



CHILDREN'S MERCY
KANSAS CITY

FAMILY ADVISORY BOARD

ANNUAL REPORT 2022



Children's Mercy
KANSAS CITY

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PATIENT AND FAMILY ENGAGEMENT

The Patient and Family Engagement (PFE) Team at Children's Mercy Kansas City continued to elevate 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 will help Children's Mercy Kansas City power the potential for every child. Through the collaboration between patients, families and staff, we will 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 improve the quality, safety and experience of care for all patients and families. 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.

2022 was a year of celebrations for Children's Mercy. The hospital commemorated its 125th anniversary, the Neonatal Intensive Care Unit celebrated 50 years, Children's Mercy

Hospital Kansas marked 25 years since opening its doors to the community, and patient and family engagement rose to an all-time high.

FAB infused the voice of patients and families throughout the hospital system by providing invaluable feedback on numerous key initiatives. These included the opioid stewardship program, procedure pre-authorization and no surprise billing, and patient experience. The security threats rapid improvement team and new security wristband system committee sought advice on the implementation of these programs to improve the safety for hospital employees, patients and guests.

In partnership with staff, members were engaged on multiple quality improvement projects such as anaphylaxis evidence-based practice, kidney transplant COVID vaccine mandate, and a pilot program for ENT surgeries. FAB members continued to serve on the Quality & Safety Council and Patient Rights Chapter Readiness Team to ensure the voice of patients and families is always represented. Additionally, feedback was given on improving family engagement in their child's care to the Hospital Acquired Conditions Pressure Injuries team.

As one of the hospital's true north pillars, patient experience was a key focus throughout the year. Members provided insight on three focus groups, inpatient room redesign, patient experience road test, and the Wichita lab. They also joined numerous hospital committees, including accessibility, care navigation, patient experience steering committee and hunger free taskforce.

At the institution level, FAB reviewed and approved the Patient and Family Engagement policy and the Patient- and Family-Centered Care policy. Members were also involved in the interview process for multiple executive positions, including the Chief Financial Officer and Fetal Health Center Chair.

FAB members were matched and prepared to serve as subject matter experts on numerous educational forums for staff and trainees. Families served as educators in the Family as Faculty program for Graduate Medical Education, which included an orientation luncheon, a death and dying workshop and monthly in-home visits. One member spoke about the family experience in the Orthopedics Division update. They also spoke on parent panels for Clinical Leadership Academy, Graduate Nurse Residency and Palliative Care.

FAB was highly valued for its insight and impact regarding education for patients and families. During the year, members reviewed multiple documents and joined the Youth Athletes Conference Planning and Transition Conference Planning committees. They also advised the PICU and CICU on updates to the Clear Care Boards to increase family engagement in infection prevention efforts.

In addition to dedicating their time to FAB, members generously gave back to Children's Mercy through their

involvement in several philanthropic programs. As grateful families, members participated in Dream Big Day and Big Slick events. One member's son was featured in the Sporting KC pre-game coin toss during the 125th Celebration at Children's Mercy Park. FAB members were special guests at the Community Harvest event that acknowledged 125 years of community partnerships and honored 12 organizations with Catalyst Community Partnership Grants. In appreciation for the empathetic and compassionate care that the nurses provide for their children, members created a thank you video for Nurse's Week.

The work of FAB members continued to be showcased on the regional and national level. One member served on a parent panel for Health Affairs about caring for those with complex needs. A video presentation was created for the Society of Pediatric Psychology Conference. Many members also served on multiple local, state and national committees advocating for improvements in children's health. Their voices have an ongoing influence beyond the walls of Children's Mercy.

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 FAB members were recognized with special awards. Bethany Luther was the November Volunteer of the Month, and Miriam Iliff received the Kindness Award for refreshing the "Welcome" rock in the Nancy Nutter Moore Garden, the outdoor space and garden just off the Lisa Barth Chapel.

The Family Advisory Board looks forward to 2023 as they continue to partner with hospital leadership to power the potential for every child and keep kids safe and healthy, fight rare diseases through research, and work with parents, schools and our community. ●

PATIENT FAMILY ADVISORY COUNCILS (PFAC)

FAB serves as the oversight group for the 20 Patient and Family Advisory Councils (PFACs) at Children's Mercy. The PFACs provide a forum for patients and families to regularly collaborate with the health care team for specific departments, diagnoses and locations. Council members share their unique perspective of the health care experience in order to have a direct impact on the planning, delivery and experience of health care with the goal of promoting quality, safety and engagement.



