

2016 PROGRESS & 2015 ANNUAL REPORT
FALL 2016

#MORETHANJUSTAWARENESS



A PUBLICATION FOR THE FRIENDS OF:



THE CURE STARTS NOW®

www.thecurestartsnow.org

LETTER FROM THE EXECUTIVE DIRECTOR

Each year The Cure Starts Now funds significant DIPG research in the hope of finding the homerun cure to all cancers. We were ecstatic to present over \$4 million in research in 2015 to our grantees in surprise check presentations with our DIPG Collaborative Foundations. This is not only an enormous achievement, it is making significant impact on our researchers understanding the biology of DIPG's and high grade gliomas, finding their weakness and creating targeted therapies. The impact of the research you are funding became unmistakably apparent when we arrived in Liverpool for the International Society of Pediatric Neuro Oncologists (ISPNO) meeting this summer. Researcher after researcher presented their findings from their studies and the majority of those presentations ended in thanks to The Cure Starts Now and the DIPG Collaborative for funding their research.

The revelations from their research were only made possible because of charities like The Cure Starts Now, who are willing to fund innovative and out-of-the-box thinking. We are taking risks in confidence that the reward will move us faster towards the cure. With children being diagnosed every day, we cannot wait for government to pass money through its bureaucracy. Funding through The Cure Starts Now allows us to fund effectively and efficiently to get results faster.

So as we allowed young researchers to pitch their breakthrough ideas to our esteemed Medical Advisory Council at ISPNO, we were so honored to award a \$50,000 grant immediately on site to the winning young researcher who is attempting to find new delivery methods for chemotherapy. It was not only revolutionary but impactful.

We can only achieve this type of nimble and innovative research funding because of your confidence in our funding efforts and ability to bring researchers together. I couldn't have been prouder of what we have achieved as when I stood face to face with the researchers we have funded and saw their earnest gratitude for our support. Gratitude for finally funding one of the deadliest types of cancer in hopes it will find that home run cure to all cancers. I am honored to pass on their gratitude to you, as it isn't possible without your support.

From the researchers and families of The Cure Starts Now...thank you!



Brooke Desserich
Co-Founder/
Executive Director
The Cure Starts Now



RESEARCH FUNDED

2008

St. Jude—\$25,000
Cincinnati Children's —\$50,000

2009

St. Jude—\$10,000
Cincinnati Children's —\$50,000
St. Jude—\$50,000

2010

Weill Cornell—\$91,470
Cincinnati Children's —\$75,000
Cincinnati Children's —\$35,000
St. Jude—\$35,000

2011

Sydney Children's—\$100,000
Doernbecher—\$100,000
Duke Children's—\$82,049
Texas Children's—\$100,000

2012

Cincinnati Children's —\$219,000
Stanford University—\$35,589
Texas Children's—\$100,000
St. Jude—\$15,000

2013

Monash Institute—\$108,840
Sick Kids Hospital—\$100,000
Texas Children's—\$100,000
Dana Farber—\$50,000

2013 CONT.

Children's Cancer Institute—\$100,000
Cincinnati Children's —\$205,000
Lurie Children's—\$100,000
Children's National—\$99,979
Yale—\$100,000
Duke Children's—\$85,394

2014

UCSF—\$100,000
Sick Kids Hospital—\$99,400
Institute of Cancer Research UK—\$95,325
VUMC, Netherlands —\$32,529
Cincinnati Children's—\$176,186

2015

Sick Kid's Hospital—\$190,065
Stanford University—\$200,000
Centre for Evolution and Cancer—\$99,470
Children's National —\$200,000
Cincinnati Children's—\$200,000
Children's Cancer Institute AU—\$145,341
VUMC, Netherlands —\$932,917
Cincinnati Children's—\$699,935
Dana Farber—\$100,000
Boston Children's—\$110,000
UCL Institute of Child Health—\$200,000
Cincinnati Children's—\$100,000
Children's National—\$125,000
Texas Children's—\$200,000
Jewish General Hospital—\$100,000

\$7.3 MILLION

Since 2007, The Cure Starts Now, in conjunction with the DIPG Collaborative, has funded over \$7.3 million in groundbreaking DIPG research.

