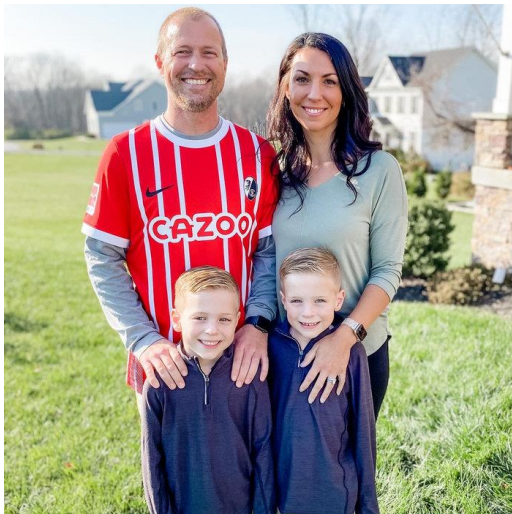




**MARCH 2024**



**Happy Spring!**

I hope this letter finds you well in this beautiful transition into spring, a time of rejuvenation and new beginnings. The triplets joined the world during spring and it was definitely a new beginning where we embarked on a journey that forever changed our lives. This year has been profoundly impactful and has brought so much hope to so many, and we are only getting started. I am thrilled to share some exciting updates and express our deepest gratitude for your unwavering support and commitment to the Heart Community.

First and foremost, I want to extend a heartfelt thank you to each and every one of you who contributed to the success of our Heart Month Fundraiser. Thanks to

your generosity and dedication, we not only met but surpassed our fundraising goal! Your support enabled us to provide lunch to local Heart Heroes, Comfort Kits to Heart Warriors, and supply Beads of Courage cardiac beads to local hospitals. Your kindness and compassion truly make a difference in the lives of those we serve, and for that, we are incredibly grateful.

As we look ahead, we are filled with anticipation for our upcoming events – the [Hearts for Hope Family Happy Hour](#) and the [Green Hearts Open Charity Golf Tournament](#). These events are not only opportunities for us to come together as a community but also crucial fundraising initiatives that enable us to continue our mission of providing support to those in need. Sponsorships are still available for both events, but please note that **sponsorship opportunities will close May 1st**. If you or your organization are interested in becoming a sponsor, I encourage you to act quickly to secure your spot.

Tickets for the [Hearts for Hope Family Happy Hour](#) are now available, and golf registration for the [Green Hearts Open Charity Golf Tournament](#) will open on April 1st. We can't wait to see you there and make unforgettable memories together!

Additionally, I want to remind you about the [Fairway Fortune 50/50 Raffle for Tiny Champions](#), which is currently open for entries. Don't miss your chance to enter and win while supporting a great cause.

As we continue our work, I want to emphasize how crucial your support is to ensuring that KHT can continue to provide vital support to Heart Families in need. With the costs of items increasing, it is becoming increasingly challenging to maintain the same level of support as we have in the past. However, with your continued generosity and dedication, I am confident that we can overcome these challenges and continue to make a meaningful difference in the lives of those we serve.

Thank you once again for your unwavering support. Together, we can create brighter futures for our Heart Warriors, Heart Families, and Tiny Champions.

With heartfelt gratitude,  
Katelin Krueger

## **Thank You For Your Support During Heart Month**

We're thrilled to announce that we not only reached our fundraising goal, but surpassed it with a grand total of \$3,284.81 raised! This would not be possible without your generosity and we are so grateful for your support. We were able to provide 60 meals to Heart Heroes, supply new Beads of Courage to local hospitals, and gift 11 comfort kits to brave Heart Warriors!



Donate

Upcoming Events



## **FAIRWAY FORTUNE**

### **50/50 Raffle for Tiny Champions**

Enter to win by purchasing a KHT Golf Ball for \$50 and get the chance to win up to \$7,500!

[\*\*Get Yours!\*\*](#)



## **HEARTS FOR HOPE**

### **Family Happy Hour**

Sunday, June 9, 2024

Twain's Tavern | Pasadena MD  
Family-friendly fun from 1 - 6 PM!

[\*\*Register Now!\*\*](#)



## **HEARTS FOR HOPE Cornhole Tournament**

Sunday, June 9, 2024

Twain's Tavern | Pasadena MD  
Family-friendly fun from 1 - 6 PM!

