

ImPACT

A newsletter from the
Parent Advisory Council



September 2021

PARENT ADVISORY COUNCIL (PAC) BACKGROUND

The Parent Advisory Council (PAC) includes parents and caregivers from the Akron and Mahoning Valley campuses whose children have received care at Akron Children's Hospital. 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. They also offer support on program development and policy upgrades. Learn more at akronchildrens.org/PAC.



PATH TO PAC: FEATURING JENNIFER KRAWCHYK, MAHONING VALLEY



What was your path to PAC?

My road to PAC started when my oldest son, Kyle (now 12), was in preschool and was diagnosed with neurofibromatosis type 1 (NF1). NF is a genetic disorder that causes tumors to grow along nerves throughout the body. Kyle has a spontaneous mutation; he is the only one in our family who has NF.

Since NF1 is a disorder not many people are aware of, it was important to me to be able to educate and advocate in my son's school system so that he could get the services and accommodations he needed to be successful. I wanted to be able to then take my experiences and help others who were in the same boat as our family. When Kyle was diagnosed at 6 months old, I knew no one with NF or even what to expect. All I had was my own research and our pediatrician's advice, and we basically carved our own path. My son's preschool teacher at the time, Christa, was already a member of PAC in the Mahoning Valley. She introduced me to PAC and encouraged me to attend a meeting to see if it was something I'd like to join. I did, and I knew from the first few minutes of the meeting that I absolutely wanted to be a part of it. I've been a part of PAC in the Mahoning Valley for 7 years.

Do you have a favorite PAC memory?

Pre-COVID, I loved visiting the different buildings in the Valley and passing out treats and beverages to the amazing staff and families. It's always so nice to let the doctors and nurses know that we appreciate them and their hard work, and also to let the parents know that they have support. My fellow PAC members are some of the best people I know. We are truly a family and I respect each of them so much.

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

I would love to see more events tailored to families with specific diagnoses and more help/guidance offered to families with disabilities regarding school issues. For example, a program/service where the hospital can help kids aging out of their respective school systems with job opportunities and basic financial planning for families with special needs.

VIEW FROM THE VALLEY

Jennifer Krawchyk, who you just met in the previous article, is the Ohio walk volunteer chairperson for the NF Network. The NF Network is a national organization advocating for federal funding for NF research and building and supporting NF communities. The NF Network was supportive in helping to guide the Krawchyk family on their NF journey.

The annual Fun Run/Walk is a way to bring NF families and supporters together for friendship, community and support.

“I am so proud that we have families from all over our state (including many local families), PA, and more who are able to come together for a few hours of community and friendship,” said Jennifer.

This year the walk will be a hybrid event on Saturday, October 9 at Boardman Park. Interested participants can register in person on October 9 or pre-register by going to nfnetwork.org > [#nfstrong](https://nfnetwork.org) events tab > Boardman, OH.



LIGHTS, CAMERA, PAC-TION IN AKRON

The hospital’s Transition committee is creating a New Pediatric to Adult Transitions of Healthcare (PATH) to ensure that high-quality transitions occur for patients aging out of Akron Children’s Hospital. PATH consists of members from Quality Services, Informatics, Population Health, Medical Staff, Nursing, Social Work, Parent Advisory Council and Summa Health (one of our partner institutions). In 2020, the committee learned more about the current state of transitions at Akron Children’s. PATH surveyed 27 community care groups (e.g., Locust Pediatrics, Adolescent Medicine), 48 medical/surgical subspecialties, and 44 PAC members. We found that only 21% of departments had a formal transition plan in place, and there was variability in age limits set for outpatient visits. PAC members provided vital input through the survey responses. Several parents mentioned that this process is stressful and daunting. Responses revealed that parents want their child’s care team to start discussions about transition earlier and that they need more support and communication. The committee is using this information to guide program development.

PATH is using the Got Transition (gottransition.org) framework as a model for transition at Akron Children’s. Got Transition’s approach includes 6 core elements: transition policy, tracking and monitoring, readiness assessment, transition planning, transfer of care and transition completion. The team is currently capturing Got Transition documents, adjusting them to fit specific needs of the hospital and trialing them with families in several subspecialty areas. The committee also developed a Complex Care sub-committee. The team recognizes that some patients and families will need more support during the transition process, and the goal is to ensure all materials can be adjusted using a complex lens. The committee’s definition of complex is broad and includes medical complexity, developmental/intellectual disabilities and social determinants of health.

LIGHTS, CAMERA, PAC-TION IN AKRON (CONT.)

PAC has been integral to PATH in a number of ways. PAC members have provided feedback to PATH about Got Transition documents and educational materials. Recently, December West connected Kim Musgrave (PAC's representative on PATH) with the Ohio Department of Health (ODH). ODH has a block grant to improve medical transition for Children with Special Health Care needs. Through this new community partnership, Akron Children's will also have a voice in transition work that is happening at the state level. Although there is still much work to be done, the committee looks forward to providing a more consistent transition roadmap to all patients and families. The team is grateful for PAC's continued assistance and support!

TAG LINE

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. 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 joined TAG because I wanted to give my input to the hospital to make things better for our patients. I also wanted to give back to the hospital that saved my life. I am celebrating 10 years as a brain tumor survivor in September, and I am proud of how far I've come and want to be an example to other patients that a diagnosis or a disability doesn't define who they are! ”
~Mackenzie Roach



“ I joined TAG to give people a voice who are scared to speak up or don't have one. I have 2 siblings who have special needs. I wanted to be able to give back. ” ~Xyia West