59 GRANTS

The Cure Starts Now, in conjunction with the DIPG Collaborative, has funded 59 innovative research grants in 6 countries.

2015 CONT.

Memorial Sloan Kettering—\$99,980
Dana Farber—\$100,000
VUMC, Netherlands —\$92,950
Lowy Cancer Research Centre —\$81,683
Stanford University —\$50,000
Lurie Children's —\$50,000
Cincinnati Children's - \$100,000



2016

Cold Spring Harbor Lab — \$100,000
Sick Kids Hospital — \$194,260
Children's Cancer Institute — \$143,884
Gustave Roussy Cancer Campus — \$93,071
Sick Kids Hospital — \$50,000

MAKING A MARK

The story of how one little girl's parents are trying to make a difference with the mark she made on the world.

Amanda "Mandy" Kuck was born in January 2011, just five days before her big brother Ben's second birthday. Mandy was a very sassy little girl. Her mother used to joke that at 4-years-old she was giving her a glimpse of what it must be like to have a teenager. She was strong-willed and confident. She loved typical girly things like makeup, getting her nails done and shoes. She loved shoes. The fancier, the better! She was goofy too and could easily laugh at herself.

Developmentally, Mandy was on target at each traditional milestone. She never experienced any significant illnesses or injuries. Then in May 2015, things changed. Mandy began to complain on and off of headaches which were accompanied by vomiting. At the same time, her right eye began to 'wander' and her gait became increasingly unsteady. As the symptoms progressed, Mandy's pediatrician sent Mandy to the hospital for a CT scan. The next day Mandy's parents were told their perfect, happy, beautiful 4-year-old daughter was living with a monster inside her brain: diffuse intrinsic pontine glioma, an inoperable tumor found in the pons of the brainstem.

"That day our family was thrown into the devastating world of pediatric cancer; our lives forever changed. We were told staggering statistics about median survival ranging from 9 to 12 months; children with DIPG have a less than 10% chance of surviving 2 years. We immediately began researching options and treatments," Kimberly recalled.

Mandy underwent two major surgeries within those first three days. On June 15, she took a turn for the worse; her tumor grew and she lost all ability to walk, talk, eat, and communicate.

Mandy was admitted to the PICU at Memorial Sloan Kettering Cancer Center where she began radiation therapy.

Only half way through treatment, she gained back all functions except walking. Her parents were excited they got their little girl back and tried their best to enjoy every moment of the summer!

Unfortunately, a mere 7 weeks later the symptoms started to reappear and on August 26, 2015 Mandy was readmitted to Memorial Sloan Kettering Cancer Center. An MRI confirmed what her parents were dreading: tumor progression. Over the next four days, Mandy lost her ability to eat, talk and communicate again.

After Mandy's diagnosis her parents, Tom and Kim decided they needed to do something after finding out how little funding actually goes to pediatric cancers, especially pediatric brain tumors. In the spring of 2016 they joined forces with The Cure Starts Now as the New York Chapter.

"Being part of The Cure Starts Now allows us to be part of an amazing organization, one that focuses on research, which was extremely important to us. It also allows us to continue to honor Mandy the best way we know how – by raising money and awareness for DIPG," said Kim.

Although Mandy's battle ended in January 2016, her legacy – her mark – will live on and continue to inspire others. Even when she could not communicate, she taught those around her to be strong. To be brave. To fight for what they want.

"We do see hope for the future. It's difficult sometimes but we also made the decision early on that we don't want to be miserable or sad for the rest of our lives. Mandy wouldn't want that. If she could go through all that she went



through and still manage to smile and laugh, then we can too," said Kim.

Like all of us, Mandy's parents are hopeful that in our lifetime, we'll see more funding, better options and eventually a cure, the homerun cure for all cancer.



Amanda with her parents Kim and Tom and her brother, Ben, about two months prior to her DIPG diagnosis.

CSN IS LED BY CANCER PARENTS

The Cure Starts Now was founded by cancer parents. Nearly all of our chapters are also run by cancer families in honor of their children. What does this mean? We are passionate about funding DIPG research in the most effective and efficient way possible. We are also acutely aware of what newly diagnosed families are facing and the support they need!

