

CHILDREN'S MERCY KANSAS CITY



# FAMILY ADVISORY BOARD

ANNUAL REPORT 2021



**Children's Mercy**  
KANSAS CITY

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## PATIENT AND FAMILY ENGAGEMENT

Patient and family engagement is a plan for improvement from the bedside to the boardroom. It is dynamic and always evolving in response to changes in the health care environment. In order to best serve our patients, we must develop partnerships between the health care team and our families. These relationships advance our programs, facilities and systems while improving the quality, safety, and experience of the care we deliver.

## VISION

The Patient and Family Engagement Team works to continuously seek out and infuse the patient and family perspective to proactively inspire a patient- and family-centered culture and influence improved quality, safety and experience.

## MISSION

To inspire health care designed in collaboration with patients and families.



# PATIENT FAMILY ADVISORY COUNCILS (PFAC)

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

- 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 that represent the populations we serve.



## PATIENT AND FAMILY ENGAGEMENT

As a nationally recognized leader in patient- and family-centered care, the Patient and Family Engagement Team at Children’s Mercy Kansas City continued to elevate the integration of the patient and family voice throughout all levels of the organization. As the COVID-19 pandemic persisted, Patient Family Advisors (PFAs) virtually collaborated with staff on committees, workgroups and educational sessions to improve the quality, safety and experience of care throughout the hospital system.

The Patient and Family Engagement Team is responsible for oversight of the Family Advisory Board and the Patient Family Advisory Councils (PFACs) and serves as the liaison between all the groups. It provides training and peer mentoring to PFAs. The Patient and Family Engagement team includes a Medical

Director, a Senior Director, a Patient Experience Specialist, 2 Program Managers and 2 Coordinators.

The Program Managers and Coordinators were intentionally hired because of their experience as parents of patients at Children’s Mercy. This move is seen as a ‘game-changer’ by Children’s Mercy’s CEO Paul Kempinski. Kempinski said, “It raised the organization to a higher standard of performance because staff know our family members are walking the halls and are in meetings every day.” The parents on staff attend numerous hospital-wide and departmental leadership meetings to provide a patient and family lens as well as work with hospital leadership across departments to identify ways in which patients and families can be more engaged.

In addition to recruiting, training,

and managing the PFAs, the PFE Team also provides training to staff on how to effectively integrate PFAs into committees and projects. The team serves as vital connections between the hospital staff, patients and families – providing a safe place for everyone to ask questions and seek advice on how to improve the patient and family engagement process.

In 2021, the PFE Team facilitated over 1,700 volunteer engagements totaling nearly 2,800 volunteer hours. Over half of the hours were accrued in PFAC meetings and related subcommittees. Staff education comprised another large portion of the volunteer hours. Members of the Family Advisory Board and Teen Advisory Board welcomed the new residents and introduced them to the culture of patient and family

**PATIENT AND FAMILY ENGAGEMENT** Continued

engagement at Children’s Mercy. Thirteen PFAs served as Family Educators in the Graduate Medical Education program and virtually hosted residents in their home to give them a glimpse into life with a child with medical complexities. A group of Family Educators participated on a bereavement panel for the residents, sharing “What Matters Most” at the end of their child’s life. This curriculum was duplicated for the Nursing Resident Program and Clinical Leaders Academy.

In support of Children’s Mercy, PFAs partnered with the Communications and Marketing department to highlight 24 patient stories on Children’s Mercy social

media channels. Several of their children were featured in the “Recognition is Sweet” campaign celebrating the US News and World Report rankings. They joined philanthropic events including Dream Big Day, Big Slick and Red Hot Night.

On a national level, the Patient and Family Engagement Team recruited PFAs to co-present with Carol Kemper, Senior Vice President, on a Children’s Hospital Association webinar entitled “Engaging the Family Voice – Exploring Patient and Family Partnerships.”

Together with PFAs, members of the PFE Team interviewed candidates for Chief Data Officer, Chief Quality Officer, Chair of Orthopedics, Vice

President of Care Management, and Chair of Cardiology to assess the applicant’s approach to patient and family engagement.

The PFE Team provides leadership to the organization to advance patient- and family-centered care principles, concepts and culture. They offer direction and expertise in planning, decision making and organizational change related to patient and family engagement.

