



The Johns Hopkins Hospital Patient & Family Advisory Councils 2024 Annual Report











Patient and Family Advisory Council Annual Report



THE JOHNS HOPKINS HOSPITAL

ABOUT PATIENT AND FAMILY ADVISORY COUNCILS

The Patient and Family Advisory Councils (PFACs) are dedicated to the improvement of quality in patient and family centered care at The Johns Hopkins Hospital. The Advisory Councils are comprised of past and present patients, family members, community members/leaders, and Johns Hopkins staff members.

Patients and their families are often the most knowledgeable members of the care team, and can offer unique perspectives and valuable feedback regarding the care they receive. Patient advisors represent the views of a diverse patient population, with members providing insight from a wide variety of perspectives including: gender, age, income, geographic location, personal inpatient and/or outpatient experience, etc.

Johns Hopkins staff advisors provide insight from their varying staff perspectives and medical disciplines. Staff membership includes physicians, nurses, safety and service specialists and managers.

This shared relationship enables the Advisory Council, which meets on a monthly basis, to:

- Identify patient and family needs and concerns
- Provide feedback on current and proposed policies, procedures, and systems
- · Generate new ideas to improve care delivery and processes
- Act as catalysts and advocates to integrate patient-centered care across the institution



Who are we?

The eight Patient and Family Advisory Councils were comprised of **230 members in FY24:**

137 Volunteers and 93 Staff members.



Where do we serve?

PFAC members serve on committees throughout the institution, such as:

- JHH Board of Trustees Patient Safety & Quality Committee
- Children's Center Nursing Quality and Safety Committee
- Comprehensive Unit-based Safety Program (CUSP) Committees
- JHM Medical Ethics Committee and Consultation Service
- Educational Seminars for staff/students
- Surgical Quality Improvement Committees
- Patient Experience Committees
- Pediatric Safety & Infection Control Committee

Adult PFAC	
Council Responsibilities	The Patient & Family Advisory Council advocates on behalf of patients and families of the Johns Hopkins Hospital for the provision of the highest quality of patient- and family-centered care. The Council infuses the perspectives of patients and families into every aspect of the Hospital so that all patients receive optimum patient-centered care.
Council Membership	34 total members: 18 patient and family advisors and 16 staff members. Advisors represent mostly adult inpatient and some outpatient services. Staff members include representation from Department of Medicine leadership, clinical and non-clinical staff. 3 new advisors joined this year.
Council Meetings	Meetings are held monthly on the first Wednesday of the month.

Adult PEAO EV 0004 Assessmelle buserts		
Domain	lult PFAC FY 2024 Accomplishments Activities	
Domain	Activities	
Committee Involvement	Representation on Johns Hopkins Hospital committees/workgroups includes, but is not limited to: Anesthesiology and Critical Care Medicine Committee Blood Clot Prevention Workgroup Neurosciences Department Quality Improvement Committee Neurosciences Zayed 12W Patient Experience Group Parking Analysis Steering Committee Patient- and Family-Centered Design Team Patient Quality and Safety on their Nutrition and Health Equity Project Patient Safety Committee Pneumonia Prevention Group Service Quality Improvement Committee Surgical Quality Improvement Committee Telemedicine Equity Working Group Venous Thromboembolism (VTE) Project Visitor Welcoming System Subcommittee Representation on the following Johns Hopkins Medicine committees/workgroups: JHM PFAC/PFCC Collaborative Participated in the JHH Parking Analysis Steering Focus Group Session in May 2024	

