug out of the infusion tubing and administered an EpiPen to save her life. Michelle described the feeling in that panicked moment as “watching your kid die right in front of your eyes.”

Doctors replaced eight scheduled infusions of that medication with more than 40 chemo shots, and Brooklyn went through intense treatment, both inpatient and at home, throughout the spring and summer.

Today, she is in the maintenance phase and has finally achieved remission. “You try not to get too high, you try not to get too low,” said Grant. “She’s so tough beyond her years,” Michelle adds, “You always want to see that your kid has a little fight in them because you don’t want them to lose the battle.”

Her family still has a long road ahead, but they hold on to simple moments when Brooklyn is feeling well — like when she plays “doctor” with her stuffed animals, rides her bike or plays with her baby brother. “My dream for Brooklyn is to just grow up,” Michelle said. 🍀

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## DISGUSTINGLY NORMAL

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*Written by Michelle Vaith, Brooklyn's mom*



I don't think we will ever get used to or get over the feeling of our stomachs sinking every time Brooklyn goes under anesthesia.

I have lost count, but sedation has happened maybe 25 or 30 times in the past 11 months. Checking in at Pediatric Sedation is a disgustingly normal Friday for us.

Think of a time when you put your child or loved one under anesthesia. Then think about holding them in your arms when they're 2 or 3 years old, listening to their high-pitched screams or hearing them shout, "The room is shaking!" or seeing their eyes roll back as their body falls limp. Then you do it over and over and over and over and over again. Week after week, month after month. Disgusting. And totally normal.

That's how today began. A totally disgustingly normal Friday.



Brooklyn happily pushed every button all the way through the parking ramp, up the elevators and even through the automatic doors in every hospital hallway. She sat on the check-in counter, recited the spelling of all three of her names and confidently stated her birthday. She reached out her right wrist and said "this one" — because she knew they would put her hospital ID bracelet on next. After a weigh-in and measuring for Brooklyn, her teddy bear and her giraffe, she watched, without flinching, as the nurse stuck a needle into her chest port and drew out the old blood. Totally normal.

The procedure went as planned; they removed spinal fluid and replaced it with a poisonous drug, just as they have done so many times before. They also gave her a flu shot as an attempt to prevent influenza. After she woke up and ate breakfast, we headed up to the pediatric oncology floor for another chemo infusion into her bloodstream. Our final stop was up, again, to the dermatology clinic to get a new medication for her poor face, covered with patches of red. Another five-and-a-half-hour morning at the hospital. The rest of the day was occupied with puzzles, books, playing outside and playing grocery store. Brooklyn flips from cancer patient to 3-year-old in a matter of seconds. Totally normal.



