Patient and Family Advisory Councils continued to meet throughout the COVID-19 pandemic, accomplishing goals via monthly meetings on Zoom.

PFAC members shared their insights into what it means to be a PFAC volunteer to create a video recording that will be used to recruit new PFAC members.
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

The seven Patient and Family Advisory Councils were comprised of 239 members in FY21:
141 Volunteers and 98 Staff members.

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
- School of Nursing Nurse Residency Program Education
- Medical Ethics Committee and Consultation Service
- JHM Clinical Community
- Diversity Councils
- Surgical Quality Improvement Committees
- Patient Experience Committees
- Pediatric Safety & Infection Control Committee
In fiscal year 2021, The Johns Hopkins Hospital Patient and Family Advisory Councils worked to recruit new members. In FY21, we completed only general recruitment efforts as COVID-19 efforts limited the bandwidth and focus on PFAC recruitment. Targeted recruitment for patient populations underrepresented on PFAC was not completed, as plans for this type of recruitment involved in-person efforts such as Patient Café events and outreach to the local East Baltimore Community.

Once bandwidth increased in late Spring/early Summer 2021, we launched general recruitment efforts that we worked on all year and had success with new applications.

The result of the efforts across all of our PFACs are documented in the chart below. In total, we welcomed 20 new members! Next steps will be to continue PFAC member recruitment with focus on underrepresented minority patient populations. PFACs will utilize patient data to create targeted marketing efforts.

<table>
<thead>
<tr>
<th>Council</th>
<th>Recruitment Goal</th>
<th>Actual Members Recruited</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult Inpatient PFAC</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td>JHCC Pediatric FAC</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Teen and Children’s Council</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>Sidney Kimmel Comprehensive Cancer Center PFAC</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Ambulatory Council</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Emergency Department Council</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Fetal Therapy Council</td>
<td>Formed after goals were submitted</td>
<td>0</td>
</tr>
</tbody>
</table>
Patient and Family Advisory Councils

FY 2021 Report
## 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

Membership consists of 41 total members: 18 patient and family advisors, 21 staff members, and 2 emeritus members. Recruitment efforts continue to increase membership and diversity.

### Council Meetings

Council meets monthly on the first Wednesday of the month.

### Adult PFAC FY 2021 Accomplishments

<table>
<thead>
<tr>
<th>Domain</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Committee Involvement</td>
<td>• Representation on the following Johns Hopkins Hospital committees/workgroups:</td>
</tr>
<tr>
<td></td>
<td>o Anesthesia &amp; Critical Care Medicine Quality Improvement Committee</td>
</tr>
<tr>
<td></td>
<td>o Antimicrobial Stewardship Committee</td>
</tr>
<tr>
<td></td>
<td>o Board of Trustees Patient and Safety and Quality Improvement Committee</td>
</tr>
<tr>
<td></td>
<td>o ED Palliative Care Research Subcommittee</td>
</tr>
<tr>
<td></td>
<td>o Empowering the Participant Voice: Stakeholder Committee</td>
</tr>
<tr>
<td></td>
<td>o Episode Care Improvement Program (ECIP) Care Redesign Program Committee</td>
</tr>
<tr>
<td></td>
<td>o Medical Ethics Committee and Consultation Service</td>
</tr>
<tr>
<td></td>
<td>o Neurosciences Department Quality Improvement Committee</td>
</tr>
<tr>
<td></td>
<td>o Patient- and Family-Centered Design Team</td>
</tr>
<tr>
<td></td>
<td>o Patient Education Review Team</td>
</tr>
<tr>
<td></td>
<td>o Patient-Centered ED Palliative Care Research Project Subcommittee</td>
</tr>
<tr>
<td></td>
<td>o Patient Safety Committee</td>
</tr>
<tr>
<td></td>
<td>o Physician Advisory Board</td>
</tr>
<tr>
<td></td>
<td>o Service Quality Improvement Committee</td>
</tr>
<tr>
<td></td>
<td>o Surgical Quality Improvement Committee</td>
</tr>
<tr>
<td></td>
<td>o Telemedicine Equity Working Group</td>
</tr>
<tr>
<td></td>
<td>o Workplace Violence Committee</td>
</tr>
<tr>
<td></td>
<td>• Representation on the following Johns Hopkins Medicine committees/workgroups:</td>
</tr>
<tr>
<td></td>
<td>o PFAC Clinical Community</td>
</tr>
<tr>
<td></td>
<td>o Johns Hopkins Home Health Group PFAC</td>
</tr>
<tr>
<td></td>
<td>o JHHS Opioid Stewardship Clinical Community</td>
</tr>
<tr>
<td></td>
<td>o Medication Management Clinical Community</td>
</tr>
<tr>
<td></td>
<td>o Patient and Family Education Advisory Council</td>
</tr>
</tbody>
</table>
### Community Participation/Engagement

