

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

# Butterfly<sup>®</sup>

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watching, waiting and skating

LIFE WITH  
NEUROFIBROMATOSIS

EMERGING  
SCIENTIST AWARD

CELEBRATING  
NURSES WEEK

GREAT CYCLE  
CHALLENGE

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## WATCHING, WAITING AND SKATING

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Colton skates in his socks across the living room wood floor to the fish tank. He shows off “Goldy” and “Yo-Yo,” his and his little brother Nolan’s prized goldfish. Like any 7-year-old boy, Colton loves Legos, trading Pokémon cards and playing soccer and hockey. But what many don’t know is that he has a four-inch tumor embedded in his leg due to a genetic disorder called neurofibromatosis type 1 (NF1).

NF type 1, a condition that causes tumors to grow in the nervous system, affects children in a variety of ways. The disorder can cause brain tumors, optic gliomas, pea-sized tumors and larger plexiform tumors. Most are benign, though plexiform tumors can become cancerous. NF symptoms also can include high blood pressure, scoliosis and learning disabilities. Typically, the disorder first appears in the form of café-au-lait marks, or spots with darker pigmentation.

When Colton was a toddler, his parents, Sarah and Nick, noticed a dime-sized mark above his eyebrow that they thought was a bruise. When the bruise didn’t fade, they brought it up to their pediatrician. She immediately recognized the difference in pigment as a café-au-lait mark. If a patient has six or more such marks larger than 5 mm in diameter, they are a diagnostic indicator of neurofibromatosis. Colton, indeed, had another fainter mark on his body, and they soon found another. Some are so faint they can be seen only with a special light, and more have become visible to the naked eye as he’s gotten older and they have darkened. Their doctor referred Colton to an NF specialist, where he was officially diagnosed with NF1. The specialist told the family to watch and wait for skin changes or tumor appearances.

Since that day, the mantra “watch and wait” has circled around their family. “It’s the tagline with NF,” says Sarah. “It seems like we’re always waiting for a big problem to occur.”

Though they were mild, Colton exhibited several symptoms of NF, including delayed speech and motor skills, intestinal problems and pea-sized tumors growing from small nerves under his skin. These cutaneous tumors have multiplied throughout his body since diagnosis. He also has a plexiform tumor in his leg, which is the largest Sarah and Nick know of, though there could be others they haven’t yet found. Sarah first sensed this tumor when she was trimming Colton’s toenails.

**“The lighting caught his leg just right,” she says.  
“I saw rippling on his skin, and something  
seemed strange.”**

Sure enough, doctors discovered a 4 x 4.5-inch plexiform tumor. “Imagine gummy worms woven around nerves,” says Sarah. “It’s bumpy and ripply and hard to tell where it begins or ends.” There are no treatments or cures available to rid Colton of the tumors like this. His tumor has grown and spread since the day Sarah discovered it, and doctors think it will continue to grow.

“With the nerves, doctors don’t want to do a surgical removal because it risks nerve damage,” says Sarah. An operation is often too dangerous and, in some cases, the tumors regrow more aggressively. Chemotherapy is an option for only the most severe, life-threatening cases such as a tumor that constricts breathing or basic body functions or that grows vastly outside the body.

Colton has had two surgeries: one to remove his adenoids and an emergency appendectomy. While there is a chance that NF1 caused the problems that led to the surgeries, that can never be known for certain.

In the three years since diagnosis, Colton has been monitored at Minneapolis Children’s Hospital, the Mayo Clinic and the University of Minnesota Masonic Children’s hospital to ensure the NF isn’t causing immediate dangers. But yearly checkups don’t always put Sarah’s or Nick’s mind at ease.

**“Even the little things make me wonder if it’s  
something bigger,” says Sarah.**

In the past year Colton had a pattern of severe headaches that he described as having bees in his head. “He’d hide under a blanket and say, ‘It hurts; it hurts,’” says Sarah. “So that prompted us to get an MRI.”

His parents took him to Christopher Moertel, M.D., a pediatric neuro-oncologist at the University of Minnesota Masonic Children’s Hospital.

Nick believed Dr. Moertel’s treatment practices were a notch above the others’. Rather than watch and wait, Dr. Moertel was willing to scan Colton’s head right away. There was evidence that an optic glioma had existed, but because there wasn’t current tumor growth, he wasn’t concerned.