[Come Play!](#)



## **GREEN HEARTS OPEN Charity Golf Tournament**

Monday, June 10, 2024

Compass Pointe Golf Course | Pasadena  
MD

Registration: 7:30 AM | Shotgun: 9:00 AM

[Register Now!](#)

LITTLE  HANDS  
**BIG HEARTS**  
BULL & OYSTER BASH

# **LITTLE HANDS BIG HEARTS**

## **Bull & Oyster Bash**

Saturday, September 14, 2024

Jimmy's Famous Seafood | Baltimore MD

6:00 - 10:00 PM

**Register Now!**

**Heart Warrior Of The Month**



## **Meet Holden!**

Holden has Tetralogy of Fallot (TOF). When Mom was 30 weeks pregnant with Holden, she was taken to the hospital after having a TIA (stroke with short-lasting symptoms). It was there that Holden's special heart was discovered. At the time, it was unknown if



Holden had Tetralogy of Fallot or Double Outlet Right Ventricle (DORV). The doctors thought that he would need to stay in the NICU until surgery at 3-4 months. Holden was born at 37 weeks + 4 days after an emergency c-section due to Holden's heart rate being abnormal. Mom was able to kiss Holden before he was whisked away to PICU and was finally able to see him about 5 hours later. After only 3 days, Holden was discharged – and Mom and Dad weren't sure what to think about it since it was originally discussed he'd be in the hospital for much longer. After a week of being home, they went for another opinion, and thank goodness they did. Holden's original diagnosis was TOF vs DORV, but after seeing his new cardiologist, Holden was officially diagnosed with TOF. Holden had his open-heart surgery shortly after his diagnosis. Mom remembers being very numb the day of Holden's heart surgery, saying she didn't know how to feel. Thankfully, Holden had an amazing recovery! Fast forward to today and he's doing so well! He loves running and playing with friends! Holden may have to have a cardiac catheterization in the future. Holden is an amazing Heart Warrior and a true champion!

[Share Your Heart Warrior Story](#)

## CHD News & Articles

### **Born With Half a Heart, This First Grader Wants to be a Pediatric Surgeon**

Reprinted from [American Heart Association News Stories](#)

Before Stephanie and Brennen Lewis could host the baby gender reveal party they were planning for family and friends, they had an ultrasound appointment to attend. They were eager for another glimpse of their first baby.

The technician looked at the baby's bones, brain and major organs. The test included a scan of the baby's heart. It didn't look right. Stephanie's doctor referred her to a pediatric cardiologist right away. That same day, she had a fetal echocardiogram, which took

pictures of the baby's heart. Afterward, the doctor sat the couple down. "This is a normal heart," he said, pointing to the drawing he'd sketched on a dry erase board. "And this is your baby's heart."

Their daughter had hypoplastic left heart syndrome. It's a rare congenital heart defect where the left side of the heart is significantly underdeveloped and can't pump blood well. Babies born with the syndrome typically need a series of surgeries after birth. The Lewises would have to wait for their baby to grow to see how severe her case might be. Stephanie was speechless. Tears flowed down her face.

That night at dinner with Brennen's parents, Brennen encouraged Stephanie to stay optimistic. "Let's keep planning the gender reveal," he said. The next several months brought regular echos and scans of the baby. Stephanie was petrified of what condition her daughter would be in at birth.

Doctors at their hospital in West Palm Beach, Florida, suggested delivering the baby at a hospital in Miami that would be better equipped to care for the newborn. The Lewises opted to deliver in the more familiar setting of their local hospital, then be transported as necessary.

Stephanie delivered McKenna via cesarean section. She held her daughter on her chest for a fleeting moment, then doctors put a tube in the baby's throat to help her breathe. Brennen rode with McKenna in an ambulance to a nearby airport. They took a medical flight helicopter to Miami. Brennen FaceTimed Stephanie with updates for two days, until she was healthy enough to join them. McKenna would need a series of three open-heart surgeries. On McKenna's fifth day, she underwent her first.

Stephanie and Brennen fell asleep on each other as doctors worked on their daughter's heart for seven hours. The procedure redirected the flow of blood away from the problematic left side, so the right side of her heart could pump blood to both her lungs and the rest of her body.

Meanwhile, genetic testing was done. It didn't explain what caused the defect. Two weeks later, Stephanie and Brennen got to hold their baby. During their hospital stay, they watched Hurricane Irma sweep through the city from their room. A month after surgery, mom, dad and McKenna went home.

