

# MEET THE HEART CENTER PFAC

The Cardiac Patient Family Advisory Council (Cardiac PFAC) is made up of family members of patients seen in the Children's Mercy Heart Center. The Cardiac PFAC works with the Heart Center staff to advocate on behalf of patients and families for the highest quality of care. The council serves as a voice for families to influence policies and procedures, as well as make the communication and education for heart patients and families better.

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## Jamie Bolen



### **Why did you become a Cardiac PFAC member?**

I thought it would be a valuable experience to be a part of a collaboration between the Heart Center and parents of children who receive cardiac care at Children's Mercy, and that it would be an opportunity to give back to the organization for all they have done for our family. I appreciate that CM values the input of the caregivers and has created this partnership. I am honored to be part of a team that helps give feedback, guide future change & continue to look for ways to maintain the high level of patient centered care that we have all come to know.

### **Tell us about your family.**

My husband and I have three teenage children. Riley and Lindsey who are both heart healthy, and Bryce who was born in 2005 with Hypoplastic Left Heart Syndrome. We also have two Golden Retrievers, Otis and Clyde.

### **Tell us about your experience at Children's Mercy.**

We have received outstanding care at Children's Mercy since before Bryce was born. He was diagnosed prenatally at CM and has had countless surgeries and procedures in his life, all done at CM. I was so inspired by the nursing care that Bryce received that I went to nursing school once he was in kindergarten. I am proud to say that I am now a nurse manager at CM. We are thankful for all that CM has done for our family. It's impossible to put into words how much we value CM, as they truly saved our son's life. They have provided family centered care throughout the years, allowing us to truly be a part of his healthcare team. We are so grateful to have a hospital so close to home that offers top-notch quality of care combined with a health care team that provides an outstanding level of compassion and empathy.

### **What kinds of activities does your family enjoy doing together?**

Our favorite activity to do together as a family is to travel. We love to go to the beach, go hiking in the mountains, or sightseeing and trying new foods all over the country.

# Alexis Bossi



## **Why did you become a Cardiac PFAC member?**

As my oldest daughter, Laney, has grown up and now thrived with a complex CHD, it has always been important to me to get involved in the heart community in a variety of ways. What started as a way for me to cope when we started this journey over 15 years ago, has turned into a passion project to help other families, empower us all with information and education, and advocate for all those affected by CHDs. I was part of establishing the Cardiac PFAC in 2017 and am very proud of what we have accomplished to date and what we will continue to push for going forward.

## **Tell us about your family.**

My husband, Eric, and I met during college in 1995 and have been together ever since. We have two amazing daughters, Laney and Collins, who are very close (most days!) despite a six-year age gap. We rescued our Border Collie mix pup, Forrest, a few years ago and he adds excitement (and maybe some anxiety) to our household.

## **Tell us about your experience at Children's Mercy.**

While we did not have Laney's three planned surgeries to complete her Fontan at Children's Mercy, we have received all our care here for the 13 years since then. In addition to Cardiology, we see a host of specialists as well, all working together to give Laney the greatest opportunity to thrive. Our journey started out rocky, but all this time later, we're embracing it and have an amazing teenager on our hands who is not stopped by half a heart at all!

## **What kinds of activities does your family enjoy doing together?**

Our family loves to travel, explore new things, eat out and generally spend time together – we like each other!

# Roger Gattis



## **Why did you become a Cardiac PFAC member?**

Throughout this journey as the parent of a heart warrior I have held in my mind the idea of just how important it is to help families in similar circumstances not only with understanding the resources available to them, but also how to help shape their expectations in a world completely foreign to most of us who find ourselves here.

## **Tell us about your family.**

My wife Savanna and I have been married since November of 2005 and have called the KC metro home since 2014. We have two children: our oldest, Maizie, was born in 2016 and is our empath while our youngest, Emery, is our heart warrior born in 2020 and is every bit a fighter.

## **Tell us about your experience at Children's Mercy.**

At Savanna's 20-week checkup it was discovered that baby #2 had Double Outlet Right Ventricle with abnormal mitral valve anatomy. The fetal care team at CMH helped us throughout the remainder of the pregnancy, and after a stint in NICU after birth, Emery was followed by CHAMP throughout her first 14 months of life. She has undergone a series of staged bi-ventricle repair surgeries at Boston Children's Hospital and is currently under the care of Dr. Kaine here at CMH.