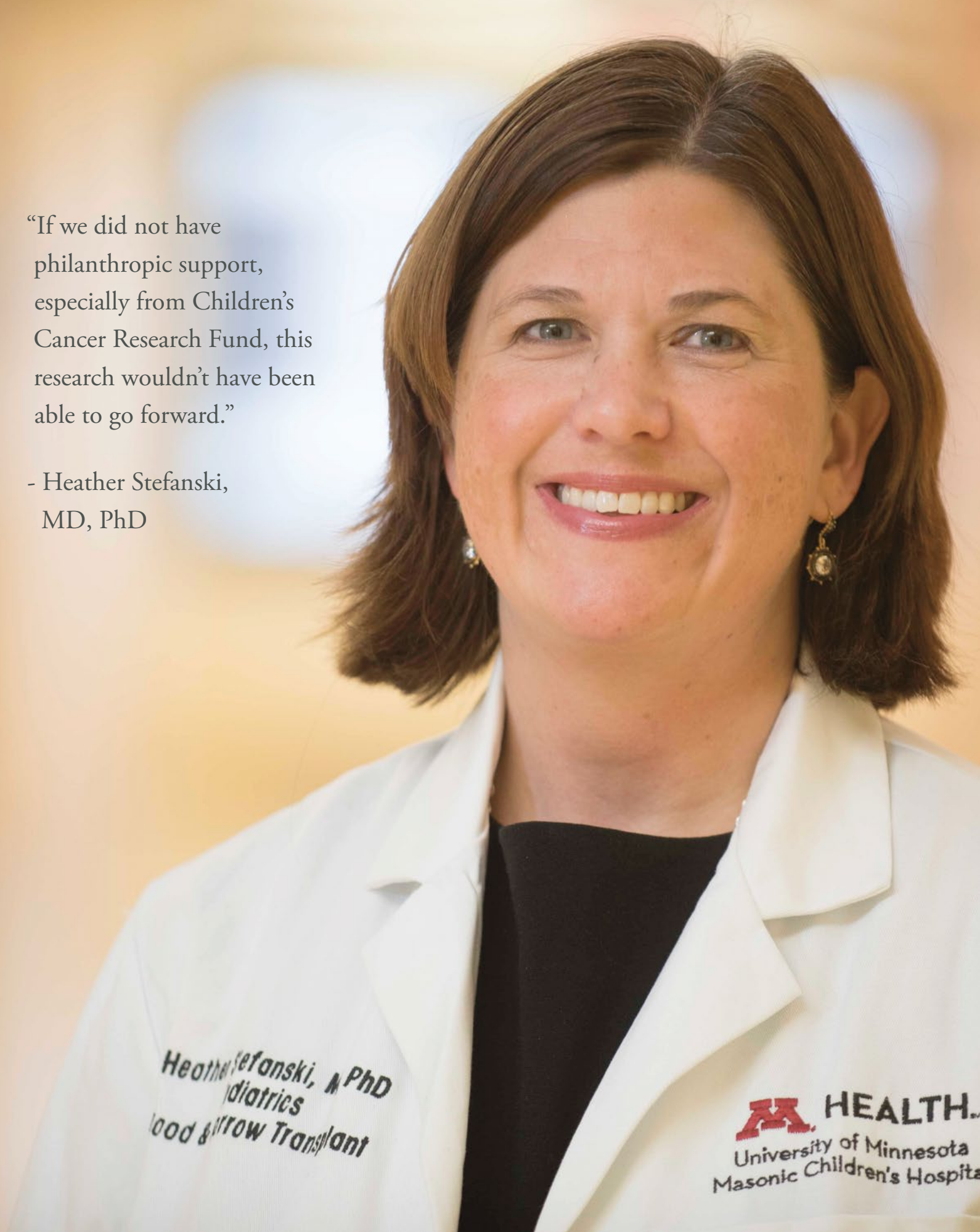
Even though this all feels totally normal sometimes, it totally sucks. There's got to be a better way. But for now, we will keep signing the consent forms that remind us how dangerous and toxic this treatment is and that there are potential side effects that will haunt us for the rest of our lives. We will continue to hold our baby girl while she screams as her eyes roll back in her head. And we will continue to feel those massive pits in our stomachs every 28 days when she has to go back for more. Because as terrible as this is, for our family and for many others, it is just ... totally ... normal. 🌸





“If we did not have  
philanthropic support,  
especially from Children’s  
Cancer Research Fund, this  
research wouldn’t have been  
able to go forward.”

- Heather Stefanski,  
MD, PhD



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## HOW YOUR GIFT IS CREATING BETTER TREATMENTS FOR KIDS LIKE BROOKLYN

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We want to create less toxic, more effective treatments for kids like Brooklyn. Here's how supporters like you are helping fund leukemia research to make that happen:

### Building Up Leukemia Patients' Immune Systems

Certain types of leukemia treatments include stem cell transplants. A stem cell transplant replaces immature blood-forming cells in the bone marrow that have been destroyed by drugs, radiation or disease. They are injected into the patient and make healthy blood cells.

After a stem cell transplant, children don't yet have an immune system. Because their immune systems are knocked down, children could die of diseases like the common cold.

#### **How your donations help:**

Heather Stefanski, MD, PhD, is doing research focused on using cells called thymic progenitors to improve children's immune function after transplant.

### 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 a subset of 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 or 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 earlier and increase a child's chance of survival.

### The Next Generation of Leukemia Therapy

Childhood B-cell leukemia can be a devastating disease that is currently treated with chemotherapy and hematopoietic cell transplantation (HCT). Though effective in some patients, chemotherapy and HCT can be highly toxic. In addition, 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. 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. Because this system does not differentiate between normal and leukemic B cells, the patient can have an impaired immune system due to loss of healthy B cells. Therefore, Osborn is developing and testing "on" and "off" switches on the T cell that will let it target the cancer, allowing the child's immune system to recover and function once the tumor is eradicated.

### Using Tiny Particles to Deliver Drugs Directly to Leukemia Cells and Other Cancers

Thanks to donors like you, Peter Gordon, MD, PhD, has already discovered how to deliver drugs to leukemia cells using nanoparticles in the lab. 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.





