

2015 ANNUAL REPORT



The Family Advisory Board (FAB) serves as the voice of experience to advance patient- and family-centered care that supports, educates, and engages patients, families, and healthcare providers to ensure the highest level of personalized care throughout Children's Mercy. Increased partnerships between families and staff result in the voice of patients and families being consistently represented throughout the hospitals and clinics. In 2015, Children's Mercy continued to be recognized as a national and local leader in patient and family engagement.

The newly renovated Kreamer Resource Center for Families was reopened and dedicated to providing families a welcoming environment that includes a wide range of services, activities, and conveniences. FAB members played an integral role in providing input for the redesigning of the space which includes a business center, an activity room, and an interactive play area. Additionally, FAB members provided input on the programming offered for patients and families, selected the artwork, and trialed the space prior to the Grand Opening. This collaboration resulted in a distinctive space that serves as the nucleus for patient- and family-centered care services.

Members of the Family Advisory Board dedicated many hours to serving as the parent voice on multiple committees in 2015. FAB members were essential partners on the 10 Solutions for Patient Safety Hospital Acquired Conditions committees. Moreover, members served on the Council on Violence Prevention, the First Impressions Steering Committee, and the Children's Mercy Archives Committee. Input from FAB members has proven to be a valuable component for each of these committees.

Representatives from Patient Family Advisory Councils (PFACs) were invited to participate in the Children's Mercy Lean System which is designed to streamline processes, become more agile and innovative, reduce waste and costs, and improve both patient/family and employee satisfaction. PFAC members provided their unique perspectives on teams from Radiology, Peri-Op Services, Environmental Services, and inpatient units. This work ensures that Children's Mercy remains patient-centered every action, every day!

As an identified priority of FAB, the transition team continued to develop the infrastructure to build a successful program. Members of FAB collaborated with the Transition Committee on the content for the public website, transitioning responsibility guidelines, and goal setting for patients and families.

Feedback from FAB continued to be requested from numerous departments throughout the hospital. Patient Financial Services, the Contact Center, Pharmacy, the Center for Pediatric Innovation, and Environmental Services were among the many groups who sought input from families. One meeting was devoted to a presentation by Dr. Jane Knapp entitled "Children's Mercy History: The Past that Created the Future".

Families played an integral role in patient- and family-centered care education for staff, families, and the community. FAB members served as educators in the Family as Faculty program which included an orientation luncheon, a death and dying workshop, and in-home visits. Parents participated on panels for graduate nurses, nursing leadership, and the pediatric intensive care unit. Two members and their children assisted in the development of an educational video for patients undergoing a VCUG. In the community, FAB provided an expert voice for the Blue Valley Supportive School Experience and Special

Needs Resource Fair. A Medical Home Advocacy training for parents was held. Individually, members spoke to the UMKC Biomedical Class and the Quality Forum at Kansas Foundation for Medical Care. A member also participated on an Equity and Diversity Community panel and a medical home learning collaborative.

FAB members assisted with furthering the mission of the hospital to serve all children regardless of their ability to pay by partnering with Philanthropy in the I Love CMH campaign, the Mother's Day message, the Circle of Care campaign, the Planned Giving Committee and the Grateful Family Program. Members also provided input on the new gift shop expansion and received a VIP tour of the shop. Individual members filmed a thank you video for a corporate donor, served as Mercy Ambassadors, and volunteered for Red Hot Nights. In addition, FAB members served on the Container Store Host Committee and participated in the announcement of Children's Mercy joining the University of Kansas Cancer Center NCI Consortium.

The Family Advisory Board of Children's Mercy is recognized as a national leader in patient- and family-centered care. Family Centered Care staff was invited to present best patient and family engagement practices at the National Patient Safety Foundation Congress, the Vermont Oxford Network Conference, the Beryl Institute Patient Experience Conference, Missouri Hospital Association webinars, and the Kansas City Quality Improvement Consortium.

Children's Mercy has an ambitious and comprehensive strategic plan that serves as a roadmap to achieve the vision to "be a leader recognized for advancing pediatric health" over the next decade. To ensure alignment with the hospital's strategic plan, a FAB Executive Committee was established. This leadership group will guide the future direction of FAB.

FAB serves as the umbrella group for other Patient and Family Advisory Councils at Children's Mercy. Utilizing the existing guidelines, these "Friends of FAB" made impressive advancements throughout 2015 and reported their accomplishments at the FAB Annual Meeting.

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) were very active in 2015. TAB members volunteered at the Ronald McDonald house, facilitated two events for inpatient teens, and reviewed literature for a variety of clinics. They created an app review process for recommending apps for patient use and sampled specialty menu food options. Members also met with Chelsea Clinton during a book signing in the Kreamer Resource Center for Families and visited the innovation center.

HOT is an extension of the Teen Advisory Board. A member from HOT is featured in the welcome video that patients will see on the Get Well Network. They also reviewed the Young Adult Guidelines and Policies for the new Hem/Onc Teen Unit and started writing a Teen Handbook for oncology patients.

KIDS KC met with staff from the Children's Mercy Government Relations Department and from Patient Care Services Research. They toured the research facility and participated in several national research surveys. A few members went to Washington DC and met with the FDA, Healthcare Canada, and Europe's FDA to learn about the various steps that a drug goes through when being trialed.

El Consejo de Familias Latinas Hispanas hosted several educational events for Spanish speaking families including CPR classes and Sex Talk for Parents and Teens. They toured the Kreamer Resource Center for Families and the Lisa Barth Interfaith Chapel. Furthermore, they hosted a booth during Children's Mercy Diversity Day and shared the accomplishments of their group with employees.

The Congenital Heart Defects Families Association (CHDFA) is a 100% volunteer run local organization. They donated care packages to families whose children were undergoing open heart surgery. CHDFA also donated \$5,000 to start The Beaded Journey program for children with congenital heart defects. They also hosted a free medically supervised summer camp, Camp Systole, for kids with congenital heart defects.

The Inflammatory Bowel Disease Patient Family Advisory Council (IBD PFAC) partnered with the GI Department to improve communication and education with patients and families. They created a video for newly diagnosed patients with IBD which can be viewed on the Children's Mercy website. Members share a common goal to improve care for patients and families living with IBD and collaborated with staff to present at a national conference.

The Intensive Care Nursey Family Staff Advisory Council (ICN FSAC) serves to enhance family-centered care in the Intensive Care Unit by identifying education, supportive programming, and creative activities while providing the perspective of families into the care experience. The documentary *Inside Pediatrics* highlighted the stories of two members of the council. Members also volunteered at NICU Night Out which provides a warm meal, entertainment and stress relief for families with a baby in the nursery.

The Cystic Fibrosis Patient Family Advisory Council, the newest PFAC at Children's Mercy, was officially organized this year. The council created a formal application process, a mission statement, and bylaws. Members participated in the development of an inpatient handbook for patients with Cystic Fibrosis. They also contributed to the CF Newsletter and assisted with CF Education Day.

The members of the Family Advisory Board are poised to partner with Children's Mercy to transform children's lives and redefine pediatric medicine in 2016. We are grateful to the Hospital Leadership for their ongoing support and commitment to partnering with patients and families to improve the quality and safety of care for patients.