## **What kinds of activities does your family enjoy doing together?**

We spend our time together exploring the outdoors, riding the area trails on our bicycles, searching for new ice cream shops, and generally making the most out of the seasonality of the Midwest.

# Mickey Hall



## **Why did you become a Cardiac PFAC member?**

I became a Cardiac PFAC member because I wanted to do something to give back to Children's Mercy as they are the reason my daughter is here with us today. I wanted to be a voice for patients and their families and shine light on our perspective. Plus, I wanted to be part of this wonderful group that is working hard to make any improvements they can to streamline processes and make patients and their families as equipped as possible to face their journeys.

## **Tell us about your family.**

We have an active, some might say rambunctious family! My husband Nathan and I have three adorable children Zane is 12, Zoie is 10, and Zali is 9. Zoie is our heart kiddo. She is a big-hearted, energetic young lady that has such empathy for anyone in distress. She often forgets about boundaries as she peers in carriers of crying babies and she's always first on the scene if someone is hurt.

## **Tell us about your experience at Children's Mercy.**

We found out in utero that Zoie had heart complications. She was the 30th child to be born at Children's Mercy in the Fetal Health Center. They took great care of her and she received her first heart surgery at 3 weeks old. She has since had 3 more surgeries and is followed by a variety of clinics. Children's Mercy has provided us with outstanding care and guidance through the years. We are so thankful to have this top-notch hospital in our city.

## **What kinds of activities does your family enjoy doing together?**

We enjoy church events, sports, family hikes, summer days at the lake and visiting friends and relatives. We try to find moments to make memories whenever we can and we are truly grateful for our three blessings.



# Michele Kieffer



## **Why did you become a Cardiac PFAC Member?**

My daughter, Macie, was diagnosed with Complex Heart Disease before she was born in 2019. She was born at Children's Mercy in July 2019 and my family and I spent the next five months living at the Ronald McDonald House / Children's Mercy as Macie underwent two complex heart surgeries. During my stay, I understood it was super important to advocate for Macie everyday. Once I came home in December 2019, I wanted to have a voice and have involvement in improving the care and hospital experience for other families and their loved ones. When the recommendation from another heart babies mom came to my attention, I joined the Cardiac PFAC to make that difference happen.

## **Tell us about your family.**

My husband, Andy, and I have been married since September 2007. We have two children. Avery, 10 year old, is the sweetest, caring and loving and always willing to help. She takes pride in everything she does and loves to play with her little sister. Macie, 2 years old, is our heart warrior children and is the strongest little girl you will ever meet. She always is surprising us with something new that she accomplishes everyday. She never gives up on exceeding her milestones with her beautiful smiling.

## **Tell us about your experience at Children's Mercy.**

Macie was born in the Fetal Health Clinic within Children's Mercy and was transferred immediately after birth to the NICU unit. She spent three days there and then was transferred to the PICU unit and spend the next five months in the PICU unit. She underwent two open heart surgeries, the Norwood at 8 days old, and the Glen, at 4 months old. She is currently followed by two specialists along with the cardiology clinic at Children's Mercy.

## **What kinds of activities does your family enjoy doing together.**

Family time is very important to all of us. We enjoy biking, being outdoors, playing games, watching movies and visiting the mountains when we have the opportunity. We try to spend as much time with our family and friends. We realize that laughing and smiling everyday is so important to our family bond.

# Kaitlin Meade



## **Why did you become a Cardiac PFAC member?**

Children's Mercy is such an amazing place, and the Cardiology Department has become a second family to us. I wanted to be a part of continuing to help make this department and hospital a phenomenal place to receive the care and answers families are seeking for their child(ren).

## **Tell us about your family.**

My husband, Scott, and I welcomed twins, William and Kameron, in December of 2019. Despite all of the prenatal care I received, our boys had undiagnosed critical congenital heart defects, which became evident on day 5 and 6 after birth. Both of our boys were transferred to Children's Mercy, where they spent five months staying in the NICU, PICU and 4S towers.

