

FAMILY ADVISORY BOARD

Annual Report FY25



Children's Mercy

Table of Contents

Patient and Family Engagement | 2

Family Advisory Board (FAB) | 3-6

PFAC Diagram | 7

Children's Mercy FY2025 True North Pillars | 8-11
PFA Alignment

Fast Facts | 12

Accessibility and Rehab | 13

Angelman Syndrome

Beacon

Cardiac | 14

Consejo de Familias Latinas/Hispanas

Cystic Fibrosis | 15

Eating Disorders Center

e-Council

Fetal Health Center | 16

Food Allergy

Hem/Onc/BMT | 17

Inflammatory Bowel Disease

Kansas

Mental Health | 18

NICU

PFAC Alumni

Rare | 19

Teen Advisory Boards

TAB

KIDSKC

Tracheostomy

Patient and Family Engagement

At Children's Mercy Kansas City, the Patient and Family Engagement (PFE) Team champions the voices of patients and families, ensuring their perspectives shape every level of care and decision-making across the organization. This dedicated team is composed of staff members who are also parents, bringing both personal experience and insights gathered from over 200 Patient Family Advisors (PFAs) to foster a culture of collaboration, empathy, and continuous improvement.



The PFE Team serves as the central liaison for the Family Advisory Board (FAB) and 21 Patient Family Advisory Councils (PFACs) throughout the hospitals and clinics. These councils bring together parents, patients, and healthcare professionals to co-design solutions that enhance the quality, safety, and experience of care.

In addition to managing the advisory groups, the PFE Team leads several key initiatives:

- Family as Faculty Program:

Trains parents and caregivers to serve as Family Educators in Graduate Medical Education (GME) and the Nurse Residency Program (NRP). By sharing real-life experiences, they help future clinicians integrate patient- and family-centered care into everyday practice.

- Family Experience Tracers:

Engages directly with patients and families during their care journey to gather real-time feedback and insights that inform hospital-wide improvements.

- Hospital Integration

Participates in committees and workgroups across the organization to ensure that patient and family perspectives are embedded in hospital policies, practices, and innovations.

- Parent-to-Parent Orientation

Coordinates parent volunteers who visit inpatient units to welcome newly admitted families and share valuable information about available resources and support.

- Patient Family Advisors (PFAs)

Supports a network of over 200 PFAs—parents and caregivers who contribute their lived experiences to a wide range of improvement efforts, including parent panels, focus groups, and participation in strategic workgroups and committees.

- POPS (Parents Offering Parent Support) Program

Trains parent and former patient volunteers to serve as peer mentors, offering non-medical guidance and emotional support through one-on-one conversations via phone, text, or email.

Through these programs and partnerships, the PFE Team advances the principles of patient- and family-centered care. By working alongside hospital leadership, staff, and families, they help Children's Mercy Kansas City deliver care that is not only clinically excellent but also compassionate, inclusive, and responsive to the needs of every child and family. Together, we are Built for Kids – bringing hope, healing, and the promise of brighter tomorrows.

Vision

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

Mission

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.



Family Advisory Board members

The Family Advisory Board (FAB)

The Family Advisory Board at Children's Mercy serves as a vital partner in shaping a culture where the voices of patients and families are not only heard but drive meaningful change. Composed of dedicated parents and caregivers, the board collaborates closely with hospital leadership to influence policies, programs and practices that reflect the principles of patient- and family-centered care. Through the lens of lived experience, members contribute meaningfully to the hospital's mission of creating a world of well-being for all children.

In FY25, the Family Advisory Board aligned its efforts with hospital priorities and identified three

key areas of focus: enhancing the patient and family experience in the Emergency Department, improving care coordination for medically complex children, and addressing access and wait times. FAB provided input on communication strategies and interventions related to ED wait times, advocated for maintaining home medication schedules during ED visits and supported the development of an inpatient needs list to better serve families prior to admission. In the area of care coordination, members learned about and offered feedback on the Care Navigation and Care Management programs, both aimed at supporting families with complex care needs. To support improvements in access, two FAB members participated in an Access Retreat, contributing the family voice to ongoing efforts to reduce wait times and improve timely care delivery.

As Children's Mercy prepares to transition electronic medical records to Epic, FAB members committed their time to join the EPIC Clinical Advisory Council, the EPIC Outpatient Advisory Council and the EPIC Digital Engagement team. These committees met regularly throughout the year, and FAB members ensured that the patient and family perspective remained central to discussions and decisions. Their involvement helped guide the design and implementation of tools and workflows that will ultimately support more connected, compassionate and efficient care.

