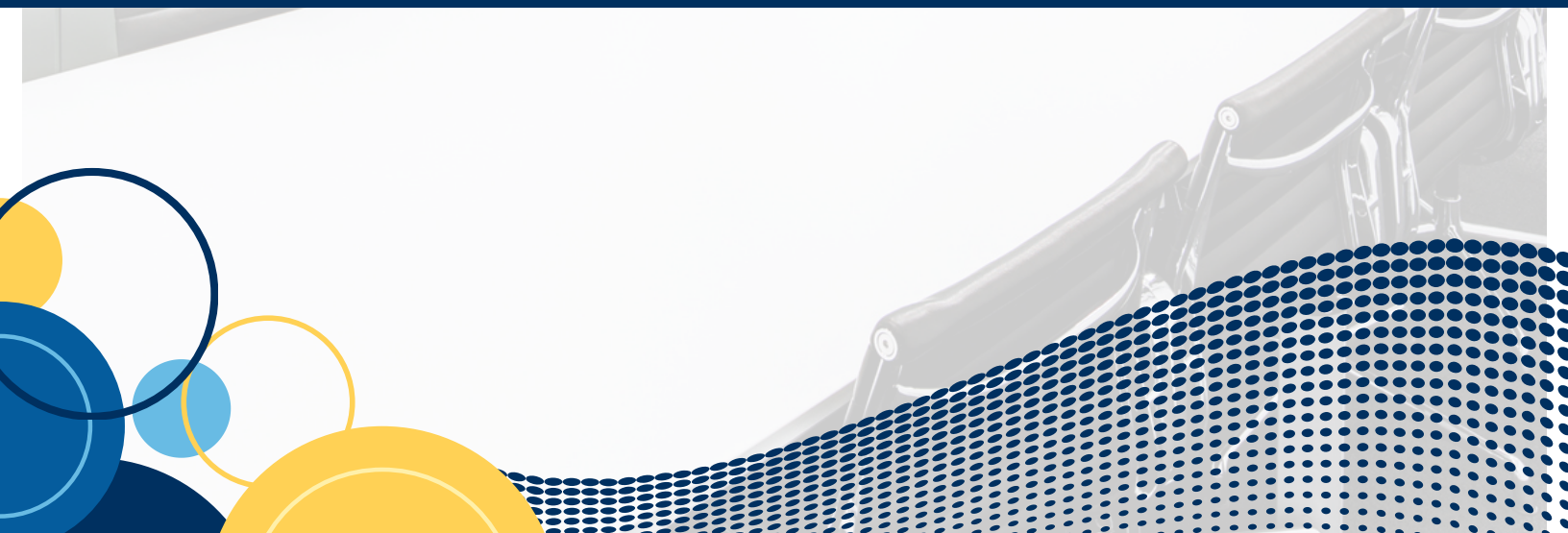




PFCC ANNUAL
REPORT
2024



JOHNS HOPKINS
CHILDREN'S CENTER



Patient- and Family-Centered Care in the Children's Center

In 2007, then Pediatrician-in-Chief, Dr. George Dover, and Johns Hopkins Children's Center (JHCC) Administrator, Ted Chambers, took the time to meet with a group of parents regarding their experiences with the care team in the Children's Center. The parents, along with Dr. Dover, Mr. Chambers, the director of social work, a PICU nurse, and the patient care coordinator would go on to help form what was the first parent advisory council at The Johns Hopkins Hospital. Known as the Pediatric Family Advisory Council (PFAC), they began to use their voices to advocate for greater prioritization and awareness for creating strong partnerships between the care team, patients and families. Thankfully, this like-minded group continued to expand, and in 2009 the Children's Center created the position of Parent-on-Staff. As of 2024, the Children's Center is the only entity in Johns Hopkins Medicine who has committed to having such a position.

Since 2009, the Children's Center has advanced patient- and family-centered care best practices. In 2011, the Teen and Children's Council (TACC) was formed. Recognizing the need to provide resources for these councils, Mr. Chambers established a dedicated, yearly budget. This money goes directly to patients and families in the way of meal vouchers, parking assistance, resources for families who are inpatient for extended periods of time, charging stations for all inpatient units; the list is long and impactful.

