



Children's Mercy
KANSAS CITY

**BEST
CHILDREN'S
HOSPITALS**

U.S. News & WORLD REPORT

**RANKED IN
9 SPECIALTIES
2023-2024**

**CHILDREN'S MERCY
KANSAS CITY**

**FAMILY
ADVISORY
BOARD**

ANNUAL REPORT 2023

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PATIENT AND FAMILY ENGAGEMENT

The Patient and Family Engagement Team (PFE) at Children's Mercy Kansas City elevates the integration of the patient and family voice throughout all levels of the organization. The PFE Team is comprised of parents on staff who utilize their personal experiences together with feedback from Patient Family Advisors (PFAs) to promote the collaboration of patient and family engagement.

The PFE Team is responsible for the management of the Family Advisory Board (FAB) and the Patient Family Advisory Councils (PFACs) and serves as the liaison between all the groups. They attend numerous system-wide meetings to provide a patient and family lens as well as work with hospital leaders to identify ways to partner with patients and families.

The PFE Team provides direction 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.

In partnership with hospital leadership, the PFE Team helps Children's Mercy power the potential for every child. Through the collaboration between patients, families and staff, we bring hope, comfort and the prospect of brighter tomorrows to children and their families.

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. ●



THE FAMILY ADVISORY BOARD (FAB)

The Family Advisory Board (FAB) partners with Children's Mercy leadership to infuse the voice of patients and families throughout the hospital system. The Board, comprised of parents and primary caregivers, collaborates with hospital executives to influence policies and practices to advance the culture of patient- and family-centered care. Through their lived experiences, members support the hospital vision to create a world of wellbeing for all children.

Children's Mercy was a trailblazer in patient- and family-centered care by establishing FAB, which celebrated its 20th anniversary in 2023. The success and sustainment of FAB over the past two decades has led to national recognition of Children's Mercy as a leader in patient

and family engagement. To commemorate this special occasion, an event was hosted in the Children's Mercy Research Institute with current and alumni family and staff members. El Consejo de Familias Latinas/Hispanas membership was also invited to celebrate their 15th anniversary.

Paul Kempinski, president and CEO of Children's Mercy, reflected on the contribution of FAB and the PFACs: "I'm always amazed at the growth, progress and evolution of our impact resulting from the engagement, support and guidance from our family members," he said. "It comes in the form of feedback from our parents and the daily delivery of patient care, but it could never advance to the levels that it has without the fundamental engagement,



evolution and growth of our Family Advisory Board and our councils.”

As valued partners, FAB was introduced to two major strategic initiatives, “Illuminate” and the Diversity, Equity, and Inclusion Strategic Plan. “Illuminate” is a 5-year strategic plan for mental health that will address the mental health needs of children and teens in the community. Some members attended the event unveiling the program as well as the groundbreaking for the new community mental health services building.

Children’s Mercy was a trailblazer in patient- and family-centered care by establishing FAB, which celebrated its 20th anniversary in 2023.

In alignment with the hospital’s true north pillars, FAB focused on projects and presentations that supported quality and safety, patient experience and delivery. Members provided feedback on medication reconciliation, patient portal upgrades and integrating the family voice into evidence-based practices. Patient experience topics included the Connected Experience, Guest Services enhancements, updates to the Contact Center and the psychosocial safety note pilot in the electronic medical record. Members collaborated on delivery of care improvements as well, including the discharge process and paperwork.

Families continued to serve as essential partners in patient- and family-centered care education for physicians, nurses and staff. In partnership with Graduate Medical Education, FAB and TAB members hosted an orientation lunch for the incoming resident class to introduce the culture of partnering with patients and families at Children’s Mercy. Some FAB members were family educators in the Family as Faculty program, providing a non-medical home immersion experience for residents while other parents shared 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 Clinical Leadership Academy.

FAB infused the voice of patient and families in facility redesign proposals. Members participated in a main lobby walk-through with the director of Facilities and contributed ideas during an Emergency Department lobby

redesign focus group. They provided feedback on the Ronald McDonald Room renovations, including ways to provide services to families during the construction phase. They also toured the newly opened Patient Progression Hub – the hospital operations center that uses artificial intelligence (AI), predictive analytics and real-time data to optimize care progression and coordination.