- Participated in the Annual Proactive Risk Assessment by submitting several proposals for consideration by the Proactive Risk Assessment Team.
- Continued the Adult PFAC Recruitment Committee to help identify new volunteer members and spread awareness about PFAC to hospital staff and the community. This group executed the following ideas:
  - A “hold music” recorded message about joining a PFAC for patients calling for prescriptions at JHOC, Monument, Weinberg, Arcade, and Bartlett Pharmacies
  - MyChart Banner about joining a PFAC on MyChart homepage in May 2021
  - PFAC ad included in a Marketing email to all JHM patients on May 21st, yielding interest from 29 new patients across the health system
  - PFAC recruitment video highlighting PFAC member stories to utilize on websites and in direct targeted social media recruitment posts
- Recruited two new members onto the Council
- Onboarded two new PFAC members onto our Executive Committee
- Conducted a workgroup session with the JHU/JHM VP for Public Safety search team; gave feedback on ideal skills, attributes, etc. for the chosen new hire.

### Complementary Therapies

- Continued to expand the Sound Rounds program:
  - Created a Zoom webinar to allow staff and patients to listen to Peabody musicians 5 days a week. This provided a way to stay connected to Arts in Health programs during the pandemic
  - PFAC member participated in a Peabody Musician training session
- Directed by the Art Cart Volunteer program, the PFAC helped to create a coloring and journaling book for inpatients by providing input on designs and themes.
<table>
<thead>
<tr>
<th>COVID-19 Related Participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Contributed to the change of the JHM visitation policy to allow care partners for inpatient and ED patients in October 2020. This contribution was recognized in an email from Paul Rothman and Kevin Sowers.</td>
</tr>
<tr>
<td>• Provided revisions for the hospital visitation exceptions in yellow and green levels.</td>
</tr>
<tr>
<td>• PFAC members volunteered to join a JHM Marketing Web Content Advisory group to review COVID-19 related content and material for JHM websites for compassionate language and understandability.</td>
</tr>
<tr>
<td>• Continued the PFAC COVID-19 Newsletter that shares important and updated information with all JHM PFAC members. It includes websites and resources, open committees and current projects, webinars and articles from national PFCC organizations, etc.</td>
</tr>
<tr>
<td>• Provided feedback to HEIC when asked 1.) how visitation can be thoughtfully broadened and 2.) how patients can virtually connect to their families.</td>
</tr>
<tr>
<td>• In collaboration with Baltimore Renters United and the JH School of Public Health, the PFAC signed a letter of support to advocate against COVID-related evictions. This letter was sent to General Assembly Leadership.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Healing Environments</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Participated in a survey that will help to enhance the JHH &amp; Peabody collaboration music programs by identifying preferred times and platforms to receive musical performances, genres of music that musicians should build into their sessions, etc.</td>
</tr>
<tr>
<td>• Suggested opportunities – outside of music – to infuse art into the patient and family experience.</td>
</tr>
<tr>
<td>• Provided feedback on the Wayfinding App that helps to navigate JHH and Bayview campuses.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient-Centered Communication</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Provided input on the selection of a new Patient Experience survey vendor for Johns Hopkins Medicine.</td>
</tr>
<tr>
<td>• Provided feedback on the Perioperative Prep/PACU flyer for “Family Presence &amp; Visitation During Your Procedural and Surgical Experience” and respective Visitation Guidelines.</td>
</tr>
<tr>
<td>• In collaboration with the Home Health Care Group, the PFAC designed the scripting that will be used in the Transition Guide patient care program.</td>
</tr>
<tr>
<td>• A PFAC experience brought attention to an issue with MyChart proxy access which the JHH Legal and EPIC Teams are now looking into.</td>
</tr>
</tbody>
</table>
| Patient Education          | PFAC feedback led the EPIC team to file a formal enhancement request to allow patients more control over their medical record release.  
|                           | Provided edits and feedback on a patient-facing email about changes to our telemedicine services.  
|                           | Provided feedback on changes to medication instructions on the patient After Visit Summary.  
| Research                  | Collaborated with the Office of Telemedicine to work through the future of telemedicine from a patient perspective.  
|                           | Continued to provide PFCC education training sessions to:  
|                           |   First year medical students  
|                           |   The Nursing Residency program students  
|                           | PFAC member is a research participant in the “ED Safety Net Model for Palliative Care” project which aims to redesign the service and improve JH ED-based palliative care.  
|                           | Provided input on The Organ Donation Project, which could allow for more available organ donations taken from those who pass away in the ED.  
|                           | PFAC member participated in the Artificial Intelligence Grant - National Advisory Board.  
|                           | PFAC member participated in the ATS Workshop on Sleep and Circadian Disruption in the ICU (May 2021).  
|                           | PFAC member participating in the PCORI Preoperative Palliative Care Trial Surrounding Cancer Surgery for Patients and their Family Members.  
|                           | Signed a PFAC letter of support for a PCORI application that equips patient partners with a tablet and key technology tools in the context of the pandemic.  

