

ImPACT

A newsletter from the
Parent Advisory Council



December 2021

PARENT ADVISORY COUNCIL (PAC) BACKGROUND

The Parent Advisory Council (PAC) currently includes parents and caregivers from our Akron and Mahoning Valley 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 LINDA JONES, AKRON



What was your path to PAC?

Another PAC Member, Kim Musgrave, suggested I join. When I discovered the meetings were held virtually, I felt I could help.

How long have you been involved in PAC and why do you believe PAC is important?

I attended my first meeting on April 13, 2021. I took my advisor/mentor training on July 27 to become a member of PAC. PAC gives parents a voice, plus it enables us to support the hospital in so many ways. I have been a member of PAC for such a short time, but the one thing that does stand out to me is the professionalism and the way everyone works together.

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

My granddaughter has not been a patient at Children's for several years. When we had to transition (about 10 years ago) to an adult hospital there was nothing in place at all for the transition. We were totally on our own. We lucked out and found Dr. William Smucker at Summa Health when she had to be admitted for the flu and pneumonia. She was his very first complex patient, and they took awesome care of both her and me for the week we were there. Everyone we met was awesome and they all said Ashley was their first patient. If it wasn't for Stephanie Allen at Akron Children's Palliative Care, we would not have known about Dr. Smucker. My dream is that a transition program is set up between Children's and area adult hospitals so that every child and parent can experience less worry and concern because there would be an established and well thought out plan for the transition to occur over time. I was happy to learn that Akron Children's is working with the adult hospitals to find ways best assist families with transitioning from pediatrics to adult healthcare.

PATH TO PAC: FEATURING LINDA JONES, AKRON (CONT.)

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

My granddaughter has a rare chromosomal disorder called [Pallister Killian Syndrome](#). I have been her legal guardian since she was 5 and she will be 30 on December 14. When she was diagnosed at 10 months old, she was the 43rd known case in the world. There are now approximately 500 cases worldwide. *(Cont. on next page)* Ashley was in and out of Akron Children's for the first 7 years of her life between seizures, respiratory issues, diabetes, orthopedic surgeries, and other issues related to her syndrome. Once we had a G tube placed, her health started to stabilize and our hospitalizations became less. If it wasn't for Akron Children's and the doctors, nurses and staff taking awesome care of her, she would not be with us today. This is the reason I want to give back to the hospital by being part of PAC and the reason we are recognizing December 4 as PKS day.

VIEW FROM THE VALLEY: AKRON AND MAHONING VALLEY PAC COLLABORATION

Collaboration is "the action of working with someone to produce or create something" according to dictionary.com. This strategy has become a key concept in many aspects of our daily lives. The foundation of collaboration is taught in the educational setting and is expected in successful business best practices. Our Parent Advisory Council experienced the success of collaboration this summer and fall when our Akron and Mahoning Valley councils met together. Bridges Out of Poverty was presented to both PACs in June. The information presented allowed all members to gain a deeper understanding of the experiences people in generational poverty face.



"It was eye opening, but more importantly, we had the opportunity to work through scenarios that will help us to put people first and assure all children have access to our hospital," said Laura Elder, PAC member.

MV PAC member, Nicole Meta, said, "I really appreciated how interactive our training was and I think we gained valuable insight that we can apply to our efforts moving forward."

In August, we had another combined meeting that focused on health equity. Pediatrician Dr. Andrea Sims informed the group of the goals and priorities of the newly formed Health Equity Steering Committee. She said the hospital's focus is shifting from equality toward equity to give everyone the treatment and care they need. She said some of the things the committee is working on include finding a way to monitor and track the hospital's health quality index and looking at facilities and other areas throughout the hospital through interactions and visits. A parent portal will be created for families to give input.

Members of both PACs currently serve on committees that examine well check disparities, Pediatric to Adult Transitions of Healthcare (PATH), and wayfinding at the hospital. Members also work on the Ethics committee and PAC newsletter. However, the piece that really blends both Mahoning Valley and Akron PACs together is the leadership. Kristin Hafford, parent advisory coordinator, keeps both councils apprised of activities that are taking place each month. She encourages PAC members to attend conferences and seminars to gain knowledge about current topics and trends that benefit all individuals who walk through our doors. Whether it's a discussion about employee appreciation or inspirations and wishes for the 3rd floor renovation project, PAC input and feedback is shared with both councils so we can continue to work together for the betterment of the entire enterprise.

"I think both PACs really benefit from each other's ideas," said member Jennifer Krawchyk. "I hope we can have more of these collaborative trainings/events in the future."

PAC IN ACTION: FEATURING THE PARENT MENTOR PROGRAM



Mahoning Valley PAC member Amy Daprile's journey to being a parent mentor began 13 years ago when her special needs 2-year-old son needed a routine childhood surgery to correct frequent ear infections and have his tonsils and adenoids removed. Nathan ended up spending 73 days in the hospital after his lungs collapsed. When the doctor recommended a tracheostomy and a vent, a parent mentor was called in to help the family with the difficult decisions that needed to be made. These medical decisions would bring about a change in lifestyle—such as introducing nursing care at home—that the family was not mentally or physically prepared for with another young sibling at home. That parent mentor turned out to be a lifeline and helped the family see what seemed like a debilitating, permanent solution was actually only a necessary step in the healing process. She gave them confidence to go forward, understanding that others had made the same difficult decision before them. She brought Amy a book to read that was an integral step in the decision-making process and helped her get over the emotional hurdles.

Amy says, "It's one thing to speak to a trusted doctor, but it's another thing to speak to someone who has lived it. Doctors don't actually have to go home and care for the child, so it was important to hear from someone who had done it successfully."

Amy has recently been able to give back by becoming a parent mentor to a family with a child needing the same care that Nathan received many years ago.

Akron Children's has proven through the Parent Mentor program that they acknowledge the wonderful resource that parents are, and they encourage the sharing of stories among families to help others who are struggling in a time of crisis. Click the link below to learn more about this wonderful resource available to families.

akronchildrens.org/pages/Parent-Mentor-Program.html



TAG LINE: FEATURING MACKENZIE ROACH

The 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. Teens offer input regarding hospital facilities and services, participate in hospital-wide events, and interact with patients and families in various ways (activity cart, peer-to-peer mentoring, etc.).

Mackenzie has been a member of TAG for 5 years. She is no stranger to Akron Children's. She spent 120 days in the hospital in 2011 after being diagnosed with a brain tumor. She had to relearn how to walk, talk and even sit up. She has used her journey to help others along the way. She has appeared in Akron Children's commercials, attended more than 250 fundraisers, has been invited to speaking engagements, and raised over half a million dollars for the hospital and Children's Miracle Network. One of her favorite events is the WKDD Have a Heart, Do Your Part Radiothon where she calls her supporters to solicit donations "for the kids". Mackenzie is celebrating some big milestones like turning 18, being a 10-year brain tumor survivor and graduating from Jackson High School in May 2022. Her favorite part of TAG is taking the craft cart around to patient rooms (pre-COVID) and talking to patients. She is looking forward to volunteering again and the return of in-person fundraisers, but she has enjoyed giving feedback and input on various projects through the virtual setting.