Of course, this wasn't the newborn experience they'd dreamed of having. The Lewises were in "survival mode." Stephanie and Brennen followed a binder full of instructions. There were multiple medicines to give, daily weight checks, and weekly doctor appointments with echos, X-rays and bloodwork. They had a nurse on speed dial and let their local fire and rescue squad know about McKenna in case of an emergency.

At two and a half months, they returned to the hospital. Doctors ran tests to see if McKenna was ready for a second surgery, which would reroute blood in another way, reducing the strain on the right ventricle. It turned out she needed it right away.

McKenna recovered nicely. Family life settled into enough of a groove that, around her second birthday, she became a big sister to a healthy baby boy named Declan. About six months later, McKenna had her third surgery. The procedure finished the rerouting, this time ensuring all of the oxygen-poor blood returning from the body flows to the lungs.

Finally, Brennen began releasing the stress he'd been carrying since learning his daughter needed not one, not two, but three open-heart surgeries. "I definitely got a lot of gray hairs," he said. Then Brennen shifted careers. He left his family's business to pursue his dream of a career in law enforcement. He's an officer in his county's sheriff's office.

Now, McKenna is a happy and healthy 7-year-old. She wants to be a pediatric surgeon when she grows up. She wrestles with her younger brother, rides her scooter with abandon, and loves cheerleading and gymnastics. "I like the rope, but my favorite part is the balance beam," McKenna said. On Christmas Eve, McKenna took her first plane flight. The family flew to Canada to see Stephanie's parents. "It was a total surprise for the kids," Stephanie said. It was also their first time seeing snow.

McKenna sees her cardiologist once a year and takes medications to keep her heart rhythm and blood pressure steady. Her medicines can be hard on the kidneys, and McKenna gets muscle cramps and dehydrated.

"She'll always have a single ventricle, and there are still obstacles," Stephanie said, "but they're manageable." Most important now is for McKenna to stay active to build muscle, eat healthy and be well hydrated. If her heart function declines, the next step is a heart transplant. But she could also never need one.

At school, McKenna is surrounded by supportive classmates and teachers. When the Lewises signed up for their local American Heart Association Heart Walk, they had team shirts made. On McKenna Day at school, her fellow first graders wore the shirts. This year, McKenna is a national AHA Heart Walk ambassador.

For now, the Lewises take comfort in the fact that there are women born with McKenna's condition now in their 20s and 30s who have their own children. "Back in the '80s, some of these kids never made it out of the delivery room," Stephanie said. "Because of advances in heart care, there's a long horizon ahead for McKenna."

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## Supporting Your Child with a Congenital Heart Defect into Adulthood

Reprinted From [HealthyChildren.org](https://www.healthychildren.org)

Having a baby is a special, life-changing experience. But families face unique challenges when their baby is born with a congenital heart defect.

A congenital [heart defect](#) is a problem with the heart that is present at birth. For example, a baby may be born with a hole in their heart or a leaky valve. Sometimes, the heart defect is more severe, and their heart has missing vessels or chambers or is not fully formed.

Fortunately, people with heart defects are living longer, healthier lives. But even if a heart defect has been surgically repaired and is not causing symptoms, your child needs to continue to see a pediatric cardiologist who can catch any problems early and keep your child healthy.

Read on to learn more about lifelong care for people with congenital heart defects.

### **Consider how congenital heart defects affect your child's development.**

Children with heart defects may [meet developmental milestones](#) at a different pace. Young children may benefit from early intervention support as they learn new skills and work through challenges.

Parents, you know your child best. Do not hesitate to ask your pediatrician if you have any concerns about the way your child plays, learns, speaks, acts or moves. Learn more [here](#). In school, they may reach milestones on a different timeline than peers without heart defects. And sometimes, your child may have to miss school for appointments, tests or other procedures.

No matter your child's age, your pediatrician can explain other types of support, such as [milestones](#), [learning](#) and [other concerns](#).

Need help understanding your medical bills and benefits? [Watch this video](#) about Medical Billing Help: Understanding Your Charges.

### **Make sure your child has a role in their congenital heart defect care.**

From an early age, your child should be involved in their own care with their pediatric cardiologist and other health care providers. This can help them feel more confident in their own health decisions as they move into their adult life. Your child's health care team can help identify risks and support their nutritional, exercise and cardiac their changing needs as they develop and grow.

