

ImPACT

A newsletter from the
Parent Advisory Council



July 2022

PARENT ADVISORY COUNCIL (PAC) BACKGROUND

The Parent Advisory Council (PAC) currently includes parents and caregivers from our Akron and Mahoning Valley (MV) campuses whose children have received care at Akron Children's. Advisors work with hospital liaisons on behalf of other families to enhance the delivery of family-centered care. Parents serve on hospital committees and participate in hospital focus groups and performance-improvement projects. Parents offer support on our program development and policy upgrades. Learn more at akronchildrens.org/PAC.



PATH TO PAC: FEATURING KIM MUSGRAVE



What was your path to PAC?

My path to becoming a member of PAC 6 years ago started with, and continues with, my angel son Luke and his many visits to Akron Children's Hospital. Luke has cerebral palsy, epilepsy, mitochondrial disease and chronic lung and gastrointestinal issues. Luke has been hospitalized many times beginning at 9 months old, and we have used many of the hospital services. He has spent time in the PICU, ED, inpatient floors, outpatient therapy and has many specialists that I feel blessed to have on his care team. The staff saved Luke's life and have helped him to achieve his highest potential! I simply don't know what I would have done without them. I am a huge fan of Akron Children's. PAC allows me to give back to the organization that has done so much for my son and our family.

Why do you believe PAC is important?

PAC is important because it provides a way for parents and caregivers of Akron Children's patients to give feedback to the hospital as it continually strives to improve. I love that Children's truly wants to hear from patients and families on how they are doing and what they can do to provide the best care possible. Not only do they hear from us, but they listen! Children's uses our committee to stay connected to the families they serve, which allows them to keep their prized focus on patient- and family-centered care. We also get to hear from hospital administrators, which allows us to be informed about what is going on behind the scenes at the hospital instead of being in the dark. It also allows us to have personal connections to the decision makers and other staff at the hospital and vice versa. (Cont.)

PATH TO PAC: FEATURING KIM MUSGRAVE (CONT.)

Do you have a favorite PAC memory?

I loved being invited to come to a mockup of the new Considine Professional Building that the hospital was planning to build. Parents were able to provide feedback on everything from hallway widths to whether wheelchairs would fit comfortably in a room. We suggested including a bed or changing table to accommodate older patients who needed a place to go for changing when they were there for the whole day. While they aren't in every department yet, they listened to us and there is at least one in every patient building on the Akron campus.

If there were no barriers, what would your dream PAC look like (service, equipment, etc.)? Dream big!

I would love for our PAC to hold an event at least once a year where we could invite patients and families to attend a big carnival-type event outside in the park area. It could have accessible carnival-type games and entertainment, face painting, balloon animal makers, ice cream, music, special needs accessible bikes, the Doggie Brigade and a free lunch!

Is there anything you would like to unPAC (any additional information that you would like to share)?

I feel so blessed to be a member of PAC. I have made friends and connections that have been a huge blessing to me. Being involved with PAC has given me an amazing sense of purpose and accomplishment because Children's makes sure we know that we are being heard and are appreciated. We can make a positive impact on people and each other and PAC gives us a way to do that.

VIEW FROM THE VALLEY



In 1989, the Mahoning Valley chapter of the Autism Society of America was formed by local families to improve the quality of life for families living with an autism spectrum diagnosis. Robin Suzelis is the part-time director of the Autism Mahoning Valley organization. She says, "We are always looking for donations for all our programming. People can form teams and raise funds and businesses can be sponsors."

The Autism Society of Mahoning Valley, which serves Mahoning, Trumbull and Columbiana counties, supports a number of events and monthly community outings, including Mom's Night Out, Morning Support and Camp Friend.

This year, Akron Children's was a corporate sponsor for the Autism Warrior Dash, which was held on June 4 at the Canfield Fairgrounds. The activities included a Kids Fun Run, Autism Support Walk, Valley Autism 5K, People Powered Tractor Pull and Strongman Competition, which is a sanctioned event. In addition, there was a special needs resource fair and interactive activities for those in attendance.

"This was our first year creating a team and raising funds for the Warrior Dash," says PAC member Jen Melia. "My son and my family enjoyed the numerous events like the dunk tank, the Autism Walk, and the special needs resource fair. We are looking forward to next year and appreciate all the volunteers and the donations from so many friends within our communities."

Proceeds from the event are used to help families with social activities, information and referrals, family support, advocacy, professional development, and resource awareness as they navigate an autism diagnosis. All monies raised in the valley remain in the valley.

PAC IN ACTION



In September 2021, the PAC and Teen Advisory Group (TAG) met with designers, architects and leaders from the hospital's planning, design and construction department to discuss and provide input for the third-floor redesign of the main building on the Akron campus. Parents and teens offered suggestions on what they would like to see when the space is redesigned. The focus of this area is to have amenities for patients and families centrally located in the hospital. Some of those amenities include the Family Resource Library, Patient and Family Education Space, Sensory Room, lower sinks in restrooms, new layout for the chapel, and space for families to meet with members of their child's medical team.

In March 2022, a few PAC members had the opportunity to walk through a cardboard mockup of the Family Resource Center. PAC member Karen Ricci says, "This area will be welcoming to all by inviting them in to have a relaxing space while at the Akron campus. It will also help to find needed resources like car seats, lodging and more. They welcomed our input on the chairs, tables and children's area to make sure all abilities could gather in those areas. The centralized location will be able to touch more families since many travel through this main corridor to the cafeteria and the ball machine. This is sure to become the new heart of the hospital."



TAG LINE FEATURING OLIVIA PORTER

Teen Advisory Group (TAG) is made up of teens ages 13–18 from the community who have been or are siblings of frequent or long-term patients at Akron Children's. Teens share their experiences to help improve hospital stays for future patients. They offer input on facilities and services, participate in hospital-wide events and interact with patients and families (activity cart, peer-to-peer mentoring, etc.).

Olivia Porter has been a part of TAG for a little over a year. Olivia says, "I was interested in TAG when I first heard about it because it gave me an opportunity to be part of some behind the scenes aspects of Akron Children's. It also allowed me to volunteer and possibly make patients' experiences in the hospital better!"