Today, while Nick and Sarah watch and wait, they focus on fundraising efforts for NF research. “We’re on the lucky side because we know Colton isn’t majorly impacted right now, but we know how it can progress,” says Nick. “We want to do our part to help find a cure. If a cure can help Colton and others with NF in his lifetime, that would be ideal.”

“More research means more options,” says Sarah. “More options mean more help down the road. We don’t know what is going to happen with Colton, but I would like to have as many options as possible.”

Between checkups, scans and countless blood draws, Colton is enjoying being a 7-year-old. He recently caught up with his speech therapy, is doing great in school and works hard at playing on his hockey team.

“When I watch him play hockey I think, ‘I bet you’re the only one skating with a giant tumor in your leg,’” says Sarah. “He’s incredible.”



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# LIFE WITH NEUROFIBROMATOSIS

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by Sarah Simpson



Picture this: You're in an ice arena cheering on 7- and 8-year-olds learning how to play hockey, and they're using the full length of regulation ice for the first time. That's a challenge for small bodies, racing back and forth and up and down on the ice while clumsily chasing after a puck.

As you watch you might see a little boy with sweaty, sandy brown hair skating. I see a little boy who has worked incredibly hard to compensate for the large tumor in his entire upper thigh.

My son, Colton, has neurofibromatosis type 1. Neuro-what? you ask: neuro-fibroma-tosis, also known as NF1. And no, I had never heard of it either before his diagnosis. That dreadful feeling sitting and waiting to learn if this is "something" or "nothing" is indescribable.

After lots of questions, a ruler, a black light and more questions, I had a sinking feeling this wasn't going to end the way I had hoped it would. "Watch and wait," we were told. That is the NF anthem.

You watch and wait for changes in tumors and for new ones to pop up. It's all you can do.

"Don't Google it," they said on the way out. I knew they were right, but when your child is diagnosed with something you've never heard of, your

new job is to know everything you possibly can about the illness. Of course you Google it!

Reading words like rare, cancer, chemotherapy, surgery, learning disabilities, bone and skin abnormalities, cardiovascular issues, no cure and obituaries caused my heart to sink lower and lower.

The images were even worse. I knew they were worst-case scenarios, but in my heart I worried. What if that was our future?

Doctors ran a blood test to confirm the diagnosis, but by then we already knew Colton had neurofibromatosis from all the other signs. Still, getting the call a few months later when the results were in felt like a punch in the gut all over again.

He has a progressive tumor disorder. There are currently no effective treatments and no cure, only chemotherapy when the tumors turn cancerous. What does that mean for Colton's future and the future of our family as we know it? Am I going to make the right decisions for his medical care? Who put me in charge? I don't know what I'm doing! Where is the manual for all this?

Some days I still feel like I don't know what I'm doing, but I'm doing what I can. I am Colton's advocate, his first line of defense, the link to his medical team and his main everyday caregiver. Any change or pattern in his health becomes a journal entry with dates, times, symptoms and details — so many details because you hope to see a pattern — something that can be explained or, better yet, treated.

In a way it all rests squarely on my shoulders to pick up on a subtle difference in his health. I was the one who noticed his large leg tumor, and I see the changes in size and the other tumors developing as he grows. The fear is always there: Is this a sign of something bigger happening? Am I noticing what I need to?

I can't control what path his body is taking, but doing nothing won't change Colton's future either. I need to do what I can to make a difference now so he can have a future when things are different. That's why we fundraise for research and raise awareness about NF whenever we can.

I don't know what Colton's future holds, but I do know that I want a lot more of it, whatever it may bring. At only 7 years old, Colton has already gone through more than some people do in their whole lives, but he doesn't know any different. And watching him play hockey, you wouldn't know it either.

## YOUR DONATIONS HELP KIDS LIKE COLTON

“We are entering a new era of cancer therapy through targeted therapy and immunotherapy that will leave the radiation and chemotherapy we know today in the dust,” says Christopher Moertel, M.D., and a professor in the Division of Pediatric Hematology and Oncology, Department of Pediatrics, University of Minnesota. His immediate interest is a new class of drugs that target very specific “signaling” proteins inside cells to restore quality of life, and sometimes life itself, to children with neurofibromatosis (NF). There are three types of NF, and type 1 (NF1) usually appears in childhood.