CHILDREN'S MERCY FY2022 TRUE NORTH PILLARS

The work of FAB and PFACs 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

- Adverse Drug Events (ADE)
- Anaphylaxis Evidence Based Practice
- Anticoagulation Management Council (AMC)
- Catheter Associated Urinary Tract Infections (CAUTI)
- Central Line Associated Blood Stream Infections (CLABSI)
- ImproveCareNow® Quality Committee
- NICU Quality Improvement Team
- Patient Rights Chapter Readiness
- Pressure Injuries (PI)
- Quality and Safety Council

FEEDBACK

- Chlamydia Screening for Latina populations
- CPAP, BiPAP education e-survey
- Medication reconciliation
- New wristbands for inpatient parents/caregivers
- Opioid Stewardship
- Pressure Injuries – engaging families in care
- Suicide Prevention Resources card

EVENTS (FOCUS GROUPS AND WORKSHOPS)

- Lean Epilepsy Monitoring Unit workshop
- Lean Supprelin Implants workshop
- Race, Ethnicity and Language (REaL) Data focus group
- Tracheostomy Program Town Hall

EDUCATION FOR PATIENTS AND FAMILIES

- Dressing Changes for Burns video
- Kangaroo Care in the NICU
- NICU parent education for patient fracture risk
- Nutrition brochure for blended diets
- Patient models for educational resources

IMPROVEMENT PROJECTS

- GetWell Network
- Kidney transplant COVID vaccine mandate
- MVP Pilot Program for ENT surgery
- My Clean Routine
- NICU Limited English Proficiency (LEP) taskforce
- Security Threats Rapid Improvement team

PEOPLE



COMMITTEES

- Patient/Family Team Member Interaction

FEEDBACK

- Provider profiles on CM.org e-survey

RECOGNITION

- Kindness Award – Miriam Iliff
- Volunteer of the Month – Bethany Luther

EVENTS

- Just Culture retreat
- Orientation lunch with new residents

PARTNERSHIPS

- Interview for Chief Financial Officer
- Interview for Chief of Cardiology
- Interview for Fetal Health Center Chair

TRAINING FOR STAFF

- Advancing Leadership Experience
- Clinical Leadership Academy parent panel
- Ethics Brown Bag Bereavement session
- Graduate Medical Education
 - » Bereavement parent panel
 - » Virtual in-home visits
- Graduate Nurse Residency parent panel
- Palliative Care parent panel
- Respect for All Education

EDUCATION FOR PATIENTS AND FAMILIES

- Recommended book list
- Transition Conference planning
- Virtual Career Fair webpage
- Young Athletes Conference planning

PROJECTS

- Appreciation event for ENT staff
- Kudos messages for PeriOp staff
- “Thank you” video for Nurse’s Week

PATIENT AND FAMILY EXPERIENCE



COMMITTEES

- Accessibility
- Care Navigation
- Hunger Free taskforce
- Patient Experience Steering committee

FEEDBACK

- Children’s Mercy Hospital Kansas and College Boulevard Patient Experience e-survey
- CM.org public website updates

EVENTS (FOCUS GROUPS AND WORKSHOPS)

- Food allergy awareness projects
- Inpatient Room Redesign
- NICU reunion
- Patient Experience Road Test focus group
- Rare Disease Day advocacy and awareness projects
- Wichita Lab

EDUCATION FOR PATIENTS AND FAMILIES

- Cardiac Parent Symposium
- Created series of Eating Disorder education videos
- Eating Disorder Center Newsletter
- Educational videos and caregiver bags for families of children with a trach
- Food Allergy Clinic Newsletter
- GI Procedure education project
- Heart Center Quarterly Newsletter
- Resources for undocumented families
- Teen Journal
- Video “A message from Fellow Parents of Heart Warriors”
- Video for parents of children with rare diseases and conditions

IMPROVEMENT PROJECTS

- Allergy labeling and allergy friendly offerings in Children’s Mercy eateries
- Beacon Clinic closed Facebook group
- NICU closed Facebook group
- PFAC Members closed Facebook group

POLICY REVIEW

- Patient and Family Engagement
- Patient- and Family-Centered Care

DELIVERY



COMMITTEES

- Aftercare
- Behavioral Health Advisory Council
- PATHWAYS Behavioral Health Access research project