*Katie Hageboeck*

In August 1978, after 11-year-old Katie Hageboeck was diagnosed with leukemia, her parents, Diana and Norm, rushed her to the University of Minnesota Children's Hospital. When they got there, they were shocked to learn from the doctors that Katie might not make it through the night.

Doctors took blood out of one of Katie's arms and put fresh blood into the other with syringes to quickly remove cancerous white blood cells from her body. "There were boxes of tossed blood-filled syringes up to the ceiling by morning," said Diana. The Hageboecks remember feeling grateful that leukemia had changed from being fatal for a large majority of patients to having a 48 percent survival rate— so they clung to hope. Katie did live through the night, but six months later, she relapsed.

About a decade before her diagnosis, the University of Minnesota performed its first successful human bone marrow transplant — a treatment the Hageboecks hoped would save Katie's life. She became about the 50th bone marrow transplant patient in the country with the help of her sister Betsy, her donor match.

After a 16-month-long journey with leukemia, Katie passed away at age 13 in December 1979. This last November, she would have been 50 years old.

Before Katie died, she asked that her savings for a new 10-speed bike be contributed to Children's Cancer Research Fund (CCRF), a little-known fund at the University of Minnesota. During this time, the government was cutting back on research spending, and when a child died, parents would pass around a hat in the hospital waiting room, to give a memorial gift in a child's name. The Hageboecks vowed to support the University of Minnesota so they could help keep research going.

In 1981, two years after Katie passed away, her parents started a fundraising effort by holding a benefit that became CCRF's signature gala, called Dawn of a Dream. "We wanted to be a source of hope for families as they sat in that hospital lounge waiting for a miracle to cure their child, knowing that there were people out there keeping the research alive and well," said Diana. Since Dawn of a Dream's inception, over \$22.5 million has been raised from this event alone for childhood cancer research.

"Because we have funded and maintained this extraordinary research, we can now tailor chemotherapy treatments to each individual and therefore lessen serious side effects. We now have better family care, better nutrition, better treatments, more advanced technology," said Diana.

Without donors, Diana said she can't imagine the event would have grown to the extent it did.

"Every dollar they give generates \$18 in additional funding," said Diana. With that kind of leverage, she said, major donors have an especially significant impact on research.

"Now we've reached donors around the globe," she said.

Funding for 90 fellowships (promising young doctors who need funding for their new ideas) is part of CCRF's global impact. "Fellows have changed the landscape of much of today's cancer research," said Diana. "We have the power to educate so many more."

As Diana reflected on Katie's legacy, she said, "People often say to us, 'Look what you and Katie started!' And we say, 'Yes, we surely started something, something that wouldn't stop.' It's been a life-changing journey. It's illustrated something I once said: 'You can't lead life; it has a funny way of leading you.'"



## MEET OUR DONORS: MICHAEL HOFFMAN



Michael Hoffman spent his childhood enjoying sports and being a regular 13-year-old teenager. That all changed in July 1990 when he was diagnosed with leukemia. Admitted to the University of Minnesota Children's Hospital, he received a bone marrow transplant from his older sister, Allison, who was a perfect donor match. Before receiving his transplant, Michael underwent chemotherapy and full-body radiation. After spending 100 days in the hospital, he returned home, and since completing therapy, Michael has been cancer-free for 26 years.

We're grateful for long-time supporters like Michael — they're truly changing the way doctors treat leukemia and other childhood cancers.

### Q&A with Michael Hoffman

**Q.** What do you hope for kids in the future?

**A.** In a utopia, I would hope everyone is disease-free when, in five years post-cancer, no physician could even tell they had cancer. The unique thing about childhood cancer is that it doesn't discriminate. Parents shouldn't have to pick the pallbearers at their child's funeral. They shouldn't have to bury their kid.

**Q.** Of all the treatments and protocols you remember, which do you want to be improved the most?

**A.** Things have come such a long way ... the facilities are just better and more comforting. But I think my biggest dream is that research takes us away from kids having to go through bone marrow transplants. I want research to create more options for kids. We need to figure out a way to have less long-term collateral damage because of treatment. Treatment is like throwing a rock in the water — I want the treatment to create ripples instead of waves post-treatment.