William was diagnosed with Interrupted Aortic Arch, a large VSD, ASD, Bicuspid Aortic Valve, and SVT. He had one open heart surgery to fix the IAA, VSD and ASD. William also required a G-Tube to help with nutrition and growth. William was discharged from Children's Mercy in April of 2019, while his brother remained in Children's Mercy. William had the sweetest smile and personality. His sweet spirit was contagious and one couldn't help but love him. Unfortunately, William passed away on May 13, 2019, from his CHDs.

Kameron's defects were similar, in that he was diagnosed with Coarctation of the Aorta, large VSD, Bicuspid Aortic Valve and PFO and first degree heart block. Kameron was more complicated and has had multiple surgeries to repair his CHDs. Kameron also had feeding difficulties and required having a G-Tube placed to help with nutrition and growth.

Kameron continues to be followed in the Heart Center and is doing great! We talk about and incorporate William in our everyday lives and are so thankful for the time we were allowed to have with him. The world of CHD is not something we ever expected or could have predicted to be thrust into, but we take it one day at a time, and stand in awe of the two Heart Warriors we have been given!

## **Tell us about your experience at Children's Mercy.**

The one-of-a-kind care we received while our boys were inpatient, and the follow up care Kameron continues to receive, is phenomenal. From his surgeons, doctor, nurses, care assistants and volunteers, it is evident they care deeply about the children and families they serve. They have celebrated every victory with us, and cried with us when we lost our precious William. Anytime we have a question or concern, we are heard. Kameron's providers are accessible, and always willing to go above and beyond to make sure Kameron has the best care possible. Truly, I cannot say enough wonderful things about Children's Mercy.

## **What kinds of activities does your family enjoy doing together?**

Right now, Kameron is interested in animals, particularly lions, as well as anything sports related. We spend a lot of time kicking and throwing balls, growling like a lion, reading and just being together.

# Harmony Misenhelter



## **Why did you become a Cardiac PFAC member?**

I wanted to become a PFAC member to help advocate for the children and the families who are going through such a difficult process such as a complex heart condition. I want to help continue to improve the quality of care they receive and make sure that they are not going without resources that they need. I also strongly believe that having a child with heart disease effects the whole family and I want to help advocate for the siblings as well because they struggle way more than most people realize.

## **Tell us about your family.**

My husband, Alan, and I have been married for almost 20 years. Makenzie is our oldest child and is 17, she was born with Hypoplastic Left Heart Syndrome. She loves small children and talks about how she hopes she can be a care assistant on 4 Sutherland one day. Allie is 16 and is loving, shy and wears her heart on her sleeve. Allie has struggled a lot throughout the years with mental health due to the severity of several of Makenzie's diagnosis. Colton is our youngest at 10 years old. He is creative, funny and way to smart for his own good. We also have 3 dogs named Toby, Tucker and Ollie.

## **Tell us about your experience at Children's Mercy.**

We have been using Children's Mercy since Makenzie was a day old. She has had countless procedures, surgeries. She has had 5 open heart surgeries with one of those surgeries being a heart transplant on 3/17/21. Makenzie is being followed by neurology, rheumatology, hepatology, gastroenterology, nephrology, psychology, infectious disease, genetics, pulmonology and a few other clinics. We have learned a lot from the staff at CM, but I know that they have learned a lot from Makenzie as well. Makenzie doesn't ever do anything "text book." Makenzie was the first case of plastic bronchitis that they had ever seen and that was a crazy experience to see so many doctors amazed at learning about a disease they had never even heard of.

## **What kinds of activities does your family enjoy doing together?**

Our family enjoys having dinner together and watching movies. We are apart of the HopeKids organization, and we do several activities though them. Our favorites are going to Main Event or Dave and Busters and playing video games together. We just recently returned from a trip to Montana that we received through HopeKids and it was a trip of a lifetime. We also enjoy camping, swimming and sitting outside by the fire pit.

# Makenzie Misenhelter



## **Why did you become a Cardiac PFAC member?**

I want to help make the hospital experience better for other kids that have heart defects.

## **Tell us about your family.**

I have 2 siblings. My sister Allie is 17 and my brother Colton is 10. I also live with my mom and dad and we have 3 dogs. My dogs' names are Toby, Tucker and Ollie.