## **Prepare to move from pediatric to adult cardiac care.**

Children with congenital heart defects need to continue their congenital cardiac care into adulthood. The pediatric cardiologist that has cared for your child may only see them up to a certain age. When they are old enough, they need to start seeing an adult congenital cardiologist who can make sure they stay healthy as an adult.

Families should begin planning for this [transition](#) well before they become an adult. Help them prepare to take on more responsibility for their health. This will help them learn how to schedule doctor visits, understand health insurance and keep track of their medications in [college](#) and beyond. Learn more about healthy living with a congenital heart defect as an adult:

- [Adult Congenital Heart Association: Heart To Heart Peer Mentors](#)
- [Planning a Healthy Pregnancy with a Congenital Heart Defect](#)

### **Stay connected with others in your community.**

It is not unusual to feel alone or isolated when you find out your child or family member has a heart defect. You may feel a range of emotions, including sadness, fear, guilt and confusion.

Ask your pediatrician or other health care provider for a referral to a community support group or connection with a family who has experienced a similar situation. Several free resources are offered to families:

- [Congenital Heart Defects Support Network: The American Heart Association and the Children's Heart Foundation](#)
- [Mended Little Hearts: Support for Heart Patients and Their Families](#)
- [Conquering CHD: Connecting with Others](#)

### **Resources**

- [Challenges Faced By Parents of Children With Congenital Heart Disease](#)
  - [Helping Children With Congenital Heart Disease Stay Healthy, Active & Fit](#)
  - [Types of Congenital Heart Defects](#)
-

## The Diagnosis Was Devastating. The Treatment Was Novel. The Results Were Everything Nathaniel’s Parents Could Have Hoped For.

Reprinted from [NYU Langone NewsHub](#)

Henya Grossman was 27 weeks [pregnant](#) with her first child when diagnostic scans revealed devastating news: her unborn baby had a severely weakened left ventricle, the heart chamber that pumps oxygenated blood throughout the body. He would likely develop severe heart failure after birth and require a heart transplant to survive.

“I went to the top doctors and hospitals in Israel,” says Grossman, an Israeli native. “But no one had experience treating unborn babies with this rare condition. I was told my baby likely wouldn’t survive. But I wanted to keep my baby and fight for him.”

Her best hope was to go to the United States. [Achiau Ludomirsky, MD](#), a pediatric cardiologist with NYU Langone’s [Pediatric Congenital Heart Program](#), part of [Hassenfeld Children’s Hospital at NYU Langone](#), spoke with Grossman and her husband, Yair Broyer. A plan was hatched: they would travel to NYU Langone for specialty prenatal and pediatric cardiac care, so that ultimately their baby could have a lifesaving heart transplant.

After arriving in New York City, Grossman began weekly prenatal care appointments with NYU Langone’s [maternal–fetal medicine](#) and [pediatric cardiology](#) specialists. A [fetal echocardiogram](#) confirmed the diagnosis first made by her Israeli doctors: life-threatening dilated cardiomyopathy. “Undergoing prenatal care with an unborn baby who was so sick felt like going into the unknown,” Grossman says. “But everyone at NYU Langone was so helpful and professional. I was so grateful there was a place like this in the world.”

At 37 weeks into her pregnancy, the first major milestone was accomplished: Grossman gave birth to a baby boy, Nathaniel, on December 6, 2022, weighing 6 pounds, 15 ounces. Nathaniel was placed on Grossman’s chest for a few seconds of bonding time before he was taken to the [Congenital Cardiovascular Care Unit](#) at Hassenfeld Children’s Hospital. “I

was so happy and relieved that he made it, and that he was crying and that he looked good,” Grossman says.

Nathaniel was alive, but at high risk for complications such as sudden cardiac death. “From our perspective, he was very sick,” says [Rakesh Singh, MD](#), medical director of the [Pediatric Heart Failure and Transplant Program](#). “He would need a heart transplant to survive.”

The second major challenge was keeping Nathaniel alive until a donor heart became available. The average waiting time for an infant for a heart transplant in the New York City area is six to nine months.

