



Ronald McDonald  
House Charities®  
Midwest | MN, WI, IA

# news from the heart

## MAY 2023

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**"Initially, we believed every call would be the call.  
But it didn't happen, and it didn't happen, and it didn't happen. Until it did."**  
- Nick, Bianca's dad

**"I could not breathe. Really—the perfect heart for my little girl? Is this real life?"**  
- Laura, Bianca's mom

# A MESSAGE FROM OUR CEO

As we head into the summer months, I am writing to share some exciting news and inspiration from the families turning to Ronald McDonald Charities Midwest MN, WI, IA. So far in 2023, we have served more than four times as many families as we did during this same time last year. The need for a home away from home for families is ever-growing and we continue to be inspired by our guest families, our volunteers, and our donors.

In the pages ahead, you will read about an amazing little kiddo, Bianca. Her journey is one of strength, hope, resilience, and joy. Bianca and her family turned to our Ronald McDonald House in Rochester while she awaited the news that she would be the recipient of a heart transplant. After nearly 300 nights at our House, Bianca and her family headed home, where Bianca is taking critical steps in her recovery and post-transplant life.

You will also read about amazing volunteers like Shona Brooks. Like so many of our volunteers, Shona brings her energy, enthusiasm, and unique abilities to the House in support of families. The unwavering commitment from all our volunteers, in supporting children and families in need, has played a crucial role in creating a warm and comforting environment and easing the burdens faced by those going through challenging times.

Lastly, the generosity of our donors and partners continues to be nothing short of amazing. It takes the gifts of many for us to serve more families than ever before. Whether that be the generosity of our corporate partners, like Crave American Kitchen & Sushi Bar, or donors like the Haugen family, our families continue to feel the outpouring of support from the many friends of our House. We are confident we can meet the growing demands of the families turning to us, largely because of the generosity of so many.

Thank you for your continued support of Ronald McDonald House Charities Midwest MN, WI, IA and to children and families turning to us in their time of need.



Nick Mueller, Chief Executive Officer



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## Marching to Bianca's Beats

As Laura glanced at her phone, it started ringing... It was their doctor's personal cell phone. "We just accepted a heart for Bianca."

The call ended a three-year journey for Bianca...and started the rest of her life.

Life was relatively normal for 18-month-old Bianca. She could play with her friends for hours on end. But when she would play outside in the snow, her cheeks, lips, hands, and toes would be bluish purple. Nick, Bianca's dad, said, "That's different."

Laura, Bianca's mom, started working through the possibilities with their pediatrician. When no other diagnosis was apparent, he referred the family for an echocardiogram—a test to take pictures of her heart. Nick and Laura assumed it was to confirm that nothing was wrong.

They were not prepared for what would happen next.

Bianca was immediately diagnosed with restrictive cardiomyopathy, a very serious and super rare condition in which the ventricles of the heart do not relax as they should. It forces the atrium to balloon up and compensate for the ventricles.

The diagnosis was both obvious and discouraging.

"There's no quick or easy solution; there's no known cure, there's no surgery to fix it," said Nick. "She needed a heart transplant."

"Even doctors who are experts in hearts are not familiar with her condition," Laura said. "That is how rare it is."

"She won the bad lottery," said Nick.

For the next two years, Nick and Laura lived on pins and needles, waiting for a life-threatening problem or a life-saving phone call. Despite continuously flowing medication and wearing a peripherally inserted central catheter line, Bianca continued to march to her own beat. She was mostly your typical busy, joyful toddler...but she was on borrowed time.



Just over two years after her initial diagnosis, Bianca developed a significant cough. Nick and Laura noticed she had been more sick, more often, so a cold was not a surprise. They lost count of how many times she had bronchiolitis or pneumonia. Laura made an appointment with her pediatrician...in hopes to confirm, once again, that nothing major was wrong. They were instantly referred to Mayo, and seen the following day.

And once again, they were not prepared for what happened next.

