Introduction

*Image*: Watercolor image of a tree, with handwritten words within the roots, trunk, and leaves. Opening words of the Mass General mission statement, “Guided by the needs of our patients and their families” extend from one root through the tree trunk. Other roots describe PFAC high level PFAC functions—Experience Expertise, Focused Feedback, Advisory Resource. Words in the leaves provide more specifics – Highlighting patient and family voices; Participating in committees and initiatives; Embracing diversity and inclusion; Dedicating time and perspectives; Promoting quality, coordinated communications; Shaping programs and services. Graphic by General PFAC Members: Concept-Joyce Smith. Image-Stuart Murphy.
MASS GENERAL MISSION

Guided by the needs of our patients and their families, we aim to deliver the very best health care in a safe, compassionate environment; to advance that care through innovative research and education; and to improve the health and well-being of the diverse communities we serve.

PATIENT AND FAMILY ADVISORY COUNCILS AT MASS GENERAL

Patient and Family Advisory Councils (PFACs) serve as one primary way for Mass General to realize the opening words of its mission statement, “Guided by the needs of our patients and their families. . .”

PFACs bring together Mass General patient, family members, staff, and clinicians in an ongoing effort to improve care and care experiences.

PFACs integrate, elevate, and promote the patient and family voice in the development and design of programs, services, and initiatives.

PFAC members lend their expertise by participating in regular PFAC meetings.

PFAC members serve on hospital committees and task forces, review educational materials, and collaborate within and across services and settings in a variety of different ways.

Current Mass General Advisory Councils include:

- General Patient and Family Advisory Council
- Cancer Center Patient and Family Advisory Council
- Emergency Department Patient and Family Advisory Council
- Heart and Vascular Centers Patient and Family Advisory Council
- MassGeneral Hospital for Children (MGHfC) Family Advisory Council
- Pediatric Oncology Family Advisory Council

Mass General PFACs have evolved significantly over time and have made a difference.

This report presents the robust contributions of Mass General PFACs over the past year.
Image: Watercolor circle of colors. Each color includes the name of a Mass General PFAC. Graphic by General PFAC Member Stuart Murphy.
General Patient and Family Advisory Council

Image: Watercolor circle of colors highlighting General PFAC section. Graphic by General PFAC member Stuart Murphy.
General Patient and Family Advisory Council

Established in 2011

OVERVIEW

The Massachusetts General Patient & Family Advisory Council (General PFAC) consists of patients and family members with recent care experiences across inpatient and ambulatory Mass General settings. General PFAC members provide valuable expertise on a wide range of important topics. Members share their time and ideas by participating in ongoing monthly General PFAC meetings. They also serve on Mass General committees, support organizational initiatives, conduct reviews remotely, and serve in an advisory capacity in many valuable ways.

MISSION

The General PFAC’s mission is to continuously embrace the opening words of the Massachusetts General Mission Statement, “Guided by the needs of our patients and their families,” to systematically integrate the patient and family voice in services, programs, and initiatives across the organization, and to promote consistently compassionate care experiences.

ACTIVITIES AND ACCOMPLISHMENTS - 2020-2021

Topics Reviewed by and Presented to the General PFAC

Throughout the past year, the General PFAC continued its practice of reviewing a wide variety of topics that spanned strategic imperatives, services, and settings. Requests for comment and guidance came from a diversity of Mass General and Mass General Brigham staff and providers. At monthly meetings, members of the General PFAC gathered in the now-familiar virtual operating mode. This monthly meeting format provided the opportunity to continue to address the many topics presented, including:

- **Cambridge Street Facility Project** – Susan Cronin-Jenkins, Director MGH Planning and Construction Kerianne Graham, Sr Associate, NBBJ, Sarah Markovitz, Principal NBBJ. An update on status of planning for a new facility which will increase capacity and allow for transition to private rooms. Members asked questions and provided feedback.

  **General PFAC member:** “It’s an honor to be able to be a voice of the patient for such a large institution – I’ve looked at it as an opportunity.”
• **Care Transitions / Care Continuum** – Tina Stone, RN, Associate Chief Nurse, Ryan Thompson, MD, Medical Director, Care Continuum and Complex Care, Elizabeth Fonseca, SM, Program Director, Population Health Management. An overview of the initiative to improve care transitions across the care continuum, with a special focus on access to care for vulnerable populations. The transition from hospital to home or post-acute setting was discussed, and members provided input on their experiences along with recommendations.

• **Disability Services & Initiatives** – Zary Amirhosseini, M.Ed, Disability Program Manager and Karen Turner, MS, OTR/L, Patient Navigator for Autism and Developmental Disorders. An overview of disability disparities and how these were highlighted during COVID. Themes stemming from an analysis of patient experience survey comments from those with self-reported disability, and several initiatives focused on the pandemic environment, were discussed.

• **Structural Equity 10-Point Plan and Patient/Family/Visitor Code of Conduct** – Elena Olson, JD, Executive Director, Center for Diversity and Inclusion, and Brian French, RN, The Maxwell & Eleanor Blum Patient and Family Learning Center. An overview of the 10-Point Plan, and review of the newly approved Patient/Family/Visitor Code of Conduct and associated Strategies and Scripting Guidelines to management of challenging behaviors. Members provided feedback on modes of effectively communicating the Code of Conduct across the Mass General community.

• **Pharmacy Equity & Inclusion Committee** – Susan Jacob, Pharma D, Attending Clinical Pharmacist, and Petrece Palmese, Outpatient Pharmacy Director. An overview of the Committee’s work and of pharmacy services more broadly. Members responded to questions about prescription accessibility and pharmacy utilization and engaged in discussion.

• **Organizational Capacity & Environment** – Mary Cramer, Executive Director Organizational Effectiveness and Chief Experience Officer. An overview of Mass General’s key Quality & Safety Goal of improving ED, inpatient, and ambulatory capacity constraints. Reallocation of space and alleviation of volume as feasible was discussed. Members asked questions and shared experiences.

