



THE AMERICAN ONCOLOGIC HOSPITAL

Patient and Family Advisory Council Annual Report January 2021

Michel Phillips and Elaine Sykes
Patient and Family Advisory Council Co-Chairs

Patient and Family Centered Care (PFCC)

Patient- and Family-Centered Care (PFCC) is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care. Patient- and family-centered practitioners recognize the vital role that families play in ensuring the health and well-being of family members. They acknowledge that emotional, social, and developmental support are integral components of health care. They promote the health and well-being of individuals and families and ensure dignity and control are evident. Patient- and family-centered care is an approach to health care that shapes policies, programs, facility design, and staff day-to-day interactions. It leads to better health outcomes, wiser allocation of resources, and greater patient and family satisfaction.

The priorities and choices of patients and their families are in collaboration with the provider to drive the delivery of health care. Interventions occur with patients and families rather than to and for them.

Core Concepts of Patient- and Family-Centered Care

- **Respect and dignity.** Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.
- **Information Sharing.** Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.
- **Participation.** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
- **Collaboration.** Patients and families are also included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.

Fox Chase Cancer Center's Patient and Family Advisory Council (PFAC)

The FCCC PFAC held its inaugural meeting in 2010 after the PFAC Steering Committee spent the prior year learning about PFCC, completing a gap analysis, setting the plan for adoption, and receiving support from the senior leadership team. Shortly thereafter, they received full endorsement from the Professional Affairs Committee of the Board of Directors. PFAC marks its 10th Anniversary at FCCC and was the recipient of an acknowledgment letter from Dr. Fisher that was shared with the FCCC faculty and staff.

The PFAC serves as a “voice” for patients who have and are receiving cancer treatment at Fox Chase Cancer Center and their family members. The council is dedicated to strengthening collaboration

between patients and family members and the health care team so as to enhance Fox Chase Cancer Center's ability to deliver the highest standard of safe, comprehensive and compassionate health care.

Information and requests flow into PFAC through hospital- and center-wide committees and councils seeking the patient and family's perspective. PFAC members continually look for new opportunities for communication and collaboration among patients, families and staff and strive to identify and support opportunities for improvement from the patient and family perspective.

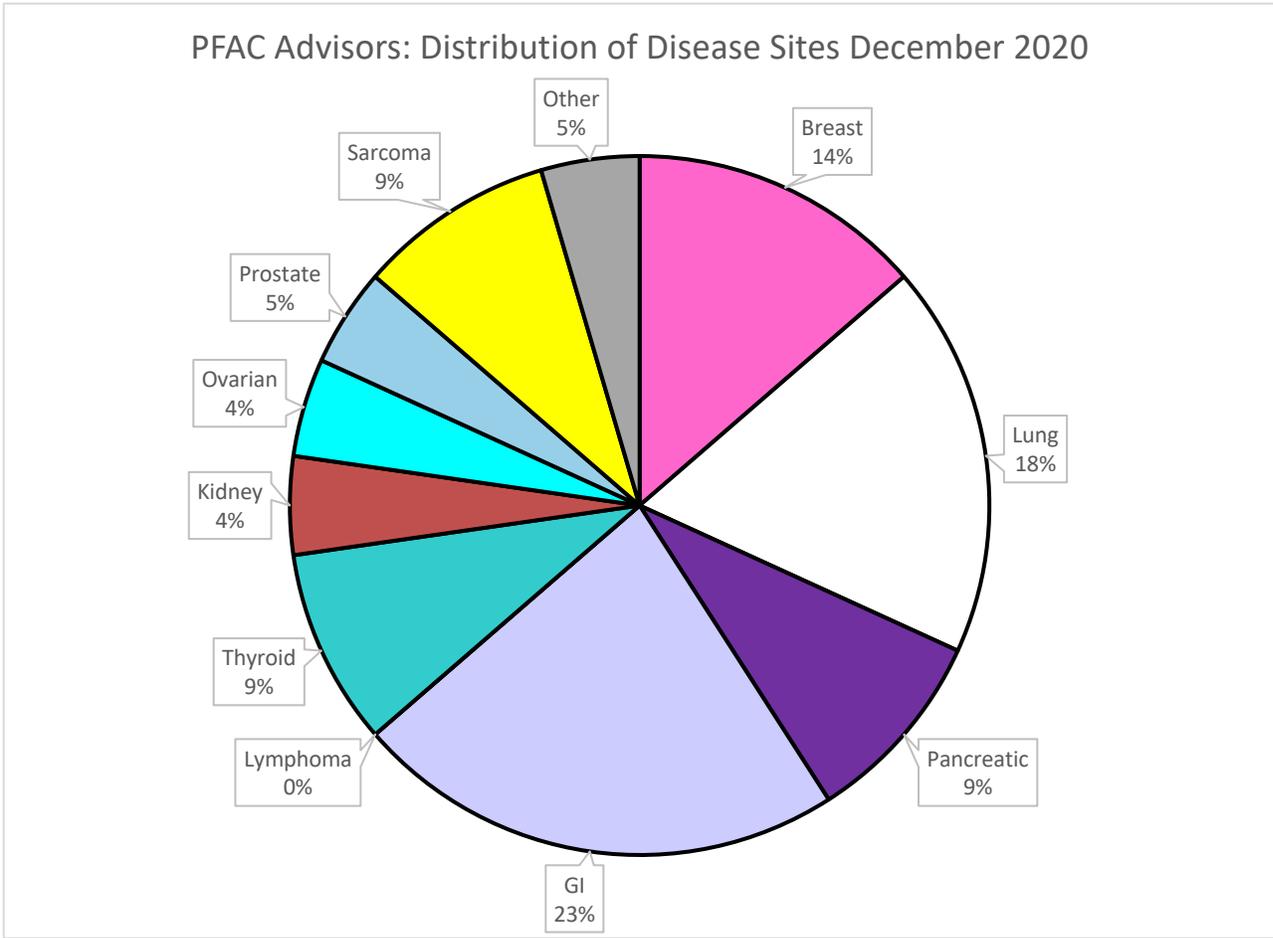
As written in our bylaws, PFAC strives to:

