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A newsletter from the Parent Advisory Council





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 NICOLE META



What was your path to PAC?

My daughter's preschool teacher introduced me to PAC. It was during a time when we were searching for answers regarding my oldest daughter's health and future. It was a perfect time for me to join PAC to learn more about Akron Children's Hospital and to share my family's experiences. I have 3 daughters: Lila, 13, Clementine, 7, and Daisy, 5. I have been a member of PAC for 7 years and have been able to sit on the Ethics Committee as well.

Why do you believe PAC is important?

PAC gives parents a voice. Parent and caregiver input is extremely valuable when it comes to a child's care. Since its beginning, PAC has given parents a platform to share their family's story.

Do you have a favorite PAC memory?

Bringing the snack cart to MV is one of my favorite memories of my time at PAC. Any opportunity to interact with other parents and staff has been a great experience. I have wonderful memories of time spent with our small but mighty group at MV. I am always impressed by their ideas and commitment to PAC.

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

I would love to have events to engage more parents. Our group becomes stronger with more members who want to share their experiences. As a mom with a kiddo with special needs, there was a time when I felt isolated. PAC afforded me the opportunity to meet other parents who faced similar challenges.

VIEW FROM THE VALLEY

The \$31 million emergency department (ED) expansion at the Beeghly campus began in fall 2021 and will continue into 2023. The construction schedule is broken down into 12 phases. Six of those phases have been completed and the project will continue with the remaining phases. This expansion will triple the size of the current department.

When the ED is completed in 2023, the new space will include 6 additional treatment rooms, bringing the total to 23. Three treatment rooms for behavioral health will be designed to meet the needs of patients experiencing behavioral and emotional emergencies. An additional triage room is also in the design.



One of the 12 phases included a mockup of the facility, where families and employees were invited to walk through and give feedback. Amy Daprile, member of the MV PAC, attended with her son, Nathan, who uses a wheelchair.

"I felt the mockup was a great representation of how Akron Children's is constantly striving to meet the needs of patients, families and the communities they serve," Amy said. "So much thought and care were put into making sure the new ED will best serve the myriad of patients cared for daily—from wheelchair accessibility to the furniture in the mental health rooms.

"I was very impressed with how they also consulted staff to make sure the patient rooms were designed for maximum efficiency," she added. "Everything from outlet placement to patient comfort was considered."

Although weather brought a few construction delays, the team plans to make up that time during the summer. Currently, there are no delays in critical project supplies and equipment. The construction team is beginning to tie the existing foundation into the new addition so that seamless connections to corridors and new ambulance bays are achieved. The hospital held a beam signing event on March 10 to celebrate the final steel beam being put in place.

Want to watch our progress? Click <u>here</u> to view our construction project in real time.



PAC IN ACTION



Our parents not only make a difference at the hospital and in our communities, but they are also involved with initiatives to improve the lives of children at the state level. Several of our members are involved with advocacy, committee and policy work. Kim Musgrave is actively involved with the Ohio Nursing Collaboration with representation from Family to Family (Ohio F2F), The Arc of Ohio, and other parents who are passionate about advocating for not only their own children with special health care needs, but for all children across the state. The group has partnered with agencies like the Department of Medicaid and Department of Developmental Disabilities to help decrease barriers for children and their families.

Kim says, "One of my suggestions to the state was approved and added to the Ohio Administrative Code Rule. This addition will help many individuals with disabilities to retain nursing, which protects their health and safety."

The Ohio Department of Health (ODH) has various committees and workgroups that seek input from parents. ODH has established a Children and Youth with Special Health Care Needs (CYSHCN) workgroup through a Maternal Child Health Grant. There are several workgroups, including: Physician/Provider Outreach, Care Coordination, Transition Healthcare, and Transition Non-Healthcare. PAC member Shawna Roach is a member of the Non-Healthcare Transition workgroup. The objective of this workgroup is to develop a plan for increasing the percent of Ohio's adolescents (ages 12 to 17) with special health care needs who received services to support transitions to adulthood outside health care.

Shawna is also involved with Opportunities for Ohioans with Disabilities (OOD) and advocates for employment of those with disabilities.

"It's important for our children to see themselves represented in the workplace and to have the same opportunities for employment as their peers," says Shawna.

December West is a member of the ODH Care Coordination workgroup. The priority of this group is to increase the prevalence of children with special health care needs receiving integrated physical, behavioral, developmental and mental health services as they relate to transition. December is also the co-chair of Ohio's Children with Medical Handicaps (CMH) Parent Advisory Council. This group works closely with the state to advocate, raise awareness, and provide input on issues concerning children with special health care needs. December is also an advocate for the National Kidney Foundation and Alport Syndrome Foundation.

"My involvement and passion to help largely comes from the experience I had being part of the Akron Children's Parent Advisory Council," she says.

PAC members' engagement at the state level has motivated our teens to develop and advocate outside the walls of Akron Children's. Teen Advisory Group (TAG) member, Mackenzie Roach, is a member of the Ohio Youth Leadership Forum (YLF). YLF is a 5-day career leadership training program for high school students with disabilities put on by OOD. Participation in YLF prepares students to become one of Ohio's future leaders by improving their leadership, citizenship and social skills through self-advocacy and leadership development sessions. Mackenzie will be attending her second YLF this summer. She is looking forward to the event being in person this year.

Are you looking for an opportunity to make a difference in the lives of children, teens and families at the local or state level? Contact *Kristin Hafford* to learn how you can get involved.



TAG LINE

March is Child Life Specialist month! Our TAG members would like to thank and recognize all of the child life specialists who go above and beyond for the patients at Akron Children's. Child life specialists help normalize the hospital experience and bring joy and comfort to hospitalized children and their families. These valuable team members play many important roles, like providing support for tests, surgeries and other medical procedures to facilitating therapeutic medical play with special dolls, stuffed animals and medical equipment. Child life specialists explain medical procedures and terms in a way that children can understand, which helps to put patients and families at ease.

TAG member Mackenzie Roach says she became very close with many of the hospital's child life specialists.

"They got to know me and learned what motivated me. They took my love for animals and arranged for visits from the Doggie Brigade and Petie the pony," she says. "They even made sure that the dogs visited me in therapy, which helped motivate me to learn to walk again.

"They taught me how to have a voice and to advocate for myself. For example, requesting the MRI machine that plays movies so I don't have to undergo sedation," she added.