• **Prospective Outpatient GI Symptoms Assessment (ProGISA) During the COVID Pandemic** – Sofi Vergara Cobos, General PFAC member. An overview of Sofi’s work in support of a Mass General research initiative to better understand functional GI disease and the interplay of race / ethnicity, socioeconomic status, and psychological distress. Members discussed this collaboration and supported increasing awareness of the importance of research in minority communities.

• **Mass General Technology to Enable Community Health (TECH) as Medicine Initiative** – Julie DeCosta, General PFAC Co-Chair. An overview of a proposal to bridge the technical divide in access to telehealth for low to moderate income families (focused on Chelsea and Revere communities). Members engaged in dialogue about the importance of work to expand telehealth access.

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*General PFAC member:* “In the world we’re living in and all the difficulty, hostilities, and disagreements — it's one of the things I enjoy when I’m in a diverse group of people and see that they are decent people trying to do good work and they respect one another, and you’re just hoping that the world will catch up.”
• **Open Notes** – Deborah Adair, Director of Health Information Management/Privacy and Karen Bogard, Sr. Manager of Data & Record Integrity. An overview of the Office of National Coordinator Final Rule requiring that all Patient Electronic Health Information be made available to patients. Members were informed of the Mass General Brigham approach to provide this information via Patient Gateway. Members asked questions and shared perspectives.

• **Joint Commission Survey** – John Belknap, Chief Compliance Officer. An overview of the Joint Commission hospital accreditation process, the history of accreditation at Mass General, and hospital preparation for visits. Members engaged in discussion about the process.

• **Social Services** – Sarah Taddei, LICSW, Mass General Pediatric Intensive Care Unit. An overview of the Mass General Social Work Department and the role of social worker. The nature of work during the pandemic, and frontline work supporting providers and staff was reviewed.

• **Betsy Lehman Center Patient & Peer Support Network** — Linda Kenney, Director Peer Support Network and Jackie Ewuso, Program Manager. The Patient and Peer Support Network provides support for those who have experienced an unanticipated medical outcome and/or error. The role of the Peer Supporter was discussed and members with relevant experience/interest were encouraged to apply to serve in this volunteer role.

• **Aunt Bertha** – Telicia Gentile, DHSc, MPH, Program Manager Population Health Management, and Jahnell Bray, Project Specialist, Population Health Management. An overview of Aunt Bertha, a resource that connects people with programs and resources, used to date by providers. Members provided feedback as to whether and how the tool would prove useful as a resource for patients.

• **Shared Decision Making – Cancer Screenings of Older Adults**, Karen Sepucha, PhD, Director, Health Decision Sciences Center and Lauren Leavitt Simmons, MA, Program Manager. An overview of shared decision-making aids and strategies for increasing reach, as well as research on shared decision making for colon cancer screening. Members answered questions regarding these aids and strategies, and discussed a proposed program in which student interns would help patients prepare for their visit and take notes.

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**General PFAC member:** “We are valued, we’re listened to . . . important people at the hospital seek us out and value our opinion – that’s why I’ve continued to do it for many years and I really enjoy it.”

**Collaborator:** “They were all articulate and refreshingly honest about their experience. They were also complimentary and gracious.”
General PFAC Member Participation in Committees and Initiatives

In addition to attending at monthly General PFAC meetings, General PFAC members participate in committees, task forces, and initiatives across the hospital and system, providing the patient and family voice and perspective within interdisciplinary groups. While the format of these meetings moved to a virtual setting due to COVID, General PFAC member participation seamlessly continued.

- **Blum Patient & Family Learning Center / General PFAC Education Committee** – A working committee of several General PFAC members collaborates closely with the Maxwell and Eleanor Blum Patient and Family Learning Center. Members use plain language review to provide feedback on educational materials and share the patient and family voice in facilitated discussions on a variety of topics.

- **Council on Disability Awareness** – Two General PFAC members serve on an interdisciplinary council consisting of representatives from across the hospital focused on disability access and awareness and creating a supportive and welcoming environment for all.

- **Quality Oversight Committee** – Two General PFAC members serve on a Mass General Senior Leadership Committee focused on reviewing quality and safety topics.

- **Structural Equity 10-Point Plan Initiative 1-Policy and Procedure Review Committee** – One General PFAC member serves on an interdisciplinary subcommittee charged with identifying a framework by which to assess current and new policies on their equity impact.

- **Cambridge Street Facility Determination of Need Public Hearing** – Several General PFAC members set forth their comments and support for the new inpatient building project from a patient perspective. These members provided comments verbally during a virtual meeting held by the City of Boston, as well as in writing.

- **Judges – Annual Patient Experience Awards** – Each year, clinicians and staff submit patient experience award nominations on behalf of colleagues (individuals and teams) that have demonstrated icare (communicate, advocate, respect, empathy) excellence. For the third year in a row, several General PFAC members served as judges, reviewing and voting on nominations, and participating in the awards ceremony. Videos of PFAC members speaking to their experiences as judges, and with care at Mass General, were created and shared during the ceremony.

*Image: Poster expressing a special thank you to PFAC members who served as Judges for the Annual Patient Experience Awards*
• **Mass General Brigham Patient Experience Leadership Committee** – One General PFAC member serves on a system-level committee consisting of patient experience leaders from hospitals and entities across the hospital and system.

• **Center for Outcomes & Patient Safety in Surgery (COMPASS) Website** – Several General PFAC members reviewed and provided feedback on iterations of body heat map surgical outcome displays prior to posting on the COMPASS website.

• **Patient Connect** – Several General PFAC members participated in a facilitated session by offering their perspectives on an early version of the platform utilized to connect patients in the hospital with loved ones through technology.

• **Advancing Digital and Virtual Opportunities for Care Access Translates to Equity (ADVOCATE)** - One General PFAC serves as a patient representative on this newly formed virtual care initiative.

• **Engagement Advisory Committee, Continuum Project** – One General PFAC member serves on the Engagement Advisory Committee of The Continuum Project — focused on “living well with serious illness” and introducing earlier and better serious illness conversations with patients and families.

• **Harvard Master of Clinical Service Operations Course** – One General PFAC member along with the Staff Co-Chair of the General PFAC, led a session focused on establishing and operating a PFAC, facilitating collaborations, and how best to measure successes.