Community Participation/Engagement	 To help spread awareness about PFAC to hospital staff and the community, the PFAC: Held an advisor recruitment/staff education table on the main loop Had a feature in Deb's Digest Created "Ask me about PFAC" buttons Created a message for patient room tv screens and work stations Maintained other marketing materials including business cards, flyers, and pens Participated in staff new hire process by creating interview questions and preferred answers Recruited 3 new advisors Formed an event planning committee as we prepare to hold our first JHH PFAC Symposium, scheduled for October 2023 Engaged with JHM State Relations/Government Relations team to explore avenues in which the PFAC can participate in local and state legislation that impacts healthcare and patients. Onboarded a new Patient Family Advisor Co-Chair 4 PFAs participated in the in the January 2024 Community Partner Session for the JHH Magnet Recognition Program PFA participated in Drug Takeback Day
Complementary Therapies	 Continued to expand the Arts-in-Health program: The Sound Rounds and Music for A While programs have more than doubled in size since 2018, most recently hiring 6 new musicians in 2024. PFAC members participated in their auditions
Healing Environments	 Continued to collaborate on the Visitor Welcoming System (VWS) that has been installed at hospital entrances: 2 PFAs serve on a subcommittee that has helped with communications, equipment designs, site observations, and surveying visitors Provided feedback on the updated Workplace Violence Signage Reviewed communication and provided feedback on the workflow for the Patient Discharge Lounge Pilot Provided input on Environmental Services staff-facing toileting signage Provided feedback on JHPD Draft Policies Advised on hospital entrance closures and badge swipe entrances Advised on what a potential Patient & Family Respite/Restorative space should include

Patient-Centered Communication	 Identified avenues to involve PFAC members in the new hire process, in an effort to ensure we are hiring staff who are person-centered Participated in defining HR Interview Screening questions and answers for the Planetree Recertification 4 PFAs volunteered for the PFAC Interview Subcommittee, to encourage the inclusion of patients and family members in staff interviews 2 PFAs participated in an IPE (Interprofessional Education) Patient Panel and Dinner at the School of Nursing. Provided feedback on the patient informed consent process. The Council's input permitted JHH to fulfill a question on this year's Leapfrog survey (question #2 about the informed consent process). Provided a second round of feedback on the Adult Patient Population Safety Precautions policy prior to it being finalized and uploaded to the web 3 PFAs participated in the effort to update patient appointment addresses, making sure they are correct and checking that the signage/messaging is appropriate Advised on how Language Access Services (LAS) can spread information about their existing services to patients/families Reviewed patient-facing communications to advertise JHH's reopening of valet services
Patient Education	 Collaborated with Quality and Safety on their Nutrition and Health Equity Project to educate patients about aspiration prevention: the Council helped to create the questionnaire that was sent to the larger patient community and develop education materials for dietary needs 1 PFA joined the project team Two PFAs provided a PFAC overview and shared patient/family stories to the JHH Nurses Leadership Forum Advised the Johns Hopkins Venous Thromboembolism (VTE) Collaborative on what medical providers should do to improve the experience of blood clot patients or caretakers

Adult PFAC FY 2025 Goals

- Co-design the permanent patient discharge lounge
- Partner with the Peds/TACC PFAC to improve the transition of care from peds to adult
- Identify ways that our PFAC can support patient/family mental health
- Develop a survey [for presenters to complete] that will evaluate the presenters experience and measure the impact of PFAC
- Continued involvement in the following topics:

- Food and nutrition
- o Visitor Welcoming System
- o Planetree Recertification
- o Role-play opportunities with staff

Pediatric PFAC	
Council Responsibilities	The Pediatric FAC 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.
Council Membership	Over 50 council members: 36 of which are family advisors, representing experiences from inpatient, outpatient, ambulatory and specialty clinics. Staff advisors include representation from leadership within the Children's Center, and frontline staff. Two new members were recruited.
Council Meetings	Meetings are held on the third Wednesday of each month, with the exception of August and December. The March meeting is just for Parent Advisors.