Throughout FY25, the Family Advisory Board played an active role in advancing quality and safety efforts across Children's Mercy. Members contributed to the development and refinement of several Clinical Pathway guidelines, ensuring that family perspectives were integrated into clinical decision-making. FAB also provided valuable feedback on the implementation of several key initiatives, including the new Virtual Nursing program, inpatient screening processes for social determinants of health, and updated isolation procedures. Additionally, members reviewed and approved the Patient Rights and Responsibilities policy, helping to ensure that it reflects the values and needs of the families served by the hospital.

FAB members supported hospital-wide initiatives by providing thoughtful feedback on a variety of patient-facing materials. They reviewed and offered input on Patient Advocate letters to ensure the tone and content reflected empathy and clarity from a family perspective. The group updated the Visitor Tip Cards, making them more accessible and relevant for new families navigating the hospital environment. The FAB guidelines were also revised and approved.

Families continued to serve as integral partners in the education and professional development of physicians, nurses and staff, reinforcing the hospital's commitment to patient- and family-centered care. In collaboration with Graduate Medical Education, members of the FAB and Teen Advisory Board (TAB) hosted an orientation luncheon for the incoming resident class, introducing them to the foundational values of family partnership at Children's Mercy. Several FAB and PFAC members also served as family educators through the Family as Faculty program, offering residents a unique, non-clinical immersion

experience within their homes. Additionally, parents shared deeply personal narratives as part of a bereavement panel, providing invaluable insight into the experience of the loss of their child. Parent panels were also convened to support learning within the Nurse Residency Program and the Clinical Leadership Academy, further embedding the family viewpoint across disciplines.

In February, the FAB hosted a powerful Grand Rounds session titled, "Through a Parent's Eyes: Caring for Medically Complex Pediatric Patients," moderated by Dr. Doug Rivard. The session opened with the FAB Chair reading the poignant piece "Welcome to Holland," setting the tone for a deeply personal and impactful conversation. A panel of five FAB members then shared their lived experiences of raising children with medically complex needs, offering invaluable insight into the daily realities, challenges and triumphs of their journeys. The qualitative feedback from attendees underscored the significance of the session, highlighting the value of hearing directly from families and the importance of continuing to center their voices in clinical education and care improvement.

As grateful families, FAB and PFAC members found meaningful ways to give back to Children's Mercy through their involvement in philanthropic and advocacy efforts. Several members participated in fundraising events such as Red Hot Night, Big Slick, Dream Big Day and T-shirt sales helping to raise awareness and support for the hospital's mission. Beyond these events, other members extended their impact by serving on local, state and national committees, where they advocated for policies and programs aimed at improving children's health. Their dedication reflects a deep commitment not only to their own families, but to the broader community of children and families served by Children's Mercy.

To deepen their understanding of the communities served by Children's Mercy, FAB members heard a presentation on the hospital's Community Needs

assessment. In addition to learning, members also took action to directly support inpatient families. They prepared and served lunch at the Ronald McDonald House, donated items from the organization's wish list, and toured the newly renovated space inside Children's Mercy.

In recognition for their continuous extraordinary service and dedication to Children's Mercy, two individuals were recognized with special awards. FAB member Allen Hall and Hem/Onc/BMT PFAC member Tracy Nagel were each highlighted as a Volunteer of the Month.

FAB and the PFACs collaborated on a range of impactful initiatives. These included active participation in numerous focus groups, advocacy for improved accessible parking across all locations, and assistance in planning the Transition Conference for patients and families. Together, the groups curated a recommended book list and used donated funds to fill the shelves in the Kreamer Resource Center. They also played a key role on the Patient and Family Seal of Collaboration taskforce, reinforcing their commitment to meaningful partnerships. Members of El Consejo and the Mental Health PFAC provided ongoing monthly input on the PATHWAY research project, with two members presenting findings at an international pediatric conference.

The FAB's held its 2025 annual meeting on April 1 in the Big Slick auditorium. More than 100 FAB, PFAC members, and staff attended in person or virtually. All Children's Mercy employees were also welcomed to join and learn more about how the hospital partners with the FAB and PFACs to elevate the patient and family experience. The meeting opened with heartfelt messages from two special guests: Diane Gallagher, chair of the Board of Directors, and Dr. Alejandra Quiroga, the new president and CEO of Children's Mercy.

Diane Gallagher shared:

"On behalf of all of our directors, we want to thank you—not only for your insights, your perspectives, and your feedback that you give to all of our staff—but also to recognize our tremendous gratitude that you are giving of your time while you are also managing the care of a child with a health issue. That is not lost on anyone who's been in that circumstance. It really does mean a tremendous amount to all of us that you are so gracious and generous with your time."

