

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 and going on vacations! We all love the beach and the warm weather, but also love spending time in the Rocky Mountains. We are a busy family and always on the go. Ayden participates in band, soccer, baseball, youth group at church and Boy Scouts. Quinn enjoys being a cheerleader for Ayden at his events. She loves swimming, movies, books, and bike riding! As a family we enjoy church events, board games, movies, and music!

Kacy Seitz



Why did you become a Beacon PFAC Member?

I first became involved with the Family Advisory Board in 2015. Since then, I knew how important it was to give back to the place we call our medical home. I believe in partnering with our kids' physicians & staff to improve care and patient experience for all. Children's Mercy listens to families and provides a safe place to express concerns so our kids and families can have the best experience possible with their medical care.

Tell us about your family.

My husband, Dan, and I have been married since 2007. We have two amazing kids: Hudsyn (born 2010) had a brain injury at birth and Damek (born 2012) has ADHD. I work full-time as a financial planner for special needs families across the country because Hudsyn opened my eyes to how complex this road can sometimes be with money, legal documents, and benefits. I love the hundreds of families I work with! Dan is a stay-at-home dad with a successful YouTube Channel called, "See The Seitz" that documents our journey as special needs parents.

Tell us about your experience at Children's Mercy.

Hudsyn & Damek are both seen by Dr. Kristi Williams in the Beacon Clinic. Hudsyn's main diagnoses is Hypoxic Ischemic Encephalopathy (oxygen deprivation to the brain) which caused her medical complexity. Her other diagnoses are Lennox Gestaut Epilepsy, Cortical Vision Impairment, dysautonomia, g-tube, wheelchair, nonverbal and global developmental delays. She is seen in numerous clinics at several Children's Mercy locations.

What kinds of activities does your family enjoy doing together?

Our family loves to travel. We've taken Hudsyn to Colorado, Florida (Disney), Texas and many other places because we believe in finding ways to constantly include her in life and community. Hudsyn loves school, music and all her friends. Damek is an avid reader, huge fan of Formula 1 racing (Red Bull is his team) and the game of Roblox.

Sol Jacobsen



Why did you become a Beacon PFAC Member?

The Beacon Clinic has provided primary care for Silas since he was born. Our increased desire to be involved came about the time we made a diet change for Silas, seeing the positive impact it had on his quality of life drove us to want to share our experience in hopes it might help someone else in a similar situation.

Tell us about your family.

Allison and I have been married since 2006 and have two boys, Silas & Jett. Allison and I both work outside the home. She is a Dental Hygienist and I work for a bank.

Tell us about your experience at Children's Mercy.

Silas and Jett are both seen by Dr. Kristi Williams in the Beacon Clinic, Silas being our medically complex kiddo. He has been diagnosed with a chromosomal abnormality that has given him several challenges to overcome: g-tube dependent, hypotonia, wheelchair dependent, scoliosis/kyphosis, and Chiari malformation, to name a few. He has had the privilege to get to know several of the specialty clinics.

What kinds of activities does your family enjoy doing together?

Jett loves the outdoors, camping, fishing, exercise and running on the trails. While Silas isn't a huge lover of the outdoors, he does enjoy going for walks and summer swimming. Besides being our books and movie kid, he does find a lot of enjoyment watching other kids being goofy and active.

Asheesh Biyala



Why did you become a Beacon PFAC Member?

Aiyana has complex medical needs that requires us to spend substantial time at Children’s Mercy for inpatient stays and clinic appointments. My purpose of joining the Beacon PFAC is to help elevate care and experience for kids like Aiyana and their families.

Tell us about your family.

My wife, Urvi, and I have been married since 2003, and she volunteers on the Rare PFAC. We have been blessed with two beautiful children. Aryav is an amazing big brother to Aiyana! Aiyana was diagnosed with CDKL5 Deficiency Disorder (also called Atypical Rett Syndrome) at 7 months old. Our family has also hosted “I Gold Fore Aiyana” golf tournaments to raise awareness and funds to help find cure for CDKL5 Deficiency Disorder

Tell us about your experience at Children’s Mercy.

Aiyana is seen by Dr. Emily Goodwin in the Beacon Clinic. Aiyana deals with a lot of issues that requires her to consult various specialists: Neurology for Epilepsy, GI (g-tube dependent), Pulmonary, Nephrology, Ortho and a few others. She is fully dependent on her caregivers for all her needs. Aiyana has been on clinical trials in various hospitals across the country to treat her epilepsy.

