

ImPACT

A newsletter from the
Parent Advisory Council



January 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 KAREN RICCI



What was your path to PAC?

After a long, scary hospital stay in October 2018 that ended in another diagnosis for my 15-year-old son, my husband and I decided to help give back to Akron Children's. Joey has always been a patient with numerous specialists, but the appropriate loving care he received as his chronological age got larger but not his developmental age really opened our eyes as to how amazing Akron Children's is for a special, medically complex kid. While my husband started an annual golf outing, raising money for Akron Children's and running in the Akron Marathon, my friend Kim, who is also a PAC member, invited me to a meeting 4 years ago. I have been a member ever since.

Why do you believe PAC is important?

Having a parent or caregiver's voice helping Akron Children's remain at the top of its class with our ideas, suggestions or changes that need made lets others know that Akron Children's truly listens and the work we do in the PAC matters.

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

I have been able to attend some of the 3rd floor redesign meetings to make sure PAC was involved with any planning for the family areas, including adult changing tables in the new restrooms.

Do you have a favorite PAC memory?

Some of my favorite memories of PAC are the in-person *PAC Gives Back* events, where we had gift baskets, massages and free food for patients and families—and, of course, cheering on the Akron Marathon runners from a patient hero zone. (Cont.)

PATH TO PAC: FEATURING KAREN RICCI (CONT.)

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

With so many patients and families in need, I would wish that PAC had many subgroups to help with the following needs: food/clothing; transportation to appointments/grouping same-day appointments; adult transition help for SSI/Medicaid/DODD/guardianship/job or day programs; parent mentors for all specialties; and working with local schools to make sure physicals, vaccine clinics or health clinics on-site are where the kids who need these services most can reach them.

VIEW FROM THE VALLEY

With several PAC members who have children approaching adulthood, there was a conversation regarding guardianship. We have discovered that information and procedures differ from county to county in Northeast Ohio as guardianship is sought. This led to our own internal discussion and realization that other families may be experiencing the same roadblocks we were navigating on our own.

Laura Elder says, "In Mahoning County, my husband and I were both granted guardianship of our daughter, but according to the courts in Stark County, Shawna Roach and her husband were only allowed to appoint 1 guardian for their daughter." PAC members were motivated to provide other families with a space to ask questions and share experiences and resources.

On Track with PAC is a new program sponsored by the PACs from Akron and Mahoning Valley. Our purpose is to have informational conversations and provide resources to help guide caregivers through life experiences. PAC will host our first virtual event on guardianship in February 2023. We will discuss what is guardianship, why it is important and when caregivers should obtain guardianship. All sessions will conclude with an opportunity for questions and answers. Future topics will include waivers, Medicaid, SSA, finances and STABLE accounts, Ohio Department of Developmental Disabilities speakers, and county boards of developmental disabilities. If you are interested in attending the *On Track with PAC* events, please email parentengagement@akronchildrens.org.



PAC IN ACTION

Written by Jennifer Burks



On September 17, 2022, my family and I participated in the 17th Annual Mychal Clayton Sickle Cell Awareness Walk. Through various interactions, I have heard about what an awesome person Mychal was. I see the signs for the walk every year and have wanted to participate, but was always too busy. This year, when it was advertised, my family and I made a commitment to participate.

It was a gorgeous day at Lock 3 when we met up with other members of the Parent Advisory Council, Teen Advisory Group, members of the Minorities and Allies Employee Resource Group and their families. This event is a mix of somber remembrance and hopeful celebration. The event featured a DJ, line dancing and many vendor tables to support current patients and honor past patients of Akron Children's that go through our Hematology department for treatment and evaluation of sickle cell disease/trait.

After the DJ warmed us up, we started our excursion. We walked through Lock 3, along the canal behind the Considine building to Exchange St., then down Main St. and back to Lock 3. It's a shorter walk because many of the participants have sickle cell disease and can fatigue easily. It was a great opportunity for my children to meet some of my co-workers, PAC members and their families, but also to engage in something that is very important to us, as my 2 sons and my stepdaughter have sickle cell trait.

I'm so glad that even though our lives have been so busy, we made participating a priority this year. We did it not only to support Akron Children's and the family of Mychal Clayton, but also so that my children could see the impact of this disease, how it touches people and how some patients have passed on from it. It also lets them know that they are not alone in having this trait and shows how the families of patients carry their memory through participation in this walk. It's something we talk about on occasion, but this lets them know that if they have questions, there is a community that can support them.

We look forward to participating in the walk again in the future. We will continue to spread the word to others about the disease, because we know that it's not widely talked about unless someone in your family or someone close to you has it or suffers complications from it. Hopefully next year you will join us too!

In early December, the Women's Board of Akron Children's Hospital hosted the 29th lighting of the Children's Tree of Lights. Employees, volunteers and families gathered to enjoy musical performances, a holiday story and tree lighting. The blue and white lights on the tree are donated in celebration, honor or remembrance of loved ones. This year's presenting sponsor and Women's Board President Peg Stalter donated the tree lighting in honor of PAC. "I have been blessed to witness the unflinching commitment that this dedicated group brings to better the lives of their families and those served," says Peg. Each month, as the Women's Board representative, Peg attends PAC meetings to engage with members and learn about the concerns and ideas of Akron Children's families. PAC is honored to be recognized this year by the Women's Board.



TAG LINE



Traditionally in December, the Parent Advisory Council, Teen Advisory Group members and their families come together for fellowship and to celebrate their accomplishments. Over the past 2 years, the pandemic has made it difficult for members to get together in person for social events. This December, PAC and TAG members were excited to gather at Twisted Olive for their annual holiday dinner. "It was so nice to be there in person with the other members. I joined PAC at the beginning of the pandemic, so this was the first time I was able to see a

few members in person," said PAC member Pamela Blackson. While the pandemic has shifted members to engage virtually, PAC and TAG have remained active and continue to accomplish their goals. "I am super proud and very grateful for our members. This group's dedication, commitment, and hard work continues to help drive improvement at Akron Children's and for our families," said Kristin Hafford, patient and family engagement coordinator.

PAC 2022 accomplishments:

- Welcomed 2 new members
- Hosted 10 guest speakers
- Reviewed 10 care information sheets
- Had 3 storytelling opportunities
- Published 3 newsletters
- Feedback opportunities included: rehab augmented reality design, NRC questions, TV channel offerings, Family Resource Center website, *Zero Suicide* caring contact buckslips, and Palliative Care quality improvement project
- Presented on a panel discussion for Akron Children's employees during Family Centered Care Week
- TAG member Mackenzie Roach raised more than \$6,000 during the Akron Children's Radiothon
- Participated in:
 - A redesign of third floor renovations and new Family Resource Center
 - 17th Annual Mychal Clayton Sickle Cell Awareness Walk
 - Intern Boot Camp training sessions
 - Adaptive Sports of Ohio event in Mahoning Valley
 - Patient Experience Conference learning sessions