Bianca was in danger, and her safety was precarious. "We were mad, scared, frustrated," said Laura. "We knew it could happen, but we weren't ready."

Mayo allowed a one-night stop home to pack clothes and other essentials, and for Bianca to say goodbye to her sister and brother. Nick and Laura didn't know when—or if—Bianca would see her siblings

again. The next morning, she was admitted to the Pediatric Intensive Care Unit at Mayo Clinic.

After she received her first heart catheter, doctors realized how serious it was. Her heart was so weak, she was put on life support and had a left ventricle assist device surgically implanted. Three days later, she coded, and they surgically implanted a right ventricle assist device with the oxygenator to exchange oxygen and carbon dioxide in her blood. She had a blood clot in the left ventricle chamber of her heart.

Nothing was functioning correctly, or going well for Bianca.

“We did not know how she was going to handle the surgeries or whether or not she would survive,” Laura said. “It was terrifying in all the worst ways you could imagine.”

After her first of three initial open-heart surgeries, she was moved to the Cardiovascular Intensive Care Unit for closer monitoring. But the move meant less rest and less resources for recuperation. Nick and Laura needed a home base: “a place to get away, sleep, recharge, collect ourselves...so we are ready to do it all again the next day.”

“You never think you will be the person who needs help,” said Nick. “The Ronald McDonald House is a great place for other people, but not for you. But it was exactly what we needed.”

Nick and Laura had a general understanding of the House, but they did not know about all the support and services. A room for sleep, spaces for recharge, family activities, snacks, and meals; “it was all essential and it helped us function.”



“Every second, every minute focused on other things—like food or finances—was a second or minute away from Bianca,” said Laura. “The House took care of our needs, so we didn’t have to worry about anything but her.”

“That is what the House provides.”

“Life as a medical family is different,” said Nick. “It is hard to explain, but the House is more than a building...it is a judgement free community with unwavering support. People going through the same or similar thing you are going through, and they truly get it, when nobody else does.”

Despite the relief they found at the Ronald McDonald House, the stress and anxiety was very real. A couple of months later, as Bianca recovered from her open-heart surgeries, she was finally healthy enough and was re-listed for a heart transplant.

But nearly 30 percent of cardiac pediatric patients die waiting.

“Waiting was very hard,” Laura said. “And we only waited an additional four months.”

After a summer together in Rochester, Nick and Laura prepared for another school year away from their other kids, waiting for a call.

They did not wait long.

“Initially, we believed every call would be the call,” Nick said. “But it didn’t happen, and it didn’t happen, and it didn’t happen.”





“Until it did.”

“I could not breathe,” said Laura. “Really—the perfect heart for my little girl?”

“Is this real life?”

Nick was nervous about accepting a heart; a successful transplant is a once-in-a-lifetime opportunity. But the doctor assured him it was not only a heart, but it was the heart for Bianca.

“That was enough for me,” said Nick.



Once the transplant team accepts a heart, everything and everyone is a whirlwind. Bianca was tested and prepped from top to bottom and whisked away for surgery. Laura and Nick waited once again... but their wait—their entire wait—was almost over.



“Bianca received such an incredible gift,” Nick said.

“We already experienced the traumatic; it was time for the excitement,” Laura said.

Following a successful September surgery and initial rehabilitation, Nick and Laura finally introduced Bianca to the Ronald McDonald House in November.

And on a snowy day in January, after 282 nights at the House...they were going home.

The first year after a transplant is the most critical, because the immune system is suppressed. But it is slowly building, and Bianca is slowly growing. Doctors expect she will march to her own beat for a full and complete life.

“We have so much hope,” said Nick.

Nick and Laura said their long and winding journey would not have been possible without the Ronald McDonald House. As he walked the halls and looked at the names of donors, he said, “people will never fully realize what their gift does for families—what it did for our family.”

“I wish I could write them all a letter and say thanks.”

Volunteers make the House a home for children and families from all over the world. Aside from keeping it safe and welcoming, Laura said the volunteers “truly knew my children and my family.”

