

CHILDREN'S MERCY

FAMILY ADVISORY BOARD



ANNUAL REPORT 2020



Children's Mercy
KANSAS CITY



THE CHILDREN'S MERCY FAMILY ADVISORY BOARD (FAB)

Established 2003, 21 family members, 11 staff members

In 2020, the COVID-19 pandemic dominated the headlines and daily life around the world. The strong foundation of patient and family engagement enabled Children's Mercy Kansas City to quickly transition to **collaborating virtually with Patient Family Advisors (PFAs)**. Health care was forced to adapt to changes due to the spread of the virus, and variations to traditional guidelines were immediately amended. For patient and staff safety, visitor restrictions were implemented, the use of telehealth grew exponentially and stringent infection control measures were put into place.

The expertise and perspectives of PFAs during this disruption were essential to the ongoing adaptation of operations. The culture of partnering with PFAs has been engrained throughout the institution; therefore, staff continued to seek their feedback, and advisors were quick to respond.

As group gatherings were restricted, the **Family Advisory Board (FAB)** successfully moved to a virtual platform without interruption to their meeting cadence. Member participation remained high despite the move to online meetings. The **Patient and Family Engagement Team (PFE)** shared this success as a model for other hospitals and published, "TeleBoard: the move to a virtual family advisory board," in the Patient Experience Journal: cmkc.link/FABpxjournal.

The **new Enterprise Strategic Plan** was presented to FAB, and parents were recruited to serve on the True North Pillar committees and strategic plan work groups. **The inclusion of a member from the Family and Teen Advisory boards during the Strategic Planning retreats ensured the voices of patients and families were represented during the development process.** As the goals and supporting strategies are executed, FAB will continue to provide feedback.

FAB members met virtually with the Magnet appraisers during their re-designation visit to highlight the patient- and family-centered care practices at Children's Mercy. **Members also represented Children's Mercy at three national events:** Children's Hospital Association Next Generation Quality Improvement Workshop, Institute for Patient- and Family-Centered Care International Conference and Pediatric Experience Collaborative Telehealth Panel. Their voices have an ongoing influence on patient and family engagement beyond the walls of Children's Mercy.

Families serve as essential partners in patient- and family-centered care education for physicians, nurses and staff. **In partnership with Graduate Medical Education, some FAB members serve as Family Educators in the Family as Faculty program.** These members provide a virtual home immersion experience for residents while other parents share their personal stories on a bereavement panel about the experience of losing a child. Additionally, parent panels were facilitated for the Graduate Nurse Residency program and the Nurse Leadership Academy.

In support of philanthropic endeavors, FAB supported several initiatives throughout the year. A generous donor offered FAB members the opportunity to attend the annual signature event Red Hot Night. For the inaugural Dream Big Day fundraiser, members assisted as Ambassadors and Dream Makers, and their children appeared in the community marketing campaign. In addition, the Planned Giving Council and Mercy Ambassadors include ongoing representation from FAB.



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 PFAC

Established 2018, 13 family members, 9 staff members

The Beacon PFAC represents the medical home for children with medical complexities and their siblings. In 2020 members focused on facility improvements including identifying and prioritizing locations for power assist doors. In partnership with the facilities and security departments, handicap spaces were repainted, and a "parking ticket" was created to raise awareness about improper parking in spaces designated for people with disabilities. Workgroups were formed to update the website, enhance nutrition education, and create a Beacon newsletter for families.



Cardiac PFAC

Established 2017, 15 family members, 1 staff member

The Cardiac PFAC collaborated with the Ward Family Heart Center to successfully create a new multidisciplinary clinic for the single ventricle patient population. In the midst of the COVID pandemic, PFAC members provided ongoing feedback to improve the quality of telehealth visits. They assisted with the planning for the Heart Center virtual reunion held during the Dream Big Day event. Goals were developed to improve parent communication, assist with the creation of a cardiac-specific transition program, and provide parent perspective on tube weaning for patients seen in the CHAMP program.

Cystic Fibrosis PFAC

Established 2015, 10 family members, 2 staff members

The Cystic Fibrosis PFAC worked with their social workers to establish a virtual Adolescent Support Group for patients between the ages of 15 and 18. They assisted with the annual CF Family Education Day and created education for parents of newborns diagnosed with CF. Members were instrumental in providing feedback about BMI discussions and mental health screenings during quarterly clinic visits as well as input on guidelines for inpatient expectations. As the recipients of a CF Foundation grant, they identified how the funds would be used to provide financial resources for families in need.

