

# Meet the Beacon Clinic PFAC

The Beacon Clinic Patient Family Advisory Council (PFAC) is made up of family members of patients seen in the Children's Mercy Beacon Clinic.

The Beacon Clinic PFAC works with the Beacon Clinic 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.



# Angie Cunningham



**Why did you become a Beacon PFAC Member?** I love being an advocate for Quinn. We spend a lot of time at Children's Mercy for inpatient stays and clinic appointments. I joined the PFAC to be a voice for Quinn and other kiddos. It gives me a sense of happiness knowing we are making the future better for families with a child diagnosed with complex medical needs!

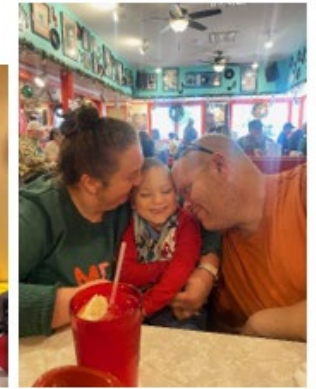
**Tell us about your family.** My husband, Ryan, and I have been married since 2005. We have been blessed with two beautiful children. Ayden (born 2008) is an amazing big brother to Quinn (born 2012)! Quinn was diagnosed with Rett Syndrome at 15 months old. I am a registered nurse but chose to stay home after Quinn was diagnosed. I now enjoy being a stay-at-home momma! Ryan is an engineer for a software company.

**Tell us about your experience at Children's Mercy.** Quinn & Ayden are both seen by Dr. Emily Goodwin in the Beacon Clinic. Quinn's main diagnoses are Rett Syndrome and Epilepsy. Her other diagnoses are asthma, g-tube dependent, hypotonia, wheelchair dependent, kyphosis, dysautonomia, chronic constipation, nonverbal and risk for long QT syndrome. She is seen in numerous clinics at several Children's Mercy locations.

**What kinds of activities does your family enjoy doing together?** Our family enjoys being outside! We love going on vacations and spending time together. We are a busy family and always on the go. Ayden participates in soccer, show choir, Boy Scouts, and sings at church. Quinn enjoys being his cheerleader at all his events. She loves movies, music, swimming, and swinging. Our family enjoys playing board games & watching movies together!



# Heather Dahmer



**Why did you become a Beacon PFAC Member?** I wanted to become involved because we have been blessed with such great medical care and I want to make sure other families have the best experience during the most difficult times!

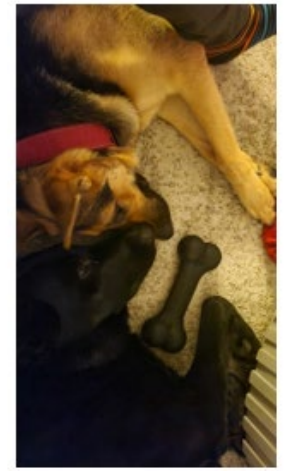
**Tell us about your family.** I have my wonderful husband Craig, we have been married for 10+ years. In 2018, we welcomed our oldest son Landon, then not too far behind, in 2019, we welcomed our youngest Lucas. Lucas was born at 27 weeks and is our medically complex kiddo.

**Tell us about your experience at Children's Mercy.** We spent 4 months in the NICU at Children's Mercy and it became a second home. We continue to follow with several specialists and the Beacon clinic! We are so grateful for such a great children's hospital close to home!

**What kinds of activities does your family enjoy doing together?** We love doing sports for our oldest, baseball and basketball, as well as adaptive softball and soccer for Lucas! We love being with family and traveling, Disney is a favorite!



# Silvia Hernandez



**Why did you become a Beacon PFAC Member?** I became a member to help advocate and give my son a voice. As an older Beacon patient, we have experienced both good and not so good encounters. I can only hope that our experiences will help others in the future.

**Tell us about your family.** We are a family of 7 or 9 if you include our dogs; Mom, Dad, and 5 children born in 2002, 2006, 2010, 2012, 2015 and two dogs.

**Tell us about your experience at Children's Mercy.** Children's Mercy is GREAT! We have been coming for 18 years. I trust that my son will get the best care possible. I love that I have a voice into my son's care and treatment. I enjoy working collaboratively with the doctors. The doctors also make sure that any treatments, medicines, and care my son receives works within our capabilities.

**What kinds of activities does your family enjoy doing together?** We enjoy hanging out with family and friends. We enjoy going for walks when the weather is nice or just hanging outside. Our extended family is large, so we have birthday parties all the time. We have a family tradition for Christmas where we gather with extended family and make over 100 tamales to share. Not to mention the 4 birthday parties on New Year's Eve. We are a social family!