FAB provided insight and feedback on educational events and resources for patients and families. Several members served on the planning committee for the “Transition to Adulthood Family Education Day” conference for medically complex teens and their families. Some members also volunteered and served on parent panels at the conference. FAB also recommended topics for the “Powering Families” webinar series and reviewed educational resources for families. Additionally, some children and teens of FAB members served as patient models in photo shoots and videos.

Acknowledging the work of staff is important to FAB. Members provided insight on two new programs, awards for non-clinical staff and the Patient and Family Seal of Collaboration. In recognition for their continuous extraordinary service and dedication to Children’s Mercy, two individuals were recognized with special awards. FAB member Rachel Callihan and Consejo member Yadira Murguia were each highlighted as a Volunteer of the Month.

As grateful families, FAB members generously gave back to Children’s Mercy through their involvement in several philanthropic programs. Some members attended Red Hot Night, Big Slick and Dream Big Day events. Other members served on multiple local, state and national committees advocating for improvements in children’s health. One member represented Children’s Mercy on the Children’s Hospital Association Race, Ethnicity, and Language (REAL) Data project.

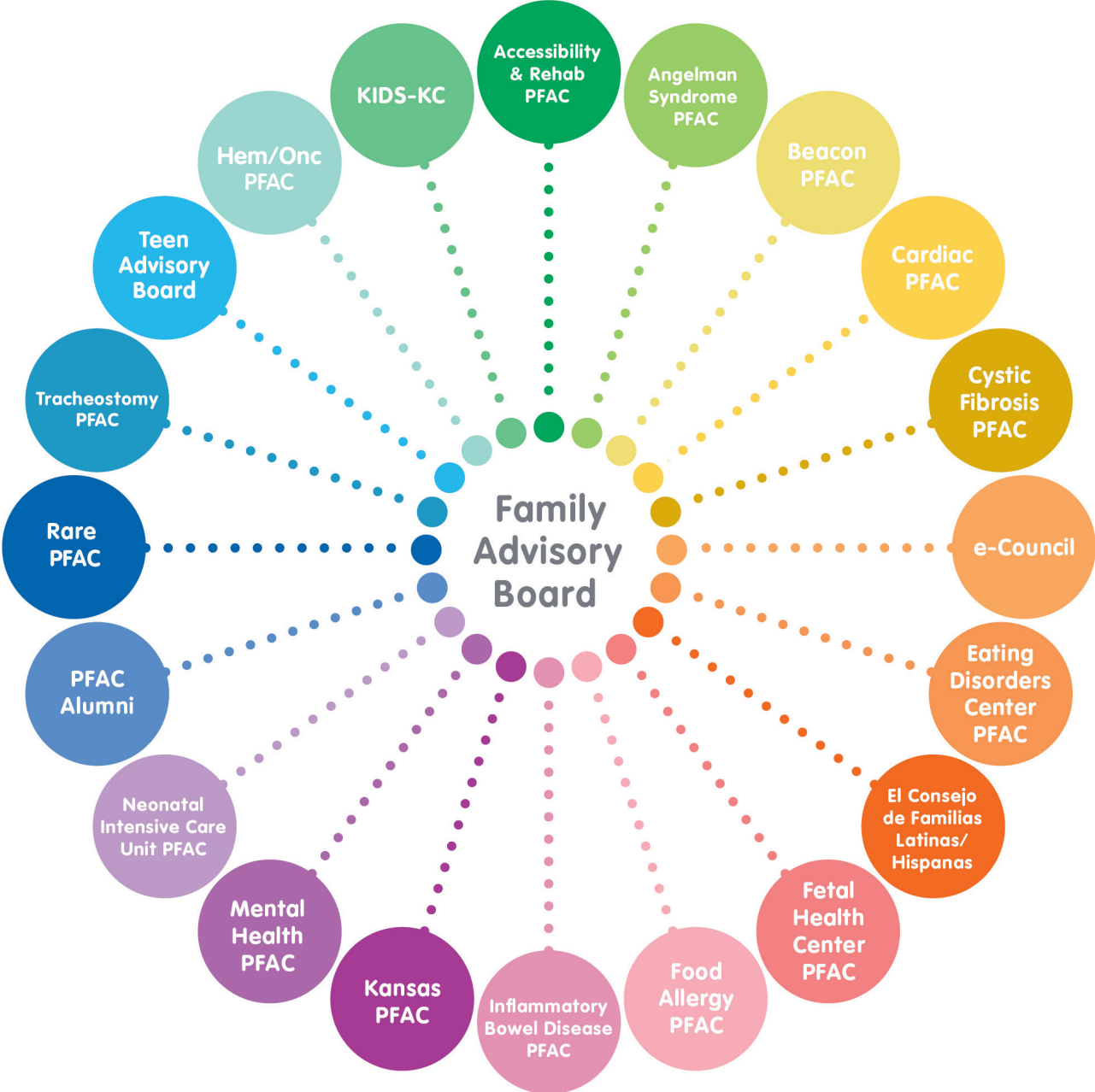


In the community, FAB members were invited to go on the Operation Breakthrough Bus Tour entitled “The City You Never See” and heard presentations from Integrated Care Solutions and Team Impact. Additionally, members participated in a Children’s Mercy Kansas City Brand Session with Communications and Marketing Creative Studio and Paul Kempinski to share feedback on the Built for Kids media campaign.

Kempinski summed up the collaboration with FAB: “Our goal is always to engage you not only as participants in your child’s care, but true partners in your child’s care.

You are our partner. You are around the table. We may bring clinical expertise, amazing research and amazing academic credentials, but you bring a keen and deep understanding of your child and the children around you – and collectively that whole is greater than the sum of those individual parts.”

In 2024, FAB looks forward to helping transform the health, wellbeing and potential of children, with unwavering compassion for those most vulnerable. ●



CHILDREN'S MERCY FY2023 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

Achieve zero harm to patients/families and team members by focusing on a culture of safety and high reliability.

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

