



# family advisory board



## 2016 Annual Report

**The Family Advisory Board (FAB) at Children's Mercy Kansas City partners with staff to advance the mission of the hospital to improve the health and well-being of children by providing comprehensive, family-centered health care and committing to the highest level of clinical and psychosocial care, and to research, academic and service excellence. By using their personal experiences, members of the Board infuse the patient and family perspective into all areas of the hospital.**

In 2016, FAB studied the hospital's strategic plan in order to prioritize its efforts. Members identified access, outcomes, communication and safety as their top four areas to influence.

In ongoing support of the Lean management system, FAB members collaborated on improvement projects in the PICU, PeriOp, 4 Sutherland, and Ambulatory clinics. They also assisted with hospital initiatives including "Nurse Shift Hand-off at the Bedside" and the "On-Time Starts" in outpatient clinics. The patient and family viewpoint remains a valuable contribution to all Lean work.

FAB members committed numerous hours to providing the voice of patients and families on hospital committees and projects. They continued to serve on all 10 Hospital-Acquired Condition committees as well as the Quality and Safety Steering Committee. Representatives from FAB and El Consejo (representing Hispanic patients and families) were engaged with the team working to enhance the Transition Program to assist our patients moving from the pediatric setting to adult health care. Moreover, members were advisors on multiple committees including Archives, Telemedicine, Home Care and First Impressions.

In partnership with the Innovation Center, parents collaborated on the discovery phase of developing an alternative for patient armbands and tested the new hospital wayfinding app. They served as consultants for the design of technology-driven health care and changes to enteral tubing adaptors. A member regularly reviews calls coming into the Contact Center and provides feedback from the parent perspective regarding the level of customer service.

Children's Mercy earned Magnet designation for nursing excellence for the fourth consecutive time in 2016. The Magnet Program Director was quoted as saying, "What really sets Children's Mercy apart is our family-centered team approach. Along with the child's referring physician, we incorporate the child's parents and guardians in the team. They know the child best." When Magnet surveyors conducted the site visit, parents from FAB and El Consejo met with them to share details about the collaboration between staff and families.

Research is a top priority of all FAB members. Tom Curran, PhD, FRS, the Executive Director and Chief Scientific Officer of the new Children's Research Institute, shared the hospital's commitment to become a leader in pediatric translational research. A FAB parent is on the new Research Institute Discovery Portal Team which will be located in the Institute. Members of FAB, the Alumni of FAB, and El Consejo were participants on two PCORI research projects focused on reducing antibiotic misuse and building a roadmap for stakeholder engagement in research. Another member joined the Children's Hospital Association CARE Award to bridge care coordination for patients with complex health needs.

To ensure that every child in our region has a better chance for a healthier, happier life through innovative, comprehensive, world-class care, FAB members teamed with the Department of Philanthropy on several events. They supported the Children's Mercy Cancer Center by participating in the Big Slick Celebrity Weekend, Holiday Heroes campaign and the KC Cares for Kids Walk. They also serve as members on the Planned Giving Council, Mercy Ambassadors and Grateful Families.

FAB members created several educational tools for patients and families. Members filmed a surgical site infection prevention video and an education video on how to effectively use the patient portal. They reviewed many documents on a variety of topics for family education.

Families serve as essential partners in patient- and family-centered care education for staff, families and the community. FAB members assist as Family Educators for the new residents by hosting them in their homes, as well as sharing their personal stories on a parent panel about the experience of losing a child. Other parent panels were facilitated for the Graduate Nurse Residency program, nurses working on the inpatient units, the Midwest Association of Administrative Nursing Supervisors from area hospitals, and during the Equity and Diversity Retreat.

As a recognized national leader in patient- and family-centered care, Children's Mercy Family-Centered Care staff was invited to present best patient and family engagement practices at the Institute for Patient- and Family-Centered Care International Conference. Additionally they served as the Quarterly Quality Platform for the Missouri Hospital Association and highlighted the exceptional accomplishments and advancement of the Family Advisory Board.

FAB serves as the oversight group for the growing number of Patient and Family Advisory Councils at Children's Mercy. These PFACs provide a forum for patients and families to collaborate with the health care team. Council members share their unique perspective of the health care experience in order to have a direct impact into the planning, delivery and evaluation of health care with the goal of promoting quality, safety and satisfaction.

- The Food Allergy PFAC held its initial meeting in 2016. Over the year, they explored the food options offered in the clinics, inpatient units and cafeteria. They also celebrated Children's Mercy being selected by Food Allergy Research & Education as one of 22 centers of excellence to be inaugural members of the FARE Clinical Network.
- The Cystic Fibrosis PFAC contributed to a newsletter that is sent to all families, as well as developed content for a new webpage.

They sponsored a booth at CF Education Day to inform families about the PFAC and talked with staff to determine how they can support the clinic. They also received approval to participate in a survey from the Cystic Fibrosis Foundation soliciting feedback from families.

- The Inflammatory Bowel Disease PFAC focused on increasing the consistency of care across the IBD population. Two members joined the IBD Clinical Quality Improvement Team at the ImproveCareNow Community Conference in Chicago, serving as leaders in the areas of provider/parent collaboration and co-production as well as transition and transfer of care from pediatrics to adult care.
- The Intensive Care Nursery Family Staff Advisory Council (ICN FSAC) integrated members as Patient Family Advisors on several ICN committees to enhance the impact of family-centered care in the nursery. Members also provided input on the renovation of the patient rooms in the Henson Tower. Members worked with community organizations to provide meaningful activities for parents on major holidays and held a successful NICU Graduate Reunion for more than 550 attendees.

2016 was a very productive year for the three teen PFACs, the Teen Advisory Board (TAB), the Hematology/Oncology Teen Board (HOT), and Kids and Families Impacting Disease through Science (KIDS KC).

- TAB members assisted the Telemedicine Department on the utilization of Dubbs the robot. They tested Dubbs at Children's Mercy Park during Sporting Kansas City professional soccer games. They also worked with Scribe, the Children's Mercy artist, on the design of the new Surgery Clinic waiting room and hosted two events for inpatient teens. During Discover Children's Mercy, they provided a panel to highlight the care experience from the perspective of the patient.
- HOT members focused on the creation of the Teen Unit on the oncology floor to provide patients with an opportunity to meet and support other teens during treatment. They also designed a teen journal, provided input to the KC Cares Walk committee, and helped plan the quarterly Teenapoloza events.
- KIDS KC had four teens attend the International Children's Advisory Network Summit in Barcelona, Spain and present about the collaborative work being done at Children's Mercy. Members teamed up on local and international research projects, and they shared the patient perspective on participation in studies at the Greater Plains Collaborative Conference.

El Consejo de Familias Latinas Hispanas represented the voice of Hispanic parents on a panel at the Voices of our Community event and hosted an educational booth during Children's Mercy Diversity Day. Members updated guidelines to reflect the changes that have occurred since its inception eight years ago. To support other families facing the challenges of having a child in the hospital, they prepared and served a meal at the Ronald McDonald House.

The members of the Family Advisory Board are looking forward to continuing their collaboration with Children's Mercy staff as we focus on continually improving the health and lives of our patients and their families. The growth of patient and family engagement throughout the organization ensures that we remain patient-centered - every action, every day.