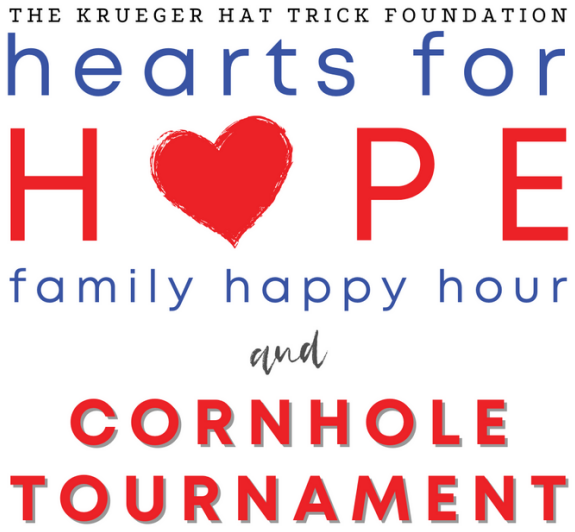
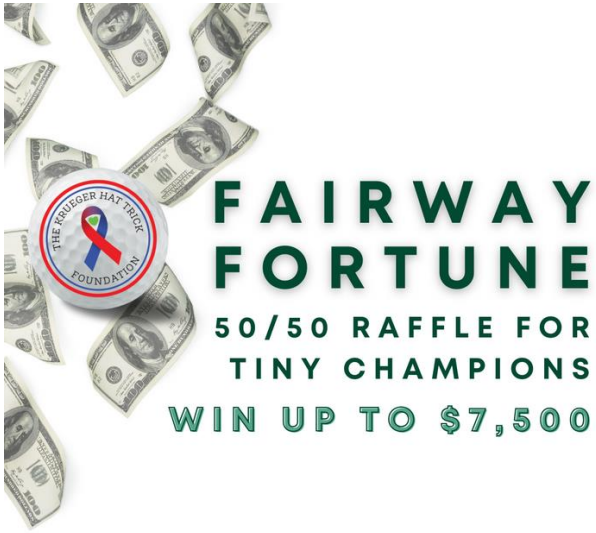
HEARTSTRINGS

Connecting CHD supporters

JANUARY 2025

Upcoming Events





HEARTS FOR HOPE

Family Happy Hour & Cornhole Tournament

Sunday, June 8, 2025

1:00 PM - 6:00 PM

Twain's Tavern | Pasadena, MD

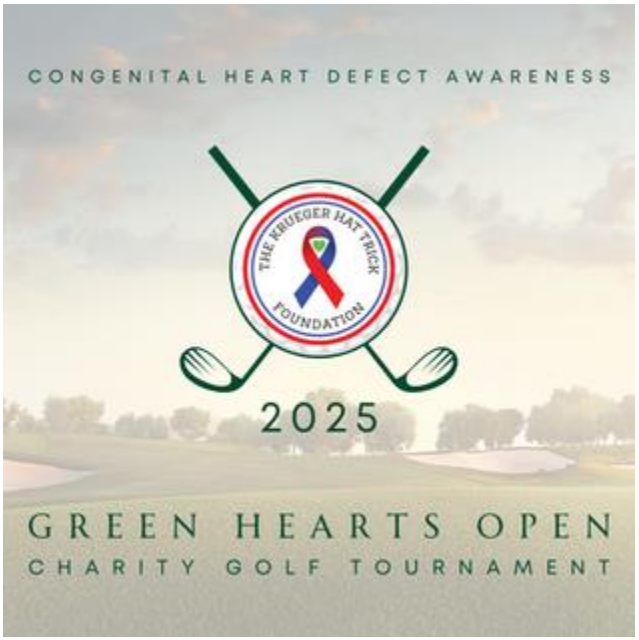
Join Us!

FAIRWAY FORTUNE

50/50 Raffle for Tiny Champions

Monday, June 9, 2024

Enter To Win!