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

FAB and PFACs interview candidates for key leadership positions and support recognition of staff. They contribute to the training of clinicians who care for patients and families.

PATIENT AND FAMILY EXPERIENCE

Consistently exceed the experience expectations of those we serve.

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

DELIVERY

Deliver excellent, timely, empathetic care that is efficient.

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

STEWARDSHIP

Responsibly manage resources to ensure affordability, advance our Mission, and achieve our Vision.

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

- Ambulatory Central Line Associated Blood Stream Infections (CLASBI)
- Antibiotic Stewardship
- Catheter Associated Urinary Tract Infections (CAUTI)
- Central Line Associated Blood Stream Infections (CLASBI)
- Ethics
- ImproveCareNow® Quality Committee
- Medication Reconciliation Steering Committee
- National Patient Safety Goal #15
- NICU Quality Improvement Team
- Opioid Stewardship
- Patient Rights Chapter Readiness
- Peripheral Intravenous Infiltrations and Extravasations (PIVE)
- Pressure Injuries (PI)
- Quality and Safety Council
- Reducing Differences in Urgent Care Encounters (REDUCE)
- Resuscitation
- Root Cause Analyses (RCAs)
- Sepsis
- Surgical Site Infection (SSI)

FEEDBACK

- Acute Brain Injury manual
- Emergency Information form for central lines

EVENTS (FOCUS GROUPS AND WORKSHOPS)

- Global Tracheostomy Collaborative conference
- Lean Language Services Alignment MGT
- Lean Pain Management RPIW
- Lean PCC FIW
- Lean Volunteer Services RPIW
- School Nurse Conference

IMPROVEMENT PROJECTS

- CHA Race, Ethnicity, and Language (REaL) Data study
- Evidence-Based Practice Clinical Practice guidelines
 - » Acute Gastroenteritis
 - » ADHD
 - » Anaphylaxis
 - » Child Abuse
 - » Community Acquired Pneumonic Clinical pathway
 - » Congenital Diaphragmic Hernia Clinic pathway
 - » Concussion Care
 - » Eating Disorders – Medical Work-up and Stabilization pathway
 - » End of Life
 - » Pharyngitis
 - » Seizure: First, Non-Febrile Clinical pathway

- » Sickle Cell Disease Management of Acute Pain
- » Status Epilepticus Clinical pathway
- My Clean Routine

PEOPLE



COMMITTEES

- Equity and Diversity Game Changers Network
- Patient/Family Team Member Interaction
- PHIL Award
- Workplace Clinical Caregivers Council

RECOGNITION

- Volunteer of the Month – Rachel Callihan
- Volunteer of the Month – Yadira Murguia

EVENTS

- Child Life Kudos Board
- El Consejo de Familias Latinas/Hispanas 15-year celebration
- Family Advisory Board 20-year celebration

PARTNERSHIPS

- Interview for Senior Director Office of Patient Experience
- Interview for VP, Chief Administrative Officer