Dr. Quiroga added:

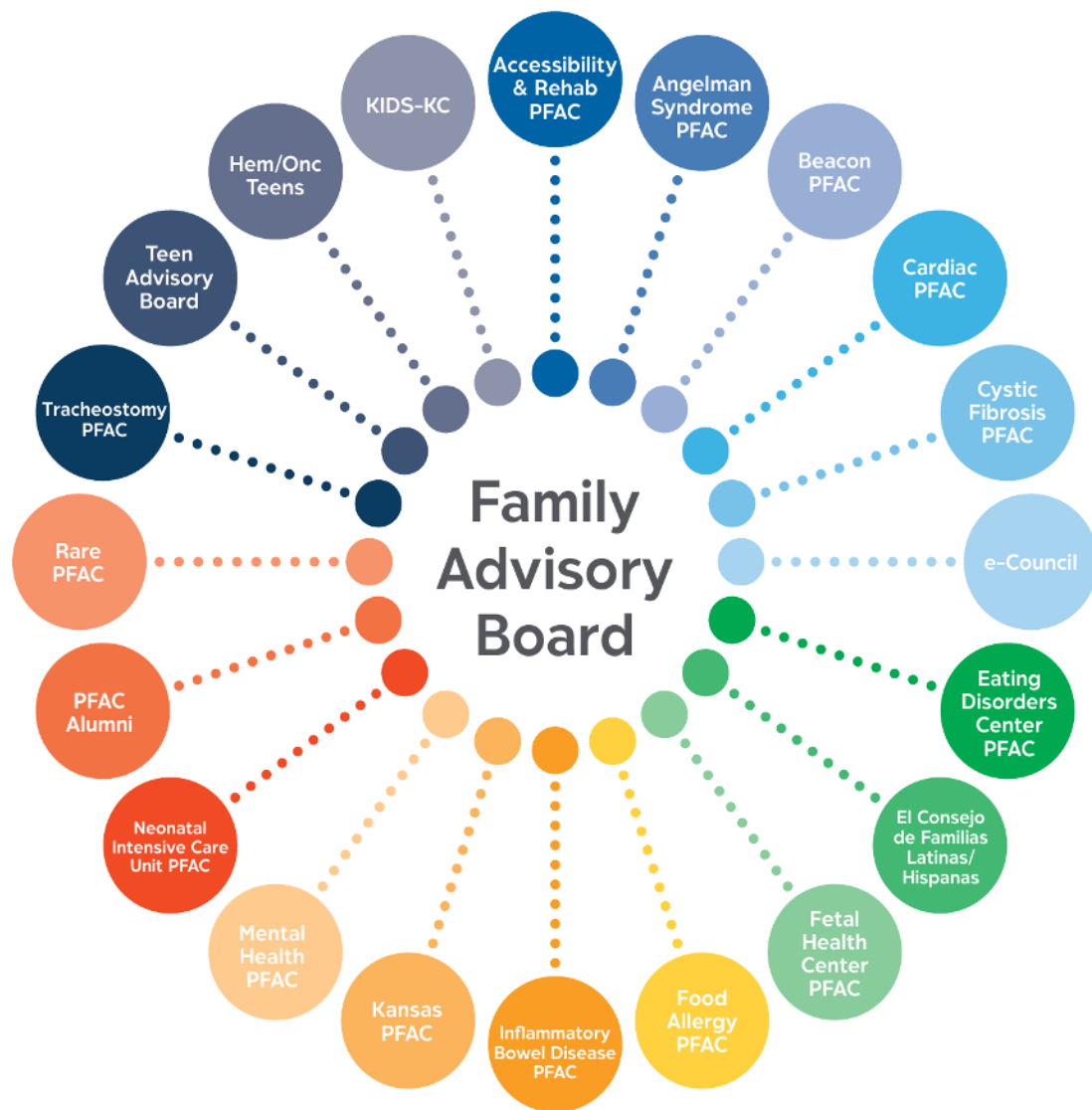
"It reassures me tremendously to see how you are embedded in everything that we're doing. We're here for your kids. We're here for the kids of the community, and you need to help us get better. And I know that's why you're here."

As we look ahead to FY26, the Family Advisory Board remains committed to strengthening our partnership with hospital leadership and continuing to ensure that the voices of families are heard, valued, and integrated into everything we do.

Together, we are – and always will be – Built for Kids.



FAB parent panel for Grand Rounds



The work of FAB, PFACs, and the PFE team align with the True North pillars to achieve the hospital's vision to create a world of well-being for all children. These pillars define how we help achieve this vision.

Children's Mercy FY2025 True North Pillars

The work of FAB, PFACs and the PFE Team align with the True North Pillars to achieve the Hospital's vision to create a world of wellbeing for all children. These pillars define how we help achieve this vision.