Pediatric PFAC FY 2024 Accomplishments	
Domain	Activities
Committee Involvement	 The following Volunteer Opportunities were fulfilled: JHH HR interview committee MyChart Proxy for Adolescent Committee Website content Review committee Social Determinants of Health in FCR project Global Trach Symposium Nurse Vitals Seminar 25 Parent Advisors on 55 different hospital committees, an increase of 5 new Parent advisors on 9 new committees. Participated in the JHH Parking Analysis Steering Focus Group Session in May 2024
Community Participation/Engagement	 Recruited 2 new PFAC advisors Consulted on forming new PFACs or hosting Patient Cafes in the NICU, Heart Center, Trauma/Burn, Renal, Transplant, and Cystic Fibrosis. Hosted a PFCC Grand Rounds Panel on "Launching PC3The evolution of Complex Care at JHCC." Held an Advisor Recruitment table on the main loop Continued management of Child Life & PFCC Social Media Channels Featured in June 2024 Johns Hopkins Medicine Dome Publication article

Complementary Therapies	 Continued the Family Support Program by hosting weekly buffet style family lunches in the Patient and Family Library, feeding nearly 3,000 caregivers. Provided weekly chair massages for caregivers in the Family Library. Partnered with Child Life to provide special Mother's and Father's Day treat bags for all inpatient units.
Food and Nutrition	 Promoted resilience and reduced stress by: Continued Family Meal Program by hosting a free family buffet lunch in the library every Thursday. Food Pantry in PICU, Oncology, and Family Library serving over 2,600 families this year. ED Comfort Cart for boarders and Bereavement Cart for PICU end of life families established. Take home food bags for food insecure families available for social work distribution. Operationalized 3 free guest trays a day for Mom's who breastfeed on all units except NICU where roll out in the next fiscal year is expected. Thanksgiving and Christmas Holiday Meals were once again hosted buffet style in our Family Library
Healing Environments	 Continued support of an Artist in Residence, 8 hours per week, to round on families in their rooms, bringing a creative outlet to them at the bedside. Performed monthly environmental audits of the family kitchens and improved refrigerator signage for families in both English and Spanish Identified and helped to operationalize the first universal changing table at JHH on Bloomberg 3rd floor near the Library, so those who have an older child with special toileting needs have a space to do so with dignity. Participated in Radiothon Innovation Grant selection
Patient-Centered Communication	 Standardized the admission folder contents that every parent is to receive upon admission. Responsible for maintaining and updating these documents. Identified barriers to handbook distribution and are exploring a better way to distribute the patient and family handbook. Worked with marketing to update the patient and family sections of the Children's Center website.

Patient Education	 22 Parent advisors in 19 staff trainings across JHH. Such educational venues include: Pediatric Intern Orientation CCSC/CCSR/UA new employee training FCR simulation training for med students FCR audits of residents PFCC Grand Round Panel SON IPE dinner and PFCC patient panel Nurse Vitals
Research	SDOH in FCR research project

Pediatric PFAC FY 2025 Goals

- Improving transitions in care
- Partnering with Access Services to improve the appointment scheduling experience
- Better supporting our behavioral health patients in the ED and Psychiatric units

Teen & Children's Council	
Council Responsibilities	The Teen and Children's Council provides a way for adolescents who receive care at Johns Hopkins Children's Center to provide insight and feedback on their hospital experiences. This provides an opportunity for the healthcare team to listen to their perspectives and incorporate this into the care that the Johns Hopkins Children's Center provides. The Teen and Children's Council also strives to give back to patients of the Children's Center through fundraising and hosting special events.
Council Membership	21 members: 15 teen volunteers between the ages of 12 and 21; 6 staff members. 5 new advisors joined this year.
Council Meetings	Meetings are held monthly on the second Tuesday of every month.