THE ELEMENT OF SURPRISE

Since 2007, The Cure Starts Now has been the leader in non-government funding of DIPG research. Started by brain cancer parents Keith and Brooke Desserich, we have made DIPG our priority.

In the fall of 2015 through early 2016, we wanted to do something special for our 2015 grant winners. We wanted to surprise them and thank them for their continued hard work and dedication to furthering research to find the homerun cure.

So, The Cure Starts Now and members of the DIPG Collaborative set out to 19 institutions in 5 countries to surprise these researchers, Publisher's Clearing House style!

In the end, over \$4 million was granted in groundbreaking research and the reactions were priceless. Each surprise presentation was captured on video and can be seen on The Cure Starts Now's YouTube channel.

We are often asked how we decide which grants to fund. Easy, we ask the experts. Our Medical Advisory Committee is made up of experts in neuro-oncology from around the world. These researchers review all of the grants submitted and only select the grants that show innovation in their ideas and feasibility in their execution.

Our Medical Advisory Council also reviews grants to ensure there is no duplication of research around the world and that no unnecessary overhead is funded.

To see the surprise check presentations, please visit our YouTube channel at [youtube.com/user/curestartsnow](https://www.youtube.com/user/curestartsnow)



2015 FINANCIALS

Balance Sheet

For the Fiscal Year Ended December 31, 2015

Assets

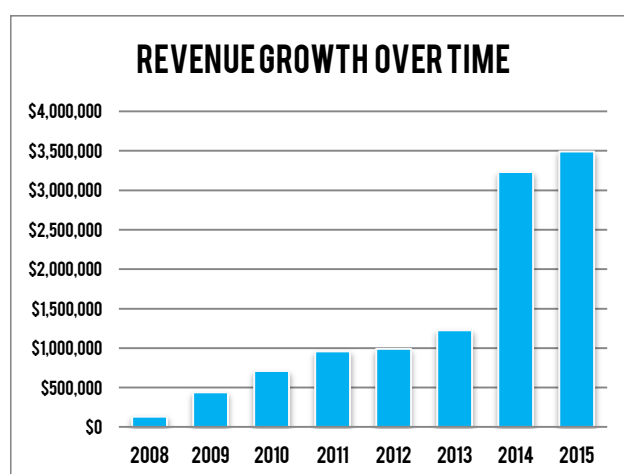
| | |
|---------------------------------|--------------------|
| Cash and cash equivalents | \$1,935,252 |
| Inventory | \$55,510 * |
| Other assets - Prepaid expenses | \$72,770 |
| Total assets | \$2,063,532 |

Liabilities

| | |
|--------------------------|--------------------|
| Accounts payable | \$13,103 |
| Grants payable | \$1,246,621 |
| Other liabilities: | |
| Accrued compensation | \$3,863 |
| Deferred revenue | \$45,737 |
| Total liabilities | \$1,309,324 |

Net Assets

| | |
|---|--------------------|
| Unrestricted | \$742,971 |
| Temporarily restricted | \$11,237 |
| Total net assets | \$754,208 |
| Total liabilities and net assets | \$2,063,532 |



2% OVERHEAD

For the last 3 years The Cure Starts Now has had less than 2% overhead.

5 YEARS

For the last 5 years The Cure Starts Now had their financials audited by a professional accounting firm to certify their books for accuracy.

Statement of Activities and Changes in Net Assets

For the Fiscal Year Ended December 31, 2015

| | Unrestricted | Temporarily Restricted | Permanently Restricted | Total |
|--|----------------------|------------------------|------------------------|----------------------|
| Revenue, Gains, and Other Support | | | | |
| Contributions | \$1,632,178 | \$29,550 | - | \$1,661,728 |
| In-kind donations | \$113,182 | - | - | \$113,182 |
| Special event revenue | \$1,704,435 | - | - | \$1,704,435 |
| Investment return | \$22,369 | - | - | \$22,369 |
| Net assets released from restrictions | \$18,313 | (\$18,313) | - | - |
| Total revenue, gains, and other support | \$3,490,477 | \$11,237 | - | \$3,501,714 |
| Expenses | | | | |
| Program services: | | | | |
| Medical research | \$4,754,376 | - | - | \$4,754,376 |
| Monkey in My Chair | \$102,618 | - | - | \$102,618 |
| Medical symposium | \$71,099 | - | - | \$71,099 |
| Family support program | \$319,677 | - | - | \$319,677 |
| Fundraising | \$675,510 | - | - | \$675,510 |
| Management and general | \$54,776 | - | - | \$54,776 |
| Total expenses | \$5,978,056 | \$0 | \$0 | \$5,978,056 |
| Increase (Decrease) in Net Assets | (\$2,487,579) | \$11,237.00 | - | (\$2,476,342) |
| Net Assets - Beginning of year | \$3,230,550 | - | - | \$3,230,550 |
| Net Assets - End of year | \$742,971 | \$11,237 | - | \$754,208 |