E-Council PFAC Coming soon

Eating Disorders Center PFAC

Established 2019, 10 family members, 2 staff members.

The Eating Disorders Center PFAC created a video for parents of children newly diagnosed with an eating disorder: cmkc.link/EatingDisorders. To increase education and awareness for eating disorders, they contributed an article to the Parent-ish blog: cmkc.link/eatingdisordermyths. Members established a partnership with the Kansas PFAC to work jointly on projects at the Children's Mercy Hospital Kansas and College Boulevard campuses. This group plans to focus on the creation of additional resources for school districts and education for inpatient nurses caring for this patient population.

El Consejo de Familias Latinas/Hispanas PFAC

Established 2008, 8 family members, 4 staff members

El Consejo de Familias/Latinas Hispanas created a video to assist with the transition to adult care specific to their culture: cmkc.link/programadetransicion. This group partnered with Latinos in Medicine to redevelop translated content for the Children's Mercy website and provided ongoing feedback to staff about COVID-19 prevention education in Spanish. To assist with recruitment, they designed an outreach bookmark that can be shared with Spanish-speaking families. Members continued to serve as Children's Mercy ambassadors within the community.





Kansas PFAC members toured the Sleep Lab before the pandemic.

Food Allergy PFAC

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

The Food Allergy PFAC worked with the new food vendor, Morrison, to raise food allergy awareness and advocated for a safe environment for patients, families and visitors. Snacks containing peanuts were removed from the clinic ordering list, and members requested that food in the cafeteria be labeled with all ingredients. Members designed a roadmap as a guide for different stages of food allergy and wrote a letter to parents for the initial patient packet. The Food Allergy Fighters Team for Dream Big Day raised over \$500, and the group welcomed the first patient member to the PFAC.

Inflammatory Bowel Disease PFAC

Established 2014, 12 family members, 1 staff member

The Inflammatory Bowel Disease (IBD) PFAC focused on the transition to adult care communication specific for patients with IBD. Members reviewed Children's Mercy and IBD specific resources with the goal to embed them in the PFAC webpage. The PFAC continued to partner with the IBD Quality Improvement Team to represent the patient and family perspective in clinic operations. Two members met with the national Improve Care Now (ICN) Engagement Trailblazers to increase parent engagement at ICN centers nationwide.

Kansas PFAC

Established 2019, 8 family members, 4 staff members

The Kansas PFAC provided recommendations for multiple projects at the College Boulevard campus. Prior to COVID restrictions, they toured the new sleep lab and provided feedback for parent preparation for sleep studies. Additionally, their insight was invaluable to the implementation of a central registration pilot program. Members worked closely with the Ophthalmology Department to address scheduling concerns and improve communication with families. They also helped Children's Mercy Hospital Kansas accommodate social distancing, visitor screening, and other operational changes due to the COVID-19 pandemic.

Mental Health PFAC

Established 2020, 6 family members, 7 staff members.

The Mental Health PFAC celebrated many accomplishments during their inaugural year. In partnership with the Developmental and Behavioral Medicine Division, members collaborated on projects for masks for children with special needs, suicide prevention training for staff, and inpatient parent caregiver kits. Several members recorded videos with words of advice for behavioral health education for nurses. One member co-presented a national webinar and published an article, "Mental Health Needs during COVID-19: Responses in Pediatric Health Care," in *Pediatric Nursing Journal*.

Neonatal Intensive Care Unit PFAC

Established 2012, 11 family members, 2 staff members

The Neonatal Intensive Care Unit (NICU) PFAC celebrated the long awaited installation of NicView® bedside cameras which allow parents, families and friends to see their infant in real-time. They provided insight throughout the development of the usage protocols for staff and families. Members worked closely with the Philanthropy Department to host their first virtual NICU reunion in conjunction with Dream Big Day. They consulted on numerous projects in the NICU including code blue responses and debriefings, palliative care, the Small Baby Unit and the creation of inpatient family surveys.