Teen & Children's Council FY 2024 Accomplishments	
Domain	Activities
Committee Involvement	Our teens continue to participate yearly in the white coat ceremony for the med students and share their story
Community Participation/Engagement Complementary Therapies	 Recruited 5 new advisors Council planned and hosted a Prom dance for current and previous Hopkins Children's Center patients as a way to celebrate their journey and provide an opportunity for those unable to attend a dance/school activities to do so; 60+people attended The teens will participate in the summer carnival for patients and families

Healing Environments	Gave input on Teen Programming
Patient-Centered Communication	 Provided feedback on: MyChart initiatives Sensitive Exams Project Protect Parent Presence on induction PFA participated in an IPE (Interprofessional Education) Patient Panel and Dinner at the School of Nursing.
Patient Education	 We continue to share our stories when appropriate Participated in Med Student Education Provided feedback on increasing technology in education for fellowship program Gave feedback on MyChart initiatives

Teen & Children's Council FY 2025 Goals

- Help with July 2024 Carnival being held by the Child Life Department
- Continue to host annual Homecoming/Prom events for adolescent patients of the Children's Center
- Continue to provide feedback to those looking for pediatric patient input

	Sidney Kimmel Cancer Center PFAC	
Council Responsibilities	The Sidney Kimmel Comprehensive Cancer Center's PFAC works to promote collaboration, communication and mutual respect among the healthcare team, patients and caregivers to support a culture of patient and family centered care. To promote safety, quality and best patient experience outcomes, the patient voice helps shape essential decisions regarding the patient experience from diagnosis through survivorship. With our SKCCC partners, we generate goals and prioritize initiatives for patient centered services and are patient advocates in the development of new oncology programs, services and policies.	
Council Membership	53 total members: 30 patients and caregivers and 23 staff. Advisors represent a variety of cancer types, and inpatient and outpatient cancer services. 5 new advisors joined this year.	
Council Meetings	Meetings are held monthly on the first Thursday of the month eleven months of the year.	

Sidney Kimmel Cancer Center Council FY 2024 Accomplishments	
Domain	Activities
Committee Involvement	 Representation on Johns Hopkins Hospital committees/workgroups includes, but is not limited to: Advanced Directive Workgroup AOA Selection Committee ASCO Bone Metastases Guideline Task Force

JH Center for Health Equity-Community Advisory Board o JHH Medical Ethics Committee and Consultation Service o JHH Surgical Quality Improvement Committee o JHH University Center to Reduce Cancer Disparities-Community Advisory Board o JHH Visitor Welcoming System (JHHS) Subgroup JHM PFAC Collaborative Oncology Home Care Operations Committee Patient and Family Services Hospice Review subcommittee Radiation Oncology CUSP (comprehensive unitbased safety program) Revenue Cycle Billing Committee School of Nursing Patient Educator Presentations for Nurse Residency Program SKCCC Cancer Committee SKCCC Falls Committee SKCCC Quality & Safety Improvement Committee Participated in the JHH Parking Analysis Steering Focus Group Session in May 2024 PFA involved in the American Society of Radiation Oncology Bony Metastases Treatment Guidelines Continued to broadcast the monthly PFAC agenda and meeting reminder on the weekly staff SKCCC event calendar to promote staff PFAC awareness Continued "Be Our Guest" for monthly PFAC meetings, inviting a new nurse who is unfamiliar with PFAC to our meeting as a way to increase awareness of who we are and what we do Participated at an advisor recruitment/staff education table Community on the main loop Participation/Engagement Recruited 5 new advisors Planned an SKCCC PFAC appreciation dinner, getting together for the first time since pre-COVID. 2 PFAs joined the AOA Selection Committee, a pilot project for selecting residents/fellows to AOA (Alpha Omega Alpha, the national honor society for physicians. PFAs reviewed applications and provided input on nominees. Created a SKCCC PFAC recruitment poster