- Provide information to administrative, clinical and research staff and faculty about the needs and concerns of patients and family members
- Work with staff and faculty to improve services that affect patients and family members
- Participate in the design of patient care areas
- Assist in the planning of new patient-related programs
- Serve as a resource to the health care team, providing the patient and family perspective on a wide variety of patient-related issues, including patient safety, staff recruitment, program planning, services, policies, and research.

PFAC Structure

Currently the PFAC has 12 of 15 full patient/family advisors and 3 serving in an ad-hoc capacity to assist with projects, as needed. It also has 12 staff advisors who represent various departments and programs within Fox Chase Cancer Center. Two patient/family advisors, Michel Phillips and Elaine Sykes, served as co-chairs in 2020. Dr. J. Robert Beck has served as the Executive Sponsor of the Council for many years. He and Anne Jadwin (former Chief Nursing Officer), as members of the PFAC, have served as representatives of the Senior Leadership Council. Members of the medical staff who serve on the PFAC include Jeffrey Farma MD, Catherine Tuite, MD, and Paula Finestone, PhD. Delinda Pendleton serves as the Staff Liaison. The PFAC continues to serve as the model for other PFACs being formed throughout the TUHS and the State.

Patient and family advisors represent 10 different disease sites, as noted in the pie chart below.



PFAC reports directly to the Professional Affairs Committee (PAC) of the Board and provides an annual report of its progress and goals. Kim Hagerich, former Co-Chair of the PFAC, has served for several years as a member of the PAC.

2020 Activities/ Projects

2020 was an extraordinary year because of the pandemic. Since last March, the advisors have met only virtually, but have maintained their strong commitment to effectively address topics of concern to our patients and families.

At the outset of 2020, PFAC recruited, interviewed and oriented six new members, an extraordinary number driven by employment changes, family concerns and the passing of former members. The PFAC is proud of the diversity of its membership and now better represents the voices of younger patients, international patients, LGBTQ patients and family members.

Since many new advisors were on-boarded in 2020, PFAC focused on team-building through a variety of formal exercises that inspired communication and collaboration. PFAC also reached out to more than 13 different staff members and clinicians in the past year (see page 6) to review and discuss areas for improvement based on the diverse concerns of its membership.