FEEDBACK

- Connected Experience
- Depression Anxiety and Youth (DAY Clinic)
- Discharge instructions in Spanish
- Family communication about surgery delays
- Genomic Answers for Kids
- IBD Young Adult Clinic

- Patient portal
- Switchboard for LEP families
- Vendor options for video interpreting
- Virtual transition appointments for the Heart Center

EVENTS (FOCUS GROUPS AND WORKSHOPS)

- Ambulatory Standards Retreat
- Emergency Department Boarding Patients focus group

EDUCATION FOR PATIENTS AND FAMILIES

- Cardiology Caregiver Discharge Road Map
- Developmental & Behavioral Clinic caregiver education
- What to Expect in the NICU video

IMPROVEMENT PROJECTS

- A3 Congenital Heart Defect transition process for Heart Center
- EMU Access QI project
- Pharmacy signage and workflow
- Transition Program Health Passport
- Welcome video for CMHK and CB

STEWARDSHIP



FEEDBACK

- Prepped and Ready
- Procedure Pre-Authorization and No Surprise Billing

EVENTS

- CMRI Tours
- Trach merchandise sale

PHILANTHROPIC AND COMMUNITY EVENTS

- Big Slick
- Children’s Mercy social media campaigns
- Community Harvest Event
- Discover Children’s Mercy
- Dream Big Day
- Fundraising direct mail campaign
- Sporting KC coin toss
- Wish List for Kids campaign

LOCAL AND NATIONAL STAGE

- Health Affairs Parent Panel
- Heartland Association Research Professionals Conference
- iCAN Summit
- Society of Pediatric Psychology Conference
- Youth Athletes Conference

COMMUNITY PRESENTATIONS

- Canine Connections
- Numotion
- Variety Playgrounds ●

PATIENT FAMILY ADVISORY COUNCILS (PFAC)

187 Patient Family Advisors

3,133 PFA volunteer hours

20 PFACs

1 new PFAC

52 new PFAs

134 PFAC meetings

ACCESSIBILITY AND REHAB PFAC

- Virtual Career Fair Webpage
 - » Collaborated with Kansas City community members who utilize adaptations for their successful employment
 - » Collected videos from six community members
- Inclusive Recommended Book List
 - » Gathered list of book recommendations highlighting characters with unique and differing abilities
- Feedback provided:
 - » Numotion
 - » Canine Connections
 - » Variety Playgrounds
 - » Genomic Answers for Kids

BEACON PFAC

- The Year of Self-Care
 - » Hosted self-care moments at the beginning of every meeting
- Beacon Family Facebook Group
 - » Shared posts on ways to care for yourself
 - » Hosted virtual social hours
 - » Shared clinic updates
- Blended Diet Brochure
 - » Published brochure
 - » Uploaded information to Children's Mercy website
- Dream Big Day Funds
 - » Distributed funds to Beacon families in need
- Psychosocial Considerations for the Child with Rare Disease: A Review of Recommendations and Calls to Action
 - » Published article written by the Beacon team
 - » Spotlighted a Beacon PFAC member and her family

ROLE MODELS NEEDED



Role models needed for an accessibility video project

Teens in the Children's Mercy Spinal Differences Clinic need to see positive examples showing working adults who utilize adaptations to be successful in their jobs.

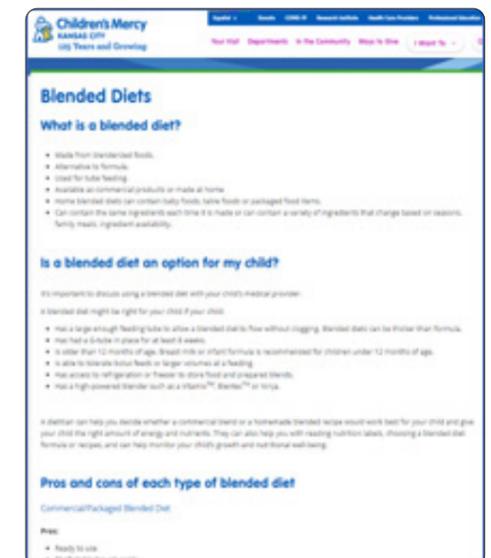
We're creating an online video montage and answering the following questions:

- What do you do for work and what is your disability?
- What type of education or training does your current job require?
- How do you get to work?
- Describe your typical day.
- Does your desk or workspace require special adaptations?
- What accommodations were made to make your job accessible?
- What do you feel you bring to the job that someone else could not?
- How did you disclose your accommodation needs?