In 2014, the then, Parent-on-Staff made the decision to step down from her role, leaving a gap in the culture actively being built. In 2015, Mr. Chambers collaborated with the Children's Center Assistant Director of Nursing to re-establish this role and form a robust team focused on patient- and family-centered care, embedding the parent voice in committees throughout the Children's Center, including Quality and Safety Committees, the Governing Board, Nursing and Resident trainings, and in executive level hiring interviews.

In addition to having a Parent-on-Staff, Children's Center leadership has been a longtime supporter of providing a dedicated, full-time Patient and Family Centered Care Coordinator. Not only has this position created an extra layer of support to patients and families, but to the clinical team as well. To round out the team, a Project Administrator role was added.

Thanks to the partnership we continue to foster with our PFACs and JHCC leadership teams, we can proudly stand by the statement: Nothing happens for the patients and families, without the patients and families.

**Patient- and Family-Centered
Care (PFCC) is at the core of
everything we do.**

Our PFCC Team



Tricia Willis

PFCC Care Coordinator



Sue Mead

Parent-on-Staff



Rebecca Trexler

PFCC Administrator

How We Work



PATIENT ADVOCACY

Real-time coordination of inpatient family complaints; often organizes family meetings and works closely with the patient, family and care team to restore a therapeutic relationship. Patient grievance review, investigation and response. Involved in Crisis Response Program, Mortality Review, Hopkins Event Reporting Online (HERO) Review, Rounding, and Disaster Co-Coordinator.



PFACS

Our Pediatric Family Advisory Council (PFAC), aims to ensure the patient and family voice is at the center of all decisions made in the Children's Center, Harriet Lane and Rubenstein Clinics. The experience of parent advisors provides the opportunity to advise, represent, support, educate, identify best practices and give back to enhance patient- and family-centered care in the Children's Center.



PATIENT AND FAMILY SUPPORT

We are committed to providing support and resources to our patients and families. We are able to do this through the dedicated funds we have in our program budget. In addition, we rely on support from donors which nearly doubles our budget and increases our reach.



PATIENT AND FAMILY EXPERIENCE

We represent the family voice on a variety of hospital committees that improve the patient and family experience, safety, and engagement. There are currently 24 different patient and family advisors (PFAs) on 53 different hospital committees.



EDUCATION

Advisors continue to enrich our faculty, staff, and graduate students by sharing personal health care stories during Grand Rounds, at staff meetings and trainings. Through panel presentations discussing the Core Concepts of Patient- and Family-Centered Care, patients and families share what they truly value and seek from their health care team.

PFCC Message



Mission

The Pediatric Family Advisory Council (PFAC) believes in its mission: Promoting a culture of patient- and family-centered care at JHCC. The Council provides resources and guidance to strengthen collaboration, communication, and mutual respect between the healthcare team, patients and families to achieve the highest quality outcomes and care possible.

Our PFAC is an interdisciplinary and diverse council consisting of over 50 families and staff. Family advisors represent experiences from inpatient, outpatient, ambulatory and specialty clinics. Staff advisors include representation from leadership within the Children's Center, and frontline staff.

As we emerge out of the pandemic, we continue to grow our presence with strong multi-disciplinary relationships and a committed PFAC with over 30 parents and 20 staff. We are supported with a small annual budget to focus on our areas of excellence: patient & family support, advocacy, staff and student education, and patient engagement and experience.

In the future, we would like to increase PFCC staffing to incorporate more programs for our patients and families, form disease or unit specific PFACs and renew and expand our parent mentoring program while continuing to increase opportunities for advisors to be involved in research, staff education, and operations.

Goals

The PFAC goals for the year revolved around access to care, recovery from the Covid-19 pandemic, and incorporating the knowledge and expertise of our parent advisors as a resource for the institution. Some of the highlights are listed here.