The parents on staff manage over 200 PFAs and 19 PFACs, utilizing their first-hand experiences to improve the care for all patients and families who rely on Children’s Mercy for their child’s care. ●

**Today’s Discussion**



**Emily Brown**  
CEO  
Food Equality Initiative



**Carol Kemper, RN, PhD, CPHQ, CPPS, FAAN**  
Senior Vice President, Service and Performance Excellence  
Children’s Mercy Kansas City



**Kacy Seitz, CLTC, ChSNC**  
Financial Advisor  
Northwestern Mutual



**Kelly Ranallo**  
Founder and President  
Turner Syndrome Global Alliance

**216** Advisors | 82 from Mo., 129 from Kan., 5 from other states

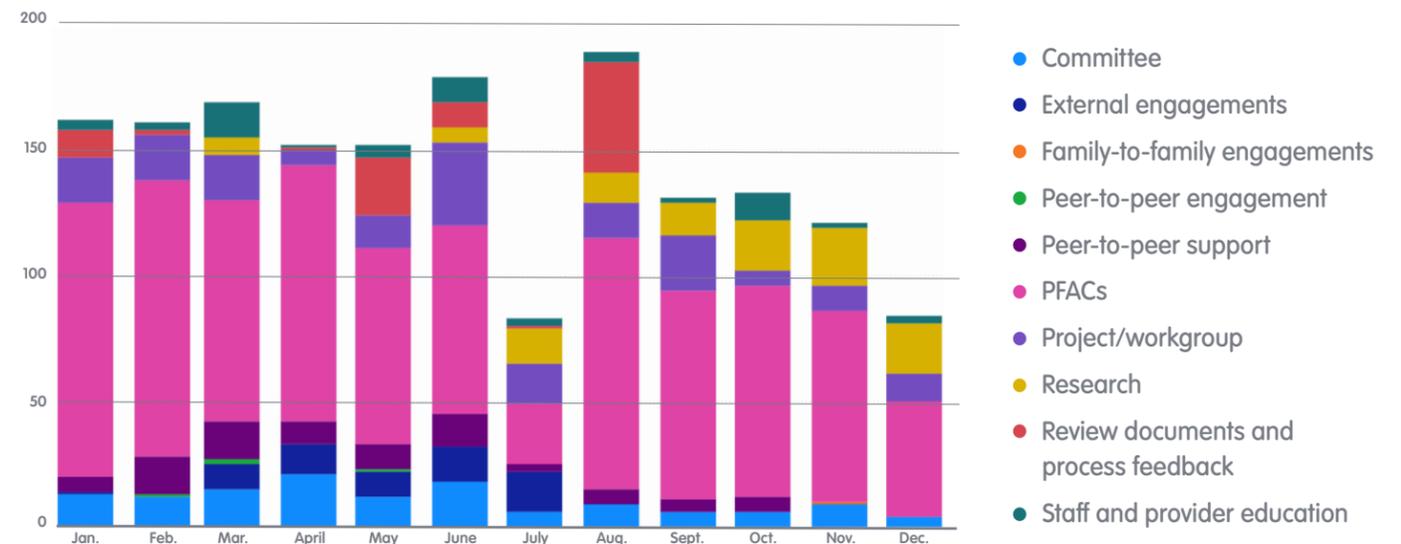
**113** Zip codes represented

**24** Patient stories shared on Children’s Mercy social media

**1,716** Volunteer engagements

**2,768** Volunteer hours

**2021 Volunteer Engagements by Type**





As ambassadors in the Kansas City area, FAB members lent their support to highlight Children's Mercy partnerships in the community.

## FAMILY ADVISORY BOARD

The Family Advisory Board (FAB) collaborates with hospital leadership to infuse the voice of patients and families throughout the hospital system. The FAB serves as the oversight group for all the Patient Family Advisory Councils at Children's Mercy.

In 2021, FAB collaborated on numerous facility improvements, including the redesign and naming of the KC Café, upgrades to increase accessibility in our buildings, evaluation of new furniture options, and upgrades to the Adelaide C. Ward Pediatric Intensive Care Unit (PICU) and Cardiac Intensive Care Unit (CICU) family waiting areas. Members also gave advice on parking improvements for Children's Mercy Adele Hall Campus, Children's Mercy Hospital Kansas, and Children's Mercy Kansas City Broadway locations. One member, together with her family, facilitated a ride-along experience with an Executive Vice President to share the reality of the parking struggles families encounter at the 3 campuses.

