

family

advisory board



Children's Mercy

LOVE WILL.

2019
ANNUAL REPORT

Who We Are

The Family Advisory Board consists of 21 families who are primary caregivers of a child who has been cared for at Children's Mercy. FAB collaborates with hospital leadership to ensure the highest level of quality, safety and experience of care is provided to every patient and family. FAB serves as the oversight group for all the Patient Family Advisory Councils (PFACs) at Children's Mercy.

Our Goals

The goals of FAB are to:

- promote and support the mission, programs, services and initiatives at Children's Mercy
- promote communication between hospital staff and families
- assist with the education of Children's Mercy staff and health care providers.

Quick Facts & Definitions

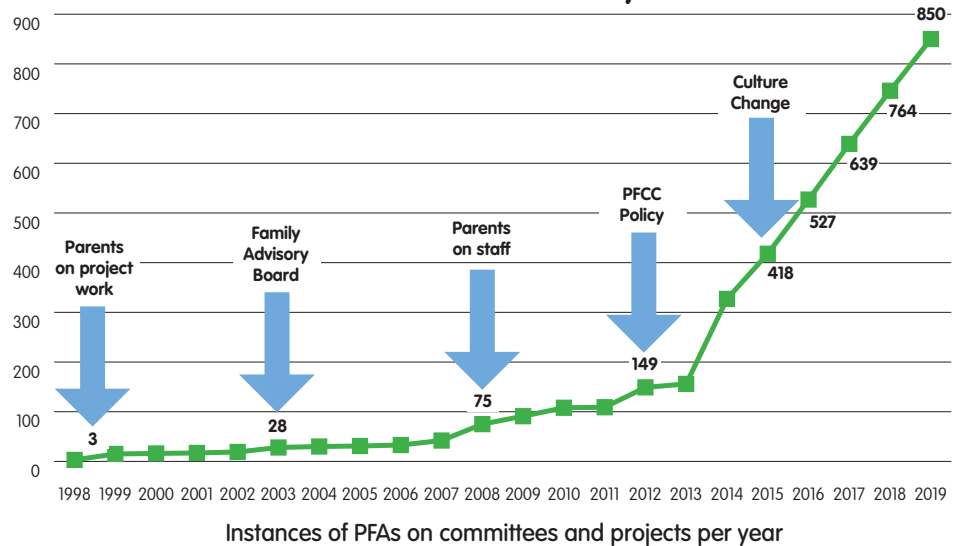
- **FAB:** Family Advisory Board
- **TAB:** Teen Advisory Board
- **PFAC:** Patient Family Advisory Council
- **PFA:** Patient Family Advisor
- **Number of Boards:** 2 (FAB and TAB)
- **Number of PFACs in 2019:** 15
- **Number of parents on staff supporting the Patient and Family Engagement efforts:** 5
- **Number of parents/caregivers involved as PFAs:** 216

Family Advisory Board (FAB)

Established 2003, 21 family members, 10 staff members

Children's Mercy Kansas City has a longstanding history of engaging patients and families as valued advisors across the health care system. As a recognized national leader among hospitals for partnering with Patient Family Advisors, Children's Mercy utilizes the expertise and perspective of PFAs to improve the quality, safety and experience of care. In 2019, the FAB's work resulted in highly impactful collaborative efforts that advanced the culture of patient- and family-centered care throughout the institution.

History of Patient and Family Engagement at Children's Mercy



Members of FAB represented the hospital on a national level on numerous occasions this year.

Children's Mercy was featured in a case study by the Center for Consumer Engagement in Health Innovation and the Health Care Transformation Task Force as an exemplar organization of patient and family engagement. The project was funded by the Robert Wood Johnson Foundation, and FAB and Consejo members joined in on-site interviews to validate the value of involving patients and families from the bedside to the boardroom.

During a Beryl Institute Pop-Up Event hosted by Children's Mercy, several members provided the parent perspective on ways to improve the patient experience. In the spring, the FAB chair attended the Beryl Institute Patient Experience Conference in Dallas. FAB and Consejo members co-presented a research project, "Let's Talk about Antibiotics," during the International Children's Advisory Network annual summit held in Kansas City.

FAB members volunteered their time during several special events including a community education program for parents of teens entitled "Prepped and Ready," the Snowflake Shoppe and the creation of the Children's Mercy Anthem Video. Vital feedback was provided regarding facility updates, care navigation, clinic access and the summer lunch program. Tours of several locations were conducted including the Fetal Health Center, Parent Exercise Room, Home Care and Refill Pharmacy at the Riverside Facility and the Executive Huddle Board.