GREEN HEARTS OPEN

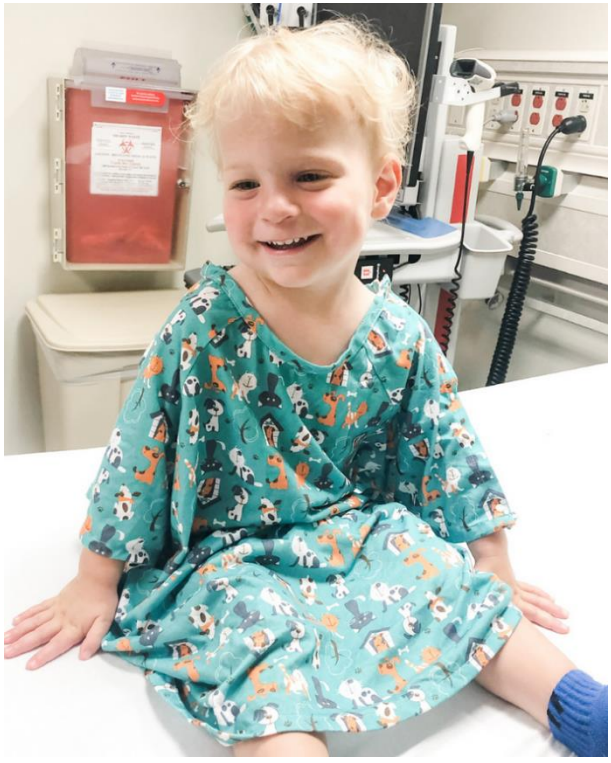
Charity Golf Tournament

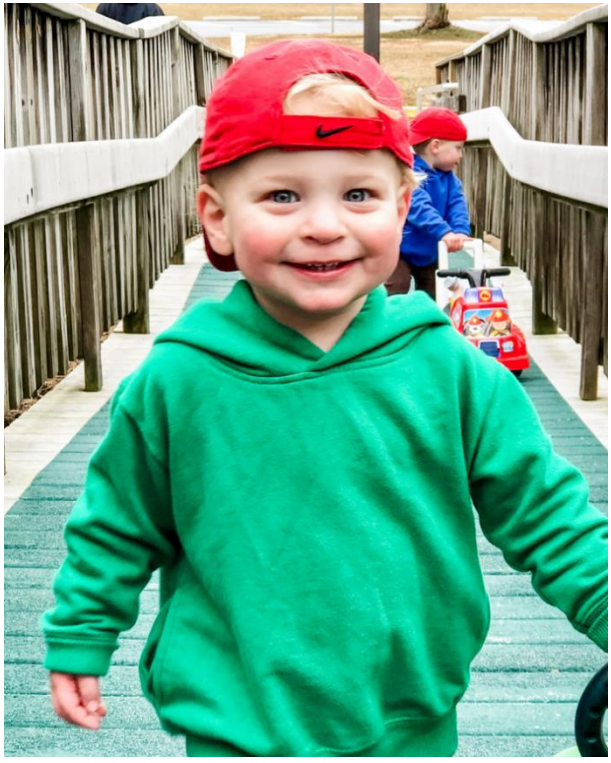
Monday, June 9, 2025

Compass Pointe Golf Courses | Pasadena, MD

Register Now!

Heart Warrior Of the Month





Meet Aiden

Aiden was born on May 2, 2017, along with his triplet brothers, Jacob & Zachary. Aiden had been diagnosed with Congenitally Corrected Transposition of the Great Arteries along with other heart complications. Aiden's two lower chambers were switched, and his two main arteries coming from his heart and feeding his lungs and body were also switched. Aiden also had a hardening of a section of his artery that carried blood to the lungs. All of this made part of his heart work harder than it was built to.

The plan was that Aiden would have open-heart surgery within the first days or months of life. In true Aiden fashion, he showed everyone that he didn't need interventions, and he

could handle these "complications" just fine. Around the triplets' second birthday Aiden started to tire easily and throughout the summer he couldn't keep up with his brothers.

Shortly after Aiden's second birthday he had an MRI followed by a cardiac catheterization which all showed that his heart was a bit more complicated than initially thought. Surgery to rebuild the pathways of his heart to ensure the blood went to the correct chambers and arteries was scheduled for October 2, 2019.

Just a couple of hours after surgery while in the Pediatric Intensive Care Unit, Aiden's little body couldn't handle the trauma that it had gone through. Aiden became an angel that evening. He continues to live through his brothers and The Krueger Hat Trick Foundation, shining light and joy to all those that are apart of the Heart Community.