Quality & Safety

Provide the best and safest care possible to every patient and family, and cultivate an environment that supports the health and well-being of patients, families and our team members.

FAB and PFACs collaborate with staff and faculty to improve quality and safety by partnering on hospital committees, projects and education for patients and families.

People and Culture

Cultivate a culture that engages employees to be and perform their best.

FAB and PFACs partner with healthcare teams to promote the core concepts of patient- and family-centered care: dignity & respect, collaboration, information sharing, and participation.

Connected Experience

Consistently exceed the experience expectations of those we serve by delivering excellent, timely, coordinated care.

FAB and PFACs work together with staff to improve the delivery and access of care. They participate in focus groups and Lean improvement events.

Stewardship

Advance our mission through responsible management of our finances and resources

FAB and PFACs are grateful families who serve as valuable volunteers in the hospital system. They are respected ambassadors in the community. .

True North Pillars (Continued)

Quality & Safety



COMMITTEES

- Adverse Drug Events (ADE)
- Ambulatory Central Line Associated Blood Stream Infections (CLASBI)
- Antibiotic Stewardship
- Bronchopulmonary Dysplasia Advocacy Committee
- Catheter Associated Urinary Tract Infections (CAUTI)
- Central Line Associated Blood Stream Infections (CLASBI)
- CMRI Community Advisory Board
- Enterprise Quality and Safety Council
- Epic Clinical Steering
- Epic Digital Engagement
- Epic Outpatient Steering
- Ethics
- ImproveCareNow® Quality Committee
- Initiative Workgroup
- Medication Reconciliation Steering Committee
- National Patient Safety Goal #1
- National Patient Safety Goal #15
- National Patient Safety Goal #15 Community Education
- NICU Chronic Lung Committee
- NICU Infection Prevention Taskforce
- NICU Quality Improvement Team
- Opioid Stewardship
- Peripheral Intravenous Infiltrations and Extravasations (PIVIE)
- PEWS Situational Awareness
- PICU Rounding
- PIVIE
- Pressure Injuries (PI)
- Reducing Differences in Urgent Care Encounters (REDUCE)
- Resuscitation
- Root Cause Analyses (RCAs)
- Sepsis
- Surgical Site Infection (SSI)
- Trach Clinical Committee
- Unplanned Extubation Committee (UPE)

FEEDBACK

- Central Line education
- Medication syringes
- NIH Letter of Support for Pain Focus
- Rare Voice article
- Tracheostomy Perceptions study

EVENTS (FOCUS GROUPS AND WORKSHOPS)

- Global Tracheostomy Collaborative conference
- KC Metro Quality & Safety Consortium
- Lean CLASBI MGT
- PCORI appendectomy study

- Pediatric Pandemic Network HRSA site visit
- School Nurse conference

IMPROVEMENT PROJECTS

- Evidence-Based Practice Clinical Practice Guidelines
 - ADHD
 - Antibiotic Allergy Assessment
 - Child Abuse
 - End of Life Clinical Pathway
 - Febrile Seizures
 - Human Sex Trafficking
 - Measles
 - NICU Cerebral Palsy
 - Opioid Treatment
 - Refractory Status Epilepticus
 - Status Epilepticus Clinical Pathway
 - Seizure: Febrile Clinical Pathway
- ED Quick Discharge Project
- ED Tap Water for Wounds
- Medical Information Form
- My Clean Routine
- REDUCE QI collaborative
- REPEAL workgroup

People and Culture



COMMITTEES

- Game Changers Network
- Nursing Strategic Plan
- Patient/Family Team Member Interaction
- PHIL Award
- PX Governance Committee
- Team Member Safety Governance Council
- Workplace Clinical Caregivers Council

RECOGNITION

- Volunteer of the Month – Allen Hall
- Volunteer of the Month – Tracy Nagel
- Why I love my Doctors videos

EVENTS

- All Abilities Fair
- Cerebral Palsy Family Education Day
- Dia de los Muertos
- GTC Webinar: Peds to Adult Care
- Maternal Fetal Health Awareness
- Rare Disease Day Awareness
- Support for Staff following Super Bowl parade shooting
- Trach Awareness
- Transition conference
- Video for AAP presentation
- Week in Rare Conference

TRAINING FOR STAFF

- Child Life Specialists
- Clinical Leadership Academy parent panel
- CM Patient Experience Tours for employees
- Culture Unfreezing facilitator
- Extremely Low Birth Weight parent panel
- Graduate Medical Education
 - Bereavement parent panel
 - Non-medical in-home visits
 - Orientation lunch with FAB and TAB
- Graduate Nurse Residency parent panels
 - Bereavement
 - Communication
- La CASA Hispanic Heritage Month panel
- New Employee Orientation
- NICU Pediatric Forum
- Non-Febrile Seizure Provider Video
- Palliative Care parent panel
- Pediatric Bioethics Certificate program
- PFCC to APP
- Summer Nurse Externs parent panel
- Trauma Informed Care Education video