To bridge that time, a left ventricular assist device (LVAD) called the Berlin Heart could help Nathaniel’s weakened heart move blood through his body. But the Berlin Heart carried an increased risk of bleeding and stroke in infants. Was there a better way? [T.K. Susheel Kumar, MD](#), surgical director of the Pediatric Heart Failure and Transplant Program, proposed a novel plan: to compensate for Nathaniel’s failing left ventricle, use his healthy right ventricle to augment blood flow throughout his body. “I felt like with NYU Langone, I was going to be in the very best hands.” -Hanya Grossman, Nathaniel's Mom

“Given that Nathaniel’s right heart ventricle was functioning well, and with the known complications of a ventricular assist device in a small baby, we decided to convert him into a single ventricle physiology, using a hybrid strategy,” says Dr. Kumar. The strategy involved using intravenous medication to keep open the patent ductus arteriosus (PDA)—an extra blood vessel in the heart that naturally closes after birth. Nathaniel would also have pulmonary artery banding, a surgical procedure to place bands on the outside of the pulmonary artery to limit blood flow. This reduces the risk of long-term lung damage. “The hybrid procedure—keeping the PDA open and pulmonary artery banding—had been performed in patients with other [congenital heart defects](#). We decided to mimic that procedure in Nathaniel even though it wasn’t the standard of care for dilated cardiomyopathy,” Dr. Singh says.



If the procedure didn't work, they had the Berlin Heart as a backup. Everyone, including Nathaniel's parents, agreed that the hybrid procedure was worth a try.

After a few touch and go weeks, Nathaniel stabilized with the PDA procedure and pulmonary artery banding. He was placed on the transplant list, and the wait for a new heart began.

While having the novel therapy, Nathaniel remained on a ventilator under mild sedation under the dedicated and specialized care of the Congenital Cardiovascular Care Unit team. "Our goal was to keep him as awake as possible so he could develop and interact with his family until an infant heart became available," Dr. Singh says.

Nathaniel's parents spent their days and nights in the hospital in shifts. "Since Nathaniel's birth, we never left him alone for more than a few hours," Grossman says. "The hospital didn't just take care of Nathaniel medically. The amazing [child life specialists](#) also took care of him mentally and developmentally, making his time in the hospital so much better. And the nurses were great. They became our friends and like family."

As the months wore on, Nathaniel had good and bad days, including a trip to the [cardiac catheterization lab](#) for a stent procedure to prop open the PDA. "The hardest part of the journey is getting to transplant, and we kept thinking of ways to get there," Dr. Singh says. Due to the lack of infant donor hearts, the chance of an infant dying while waiting for a heart transplant is as high as 20 percent, which is higher than that of all other patients awaiting a solid organ transplant. "It felt like we were fighting for every minute of Nathaniel's life," Grossman says.

After five and a half months in the Congenital Cardiovascular Care Unit, Nathaniel began showing signs of worsening heart failure. "We were having ongoing discussions with the parents about whether we should go ahead with the Berlin Heart," Dr. Singh says. Fortunately, on June 16, 2023, a donor heart became available, and Nathaniel had lifesaving heart transplant surgery. A team of doctors, including Dr. Kumar and [Ralph S. Mosca, MD](#), co-director of the Pediatric Congenital Heart Program, performed a heart

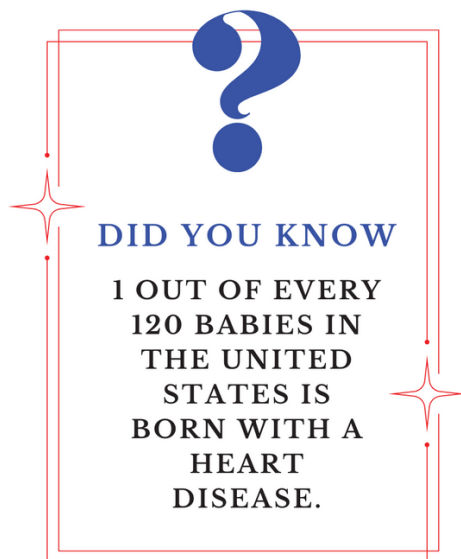
transplant after rebuilding Nathaniel's pulmonary arteries. "The donor heart worked perfectly from the moment it started beating," Dr. Kumar says.

Two months later, Nathaniel's parents, who have moved to New York City, took their son home for the first time. Nathaniel has been receiving outpatient [occupational](#), [physical](#), [speech](#) therapy, and other [pediatric rehabilitation services](#) through [Rusk Rehabilitation](#) to catch up on developmental milestones, such as crawling, standing, and eating by mouth.

