



MASSACHUSETTS
GENERAL HOSPITAL

Massachusetts General Hospital Patient and Family Advisory Councils



2019-2020 Annual Report



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
- Ambulatory Practice of the Future Care Alliance
- 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) Parent and 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.



MASSACHUSETTS
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General Patient and Family Advisory Council

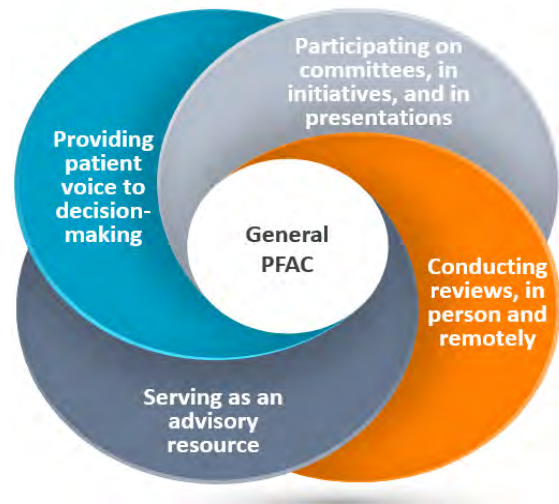


GENERAL PATIENT & FAMILY ADVISORY COUNCIL

Established in 2011

OVERVIEW

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 PFAC meetings, *participating in committees and initiatives across the organization*, conducting reviews remotely, and serving as an advisory resource in many additional ways.



MISSION

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.

“One aspect of our work on the General PFAC that is especially gratifying is knowing that our opinions as patients are valued within the hospital community.”

“I greatly value the camaraderie that exists between the members of the General PFAC. We all come from different walks of life but share the common experience of being patients at MGH. There is a definite feeling of mutual respect and interest in the comments and ideas of others.”

ACTIVITIES AND ACCOMPLISHMENTS - 2019-2020

Topics Reviewed by and Presented to the General PFAC

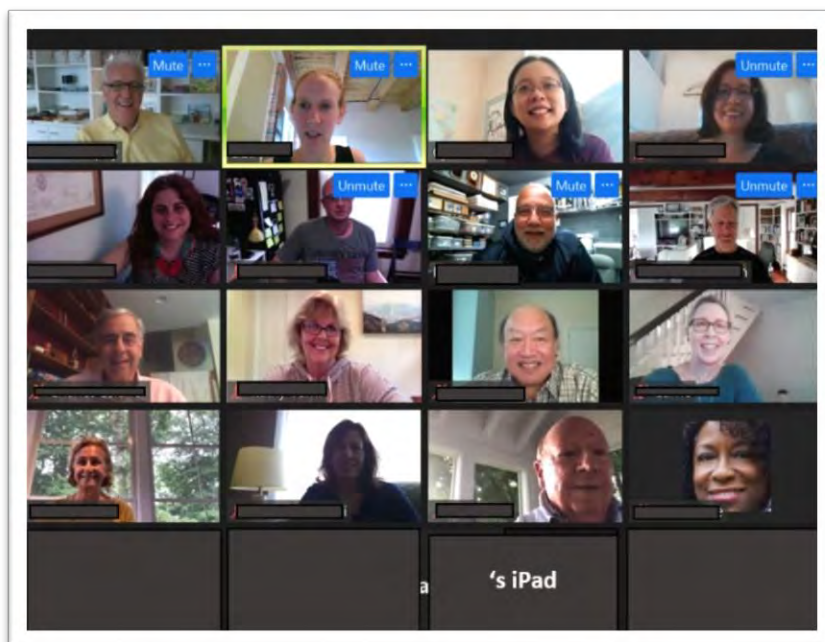
During *monthly meetings and through many targeted requests*, the General PFAC *reviewed and provided feedback* on a variety of topics spanning settings and strategic imperatives. Each collaboration is lively and engaging allowing for mutually beneficial *sharing and learning*. These topics included:

- **Diversity & Inclusion** – Joseph Betancourt, MD Vice President and Chief Equity and Inclusion Officer presented his vision for the future of equity and inclusion at Mass General. Patients were invited to share ideas and feedback.
- **Behavioral Health** – Sara Macchiano, Sr. Administrative Director, Psychiatry and Justin Chen, MD Medical Director, Ambulatory Psychiatry shared current challenges and opportunities in the field of behavioral health. Members engaged in dialogue about experiences and possible ways they might contribute.
- **Spiritual Care and Education** – Rev. Alice Cabotaje, Director of Spiritual Care of Education shared comprehensive services provided to patients, staff and visitors, and Imam Elsir Sanousi, Spiritual Care staff member of the General PFAC shared his personal account of providing care. Discussion heightened awareness of this critical component of care and wellness.
- **Safety and Security** – Bonnie Michelman, Executive Director of Policy and Security and Outside Services along with Robin Lipkis-Orlando, RN Director of Office of Patient Advocacy shared experiences and interventions on handling difficult patient experiences using a variety of strategies. Discussion highlighted the breadth and depth of the departments' respective and collaborative work.
- **Chief Nurse & Senior VP of Patient Care Services** – Debbie Burke, RN Chief Nurse & Senior VP of Patient Care Services visited with members to discuss strategic initiatives, challenges, and opportunities, and to engage in dialogue with members. Annual visit with General PFAC accompanied by year-end celebration of accomplishments.