## **Tell us about your experience at Children's Mercy.**

I have been going to Children's Mercy since I was a day old. My favorite part is the relationships I have made with the nurses and doctors and getting to go to camp systole since I was 8. My least favorite part is all the blood draws I have had to have and when I am in the hospital getting woken up in the middle of the night for vitals. (It is the worst.)

## **What kinds of activities does your family enjoy doing together?**

Going to the lake and going camping. We are a part of HopeKids KC and we do a lot of fun things through them. We also spend a lot of time hanging out with our family friends and doing bbqs and going swimming.



# Amanda Rupp



## **Why did you become a Cardiac PFAC member?**

My husband and I were very involved with care during my daughters almost one year inpatient time, staying bedside day and night. Since we have been home, I find myself reaching out to heart families in my own community, especially parents new to the heart warrior world, offering advice and a peer connection so far away from the specialties of the hospital. It is rewarding for me personally to find ways to be involved, share and help improve our experiences when so much of this life feels uncontrollable.

## **Tell us about your family.**

I live with my husband, Jonathan, in Hays, Kan. He is a police officer and I currently work part-time as interim director of the local historical society. We have a HH son, Ivan, who is a 6-year-old first grader. Amelia is our Heart Warrior. She is 4, attends half-day preschool and loves it. Ivan is an advocate for his sister almost more than I am at times. Our family and community have been huge supports.

## **Tell us about your experience at Children's Mercy.**

We did not know of any CHD prior to birth. Born in July of 2017, Amelia spent almost the first entire year at CM (a 6+ month straight PICU stay included). During that time she had a Gtube placed, 3 open heart surgeries and one stent on ECMO. She now has a mechanical mitral valve. She had a 4th OHS in April 2021 and will have a couple more by adulthood. Her original diagnosis is AVSD or AV Canal but has been the extreme case at every turn.

Dr. Douglas has performed all of Amelia's 4 OHS and we absolutely love him. His bedside manner is exceptional. It wasn't until his first explanation of the first OHS that I truly understood Amelia's anatomy and defect.

Amelia's cardiologist is Dr. Natalie Jayaram, whom we are so thankful for! Dr. Jayaram goes above and beyond any other doctor or specialist we have had experience with. Absolute caring is her way and she values my concerns in every situation.

## **What kinds of activities does your family enjoy doing together?**

Besides school, work and the occasional rec. activity we are homebodies. Our days are spent making crafts, playing games and watching kid shows. Typical "living the dream" adult life. Amelia is in gymnastics and Ivan enjoys soccer and basketball. Most family trips revolve around traveling to KC for follow-up appointments, but we make the most of it.

# Katy Shepherd



## **Why did you become a Cardiac PFAC Member?**

My daughter, Mila, has complex medical needs, primarily heart related, and has spent substantial time at Children's Mercy for inpatient stays and clinic appointments. I have learned how important it is to be an advocate for her and our family. I joined the Cardiac PFAC because I wanted to become more involved in the heart community to help improve care and improve the hospital and clinical experience for patients and their families. I also love meeting other families like ours and forming that bond that many don't understand.

## **Tell us about your family.**

My husband, Dustin, and I have been married since 2013. We have two children, Luke and Mila. Luke is our typically developing child who has the best sense of humor and is so loving and accepting of everyone and everything. Mila is our heart warrior who is the strongest and most unpredictable person I know. To say she keeps us on our toes is an understatement.

## **Tell us about your experience at Children's Mercy.**

Mila spent the majority of her first year of life inpatient on and off at Children's Mercy and continues to have frequent stays. She underwent G-Tube surgery when she was two months old and underwent open-heart surgery when she was 6 months old. She is currently followed by ten specialists at Children's Mercy so we have appointments often. Also, both kids received outpatient therapy (physical and occupational for Mila and speech for Luke) through Children's Mercy. At one point it felt like we were at CM every day.

## **What kinds of activities does your family enjoy doing together?**

Our family enjoys walking to the park, eating, listening to music and dancing, joking with each other and surprising one another. We all have a light-heartedness about us so it is important to smile and laugh as much as possible. We are also an outgoing family, so we love spending time with family and friends, as well as meeting new people.