TRAINING FOR STAFF

- Clinical Advances in Pediatric Symposium workshop
- Clinical Leadership Academy parent panel
- CM Cares parent panel
- CM Patient Experience Tours for Employees
- Culture Unfreezing facilitator
- Ethics Brown Bag NICU session
- Guest Services
- Graduate Medical Education
 - » Bereavement parent panel
 - » Non-medical in-home visits
- Graduate Nurse Residency parent panels
 - » Communication
 - » Bereavement
- New employee orientation
- Palliative Care parent panel
- Patient Access Council
- Pediatric bioethics certificate program
- Pediatric ethics podcast
- Research Administration

EDUCATION FOR PATIENTS AND FAMILIES

- Recommended book lists by diagnosis
- Transition Conference planning

PATIENT AND FAMILY EXPERIENCE



COMMITTEES

- Accessibility
- CYSHCNet Cohort - Bilingual Parent Partner
- Decedent Affairs
- Food Service
- Health Literacy

- Hunger Free task force
- Patient and Family Seal of Collaboration
- Pediatric Experience Collaborative

FEEDBACK

- e-Council Surveys
 - » Comfort Promise
 - » Inpatient Room Cleaning
 - » Mental Health Crisis Center
 - » Volunteer Services donations

EVENTS (FOCUS GROUPS AND WORKSHOPS)

- Food allergy awareness projects
- IPFCC Diversity, Equity and Inclusion in pediatric PFACs focus group
- Naturescapes focus group
- NICU reunion
- Rare Disease Day advocacy and awareness projects
- VMLY&R Focus Group for Augmented and Virtual Reality

EDUCATION FOR PATIENTS AND FAMILIES

- Child Life preparation photos
- Cardiac Parent symposium
- Central Line education
- Eating Disorder Center newsletter
- Feeding Tube roadmap
- Food Allergy Clinic newsletter
- Heart Center quarterly newsletter
- Parent-ish articles
- Transition Conference
- Transition video project
- Video "A message from Fetal Health Center Parents"

IMPROVEMENT PROJECTS

- Beacon Clinic closed Facebook group
- Inpatient room cleaning
- NICU closed Facebook group
- PFAC Members closed Facebook group

POLICY REVIEW

- Guidelines for Family Presence During Resuscitation and Procedures

DELIVERY



COMMITTEES

- Aftercare
- Anticipatory Guidance for CMC
- Behavioral Health Advisory Council
- Clear Care Board oversight
- Facilities master plan leadership
- Fruit and vegetable screening tool
- GetWell Network Advisory Council
- New initiatives
- PATHWAYS behavioral health access
- Patient Portal

FEEDBACK

- Behavioral health plan signage
- Comfort Promise

- Milk Room
- Depression Anxiety and Youth (DAY Clinic)
- KU clinical trials materials review
- Patient portal
- Switchboard for LEP families
- Trauma sensitive practices education

EVENTS (FOCUS GROUPS AND WORKSHOPS)

- ABC News mental health interviews
- Acute Mental Health Crisis Center 3D mockup
- Connected Experience
- Eating Disorder Clinic workshop
- Emergency Department Green Zone 3D mockup
- Emergency Department lobby renovation
- FHC Fetal Counseling Project
- Illuminate mental health announcement
- Lobby redesign
- Neonatal Follow Up Clinic
- Discharge Paperwork focus group
- Project HOME in NICU
- Sibling Support Project

IMPROVEMENT PROJECTS

- Inpatient phone upgrades
- PICU Interview Guide
- Religious dietary needs
- Welcome video for CMK and CB

STEWARDSHIP



COMMITTEES:

- Financial Assistance

FEEDBACK

- U.S. News & World Report promotional campaign

EVENTS

- Back to school social media campaign
- Children's Mercy Research Institute tours
- Trach merchandise sale

PHILANTHROPIC AND COMMUNITY EVENTS

- Big Slick
- Children's Mercy social media campaigns
- Discover Children's Mercy
- Dream Big Day
- Giving Tuesday campaign family stories
- Kansas City Royals
- PBR dinner with KC Outlaws Professional Bull Riding Team
- Sporting KC
- United Way kick-off

LOCAL AND NATIONAL STAGE

- Global Tracheostomy conference
- U.S. News & World Report photo shoot



196 Patient Family Advisors

3,172 PFA volunteer hours

22 PFACs

2 new PFACs

68 new PFAs

169 PFAC meetings

117 POPS matches

PATIENT FAMILY ADVISORY COUNCILS (PFAC)