“They are joyful hearts and are calming in a very chaotic situation.”

Bianca is home again with her sister and brother, though she will need regular appointments with her heart team. But as she played at the train table, she said, “Can we come back? I love the Ronald McDonald House.”



[Click here to support families like Bianca's by donating to RMHC Midwest MN, WI, IA!](#)

# RMHC Midwest MN, WI, IA Receives Transformational Gift

Ronald McDonald House Charities Midwest MN, WI, IA received a \$250,000 gift from Tom and the Haugen family, in memory of Sue Haugen, to support children and families staying at the House in Rochester. It is the largest non-campaign donation the organization has ever received.

"We are honored to work with Tom and his family on this inspiring gift that will bring comfort and relief to so many families during their time in Rochester," said Nick Mueller. "We have all been touched by honoring Sue's legacy, in a way that impacts so many people."



# **2023 DISTINGUISHED VOLUNTEER AWARD RECIPIENT** **SHONA BROOKS**

We are in our 4th year of our Distinguished Volunteer Award, an award to honor a volunteer who exemplifies the core values of Ronald McDonald House Charities, and who stands out for their extraordinary service and dedication.

Shona Brooks is this year's Distinguished Volunteer Award recipient.

She began her involvement with RMHC Midwest MN, WI, IA in 2013, in collaboration with fellow artist Andrea Costopoulos.

Together, Shona and Andrea created the Visiting Artist Program.

While Andrea has since retired from her volunteer role at our House, Shona has continued to enhance and expand the treasured program for children and families.

Shona is recognized not only for the tremendous skillset she brings to the family experience and programming at our House, but also for the countless hours of time she gives to planning for upcoming Visiting Artist nights and preparing art kits and specialty themed bags. She does all of these things alongside working full-time and owning and operating an art supply and gift store, *The Goat*, in Northfield, Minn.

Shona is a pure joy to work with and her energy and passion for the Visiting Artist Program shines through all she does; bringing art alive at our House through color for everyone to experience. She encourages children to make meaningful messes with paint, glitter, markers, and crayons. She helps each child to be a kid and alleviate some of the stress of their day. Shona brings laughter to the room and helps everyone find their inner artist, and excels at connecting with the parents and making everyone feel comfortable.

**We are truly honored and excited to recognize Shona for her above-and-beyond efforts and support in all she does for the families and our House!**







AND



Ronald McDonald House Charities®  
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Children and families at our House were treated to a very special House Dinner provided by [Crave American Kitchen & Sushi Bar!](#)

Highlighted by their famous sushi boat, Crave's Executive Chef and General Manager and Kaskaid Hospitality's Vice President of Operations served each guest at our House!

Crave serves a House Dinner monthly, and also donates one date night every month for one family staying at our House!

**LEARN HOW YOUR GROUP OR BUSINESS CAN BECOME A MONTHLY HOUSE DINNER HERO!**







45TH ANNUAL

# SWING YOUR BIRDIE GOLF CLASSIC

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**Monday, June 12, 2023  
at SOMERBY GOLF CLUB**

Brunch and Registration at 10:00 am  
Shotgun Start at 11:00 am

## SOLD OUT

**Join the Waiting List Today  
Save the Date**

**Monday, June 10, 2024**

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## UPCOMING EVENTS

<b>Cans for Kids</b>	Saturday, June 10, 2023
<b>Swing Your Birdie Golf Classic</b>	Monday, June 12, 2023 <b>JOIN THE WAITING LIST</b>
<b>Rochester Honkers Medical Professionals Night</b>	Saturday, June 24, 2023 <b>CLICK HERE TO PURCHASE TICKETS</b> Half of the ticket sale proceeds will benefit RMHC Midwest MN, WI, IA

## SHARE YOUR STORY!

Each family who has stayed at our House has a unique and beautiful story!

Your story is the reason people support RMHC Midwest MN, WI, IA!

Contact [Jacob Dreyer, Communications Director](#), for more information.

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