Complementary Therapies	 Peer-to-peer (P2P) mentoring: Several members met with SKCCC leadership to begin conversations around the need for a program/resources Involved in conversations with new SKCCC/CHN partnership Provided suggestions on how to identify mentors and market the program Supported the JHCC Family Support Program by serving buffet style family lunches in the Patient and Family Library Celebrated the SKCCC PFAC's 10th anniversary
Healing Environments	 The Oncology Council has been instrumental with improving food and nutrition for patients. Efforts include: Co-designed patient and staff communications with SKCCC Administrative staff Continued to play a key role in the addition of food vending in Oncology spaces and reopening the Skyline Café for seating Continued to provide feedback on the Visitor Welcoming System that has been installed at hospital entrances 2 PFAC members continued to participate on a subcommittee that has helped with communications, equipment designs, site observations, and surveying visitors 4 PFAs participated in A Day in the Life of the Viragh to show how Viragh spaces move oncology care forward. PFAs volunteered as acting patients and were photographed Advocated for the importance of wheelchair availability in the Cancer Center Provided suggestions on the return of valet parking to JHH and reviewed patient-facing communications
Patient-Centered Communication	 2 PFAs participated in an IPE (Interprofessional Education) Patient Panel and Dinner at the School of Nursing. Collaborated with SKCCC Center Quality and Safety on a number of patient-centered projects including identifying methods to increase the number advanced directives on patient's files, encouraging fertility counseling, and reducing the number of central line associated bloodstream infections

	 Partnered with SKCCC Leadership to revise the Oncology Patient Phone Tree, creating a general line for medical oncology patients and ensuring the phone tree options are appropriate and easy to use. Identified avenues to involve PFAC members in the new hire process, in an effort to ensure we are hiring staff who are person-centered Established a list of interview questions that was shared with JHH Talent Acquisition to use as part of their screening tool to hire staff 3 PFAs volunteered for the PFAC Interview Subcommittee, to encourage the inclusion of patients and family members in staff interviews 2 PFAs participated in the JHHS "Virtual Nurse Design Summit" in September 2023. Reviewed and provided improvement suggestions for the new SKCCC patient resource/packet
Patient Education	 3 advisors in staff education trainings across JHH. Trainings include: First year medical students The Nursing Residency program students CCSC/CCSR/UA new employee training Reviewed 3D video animations and participated in a survey to ensure that it is appropriate for ovarian cancer patients Provided input on pre-operative patient education for breast surgery to help ensure that patients, regardless of which location they go to, will receive the same standardized information and a visit with an Oncology nurse navigator
Research	 PFAC wrote a letter of support encouraging research around patient education limiting central line infections at home PFAs cowrote fellow ASCO grants

Sidney Kimmel Cancer Center Council FY 2025 Goals

- Support the new SKCCC/Cancer Hope Network partnership for peer-to-peer support
 - o Help to identify patient mentors
 - Continue to promote the benefit of peer-to-peer mentoring for patients and clinicians
- Continue to advocate for and identify clearer dissemination of patient resource information
 - Support the creation of a digital, user-friendly patient resource guide for all SKCCC patients
- Continue to work with SKCCC QI on Oncology patient safety initiatives
- Continue to be a patient resource for SKCCC research and education projects

- Help promote patient-centric patient education by expanding our tools to meet the patients' preferred learning styles
- Continue to support professional education, nurses, oncology fellows and clinical oncology research
- Develop a deeper understanding of how PFAC advisors can most effectively be the best SKCCC ambassadors/allies possible to promote early and consistent involvement with SKCCC projects that support patient-centered survivorship care
 - Stay in-the-loop on medical topics, literature reviews and studies, patient-centered initiatives
 - Encourage membership with diverse skills and interests to take our work to the next level

Ambulatory PFAC	
Council Responsibilities	The primary focus of the Ambulatory PFAC is centered on the four components of an outpatient visit (pre-visit/scheduling, arrival/check-in, visit/treatment/check-out, post visit follow). The council's goal is to create an ideal patient experience at the Johns Hopkins Outpatient Center.
Council Membership	16 total members: 6 patient and family advisors and 10 Johns Hopkins staff members.
Council Meetings	Meetings are held monthly on the third Thursday of the month.