# Brandie Stoddard



## **Why did you become a Cardiac PFAC Member?**

Our lives were changed in the blink of an eye, when our youngest daughter, Haevyn, went into heart failure at 4 months old and later diagnosed with dilated cardiomyopathy leading to a heart transplant. Because of the expertise and amazing care, she received at Children's Mercy, she is now a thriving, spunky, 10 year old. It's important for me to give back in some way. I learned of the PFAC through their newsletter and thought this could be a way to share knowledge and experiences we've received as a family through all our complex medical struggles. I want other families in similar situations to know they aren't alone. Being a part of continuing to evolve the Heart Center and the type of care future heart families receive is something I am passionate about.

## **Tell us about your family.**

My husband, Dustin, and I were high school sweethearts and have been married for 17 years. We have 2 heart warriors, daughters Ashlyn (14) and Haevyn (10).

Through genetic testing, we learned that the type of cardiomyopathy Haevyn was diagnosed with was familial, therefore, we also learned Ashlyn also has cardiomyopathy, but we were able to catch it in enough time to treat with medication. Ashlyn also has Turner Syndrome, another condition we were able to have diagnosed by Children's Mercy.

We also have a fur pup named, River a German Shorthair Pointer, who loves hunting with Dustin.

## **Tell us about your experience at Children's Mercy.**

When our local doctor met us in the ER and said we were being transported to Children's Mercy in Kansas City, I instantly knew the situation was dire because I knew Children's Mercy was where kids in our region go when things are serious. Once we arrived in the ICU by Life Star, all the nurses, physicians, surgeons and therapists made sure we were informed of all procedures and understood the challenges ahead whether good or bad. Dustin and I respect, trust and are truly thankful for the outstanding care our girls receive from many of the specialties offered at Children's Mercy.

## **What kinds of activities does your family enjoy doing together?**

As a family we love to travel and spend time with relatives!

# Kaitlyn Tennant



## **Why did you become a Cardiac PFAC member?**

When our son was born, we spent a month inpatient at CMKC. We know our hospital stay would have been much more difficult for us as a family if I hadn't been a cardiac nurse myself. When I found out about the PFAC I wanted to join to help bridge the gap between the Care Team and the family.

## **Tell us about your family.**

My husband Kyle and I got married in 2018. He works for Cerner and I have been a nurse for CM and at Saint Luke's Health System. We have two dogs - Sadie and Simba - and our now 2.5 year old son Jay. Jay was born with D- Transposition of the Great Arteries with a Ventricular Septal Defect. We love spending time outside and are trying to complete the 1,000 Hour Outside Challenge. We are big sports fans, and frequent baseball, hockey, and football games. We have lived in Kansas City since 2014 and love giving back to our local community at any opportunity.

## **Tell us about your experience at Children's Mercy.**

I completed a Capstone in nursing school on an inpatient unit at CM and worked in a CM outpatient clinic prior to the start of COVID. I left my clinic position a month before Jay was born but I wasn't gone very long. The day after Jay was born, he was flown to CM's NICU and taken into the cath lab. A week later he had open heart surgery to correct his TGA. The cardiothoracic surgical team was amazing. Dr. Douglas and Dr. Gibson were great at explaining the procedure to us and made us feel as comfortable as possible with the process. Unfortunately, Jay developed chylothorax following surgery which delayed his healing time and impaired his ability to eat. The lactation team was helpful in teaching us how to skim milk to keep him on breastmilk while he healed from chylothorax and so we could go home. Jay is still seen by many specialists at CM and all have been happy to educate us and listen to our concerns about taking care of Jay.

## **What kinds of activities does your family enjoy doing together?**

Together we enjoy hanging out with our dogs, traveling, attending sports events, and spending time with our families.



# Taylor Vitzum



## **Why did you become a Cardiac PFAC member?**

The heart journey is full of ups and downs. After going through our son's own traumatic ICU stay, I knew that I wanted to get involved and help make a difference in the lives of other heart families.

## **Tell us about your family.**

My husband, Robert, and I are high school sweethearts. We have been together for almost 13 years. We have two children. Isabella (Izzy) is almost 4 and is the best big sister — empathetic, silly, loving, and kind. Callan (born 9/9/22 in the Fetal Health Center) is our Hypoplastic Right Heart Syndrome Warrior. He is always smiling, laughing, or getting into everything! He's a typical toddler! We also have two little doggies that complete our family.