### Adult PFAC FY 2022 Goals

- **PFAC recruitment:**
  - Continue to recruit new volunteer members to the PFAC, with an attention to under-represented populations.  
  - Using the Recruitment Committee that is in place, visit internal and external areas/organizations to spread awareness about PFAC.  
  - Increase diversity on the PFAC.  
- **Encourage patient and family engagement:**
  - Increase the percentage of PFAC members on hospitals committees and/or workgroups.  
- **Continue to hold Cafés & Town Halls as a way of engaging the patient community.**  
- **Find avenues to educate staff about PFAC to allow them to partner with us to identify and recommend new members.**
• Continue the expansion of the Arts-in-Health (Peabody Institute and JHH collaboration) programs to additional areas of the hospital and/or virtual platforms.
• Create partnerships with other JHM departments and committees, such as the JHM Employee Resource Groups (ERG), for the purpose of spreading awareness about PFAC and making sure the patient/family perspective is threaded throughout the organization.
• Partner with Johns Hopkins Hospital leadership to identify a new visitor management system.
• Continue to leverage technology to increase participation and flexibility, allowing a larger network of people to join PFAC.
• COVID-19:
  o As the organization moves back in the direction of patient- and family-centered policies like allowing family and visitors into the hospital, PFAC will continue to be involved in the process to establish new norms in a collaborative, communicative fashion.
  o Due to the pandemic, many PFCC practices shifted for safety reasons. Identify ways to restore these practices.

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**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**

An interdisciplinary, diverse council consisting of families and staff. Over 50 council members; 30 of which are family advisors. Family advisors represent experiences from inpatient, outpatient, ambulatory and specialty clinics. Staff advisors include representation from leadership within the Children’s Center, frontline staff and 3 Nursing and 3 Medical Students. Four new members were recruited during COVID-19.

**Council Meetings**

Council 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.