* Inventory consists of stocking Monkey in My Chair kits to prepare for demand.

RESEARCHER Q&A

We sat down with some of the brightest minds in the cancer research realm and got answers to your questions.



HAVE you seen a huge change in the collaborative effort of doctors and researchers 10 years ago versus now?

“I started working on DIPG in 2007. Back then no body was studying DIPG, I think I was one of two or three people. Today, I would say there are probably 30 or 40 researchers around the world that are studying DIPG.”

– Dr. Oren Becher, Duke University
DIPG Collaborative Grant Recipient



WHY is the need for private funding so important?

“As you’re aware, federal funding for pediatric cancer in general is a small drop in the bucket of cancer research dollars. Then, taking that down to pediatric brain tumors, it becomes even more fractional.”

– Dr. Stewart Goldman, Robert & Ann Lurie Children’s Hospital of Chicago
CSN Medical Advisory Committee Member



WHAT have been some of the most exciting advancements you’ve seen in your field?

“One of the most exciting advancements in the field of neuro-oncology, specifically DIPG work, is that we are now able to understand more about the biology of the tumor.”

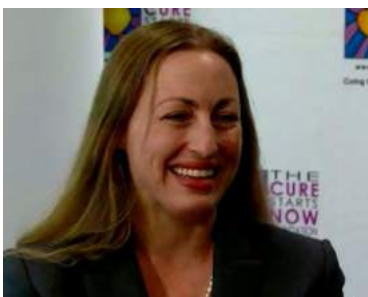
– Dr. Trent Hummel, Cincinnati Children’s Hospital Medical Center
DIPG Collaborative Committee Head



DIPG is a terrible disease with a 0% chance survival. Do you see hope in any of this?

“I absolutely see hope. We now know a huge amount about the biology. We know that it’s different; we know some of the ways in which it’s different, some of the particular genetic drivers of the disease.”

– Dr. Chris Jones, Institute of Cancer Research, UK
DIPG Collaborative Grant Recipient



WHY is collaboration among researchers within the DIPG Collaborative so important?

“We have to work together, this is a small scientific community and whatever resource is available to one researcher should be available to all researchers so we can work together to move forward.”

– Dr. Michelle Monje, Stanford University
CSN Medical Advisory Committee Member & DIPG Collaborative Grant Recipient

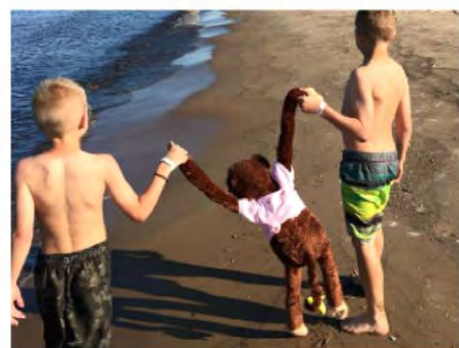
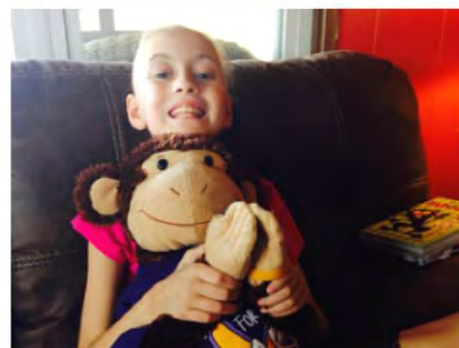
MONKEYS GOING VIRAL

See how one monkey went from a classroom star to a social media and television star!