EDUCATION FOR PATIENTS AND FAMILIES

- Comfort Promise video
- Mo EMSC Home Health course
- NG or NJ Tube Placement
- Outpatient Lab photoshoot
- Parent-ish Mother's Day quotes
- Patient models for CT and Anesthesia
- Patient models for Cystic Fibrosis
- PFAC recommended books for Kreamer Resource Center
- PPN Podcast Ready, Prep, Go
- Transition conference

Connected Experience

COMMITTEES

- ACCESO
- Accessibility
- Aftercare
- Anticipatory Guidance for CMC
- Behavioral Health Advisory Council
- Clear Care Board Oversight
- Coordination and Experience Steering Committee
- CYSHCNet Cohort - Bilingual Parent Partner
- Decedent Affairs Steering Committee
- First Impressions Steering Committee
- Food Service
- GetWell Network Advisory Council
- Health Literacy
- Heart Center Strategy Planning for Outreach
- Hunger Free Taskforce
- New Initiatives
- NICU CHNC Project Home
- NICU Developmental Care Champions



- NICU Early Mobility Workgroup
- NICU Ease
- NICU Kangaroo Care
- NICU LEP Workgroup
- NICU Multidisciplinary Rounds Workgroup
- NICU Psychosocial Rounds
- NICU Trauma Informed Care
- Nursing Patient Family Experience Strategic Planning
- PATHWAYS Behavioral Health Access
- Patient and Family Seal of Collaboration
- Patient Portal
- Pediatric Experience Collaborative
- PeriOp Patient Experience
- Psychosocial Safety Notes
- Psychosocial Task Force
- Trach Discharge Rounds
- Transition
- Website content

FEEDBACK

- e-Council Surveys
 - Antibiotic Duration in the ED
 - ED Follow-up calls
 - Kreamer Resource Center – English
 - Kreamer Resource Center – Spanish
 - Mental Health Crisis Center TVs
- Behavioral Health Scrubs for Patients
- Comfort Promise
- Depression Anxiety and Youth (DAY Clinic)
- Diabetic Friendly Snacks on 6H
- Emotional Harm Scale
- Neurology Movement Disorder Transition to Adult Care
- NICU Virtual Nursing
- School Friendly Health System Inquiry
- Trauma for AdHoc in ED
- Wichita Clinic Room Survey

EVENTS (FOCUS GROUPS AND WORKSHOPS)

- Access strategic planning retreat
- Care Navigation workshop
- CMK Preop/PACU/Postop
- Emergency Department Quick Discharge
- IPFCC Learning Community
- Menstrual Product Workgroup
- NICU reunion
- Patient Portal notification testing
- Focus Groups
 - ECMO
 - ED Intervention on IPV
 - Epilepsy Monitoring Unit
 - Feeding and Swallowing Clinic
 - Hearing Loss Clinic
 - Informed Consent for ECMO
 - Intimate Partner Violence

- Nurse Leader Rounding
- Nurse Leader Rounds
- Parent Psychological Flexibility
- Patient Advocate Letters
- PCORI Appendectomy
- Pediatric Pandemic Network
- Rheumatology
- Sibling Support
- Walking Park Hospital Hill

EDUCATION FOR PATIENTS AND FAMILIES

- All Abilities Resource Fair planning committee
- Cardiac Parent symposium
- Central Line education
- Child Life preparation photos
- Eating Disorder Center newsletter
- Food Allergy Clinic newsletter
- Gynecology website education
- Heart Center quarterly newsletter
- Illuminate Mental Health TV commercial
- Parent-ish articles
- Pulse Ox Experience video

IMPROVEMENT PROJECTS

- Beacon Clinic closed Facebook group
- BV UCC Communication Boards
- Community Listening Session
- FHC Lean Value Stream
- Heart Center Strategic Planning
- NICU closed Facebook group
- PFAC Members closed Facebook group
- PFAs in Hearing Loss Clinic
- PFAs in Rheumatology Clinic
- PICU Rounding
- Timely Diagnosis of Rare Disease: PCORI
- Wagons & Wheelchairs RPIW MGT

POLICY REVIEW

- Patient Rights and Responsibilities
- Preserving Professional Boundaries

Stewardship

COMMITTEES

- Financial Assistance

PROJECTS

- T-shirt sales: Cardiac, NICU, and Trach PFACs
- Video for Red Hot Night

EVENTS

- Back to school social media campaign
- CMRI tours
- Graduating Senior story on social media
- Hyundai Hope on Wheels
- Illuminate photo shoot
- Logan Project