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**Pediatric PFAC FY 2021 Accomplishments**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Committee Involvement</td>
<td>• The following Volunteer Opportunities were fulfilled:</td>
</tr>
<tr>
<td></td>
<td>o I-PASS FCR observations and research study</td>
</tr>
<tr>
<td></td>
<td>o JHCC Quality &amp; Safety Committee</td>
</tr>
<tr>
<td></td>
<td>o CUSP XT</td>
</tr>
<tr>
<td></td>
<td>o Vaccines for Patients Workgroup</td>
</tr>
<tr>
<td></td>
<td>o JHCC Diversity Council</td>
</tr>
<tr>
<td></td>
<td>o Peri-Op Patient Experience Committee</td>
</tr>
</tbody>
</table>
### Community Participation/Engagement

- Parent on Staff audits medical team rounds weekly via Zoom to provide Residents PFCC feedback on Family Centered Rounds.
- Recruited 4 new FAC advisors.
- Participated in the annual Proactive Risk Assessment.
- Parent Advisor on Staff volunteered in JHH Vaccine Clinics and was part of the patient vaccine workgroup.

### Complementary Therapies

- Continued support of Parents Supporting Parents Program in Pediatric Cardiology, Oncology and the CDH.
- Continued the Family Support Program by distributing weekly individually packaged lunches to families on the units. Have fed over 3,360 parents.
- Development of weekly Parent Bingo Program on CCTV.
- Launched food pantries in the PICU and Oncology. Have fed over 400 people.
- Launched a Weekly Caregiver Coffee Hour via zoom in partnership with social work.
- Partnered with Child Life to provide special Mother’s and Father’s Day treat bags for all inpatient units.

### COVID-19 Related Participation

- Provided Leadership with insight and guidance on messaging related to COVID-19 regarding the closing and re-opening of visitation.
- Continued participation in Family Centered Rounds Simulation training for rising senior residents and interns; providing input on implementation of I-PASS Family Centered Rounds during COVID. Purchased monitors/screens for all team workrooms and iPad carts to the teams to continue FCR during COVID.
- Created and manage a Facebook page for Child Life/PFCC. Target audience is inpatient parents, so they know what is happening on CCTV and around the hospital with the constant COVID-19 changes.
- Worked with the Perioperative Patient Experience Group to create a handout for parents preparing for surgery during COVID-19.
- Developed the Patient COVID-19 Town Hall concept adapted by JHCC Leadership and 7 different divisions. Coordinated the IT and slides for each Town Hall.
- Created a closed Facebook Group for Parent Advisors to be able to give quick real time feedback on hospital issues.
| Food and Nutrition                                                                 | • Promoting resilience and reducing stress by:  
|                                                                                      |   o Continued Family Meal Program. Weekly meals are provided to all units for families.  
|                                                                                      |   o Secured private funding to have Dome gift cards given to all pediatric patients and their families on Thanksgiving and Christmas so they could buy a holiday meal.  
|                                                                                      |   o Food Pantry in PICU and Oncology for families.  
|                                                                                      |   o Coordination of Justin Powers Kids meals to Oncology families 2x/month  
|                                                                                      | • Parent Advisor on the Sodexo workgroup, giving patient perspective on menu changes and cafeteria enhancements. |
| Healing Environments                                                                | • Hired an Artist in Residence, 4 hours per week, to round on families in their rooms. Since hired in Jan of 2021 she has seen over 175 parents and patients, bringing a creative outlet to them during the pandemic.  
|                                                                                      | • Gave feedback to environmental enhancements for the Rubenstein building.  
|                                                                                      | • Participated in Radiothon Innovation Grant selection. |
| Patient-Centered Communication                                                       | • Launched a Discharge Checklist for patients and families.  
|                                                                                      | • Collaborated with Child Life on the creation of Covid-19 patient friendly materials for children and families.  
|                                                                                      | • Involved in the creation of the visitation grid and gave feedback and led discussion with Children’s Center Leadership on every change. Created patient materials explaining the changes.  
|                                                                                      | • Created a handout for parents preparing for surgery during COVID-19.  
|                                                                                      | • Led the drive to host COVID-19 Patient town halls.  
|                                                                                      | • Gave feedback on patient handouts for:  
|                                                                                      |   o 21st Century Cares Act  
|                                                                                      |   o Eating Disorders  
|                                                                                      |   o Biomode Units  
|                                                                                      |   o PICU-FCR Brochures  
|                                                                                      |   o Sepsis research handout  
|                                                                                      |   o Cardiac Pre-Surgery Binder |
| Patient Education                                                                    | • 12 Parent advisors in 15 staff education trainings across JHH  
|                                                                                      | • Such educational venues include:  
|                                                                                      |   o Core 2 Adult and Pediatric Nursing  
|                                                                                      |   o Pediatric Intern Orientation  
|                                                                                      |   o CCSC and CCSR new employee training  
|                                                                                      |   o SON-Death & Dying panel  
|                                                                                      |   o PFCC Grand Round Panel |
| Research                                                                            | • PFAC member volunteered for the Music in Pain PCORI Project. |
### Pediatric Standing Goals & Initiatives