ACCESSIBILITY AND REHAB PFAC

- Created virtual career fair videos for external website
» <https://cmkc.link/employment-resources>
- Donated books to the Kreamer Resource Center for Families
- Designed bookmarks with book list for inclusive books



Inclusive Children's Book List, recommended by Children's Mercy Kansas City Accessibility & Rehab PFAC

ANGELMAN SYNDROME PFAC

- Attended opening of Angelman Syndrome Clinic
- Collaborated on welcome packets for new patients
- Designed and implemented a clinic research study
- Served as a pilot for the "All About Me" guide
- Attended Foundation for Angelman Syndrome Therapeutics (FAST) Global Science Summit & Gala
- Supported national therapeutic research linkage and goals
- Received updates on CMRI clinic research



PFAC members at the opening of Angelman Syndrome Clinic

BEACON PFAC

- Volunteered at Transition to Adult Care Conference for Medically Complex Patients
- Advocated for accessible parking at all Children's Mercy locations
- Contributed to education for families on gastrostomy tube changing and maintenance
- Participated in research study, "Home Nurse Staffing, Utilization, and Wellbeing in Children with Medical Complexity"
- Engaged Beacon families in closed Facebook group



PFAC members at the Transition to Adult Care Conference for Medically Complex Patients

CARDIAC PFAC

- Served on committee to develop a program to transition from pediatric to adult care
- Published quarterly newsletters to over 47,000 recipients
- Held t-shirt fundraiser
- Planned and hosted the annual Parent Symposium
- Authored scripts for several videos to explain “what to expect” for cardiac procedures



PFAC members at the Parent Symposium

CYSTIC FIBROSIS

- Attended CF team quarterly updates
- Created book list for youth with CF and their caregivers
- Utilized CF Foundation grant money to purchase educational books and pill boxes for families
- Replenished newborn CF Diagnosis bags
- Member served as CF Program liaison to review Patient Experience data
- Member served on the PHIL Award Committee



Newborn CF Diagnosis bags

EATING DISORDERS CENTER PFAC

- Contributed to EDC newsletters
- Designed bookmarks with QR codes for informational videos and websites
- Hosted table at School Nurse Conference
- Provided feedback about new intake process, screenings, scheduling and research initiatives
- Continued participation in POPS program
- Updated Holiday Tips list



School Nurse Conference

e-COUNCIL

- Inpatient Room Cleaning – Environmental Services
- Impact of Donations on Patient Experience – Volunteer Services
- Comfort Promise in PCC – Pain Management
- ED Nurse Follow-Up Call – Emergency Department



EL CONSEJO DE FAMILIAS LATINAS/HISPANAS

- Celebrated Consejo's 15-year anniversary
- Recognized Yadira Murguia as Volunteer of the Month
- Gathered for a holiday family fiesta
- Participated in research:
 - » PATHWAYS care navigation project
 - » ReSET – Restarting Safe Education & Training for Children with Medical Complexity
- Served a meal in the Ronald McDonald Family Room
- Donated items for 4 Henson Parent Room
- Provided feedback on hospital programs and initiatives



Consejo members at 15-year celebration.



Consejo members delivered items to 4H Parent Room.

FETAL HEALTH CENTER PFAC

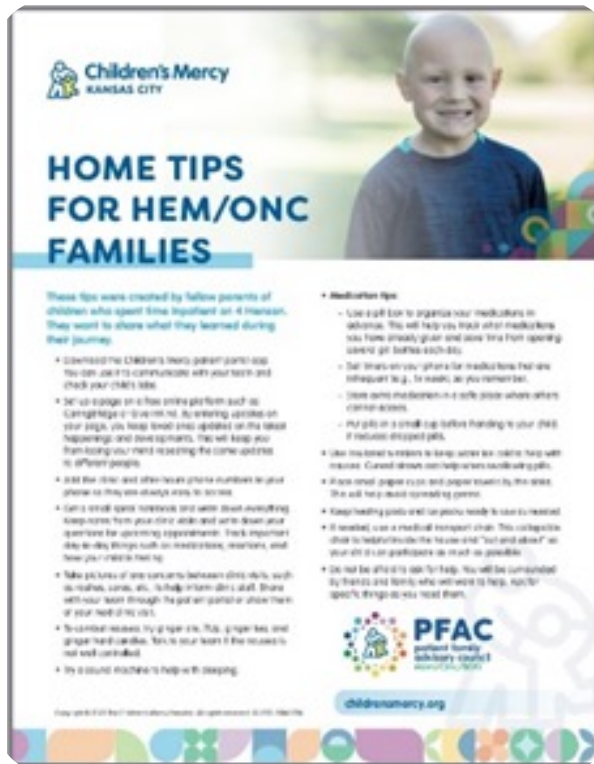
- Wrote a letter and filmed a video for new FHC families
- Toured the remodeled FHC, Milk Bank and Patient Progressive Hub
- Planned FHC reunion tent activities for Dream Big Day
- Led the fundraising for the FHC Dream Big Day team
- Provided feedback on resources for families



