



# family advisory board



## 2017 Annual Report

**Family Advisory Board (FAB) members are essential partners in the advancement of patient and family engagement to improve the quality, safety and experience of care at Children's Mercy Kansas City. The board is comprised of parents and caregivers of children who have received care at Children's Mercy and hospital leaders who influence policies and practices. These individuals collaborate to ensure the voices of patients and families are embedded within the health care system.**

In 2017, the Patient Family Advisory Councils (PFACs) aligned with the Center for Clinical Effectiveness reporting through the Vice President of Quality and Clinical Safety. This transition further elevates the platform recognizing Children's Mercy as a national and local leader in patient and family engagement.

FAB members continued to participate as consultants on Lean improvement projects in Perioperative Services and ambulatory clinics. They also contributed on hospital initiatives such as outpatient clinic appointment scheduling and Hospital Acquired Condition committees. A FAB representative actively served on the Quality and Safety Steering Committee, providing the patient and family viewpoint at the executive level.

Leaders of various departments and projects requested feedback from the Family Advisory Board. Throughout the year FAB members advised the Transition to Adulthood Program, universal screening for suicide tool, and family engagement in caring for patients with sepsis by identifying opportunities to increase patient and family centeredness. In addition to improving the Same Day Surgery drop-off zone and the parking garage signage, parents were integral partners in the redesign of the hospital website and the patient portal, as well as the launch of the Children's Mercy mobile app.

As champions of patient- and family-centered care, it is critical that FAB members continuously increase their knowledge about all aspects of Children's Mercy. In 2017, the board was informed about the Thrive program, First Impressions and Guest Services, the Genomic Medicine Center, the CHAMP® app, and the GetWell Network. The partnership between Sporting KC and Children's Mercy Park was introduced, and the board heard presentations about several Philanthropy initiatives, a new patient experience survey, and the history of Children's Mercy. Additionally, members toured the Contact Center, the Adele Hall campus and the Elizabeth J. Ferrell Fetal Health Center.

FAB was highly valued for its insight and impact regarding education for patients and families. During the year, members reviewed multiple documents including brochures for Pharmacy, a fertility handout and several Transition Program materials. To maintain the tradition of parents educating patients and families, a FAB member filmed the GetWell Network welcome video.

In addition to dedicating their time to FAB, members generously gave back to Children's Mercy through their involvement in several philanthropic programs. As grateful families, members shared their experiences at United Way events in Kansas City, served as Mercy Ambassadors, and advised Ronald McDonald House Charities. Members dedicated numerous hours to the Archives Committee and one member edited the newly released book, "For All Children Everywhere," outlining the history of Children's Mercy. In appreciation for their service, all Patient Family Advisory Council (PFAC) members were given a copy of this book authored by Tom McCormally.

Board members played an integral role in patient- and family-centered care education for staff and trainees. As Family Educators in the Family as Faculty program, parents facilitated resident education during an orientation luncheon, in-home visits, and a parent panel where one member shared his personal story about what mattered most when his child was dying. FAB also spoke to nurses in the Graduate Nurse Residency program about communicating with families during hospital inpatient stays.

Research is a top priority for members of all the PFACs. Since 2016, FAB and Consejo parents have actively engaged on a PCORI research project focused on reducing antibiotic misuse. A FAB member operates as the Parent Research Assistant. Another member was selected as a scholarship recipient to attend the PCORI national conference and acted as a grant reviewer. One member remained on the Children's Hospital Association CARE Award to bridge care coordination for patients with complex health needs.

FAB serves as the oversight group for the many Patient Family Advisory Councils at Children's Mercy. These PFACs provide a forum for patients and families to collaborate with the health care team specific to their patient population. Council members share their unique perspective of the patient and family experience in order to have a direct impact on the planning, delivery and evaluation of health care with the goal of promoting quality, safety and satisfaction. In appreciation for their essential contributions to Children's Mercy, PFAC leaders were invited to sit in the Children's Mercy suite during a Sporting KC game, and all members were honored at a special volunteer recognition event with Randall L. O'Donnell, PhD, President and CEO, and Karen Cox, PhD, RN, Executive Vice President and COO.

