



family advisory board



2018 Annual Report

Children's Mercy Kansas City remains committed to partnering with patient and family advisors across the hospital system. The Family Advisory Board serves as the foundation for guiding hospital leaders in implementing engagement strategies to improve the quality, safety and experience of care for all patients and families who receive services at Children's Mercy. FAB's work in 2018 resulted in highly impactful collaborative efforts that advanced the culture of patient- and family-centered care.

Three workgroups were launched to focus on the areas of transition, onboarding new members and a formalized alumni group. The transition workgroup provided guidance to the Transition Program manager on topics including patient and parent testimonies, the patient portal and adult provider lists. The onboarding workgroup created standard work for new parents and staff members joining and exiting FAB, as well as designed a member profile that displays before each meeting. The alumni workgroup established PFAC Alumni, which will give all former Children's Mercy PFAC members the opportunity to continue their volunteerism.

FAB members were matched and prepared to serve as subject matter experts on numerous committees and projects. They were essential partners on hospital-acquired conditions committees, website redesign and facility upgrades. Various members also served on the Quality and Safety Council, the Financial Clearance Team, the Transition Education Committee, the Hunger-Free Hospital Task Force and the PHIL Award Committee honoring respiratory therapists. Some members volunteered with state and national organizations including Children's Hospital Association, Patient-Centered Outcomes Research Institute, Heartland Association of Research Professionals, Kansas Department of Health and Environment and the Greater KC Healthcare Foundation.

In an effort to expand members' knowledge and understanding of Children's Mercy and our surrounding community, multiple tours were provided throughout the year. These included a visit to the inpatient pharmacy and an Operation Breakthrough bus tour. The Transport Department took members to the transfer center, the ambulance bay and the helipad. Additionally, information was presented about the hospital strategic plan, equity and diversity initiatives, financial processes, psychosocial care, infection prevention, the Center for Clinical Effectiveness, and outcomes from the Ward Family Heart Center.

FAB members played an integral role in patient- and family-centered care education for staff and families. Families served as educators in the Family as Faculty program for residents, which included an orientation luncheon, a death-and-dying workshop and monthly in-home visits. One member spoke about the family experience in the Emergency Room during their department updates. PFAC members participated on panels for Social Work, Graduate Nurse Residency and Nurse Leadership Academy.

Several videos were created that featured FAB members educating staff and families on topics such as suicide screening, sepsis awareness and transitioning to adult care. The New Journeys handbook, a resource created by FAB for other families, was reviewed and updated.

As grateful families, giving back to Children's Mercy continued to be a priority. Members were involved in many philanthropic efforts such as the Planned Giving Council, Mercy Ambassadors and the 2018 Wish List Campaign. Furthermore, FAB hosted an Amazon book drive and collected over 1,500 books for the outpatient clinics.

In 2018, leaders from all the PFACs gathered together for two PFAC Leader Workshops to learn about best practices and share experiences. In recognition for their contributions, they also enjoyed an afternoon together in the Children's Mercy suite during a Sporting KC match. The Patient and Family Engagement team supported the growth of parent partners, while assisting with the development of one new PFAC.

- The **Beacon PFAC** held their first meeting this year. They concentrated on providing additional resources to families and were instrumental in the planning of the Parent Panel for a Social Work Lunch-n-Learn. Increased communication between the Beacon Team and families was a priority focus and next year they will work to optimize clinic workflow from the patient and family perspective to reduce redundancy and ensure value-based care team interaction.
- The **Cardiac PFAC** partnered with the Heart Center to improve the scheduling process, the website and educational handouts for patients and families. Members participated in two Lean workshops about clinic flow and the timeframe between when the family learns of their child's surgery and the pre-admission testing appointment. Feedback was gathered from 87 families via a survey about topics for parent education forums and additional POPS mentors were trained.
- The **Cystic Fibrosis PFAC** collaborated with the staff on 6 Henson to provide exercise equipment for inpatients. Newborn kits were created and distributed to families upon their infant's diagnosis. Members worked with the staff to create laminated clinic action plans for each visit and advocated for CF education days to add a virtual attendance option. They also provided input on quarterly clinic visits, mental health screenings and inpatient expectation guidelines.
- **El Consejo de Familias Latinas/Hispanas** hosted a table during Diversity Day and also participated in the first annual Día de Muertos service in the hospital chapel. Members gave feedback about the "Save My Spot" app and text message reminders. Two members began conducting Family Experience Tracers in Spanish. In the community, they hosted a CPR class in Spanish, a workshop "How to Talk About Sex with Your Teens," and a dinner at the Ronald McDonald House.
- The **Food Allergy PFAC** held a community event entitled "The Peanut Problem: A Discussion of Food Allergies" at the Kauffman Foundation. They presented to Ambulatory Leadership and were instrumental in the removal of snacks containing nuts in all outpatient clinics. They updated the information on the Food Allergy website and worked to maintain the Children's Mercy designation by Food Allergy and Research Education (FARE) as a national Center of Excellence.
- The **Inflammatory Bowel Disease PFAC** continued to provide insight for the MyCare App for chronic care and updated the IBD New Diagnosis Handbook. Working with ImproveCareNow, members assisted in the development of an IBD Flare Identification Tool and attended the Community Conferences. Two members rotated attendance at the monthly clinical quality improvement meetings, and work has begun on specific treatment plan communication tools.
- The **Neonatal Intensive Care Unit PFAC** hosted a successful NICU Reunion at the Kansas City Zoo with 700 attendees including former patients, their families and NICU staff. A celebration committee was formed to help community groups provide a monthly memory making item for parents. Members created a family information webpage and redesigned the My Baby's Notebook to help families navigate their baby's schedule and prepare for life after the NICU.
- The **Rare PFAC** increased hospital and community awareness to the unique challenges and unmet needs of children with rare conditions. They met with staff from subspecialty areas and spoke to 170 medical students at KUMC about providing medical care to individuals with rare diseases. Members participated in the 2018 Children's Mercy Genetics Medicine Training Conference and promoted the RareKC community fundraising event to support rare disease innovation.
- The **Tracheostomy PFAC** edited the new binder containing medical information and advice from parents that is given to families following their child's trach placement. They met with the PICU staff and shared their hospitalization experiences, served two dinners in the Ronald McDonald Family Room, and traveled to Jefferson City and met with Lt. Governor Mike Parson to advocate for in-home nursing. PFAC members helped plan and host the first Trach Family Day event.

The three Teen Boards provided patient perspective and guidance to various teams throughout Children's Mercy. Together, they served dinner at the Ronald McDonald Houses and worked to increase peer connections. They celebrated the holidays together with a group meal.

- The **Teen Advisory Board** designed the Charlie Hustle Giving Tuesday shirt and 25 percent of the sales were donated back to Children's Mercy. They collaborated with the Innovation Center on the MyCare App and provided input on resources and experiences in transitioning to adult care. TAB also shared ideas regarding suicide prevention efforts.
- The **Hematology/Oncology Teens** collaborated with the KC Cares Walk committee and facilitated a teen area at the walk. HOT continued to help plan the quarterly Teenapaloza events and began hosting regular inpatient activities in the 4H teen room.
- **Kids and Families Impacting Disease Through Science Kansas City** represented Children's Mercy at the annual International Children's Advisory Network summit in Scotland, and they will host the iCAN summit in Kansas City in 2019. Additionally, KIDS KC provided input to the hospital Human Trafficking workgroup.