The most significant accomplishments of the PFAC this past year are briefly described below:

- 1) **PFAC Workgroups:** The advisors formed three internal workgroups (First Impressions, Wayfinding and Environmental Safety) based on priorities identified at their inaugural retreat in November, 2017. Since that time these workgroups have partnered with FCCC staff and committees to address opportunities for improvement and pursue joint strategies to accomplish them. These workgroups monitored on-campus developments as best they could during the pandemic and were able to address the following:
 - a. First Impressions: Advisors recommended changes to enhance the appearance and comfort of our physical plant, including identifying areas needing fresh paint, decluttering, replacing easels with framed posters, and cleaning parking garages and entryways.
 - b. Wayfinding: Advisors updated their list of printed directions and met with a nurse who is working on a project that involves the use of QR codes to help with wayfinding.
 - c. Environmental Safety: The PFAC has been following with interest the use of BioProtect Technology and looks forward to future updates from Jonathan Wright, Director of Environmental Services.
- 2) **Patient Escort Waiting Area:** PFAC strongly endorsed the opening of the Patient Escort Waiting Area in June 2020 and assisted in preparing an instructional handout for escorts utilizing this space. This area helps to address the needs of patients and families who must face cancer while dealing with the limitations imposed by the pandemic.
- 3) **Ways to Be an Engaged Patient:** Advisors simplified “*50 Ways to be an Engaged Patient*” (*Planetree*) to encourage our patients to speak up and engage in candid dialogue with their health care team about treatment plans, concerns and priorities during their cancer journeys. Advisors worked closely with the marketing team to post the guideline on the FCCC website.
- 4) **Ambulatory Care Patient Flow:** Numerous PFAC advisors participated in a two-hour focus group and a brainstorming/affinity diagram exercise in an effort to reduce wait times in reception areas and examination rooms. They provided feedback based on their own experiences in ambulatory care and offered suggestions to improve patient flow and patient comfort and satisfaction.
- 5) **Skin Breakdown Prevention Bags:** Advisors met with DRU nurses who have designed bags of products for distribution to patients to prevent skin integrity and pressure wound problems. The PFAC made several suggestions to meet the needs of patients, including those who are financially compromised.
- 6) **Teaching Cycle 1 Chemotherapy/Immunotherapy:** PFAC provided input on the proposed workflow for nurses who are teaching patients undergoing cycle 1 chemotherapy and immunotherapy.
- 7) **Discharge Planning Checklist (DPC):** Advisors learned about the pilot of the DPC drafted by the transitional care nurses for nurses who must prepare patients for discharge and make recommendations.
- 8) **Coronavirus Information on FCCC Website:** PFAC advisors worked closely with the Marketing Department to provide thorough and reassuring information on our website

about Covid-19 practices and policies affecting patients undergoing treatment, procedures and hospitalizations during the pandemic.

- 9) **Trauma Informed Care Patient Survey:** Advisors were given an overview of this proposed research study and provided feedback.
- 10) **Security on Campus:** PFAC Co-chairs met with the security director to express concerns about campus security, particularly in the parking garages. They provided suggestions on how PFAC could partner with him to educate patients and families about current and future security measures. Signage has since been posted in the garages encouraging visitors to report suspicious activity to the hospital operator.
- 11) **Articles Featuring PFAC Advisors:** Two PFAC advisors were featured and quoted in articles in FCCC publications, including “*Living with Lung Cancer – A Patient Perspective*” (Prevention Matters) and “*Riding the Caregiver Roller Coaster*” (Forward Magazine). The articles focus on overcoming challenges associated with treatment, recovery, survivorship and caregiving.
- 12) **Continuing Medical Education (CME):** Our Co-Chairs, Mike Phillips and Elaine Sykes, partnered with Paula Finestone PhD on a one-hour CME presentation that addressed the evolution of patient-and family-centered care (PFCC) nationally and at FCCC. Elaine shared perspectives from her experience as a caregiver and patient, while Mike addressed PFAC’s accomplishments this past year that support the principles of PFCC.
- 13) **Honoring our Staff Liaison:** PFAC advisors worked behind the scenes to collaborate on a gift to honor Delinda Pendleton, Staff Liaison, on the occasion of PFAC’s 10th anniversary. The advisors selected a print of a paper collage created by a cancer survivor that portrays blooming flowers. This print symbolizes Delinda’s decade-long campaign to grow the PFAC from a small seed to the flourishing organization that it is today. With this gift, the advisors commend and thank Delinda for her superior energy, vision and tenacity in improving the lives of patients and families at FCCC.