Hospital projects were enhanced through the feedback and personal perspectives of FAB members including participation in executive recruitment interviews, the redesign of patient billing statements and improvements to the patient portal. Members focused on reviewing patient-facing materials, including the hospital website and brochures. The Patient- and Family-Centered Care policy and the Patient and Family Engagement policy were reviewed and approved. Input was provided on Children's Mercy brand positioning, the surgery EASE app and the Parentish marketing initiative. FAB and TAB participated in the development of the new hospital strategic plan and new mission, vision and values.

Board members played an integral role in patient- and family-centered care professional development for physicians, nurses and students. As Family Educators in the Family as Faculty program, members partnered with Graduate Medical Education on the resident quality improvement projects that focused on enhancing communication with families during inpatient stays. Additionally, parents facilitated resident education during an orientation lunch, monthly in-home visits and a death and dying workshop. PFAC members participated on parent panels for Nurse Leadership Academy and the Graduate Nurse Residency program.

The members of the Family Advisory Board, together with the Patient Family Advisory Councils, look forward to supporting Children's Mercy as active consultants and contributing patient and family engagement expertise. Love Will bring patients, families and hospital leaders together to create a world-class health care system.

Children's Mercy Teen Boards

The voice of teen patients is highly valued at Children's Mercy, and there are three PFACs focused specifically on their unique needs. The teen groups have offered their feedback and guidance to various departments throughout the hospital, including the new Children's Mercy Vaping Task Force. Opportunities for all board members include working together, increasing peer connections, active participation and recruitment.

Teen Advisory Board (TAB)

Established 1999, 12 members, 2 staff members

This board of engaged teens represents various ages, backgrounds, diagnoses and communities. This year they worked with Truman Medical Center to develop and record a script to create a guided facility tour. One of their favorite activities involved partnering with Shatto Milk as taste testers for the Children's Mercy Special Edition milk.



Hematology and Oncology Teens (HOT)

Established 2013, 9 members, 2 staff members

This group continues to provide valuable feedback to the Innovation Center for the MyCare App and plans the Teenapaloza quarterly events for Children's Mercy teens. Their ongoing goal is recruitment for new members.

Kids Impacting Disease through Science (KIDS-KC)

Established 2014, 12 members, 2 staff members

KIDS-KC is the local chapter affiliated with the International Children's Advisory Network (iCAN). This year, they hosted the annual summit, involving over 120 youth and parents from around the globe. To prepare

for the iCAN summit, members reviewed abstracts, educational materials and developed the week's agenda.



Patient Family Advisory Councils (PFAC)

The Patient Family Advisory Council (PFAC) is a formal council made up of patients, parents or primary caregivers of a child(ren) who has been cared for at Children's Mercy. PFAC members meet regularly and partner with hospital staff and leaders to carry out the following:

- Support the mission and vision of Children's Mercy.
- Provide ongoing feedback to collaboratively problem solve for solutions that are patient- and family-centered.
- Promote an environment in which family members and professionals work together to ensure the best services for children and families.
- Incorporate diverse perspectives representing the populations served.



Beacon

Established 2018, 13 family members, 9 staff members

This team's focus is on the provision of a patient- and family-centered primary care medical home for children with medical complexity and their siblings. This year, they advocated for Beacon Program resources, reviewed the new patient portal design and created the Beacon Family Newsletter. Members partnered with staff to create a roadmap for families, as well as provided feedback about their unique needs to Children's Mercy Home Care and Refill Pharmacy.

Cardiac

Established 2017, 15 family members, 1 staff member

In 2019, this team planned and hosted the Parent Symposium, where 35 parents attended sessions on mental health, trauma-informed care, exercise tolerance and preparing for transition to adult care. During the year, the group focused on increasing awareness of support programs within the hospital, created a surgery informational handout for parents, provided feedback to an exercise physiology study and gave input on establishing boundaries between staff and patients and families. Members also participated in the Heart Center Lean Realignment workshop.

Cystic Fibrosis

Established 2015, 10 family members, 2 staff members



In addition to their regular PFAC meetings, this team is committed to participating in the CF Clinic Team quarterly meetings to provide family insight on current projects including mental health screenings and inpatient expectation guidelines. They advocated for a stronger website presence for the PFAC and continued working on CF Education Day to help shape the agenda for family participants. One exciting accomplishment was collaborating with 6 Henson to provide exercise equipment for inpatients and a CF-specific mural created by Scribe.