# Ryan Jolly



**Why did you become a Beacon PFAC Member?** The care my children have received from Children's Mercy has been truly lifesaving. And the care and compassion we have received from the providers and staff of the Beacon Clinic have been truly life-enhancing. I joined the Beacon PFAC to help support medically complex kids, their families and the providers/staff that care for them.

**Tell us about your family.** My family was built through foster care and adoption and today I'm Mom to four amazing children. Two of my kiddos have significant medical complexity. 4p Trisomy, CP, developmental delay, and a Tracheostomy top the list for my beautiful and effervescent Miya. The top line diagnoses for E.J., the baby of our family, are TBI, dysautonomia, CP, 3 types of epilepsy and a cervical spinal cord injury. Diana and Max each have diagnoses related to Fetal Alcohol Syndrome and Max has Von Willebrand Hemophilia. They all receive care from Dr. Kristi Williams at the Beacon program.

**Tell us about your experience at Children's Mercy.** All my children benefit from the specialized pediatric care that Children's Mercy excels at providing. Between the four we've seen more than 36 providers.

**What kinds of activities does your family enjoy doing together?** My oldest kids love a good road trip, family movie night and an impromptu dance party. EJ loves snuggles with Nana and any type of music. He may be the only person on the planet that thinks this off-key momma is a great singer. As for me, I'm a work-from-home registered nurse currently studying for a nurse practitioner's certification.



# Caitlin Rowland



**Why did you become a Beacon PFAC Member?** I wanted to become more involved and active in Children's Mercy. We spend so much time at the hospital from appointments, admissions and surgeries I wanted to advocate for my son Matthew but also other children and families.

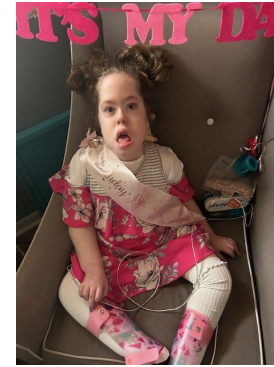
**Tell us about your family.** My husband and I have been together since 2010. We have 4 beautiful children. Matthew, my Beacon kiddo was born in 2014.

**Tell us about your experience at Children's Mercy.** Matthew is my Beacon kiddo. He has been a patient of Children's Mercy since his birth. He was life lighted to the hospital at birth from our rural hospital. Matthew has numerous diagnoses including Cerebral Palsy, epilepsy, TPN dependent, non mobile and several other chronic conditions. He along with my other kids all have benefited from the care that Children's Mercy provides our family.

**What kinds of activities does your family enjoy doing together?** As a family we love to get outdoors. My husband and I run a cattle herd and all of kids help out. They are all active members of 4H and are heavily involved in sports. We love going to Truman Lake and spending time out on the water. Matthew loves to feel the wind on his face!



# Kati Kennedy



**Why did you become a Beacon PFAC Member?** I first started my CMH volunteer journey in 2020 in the NICU PFAC. As my daughter has gotten older, I wanted to join the Beacon PFAC to get more involved with her current medical journey. This gives me the opportunity to be an advocate for changes and improvements for my daughter and other kids at CMH, while also building strong relationships with the Beacon providers and other staff members. CMH really values the parents' aspect and advice.

**Tell us about your family.** My oldest is Kaden (born in 2012) and my youngest is Haylee (born in 2018). My son, Jaxon, was born in 2016 and passed away at birth. Most likely, Jaxon had the same genetic diagnosis as Haylee (RYR-1) but we didn't know at the time. I have worked from home (at a bank in the commercial lending department) since Haylee was born. Our life changed dramatically when Haylee was born but we have and continue to adapt to this complex medical journey.

**Tell us about your experience at Children's Mercy.** Haylee was transferred to CMH at 10 days old and spent 8 months in the NICU (2018). She received a genetic diagnosis of RYR-1 and went home with a ventilator and bipap machine, cough assist, suction machine, gtube, pulse ox, and supplemental oxygen. Over the next three years, Haylee went to lots of therapy, including physical therapy, occupational therapy, speech therapy, music therapy, feeding therapy, and aquatic therapy. She went to preschool, learned how to use her motorized wheelchair, developed strength to sit independently, and so many more inchstones that doctors didn't think was possible. In October 2022, she got RSV, suffered a cardiac arrest with a subsequent anoxic brain injury. Since then, we started a new and different chapter of our medical journey. She lost the ability to sit on her own, became nonverbal, could no longer use her wheelchair on her own, and received new diagnoses of cortical vision impairment and dysautonomia. She spent the next couple of years with several long PICU stays. She continues to fight with everything she has and I'm amazed everyday at her determination and strength. She is seen in numerous clinics at Children's Mercy.