Nathaniel is expected to live a full life. "Infants who make it to transplant have a greater than 50 percent chance of doing well with the same heart 25 years later," Dr. Singh says. "Children can go to school with their peers, in regular classes. They can play sports, go to college, get married and have kids, all the things parents want for their kids."

On December 6, 2023, Nathaniel celebrated his first birthday with balloons and video calls with his extended family in Israel. "I have the most amazing baby in the world, thanks to God and the amazing medical team at NYU Langone that he sent to us, who saved his life," Grossman says. "I can't thank them enough for helping me have my miracle child."

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**DID YOU KNOW**

**1 OUT OF EVERY  
120 BABIES IN  
THE UNITED  
STATES IS  
BORN WITH A  
HEART  
DISEASE.**



**WHAT DOES KHT DO?**

- Hospital Comfort Kits
- Family Financial Aid
- Hospital Wish List Donations
- UMMS Children's Hospital Children's Heart Program
- CHD Week Goodies
- Funding Beads of Courage
- And more!

[Learn More](#)

## CHD Resources

### General CHD Support

- [Kids Health](#)
- [My Heart Visit- Peer Support](#)
- [Children's Hospital of Philadelphia](#)

### Sibling Support

- [Sibling Support Project](#)
- [Comfort Zone Camp](#)

### Family Support

- [Medicine Assistance Tool](#)
- [Rx Hope](#)
- [CDC](#)

[View More](#)

## Sponsorship Opportunities

This year, we are thrilled to introduce corporate sponsorships that extend beyond a single event. By becoming a corporate sponsor, your organization will receive year-round recognition on our website, social media platforms, and newsletters. This ensures that your commitment to our cause is acknowledged prominently throughout the year, not just during the tournament. You can find the benefits of our corporate sponsorships below and view our various packages. **Sponsorship opportunities close May 1st**, so act now to secure your spot!

	MIRACLE MAKERS DIAMOND \$15,000	HEALING HEARTS PLATINUM \$10,000	HEART HEROES GOLD \$7,000	LITTLE ANGELS SILVER \$4,000	LITTLE WARRIOR SUPPORTERS \$1,500
<b>BRAND EXPOSURE</b>					
Name on KHT Heartstrings Newsletter	♥ LOGO	♥ LOGO	♥ LOGO	♥	♥
Featured social media posts throughout 2024	♥ 12	♥ 12	♥ 6	♥ 4	♥ 3
Name placement on official event website	♥ LOGO	♥ LOGO	♥ LOGO	♥	♥
Gratitude posts on event-related social media platforms	♥	♥	♥	♥	♥
Opportunity to provide items in welcome gifts and/or auction items	♥	♥			
Opportunity to set up info booth	♥				
<b>EVENT RECOGNITION</b>					
Name featured in promotional materials & event signage	♥ LOGO	♥ LOGO	♥ LOGO	♥	♥
Name in electronic programs	♥ LOGO	♥ LOGO	♥ LOGO	♥	♥
Verbal recognition during events	♥	♥			
<b>VIP ACCESS &amp; EVENT TICKETS</b>					
Hearts for Hope Family Happy Hour June 9th   Twain's Tavern	♥ 10 tickets	♥ 8 tickets	♥ 6 tickets	♥ 4 tickets	
Green Hearts Open: Charity Golf Tournament June 10th   Compass Pointe Golf Courses	♥ 2 foursomes	♥ 2 foursomes	♥ 1 foursome	♥ 1 foursome	
Entry into Fairway Fortune: 50/50 Raffle for Tiny Champions Drawing June 10th	♥ x3	♥ x2	♥	♥	♥
Little Hearts, Big Hopes Bull & Oyster Bash Fall 2024   Jimmy's Famous Seafood	♥ 2 tables	♥ 2 tables	♥ 1 table	♥ 1 table	
Entry into Tiny Beats Jackpot: 50/50 Raffle for Heart Warriors Drawing Fall 2024	♥ x3	♥ x2	♥	♥	♥
Merry Morning for Little Hearts: Breakfast with Santa Charity Event Winter 2024   More Info to Come	♥ 10 tickets	♥ 8 tickets	♥ 6 tickets	♥ 4 tickets	

[Sponsorship Spec Sheet](#)

[Become A Sponsor](#)

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# XPO



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