Share Your Heart Warrior Story

CHD News & Articles

Newborn Was In Heart Failure. Now 13, He Helped Pass A Pulse Ox Law For Babies.

Reprinted From American Heart Association News

One week after their son was born, Melissa and Cory Berlin of Mayfield, New York, arrived at the pediatrician's office for Colton's first well-baby checkup. The 23-year-old, first-time parents were eager to learn his height and weight measurements.

While examining Colton, the doctor said she'd be right back. She needed to get the practice's other doctor. Melissa looked at Cory, wide-eyed. "Something is really wrong," she said. "I'm sure he's OK," said Cory.

Melissa squinted at Colton's arms. They were tinged blue. Maybe he's just cold, she told Cory. The doctors returned to the room in a flurry, their faces somber. They listened to Colton's heart and breathing again. "Your son is in heart failure," the other doctor said. "You have to get to the ER right now."

An ambulance rushed the family to a medical center in Albany, an hour away. Doctors did an echocardiogram, an ultrasound that takes an image of the heart and its blood vessels. It showed Colton's left ventricle was tiny and not functioning.

He had a congenital heart defect known as hypoplastic left heart syndrome. His organs were slowly shutting down because not enough blood was reaching them. That caused a condition called disseminated intravascular coagulation, or DIC, a rare blood clotting disorder that can lead to uncontrollable bleeding. For Colton, it prompted a stroke.

Colton spent five days in the neonatal intensive care unit. At one point, he stopped breathing. Doctors were able to stabilize him. They also drew up a plan. Colton needed a series of surgeries starting right away to re-route blood flow in his heart.

At 12 days old, the first operation re-routed blood so Colton's right ventricle could take over for the left, pumping blood to his body and lungs.

The surgery was successful, and Colton came home a few weeks later. Melissa's parents, both nurses who've worked with cardiac patients, lived across the street. They came over to check on Colton every day.

At nearly 8 months old, Colton had a second surgery to refine the re-routing of blood. That operation went well, too.

Colton was lucky that his condition was detected when it was. But it likely would've been caught even sooner had he undergone a non-invasive test to measure his oxygen level right after birth.

A low oxygen level can signal a congenital heart defect, which is the most common kind of birth defect. Around 1 in 100 infants born each year in the U.S. have a heart defect, and pulse oximetry screening is estimated to help single out over 90% of cases.

Since 2018, all 50 states and Washington, D.C., have newborn screening programs to test for critical congenital heart defects. However, when Colton was born, New York did not have those in place.

Around Colton's second birthday, the Berlins were among several parent advocates who shared their story with legislators at the New York State Capitol in support of a pulse ox law.

"He had a single functioning ventricle in his heart and it was missed in utero, but was something that would have been picked up had he had pulse ox testing," Melissa said in her testimony, tearing up as she held Colton in his red "Heart Hero" cape.

Meanwhile, Colton had his final surgery to complete the re-routing of blood in his heart. It was a success. After that came more good news.

New York Gov. Andrew Cuomo signed the pulse ox bill into law, and it took effect in January 2014. Now, every baby born in New York state has their oxygen level tested before they're discharged from the hospital.

Today, Colton is 13 and he's thriving. The eighth grader can't play contact sports, but he plays soccer and basketball and runs track. He was recently inducted into the National Junior Honor Society for his academic performance.

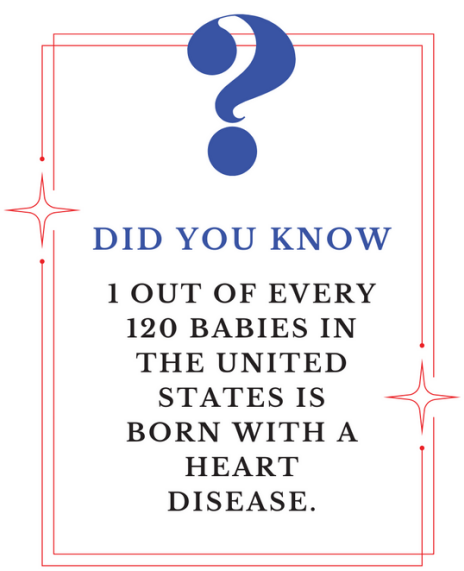
"He's a typical 13-year-old boy," Melissa said. "You would not have any clue if you saw him that he has anything going on with his health. Nothing holds him back. It's a hidden disability. Sometimes I can't even believe that we went through what we went through." Colton loves to wake surf and downhill ski, too, and he's interested in becoming a firefighter. He gets an echocardiogram every six months and takes various medications. He also sees a liver specialist.