Scan this code to register as a Role Model

Contact: Kaitlin Woodson
Spinal Differences Nurse Coordinator
Email: kwoodson1@cmh.edu
Phone: (816) 302-3405



CARDIAC PFAC

- Adult Transition Sub-Committee
 - » Worked with A3 group to break down and rebuild the current adult CHD transition process for the Heart Center
 - » Began virtual transition appointments
 - » Created a health passport PDF
 - » Continued efforts toward ACHD accreditation
- Communication Sub-Committee
 - » Recorded the parent letter authored in 2021
 - » [youtube.com/watch?v=zx5z6ju0Nng](https://www.youtube.com/watch?v=zx5z6ju0Nng)
 - » Provided quarterly Heart Center newsletters
- Discharge Sub-Committee
 - » Created emergency form to be used once families are discharged
 - » Improved communication regarding charting methods between parents and staff
 - » Worked with A3 group to create a discharge pathway, care team roles sheet and a welcome brochure
- Parent Symposium Sub-Committee
 - » Hosted Parent Symposium in Excelsior Springs on June 18, 2022 with multiple staff presenters/panelists

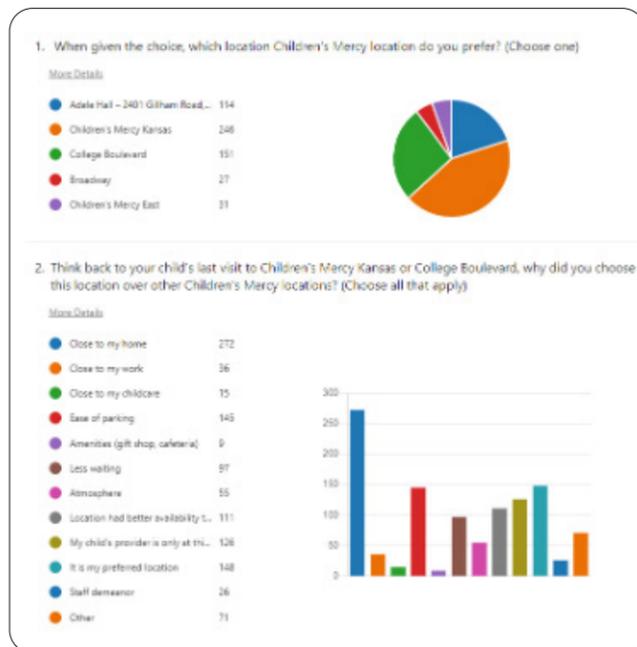


PFAC members at the Parent Symposium



EATING DISORDERS CENTER PFAC

- Window display at CM Hospital Kansas to raise awareness for eating disorders
- Books collected and distributed to newly diagnosed families
 - » Created PFAC sticker to add to front cover
- EDC newsletter contributions
 - » Tips for summer break
 - » Eating disorder fact sheet for school nurses
 - » Recruitment
- Eating Disorder educational videos featuring PFAC parents sharing their stories
 - » First Warning Signs
 - » Caregiver to Caregiver
- Parents Offering Parent Support (POPS) program
- Feedback provided:
 - » Government Relations



e-COUNCIL

- Feedback requested from identified parents or guardians of a child who receives care at Children's Mercy
 - » CPAP, BiPAP education
 - » Provider Profiles on CM.org
 - » CMK and CB patient experience
 - » CM.org home page

EL CONSEJO DE FAMILIAS LATINAS/HISPANAS

- PATHWAYS Behavioral Health Access Research project
- Dream Big Day Ambassador
- Patient Models for preparation photos and burn dressing change video
- NICU LEP Taskforce
- Feedback provided:
 - » Resources for undocumented families
 - » Discharge instructions for LEP families
 - » Prepped and Ready
 - » Respect for All education
 - » Video interpreting vendors
 - » Emergency Department Communication project
 - » Chlamydia Screening project
 - » No Surprise Billing Act
 - » Patient Portal
 - » Switchboard updates for LEP families
 - » Center for Families and Community Connections



FETAL HEALTH CENTER PFAC

- Inaugural members recruited
- By-laws created and approved
- Updates received:
 - » Inpatient processes, materials and focus areas
 - » Outpatient processes, materials and focus areas
- Brainstorming sessions held on potential areas of improvement