El Consejo de Familias Latinas/ Hispanas

Established 2008, 8 family members, 4 staff members

This PFAC is focused on meeting the diverse health care needs of the Spanish-speaking community. They provided feedback on several topics, including genetics, human trafficking and employment opportunities for young adults with disabilities. They reviewed the Children's Mercy website and the branding campaign, developed a bilingual bookmark outreach tool and consulted with the Safe Sleep team. Members enjoyed gathering in person and celebrating at the annual holiday potluck, volunteering at the Ronald McDonald Family Room, participating in the Annual Day of the Dead Service and sharing their cultural pride at the annual Diversity Day event.

Eating Disorders Center

Established 2019, 10 family members, 2 staff members

In their first year, the EDC PFAC reviewed and revised the New Family packet to streamline and standardize information and included a technology option of a QR code that linked to educational videos. Members created several resource documents; one for school nurses which includes facts, statistics and awareness information, and one for parents to help with feelings of being overwhelmed and alone. They also became trained mentors in the POPS (Parents Offering Parent Support) program.

Spinal Differences

Established 2019, 8 members, 1 staff member

In just 9 months, this team accomplished much, including successfully advocating for Orthopedics to return to the Spinal Differences Clinic. Members completed POPS mentor training, served dinner in the Ronald McDonald Family Room and requested automatic doors throughout the hospital. Work in progress includes new patient information packets, inserts for NICU binders and working with the National Spina Bifida Association on agenda topics for Kansas City Education Day.



Food Allergy

Established 2016, 7 family members including 1 teen, 5 staff members

This PFAC planned and hosted a Top 8 Free Food Allergy Cooking Class for parent/child teams. They met with the new food vendor at Children's Mercy to ensure safe options for patients, families and visitors with food allergies. They gave



input on labeling of food allergens in the cafeteria, as well as on inpatient menus. Members participated on Community Food Projects and eliminated the use of peanut butter in food demonstrations. They created a tool for

families "Pathways for Food Allergies for Every Stage of Life" which will be available next year.

Inflammatory Bowel Disease

Established 2014, 12 family members, 1 staff member

Members took turns attending clinical QI monthly meetings to ensure the voice of the patient and family were represented. Two PFAC members participated in Engagement Campaign work with the Improve Care Now international collaborative and presented at the fall conference, along with the Children's Mercy clinical team. They finalized the MyCare App for chronic care and revised the IBD New Diagnosis Handbook. Focused on the school-based experience, trauma-informed care information was added to the school letter distributed to area districts.

Kansas

Established 2019, 8 family members, 4 staff members

This newly established PFAC provides support to Children's Mercy Hospital Kansas and Children's Mercy College Boulevard. Members toured the locations to learn about operations and services. They provided feedback regarding wayfinding signage, the new parking structure, the patient experience in the Emergency Room, food services, metal detectors and the surgery Ease App. They were successful in advocating for additional wheelchair scales and increasing the hours that Hunter and Hope, the Children's Mercy facility dogs, provide furry love and support for patients and families.



Neonatal Intensive Care Unit

Established 2012, 11 family members, 2 staff members

This advisory council offered their expertise by contributing to several parent educational materials: The Small Baby Unit, "Lighting the Way" discharge planning, My Baby's Notebook and Safe Sleep. They provided feedback to the unit staff on the topics of professional boundaries and empathy huddles. The NICU Reunion at the Kansas City Zoo was a huge success with 930 attendees, including families, former patients, donors and staff volunteers.

PFAC Alumni

Established 2019, 10 members, 2 staff members

This group consists of former PFAC members wishing to remain active and involved in the collaborative process with Children's Mercy. They meet quarterly and serve as ad hoc consultants. In their first year, members participated on the PICU expansion design team and joined clinicians and architects to provide onsite feedback during the PICU mock-up walk-through. One member served on the Transition Education and Marketing Workgroup and the Call Center calibration reviews.

Rare

Established 2017, 10 family members, 2 staff members

This group representing 8 rare conditions launched a hospital-wide rare disease "Show your Stripes" awareness campaign centered around Rare Disease Day in February. They connected families to the Genome Answers for Kids program, and two members joined the Genomics Ethics Committee. PFAC members spread their message during several local and national speaking engagement opportunities to medical students and at a genomics training conference.

Tracheostomy

Established 2017, 10 family members, 3 staff members

The 2nd annual Tracheostomy Family Day themed "Every Hero has a Story" was a huge success and supported by this group who raised over \$1,000 with their trach T-shirt fundraiser. They hosted a monthly Q & A session to support newly diagnosed parents, by pairing them with others who have experienced the same journey. Members created an educational display to share information during Global Tracheostomy Week and made updates to the Emergency Go Bag design.