NF1 syndrome is an inherited condition in children involving one copy of a mutant NF gene that causes a major cancer gene called RAS to turn on, resulting in NF1. Everyone has NF genes, but mutations can lead to NF1. “RAS was previously thought to be undruggable,” says Moertel, but he and David Largaespada, Ph.D., and professor in the College of Biological Sciences, have learned much about what happens downstream with the RAF/MEK pathway, making RAS now treatable.

“I see NF1 patients every single day I’m in clinic,” Moertel adds. “About one in every 3,000 individuals has NF1.”

Often, the first symptom is a birthmark. As children age, they develop more manifestations of the condition, including nerve tumors on the outside of the brain and spinal cord. Those can become malignant, killing half of the patients within five years. Children also may develop brain tumors or leukemia.

“We have learned there are major signaling pathways in regulating tumor growth in patients with NF1,” says Moertel. “Being knowledgeable about the MEK pathway has enabled us to identify new drugs.” He is particularly intrigued by a new class of drugs with anti-RAF and MEK chemicals that have been used to treat melanoma successfully. As those drugs became commercially available, he began giving them to his patients with previously untreatable progressive brain tumors — and the tumors disappeared. His ultimate goal is to find alternatives to traditional therapy for brain tumors, radiation and chemotherapy, to eliminate or reduce serious side effects.

Moertel and Largaespada each have been working with NF1 for 20 years. “One of my primary reasons for coming to the university in 2008 was to bring Largaespada’s science closer to my patients and to bring my patients closer to his science,” says Moertel. “We have had a rich collaboration over the years.”

The university’s nationally recognized NF1 program also includes drug development specialists Gunda Georg, Ph.D., director of the Institute for Therapeutics Discovery and Development (ITDD); Jon Hawkinson, Ph.D. associate program director, ITDD; Adrienne Watson, Ph.D., Recombinetics; and Nancy Ratner, Ph.D., professor, University of Cincinnati Department of Pediatrics.



*Dr. Moertel*

“The work we’re doing has been supported by Children’s Cancer Research Fund,” Moertel says. “Without CCRF, we wouldn’t have been able to do the formative work that led to these major grants and major reputation-building.” Moertel’s professorship is funded by the Children’s Cancer Research Fund, and Dr. Largaespada currently holds CCRF’s Hedberg Family Chair.

Recently, Largaespada and Moertel received a \$2 million grant from the Children’s Tumor Foundation to explore new drug treatments for kids with NF1.

Previous work with mouse models and Largaespada’s unique Sleeping Beauty transposon technology is now being supplemented with a special pig model. That model will help speed drug discovery and development by testing the toxicity of new drugs, particularly for the treatment of peripheral nerve tumors.

“We have learned a lot about NF1 in 20 years,” Largaespada adds. “Research has evolved, and we are starting to see evidence that the first targeted therapies are working. Our enthusiasm has not diminished.”

Moertel agrees. “In the past,” he says, “we would have told a patient with an NF1 tumor there was nothing more we could do. Now, with a new generation of drugs, we are snatching kids from the grave.”

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## EMERGING SCIENTIST

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Kyle Williams, recipient of a Children's Cancer Research Fund's new Emerging Scientist Award, has always been attracted to high-risk, high-reward activities. That's what is driving him to discover new ways to treat aggressive tumors and malignancies, especially in children, arising from neurofibromatosis type 1 (NF1), a genetic disorder that attacks cell growth in the nervous system.

A postdoctoral research fellow in the laboratory of David Largaespada, Ph.D., professor, College of Biological Sciences, Williams is pursuing unique methods to treat NF1 patients. Currently, the disease is treated with surgery and broad-spectrum chemotherapy, but Williams believes there is a better way to combat the condition that doesn't result in the pain, nausea and other potential side effects of those therapies.

To find better treatments, Williams and his colleagues are assessing the effectiveness of existing therapeutics and searching for novel pathways to target for therapy.

"The Emerging Scientist Award can jump-start a young scientist's own independent research career," says Williams. The funding that accompanies the award is paying for portions of Williams' basic science, including some of the substances used in his analysis of cells. It also is enabling him to travel to conferences and present some of his work.

"Being a young investigator with a background outside of cancer research, building these collaborations is probably just as important as the basic science side for me," he says. "Conference attendees have seemed encouraged by our research and are eager to see what will come from it. They think it is pretty ambitious."