“The presentations by Safety and Security and Spiritual Care and Education were very impressive. They enlightened me to the comfort, safety and security that is provided not only to patients and families, but very importantly to all the employees of MGH.”



- **Medicine Unit Operations & Interventions** – Colleen Gonzalez, RN Nurse Director of a Medical Unit, shared challenges and opportunities of leading a Medicine Unit, and discussed interventions in progress to address some of these areas.
- **Discharge Summary** – Jack Rowe, MD Attending Medicine physician provided an overview of changes to discharge summary approaches. Members provided feedback and suggestions to assist with the care transition process.
- **COMPASS Website Body Heat Map** – Members provided feedback on a Center for Outcomes & Patient Safety in Surgery (COMPASS) body heat map concept to view surgical quality and outcomes data.
- **Patient Gateway Communications During the Pandemic** – Members provided input on language on a resource document disseminated through Patient Gateway towards the beginning of the pandemic. Members also reviewed and suggested revisions to service-line communications regarding reopening.
- **Harnessing the Healing Powers of Stories** –Annie Brewster, MD Health Story Collaborative Founder and Executive Director presented the healing powers of patient storytelling and the philosophy and motivation behind the use of storytelling as a therapeutic tool. Patients were provided techniques on how to share their health story.
- **Patient Safety During the Pandemic**
Elizabeth Mort, MD Senior VP
Quality and Safety and Chief Quality Officer for Mass General discussed current state of patient safety, engaging in conversation with members about policies, resources, and collaborative initiatives across the hospital.
- **Ambulatory Behavioral Health Social Work Virtual Visits During the Pandemic** – Lourdes Barros, MSW, LICSW Clinical Director of Social Work, along with Lisa Scheck, LICSW Clinical Specialist, and General PFAC staff member, provided an overview of Social Work’s support to patients, families, and colleagues during the pandemic, with focus on the transition to virtual visits. Members discussed experiences with virtual visits, and Social Work support broadly.



“Having served as a patient representative on the Mass General Brigham Telehealth Taskforce & Coordination Committee, I had the opportunity to lay a foundation at the system level enhancing patient experience. Today’s environment has provided an opportunity for patients to continue to receive excellent care through use of telehealth. Quick adoption has been necessary and impressive!”

General PFAC Member Participation in Committees and Initiatives

In addition to attendance at monthly meetings, General PFAC members continued to *participate in ongoing committees, task forces, and initiatives* across the hospital and system, providing the *patient/family perspective within interdisciplinary groups*.

- **Blum Patient & Family Learning Center/General PFAC Education Committee** – A working committee of several General PFAC members collaborates closely with the Blum Patient & Family Learning Center to review educational materials using plain language review and facilitated discussion.
- **Quality Oversight Committee** –Senior leadership committee reviewing quality and safety topics- includes two General PFAC members.
- **Mass General Brigham Patient Experience Leadership Committee** –System-level committee consisting of patient experience leaders from hospitals and entities across the system-includes one General PFAC member.
- **Patient Experience Leadership Committee (PELC)**– Committee consisting of leaders from across Mass General Hospital and Physicians Organization who focus on the patient experience strategy and initiatives to enhance the patient experience – includes one General PFAC member, first patient to be included as a committee member.
- **Council on Disability Awareness** – Interdisciplinary Council consisting of representatives from across the hospital focused on disability access and awareness and creating a welcoming environment for all – includes two General PFAC members.
- **Facility Design** - Architects for the large new inpatient building facilitated sessions with interdisciplinary clinicians and staff and PFAC members - included four General PFAC members.
- **Engagement Advisory Committee, Continuum Project** - The Continuum Project is an organization wide initiative focused on living well with serious illness and introducing earlier, better, and more frequent serious illness conversations. One General PFAC member participates in this interdisciplinary committee focused on engaging patients and family members.

- **Judges – Annual Patient Experience Awards** – Each year clinicians and staff submit patient experience award nominations for colleagues who have demonstrated icare (communicate, advocate, respect, empathy) excellence. In 2020, five General PFAC members served as judges for the second year in a row, reviewing and voting on nominations.
- **Harvard Master of Clinical Service Operations Course** – Session focused on establishing and operating a PFAC, and incorporated patient perspectives about experiences serving on a PFAC and participating in various PFAC-related collaborations – included 2 members and the Staff Co-Chair of the General PFAC.
- **Perioperative Communications about Delays** – General PFAC member joined Perioperative Nursing Leadership to share experiences with information about delays on the day of surgery.
- **AI Imaging Ethics Workgroup** – System-level workgroup formed to consider ethics around incidental imaging findings – included 2 General PFAC members.
- **WeSolve Inpatient Experience Sessions** – Consortium for Affordable Medical Technologies (CAMTech) facilitated a series of 3 sessions focused on enhancing inpatient experience – six General PFAC members participated in these sessions.
- **Conferences & Webinars** – Members attended several conferences: Beryl Patient Experience Conference 2020 Virtual – PFAC Scholarship; Schwartz Conference 2019 – Compassion in Action; Vizient webinar – Connecting with Patients during COVID-19.