Although Monkey In My Chair has its own Facebook page, one of our monkeys has gone viral and now has her own Facebook page. Cary's monkey, Coco, arrived in her classroom to help with her time away during treatment. Shortly after Coco made her appearance, the class decided to share her adventures through Facebook. Coco now has her own page, Coco's Adventures in 3rd Grade, and shares many fun pictures with her followers. Coco has been on mini vacations, watched softball games, went on a poker run, spent a day on a boat, collected Easter eggs and much, much more.

This has been a creative and fun way for Cary to see her monkey, Coco, and what she is up to. Her classmates have been able to take Coco on adventures and share her with their family and friends as well. Coco's adventures even caught the attention of the local news station who shared her story.

The impact one of our monkeys makes can go a long way, especially when the classroom embraces the monkey and the idea behind it. By interacting with the monkey in the child's absence, each classmate is able to feel more connected with their friend when they aren't able to be in the classroom due to a cancer diagnosis.



JOEY LOGANO FOUNDATION FUNDS 133 MONKEYS

The Cure Starts Now is proud to have such incredible donors. Back in July, the Joey Logano Foundation presented The Cure Starts Now with a \$10,000 grant to fund 133 Monkey in My Chair kits.

Representatives of The Cure Starts Now Foundation met Logano at the Kentucky Speedway before the Quaker State 400.

"We really want the Joey Logano Foundation to support innovative organizations finding solutions to community issues. We think the Monkey in My Chair program is a unique way to not only help children fighting cancer, but also a unique way to help the child's school community understand what that child is going through. It teaches compassion and empathy which I think are very important lessons to learn," said NASCAR Sprint Cup Series Driver, Joey Logano.



Joey Logano along with brain tumor patient, Kelly, presenting The Cure Starts Now with a \$10,000 grant for the Monkey in My Chair program.

CHAPTERS

Mobile, Alabama - Erica Bonner
Montgomery, Alabama – Elizabeth Adams
Arizona - Chris Hallsey
Arkansas – Nicole McCoy
Australia – Ren Pedersen
Northern California – Jackie Harrison
Southern California – Shannen Nelson
District of Columbia – Neely Agin
India – Ratesh Khanna
Indiana - Lynn & John Whittington
Iowa - Mikinzie Smith
Kansas – Heidi Feyerherm
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 Lisa Hill, Event Coordinator
 Heidi Feyerherm, Monkey in My Chair Administrator
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 Jeff Branhan, National Race Director
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2015 Top Individual Donors* (Donors not listed in alphabetical order)

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 USEN Fam Foundation
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 Warren County Foundation Depository
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*Categories are not determined by net value of gifts received.

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2015 Top Individual Donors* (Donors not listed in alphabetical order)

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 Children's Dentistry
 CSX Transportation
 Edenton Street United Methodist
 Church
 Gephart Hill Properties &
 Construction. LLC
 Mason, Schilling & Mason Co., LPA
 Mission Pharmacal Company
 PNC Institutional Asset Management
 Steve Francis
 Dennis & Margaret Gartman

David Hughes
 Southwest Displays
 George Skritakis
 Mark & Erin Hughes
 Anthony School, Inc
 Melissa Goldberg
 Dlynn Souba
 Buffalo Wild Wings
 Thomas Dale High School
 Wallace Memorial United Methodist
 Church
 Hanover College
 Dan & Lisa McPherson
 Erich & Amy Jones
 Bank Of America Charitable
 Foundation
 ITF For Khylee Monson
 Chick-fil-A at Bridgewater Falls FSU
 Joe & Carol Hinnenkamp
 James & Pam Ulanoski
 Cappy's Liquors
 Syed & Mary Hossain
 Nathan & Tina Wagler
 Elizabeth Walsler
 Booster U.S.
 Buffalo Wings & Rings-Greendale
 Western High School & Luman Christi
 High School
 Burnet Ridge, Inc.
 Sally & Sparky Merk
 Ro A. Whittington
 Clarendon Flavors
 Gronberg Orthodontics
 Medical Solutions
 Rebel Innovative
 SC Ministry Foundation
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 Xavier University
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 Joey Logano Charitable Foundation, Inc.
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 Cors & Bassett
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 Bryan & Katie Towne
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 Navient Solutions, Inc.
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 Lesley & Brian Harris
 Admonish Clothing Co.
 Gavin & Fatema Baumgardner
 Florence Freedom
 Lew Lahr
 Drums/Butler Township PTA

*Categories are not determined by net value of gifts received.