What kinds of activities does your family enjoy doing together?

Other than caring for her health-related needs, Aiyana enjoys being outdoors in great weather. She also enjoys being in water. Our family enjoys going on vacations. She has been to Florida, North Carolina, South Dakota, and a few other states for her vacations. When Aiyana was two years old, she also went to Europe on vacation with her family. It’s been difficult to travel as Aiyana is getting older, but we try to make most out of any small opportunity to take Aiyana out and let her see new places.

Kayla Lyman



Why did you become a Beacon PFAC Member?

I love being involved with Phin's care as much as I can be, learning new things, and connecting with people. I have always enjoyed interactions with doctors and nurses and engaging more personally with families who have similar life experiences. Learning from others and bringing new ideas to the table to make life better for medically complex kids is so rewarding!

Tell us about your family.

I am a single mama to four kids, and Phin gets to be the very doted on youngest brother of three sisters!

Tell us about your experience at Children's Mercy.

Phineas sees Dr. Wright in the Beacon clinic. He has Foxg1 Syndrome and has seen over 25 specialists at Children's Mercy. He has a feeding tube, is nonverbal and immobile, besides some great rolling skills.

What kinds of activities does your family enjoy doing together?

Our family loves being outside, watching movies, good food, and time with friends. Phineas especially enjoys anything with music, balloons, and all things people. He's my social guy!

Silvia Hernandez



Why did you become a Beacon PFAC Member?

I want my son Aaron to have accessibility everywhere we go. We have visited with almost every specialty at Children's Mercy during inpatient stays and outpatient clinic appointments. I am Aaron's advocate and his voice. That is why I joined the Beacon PFAC. I am extremely proud in knowing that the PFAC is dedicated to helping those families that have children with complex medical needs!

Tell us about your family.

My husband, Javier, and I have been married since 2001; we are blessed with five beautiful children. All our children are amazing to Aaron! Aaron was diagnosed with Traumatic Brain Injury at two-months old.

Tell us about your experience at Children's Mercy.

Aaron is seen by Dr. Christopher Sweeney in the Beacon Clinic. Aaron's main diagnosis is Cerebral Palsy. His other diagnoses are g-tube dependent, hypotonia, wheelchair dependent, Neuromuscular Scoliosis, chronic constipation, airway clearance impairment, spasticity, tracheostomy present and nonverbal. He 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 and hanging out with family and friends! We are constantly busy with five kiddos and their activities. As a family we enjoy dinner together, board games, playing pool, watching movies and dancing to music! Javier and I both work full time and manage to run a full house that is not quiet. We enjoy every part of our lives and see everything as a blessing.

Caitlin Rowland



Why did you become a Beacon PFAC Member?

I wanted to become more involved with Children's Mercy. As a family we spend so much time there, from clinic appointments to hospital admissions and surgeries. I wanted to help advocate, not just for my son Matthew, but for all the families who walk through the doors of the hospital.

Tell us about your family.

My husband and I have been together since 2010. We have three children together and I am the bonus mom to another daughter. All our kids are active in sports and 4-H.

Tell us about your experience at Children's Mercy.

Matthew is our Beacon child and is seen by Dr. Emily Goodwin. Matthew was born premature and was diagnosed with Cerebral Palsy at 18 months old. Along with his CP he has epilepsy, wheelchair dependent, GJ-tube dependent, PVL, TPN dependent, and dysautonomia. He is seen at several clinics at Children's Mercy and has numerous inpatient stays every year.

What kinds of activities does your family enjoy doing together?

As a family we love to be outdoors. We come from a ranching family and love to go help out on the ranch. All my kids are active 4-H members and show their livestock at the fair every summer. We enjoy going fishing, 4-wheeling, and hiking as a family. Matthew loves being outside and with his horses. We are active in our parish and school community. We are always on the go with all kids' different activities sports, band, 4-H, and the ranch. I have been a stay-at-home mom since the day Matthew was born and my husband is a foreman and rancher.

Jeanette Wood



Why did you become a Beacon PFAC Member?