• **Vizient Focus Group** – Three General PFAC members participated in two focus groups conducted by Vizient, which facilitates a network of health care organization members nation-wide. The focus groups addressed the experiences of patient and family members receiving care during the pandemic. Results of these nation-wide focus groups were published.

• **Additional Contributions** – In addition to the above committee and initiative participation, members provided feedback on visitor policy videos and various communications relating to Open Notes, Mass HiWay, Patient Gateway messaging. Members also provided input into the Quality and Safety Goal-setting process, along with interdisciplinary stakeholders across the community.

**Additional Accomplishments**

• **Continued serving on a virtual basis** and explored new ways of connecting with one another; attendance and participation remained strong.

• **Continued increase in number of requests** for PFAC member participation and feedback.

• **100% term renewals** across several members with terms up for renewal

• **Continued consultation** with areas looking to form a PFAC or partner with patients/ families.

• **The General PFAC celebrates its 10-year anniversary!**
Image: Photograph montage of several General PFAC members. Please note photos do not represent the entire membership of the General PFAC.
### GENERAL PFAC MEMBERS

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<tr>
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<tr>
<td>Neelesh Ajmani</td>
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Image: Watercolor circle of colors highlighting Cancer Center PFAC section.
Graphic by General PFAC member Stuart Murphy.
CANCER CENTER PATIENT AND FAMILY ADVISORY COUNCIL

Established in 2001

OVERVIEW

As an advisory council to Cancer Center administration and staff, the CC PFAC’s primary objectives are to promote and support patient and family-centered care, to provide education on the patient and family experience, and to expand the voice of patients and families throughout the Massachusetts General Hospital by participating in hospital wide committees and engaging with other patient and family advisory councils.

The Cancer Center PFAC has an ongoing commitment to meet these objectives by advising Cancer Center leadership on important initiatives such as space planning, program development, and the Cancer Center’s ongoing evaluation of the quality of care and other important initiatives.

MISSION

The mission of the Mass General Cancer Center Patient and Family Advisory Council is to ensure that the voices of patients and families are represented in an effort to enhance their entire experience at the Massachusetts General Hospital Cancer Center.

OPERATIONS OVERVIEW

Council Operations

The CC PFAC meets on the second Wednesday of each month from 5pm - 6:30pm. Meeting minutes and materials are stored electronically for at least five years. Council minutes and a summary of the council’s accomplishments are provided to the hospital’s governing body.

Membership

The CC PFAC currently consists of 13 active members, 15 alumni members, and 8 staff members. Members represent diverse perspectives and diversity in age, gender, diagnosis, treatment history, race/culture, and socioeconomic status. Current members represent at least five different Cancer Center disease programs, as well as three different sites (Boston/Main Campus, Mass General/North Shore Cancer Center in Danvers, and Mass General Cancer Center at Mass General Waltham).

Staff members of the CC PFAC include the Cancer Center Executive Director, Cancer Center Nurse Director of Ambulatory Oncology Clinical Services, Associate Chief of Nursing, Cancer Center Director of Communications, Marketing and Education, an Oncology Social Worker, two project/program managers, and a medical oncologist.
Qualifications for Membership

To serve on the CC PFAC, patients and family members must have a recent history of receiving cancer care at the Mass General Hospital Cancer Center. They must be able to use their own individual cancer experience in an objective way so that they can ask questions and offer a perspective that could be applicable to many patients and families living with cancer. They must possess good listening skills and be able to work collaboratively with others. CC PFAC members are asked to commit to attending monthly CC PFAC meetings as well as serving on committees throughout the Cancer Center and MGH, as well as CC PFAC subcommittees. Members are asked to make a two to four-year commitment. Alumni members have the option to remain involved by attending select CC PFAC activities, if available, but do not attend the monthly council meetings.

Membership Requirements and Training

CC PFAC members are required to meet Mass General volunteer standards which include the completion of HIPAA training and annual signing of the MGH confidentiality statement. CC PFAC members play an active role in orienting new members. Members serve as “buddies” to new members and provide peer mentoring on the role. New members are also encouraged to attend Cancer Center new staff orientation as well. Ongoing education is provided throughout the year by invited staff who present on a variety of topics such as cancer survivorship programming, quality of care, supportive care resources and changes in clinical care.

PFAC Member Recruitment

Prospective members are nominated by Cancer Center physicians, staff or current CC PFAC members with the patient or family member’s permission. Nominees are asked to complete an application which is reviewed by a CC PFAC staff member prior to an interview with select candidates. CC PFAC staff selects new CC PFAC members with a goal of having a diverse membership representing the cultural and socioeconomic diversity of Cancer Center patients and a variety of cancer diagnoses and treatments.
**CC PFAC Leadership**

By choice, the CC PFAC has no formal chair or elected officers. Currently the meetings are facilitated by Cancer Center leadership. Agenda items are prioritized by staff members based on topics discussed at CC PFAC meetings and requests from Cancer Center and MGH-wide staff that wish to consult the council.

**Roles and Activities**

In addition to their attendance at monthly CC PFAC meetings, members are also asked to serve on Cancer Center and Mass General steering and review committees. Committees on which CC PFAC members have served include the Patient Experience Council, Care Redesign Projects, Quality and Safety Committee, Patient Education and Communications Subcommittee, and the annual Survivorship Conference.

CC PFAC members have participated in the interview process for oncology nursing leaders, the review of patient satisfaction and quality data, and the design of programming and patient education efforts. They have also been involved in Cancer Center initiatives to improve clinical operations such as feedback on new nursing communication devices, the design of new clinical units, and projects to improve wait times and workflow.

Members also serve in an educational capacity by providing Cancer Center staff with a forum to discuss patient/family member perspectives and to address strategies on how to address different interactions across the continuum of care. Residents and fellows, support staff and nursing staff have all participated in these sessions.

**ACTIVITIES AND ACCOMPLISHMENTS - 2020-2021**

**Topics Reviewed by and Presented to the Cancer Center PFAC**

The PFAC has had many *accomplishments* over the past year. Each year, PFAC members are surveyed to identify their *goals and priorities as advisors* to the Cancer Center.