**Parent Presence on Hospital Committees**
- Currently 14 advisors on 46 hospital committees

**Diversity in Recruiting FAC Members**
- Added 4 new parent advisors

**Family Centered Rounds (FCR)**
- Parent advisor conducts monthly audit of FCR
- Parent advisor involved in I-PASS FCR training and implementation
- Continued involvement with HR and HR initiatives/practices

### Pediatric PFAC FY 2022 Goals

- Explore ways to make JHCC more accessible to those we currently serve and to the surrounding community.
- Due to COVID-19, many processes related to PFCC changed for safety reasons—Identify ways to restore PFCC processes, examine what changed, what we should keep and what we can expand on.
- Use Parent Advisors to create more resources for both staff and families that could benefit from their insight and expertise. This can be done through written materials, video creation, and increased participation in educational sessions, panels, and support groups.

### 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, such as Prom.

**Council Membership**
Membership consists of 30 members: 21 teen volunteers between the ages of 12 and 21; 9 staff members.

**Council Meetings**
Council meets monthly on the second Tuesday of every month.

### Teen & Children’s Council FY 2021 Accomplishments

<table>
<thead>
<tr>
<th>Domain</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Participation/Engagement</td>
<td>Created a new recruitment video to air on Child Life TV. Made a virtual video to post on social media.</td>
</tr>
</tbody>
</table>
| Complementary Therapies       | The money raised from the Baltimore Boogie/30-day miracle movement supported the following initiatives:  
  o Funded for the Beads of Courage Program  
  o Healing Arts Program  
  o The Patient and Family Centered care gift fund, used to provide holiday and monthly community-style meals for in-patient families. |
### COVID-19 Related Participation
- Provided feedback on COVID-19 resources and support for teens.

### Healing Environments
- Volunteered and participated in Snowflake Station with our Child Life colleagues
  - Due to COVID-19, we had to postpone
- Participated with Child Life in their virtual programming each Friday by engaging with patients through games and trivia. Gave lots of feedback on teen virtual engagement.

### Patient-Centered Communication
- Provided feedback on How to Involve Teens in Decision Making.

### Patient Education
- We continue to share our stories when appropriate.
- Participated in Med Student Education.
- A teen joined the SOGI group and participates in monthly meetings.

### Research
- Provided feedback on “Music for Pain Implementation Science” research study.

### Teen & Children’s Council FY 2022 Goals
- Host 2 events for patients of the Children’s Center in the great room once we are allowed back in the building
- Continue to provide feedback
- Continue hosting Baltimore Boogie or host one event for the Miracle Movement
- Continue to host Prom for adolescent patients of the Children’s Center.
- Continue to leverage technology to increase participation by using zoom, having council members zoom into virtual events

### 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
Membership consists of 55 members: 37 patients and caregivers, 18 staff.