The Emerging Scientist Award was created in 2015 to provide critical seed funding to promising young researchers. "Children's Cancer Research Fund is a great example of how a smaller grant can be used to generate enough preliminary results that secure a much larger research award," says Williams. He already has acquired fellowships through the University of Minnesota and the National Institutes of Health.

"This award has given me a lot of confidence as I've transitioned to a new area of research," he adds. "It is great to receive some validation that the research ideas I've developed using my previous training in biochemistry and microbiology can be applicable to cancer research. I hope to make meaningful contributions to the field of cancer biology and increase the use of new technologies such as next-generation sequencing and genome-wide genetic screens to tease apart complexities of diseases."

If you are interested in funding an emerging scientist, please contact Amy Polski Larson at [apolskilarson@childrenscancer.org](mailto:apolskilarson@childrenscancer.org) or 952-224-8486.



## NEW MICROSCOPE AIDS BRAIN SURGERY

What does a canine brain tumor look like when it's magnified 40 times? Liz Pluhar, D.V.M., professor in the College of Veterinary Medicine at the University of Minnesota, can now tell you, thanks to a new microscope provided with funds from Children's Cancer Research Fund.

This microscope is similar to the microscope used in human surgeries. If researchers can cut out (or resect) tumors to the same extent in dogs as neurosurgeons do with human tumors, the results from clinical trials in dogs and humans are more comparable. With comparable data, researchers can more quickly find better treatments and cures for brain tumors in children.

In December, Dr. David Largaespada, professor in the College of Biological Sciences, used \$40,000 from his Children's Cancer Research Fund Hedberg Family Chair to purchase a refurbished microscope for Dr. Pluhar and her colleagues.

"We can manipulate [the microscope] easily to enable us to see any residual tumor left and perform a better resection," says Dr. Pluhar. "There is a correlation between life expectancy and how much tumor is removed. The more left behind, the shorter the time before the cancer comes back."

Although the microscope is currently being used to view tumor resections in dogs, it also will be used with other animal species and for other surgeries, including microvascular surgeries.

She is grateful to Dr. Largaespada for using some of his donor money to provide the microscope. "It has made a huge difference, enabling us to remove tumors more completely," Dr. Pluhar says. "We hope it will result in improved outcomes for our patients."



*Dr. Pluhar  
with a patient*



From providing caregiving to emotional support, nurses are vital to the way families experience childhood cancer.

To celebrate Nurses Week (May 6-12) we asked four pediatric oncology nurses and nurse assistants, Jenn, Lisa, Mike and Rachel, to weigh in on their experiences.

### Why did you become a nurse?

I was inspired by my grandmother who was a nurse for over 30 years. She did this with a warm heart, and through her I learned even more about the joy of giving and helping others ... Becoming a nurse has ... confirmed the beauty in putting others before myself.

— *Jenn*

I like taking care of people and love being the bedside caretaker. I have always wanted to work in the medical field.

— *Rachel*

I've been a nurse for 29 years. What inspired me was the compassionate care I saw with my own family members. Their recoveries occurred not only because of medical care but because of the nursing staff too. I wanted to give back with that compassionate bedside care and with emotional and spiritual support.

— *Lisa*

I've always wanted to serve others. I care more about others than myself, probably a fault. Taking care of my grandpa when he was sick and being a part of his care visits at the hospital gave me a lot of experience.

— *Mike*

### What do you love about your job?

What I love seeing is that we're at the forefront of new treatments and research. I've seen so many positive changes that have made me think cancer can be cured.

— *Lisa*

Throughout my whole life, I have never found more joy than the feeling I get with helping others and making a difference in the lives of my patients. The difficult moments are definitely worth it, as I have gained so much by caring for my patients and their support system.

— *Jenn*

### What's the hardest part about your job?

The most difficult part is watching patients and families go through the process of realizing that all the treatment options have been utilized. It's difficult to see someone so young have their life end prematurely. It's so unnatural. I hope that in my work I can bring grace to these situations. I try to bring grace by allowing myself to be completely present with families.

— *Rachel*

The hardest moments have been when I take care of the teenagers who know they aren't going to make it. I've been a part of funeral planning and writing letters to family members.

— *Lisa*

### If you could give one piece of advice to a family going into treatment, what would it be?

"There is a time to cry and a time to laugh, a time to mourn and a time to dance." During each of these moments we learn to embrace them all. As a caregiver it is our job to remind them to never lose hope, that there will be hard times during this journey and times that laughter will truly be the best medicine. This time will change and mold them, but with all these moments I will be there for you to be your biggest cheerleader.