Ambu	latory PFAC FY 2024 Accomplishments
Domain	Activities
Committee Involvement	 Representation on Johns Hopkins Hospital committees/workgroups includes, but is not limited to: Ambulatory Patient Experience Committee Ambulatory PFAC Executive Committee Care Coordination Workgroup/Ambulatory Resource Center Planning Committee ED Messaging Review Group JHH Adult PFAC JHH ED PFAC JHH PFAC Collaborative JHH PFAC Interview Subgroup Visitor Welcoming System Subgroup
Community Participation/Engagement	Participated in Johns Hopkins Drug Take Back DayRecruited 1 new member
Healing Environments	 Advised Ambulatory Quality and Patient Safety on reducing or eliminating falls in JHOC Advised on chaperone workflow: MyChart or/and PSC or/and CMA or/and Provider Outcome: CMA and Provider

- Discussion on lengthy patient check out process and need for schedulers to have broad access to other specialists.
 Specialty care at JH is compartmentalized
 - Outcome: need for more Generalists
- Advised on communicable disease screening at Kiosks in JHOC – Masks recommended but not required
- Advised on provider masking during patient encounter
- Advised on medication reconciliation and recommended that the patient review medication list while waiting to be seen. This may help to eliminate errors in the patient's medication list
- Provided advice regarding better communication from CMAs to patients
- Discussed patient reactions to a disgruntled patient in a waiting area and what the expectation is from the practice area leadership.
- Advised Office of Johns Hopkins Physicians on billing for MyChart patient advice
- Advised Office of Johns Hopkins Physicians on setting parameters for misbehavior and misuse of MyChart messages
- Advised on cashless food venues and how it causes disparities for those without a credit card
- Advised on lack of food
- Participated in discussion surrounding Star Card (physician rating) transparency for the healthcare consumer
- Arrival time versus appointment time discussed with Clinical Practice Assoc. We advised regarding e-check in and arriving 15-20 minutes prior to the scheduled appointment time

Advise on Workplace Violence insight offering insight to providers and front-line staff.

- PFA participates on the Ambulatory Resource Center (ARC) planning committee, an initiative to develop a center that explores the need for care coordination services in the ambulatory care setting
- Identified avenues to involve PFAC members in the new hire process, in an effort to ensure we are hiring staff who are person-centered
 - Participated in defining HR Interview Screening questions and answers for the Planetree Recertification
 - 1 PFA volunteered for the PFAC Interview Subcommittee, to encourage the inclusion of patients and family members in staff interviews

Patient-Centered Communication

Levi Watkins Outpatient Pharmacy will revert back to pre-Covid hour of 8a-6p. We advised on how best to communicate this Valet Parking will return to Levi Watkins Outpatient Center. Reservations and payment will be completed by electronic communication. We advised that this represents a social caste system for those who can afford it while others without resources park on the street Advised on Drug Take Back Day communication efforts and participation Advised on the overwhelming number of Weapons Detection System security staff in the Levi Watkins Outpatient Center

Ambulatory PFAC FY 2025 Goals

- Recruit 2 new members with a focus on under-represented patient advisor
 - o Ambulatory PFAC Fair in the Levi Watkins Outpatient Center
 - Provider nominations
- Story Sharing
 - o What led us to the Ambulatory PFAC?
 - Is the work that we do evident during our interactions with clinical staff and providers?
- Volunteer as a Group within Johns Hopkins
 - o Ambulatory PFAC Fair in the Levi Watkins Outpatient Center
- Participate in the Planetree site visit
- Continued involvement in the lack of food other than vending in the Levi Watkins
 Outpatient Center

Emergency PFAC	
Council Responsibilities	The Johns Hopkins Emergency Department Patient, Family, [and Community] Advisory Council – in partnership with departmental leadership, clinicians, faculty, and staff – provides the voice of the patient/family member when making operational and day-to-day decisions. The PFAC aims to provide the highest quality of patient- and family-centered care to the visitors of our Emergency Department.
Council Membership	21 total members: 9 patient, family, or community members and 12 staff members. 1 new member joined this year.
Council Meetings	Meetings are held monthly on the second Wednesday of the month.