- **Radiation Oncology Presentation**: Ted Hong, MD. and Henning Willers, MD.
- **Overview of Inpatient Oncology, Initiatives and Goals**: Meg Soriano, RN.
- **The Dangers of Vaping and its Effects on Lungs**: Kristin Beauparlant, RN.
- **State of the MGH Cancer Center in the Era of Covid-19**: Mara Bloom and Barbara Cashavelly, RN.
- **State of the Cancer Center**: David Ryan, MD.
- **Outpatient – Inpatient Council Overview**: Barbara Cashavelly, RN, Beth Souza, Courtney McLeish, and Courtney Jenkins.
- **R-Epoch Project**: Julie Cronin, RN and Meg Soriano, RN.
- **Development Office Updates**: Megan Daniels, Keith Erickson, Jenn Ryan, Bob O’Brien, Bell Camelo.
- **Update on the Peer Mentoring Program**: Nova Hodge, MSW.
• **Bamlanivimab clinic within the Respiratory Ambulatory Care Center:** Kelly Goodwin, NP, Caryn Liebowitz, RN, and Michael Dougan, MD, PhD.

• **Caregiver Research through Cancer Outcomes Research and Education Program (CORE):** Jamie Jacobs, PhD

• **Lung Cancer Clinical and Research Updates:** Lecia Sequist, MD

• **New Building Updates:** Sarah Markovitz, Noelia Bitar, and Mahta Ostovari.

• **Oncology Social Work Overview and Remote Work:** Lourdes Barros, MSW.

• **International Updates:** Evelyn Abayaah, MS.

• **CAR-T Overview – Research and Nursing:** Marcela Maus, MD, PhD, Noopur Raje, MD, Matt Frigault, MD, Sally Geary, RN, and Laura White, RN

• **ASCO Equity Grant - Underrepresented Minority Clinical Trial Enrollment:** Erica Warner, SC.D

**Cancer Center PFAC Member Participation in Committees and Initiatives**

- **Patient Experience Summit - Panel Participation**
- **Department of Public Health (DPH) hearing** for new building proposal
- **Department of Public Health (DPH) letter writing** in support of new building

**CANCER CENTER PFAC MEMBERS**

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Image: Watercolor circle of colors highlighting Emergency Department PFAC section. Graphic by General PFAC member Stuart Murphy.
Emergency Department Patient and Family Advisory Council

Established in 2018

OVERVIEW

Because of the unique nature of ED care, patient and family experience is a challenge in the MGH ED. Growing patient volume and overcrowding make providing outstanding patient experience even more difficult.

Despite these challenges, as the ED frequently represents a point of “first contact” with MGH, ED visits present a novel opportunity to make a positive impression on our patients and their families.

Given this, the ED PFAC was created to do the following:

1) Gain unique insight into the MGH ED patient/family experience through meeting with invested members of the community
2) Discover novel patient-driven approaches to improving the MGH ED patient experience
3) Receive feedback on existing initiatives to focus efforts and resources
4) Strengthen relationships with patients with existing interest in ED patient experience improvement

MISSION

Patients and their family members come to the emergency department when they are having their worst days.

Poor communication, a lack of perceived empathy, and a challenging environment make those days worse.

The MGH ED PFAC is going to work on making those days better.

ACTIVITIES AND ACCOMPLISHMENTS - 2020-2021

Topics Reviewed by and Presented to the Emergency Department PFAC

Through quarterly meetings and additional ongoing targeted requests and projects, the MGH ED PFAC has contributed throughout a wide spectrum of ED patient experience initiatives.

In 2020/2021, areas of focus for the ED PFAC included:

- ED Patient Texting Program
- COVID-19 effects on ED patient experience
- Acute Psychiatric Service space
- Patient Experience Surveying (NRC vendor transition)
• ED Center for Disaster Medicine
• ED Patient Callback Program

Previous topics/projects reviewed by the ED PFAC have included the following:
• ED Welcome Video
• ED See What Our Patients Are Saying About Us poster
• Attending informational business cards
• ED Comfort Menu
• ED signage
• Clinical Decision Unit (CDU) redesign
• Geriatric ED care
• Emergency Medicine intern orientation
• ED Code of Conduct
• “Weekly Pulse” staff newsletter
• Survey vendor changes/question item selection

Presentation topics have included the following:
• ED Center for Disaster Medicine
• ED background and volume/care statistics
• Current ED patient experience efforts
• ED flow and acuity areas/tour
• Current ED patient experience challenges
• Geriatric ED patient experience
• Police and Security role in ED

Emergency Department PFAC Member Participation in Committees and Initiatives
While the ED PFAC is brand new, several patient/family members have already participated in initiatives including:

• Providing public comment for Determination of Need for future ED expansion
• Participation in What Matters to You event
• Emergency Medicine resident conference
## EMERGENCY DEPARTMENT PFAC MEMBERS

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<td>Rosemary Marbach</td>
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<td>Kevin Prophete</td>
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<td>Ralph Verni</td>
<td>Jonathan Sonis (co-chair)</td>
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<td>Beth Walsh</td>
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Heart & Vascular Centers
Patient and Family Advisory Council

Image: Watercolor circle of colors highlighting Heart and Vascular Centers PFAC section. Graphic by General PFAC member Stuart Murphy.
HEART and VASCULAR CENTERS PFAC

Established in 1999

OVERVIEW

The MGH Heart and Vascular Patient and Family Advisory Council continues to be an important and integral group that provides input and feedback to a variety of service related and institutional initiatives related to practice, programs, patient safety and innovation. This has been a long-standing group of very active members from all areas of both the heart and vascular centers. The unique perspectives of the individuals help provide valuable guidance and perspectives to existing and newly proposed programs, models of care and practice. All join with the goal to enhance the patient experience while maintaining the excellent patient and family centered care that is a hallmark of the Heart and Vascular Centers at MGH.

MISSION

To ensure that the voices of patients and families are represented in a multidisciplinary effort to enhance the experience of care at the Massachusetts General Hospital.