— *Jenn*

Be brave. It's my motto. We work with kids from six weeks to 22 years old, and everyone is going through something, and it applies to everyone. I'd say to take it one day at a time.

— *Mike*

### What's one procedure or therapy that you hope research can improve?

I probably would say chemotherapy side effects. We're making great strides with the integrative therapy program and finding the balance to help diminish side effects. Well, I guess I wish we didn't have cancer, period.

— *Lisa*

A lot causes pain, and it's hard to gauge it with kids. I think pain management can be improved with holistic medicine like music therapy and acupuncture. Of what I've experienced, it's wonderful, and I'd love to see more.

— *Mike*

If you could say one thing  
to your favorite patient,  
what would it be?

Keep the end in sight, and keep your head up  
in the meantime. You can do it.

— Rachel

Thank you for letting me be part of your lives.  
Thank you for showing me joy.

— Lisa

You are beautiful; you are strong. Don't ever lose  
hope. I will walk through this journey with you.

— Jenn

I'm really proud of you. You've done so well with  
everything you've gone through. And thanks for  
the snacks.

— Mike (Mike's patient would always give him  
snacks during his shift.)



Join us on Facebook and Twitter  
to celebrate Nurses Week and  
learn about the moments that  
changed these nurses' lives on the  
blog at [ChildrensCancer.org](http://ChildrensCancer.org).



*Norma Angell with  
her husband, Charlie*

## We Remember Norma Angell

With great sadness, we share that Norma Angell, an influential fundraiser for Children's Cancer Research Fund, passed away from complications of brain cancer last February.

We are forever grateful for the amazing work she and her family did for our organization. She and her husband Charlie started a fundraiser called Angellfest in honor of their 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 years to reach it. Having attained their initial goal, Norma set a new one of \$250,000. You can contribute in memory of Norma and Marissa at the Marissa Angell Brain Cancer Research Memorial Fund at [ChildrensCancer.org/Angell](http://ChildrensCancer.org/Angell).

Norma was also the recipient of the 2014 Butterfly award (pictured) for her amazing community fundraising. We send our deepest condolences to Norma's family.

## We Remember Marion Gray

We are sad to report that Marion Gray, a founding staff member of Children's Cancer Research Fund, passed away on March 24, 2016. We will remember Marion's contributions in a future issue, and we send our deepest sympathies to her family.



## \$1 Million Gift Creates a New Professorship

Children's Cancer Research Fund received a wonderful surprise last summer — \$1 million — a partial distribution from the estate of Carrie Ramey.

While we were not able to thank Carrie during her lifetime, we and her estate executors wanted to honor Carrie and create a meaningful legacy with her gift. We worked with our research partners and chief medical advisors at the University of Minnesota to establish the Carrie Ramey/Children's Cancer Research Fund Endowed Professorship. This professorship not only provides that legacy, but it also supports researchers

working to find a cure for childhood cancer and helps recruit and retain the brightest minds.

Michael Kyba, Ph.D., recently was appointed to the professorship. A pioneer in the field of cell therapy, his research currently focuses on finding new sources of bone marrow stem cells for bone marrow transplants (BMT) and creating targeted, less toxic treatments for children receiving those transplants.



## VOLUNTEER SPOTLIGHT: LINDA CERNI

Care Partners volunteer Linda Cerni knows personally the impact that cancer has on families. Her family was affected by the devastating disease when her 26-year-old nephew passed from Ewing sarcoma.

A longtime supporter of Children's Cancer Research Fund, it was an easy decision for Linda to volunteer to help families and children affected by cancer. Since the spring of 2012, she's helped make hospital stays a little easier for families and children with cancer.

"It's fun to make the lives of children and families a little better each time I'm there," says Linda. The moments she treasures most are spent with infants and young children. When she is able to provide them with comfort by holding them, reading to them or just watching television alongside them, it provides a normalcy in a not-so-normal situation. When she's volunteering, Linda realizes it truly is the small things that can make a huge difference.

As a retired elementary school teacher who loves working with kids, Linda has long been inspired by the strength of children. "You learn so much from students, and it is the same with patients," says Linda. "They always make the best of their situation."

Linda finds comfort in knowing that relief is being given to the families when she is volunteering. "I'm grateful to be able to do this and honored that I can spend time with patients and families."