PFAC Advisor Orientation and Ongoing Education

Each patient/family advisor is on-boarded as a volunteer and oriented specifically to his/her role as an advisor. Advisors are invited periodically to attend regional and national patient- and family-centered care webinars that support their competency. Speakers are invited to attend PFAC meetings on a regular basis to educate advisors regarding FCCC programs, initiatives, and departments. Topics are identified based on opportunities for improvement, as well as advisors’ expressed interest. Speakers also attend the meetings to gather patient and family perspectives regarding existing and proposed programs, processes, and initiatives.

Presentations/ Speakers at 2020 PFAC Meetings
Skin Breakdown Prevention Bags (Crystal Greco/Ruthanne Gough, DRU Nursing)
Discharge Planning Checklist (Chrystal Lucas, Transitional Care Nurse Navigator)
Coronavirus Communication to Patients (Ryan O'Neill-Moon, Marketing)
LGBTQ Matters (Jonathan Bidey, Surgical Nurse Practitioner)
Patient-to-Patient and Caregiver Networks (Nina Galpern, Resource & Education Center)
Supportive Oncology & Palliative Care (Drs. Marcin Chwistek/Dylan Sherry)
FCCC Retail Pharmacy Update (Jeff Karcsh)
Environmental Services Technologies (Jonathan Wright)
Patient Advocacy Committee (Christina Passio, Nursing)
Board of Associates (Jill Horne)
Clinical Nutrition Program (Kara Stromberg)

Hospital Committees & Performance Improvement Teams

Over 400 Hours

Patient and family advisors provided nearly 350 total volunteer hours in 2020 serving on the PFAC plus 66 additional hours serving on committees and improvement teams representing PFAC. This represents more hours when compared to the prior year, despite the current challenges of the pandemic. Advisors represent the voice of patients and families as they serve in this capacity. In addition, they provide semi-annual committee reports to the PFAC.

Hospital Committees & Performance Improvement Teams	
Art Committee	Patient Education Committee
Campus Experience Committee	Patient Experience Leadership Team
Falls Prevention Committee	Patient Safety Committee
Infection Control Committee	Performance Improvement Committee
Institutional Biosafety Committee	TUHS Patient Satisfaction Team

PFAC Dashboard

Advisors review a quarterly dashboard that houses important information and statistics. This information reflects updates on internal projects and progress toward meeting standards of patient – and family-centered care. In addition to HCAHPS, CGCAHPS and OSCHAPS data, performance data, based on Press-Ganey custom patient-centered care questions, are also reviewed on a quarterly basis.

PFAC 2021 Goals

For the past two years, advisors participated in a PFAC mini retreat to review accomplishments from the prior year, highlight patient experience, and share ideas regarding areas of improvement. In addition, some advisors participate in the annual TUHS Patient Value Council Quality & Patient

Safety retreat, along with faculty, staff, and other advisors to review performance data from the prior year and work with teams to identify goals and tactics for the upcoming year. From these two annual events, key themes and future goals are identified by the PFAC advisors. For 2021, the goals are:

- 1) Alignment with TUHS' Patient Experience annual goal, "CAHPS will improve by 2% in the areas of care transitions.
- 2) Partner with FCCC clinical staff to work on opportunities for improvement related to care transitions
- 3) Partner with FCCC staff and the marketing team to increase internal awareness of PFAC
- 4) Increase level of advisor engagement in performance improvement, patient safety, and research projects
- 5) Resume advisor participation in the New Employee Orientation
- 6) Continue to address opportunities for improvement identified by the PFAC Workgroups (First Impressions, Wayfinding, Environmental Safety)
- 7) Continue to recruit advisors with an eye on diversity

Current Members of the PFAC



Patient/Family Advisors	Staff Advisors
Emily Bakaj Elizabeth Cosline Julia Eidelman Susan Galeone Lydia Henson Linda Johnson James Lajeunesse Rick Lamb Donna McAllister Mike Phillips Anne Prousi Larry Risch John Rossi Elaine Sykes Johanna Vanegas Janice Wormington	Nancy Baumann, <i>Nutrition & Hospitality</i> Theresa Capella, <i>Marketing</i> Jeffrey Farma, MD, <i>Surgical Oncology</i> Paula Finestone, PhD, <i>Psychiatry</i> Helen Gordon, <i>Volunteer Services</i> Jill Horne, <i>Communications</i> Anne Jadwin, <i>Nursing</i> Delinda Pendleton, <i>Patient Experience</i> Catherine Tuite, MD, <i>Diagnostic Imaging</i> J. Robert Beck, MD, <i>Executive Sponsor</i>

Report prepared by Delinda Pendleton, PFAC Staff Liaison