FOOD ALLERGY PFAC

- Cafeteria changes to support those with food allergies
 - » Labeling enhancements
 - » Additional pre-packaged options with ingredient labels
 - » Ingredient labels for in-house items to align with FDA regulations
- Food Allergy Clinic Newsletters
- CMRI and downtown Kansas City Lighting It Teal in support of Food Allergy Awareness Week
- Feedback Provided:
 - » Allergy friendly snacks for Dream Big event
 - » Allergy friendly kiosk for cafeteria
 - » University Health research study on CBT for Parents of Children with Food Allergies
- 504 Plan project for students with food allergies

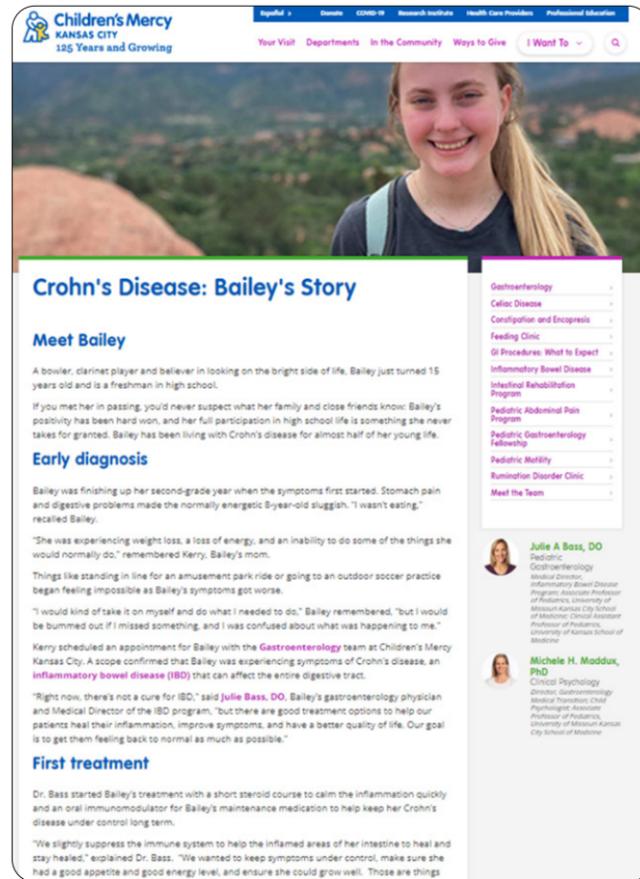


INFLAMMATORY BOWEL DISEASE PFAC

- GI Procedures parent education project
- Feedback provided:
 - » Patient/parent educational handouts
 - » Young Adult Clinic
 - » IBD Brochure
 - » Improve Care Now (ICN)
- Peer Mentor project for teen patients

KANSAS PFAC

- Welcome Video for CMHK and CB
- Visited Sleep Lab at 5520 College Blvd and tested new chairs
- EMU Quality Improvement Project to improve access
- Feedback provided:
 - » e-Council survey about consumer preferences about CMHK
 - » No Surprise Billing
 - » Kansas Lab and Radiology Registration Hours
 - » CMHK Exterior Renovations
 - » Resources for Families on CM Public Website
 - » Facility Dog Program
 - » New Snack Policy for Clinics
 - » Outpatient Pharmacy
 - » Vending Machines with Personal Items
 - » Communication Regarding Surgery Delays



MENTAL HEALTH PFAC

- PATHWAYS Behavioral Health Access Research Project
- Just Culture retreat
- Behavioral Health Advisory Council member
- Patient/Family Team Member Interaction participant
- Feedback provided:
 - » Resources for patients and families in D&B
 - » DAY Clinic (Depression Anxiety and Youth) feedback
 - » Prepped and Ready - Supporting access to program in school districts
 - » MandH® training for families
 - » Emergency Room visits protocol for AHMS (Acute Mental Health Screening)
 - » Developmental & Behavioral Health waiting rooms sensory friendly ideas

NICU PFAC

- Quality Improvement project about ICN Culture Statement
- What to Expect in the NICU video
- Kangaroo Care video
- Feedback provided:
 - » Parent education for fracture risk patients
 - » Research study recruitment for infants exposed to radiation
 - » Parent Education for Parent Care Unit
 - » Trauma Informed Care survey questions
- NICU Parent and Caregiver private Facebook page