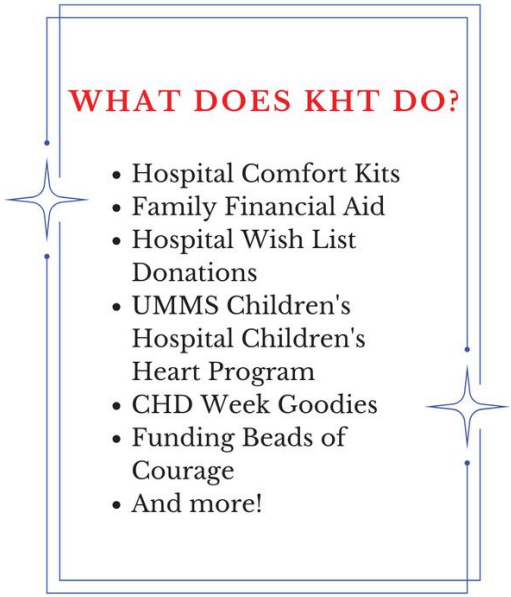
Some people with his condition ultimately go into liver failure because the re-routing of blood ends up damaging the liver. "They can't really give you a road map," Melissa said. "His surgeries are considered palliative, and his condition is lifelong. So, it's wait and see."

The Berlins also have a 9-year-old daughter, Callie, who's healthy. Together, the family continues to share Colton's story to spread awareness about congenital heart defects. Colton was an auctioneer at the American Heart Association's 2024 Capital Region Heart Ball. He's also an active member of his local AHA Cardiac Kids group.

The Berlins participate in the AHA's annual Capital Region Heart Walk, and Colton has spoken to school assemblies as part of the nonprofit's Kids Heart Challenge.
"I do it so other people can hear my story," Colton said. To kids he meets with heart issues, he tells them to "just keep pushing through it."

Melissa and Cory often think about what their pediatrician told them years after they knew Colton would be OK. The doctor said that had they not had an exam that day, they likely would have put Colton down for a nap and he never would have woken up. "We are so fortunate," Melissa said. "Not a day goes by that we don't think he's a miracle."





Learn More

Teens Dealing with Congenital Heart Defects

Reprinted From Mended Little Hearts Blog

Your high school classmates are picking out prom gowns, and you're donning another hospital gown. They're choosing colleges, and you're meeting with your medical team to discuss your treatment plan. Getting a heart disease diagnosis at any age is hard, but it's especially difficult on teens.

At 17 I was diagnosed with hypertrophic cardiomyopathy. I was on the edge of adulthood but not yet fully equipped with the tools to handle it. Like most of us, my first experience with heart disease was hearing of an older relative with a heart ailment. When they discovered my condition, I was given pamphlets upon pamphlets with clinical information from my cardiologist but I had no peers to talk with about my daily struggles and fears.

To the newly diagnosed patient; I want you to know that you're not alone. Heart disease is scary and by no means easy. Many years later I'm still trying to figure things out. But I want you to know a few important things I've learned since my diagnosis.

1. You will get through all of this. The shock of the diagnosis will fade, however, the pain might still remain. It's all part of the process of accepting a new normal. It's reasonable that it will take a while for reality to set in, but when it does, the healing can begin.

   There might be byproducts of your condition like anxiety, depression, rude doctors or relatives and hours upon hours of tests that can seem overwhelming. Restructure them as opportunities for growth and learning. Deepen your understanding of yourself, others and the world around us. There are hidden blessings that come with all hardships in life, such as strength, wisdom and empathy.

2. Your head is probably spinning right now, trying to understand anything surrounding your disease, but that's OK. Soon you'll become a pharmacist and a doctor without even having to go to med school. You'll understand your disease better than your doctor. Knowledge is power, and so is becoming an expert patient involved in your own healthcare. But don't let your diagnosis dictate your life. You are so much more than a cluster of mutated cells in an organ. Your true self is that deeper entity within that is perfectly whole and well no matter what you are experiencing.