Children's Mercy continued to value the vision and expertise from the Family Advisory Board. Staff sought input from the board on various projects, including the patient portal, telemedicine, My Needle Procedure Plan, and the new Center for Family Connections. The Mildred Lane Kemper Emergency Center facilitated a listening session with members to enrich the quality improvement projects in their section. Outside of meeting times, members served on hospital committees, including the

Care Navigation Steering Committee, Diverse Hair and Skincare Solutions, Patient & Family Experience Steering Council, 125th Anniversary Steering Committee and Patient Rights Chapter Readiness. The Lean Improvement Teams utilized several members to infuse the family perspective into the Vancomycin Administration Preop Timing Rapid Process Improvement Workshops.

Focus groups allowed FAB members to openly share their viewpoints on many time-sensitive topics. Paul Kempinski, President and CEO, assembled the group to discuss potentially requiring the COVID-19 vaccine for all employees, volunteers and contractors. An outside consultant gathered the members to discuss the patient and family experience around care coordination and navigation, access and connectivity. A marketing agency collected FAB's perceptions on a proposed marketing campaign, and an ambulatory task force met with members about standardizing the depart process in clinics.

FAB championed 2 new projects this year. Members narrated and starred in the new Welcome and Safety video which is shown to all patients and families upon admission to the hospital. To introduce themselves, they created a new member bio page for the public website now available at [childrensmercy.org/FAB](https://childrensmercy.org/FAB).

As ambassadors in the Kansas City area, FAB members lent their support to highlight Children's Mercy partnerships in the community. Their children were featured in a promotion for the 15 and the Mahomies Foundation which showcased the Kansas City Chiefs jerseys for the Super Bowl. One member and her son appeared in a Sporting Kansas City commercial which launched the partnership featuring The Victory Project and Children's Mercy on the new team jerseys. The daughter of another member shared her personal story for the Children's Mercy Red Card bullying prevention campaign in partnership with Sporting Kansas City.

The work of FAB members was showcased on the national level. One parent served as a subject matter expert on a Patient Experience Collaborative session entitled "Religious and Cultural Needs Panel Discussion." Two parents were interviewed by the peer-reviewed health care journal Health Affairs for an article, "Gaining Family Input At A Children's Medical Center," while another parent was invited to present on a Health Affairs briefing, "Caring for Those with Complex Needs: A Health Affairs Virtual Event."

FAB members look forward to their continuing partnership with Children's Mercy on the 5-year strategic plan to guide the mission to create a world of well-being for all children. Today, tomorrow, always. ●



FAB members, Emily Brown and Terrence Gallagher

# Patient Family Advisory Councils (PFAC)

## ACCESSIBILITY AND REHAB PFAC

The Spinal Differences PFAC broadened their scope and was renamed the Accessibility and Rehab PFAC. This increased membership to include those from the Muscle/Nerve Clinic and General Rehab. They partnered with hospital departments and community organizations to share the perspective of patients and families. The group is developing a virtual career fair on the Children's Mercy webpage with videos featuring people working in the community, who also happen to be in wheelchairs and/or utilizing adaptive equipment.

## BEACON PFAC

The Beacon PFAC established a closed group Facebook page which supports families seen in the Beacon Clinic. Workgroups were formed to concentrate on different projects. One workgroup focused on the public Children's Mercy website and added member biographies as well as partnered with Social Work to update the comprehensive community resources list. A workgroup co-designed an educational blending brochure with Beacon registered dietitians. Members wrote a welcome letter for new families seen at the Beacon Clinic and formed a team for Dream Big Day which raised \$7,400 specifically for the Beacon Clinic.

## CARDIAC PFAC

The Cardiac PFAC created 3 workgroups to focus on transition, tube weaning and communications. The transition subcommittee helped develop a cardiac-specific Adult Transition Program and assisted with the accreditation process in conjunction with St. Luke's Health System. The tube weaning subcommittee provided feedback on a program being developed for all heart patients. The communications subcommittee authored a letter from the parent's perspective to provide encouragement and support to all parents whose child has been diagnosed with a complex heart condition. They composed the Ward Family Heart Center's new quarterly newsletter, which is distributed to over 25,000 heart families.