#### Council Meetings
The Council meets monthly on the first Thursday of the month eleven months of the year.
<table>
<thead>
<tr>
<th>Sidney Kimmel Cancer Center Council FY 2021 Accomplishments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Domain</strong></td>
</tr>
</tbody>
</table>
| Committee Involvement | • Advisors are represented on the following JHH and SKCCC committees and workgroups:  
  o SKCCC Quality Improvement Committee  
  o SKCCC Radiation Oncology CUSP (comprehensive unit-based safety program)  
  o SKCCC Falls Committee  
  o SKCCC Inpatient Mobile Hospice Bed Initiative  
  o SKCCC Annual Cancer Survivors Day planning Committee  
  o Oncology Home Care Operations Committee  
  o JHH Partners Aligned in Care Transitions (PACT) Teams  
  o JHH Surgical Quality Improvement Committee  
  o JHH Medication Management Clinical Community  
  o School of Nursing Patient Educator Presentations for Nurse Residency Program  
  o Johns Hopkins Center for Health Equity-Community Advisory Board  
  o Johns Hopkins University Center to Reduce Cancer Disparities-Community Advisory Board  
  o Johns Hopkins Medicine Patient and Family Centered Care Clinical Community |
| Community Participation/Engagement | • Recruiting efforts led to the onboarding of 6 new advisors  
  • Added the monthly PFAC agenda and meeting reminder to the weekly staff SKCCC event calendar to promote staff PFAC awareness.  
  • PFAC article in CenterWide, the digital publication for Kimmel staff.  
  • Quarterly meetings with SKCCC leadership.  
  • Annual State of the Center address by Dr. William Nelson, Director of SKCCC.  
  • PFAC advisor participated as a panelist in the JHH Ethics for Lunch: 21st Century Cures Act - ethical implications of immediate lab and note release.  
  • Feedback on Center to Reduce Cancer Disparities’ Facebook launch of Kimmel in our Community. |
| COVID-19 Related Participation | • Successfully transitioned PFAC meetings to Zoom format due to COVID-19  
  • PFAC advisor participated as a speaker at the JHH Patient Experience Grand Rounds by sharing her caregiver experience of treatment of Hodgkin’s Disease during COVID  
  • Continued input to leadership regarding: |
| **Healing Environments** | • SKCCC Urgent Care Center Design:  
  o PFAC member was the recipient of the Cancer Community (C2) President’s Award 2020  
  o The award celebrates people and organizations changing the lives of patients with cancer.  
• Feedback on development of The Caregather App for patients and families during treatment.  
• Feedback on launch of Wayfinding App to help navigate JHH and Bayview campuses. |
| **Patient-Centered Communication** | • 21st Century Cures Act: Provided input on the patient impact of immediate lab result and note release.  
• PFAC members participated in a Storytelling workshop to learn how to use patient-centered care principles to guide how the patient story is told as a patient educator. |
| **Patient Education** | • Created a work process for PFAC members to evaluate patient education materials.  
• Advisor educators for Core 2 Nursing, School of Nursing. |
| **Research** | • Co-wrote Jennifer Brager Research proposal with SKCCC and JHH staff  
  o Virtual Reality Mindfulness Training to Relieve Anxiety and Depression in Women with Breast Cancer Receiving Outpatient Infusion Therapies: A Feasibility Study.  
• Provided PFAC letters of support for NIH funded research studies  
  o Provider Impacts on Oral Anti-Cancer Medication Use  
  o Auricular acupressure for self-management of chronic pain |

**Sidney Kimmel Cancer Center Council FY 2022 Goals**
- Continue to promote collaboration with SKCCC  
  o PFAC Advisor Education of Advanced Practice Providers to promote PFAC advisor referrals  
  o Develop a recurring presence in the digital staff newsletter to increase PFAC member referrals  
- Continue to increase advisor participation in committees and workgroups, particularly those related to safety and quality.
• Young adult cancer survivorship
  o Identify opportunities across departments to provide increased access to consultation, networking and support services for young adults with cancer.
• Mobility and activity in survivorship
  o Empower patients to identify/access external support resources to promote physical activity in Survivorship.
• Navigation
  o Partner with JHM, SKCCC staff to identify opportunities to optimize the experience of patients entering our system regardless of point of entry.
• Support SKCCC research efforts
• Continue to look for opportunities to participate in SKCCC or JHM venues where the patient voice can help shape decisions regarding patient experience

### 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
Membership consists of 16 members, which includes 8 Johns Hopkins staff and 8 patient volunteers.