3. Not many people will understand the things you are going through. In their world, young people don't get diseases like we did. You will probably get some rude comments that might make you angry or cry. It's alright to be hurt; they just don't understand. We don't even understand everything going on with us at times.

   I'm an anomaly and have been lucky enough to almost always be surrounded by people who seek to understand my disease and not define

me by it. I've only encountered a boyfriend with parents who had a hard time accepting it. At first it made me feel so small that every other trait I possessed was trumped by a medical condition I had no control over. However, It was through this experience that I learned that these negative interpretations are more a reflection and educational ignorance of the person judging you rather than the attributes you have to offer. Seek to educate those around you, but don't take it personally if they don't elicit a response of compassion or empathy. It's just a lack of understanding.

4. Others may say "you're strong for someone so young," and call you an "inspiration." It's a very sweet sentiment but you don't always have to be strong. Faking smiles to make other people feel more comfortable will only make you feel worse and more alone. You're allowed to show weakness or cry. You are not expected to be anything but yourself. You are not expected to put on a show.

5. Find your allies. Social media is a valuable resource to connect and empower patients. You can gain knowledge of your condition and support from peers who understand all the obstacles you are facing. Find support groups, join Facebook groups, search hashtags and message others. Find peers going through what you are. You will learn there's a unique "heart buddy" bond we all have to each other and that often, the best "medicine" is talking to someone who has walked in your shoes.

She Solved Her Heart Problem. Then She Learned Her Unborn Baby Had One.

Reprinted From American Heart Association News

Ashley Boyea had asthma, so she wasn't surprised when she got breathless at work. But when she began gasping for air just walking around, the then-25-year-old sales associate went to her pulmonologist for a checkup.

The doctor had her wear a heart monitor for a few days. It showed her heart was beating too fast. More testing revealed that, in addition to a rapid heart rate, she had sick sinus syndrome, a condition in which the heart's sinoatrial node is damaged and can't produce normal heartbeats.

First, Boyea tried to control it through medication. When that didn't work, her doctor suggested she see an electrophysiologist, or cardiologist specializing in heart rhythm disorders. This led to Boyea undergoing an ablation, a procedure that creates tiny scars in the heart to help break up the signals that cause irregular heartbeats.

Her irregular heart rhythm didn't improve, so she had a second ablation. In the days and weeks that followed, Boyea was so exhausted that she could barely function. Her doctor suggested a pacemaker. The battery-powered device implanted in the chest helps regulate a person's heartbeat.

Boyea got hers two months before her wedding. During the "I do's," it was only her fiancé, Ben Boyea, who made her breathless.

About three years after her wedding, Ashley found out she was pregnant. Then, during a routine anatomy scan, she and Ben learned their baby had a problem with his heart – transposition of the great arteries, a massive plumbing issue. It's a rare congenital heart defect in which the two main arteries that leave the heart are reversed.

"Of all the heart conditions to have, this is a straightforward one," the doctor told the Boyeas. Just after birth, their baby would need an "arterial switch," or surgery to switch his pulmonary artery and aorta. The explanations helped put them at ease.

The Boyeas' local hospital in Plattsburgh, New York, wasn't equipped to care for a baby with the defect. Ashley was high-risk, too, because of her own heart issue. So, the Boyeas regularly drove nearly three hours to a hospital in Albany for care, including monthly scans of the baby. Ashley also had to be close to the hospital well before her due date, just in

case she went into labor early. Luckily, Ben's aunt and uncle lived in Albany, so she stayed with them.

Doctors decided to induce labor so they could better plan for the baby's surgery. After birth, baby Gabriel looked blue and lethargic. Knowing he'd need immediate care, Ashley wasn't expecting to hold him. But a nurse placed Gabriel in her arms for a minute before whisking him off to the neonatal intensive care unit.

Gabriel underwent surgery at 6 days old. It was a success. After three weeks in the hospital, the Boyeas brought him home.

Like his mom, Gabriel, now 8, is doing well. He plays soccer and loves Legos. Both regularly visit a cardiologist.