## **Tell us about your experience at Children's Mercy.**

Children's Mercy made a very scary time a little easier. We learned about Callan's special heart at my 20-week anatomy scan. We had our first fetal echo in the Fetal Health Center at 21 weeks and transferred my prenatal care to CMH. I gave birth to Callan via caesarean section at 38 weeks pregnant. Callan spent 95 days in the NICU. In his time there, he underwent a valvuloplasty, developed NEC and survived becoming septic, had an ileocolostomy which resulted in an ileostomy bag, dehisced, and had to have a second intestinal surgery, and also contracted rotavirus. He came home on 12/13/22 with an ostomy bag and an ng-tube. In February 2023, he had his ostomy reversed and had a g-tube placed. In November 2023, he had a posterior tongue tie revised. He currently sees cardiology, neurology, gastroenterology, feeding therapy, and neonatology. He also receives occupational therapy through Infant Toddler Services of Johnson County. He keeps us very busy, but we love every moment of it. He is worth it. Shout out to our NICU nurses who saved Callan's life and became our family over the 3 months we spent inpatient. We will forever be grateful for you.

## **What kinds of activities does your family enjoy doing together?**

We are home bodies! We love watching movies with our kids and snuggling with them. We have lots of dance parties with our toddlers. We also enjoy trying new foods and exposing our children to different foods from other cultures.

# Cassie Wiederholt



## **Why did you become a Cardiac PFAC Member?**

There is so much I wish I would've known as a brand new mother with a son entering the world with a CHD. Although the CHD journey is different for everyone, I have found great healing in connecting with other heart families along the way. In being a member of the Cardiac PFAC, as well as the POPS mentoring program, I hope I am able to support other parents in learning the importance of advocating for themselves and their children, while also helping to improve the care provided - whether that is within the clinic and/or hospital setting, or finding additional resources to assist all family members affected by CHD.

## **Tell us about your family.**

My husband, Adam, and I got married in 2016. We had our son, Gordon, born with HLHS, in 2017, and our daughter, Jocelyn, was born heart-healthy in 2019. Our youngest, Rudy, was born in 2022 with a Bicuspid Aortic Valve. We live in a small town in northwest Missouri. Gordon has an innate love for farming, and Jocelyn is equally as passionate about reading books. Adam works in ag retail and has a cattle/row crop farming operation with his brother and dad. I work as a seasonal tax collector from within the home, while also caring for our children and a niece full-time, and greatly enjoy coaching softball any chance I get.

## **Tell us about your experience at Children's Mercy.**

Due to Gordon's diagnosis of HLHS in-utero, he was delivered at Children's Mercy, and spent his first 3.5 months of life there before getting to go home for the first time. He has returned numerous times for various catheterizations and inpatient stays, has been followed by multiple clinics, and has had three open-heart surgeries in total.

## **What kinds of activities does your family enjoy doing together?**

We enjoy spending as much time outdoors as possible, and especially love being with our families and friends. We use our camper any chance we get, love to sing and dance together, frequently visit our family farm, and love on our three dogs - Jackie, Jasper and Mercy.

# Jessica Wiley



## **Why did you become a Cardiac PFAC member?**

I became a Cardiac PFAC member to be able to help and advocate for other families and patients that are going through the same as we did for our complex health child.

## **Tell us about your family.**

My husband, Bob, and I have been married since May 2013. We have 3 children. Our oldest Beckett is about to turn 6 and is quite the loving but ornery oldest! Cohen, our complex heart Child is about to turn 3 and is so full of love, attitude and determination! We always wanted 2 kids but didn't fill complete so 18 months after having Cohen, we had our little girl, Cambree. She loves her brothers and is always on the go!

## **Tell us about your experience at Children's Mercy.**

We started out at Children's after our 20 week anatomy scan showed major abnormalities of Cohen's heart. We were followed by fetal care the rest of the pregnancy and had Cohen there. He was considered quite big (8lb5oz) in the NICU waiting for his first surgery at 7 days old. He did great, and we were inpatient a total of 30 days with some other surgeries not heart related. He was followed by CHAMP for 7 months, and had his 2nd OHS at 6 months old. He has done great since!

## **What kinds of activities does your family enjoy doing together?**

We enjoy watching movies, playing outside, going to the zoo and spending time together.