PFAC Alumni

Established 2019, 10 members, 2 staff members

The PFAC Alumni shared their experiences and guidance in preparation for the first Transition Conference to be held in 2021. Members serve on Children's Mercy's Transition Education and Marketing Workgroup and participated on the bereavement parent panel "What Matters Most" for Graduate Medical Education. The PFAC welcomed three former patients to the group. In February, they hosted dinner and met with families in the Ronald McDonald Family Room. This group is available to provide support to all the other PFACs.



PFAC Alumni serving dinner in the Ronald McDonald Family Room before the pandemic.



Window display raising awareness about rare diseases.

Rare PFAC

Established 2017, 10 family members, 2 staff members

The Rare PFAC sponsored a campaign to raise awareness about rare diseases within Children’s Mercy and the community. Parents participated in educational events for KU and UMKC medical students to share the effect of rare diseases on families. Members participated with Rare Across America in state legislative advocacy events, continued their partnership with RareKC, and two members joined the Genomics Answers for Kids ethics committee. The PFAC contributed to the creation of a video, “Live, Love, and Rare Disease” cmkc.link/LiveLoveRareDisease that connects the viewer to the life behind a rare disease diagnosis, provides information about the prevalence of rare diseases and shows the impact research can have on the quality of life for patients and families.

Spinal Differences PFAC

Established 2019, 8 family members, 2 staff members.

The Spinal Differences PFAC welcomed their first former patient to the group who met separately with children of PFAC members to gather ideas on how to improve the clinic experience from the patient perspective. This resulted in the design of an “About Me” tool which the patient completes, and staff utilizes to personalize the visit. Members collaborated to improve the Spina Bifida Newborn Education Booklet as well as information and resources for the clinic website. They gave input for Children’s Mercy Education Day hosted virtually in October with the National Spina Bifida Association.

TEEN ADVISORY BOARDS

The three patient advisory councils, the Teen Advisory Board (TAB), the Hematology and Oncology Teens (HOT) and Kids Impacting Disease through Science (KIDSKC), joined forces virtually in 2020 to provide Children’s Mercy with feedback from teenage patients. TAB and HOT continued collaboration with the Innovation Center on the development of the MyCare App. KIDSKC participated in the virtual iCAN Conference and submitted a personal video story to inspire researchers, scientists and pediatric health care stakeholders. They also toured the Children’s Mercy Research Institute.

- Teen Advisory Board
- Hematology Oncology Teens
- Kids and Families Impacting Disease Through Science



Tracheostomy PFAC

Established 2017, 10 family members, 3 staff members

The Tracheostomy PFAC sold over 200 George the Giraffe T-shirts and hosted a fundraising team for Dream Big Day. The proceeds were used to purchase trach bags for families and educational equipment for the Tracheostomy program. Children’s Mercy was represented at the Global Tracheostomy Collaborative. Flipcharts and videos were created to assist with patient and family education, and a window display was designed to share information during Global Tracheostomy Week. Members held bi-weekly virtual chats for other families and caregivers.



PFAC News

The PFE team partnered with researchers in Health Services and Outcome Research to assess the demographic characteristics of FAB and the other 17 Patient Family Advisory Councils. The primary aim of this project was to assess demographic characteristics of PFAC members compared to the patient population. FAB plans to use this information to co-design interventions to achieve diversity and inclusion goals for targeted recruitment and retainment of diverse board members and continuous monitoring for areas of opportunity to improve engagement.

The results of the demographic survey were shared with all PFAC leaders during the 3rd annual Leader Workshop. During the breakout sessions, family leaders and staff facilitators discussed recruitment and retention strategies,



projects and goal setting, and virtual meeting logistics. Additionally, the new logos for each PFAC were revealed.

FAB and PFAC members continued to make meaningful and sustainable improvements throughout the hospital system. In recognition for their extraordinary service and dedication to Children’s Mercy, two PFAs were recognized in 2020 as Volunteers of the Month.



Brenda Saenz Quintana
May Volunteer of the Month
El Consejo de Familias Latinas/Hispanas



Kacy Seitz
December Volunteer of the Month
FAB and Beacon PFAC

**PATIENT
FAMILY
ADVISORS
ADD TO THE
SUCCESS
OF OUR
PROGRAMS**

Congratulations
Brenda and Kacy



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