FHC PFAC members

FOOD ALLERGY PFAC

- Collaborated with Children's Mercy educators to increase inclusivity on 504 school template
- Partnered with cafeteria to increase gluten sensitive and allergy friendly options
- Hosted a resource table at School Nurse Conference
- Joined Food Allergy Fighters team at Dream Big Day
- Provided content for biannual newsletters that go out to 10,000 people
- Lit it Teal for Food Allergy Awareness Week in collaboration with downtown KC



School Nurse Conference

HEM/ONC/BMT

- Started PFAC in January
- Created book list for patients, parents and siblings
- Provided feedback on accessing ports in Emergency Department, CLABSI education and oral care
- Wrote tip sheets for parents:
 - » Clinic, Inpatient, BMT Unit and Home

INFLAMMATORY BOWEL DISEASE PFAC

- Provided feedback on educational materials for IBD Clinic
- Participated in Crohn's and Colitis Foundation Walk
- Created flyers for PFAC recruitment at CCFA Walk
- Created an IBD book list
- Updated CM.org webpage: <https://www.childrensmc.org/departments-and-clinics/gastroenterology/inflammatory-bowel-disease/>



Crohn's and Colitis Foundation Walk

KANSAS PFAC

- Participated in interview for Chief Administrative Officer
- Collaborated on Lab/Radiology Patient Tracker in waiting room
- Provided feedback to Guest Services and Patient Experience
- Created script for welcome video for CMK
- Partnered with Pain Management on Comfort Promise initiatives



MENTAL HEALTH PFAC

- Partnered on Illuminate campaign
- Hosted a mental health resource table at School Nurse Conference
- Provided ongoing feedback for PATHWAYS project
- Offered guidance and feedback for Zero Suicide initiative
- Reviewed community programs to support PFAC work
- Evaluated parent handout documents for D&B Clinic



Illuminate Announcement

NICU PFAC

- Added member bios to the NICU PFAC webpage
- Partnered with Nurse Council on Parent Care Unit initiatives
- Created NICU parent library
- Planned NICU reunion
- Raised over \$3,000 at Dream Big Day
- Added parent voices to hospital-wide committees
- Provided feedback on hospital initiatives impacting NICU families



NICU Reunion



FAB 20th Anniversary Celebration

PFAC ALUMNI

- Served on Planning Committee for FAB and Consejo anniversary celebrations
- Volunteered at Big Slick fundraising event
- Celebrated 22Q Clinic 10-year anniversary
- Provided feedback on multiple projects



FAB 20th Anniversary Celebration



Rare PFAC members

RARE PFAC

- Hosted Rare Disease Day advocacy and awareness displays
- Finalized parent letter and video
» <https://cmkc.link/rare-pfac-video>
- Shared impact stories and gave feedback for Connected Experience
- Participated in Primary Care Clinic Connected Experience pilot





Caption needed

TEEN ADVISORY BOARDS (TAB, HOT, KIDS KC)

- Participated in FAB/TAB welcome lunch with the incoming residents
- Engaged with Transition to Adulthood Education and Marketing Work Group
- Continued to connect with iCAN through surveys, workshops, newsletters and connecting opportunities to share patient and family voice at a national level
- Provided guidance on topics and structure for the Transition Conference
- Shared feedback regarding teen topics including birth control and sexually transmitted infection testing
- Learned about professions including pediatricians, neurologists and genetic counselors

TRACHEOSTOMY PFAC

- Provided feedback for Emergency Go-bag revisions
- Held successful t-shirt sale
- Created Kreamer book wish list and donated books
- Shared feedback on policy change for Private Duty Nursing
- Hosted trach education table at School Nurse Conference
- Presented family voice at Global Tracheostomy Collaborative in Baltimore, Maryland, at John Hopkins



Global Tracheostomy Collaborative