### Thanks to You

More than 100 valued donors and fundraisers gathered at The Minikahda Club for our first annual Thanks to You event. Guests enjoyed dinner and cocktails while they heard hopeful research stories from Chief Medical Advisors Logan Spector, PhD, John Wagner, MD, and Brenda Weigel, MD, MSc. Afterward, two families who have experienced the impact of research in their own lives shared their stories with guests. A highlight for some was receiving a special thank-you gift at the end of the evening from cancer survivors Griffin and Lexyn, both 9 years old.

If you're interested in making a planned or major gift, contact Amy Polski Larson, Director of Development and Donor Relations, at 952-224-8486 or [apolskilarson@childrenscancer.org](mailto:apolskilarson@childrenscancer.org).



*Left to right: Griffin and Lexyn, cancer survivors*

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## BUTTERFLY AWARDS

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Each year, Children's Cancer Research Fund (CCRF) presents Butterfly Awards to individuals, teams and organizations that 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**

#### *Family Ambassador*

The Dykes family first shared the story of Connor's battle with cancer during the 29th Annual Dawn of a Dream gala. 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 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 \$120,000 to CCRF. Each September, Punch honors 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, Punch has donated proceeds from store grand-opening events and continues 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 teammates! 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, have continued the Laura League in her memory since she passed away in September 2014.

### **Logan Spector, PhD**

#### *Medical*

Logan Spector, PhD, joined the University of Minnesota in 2002 as a postdoctoral 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 co-chief medical advisor for CCRF. Spector has been the principal investigator of four grants from the National Institutes of Health totaling over \$10 million and is the 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 postdoctoral fellows who now conduct childhood cancer research around the nation. 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."











This June, riders from around the country will once again unite to fight childhood cancer. Whether you're a cycling enthusiast or recreational biker, this is a great way to get healthy and support groundbreaking childhood cancer research.

With Great Cycle Challenge, it's easy to participate. You set a personal riding goal and bike whenever or wherever you want. Invite your friends and family to get involved with you!

"GCC has been the most rewarding thing I have ever done," said Joel Falter, one of 2016's leading fundraisers. "The goal is simple: Help the cause to fight children's cancer. Each day generates new levels of excitement and enthusiasm as donations came in. I cannot wait until June 2017!"

Last year, we raised \$3 million together and helped fund new research and clinical trials at 10 hospitals around the country.

**Learn more at [GreatCycleChallenge.com](http://GreatCycleChallenge.com).** Registration begins in April. We look forward to riding with you!



## 13th Annual 140 Invitational Golf Tournament

The 13th annual 140 Invitational Golf Tournament was held at Oak Ridge Country Club on Aug. 20, 2016. Dedicated golfers played in looming clouds until the rain chased them off the course. The energy from the golfers did not stop there. Guests enjoyed dinner and bidded on exciting items from luxury vehicles to relaxing getaways. Guests also heard a Ewing sarcoma research update from Logan Spector, PhD. The event successfully raised more than \$250,000, bringing the grand total to over \$1 million raised in the past 13 years.



# 36TH ANNUAL DAWN OF A DREAM

## limitless

DAWN OF A DREAM 2016

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**WINDMILL DESIGN**

Longtime supporters, families affected by cancer and friends gathered in the decorated halls of the Depot in Minneapolis for one cause: to end childhood cancer. Their committed support at our 36th annual Dawn of a Dream raised nearly \$1.2 million!

Taylor Lieber is an amazing young woman who is directly affected by Children's Cancer Research Fund (CCRF) supported research. A two-time cancer survivor, Taylor shared her inspiring story and surprised guests by singing Andra Day's *Rise Up*.

"This year's Dawn of a Dream was truly inspiring. It is amazing to witness a room so full of hope, passion and a desire to make a profound difference," said Mindy, mother of Connor, a brain tumor survivor.

During the program led by emcee, Belinda Jensen, CCRF honored Thrivent with the Dream Maker Award. For nearly two decades, Thrivent Financial and Thrivent Mutual Funds have generously supported CCRF, contributing more than \$1 million for childhood cancer research. Thank you to all of our guests, sponsors, donors and volunteers for a magical night!



Taylor Lieber



## Picnic of Hope

This past August, family and friends gathered at the University of Minnesota Masonic Children's Hospital for Children's Cancer Research Fund's (CCRF) annual Picnic of Hope. Families and doctors joined in the Wilf Auditorium to hear research updates and family stories directly impacted by CCRF's work.