1

Resources

- Updated the patient & family section of the JHCC website.
- Standardized the admission folder and the information families receive upon admission.
- 25 parent advisors on 55 different hospital committees including MyChart Proxy for Adolescents, HR Interview Committee, and Psych CUSP.
- Hosted a PFCC Grand Rounds, "Launching PC3: The Evolution of Complex Care at JHCC."
- Provided complimentary weekly chair massage for parents.
- Special holiday meals and gifts.

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Access

- Advocated for and operationalized the first Universal Bathroom at JHH.
- Performed monthly environmental audits of units and improved kitchen signage in Spanish.
- Advocated for and operationalized 3 free guest trays a day for breastfeeding moms.

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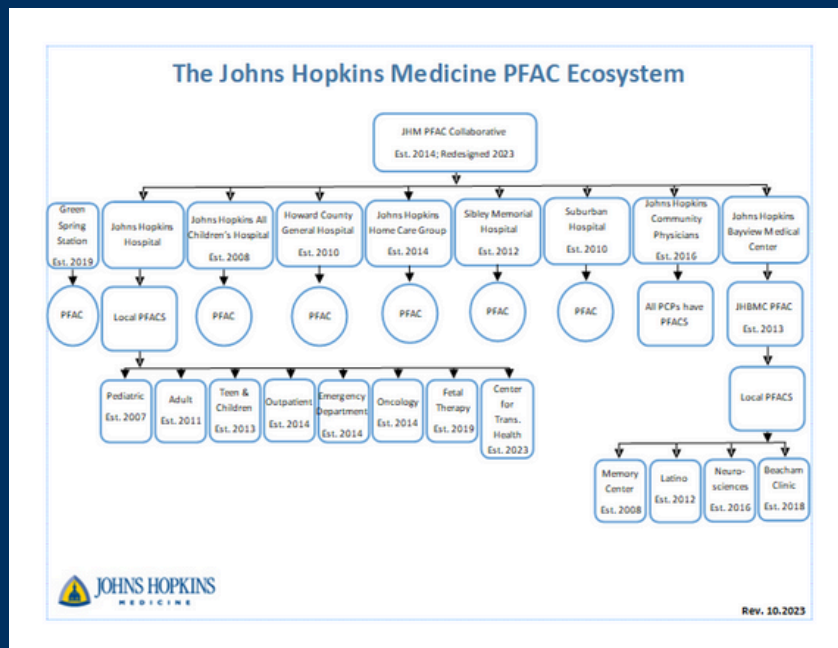
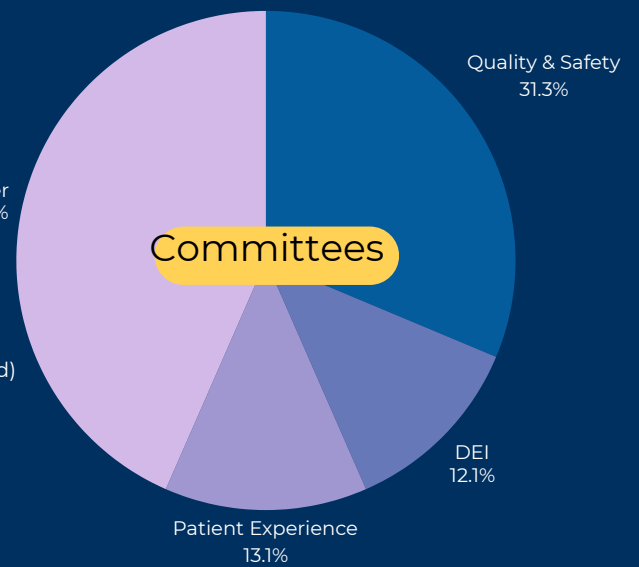
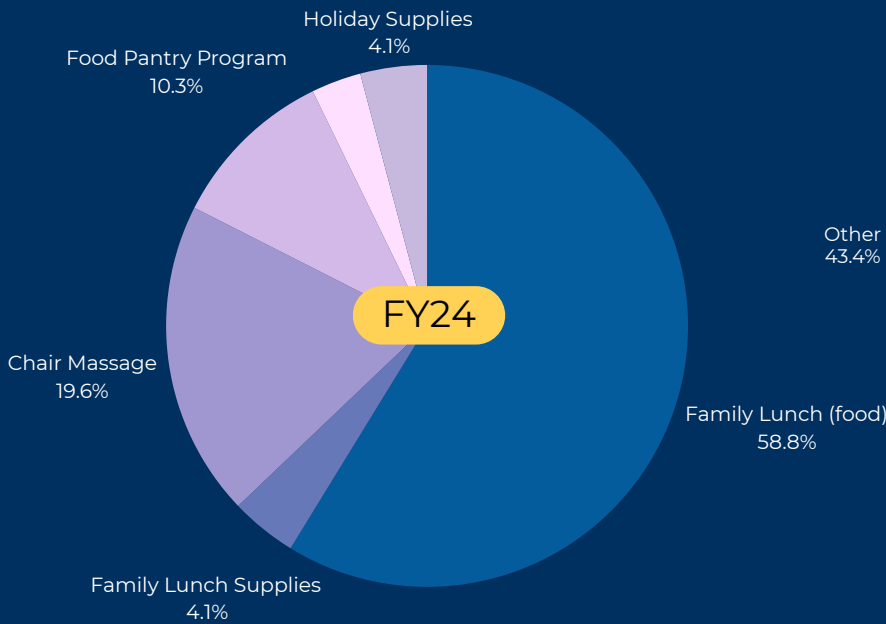
Recovery