Emer	gency PFAC FY 2024 Accomplishments
Domain	Activities
Committee Involvement	 Representation on Johns Hopkins Hospital committees/workgroups includes, but is not limited to: Adult ED Patient Experience Committee ED Messaging Design Group EPIC Patient & Family Design Team JHH Adult PFAC JHH Ambulatory PFAC JHH PFAC Collaborative Visitor Welcoming System Subgroup Representation on the following Johns Hopkins Medicine committees/workgroups: JHM PFAC/PFCC Collaborative Participated in the JHH Parking Analysis Steering Focus Group Session in May 2024
Community Participation/Engagement	 Onboarded 1 new PFAC member Held 2 in-person dinner meetings to encourage teambuilding and a sense of community Held an advisor recruitment/staff education table on the main loop Participated in staff new hire process by creating interview questions and preferred answers This year, the PFAC made sure to invite all new patient experience staff members to the meetings to introduce PFAC, learn more about the person and their role, and establish a partnership
Complementary Therapies	 PFA participated in the Arts in Health interview process to onboard professional musicians to the JHH and Peabody program, Sound Rounds.
Healing Environments	 Participated in the implementation of Swank Entertainment in the adult emergency waiting room by participating in demos and providing marketing suggestions. Provided feedback on the Visitor Welcoming System PFA completed Patient Comfort Cart waiting room rounding with ED Sr. Patient Experience Coach, supporting patient and family wellbeing by creating positive distractions Received a tour of the new renovated ED space Provided feedback on the ED Kindness/Courtesy Campaign; created methods to launch the campaign Advised on what a potential Patient & Family Respite/Restorative space should include

Patient-Centered Communication	 Instrumental in the development of ED texting updates for patients PFAC member continues to participate on the ED Messaging Design Group Subcommittee Provided feedback on ED Self-Registration Provided communication tips for how best to inform patients about ED Surge I & II Plans, when people may need to be relocated to another waiting area Collaborated with the ED Associate Clinical Director to identify the best patient engagement strategies to increase patient activation in coronary artery disease Provided the patient/family perspective on health literacy needs during ED discharge
Patient Education	 Advised on Adult ED trauma prevention efforts and how to effectively get the word out that these resources exist
Research	 Provided feedback on the best ways to engage the community and ED patients in research studies: A Self-Study of Racism and a Path towards Reparative Justice in the Johns Hopkins Hospital Emergency Department. BOOST-3 Trial (Brain Oxygen Optimization in Severe Traumatic Brain Injury community consultation)

Emergency PFAC FY 2025 Goals

- Participate in at least 2 role-playing opportunities with staff (e.g. Guest Services & Clinical Customer Service Coordinators)
- Partner with Certified Nursing Associates (CNAs) to walk through scenarios about wait times and appropriate communication
- Create/participate in at least 2 marketing/recruitment activities for PFAC

The Center for Fetal Therapy Medicine Parent Council	
Council Responsibilities	The Center for Fetal Therapy Medicine Parent's Council was started in January of 2020 in an effort to improve care and broaden the outreach of the Center for Fetal Therapy. After a brief hiatus beginning during the pandemic of 2020, the Council has begun work to reconstruct the structure of the council and re-focus its mission to connect patient families with one another in an effort to grow the community and provide support.
Council Membership	20 total members: 12 patient and family members and 8 staff members including development and administrative staff.

Council Meetings	Meetings are held on a monthly basis based on membership
	availability.

The Center for Fetal The	erapy Medicine Parent Council FY 2024 Accomplishments
Domain	Activities
Committee Involvement	Created subcommittees for parents to participate in
Community Participation/Engagement	 Recruited additional advisors Assisted in the planning and implementation of the Center for Fetal Therapy's Annual Picnic in an effort to encourage connections between patient families and center staff Featured in June 2024 Johns Hopkins Medicine Dome Publication article; 2 members were interviewed
Complementary Therapies	The Council launched a peer-to-peer program, intended to match patient families with former patients for the purpose of creating a community of support
Patient-Centered Communication	 Established newsletters and other communications as a way to engage families and increase the visibility of updates from the center The Communications Chair has re-focused efforts to utilize our existing social media channels to share news and updates about the center, events, research, patient stories, and staff bios with current, former, and potential patients of the center