**What kinds of activities does your family enjoy doing together?** Haylee loves to go swimming, listening to Taylor Swift, and watching Disney movies. We also love going to HopeKids events, local to Kansas City. We love watching live sporting events, most importantly big brother's football and baseball games. Haylee is very sensitive to the weather, so anything we can do indoors, she is game for.

# Kacy Seitz



**Why did you become a Beacon PFAC Member?** To more fully participate in the advocacy of both our kids' primary healthcare, but also to actively contribute to the improvement of systems and capacity for medically complex families everywhere. There are very few places like the Beacon Clinic, and we are grateful for the support and collaboration they offer our family as a whole...but it is imperative we continue to elevate the expectations and quality of care for those with medical complexity who very rarely have a voice at the table.

**Tell us about your family.** Hudson was born in 2010. Damek was born in 2012.

**Tell us about your experience at Children's Mercy.** We are excited and grateful for the healthcare collaboration of Children's Mercy and always support the Patient & Family Engagement team for allowing the hospital and clinics to have a more robust (and prioritized) conversation around patient-centered care. In our experience, this has been the main reason why both of our kids have higher quality of lives than when we compare it to a life where they wouldn't have this type of healthcare team.

**What kinds of activities does your family enjoy doing together?** Traveling, swimming, fitness, cooking, reading and playing games with our family.



# Kevin Sullivan



**Why did you become a Beacon PFAC Member?** My wife had been a member early on in our child's diagnosis while I was working. When I began Medical School, my wife began working and we both felt that it was important to stay involved with the organization to ensure that we could best advocate for our own child while helping to shape care for other complex children. The experience has been very rewarding. Our child's illness began with acute gastroenteritis and resulted in HUS and hundreds of strokes. The Beacon PFAC gave me the opportunity to serve as a Parent participant in the Clinical Pathway revision for Acute Gastroenteritis which was particularly meaningful for me.

**Tell us about your family.** My daughter was born in 2011 and we have 4 children total and she is our oldest. We are extremely active. Our oldest is able to attend middle school with her nurse while our other 3 are in elementary school. All of our children have a good number of activities. Our oldest goes to school, pool therapy, PT, OT, Speech and multiple appointments with specialists and equipment providers. She also has a service dog, Gus who is a wonderful companion and will sometimes assist in PT/OT. Our middle daughter is in volleyball, cheerleading, voice lessons, is writing her own song for a talent show, and has done some pageants! Our middle son loves soccer and basketball and One Piece anime. Our youngest son also loves basketball and his other favorite sports are baseball and wrestling. I coach both of the boys' basketball teams through Blue Valley Rec.

**Tell us about your experience at Children's Mercy.** Children's Mercy has been our second home for over 10 years. Our daughter became ill with e.coli O157:H7, STEC, in 2013. The oldest daughter of our closest family friends had a birthday party at a petting zoo where their youngest daughter became ill the following week from STEC, resulting in HUS and ultimately she died from complications of HUS. Our daughter began having symptoms around Thanksgiving of 2013 while we were driving home from a stay in Virginia with my wife's parents. A week after we got home we were in Wesley PICU with STEC, although it wasn't confirmed until a few days after admission. Our daughter developed HUS, suffered complications while in Wichita, KS and was Life Flighted to Children's Mercy. The care provided by Children's Mercy in the PICU, Rehab floor, acute rehab, and neurology, nephrology, and GI over the next several months was crucial. I honestly do not know how we would have survived, literally, without the interventions and experience at Children's Mercy. I believe in 2013, our daughter was the first to have Continuous Renal Replacement Therapy (CRRT) while simultaneously receiving plasma replacement therapy. You would have never guessed that it was the first time it had been done because the entire team in the PICU was so fine tuned. Following her initial recovery, CMH identified significant strokes in our daughter's MRI and we were placed with the appropriate specialists during her recovery. Back then, I believe the Beacon Program was just beginning and while our experience has been devastating, we are eternally grateful for the Beacon Program, which, as the name suggests, has been a guiding light through our family's navigation of "normal". I do not know how we could have gotten through the last 11 + years without them.

**What kinds of activities does your family enjoy doing together?** Our family enjoys going to Main Event for bowling, video games, and laser tag where everyone, including our oldest participates. Swimming in the summer months is our oldest daughter's favorite activity as her barriers to movement are significantly reduced in the water and all our kids are a fan of swimming also! Sports, sports, sports! We are always carting our kids off to sports. Our oldest enjoys watching her siblings participate and occasionally, with assistance, participates in basketball or soccer practice from her wheelchair. We enjoy living room dancing, baking, and movies as well. And we better have popcorn for the kids!