## CYSTIC FIBROSIS PFAC

The Cystic Fibrosis PFAC collaborated with the clinic to establish an Adolescent Support Group. They provided input on the CF Newborn presentation for newly diagnosed families. One member served on the PHIL Award Committee and partnered to create a flier to display in the clinic about the award as well as reviewed nominations to honor an outstanding respiratory therapist. Members made recommendations on how to utilize funds received from the CF Foundation.

## EATING DISORDERS CENTER PFAC



The Eating Disorders Center PFAC made great strides in educating the community about eating disorders by presenting at the School Nurse Conference and writing an article for the *Parent-ish* blog entitled, "9 Truths About Eating Disorders and Tips for Parents." The group also created a video message for parents which can be viewed on the Children's Mercy website. National Eating Disorder Awareness Week was highlighted in the window display at Children's Mercy Hospital Kansas, and thank you notes and treats were delivered to the Eating Disorders Clinic staff. PFAC parents were invited to share their perspective with the staff on the Paul and Betty Henson Tower 6th floor about what it is like to be on the receiving end of care.

## e-COUNCIL

The newest PFAC is the Children's Mercy e-Council, which is an online advisory group created in 2021 to work with hospital teams to improve the quality, safety and experience of care. Members include any parent or guardian of a child who receives care at Children's Mercy and has shared an email address. In collaboration with the Communications and Marketing department, the PFE Team sent a questionnaire about the patient portal to 103,111 email addresses and received over 3,000 responses. The feedback will be utilized to inform future patient portal upgrades.

## EL CONSEJO DE FAMILIAS

El Consejo de Familias Latinas/Hispanas influenced the creation of the "Legal Challenges to Guardianship for Immigrant Families" video and resources for the website. They collaborated on the script and recording of the Spanish version of the Youth Transition video and also narrated the Spanish version of the Welcome video. In addition to providing feedback on multiple projects, the group submitted a letter of support to reduce disparities among BIPOC (Black, Indigenous and People of Color) in the Primary Care Clinic. The parent chair co-presented to The Pennsylvania Health Literacy Coalition about the impact of a Spanish-speaking Council. Members also participated in the Day of the Dead celebration and wrote Calaveras Literarias for the Employee Resource Group La Casa Latino newsletter.



## FOOD ALLERGY PFAC

The Food Allergy PFAC persisted in their efforts to raise awareness about the impact of food allergies in the hospital and clinics. Their work led to the development of the Patient and Food Safety Workgroup and new snack distribution guidelines. Representatives from Morrison, the hospital's food service vendor, regularly attend meetings to gather advice on how to make the cafeteria more allergy friendly. PFAC participation in Dream Big Day resulted in the purchase of 250 Children's Mercy branded Epinephrine bags which are provided to clinic patients. Members co-created a new Food Allergy Newsletter, which is distributed twice a year, and updated their parent letter, which is available in English and Spanish.



## INFLAMMATORY BOWEL DISEASE PFAC

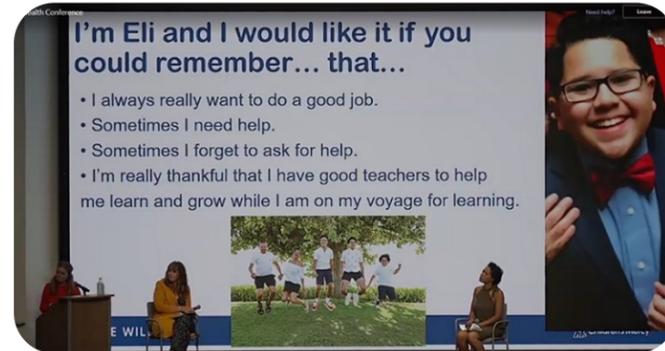
The Inflammatory Bowel Disease PFAC continued their strong collaboration with the Quality Improvement Improve Care Now network. Members virtually attended the Fall Community Conference. PFAC members brought to attention the need to address improvements in virtual visits, process changes in the Children's Mercy Hospital Kansas Lab/Radiology and Pharmacy departments, patient portal depart forms and transition. The Vascular Access Team partnered with the group on strategies to successfully implement the Comfort Promise for this patient population.