The Center for Fetal Therapy Medicine Parent Council FY 2025 Goals

- Continue building the peer-to-peer program to make support for patient families more readily available
- Recruit additional members to support subcommittee initiatives
- Continue to plan the Center for Fetal Therapy's Annual Picnic

The Center for	Transgender & Gender Expansive Health PFAC
Council Responsibilities	The Center for Transgender & Gender Expansive Health PFAC was established in 2023 in an effort to improve the patient experience and broaden outreach for the center. The council provides insight into the patient experience, applies feedback to continuous improvement efforts, creates project work groups, and discusses healthcare needs within the transgender and gender expansive community, allowing the council so we can reference the needs as we further develop the service line/program.
Council Membership	15 total members: 11 patient and family advisors, 2 faculty members, 2 staff members including the senior program manager and a clinical licensed social worker.

Council Meetings	Meetings are scheduled on a bi-monthly basis and based on
_	council members availability. These meetings are typically
	hybrid with some members meeting in-person while others
	attend virtually via Zoom.

The Center for Transgender & Gender Expansive Health Council FY 2024 Accomplishments		
Domain	Activities	
Committee Involvement	 Council co-chair participated on a panel for the Health Mentors Dinner with School of Nursing on April 10, 2024. Council participates in the PFAC collaborative and receives all requests for committee involvement via email/at meetings. Participation in a parking study focus group. 	
Community Participation/Engagement	 Council advisor provides legislative updates related to the transgender & gender expansive community at each meeting. Faculty members provided verbal and written testimony that helped pass the Trans Health Equity Act which went into effect 1/1/24. This deemed gender affirming care medically necessary. This opened access to gender affirming care for Medicaid payors. Faculty members provided written testimony for HB 722 Health – Minors – Gender and Sex Transition Procedures which had no further actions after initial hearings. Baltimore Trans Pride 2024 Council advisor worked with The Pride Center of Maryland to set up a resource for the transgender & gender expansive community. This resource includes a supply closet with non-perishable surgical supplies for patients as well as a clothing closet. Council co-chair provided an interview for Dome magazine about the launch of the JHCTH PFAC. 	
Complementary Therapies	 In collaboration with Johns Hopkins The Access Partnership (TAP), the council is working towards improved access for undocumented and uninsurable patients. JH does not currently offer hormone therapy implants. Council is exploring insurance coverage for implants and opportunities to offer this treatment at JH. Council has established a work group to develop a peer-to- peer support group. Council is almost finished with the onboarding development and will shift focus to the structure of the support group meetings. 	
Healing Environments	Gave input on what key components are necessary for accessible mental health services at JH.	

	 Fertility preservation is important when a treatment plan could potentially result in infertility. JHCTH has explored services JH offers to ensure that trans patients have the same opportunity to build families as any other patient undergoing treatment. Council gave input on the best way for providers and clinicians to approach fertility preservation services to minimize triggers when family planning is discussed.
Patient-Centered Communication	 Provided feedback on: Intake process for returning patients Pelvic Floor PT scheduling process Dermatology access Community Psychiatry Program at Johns Hopkins Bayview Medical Center's DBT Skills Training Group Community perception of Transhealthcare.org JHCP scheduling team unaware of gender affirming providers and appointments Insurance authorization process for surgery Online look books
Patient Education	 Creating a list of social transitioning resources for JHCTH website Internal and external resources for physical medicine support – JH nutrition services, Nourish Family Nutrition, Capital Diabetes Clinic, Out Care Health, and online videos

The Center for Transgender & Gender Expansive Health FY 2025 Goals

- Launch the JHCTH Peer Support Group
- Launch online look books
- Review and update patient education materials
- Initiate provider education work group
- Recruit additional council advisors with a focus on underrepresented advisors
- Continue to identify legislative efforts related to transgender and gender expansive health