"He's watched very closely," Ashley said. "We are nervous about him." Ashley never learned the underlying cause of her electrical issue. Her doctor didn't think it was genetic. Even if it was, as an adoptee, Ashley didn't have any details about her birth family's health history.

Gabriel's heart issue didn't have an explanation, either. "We were told this was just a fluke," Ashley said. "That it's not at all connected to me."

Ashley and Ben have two other healthy boys – Marcus, 6, and Joseph, 2. They had extra anatomy scans before birth, and their hearts looked OK.

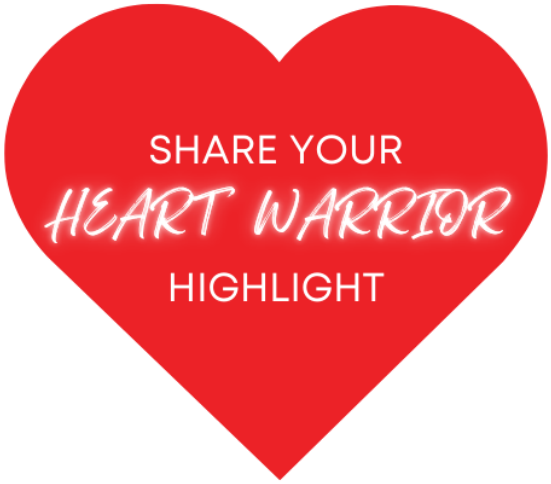
Now, Ashley's pacemaker is nearing the end of its battery life, and she needs a new one. It's a challenge to balance scheduling the appointment – she has to drive to Albany to get it replaced – with taking care of her boys and the busyness of life. "We're kind of in a health care desert where we live," she said. "There aren't enough doctors here, and we have to travel for our medical care. It means a lot of long drives."

Along the way, joining VT Cardiac Kids – a support group for kids with congenital heart defects – has helped the Boyeas navigate obstacles. Ashley and Gabriel attend events

such as apple picking and baseball games. Ashley also speaks about heart disease to help dispel misconceptions.

"It's so important for people to understand that heart disease isn't just high blood pressure or cholesterol," she said. "It's also heart defects and rhythm issues."

Heart Families



Want your Heart Warrior's courage to be featured by KHT? Email us your story. By sharing, you're raising CHD awareness and giving hope to other Heart Families.

Share Heart Warrior Highlight

If you've navigated life with a CHD, your advice could be a lifeline to others. Share your helpful tips to support the Heart Family community.

Share Helpful Advice

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

Become A Sponsor & Make A Difference!

Corporate sponsorships are open for 2025! Partner with us to enjoy year-round recognition while helping us meet our goals and create meaningful change.

Your support directly impacts the lives of heart warriors and their families. Join us as a sponsor today and make a lasting difference!

THE KRUEGER HAT TRICK FOUNDATION

CORPORATE SPONSORSHIPS

**To be included in Hearts for Hope & Green Hearts Open, sponsorship must be purchased by May*

	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
BRAND EXPOSURE					
Name on KHT Heartstrings Newsletter	♥ LOGO	♥ LOGO	♥ LOGO	♥	♥
Featured social media posts for one rolling year	♥ 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	♥				
EVENT RECOGNITION					
Name featured in promotional materials & event signage	♥ LOGO	♥ LOGO	♥ LOGO	♥	♥
Name in electronic programs	♥ LOGO	♥ LOGO	♥ LOGO	♥	♥
Verbal recognition during events	♥	♥			
VIP ACCESS & EVENT TICKETS					
Hearts for Hope Family Happy Hour + Cornhole Tournament Sunday in June	♥ 10 tickets	♥ 8 tickets	♥ 6 tickets	♥ 4 tickets	
Green Hearts Open Charity Golf Tournament Monday in June	♥ 2 foursomes	♥ 2 foursomes	♥ 1 foursome	♥ 1 foursome	
Entry into Fairway Fortune: 50/50 Raffle for Tiny Champions Drawing at Golf Tournament	♥ x3	♥ x2	♥	♥	♥
Little Hearts Big Hopes Bull & Oyster Bash Saturday in September	♥ 2 tables	♥ 2 tables	♥ 1 table	♥ 1 table	
Santa Brunch Weekend in December	♥ 10 tickets	♥ 8 tickets	♥ 6 tickets	♥ 4 tickets	

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