- The food pantry program served nearly 3,000 individuals.
- Weekly free family lunch served nearly 4,000 individuals.
- Held Recruitment table in Main Lobby and posted recruitment materials on every unit.
- Consulted on formation of 5 new Pediatric PFACs.



The Review In Year

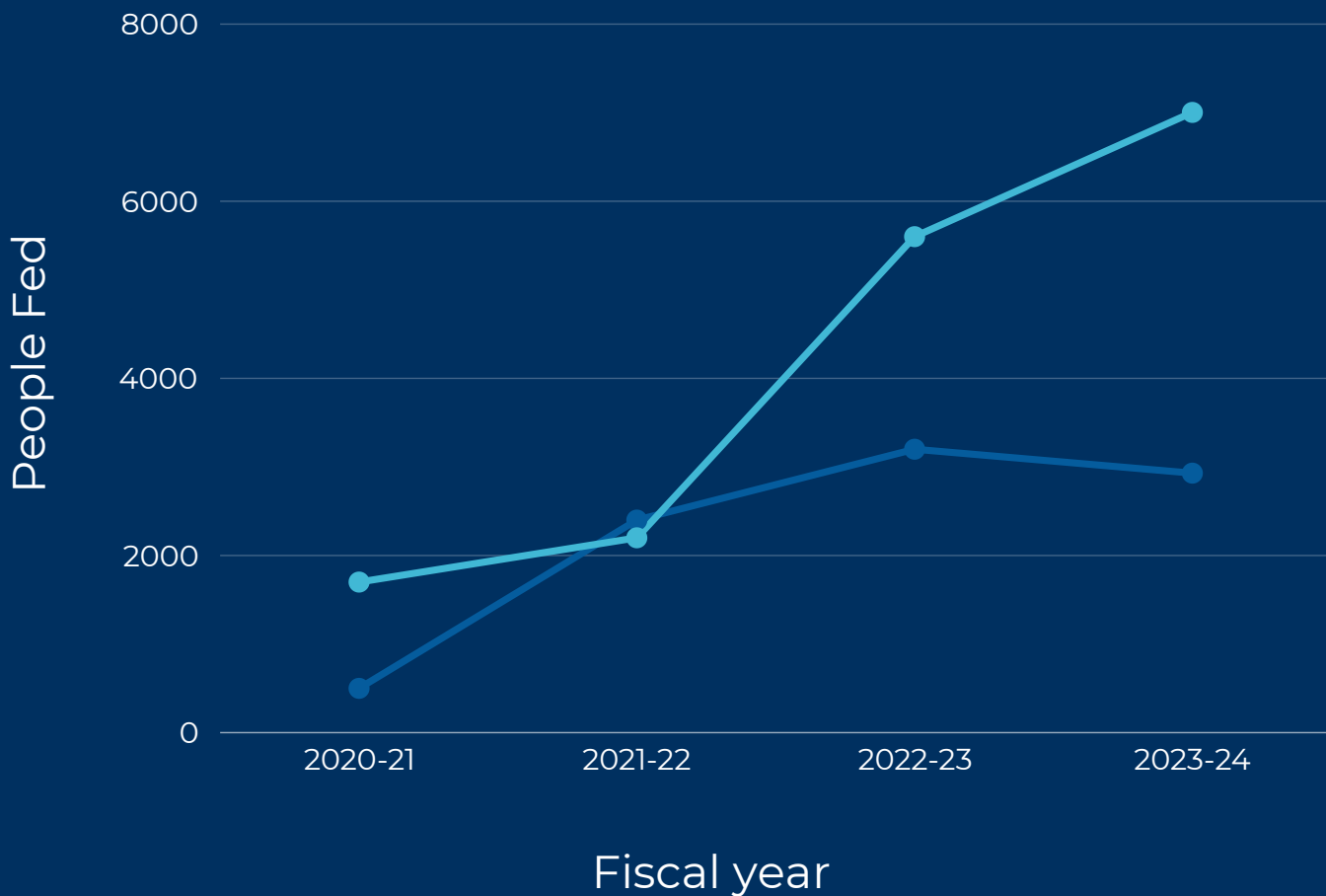
The Johns Hopkins Children's Center had roughly 92,000 visits last year and nearly 9,000 admissions. These are the families we represent, serve, and support.