PHILANTHROPIC AND COMMUNITY EVENTS

- Angelman Walk
- Big Slick
- Children's Mercy social media campaigns
- Discover Children's Mercy
- Dream Big Day
- Giving Tuesday Campaign family stories
- Kansas City Royals
- Maddie's Mission
- PBR dinner with KC Outlaws Professional Bull Riding Team
- Red Hot Night
- Sporting KC
- United Way Speaker

LOCAL AND NATIONAL STAGE

- Beryl Institute
- Global Tracheostomy Collaborative
- Institute for Patient- and Family-Centered Care
- Missouri Emergency Medical Services for Children
- Missouri FAN Network
- Missouri Hospitals Association
- NICU FCC Taskforce
- Pediatric Experience Collaborative
- Vermont Oxford Network



*FAB/TAB members
attending resident
orientation*



190 Patient Family Advisors

3145 PFA volunteer hours

22 PFACs

14 Focus groups

139 PFAC meetings

150 POPS mentors

111 POPS matches

Patient Family Advisory Councils (PFAC)

Accessibility & Rehab

- Created a parent approved accessible activity list
- Compiled IEP and 504 tips for families
- Gave feedback for Rehab Clinic renovations
- Expanded Joy Gallery to the Rehab Clinic



Joy Gallery with pictures of Children's Mercy patients

Angelman Syndrome

- Conducted research project about clinic design
- Participated in Angelman Syndrome Advocacy events
AS Foundation walk, International AS Day, ASF Family Conference, FAST Research Conference
- Supported clinical trials awarded to Children's Mercy
- Created an Angelman Clinic handbook
- Participated in patient-focused drug development meeting with the FDA
- Hosted fundraisers at Culvers and Maddie's Mission Block Party



Angelman Syndrome PFAC families celebrating International Angelman Day on Feb. 15, 2025

Beacon

- Provided feedback on new procedure for directing after-hours calls from Beacon families
- Offered insight on care team assignments for Beacon patients upon admission
- Increased engagement with the Beacon Family Support Facebook page
- Toured the Patient Progression Hub
- Brainstormed ideas for a medical information form that families maintain



Children's Mercy Kansas City Beacon Family Support
Beacon Family Support Facebook page



Cardiac PFAC gathered for a social event

Cardiac

- Planned and hosted two parent symposiums in collaboration with staff, which included a Fontan Forum, age-related break-out sessions, and tours of the OR, Cath Lab, PACU and Kreamer Resource Center
- Authored quarterly newsletters and distributed to more than 30,000 recipients
- Designed a T-shirt and hosted three fundraisers to purchase books for cardiac patients
- Created "What to Expect" scripts and filmed welcome videos for heart families going to Surgery/Cath Lab, CICU and 4 Sutherland
- Increased awareness on the importance of exercise for cardiac patients
- Hosted several social gatherings for inpatient families, providing snacks and fun activities



Consejo members during Dia de los Muertos event

Consejo de Familias Latinas/Hispanas

- Presented during the Dia de los Muertos event in the Lisa Barth Chapel
- Prepared and delivered meals and snacks to Ronald McDonald Houses
- Gathered for annual holiday meal and celebration
- Held monthly conversations to get member perspectives on immigration concerns
- Provided insight to increase utilization of the Comfort Promise among Spanish-speaking families
- Gave feedback on how to address domestic violence with caregivers in the Emergency Department
- Organized drive to collect Spanish children's books for the Kreamer Resource Center

Cystic Fibrosis

- Hosted contributing author for Parent-ish article, "Making the most of being inpatient and resources to make the most of your stay"
- Designated Cystic Fibrosis Foundation grant money for resource bags for inpatients
- Developed list of items for inpatient bags based on patient personal experiences
- Advocated to allow patients in the hospital with CF to be eligible for a therapy dog visit
- Used grant funds to make pill swallowing kits for patients
- Participated in CF team quarterly updates
- Served as models for patient education



Patient with Dr. Singh

Eating Disorders Center

- Hosted an information table at school nurse conference and distributed resources
- Established a parent room bookshelf at CMK with resources for inpatient EDC parents
- Contributed content for quarterly newsletters with parent tips and perspectives
- Created "Warning Signs & Symptoms" handout for school staff
- Authored PFAC holiday edition newsletter for EDC families
- Held information table at Adele Hall during ED Awareness Month for staff and families



EDC PFAC Awareness Table

e-Council

- Provided feedback on TVs for Mental Health Crisis Center ED rooms
- Offered feedback on programming in the Kreamer Resource Center in English and Spanish
- Provided feedback on antibiotic duration following a visit to the Emergency Department



Patient and family Seal of Collaboration



As parents who delivered in the Fetal Health Center, we want to share this information with you. These are things we wish we would have known before our stay. Whether you are preparing for a first pregnancy or a pregnancy very different from your previous pregnancies, we hope you find this packing list helpful, and that it provides some clarity and comfort.