A complimentary lunch was then served by Chick-Fil-A Apple Valley outside on the sunny summer day, where guests enjoyed face painting, a photo booth and other fun activities. CCRF's very own mascot, C.C. Bear, joined the crowd to say hello and to celebrate the day with them. Thank you to the University of Minnesota Masonic Children's Hospital, Fairview volunteers and Delta Air Lines volunteers for providing a day of fun!



## 18th Annual KS95 for Kids Radiothon and "Clouds" Choir for a Cause

Families came together at the Mall of America for the KS95 for Kids Radiothon and "Clouds" Choir for a Cause this year. Listeners tuned in to 94.5 KS95 to hear stories of families affected by cancer and special medical needs. Donations flooded in throughout the day to provide a better tomorrow for the kids and families. The one-day event garnered \$541,839.67 for innovative medical care and research at Children's Cancer Research Fund and Gillette Children's Specialty Healthcare. After the Radiothon, over 5,000 people gathered to celebrate by singing to Zach Sobiech's "Clouds," carrying on Zach's story of hope.

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## about us

Children's Cancer Research Fund supports the brightest scientists whose ideas make the greatest impact for children with cancer. We also support vital family services and advocate for childhood cancer education and awareness.

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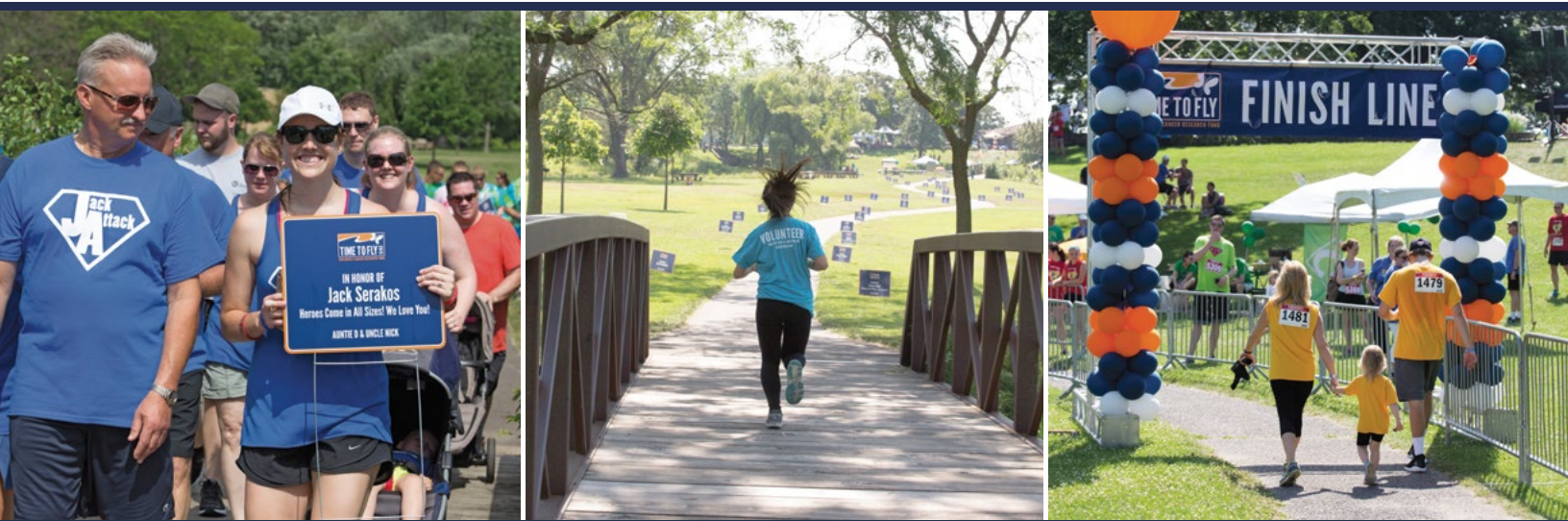
If you have any questions or comments, please contact HaiVy at 952-224-8848, or [hthompson@childrenscancer.org](mailto:hthompson@childrenscancer.org).

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**New this year! Join us Saturday, Sept. 9, 2017, at Phalen Park in St. Paul!**

Time to Fly is moving to September to celebrate Childhood Cancer Awareness Month. Walk, run and raise funds as a team or as an individual to end childhood cancer. Can't make it to the event? Try our virtual fundraising option!

In the event's 14 years, we've raised over \$2.2 million together.

Visit [ChildrensCancer.org/TimetoFly](http://ChildrensCancer.org/TimetoFly) for more information and updates on the 15th anniversary of Time to Fly.

#RaiseWalkCure