Case Study: Food Pantry Program

We began our food pantry program during Covid-19 in May of 2020 and it has grown to having shelves in the PICU, Oncology Unit, and Family Library. It is typically stocked weekly with complimentary grab and go meals and snacks for families to enjoy without having to go far from the bedside.

As shown in the graph below, we have reached a plateau in the number of people we can feed with our current staffing and budget, despite the significant increase in food costs.



Highlight

The opening of the first Universal Bathroom at Johns Hopkins Hospital was a proud accomplishment for our PFAC this year. This need was brought to us by a staff PFAC Advisor and family member. The concept was pitched by a PFAC Advisor to a Quality & Safety Committee and then operationalized with family input. Check out the photo from our ribbon cutting below.



As seen below, we are steadily working back towards our pre-Covid-19 benchmark of parent and family advisors (PFAs) on hospital committees. This past year saw a significant bump as we saw the inclusion of 5 more PFAs on 9 more committees. The top bar in darker blue represents the number of parent advisors, the lower bar in lighter blue represents the number of committees.



THANK YOU

For the last 17 years, the Pediatric Family Advisory Council has grown from a small council of 10-15 committed parents and staff to a robust council of nearly 50 members, the majority of which are parents. The list of things we have worked on is long and vast. From creating comfort bags for unexpected admissions to navigating and creating Covid-19 visitation policy to providing food support for families during hospitalization. We are a living testimony that every voice matters!

Families with chronically ill children spend long periods in the hospital away from home and work, while incurring substantial medical bills and other out-of-pocket expenses. Often in these situations, parents can become overwhelmed, exhausted, and emotionally drained. Patient- and family-centered care programming encourages resiliency by providing stress management resources that promote comfort, hope, and healing for pediatric patients and their families. These programs contribute to the overall wellbeing of our patient families dealing with the significant stressors associated with serious illness—offering care that extends beyond medical treatment—and results in patient satisfaction and reduction in escalation events.

Philanthropy plays an essential role in patient- and family-centered care initiatives at the Children's Center, allowing us to continue offering and expanding these critical resources for families to reduce stress and increase resilience.



FOR MORE INFO, EMAIL: FAMILYSUPPORT@JH.EDU

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