When it comes to Danny, advocating for him seems to come naturally. I enjoy seeing that the work I do not only helps him but helps other families in our community too. Children's Mercy has been there for Danny since his birth in 2011. He's had many long days of appointments, surgeries, and hospital stays. I am confident he wouldn't be as healthy and happy without the care they have provided to him. Serving on the PFAC team is just a small way I can say, "thank you."

Tell us about your family.

My husband and I have been married since 1991. We have 11 children, ages 33 to 9. We gave birth to six children and have adopted five. We are also the grandparents to seven adorable grandchildren.

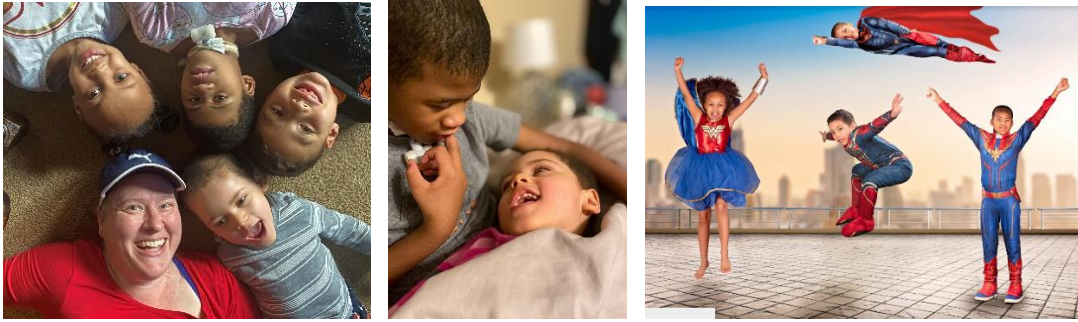
Tell us about your experience at Children's Mercy.

Dr. Emily Goodwin has seen Danny in the Beacon Clinic for several years. Daniel's main diagnosis is Duchenne but like most complex children he has a host of other needs as well. Diagnosis such as heart failure, restrictive lung disease, dysphagia, G-tube, GERD, airway clearance impairment, asthma, osteopenia, laryngeal cleft repair, social communication disorder, mixed language receptive-expressive language disorder, developmental delays, fine motor developmental delays, and impaired mobility-wheelchair dependent. We have regular appointments with several clinics at Children's Mercy, many of the providers have treated Danny since he was an infant.

What kinds of activities does your family enjoy doing together?

Our family enjoys traveling; we've been blessed to be able to take Danny on several trips including Paris, London, and Rome. Danny has been to 40 states, has played in the Pacific and Atlantic Oceans, as well as the Gulf of Mexico. Danny always wants to be outside playing and is the inspiration behind the 30-acres we are turning into a fully wheelchair accessible garden. Danny also enjoys swimming and would spend the entire day in the pool if we'd let him.

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.

Rachel Callihan



Why did you become a Beacon PFAC Member?

Children's Mercy has become a home away from home for me and my family. Harper and Laiken have always received exceptional care and I have established amazing relationships with their medical team. I joined the PFAC because I want all families to receive the level of care that we have and to love Children's Mercy as much as we do!

Tell us about your family.

Harper and Laiken were born in 2013. They were premature, just 28 weeks, and spent two months in the Children's Mercy NICU before coming home. We have a wonderful support system that includes my mother (Mamaw) and her husband (Pop Pop) as well as my younger sister. And of course, we can't forget the man of the house, our beagle Murphy!

Tell us about your experience at Children's Mercy.

Both Harper and Laiken each have their own journey within the Children's Mercy system. Harper suffered significant complications because of her prematurity and underwent nine brain surgeries before her first birthday. Her primary diagnosis is cerebral palsy, but other medical issues include epilepsy, dysautonomia, adrenal insufficiency, diabetes insipidus, cortical vision impairment, and respiratory insufficiency. She was referred to the Beacon Program in 2014 to help monitor her complex medical needs and coordinate with the specialists who help manage them. Laiken was diagnosed with Autism in 2019 with the support of Dr. Leslee Belzer through the Beacon Clinic.

What kinds of activities does your family enjoy doing together?

When we don't have an appointment, we love spending time outside! The girls like swinging and swimming the most. We enjoy participating in events with Hope Kids and exploring the city by going places like the Kansas City Zoo, Sea Life Aquarium, Variety KC Parks. Harper and Laiken also love music and being silly together.