ACTIVITIES AND ACCOMPLISHMENTS - 2020-2021

Topics Reviewed by and Presented to the Heart & Vascular PFAC

During quarterly meetings, the Heart Vascular PFAC reviewed, provided feedback on, and learned about a variety of topics spanning settings and strategic imperatives. These topics included but not limited to:

- **MGH Race and Equity Plan**: Natalie Johnson, Administrative Director of MGH Equity and Inclusion discussed MGH’s 10-point structural plan to improve equity & inclusion for patients and staff, and how the transition to a COVID response compelled them to accomplish some goals more quickly.
- **MGH Biothreats Program and the Covid-19 Response**: Rob Krupa, Senior Program Manager, & Jen Andonian, Program Manager, both from the Center for Disaster Medicine discussed recovery operations for the hospital, and the plan for a potential second surge in the fall and winter.
- **Heart and Vascular Centers’ Recovery Plans**: Jamie Breed, Administrative Director for the Heart Center, discussed the anticipated fall and winter recovery plans for the Heart and Vascular Centers with a commitment to patient safety, including patient outreach and education
- **Covid-19 Updates**: Q&A with members regarding Infection Control, vaccination updates, etc.
- **New Building Updates**: Architect Group NBBJ provided updates on the new building set for Cambridge Street in 2030, including virtually touring around at one of the new room concepts.
Heart & Vascular PFAC Member Participation in Committees and Initiatives

PFAC members participated in initiatives across the hospital and system, providing the patient/family perspective within interdisciplinary groups.

- **CMS patient engagement opportunity:** CMS was seeking patients, families and caregivers with experiences in the following areas:
  - Heart Failure
  - Mental and Behavioral Health with a focus on Depression
  - Low Back Pain management through physical therapy or surgery
  - Visit to an Emergency Room

- **Department of Public Health/Determination of Need Public Hearing on New Building:**
  Members offered verbal or written testimonies publicly supporting the need for a new building.

Additional Accomplishments

- Recruited 2 new members
- Developed Heart & Vascular PFAC website
HEART AND VASCULAR CENTERS PFAC MEMBERS

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<td>Teri Fryer</td>
<td>Michele Anastasi (<em>joined April 2021</em>)</td>
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<tr>
<td>Tom Fryer</td>
<td>James Breed (<em>resigned June 2021</em>)</td>
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<tr>
<td>Phil Geary</td>
<td>Marie Elena Gioiella</td>
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<tr>
<td>Susan Gerry</td>
<td>Glenn LaMuraglia (<em>joined July 2021</em>)</td>
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<tr>
<td>Pat Hollenbeck</td>
<td>Cindy Sprogis</td>
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<td>Denise Mallen</td>
<td>Carolyn Velez</td>
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<tr>
<td>Tom Quirck (<em>resigned June 2021</em>)</td>
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<tr>
<td>Matt Smith</td>
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<td>Sarah Strope</td>
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<td>David Wooster</td>
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Image: Watercolor circle of colors highlighting MassGeneral Hospital for Children FAC section. Graphic by General PFAC member Stuart Murphy.
MassGeneral Hospital for Children Family Advisory Council

Established in 1999

OVERVIEW

The Family Advisory Council is a partnership of family members, hospital leadership, and staff dedicated to working together to improve the care and experience of patients and their families. We are a diverse group of family members whose children have received care at MassGeneral Hospital for Children (MGHfC). The FAC is co-Chaired by a family member and a staff member. The Council is integral to the Pediatrics Department, providing input and guidance around clinical practice, program planning and education, and the family experience. The Council is the longest standing active advisory group of patients and families at MGH. It has a particular focus in helping MGHfC care teams’ practice with a family-centered perspective.

MISSION

The Massachusetts General Hospital for Children Family Advisory Council is dedicated to fostering the partnership of parents, children and professionals working together to ensure a climate of responsiveness to the needs of children and their families in all areas of care within the hospital.

ACTIVITIES AND ACCOMPLISHMENTS - 2020-2021

Goal Setting in the context of Covid-19 – During our annual goal setting session, staff posed this question to parents: Is MGHfC meeting your needs at this time? Parents noted that they were experiencing isolation in the context of inpatient stays and needed more guidance around protecting their children from the Covid 19, especially children with complex medical needs. Our goals for the year (below) reflect our efforts to take direct action to meet families’ needs.

- **Parent Support in PICU/NICU and the wards** – Parent members voiced a desire for more parent-to-parent supports so that they could interact with parents whose children’s health journeys are like their own. FAC put together a list of all parent-to-parent programs at MGHfC and have distributed it to social workers in the NICU, PICU and wards so they can alert appropriate families to the existence of the programs.
• **Development of a parent-facing newsletter** – Given the high-quality educational material generated by MGHfC and its providers, the Family Advisory Council is investigating the feasibility of creating a parent-facing newsletter modeled on Totline, an internally-focused monthly newsletter. This will enable all parents to have easy access to the educational materials developed by hospital personnel.

• **Development of process for parents to advise on patient experience data** – The group received quarterly summaries of patient experience metrics from the Director of Quality and Safety. The group is strategizing ways for parents to be involved in the development of improvements based on the data.

• **Creation of online relaxation and meditation sessions** – Dr. Miri Bar Halpern, parent member and clinical psychologist, created 6 mindfulness meditation audios that have been posted on the MGHfC YouTube channel and are available to parents. In collaboration with the PICU, she developed brochures to alert parents of their existence so that they can take advantage of this support during their children’s stays.

• **Family Advisory Council Grand Rounds** – Members of the Family Advisory Council and several staff members spoke at Pediatric Grand Rounds about the Journals of Hope program created by FAC parent and co-chair Faith Wilcox. The program now provides journals and writing prompts to parents, guardians and children in the NICU, PICU, Pediatric Wards and Radiation Oncology. Parents spoke about the beneficial aspects of writing in a journal when they were experiencing long hospital stays with their children, while staff members talked about their role in the development of the program and their own experiences of journaling for stress relief. Several members of the audience voiced their desire to extend the program to their departments.

Image: Sunset scene displayed throughout the MGHfC YouTube Affectionate Breathing Meditation Video

Image: Caring Headlines article about the MGHfC Journals of Hope program
• **Website updates/contributions** – The group worked with website development and marketing to update the ‘News’ section of the MGHfC website with stories about FAC and sections of videos parents had produced on the subject of why they chose MGHfC for their children’s care.