CHILDREN'S MERCY AUTISM CAREGIVER EDUCATION

The Division of Developmental and Behavioral Health at Children's Mercy offers the following Caregiver Trainings. These sessions are designed for caregivers of youth diagnosed with autism and/or other developmental disabilities, but all are welcome. There are two ways you can access our Autism-related trainings:

1. ATTEND OUR LIVE MONTHLY VIRTUAL OFFERING
Registration is REQUIRED, training is FREE. childrensmercy.org/autism
2. WATCH CLINIC RECORDED TRAININGS
Go to childrensmercy.org/autism and select the panel on the right "Recorded Trainings"

TOPICS INCLUDE:

- Sleep 101 for Persons with Autism
- Next Steps after Autism Diagnosis
- Setting Up for IEP Success
- Imitate to Communicate
- Transition to Employment: Setting a Foundation for Success
- Supporting Social Engagement in Early Childhood
- ASD and Co-Morbid GI Conditions
- Addressing Puberty and Sexuality in Persons with DD and ASD
- Promoting Social Skills and Independence
- Toilet Training Part 1 and Part 2
- Eating and Enjoying It
- Applied Behavior Analysis
- Managing Problem Behavior
- Managing Your Child's Home and School Programs and MORE!

Registration is required. There is no cost to participate.

Children do not attend training.

Childcare is not provided.

If you have any additional questions, please contact:

Mary Anne Hammond
Education Coordinator for Autism
(913) 696-5711 or
autism@cmh.edu



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PFAC ALUMNI

- Quality Improvement Supprelin Implants workshop
- Discover Children's Mercy participant
- Graduate Medical Education family educators
 - » Bereavement parent panel
 - » Virtual in-home visits
 - » Palliative Care parent panel
- Children's Mercy Philanthropic events
 - » Big Slick
 - » 2022 Wish List for Kids campaign

RARE PFAC

- Rare Disease Day advocacy and awareness projects
 - » Displays at Adele Hall and CMHK
 - » "Why fit in when you were born to stand out" t-shirt sale
 - » Social Media campaign #rarediseaseday
 - » Care-for-Rare awareness event
- Connected Experience
 - » Impact stories shared
 - » Feedback provided
- Rare video welcome for parents



TAB, HOT, KIDS KC

- Feedback provided:
 - » Suicide prevention resources cards
 - » Developmental and Behavioral DAY clinic and support groups
 - » Research study recruitment
 - » Sexually transmitted infection screening questions
- 2022 Heartland Association Research Professionals Conference presentation
- Teen Journal updated
- Children's Mercy website enhancements
- iCAN Summit poster presentation
- Hospital career and education paths presentations:
 - » Resident
 - » Surgeon
 - » Nurse researcher
 - » Facility dog handler
 - » Child Life Specialist

TRACH PFAC

- Trach awareness merchandise sale
- Caregiver bags provided to parents
- Recognition event for ENT team
- Feedback provided:
 - » Parent Education classes
 - » Stroller walks
 - » PCU stays
- Caregiver/Parent Educational videos
- Tracheostomy Program Town Hall

Research	KIDS KC 2022 Highlights	Team members
Provided input on: <ul style="list-style-type: none"> • "Key information" in consent forms • Mobile devices and wearable sensors (a smart watch) research • Raising awareness on available research projects 	<ul style="list-style-type: none"> • 11 virtual meetings (attended virtual summit for July meeting) • 17 current members who are all patients at Children's Mercy • Advocated for resources for suicide prevention when we learned that the suicide screening processes had changed at CMH. Shared input on how best to share resource information, how the resource would look visually, and what information was available through this. • Provided input on changes being made to the Hematology and Oncology teen journal. • 5 teens are planning to go into health care as a profession. • Provided input on accessibility for people with disabilities. 	<ul style="list-style-type: none"> • Anna S • Surya R • Katherine S • Petra U • Payton B • Lauryn B • Audrey B • Nevea B • Avery R • Anya K • Addie S • Nola G • Shucayb S • Sam K • Muneria N • Peter S • Meirah P
Provided input on: <ul style="list-style-type: none"> • Sharing information on the COVID-19 Vaccine • Parent-ish blog: Common Sense 101 what you wish you learned more about in school • Through iCAN on how to reach patients and families using social media and describing social media 		Facilitators <ul style="list-style-type: none"> • Amanda Woelk • Melissa Pulis • Amanda Trout