#### Council Meetings
Council meets monthly on the third Thursday of the month.

### Ambulatory PFAC FY 2021 Accomplishments

#### Domain | Activities
--- | ---
Committee Involvement | • Representation on the following Johns Hopkins Hospital committees/workgroups:
  o Ambulatory Patient Experience Committee
  o JHH Adult PFAC
  o Ambulatory PFAC Executive Committee
  o JHH PFAC Collaborative
Community Participation/Engagement | • Participated in Johns Hopkins Drug Take Back Day
• Participated in and recruitment effort at Ambulatory Diversity Council fair.
COVID-19 Related Participation | • Advised on JHM website content for COVID State Certification and Safety Auditors.
• Advised JHM Marketing and Communication and Security on patient screening at entrances.
• Implementation of the I’ve Been Screened stickers for patients and caregivers.
• Advised on JHM MyChart screening with a QR code.
• Advised on JHM Ramp Up to Normal – a detailed plan to incrementally resume operations while putting safety measures in place.
| Healing Environments | • Advised Environmental Care on keeping us safe from pathogens.  
| | • Advised Quality & Patient Safety on physical distancing, seat covers, floor decals and Plexiglas shields in clinical areas. |

| Patient-Centered Communication | • Aligned our improvement initiatives with the JHM PFCC Strategic Goals  
| | • Advised on defining practice standards for providers as it relates to telemedicine  
| | • Advised Marketing and Communication on video “preparing for your telemedicine visit”  
| | • Implemented changes to the Smart Source appointment letter by funding bulk edits  
| | • Guided Telemedicine on their practice standards for a telemedicine visit. |

| Patient education | • Advised on Johns Hopkins Drug Takeback Day signage/communication and locations of collection sites  
| | • Advised on JHM Pre-registration process and how technology might improve the clinical experience |

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### Ambulatory PFAC FY 2022 Goals

- Recruit 4 new members with a focus on under-represented patient advisors
- Set a communication standard for our providers/practices, develop parameters of communication for The Clinical Practice Association which is the governing body of clinicians.
- Update the 1987 Bylaws on Provider Communication

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### 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 | Membership consists of 23 people: 9 patient, family, or community members and 14 staff members |

<p>| Council Meetings | Council meets monthly on the second Wednesday of the month. |</p>
<table>
<thead>
<tr>
<th>Domain</th>
<th>Activities</th>
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<tbody>
<tr>
<td>Committee Involvement</td>
<td>• Representation on the following Johns Hopkins committees/workgroups:  &lt;br&gt;   o Adult ED Patient Experience Committee  &lt;br&gt;   o EPIC Patient &amp; Family Design Team  &lt;br&gt;   o JHH Adult PFAC  &lt;br&gt;   o JHH Adult Recruitment Committee  &lt;br&gt;   o JHH Ambulatory PFAC  &lt;br&gt;   o JHM Patient and Family Education Council  &lt;br&gt;   o JHM Renal Patient Education Workgroup  &lt;br&gt;   o Patient Engagement Program (PEP) Leadership Committee  &lt;br&gt;   o Pharmacy Opioid Stewardship Clinical Community: Community Engagement and Public Policy Workgroup  &lt;br&gt;   o Johns Hopkins Howard County PFAC</td>
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<tr>
<td>Community Participation/Engagement</td>
<td>• Created materials for ED PFAC recruitment efforts including a written letter and flyer.  &lt;br&gt;   • In April of 2020, we made the monthly meetings virtually accessible due to the pandemic, and moving forward we will continue to offer a virtual option for easier access to members.</td>
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<td>COVID-19 Related Participation</td>
<td>• PFAC member volunteered to join a JHM Marketing Web Content Advisory group to review COVID-19 related content and material for JHM websites for compassionate language and understandability.  &lt;br&gt;   • Kept PFAC and community members up to date with COVID-19 information so that they could share with their networks.  &lt;br&gt;   • Provided feedback on telemedicine services in the ED.</td>
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<tr>
<td>Healing Environments</td>
<td>• Developed ways to honor ED nursing staff during 2021 Nurse Appreciation Week. The Council created:  &lt;br&gt;   o An e-card and video message from AED leadership and PFAC members  &lt;br&gt;   o A heartfelt letter that was printed and shared in staff areas  &lt;br&gt;   o Treat bags  &lt;br&gt;   • Provided feedback on the Johns Hopkins Find Your Way mobile app and marketing strategies.  &lt;br&gt;   • Worked in collaboration with the Sr. Patient Experience Coach to design possible signage for the ED redesign: explaining the stages of the process and a rendering of the future ED.  &lt;br&gt;   • Provided suggestions on a letter and flyer that patient’s receive pertaining to the Laurel COVID-19 Field Hospital.</td>
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## Patient-Centered Communication