The Fetal Health Center Patient Family Advisory Council

Advice from Parents

- For comfort care, have memory-making items ready, including extra blankets and a personal care kit.
- Children's Mercy has small size clothes, which can be used for second from baby to mom and vice versa for NICU stays.
- Covers with buttons were used for babies with tubes or new leads for monitoring.
- Pack various clothing sizes (preemie and newborn for baby).
- If you have gestational diabetes, bring a list of food items or snacks of your dietary restrictions.
- Take off the picture! You will cherish them. It may not be what you expected, but you can go back and rephoto those memories with your baby.
- Consider having a "birthday party" to celebrate your baby. Cakes and party hats can be useful to create wonderful memories, especially for older siblings.

Elizabeth J. Fennell
Fetal Health Center

For more information, contact us at 816.855.1800 or toll-free 1.866.264-4652. Visit our website at childrensmc.org



Fetal Health Center Packing List



For Mom:

- Butter-up pajamas for skin-to-skin infant care
- Nursing bra and/or hands-free pumping bra
- Comfortable C-section-friendly underwear
- Clothing for post-delivery (e.g., loose, comfy clothing or pajamas)
- Clothes to wear home
- Robe and/or covering clothing
- Rip flops for bathroom and slippers
- Personal toiletries (e.g., lip balm, make-up, face wash, lotion)
- Hair accessories (e.g., hairbrush, hair ties, headbands)
- Soft blanket and pillow and any other home comfort items
- Hospital forms and medical directives
- Protein snacks, mints and gum
- Phone charger with a long cord
- Pain and notebook
- Water bottle
- Electric fan

For Baby:

- 1-2 outfits
- Headbands or bonnet
- Lowie or other comfort item
- Niterns/gloves for hands
- Socks
- Books to read to baby
- Sound or music machine
- Car seat

For Support Person:

- Clothing for length of stay including layers for warmth
- Zip-up hoodies for skin-to-skin infant care
- Rip flops for bathroom and slippers
- Personal toiletries including any medicine
- Soft blanket and pillow and any other home comfort items
- Snacks, gum and mints
- Phone charger with a long cord
- Pen and notebook
- Water bottle
- Lot of peace to "contact" when your baby is born in the hospital

For Families Preparing for Comfort Care:

- Personal items for memory making (e.g., blankets, toys, special clothing)
- Any items needed for a religious ceremony
- Clothing or personal items needed for professional photographs
- Gifts for siblings from baby or gifts from siblings to baby
- Birth plan or any special requests in writing
- Bag to take home baby's items

For Moms with In-Patient Stays:

- Compression socks
- Rip flops for bathroom and slippers
- Eye mask to block light
- For plugs for noise
- Clothing for daytime
- Multiple sets of pajamas
- Personal toiletries (e.g., lip balm, make-up, face wash, lotion, nail clippers and file)
- Hair accessories (e.g., hairbrush, hair ties, headbands)
- Soft blanket and pillow and any other home comfort items
- Small items from home for comfort and decor such as framed pictures
- Laundry bags for clean and dirty clothing
- Water bottle
- Pen and notebook
- Small humidifier
- Things to keep busy: magazines, books, puzzles, tablets, laptop, Roku, Bluetooth speaker, inspirational books

For Moms Delivering at University Health:

- Small purse with (e.g., driver license)
- Sand machine - 1 for mom's bedside and 1 for baby's
- Slippers or easy slip-on shoes to walk from Children's Mercy to University Health
- Umbrella for family to go from one hospital to another

Fetal Health Center packing list

Fetal Health Center

- Developed a bulletin board in FHC for inpatient family resources
- Compiled a diagnosis-specific resource list
- Collaborated with Child Life and PaCT about ways to discuss a child's diagnosis with their siblings
- Partnered with the FHC team to align PFAC goals with the FY strategic goals of the FHC
- Designed and began distributing a packing list trifold to families who will deliver in the FHC



March 2025

Meet Mary Nguyen Jacobson, MD
Assistant Professor of Pediatrics, Allergist/Immunologist



Dr. Jacobson loves making a significant impact on the lives of her food allergy patients. [Learn more about Dr. Jacobson](#) and the journey that brought her to Children's Mercy Kansas City.