• **Bedside Rounding Surveys** – FAC parents filled out surveys provided by the MGHfC Residency Program about their preferences surrounding morning rounds. These included questions about parents’ understanding of the purpose of rounds, their desired levels of participation, and comfort in taking part in discussions during them.

**Topics Reviewed by and Presented to the MGHfC FAC**

• Emily Kung, MD presented the work of the MGHfC Diversity, Equity and Inclusion Committee and received feedback from FAC members

• Katherine Schiavoni, MD from the MGH Integrated Care Management Program asked for parents' feedback on plans to improve transitions from inpatient pediatric to adult care for patients with complex medical needs

• Caitlin Li, MD, Harvard Medical School Fellow in Patient Safety and Quality joined two meetings to observe the workings of a Family Advisory Council

• Ellen O’Donnell PhD and Mary Bennett LICSW from the Pediatric Diabetes Transitions Program spoke to the group about their program that prepares pediatric patients for the world of adult medicine and is a model for other departments

• Emma Materne, MD apprised the group of efforts to improve the practice of bedside rounding. FAC parents have a long history of providing their feedback based on their experiences of care. Parents’ feedback will inform the changes made to the current processes

• Dr. Miri Bar Halpern, parent member and clinical psychologist, spoke to the group about her experiences of long hospital stays in the PICU, the traumatic effects of such stays, and ways staff and parents can mitigate those effects. She had previously given the presentation to PICU staff.

• Throughout the pandemic, hospital staff and leadership thoroughly apprised the group of the hospital’s current policies around Covid 19, measures undertaken to ensure patient safety, as well as case numbers in the hospital and throughout the state

**MGHfC FAC Member Participation in Committees and Initiatives**

Family Advisory Council members continued to participate in ongoing committees, task forces, and initiatives across the hospital and system, providing the patient/family perspective within interdisciplinary groups.

• **Pediatric Ethics Committee** – Hospital-wide committee that reviews and consults with staff about ethical issues regarding care of children who are MGHfC patients

• **Inpatient and Outpatient Patient Experience Committee** – Committee focused on improving the experience for patients and families throughout the hospital
• **Quality and Safety Committee**—Hospital-wide committee that oversees safety initiatives and evidence based-care models to ensure high quality, safe and patient-centered care to MGHfC families

• **Gun Violence Prevention Committee** – MGH-wide multidisciplinary committee dedicated to preventing firearm-related violence and promoting safety in the homes and communities of the patients MGH serves

• **Transitions Committee** – Committee whose mission is to facilitate the transition from pediatric to adult care for inpatients.

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**MASSGENERAL HOSPITAL FOR CHILDREN FAC MEMBERS**

**Patient/Family**

- Seta Atamian
- Miri Bar-Halpern
- Lisa Cimino
- Ashley Conti Smith
- Charlene Harper
- Roxanne Hoke-Chandler
- Matthew McGuiness
- Janice Morris
- Colleen Newland
- Erin Quinney
- Sarah Romano
- Ann Skoczenski
- Randi Stempler
- Faith Wilcox (Co-Chair)

**Staff**

- Barbara Cashavelly
- Sandra Clancy (Co-Chair)
- Brian Cummings
- Esther Israel
- Emily Lloyd
- Sandra Dodge McGee
- Anne Bouchard Pizzano
- Lisa Scheck
- Kim Whalen
- Glynis Wood
Image: Watercolor circle of colors highlighting Pediatric Oncology FAC section. Graphic by General PFAC member Stuart Murphy.
Pediatric Oncology Family Advisory Council

Established in 2003

OVERVIEW

The Pediatric Oncology Family Advisory Committee (FAC) has continued to remain integral to the Pediatric Oncology clinical service, providing input around clinical practice, program planning and patient safety. This has been a long-standing active group since 2003 with a changing membership to reflect the needs of the parents and the practice. Parents of children receiving cancer treatment and parents of those children who have completed treatment join with members of the multidisciplinary team of clinical professionals to collaborate with the common goal of providing excellence in pediatric family centered oncology care and enhancing the patient and family’s experience.

MISSION

Massachusetts General Hospital for Children’s Cancer Center Family Advisory Committee (FAC) is committed to fostering a partnership between families and caregivers to promote excellence in the care of children with cancer.

ACTIVITIES AND ACCOMPLISHMENTS - 2020-2021

Topics Reviewed by and Presented to the Pediatric Oncology FAC

Meetings continued to be held virtually throughout the year to ensure the safety of our members during the COVID-19 pandemic. Pediatric Oncology Family Advisory Committee continued to review programs and issues impacting the Pediatric Oncology clinic. During this pandemic, the group has provided added guidance to our clinic as we navigate new practices to care for our patients safely. The meetings also offered an opportunity for mutual support amongst members during these very uncertain and worrisome times. The topics addressed this year included the following:

• Identifying topics to be addressed in the parent support/informational series entitled Conversations in Challenging Times.
• Diversity and racial disparities in health care and opportunities for enhancement to our clinical program in this arena.
• Review of the Pediatric Hematology-Oncology website and work with web designer of MGHfC to plan for amendments
• Programming for National Childhood Cancer Awareness month
• Review of Patient Experience data
• Report from the Chief – update on coronavirus in pediatric oncology and changes in clinic practice
• Review of informational materials to be distributed to patients/families to address issues of concern related to safety in coming into the hospital and clinic
Additional Accomplishments

- Member was funded to attend the ACCO (American Childhood Cancer Organization) Advocacy Days which was held virtually in April 2021. She shared experience of meeting with congressional representatives to advocate for passage of Childhood Cancer Research initiatives.

- Subcommittee developed a draft of a questionnaire to be distributed to Pediatric Hematology-Oncology families to assess satisfaction in care and communication with diverse patient populations and those with limited English proficiency. Planning for the implementation of this study for the fall of 2021.