## KANSAS PFAC



The Kansas PFAC created a service project challenge for all Children's Mercy PFACs and collected pop tabs for Ronald McDonald House Charities. They participated in a focus group with Prairie Dog Healthcare Marketing Agency to provide guidance on future marketing campaigns. Children's Mercy Hospital Kansas staff sought feedback on multiple topics, including the patient experience in the Epilepsy Monitoring Unit, snack policy for clinics, and process improvements in the Children's Mercy Hospital Kansas Laboratory and Radiology. In recognition of the stress staff experienced during the pandemic, the PFAC hosted an appreciation event and distributed thank you messages and snacks.

## MENTAL HEALTH PFAC



The Mental Health PFAC successfully initiated the use of temporal thermometers for patients with sensory needs. Within Children's Mercy, members served on numerous committees to provide the parent perspective on mental and behavioral health services and offered their support for a study for teens with depression. The Greater KC School Nursing Conference served as a platform for a member to raise awareness about ways schools can partner with families to improve the educational experience for students.

## NICU PFAC

The Neonatal Intensive Care Unit (NICU) PFAC established a closed Facebook group to foster communication among parents who currently have a baby in the NICU. They contributed to the creation of the NICU Thrive Guide, a flyer to share about trauma-informed care at Children's Mercy and Parent Lab handouts as well as scripting for night rounds and prenatal visits. In September, they celebrated NICU awareness month, and the Children's Mercy Research Institute was lit up green for 2 weeks in recognition. The NICU Dream Big Day Team was the 2nd highest fundraising clinic-led team. The PFAC continues to provide parent feedback on new initiatives and ongoing projects in the NICU.



## PFAC ALUMNI



The PFAC Alumni consists of parents and former patients who previously served on other Children's Mercy advisory councils. They were actively engaged in the transition program, assisting with the Transition to Adulthood conference planning as well as serving as presenters and moderators for multiple sessions. Members added insight on various focus groups, including the patient portal, naming the cafeteria, and Healthcare Education Assessment and Response for Teen Relationships. They also provided feedback on the sepsis video, suicide screening process and the Equity and Diversity employee sticker. The group also supports Children's Mercy philanthropic events.

## RARE PFAC

The Rare PFAC continued to advocate for supporting children with a rare diagnosis. To raise awareness around rare conditions, they presented an Ethics Brown Bag lunch event entitled "Rare Disease and the Impact on Families" to Children's Mercy employees. In an effort to educate medical students at University of Missouri-Kansas City and University of Kansas Medical Center, they assembled a parent panel and shared the "Rare Disease Family Perspectives." Members served on the Genomic Answers for Kids committee, the Children's Mercy Research Institute Community Advisory Board, and the Genetics Clinic Situation/Target/Proposal committee. They provided support to the RareKC Symposium and participated on the Rare Voices Advisory Group.

## TAB/HOT/KIDS KC

Teen patients are represented on 3 unique groups: the Teen Advisory Board (TAB), Hematology Oncology Teens (HOT), and Kids and Families Impacting Disease through Science (KIDS KC). Members represented Children's Mercy virtually at the iCAN Summit and shared the teen perspective on developing adult learning tools for social media. They contributed ideas for the *Parent-ish* blog, "Life Skills Teens Want to Know," consent forms and COVID-19 vaccination education materials. The group engaged in discussion regarding accessibility for people with varied abilities and provided input on flyers for clinics about suicide screening. Members were able to see the new Children's Mercy Research Institute through a virtual tour, and they provided feedback on the cafeteria design. In honor of the Doctor's Day Celebration, the members sent cards of recognition to providers as a way to say thank you.

## TRACHEOSTOMY PFAC

The Trach PFAC collaborated on a problem-solving initiative to transition patients from the Infant Home Vent Program to the Pediatric Home Vent Clinic. Members reviewed the Children's Mercy tracheostomy webpage and provided suggestions for additional education and resources for families. The group created parent training videos for trach education and purchased sympathy cards for bereaved trach families. Merchandise fundraisers were held to provide support for family education days and a simulation baby for trach education. Members began the planning for Tracheostomy Town Halls which are scheduled to begin in 2022.

