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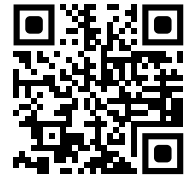
A newsletter from the
Parent Advisory Council



August 2023

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 PAMELA BLACKSON



What was your path to PAC?

Kristin Hafford introduced me to PAC. I own a daycare center and work with many different families. Since I relocated the daycare in the North Hill area, I have established new relationships with many families from a variety of backgrounds. I have a desire to strengthen the family unit. Being a PAC member has allowed for me to learn of new resources to share with the families I work with.

How long have you been involved in PAC?

I have been a member for 2 years.

Why do you believe PAC is important?

PAC is important because it really encourages families to get involved. Some people feel like they don't belong in a space like PAC—meaning attending meetings, sharing their ideas and providing feedback. At first, I didn't feel I could fit into the space. But after joining, I've been included in conversations that are truly making a difference at Akron Children's.

Have you been involved in any hospital committees, PAC subgroups or FACT groups?

I haven't participated on committees yet, but have participated in PAC events.

Do you have a favorite PAC memory?

It's hard for me to pick just one. I enjoyed when Mackenzie and Shawna Roach shared their story with the group. It was heartwarming and very encouraging. I enjoy hearing about the Chief Moment Officer at the end of each meeting because it sheds light on the staff and how they do such a good job. It's good to know that people are noticing these staff members and even more encouraging that the recognition comes from the patient and family voice. This shows the impact staff make when people are going through hard times. It's what Akron Children's is all about. *(Cont.)*

PATH TO PAC: FEATURING PAMELA BLACKSON (CONT.)

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

I know this is big, but my dream would be to have no cost for things outside of what insurance covers and eliminating copays. For some, a copay may prevent them from coming to the hospital or cause more stress. There are times when insurance denies a certain service and families can't afford to pay so they go without. I just want everyone to have access to the same resources and services without money being a concern. Can't we eliminate this barrier?

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

I enjoy being part of PAC and listening to how encouraging other parents are. Some of these parents have children with chronic conditions and they find time to give back to hospital. It is such an inspiration. This entire group looks beyond their family situations and wants to help others.

VIEW FROM THE VALLEY—AUTISM WARRIOR EVENT



One of the goals for PAC in 2023 was to be more active in community events. On Saturday, June 3, the annual Mahoning Valley Autism Warrior Event was held at the Canfield Fairgrounds. During the event, a 5K run, kids fun run, family walk, people-powered tractor pull and two strength events were held. All proceeds benefited the Autism Society of Mahoning Valley. A Resource Fair was also held in conjunction with the Warrior Event.

Nearly 30 organizations participated in the fair, including Akron Children's Hospital and PAC. Some of these fair participants are highlighted below.

Ainsley's Angels of America's goal is to ensure everyone can experience endurance events. Each athlete rider is pushed by an Ainsley Angel in a race chair or chariot and has two runners who tend to the race course and rider. Race events are scheduled around the country, but the Mahoning Valley is proud to be a part of the Cleveland chapter. Watch for their hot pink presence, because they believe *#togetherweshall*. For more information, please contact ainsleysangels.org.

Boundless is a family of nonprofit companies that provide person-centered care to people with intellectual and developmental disabilities and behavioral health challenges. This organization has an after-school program for children and adolescents that helps students transition from school to home. For adults, Boundless Community Gateway is an innovative day treatment program. For more information, please contact iamboundless.org.

@who_isyomama is a Youngstown company that focuses on easy, interactive and stress-free sensory-based play by offering products to enhance calmness and mindfulness. Sensory play encourages learners to establish developmental and problem-solving skills through the use of their senses. The Yo Mamas create play kits in bins that can be tailored to events and holidays—encouraging kids of all ages to dig into the fun.

The Knapp Center for Childhood Development has developed several types of programming for children 1–22 years of age on the autism spectrum or who have developmental delays. They offer day treatment, enrichment, outreach and STEPS programs to address academic, behavioral and social deficits with the ultimate goal of increasing independence into adulthood. An interesting booklet they provided is the Autism Safety Guide, which shared tips, products and strategies to keep children safe. For more information, please contact knappcenter.org.

PAC IN ACTION AT OH SNAP

PAC, the Teen Advisory Group (TAG) and their families came together for a fun-filled afternoon at the end of May at OH SNAP Photo Lab. OH SNAP is Akron's premier selfie museum. It's located in the heart of downtown Akron and offers about 20 curated rooms, unique mini studios and a lounge. No matter what age or ability, all in attendance were able to relax, enjoy great food, laugh, smile, dance and so much more while taking as many photos as they wanted.

"It was fun taking pictures in the different rooms, hanging out with my family and the people from PAC and TAG! At this point, I think I'm a selfie pro," said 10-year-old Sparrow Hafford. The OH SNAP event provided Sparrow and guests ample space for children who use wheelchairs and others to run wild. Guests ventured from room to room, taking in the many different themes, sounds and artwork that allowed them to find their style before snapping some pictures. TAG member Xyia West shares, "It was a great break from reality."

This gathering provided an opportunity for members and their families to relax and check in with each other to see what has been going on and if they have plans for the summer. PAC member Karen Ricci said, "My son, Joey, really enjoyed the lights and bright colors in the rooms and watching everyone have fun. Being able to talk and connect in person while having fun made for a perfect evening." Another goal for PAC in 2023 was to do more family engagement with PAC and TAG members so that they could get to know each other. This event was a great start to getting back to making in-person connections.



TAG LINE FEATURING MOLLY



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.)

"I wanted to join TAG because, being in the hospital for a large part of my life, the idea of chipping in suggestions for designs or different things that could become a reality for other kids to make it easier for them sounded amazing," said the newest TAG member, Molly.