[Meet Dr. Jacobson](#)

Xolair (omalizumab) for Food Allergy
Chambazone, Inc. Allergan, Inc. 2025. 2025. 2025. 2025.

Food Allergy newsletter

Food Allergy

- Created 504 Plan informational webpage to share resources specific to food allergies
- Reviewed "What to Expect with Food Challenges" parent handout to be used in clinic
- Recruited three new parent members
- Recognized as first PFAC to have a CM patient serve as the chair
- Authored newsletter for families including new treatment options, 504 Plan resources, parent perspectives and recipes

Hem/Onc/BMT

- Toured CMRI and heard Hematology/Oncology research presentations from Dr. Jay Vivian and Dr. Doug Myers
- Provided feedback on CLABSI education and managing the holidays during treatment
- Reviewed central line parent education books
- Discussed NRC survey feedback from Hematology/Oncology Clinic to brainstorm PFAC project ideas
- Offered feedback on new flyer on neuropsychological testing for children undergoing chemotherapy
- Shared parent perspective following presentations regarding Spiritual Services and fertility preservation



Hem/Onc/BMT PFAC touring the CMRI

Inflammatory Bowel Disease

- Reviewed and updated new diagnosis handbook
- Provided feedback during monthly quality improvement meetings
- Reviewed ImproveCareNow website
- Participated in Crohn's and Colitis Foundation (CCF) walk
- Attended IBD Top Golf event with CM staff



IBD PFAC members at Top Golf event

Kansas

- Partnered on Comfort Promise initiatives, including presentation to CMAPs
- Awarded Patient and Family Seal of Collaboration for Comfort Promise projects
- Toured Children's Mercy Kansas City
- Gave feedback on parking signage
- Heard presentations from Project Rise, Philanthropy, Patient Experience, POPS and Same Day Surgery expansion project
- Co-designed lidocaine video, flyers and survey for patients and families



Lidocaine numbing cream applied to a child's hand

Mental Health

- Filmed encouraging video for other parents of children who receive mental health services
- Provided feedback on new SPACE workshops for parents of children with anxiety disorders
- Discussed success of recently opened PATH Clinic and shared parental insights
- Reviewed parent brochure for behavioral health patients in crisis
- Contributed to PFAC parent letter of support for behavioral health navigators
- Heard Illuminate update from Dr. Rebecca Johnson and gave input on Partial Hospitalization Program



Illuminate logo

NICU

- Developed and launched a book cart for NICU families
- Designed and sold NICU journey shirts as a fundraiser
- Gave feedback on new NICU virtual nursing program
- Co-designed scripting for EASE app in the NICU
- Welcomed new spiritual care provider and clinical psychologist
- Planned and hosted NICU reunion



NICU reunion at Dream Big Day event

PFAC Alumni

- Served on Medical Information Form Workgroup
- Participated on Opioid Stewardship Committee
- Starred in "Doctor for a Day" video
- Inspired the "Legacy of Love" article featuring Blue Iliff's gift to donate his brain tissue to medical research on kernicterus



Blue Iliff

Rare

- Created Rare Resources webpage
- Hosted a resource table at the Global Genes conference
- Championed Rare Disease Day awareness activities
- Provided insights for patient facing capabilities in Epic
- Contributed parent feedback on various research projects being conducted in the CMRI
- Toured CMRI



Rare PFAC during CMRI tour

Teen Advisory Boards

TAB

- Attended community stakeholder meeting with Magnet surveyors
- Collaborated with staff to improve IUD education and processes
- Engaged with members of Adolescent Medicine to provide feedback on various educational resources for teens
- Worked with Orthopedics team on spine education and created helpful tips
- Provided input on sexual health resources and research projects for Adolescent and Young Adult Medicine and Emergency Room teams
- Assisted in planning the transition conference 2024, and TAB alumni participated in a panel discussion for other teens on their experience with medical transition and college/job experiences



KIDSKC member making placebo pills at iCAN conference

KIDSKC

- Attended International Children's Advisory Network (iCAN) Summit 2024
- Joined iCAN Youth Committee and assisted with illustrations in the first iCAN Coloring For a Change coloring book
- Provided feedback for various studies and research questionnaires

Tracheostomy

- Developed easy-to-understand trach education kits to support families teaching their communities
- Held annual T-shirt fundraiser
- Participated in Global Tracheostomy International Tracheostomy symposium
- Created a display in the CMRI for Tracheostomy Awareness Week
- Organized a tracheostomy information table at the Adele Hall campus
- Hosted trach reunion at Dream Big Day



Trach PFAC at Dream Big Day event



Copyright © 2025 The Children's Mercy Hospital. All rights reserved.

25-CS-1014 10/25