YOUR DONATIONS IN ACTION

"It was with great delight that I opened my post and found the cheque from The Cure Starts Now Foundation... we can now start working on this exciting project. We are honoured you allow us to use your resources to do this important work."

- Dr. Karin Straathof
 UCL Institute of Child Health,
 London



VOLUNTEER SPOTLIGHT

Katie Towne has been a longtime supporter and volunteer of The Cure Starts Now.

What do you do as a volunteer at The Cure Starts Now?

"I started volunteering for The Cure Starts Now several years ago as a "small task" person for the Once In a Lifetime Gala and Auction. I would help with things like wrapping baskets or stuffing envelopes. Now, I do that type of thing for other events, but I primarily spend a few months a year working in the silent auction's computerized data program; I input donations, group them into packages, write descriptions, and make sure everything is accurate for bidding on the big night!"

Tell me how you first got involved in with The Cure Starts Now?

"My then pre-school aged daughter was diagnosed with an inoperable brain tumor as we were waiting to move into our house 8 years ago. When I went to my son's kindergarten parent-teacher meeting, I talked to his teacher about the development and it turned out that she was Elena Desserich's kindergarten teacher as well. She invited me to the gala that year as an attendee and I've been involved since!"

What do you wish other people knew about The Cure Starts Now?

"I wish they knew that The Cure Starts Now is a way to fight back against the underfunding of pediatric cancer research, that they do everything with the thought that each volunteer hour, each donor, and each effort made is a step closer to curing cancer, that researchers collaborate to make the best use of each research dollar, and that this organization is powered by the love that our families and friends have for the children that fight this awful disease."

Tell me about some of the people you've met while volunteering.

"I've said before that the beauty of "ordinary" is that we all are ordinary until we are extraordinary, and

"extraordinary" is fueled by love and selflessness. Volunteering for CSN allows me to witness the love and selflessness of hundreds and sometimes thousands of people each year and it is so good for the soul to see so much good in a life that is hard! I meet fighters and grieving families, hear the stories of other volunteers, see children empty their change purses into donation jars, and receive auction items that are twice as valuable than what we expect because business owners had their hearts touched by the stories of lives cut short, and have waited for gentlemen to stop sobbing before they could donate in honor of their wives and mothers during telethons. This fight matters to so many people!"

What do you think will change about The Cure Starts Now over the next five years?

"I think as the word spreads that historically only 4% of national research dollars have gone to fund pediatric cancer research and, hopefully, the home run cure, people will be fueled to take action both by that injustice and by the amazing things already accomplished through research funded by The Cure Starts Now. So many have already been inspired to help by the passion, and integrity, and mission of this organization, and I think it will continue to grow as people continue look to this organization and its research symposiums to model what effective action looks like. While a ribbon, a color, or a slogan helps raise awareness, I think people really want what CSN has been offering—a focus-driven purpose to cure cancer."



Katie Towne with her daughter, Cynthia, at The Cure Starts Now and Cincinnati Ballet's "Ballerina for a Day" event.

What would you tell someone who is thinking about volunteering?

"I think all people who have volunteered already know about the sense of personal satisfaction you receive from doing something of significance for others, so I would tell someone thinking about volunteering that it is also FUN! The events across the nation and the world funding research through The Cure Starts Now span many interests—galas, races, beer, wine & food festivals—you name it! I think many people worry that they will have to do a job they feel unprepared to do, but that is not the case—there is something for everyone!"

What might (someone) be surprised to know about you?

"Before chronic conditions forced me to seek other hobbies, I was a violinist and a clogger! Yes, my faulty body has spared you all the sight of me busting out my Rocky Top routine! Ha!"

What do you do when you're not volunteering?

"I spend an enormous amount of time in doctor offices and hospitals, mostly for appointments, but also to volunteer in the NICU at UCMC! I also lead a Girl Scout troop, help as a room parent, get my crafty on, love on my family, laugh a lot, and spend time each week wishing I could burn all the paperwork in my life."

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