- The Cardiac PFAC was established in 2017 to support the highest standard of excellence in cardiac care at Children's Mercy through meaningful collaboration between families and hospital staff. During its inaugural year, members provided feedback on the Ward Family Heart Center webpage, the CHAMP binders and patient milestone cards. Additionally, they worked with staff on the ICU care pyramid, the patient acuity system, and helped build momentum for the single ventricle survivorship program.
- The Cystic Fibrosis PFAC hosted an infant/toddler education day for families which included a parent and patient panel along with breakout sessions. In an effort to support families, they assembled newborn kits to be distributed to parents upon their child's diagnosis. They also provided input for a new inpatient expectation document outlining goals for hospitalization and met with the Department of Philanthropy to discuss future fundraising events.
- El Consejo de Familias Latinas/Hispanas represented the voice of Spanish-speaking patients and families on several projects including the patient portal, valet parking and a PCORI research grant. They hosted an open house for potential members, staffed a booth during Diversity Day, and attended an ideation session to improve the Children's Mercy experience. One member filmed the Spanish version of the GetWell Network welcome video.
- The Food Allergy PFAC surveyed the ambulatory clinics about snacks for patients and created a proposal with recommendations for allergy friendly snack alternatives. Several members took part in a food allergy education awareness video and also provided feedback on the food allergy webpage. They also constructed a tri-fold display for informational events and were trained as peer mentors in the Parents Offering Parent Support program.
- The Inflammatory Bowel Disease PFAC focused on the development of a chronic care management app and partnered with the clinical team to assemble a comprehensive resource list for families. Two members attended the national Improve Care Now community conference. Additionally, they developed a standardized process for onboarding new members and a key driver diagram to define and guide their work.
- The Intensive Care Nurse PFAC assisted in the creation of the Parents First Encounter video to help orient new families to the ICN, reviewed and revised unit policies, and updated their PFAC by-laws. Members served on several committees including brain builders, safety and infection prevention. One member participated on the national Children's Hospitals Neonatology Consortium.
- The Rare Disease PFAC was formalized to represent families whose children have a condition that affects fewer than 200,000 people in the world. Parents were actively involved in the recruitment of members who would bring diversity in diagnoses. Their first meeting was in September and plans were made to assist with the 2018 Rare Disease Week, a hospital awareness campaign, and a RareKC Townhall meeting.
- The three teen boards were very active this year. The Teen Advisory Board provided a patient-focused activity, worked with the Ronald McDonald House on teen activities and design of their spaces, and collaborated with KU students on a patient use interactive robot project. Two members were honored as the 2017 Youth Philanthropists of the Year by the Association of Fundraising Professionals for the non-profit they founded, Henson's Heroes. The Hematology and Oncology Teen Board completed the teen journal, facilitated a teen area at the KC Cares Walk, and helped plan the quarterly Teenapalooza events. The Kids and Families Impacting Disease through Science Board represented Children's Mercy at the iCAN Summit in Orlando, Fla. They worked on projects aimed to provide psychological first aid after trauma and with the anti-microbial stewardship team. They also learned about research done at Stowers Research Institute, Quintiles and the Genomic Medicine Center.
- The Tracheostomy PFAC was established and had an immediate impact by trialing and sharing improvement ideas for new standardized tracheostomy emergency bags. They provided input for the new "Roadmaps for Home" tool and the educational materials for families making the tracheostomy decision. Members traveled to Jefferson City, Mo., and met with senators and representatives to highlight the importance of home nursing.

The members of the Family Advisory Board look forward to continuing their collaboration with Children's Mercy staff as they provide multi-faceted approaches to engage patients and families in quality improvement from the bedside to the boardroom. It is both an honor and responsibility to work with hospital leadership to ensure the children of our community receive the best care possible.