### Roller Coaster Your Way to Better Treatments and Cures

Valleyfair Cares returns this summer. The program provides an opportunity to purchase discounted admission tickets, starting in late July, which can be redeemed August 22 through September 2. One dollar of each specially priced ticket sale will be donated to Children's Cancer Research Fund. Your dollar could be the dollar that, when placed in the hands of the brightest minds, could uncover a cure. Last year the program raised \$45,000. To join in the fun, visit [Valleyfair.com/Cares](http://Valleyfair.com/Cares) in mid-July.





Mason,  
leukemia patient

### Meet one of our GCC ambassadors!

Mason, age 4

Diagnosis: B-cell acute lymphoblastic leukemia

Mason was diagnosed in October 2013 when he was only two. After months of chemotherapy, spinal chemotherapy transfusions and lumbar punctures, he is now in the maintenance phase of his treatment. Some days Mason has to take up to 17 pills.

Mason's stuffed owl "O" never leaves his side. When it's bedtime, Mason makes a bed for O, and during hospital visits, O will wear a mask and perch next to him. We think O will make a great riding partner this June. Learn more about our ambassadors and register at [GreatCycleChallenge.com](http://GreatCycleChallenge.com)



How far can you ride to fight kids' cancer?  
Join Great Cycle Challenge USA to find out.

It doesn't matter whether you're a cycling enthusiast, a recreational biker or an avid spinner, you can join Great Cycle Challenge USA and help fight kids' cancer. Just by biking, you can be the catalyst for a childhood cancer cure.

### What is the Great Cycle Challenge USA?

GCC USA is an easy way to challenge yourself while supporting a great cause. Simply ride your bike whenever you want during the month of June, log your miles with the free Great Cycle Challenge App, monitor your progress via your own personal ride page and ask your friends to donate and support your fundraising goal to fight childhood cancer.

### How can I get involved?

Visit [GreatCycleChallenge.com](http://GreatCycleChallenge.com) and register. Set your personal challenge, recruit family and friends to pledge dollars and log your progress in a mobile app. You can download the app on your mobile device. Then start riding beginning June 1. You can ride on the trails or ride to work. You can ride indoors on a stationary bike or in spin class.

### Where can I ride?

You can participate anywhere. You can ride your bike outdoors, solo, with a team or with your family and friends. You can also ride at the gym or on a stationary bike. If you are already riding your bike, now you can do it to support a great cause. Just remember to log your miles.

### When do I ride?

You can ride anytime during June. Miles are officially counted from June 1 to June 30. And again, you can ride anywhere, even on a work trip or on vacation.

### How does this benefit childhood cancer research?

Nearly four of five children diagnosed with cancer can be successfully treated today because of research, but cancer is still the leading cause of death by disease among children. Great Cycle Challenge USA benefits Children's Cancer Research Fund and helps eradicate childhood cancer by providing funds to Children's Oncology Group hospitals across the United States.

## UPCOMING EVENTS

### We Fly for Kids Like Noah

Each June we “fly” for kids and families affected by cancer. Through fundraising events like Time to Fly, we believe we will find a cure so children like Noah can lead healthy lives as survivors.

The Lease family knows firsthand that raising funds for childhood cancer and blood-related diseases could determine a child’s quality of life. Ten-year-old Noah, the son of Brian and Amanda Lease, was diagnosed with neurofibromatosis (NF), a genetic disorder that affects more than 2 million people worldwide. Noah has spent 26 months in chemotherapy treatments, which have included three types of chemotherapy protocols, due to an optic glioma (brain tumor) that was impacting his eyesight. Poor vision is just one of the late effects Noah has as a result of NF, and he could develop tumors along his nervous system at any time. Noah is why Brian runs for a cure.

“Without people dedicating their lives to research, bringing awareness and fundraising, we would not be where we are today,” says Brian. “I do not want to see anyone’s child go through what our child has gone through.” Fly with the Lease family and many others at Time to Fly on Saturday, June 25, at Phalen Park in Saint Paul. Register and learn more details at [ChildrensCancer.org/Timetofly](http://ChildrensCancer.org/Timetofly)

### Join Us at Our Picnic of Hope

We are excited to invite all pediatric oncology and BMT families to join us for this complimentary picnic loaded with exciting children’s activities. The picnic is scheduled for late August as a chance to connect and reunite with other pediatric cancer families. Please email Mindy Dykes at [mdykes@childrenscancer.org](mailto:mdykes@childrenscancer.org) for more info and to be included on our invitation list.