PEDIATRIC ONCOLOGY FAC MEMBERS

<table>
<thead>
<tr>
<th>Patient/Family</th>
<th>Staff</th>
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<tbody>
<tr>
<td>Dawn Regan (Co-Chair)</td>
<td>Elyse Levin-Russman, MSW, LICSW (Co-Chair)</td>
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<tr>
<td>Claudia Cardona</td>
<td>Alison Friedmann, MD</td>
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<tr>
<td>Mary Cincotta</td>
<td>Patti Scott, RN</td>
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<td>Michael Doiron</td>
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<td>Tim Dunne</td>
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<td>Susan Jacobson</td>
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<td>Paula Marshall</td>
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<td>Chau Nguyen</td>
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<td>Jerry Schindler</td>
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<tr>
<td>Janice Theriaque</td>
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<tr>
<td>Tarrah Zedower</td>
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Forthcoming
Patient and Family Advisory Councils

Image: Watercolor circle of colors to be expanded with formal addition of evolving PFACs. Graphic by General PFAC member Stuart Murphy.
Dementia Care Collaborative Patient and Family Advisory Council

Forthcoming

OVERVIEW

The Division of Palliative Care and Geriatric Medicine is launching a new PFAC for MA General Hospital. The Dementia Care Collaborative-PFAC will consist of patients living with dementia, caregivers and family members with recent care experiences across inpatient and ambulatory Mass General settings and community members with special expertise and experience in dementia and caregiving. DCC PFAC members will provide valuable expertise on a wide variety of important topics. Members will lend their time and ideas by participating in ongoing DCC PFAC meetings, by participating in committees and initiatives across the organization, by conducting reviews, and generally by serving as an advisory resource in many additional ways.

Charlestown HealthCare Center Patient and Family Advisory Council

Forthcoming

OVERVIEW

The Mass General Charlestown HealthCare Center is launching a PFAC which will consist of patients, family members with recent care experiences at Charlestown HealthCare Center and hospital staff dedicated to improving care experiences. Members will participate in monthly meetings, provide their unique perspectives, and play a crucial role in shaping services, programs, and initiatives. Charlestown HealthCare Center greatly values PFAC collaborations, and is in the process of forming its membership and structure.
Image: Watercolor image of a lotus flower displaying PFAC values in the center, and selected values in each petal: Respect, Commitment, Passion, Equity, Inclusion, Collaboration. Graphic by General PFAC Members: Concept-Joyce Smith. Image-Stuart Murphy.
Appendix
Bylaws

General PFAC Bylaws are provided for purpose of this Annual Report. Additional Mass General PFAC bylaws are available upon request.
MGHGeneralPFAC@partners.org
General Patient and Family Advisory Council
Bylaws

Article 1. Overview
Patient and Family Advisory Councils (PFACs) bring together Mass General patients, family members, staff, and clinicians in an ongoing effort to improve care and the patient and family experience. PFACs integrate, elevate, and promote the patient and family voice in the development of programs, services, and initiatives. The needs of those who entrust Mass General with their care lie at the heart of the organization’s Mission; listening to their voices, examining care delivery through their eyes, and tapping into their expertise helps Mass General strive for excellence.

The Massachusetts General Hospital General Patient Family Advisory Council (General PFAC) consists of patients and family members with recent care experiences across inpatient and ambulatory Mass General settings. General PFAC members provide valuable expertise on a wide variety of important topics. Members lend their time and ideas by participating in ongoing General PFAC meetings, by participating in committees and initiatives across the organization, by conducting reviews, and generally by serving as an advisory resource in many additional ways.

Article 2. Mission Statement
To continuously embrace the opening words of the Mass General Mission Statement, “Guided by the needs of our patients and their families,” to systematically integrate the patient and family voice in services, programs, and initiatives across the organization, and to promote consistently compassionate care experiences.

Article 3. Goals
- Influence & align General PFAC activities with strategic imperatives of the hospital/system, including focus on equity and inclusion and adaptation to a health care landscape changed by the pandemic.
• Promote General PFAC member participation on committees and initiatives across the hospital/system, so as to facilitate integration of the patient/family perspective in shaping services, programs, and initiatives.
• Continue to recruit General PFAC members who represent the diverse population of the patients served by Mass General.
• Enhance General PFAC member understandings of the hospital/system infrastructure, and operations to facilitate capacities to contribute as Advisors.
• Continue to expand awareness of the General PFAC across the hospital/system.
• Advance and support high quality, coordinated communications between patients and their care team members.

Article 4. Overarching Structure and Membership
The General PFAC consists of at least 16 patient/family members. Up to 8 Mass General staff members also may serve on the General PFAC. Leadership of the General PFAC will include a Patient/Family Co-Chair, a Staff Co-Chair, and an Executive Committee, as provided for in Articles 7 and 8. The structure of the General PFAC may change over time.

Article 5. Membership Processes
Section 1. Recruitment
Recruitment of patient and family General PFAC members is initiated by referral, website application, targeted information dissemination, survey responses, and interest otherwise expressed by potential candidates.

Section 2. Membership Valued Qualities
Members are selected with consideration of the following criteria:
• Recent experience as a patient or family member at Mass General.
• Comfort with sharing ideas and experiences in a group setting.
• Embrace of diverse backgrounds and viewpoints, respect for others’ perspectives, and ability to interact well with a diversity of individuals.
• Aptitude for active listening.
• Ability to advocate effectively for the needs and priorities of patients and families.
• Enthusiasm about work in an advisory role through participation in organizational committees or initiatives.
• Ability to participate in a consistent and agreed upon schedule of virtual or in-person meetings.
• Commitment to serve for a 2-year term with potential to renew at the end of the term.
• Support of Mass General’s Mission.
• Passion about making a difference.
Section 3. Membership Selection
Applications are available on the Mass General website, and otherwise shared with identified prospective members. Applications are reviewed on an ongoing basis. Applicants are screened and subsequently interviewed, as deemed appropriate, by General PFAC Co-Chairs and/or Executive Committee members and/or designated individuals. Those who are identified as top candidates by interviewers will be reviewed by the Executive Committee, and subsequently notified by the Co-Chairs of the General PFAC as to their selection.