- ED Staff asked ED PFAC for input and feedback on ED Nurse Discharge Communications for Patients.
- Provided feedback on the 2021 installation of metal detectors in the Adult ED: possible community feelings and what signage should be shown.
- Gave feedback on Patient Rounding Templates that will be used to ensure hourly rounding and minimize falls and feelings of isolation.
- Helped to design a Face Masking & Social Distance sign that was posted in patient ED areas.
- Shared the patient perspective as it pertains to ED challenges: informing patients about wait times, updates triage process, outdoor areas, etc.

## Research

- PFAC member is a research participant in the “ED Safety Net Model for Palliative Care” project which aims to redesign the service and improve JH ED-based palliative care.
- Provided perspective on The Organ Donation Project, which could allow for more available organ donations taken from those who pass away in the ED e.g. what is the best way to engage the community and communicate the idea to patients/families.

## Emergency PFAC FY 2022 Goals

- Continue to recruit new PFAC members: add at least 2 in FY22
- Collaborate with the ED Sr. Patient Experience Coach with Adult ED New Hire Orientation
- Increase staff awareness to the Adult ED PFAC
- Partner with new ED CCSC to improve the patient experience journey
- In collaboration with Adult ED Leadership, improve the ED waiting experience to allow for a more comfortable visit
- Reestablish the PFAC Executive Committee
- Organize at least one appreciation event for AED staff

## Fetal Therapy Medicine PFAC

### Council Responsibilities

The Fetal Therapy 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. The Council has adopted a 3-part focus: peer patient support, social media support, and fundraising/research support.

### Council Membership

Membership consists of 15 – 20 patient families, 3 faculty members and 5 staff members including social work and development.

### Council Meetings

The Council meets on a quarterly basis but primarily communicates via email.
## Fetal Therapy Medicine PFAC FY 2021 Accomplishments

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<th>Domain</th>
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| Community Participation/Engagement | • Launched the Fetal Therapy Facebook page which is now maintained by our Communications team. Council members continue to monitor our Facebook and web pages, and offer feedback.  
• Explored options to organize a 5K with the goal of raising funds, spreading awareness, and engaging our community—but these plans were tabled due to COVID-19. |
| Complementary Therapies | • Parents Supporting Parents: We have established a network of previous-patient parents who have been vetted through the Department of Volunteer Services and are available to be a 1:1 resource to new patients/families with a similar diagnosis. |
| COVID-19 Related Participation | • The group was only able to meet once in person before the COVID-19 pandemic began but has since created a Zoom option to continue meetings.  
• Compiled a short video to share our gratitude to our families for their support in the midst of the past year. |
| Food and Nutrition      | • Council members initiated and continues to support a program which donates GrubHub gift cards to current patient families, especially those who are inpatient and prognoses for NICU stays, as a way of offering support and letting families know they are not alone. |

## Fetal Therapy Medicine PFAC FY 2022 Goals

• Resume the Annual Family Picnic in Spring 2022. This event engages the nearly 400 families in comradery and connection.  
• Recruit new members to the Council  
• Continue raising funds, spreading awareness, and engaging the community