### 13th Annual 140 Golf Invitational

Thanks to the ongoing commitment from Lubrication Technologies, Children’s Cancer Research Fund mission partner, we anticipate another great year at the 13th Annual 140 Golf Invitational. The event is scheduled for Saturday, August 20, for their longtime vendors and suppliers. The committee is excited to be playing at Oak Ridge Country Club, with a special performance by Kat Perkins. To register or learn more, please visit [ChildrensCancer.org/Events](http://ChildrensCancer.org/Events)



*Time to Fly*



*Picnic of Hope*



*140 Invitational*



*Date for Life*

## COMMUNITY HIGHLIGHTS

### *Date for Life*

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. The event is held in memory of Katie Jurek, who passed away from osteosarcoma. Nearly \$70,000 was raised this year, with a record attendance of 600 participating in all elements of the event.

Jack Tomczak, from "Up and At 'Em" on NewsTalk AM 1130, and auctioneer Karen Sorbo introduced the bachelors and bachelorettes. The event also included a fantastic silent auction, ring toss and traveling photo booth. It's Just Lunch, the premier matchmaking service for busy professionals, hosted the event. We thank Minnesota Monthly, Media Bridge Advertising, and Spark Starter for promoting the event.

### *Mounds View High School Mustang Managers*

Hosted by Mounds View High School's business management class, this fundraiser collected over \$3,800. Childhood cancer survivor Danielle spoke at the event. She is a longtime CCRF ambassador who battled stage V Wilms tumor. The event also included a gourmet meal, silent auctions, door prizes and selected local vendors.

#### **A special thank-you to these amazing community fundraisers:**

- Aldrin Elementary School Spring Choral Concert
- Brookside Student Council Donation
- Burrell Senior High School Interact Club Spaghetti Dinner Fundraiser for Osteosarcoma
- Choirpalooza Fundraiser ISD #192
- Corvel Corporation Casual for a Cause
- ECW Fundraiser in honor of Brylie Lundy
- Eradicate Car Cruise
- Floyd T. Binns Middle School
- Friends of Golf Tournament
- Love Beer. Hate Cancer. Kickball and Softball tournament
- Lowery Freshman Center Student Council of Allen ISD
- Maplewood Imports Client Appreciation Day
- Metro Concierge Holiday Fundraiser
- Monticello Middle School 6th Grade
- Nuveen Investments Jeans Day
- O'Connor Davies Charity Jeans Day
- PJ Arnold and Chip Miller Fundraiser
- Rachel's 5K
- Ryan's 11th Birthday
- Weitz Fundraising Party
- West Windsor Plainsboro High School South Field Hockey
- Zo & Friends

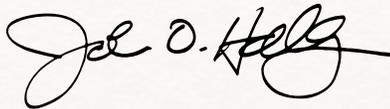
## IN THIS ISSUE

I'm past the age where spring's arrival encourages me to get back in shape after a long winter. I know I'd be better off if I developed a more disciplined exercise routine that targeted all the areas that need work, both my mind and my body. But despite good intentions, I'm rarely able to get it done.

Thankfully, Children's Cancer Research Fund takes a more disciplined approach. For those of you who do want to get in shape and fight childhood cancer, we have launched the second annual Great Cycle Challenge USA. Our goal this year is to raise over \$2.2 million during June. You could join over 5,000 participants from across the country in riding a bike to raise funds for cancer research and help us invest in the best ideas and the brightest minds, some of whom are featured in this issue.

Strong minds also need a strong body for support. When I was in Florida earlier this spring at an event that included many longtime supporters, I was reminded that our team today stands on the broad shoulders of the people who helped build the foundation of this organization. That support has many names and faces.

In this issue we honor Norma Angell, who passed away in February. When their daughter Marissa died from a brain tumor in 2009, Norma and Charlie Angell started a local fundraiser with a dream to raise \$100,000 in 10 years for brain tumor research. They achieved their goal in only four years. Your support gives strength to the patients we serve, and for that we are grateful.



John Hallberg, CEO

thank you to  
our mission partner:



## 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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Fundraise for Children's Cancer Research Fund! Join our 10K run & 5K run, 5K walk and kids' 1K fun run!

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](http://ChildrensCancer.org/TimetoFly) for event info and registration.

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