Section 4. Terms of Appointment
- General PFAC patient/family members are appointed for a term of 2 years, commencing upon the date of their selection.
- General PFAC patient/family members may request to be reappointed for additional terms of 2 years, upon mutual agreement between General PFAC Executive Committee and the member, with total consecutive years not to exceed 10.
- Resignations should be submitted in writing or via e-mail to the Co-Chairs.
- Appointments are granted on an ongoing basis, and vacancies may be filled during the year as needed.

Article 6. Roles and Responsibilities of Members
Section 1. Roles and Responsibilities of Patient/Family Members
- Attend virtually or in-person each General PFAC meeting or notify a Co-Chair in advance (barring prohibitive circumstances), if unable to attend.
- Prepare and engage thoughtfully and constructively with respect to the issues and ideas discussed during General PFAC meeting and all additional committees attended.
- Respect the unique background and perspective of each member.
- Represent the General PFAC positively on all organizational committees and initiatives attended.

Section 2. Roles and Responsibilities for Staff Members
- Attend each General PFAC meeting or notify one of the Co-Chairs in advance (barring prohibitive circumstances), if unable to attend.
- Help to identify prospective General PFAC members, with consideration of valued General PFAC member qualities, and provide referrals as appropriate.
- Interview and/or orient potential General PFAC patient and family members, as appropriate.
- Present to the General PFAC on areas of focus or organizational initiatives.
• Take minutes on a rotational basis as needed, if Secretary role is not filled.
• Serve as an advocate for the General PFAC and promote awareness across the organization about the value of PFACs and PFAC contributions.

Article 7. Roles and Responsibilities of Officers of the General PFAC

Section 1. Patient/Family Member and Staff Co-Chairs
• Attend and preside at each General PFAC meeting.
• In collaboration with the Executive Committee, develop and implement goals and strategic initiatives of the General PFAC.
• In collaboration with the Executive Committee, set agendas for meetings, and respond/outreach to potential General PFAC presenters and visitors.
• In collaboration with the Executive Committee, manage the patient and family member recruitment process.
• Manage communications with General PFAC members, including distribution of agendas, minutes, and any additional materials.
• Maintain minutes for a minimum of 5 years as provided for in Article 12, Section 2.
• Communicate activities of the General PFAC to Mass General leadership.
• Serve as an advocate for PFACs across Mass General and Mass General Brigham.
• Represent Mass General PFACs in the health care community, as appropriate.
• Facilitate Mass General PFAC Leaders meetings, dialogues, and collaborations.
• Prepare annual General PFAC report in collaboration with additional designated General PFAC members, as appropriate.

Section 2. Secretary
• Record minutes of each General PFAC meeting.
• Provide minutes to Co-Chairs, and/or Executive Committee member(s) in a timely manner, for their review prior to distribution to members of the General PFAC.

Article 8. Executive Committee of the General PFAC

Section 1. Membership
• The Executive General PFAC Committee consists of the Patient/Family Member Co-Chair, the Staff Co-Chair, Secretary, and selected staff members, and may include selected General PFAC members at large. The total membership shall not exceed 7.
Section 2. Duties and Responsibilities

- Act as the nominating committee of the General PFAC membership, bringing forth nominations for Patient/Family Member Co-Chair, and Secretary.
- Participate in the General PFAC membership selection process, as provided in Article 5, Section 3.
- Participate in the setting of agendas for each General PFAC meeting, and other such duties as may be determined.
- Act on behalf of the General PFAC between meetings, as necessary.

Article 9. Terms of Officers

The terms of General PFAC Officers are as follow:

- The term of the Co-Chair is not to exceed 8 years.
- The term of the Secretary shall be 2 years, subject to renewal for 2 subsequent 2-year terms.
- Vacancies will be filled as necessary.

Article 10. Orientation and Training

Section 1. Mass General Orientation and Training

All selected General PFAC patient/family members receive orientation and training as to the mission and goals of Mass General. Training includes hospital regulatory and privacy issues, and through this training, PFAC members commit to adhering to Mass General guidelines and Health Insurance Portability and Accountability Act (HIPAA) requirements.

Section 2. General PFAC Orientation

All selected General PFAC patient/family members receive orientation specific to the General PFAC, including review of the bylaws.

Article 11. Confidentiality

General PFAC members must not discuss any personal or confidential information revealed during General PFAC meetings, through communications, or through the secure file sharing outside of these forums. General PFAC members must adhere to all applicable HIPAA standards and guidelines. If a member violates these guidelines, the Co-Chairs will remind them of the guidelines. Repeated violations may result in repeating HIPAA training or reevaluation of membership status.
Article 12. General PFAC Meetings
General PFAC meetings are held monthly. Each meeting is scheduled for 1.5 or 2 hours in length.

Section 1. Agenda
The General PFAC meeting agenda is set by the Executive Committee and distributed to the membership prior to each meeting, along with any pertinent materials for discussion during the meeting.

Section 2. Meeting Minutes
The Secretary takes minutes of each General PFAC meeting. Minutes are retained for a minimum of 5 years.

Section 3. Attendance
It is expected that the members of the General PFAC will make every attempt to attend each monthly meeting either virtually or in-person. Participation by every member is expected and welcomed. Notice of inability to attend is requested for each meeting. If a member is not able to attend 3 consecutive meetings, the Co-chairs contact the member to discuss their commitment to the General PFAC.

Article 13. Additional Committees and Initiatives
It is encouraged that General PFAC members participate in additional committees and initiatives, as feasible. General PFAC Co-Chairs will share requests and opportunities as they arise.
It is expected that, if a General PFAC member engages in additional volunteer or other work at Mass General or Mass General Brigham, the member share the nature of this work with the General PFAC Co-Chairs.

General PFAC members may be asked to provide reports and updates about this additional work to the General PFAC.

Article 14. Termination
The General PFAC Executive Committee reserves the right to dismiss any member whom the committee deems not to be compliant with the responsibilities as set forth by the bylaws.
Article 15. Bylaws
The bylaws of the General PFAC shall be reviewed at least every 3 years. These bylaws are reviewed by the Executive Committee of the General PFAC and accepted via a voting process in which at least 75% of the members of the General PFAC participate. The bylaws may be amended as necessary by the members of the General PFAC, as stated herein.

Updated: January 2021