SPECIAL THANKS

A very special thank you to our General Patient and Family Advisory Council (PFAC) members who volunteered to select this year's nomination award recipients.

Pivoting During the Pandemic

The General PFAC quickly pivoted at the start of the pandemic and adjusted well to 100% virtual participation (from a small percentage previously), transitioning to a new rhythm of discussion and contribution. During and between monthly meetings, members have continued to reflect on and respond to various topics, as covered in the sections above.

“We have not missed a beat. While members miss the lack of physical engagement, we have continued to foster our growth together with technology.”

Additional Accomplishments

- **Recruitment of 5 new members.**
- **Continued increase in number of requests** for PFAC member participation and feedback.
- **Expanding awareness** of General PFAC, and breadth and depth of PFAC member involvement.
- **Continued facilitation of cross-PFAC** leader dialogues and initiatives.
- **Continued consultation** for areas looking to form a PFAC or otherwise partner with patients and families.

“As a new PFAC participant, I have been greatly impressed by what I have learned about the many complex facets involved in maintaining and striving to constantly improve patient care at MGH, as well as the dedication of fellow PFAC members whose volunteer work provides needed feedback to the caregivers.”

GENERAL PFAC MEMBERS

Patient/Family

Neelesh Ajmani
Stephen Brown
Bob Chen
Linda Cline
Julie DeCosta (Co-Chair)
Hilary Deignan
Catherine Duffek
Melissa Hoyt
Susan Keshian
Bill Kieffer
Charles Leidner
Cynthia Lo
Stuart Murphy
Rhonda Pieroni
Fifi Reed
Matt Reid
Joyce Smith
Paul Smith
Carrie Stamos
Lisa Stein
Josselyn Sofia Vergara Cobos
Kathy Verni

Staff

Evelyn Abayaah
Stephen Keizer
Robin Lipkis-Orlando
Liza Nyeko (Co-Chair)
Elsir Sanousi
Lisa Scheck



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Ambulatory Practice of the Future Care Alliance



AMBULATORY PRACTICE OF THE FUTURE

Established in 2010

OVERVIEW

The Ambulatory Practice of the Future (APF) uses a team-based approach to deliver innovative, patient-centered primary care services to Mass General employees and their adult dependents. The Care Alliance (the APF PFAC) ensures that the ones care experience is rewarding promotes the values that define the APF.

The Care Alliance focuses on communication to help patients become more engaged in their own health care, to keep patients better up to date on practice- and hospital-based news, and to collect information from patients about their care experience.

As the world faces unprecedented challenges, we are here as committed as ever to facilitate the conversation between provide and patient to maximize the potential of holistic, transparent healthcare.

MISSION

The mission of the APF Care Alliance, a partnership of patients, family members, and providers, is to promote innovation and the optimization of the care experience for all.

Topics Reviewed by and Presented to the APF Care Alliance

With *bimonthly meetings with the APF Staff and monthly Care Alliance Meetings*, the Care Alliance has been able to *participate in and provide feedback* for the APF across a range of topics. These include:

- Revisiting and adapting our bylaws
- Quarterly to bi-annual Newsletter
- Health and Wellness Lifestyle coaching
- Referrals through Patient Gateway
- End of life care conversations
- Direct Scheduling
- Discussed stress relieving practices for clinicians and patients

APF Care Alliance Member Participation in Committees and Initiatives

Care Alliance members have collaborated with the APF staff *to bridge communication and transparency between provider and patient* via 2 main channels historically:

1. Newsletter: “The Link”
2. Vidscrips content which has now been migrated to the Youtube channel.

Operations During the Pandemic

The climate of Covid-19 and the reassignment of APF staff and Care Alliance members alike throughout the hospital forced us to suspend meetings and initiatives with the APF. As with much in healthcare this is also now creating a once in a decade opportunity to reinvent the Care Alliance to grow and adapt with the APF in the new and altered healthcare climate as the pandemic continues for the foreseeable future. We plan to discover new avenues of communication to ensure optimal healthcare in a growing digital environment and to accelerate our early work in the application of digital health, applications and connected devices in service to this new paradigm of physical and virtual care delivery as we witness this reinvention.

APF CARE ALLIANCE MEMBERS

Patient/Family

Jarrett Maggio (Co-Chair)
Julie Martin (Co-Chair)
Nancy Davis
Lonn Drucker
Ann Erwin
Josue Espinoza
Paul O'Leary

Staff

Adriana Mesa Balbin
Angelique Brown
Tina Byrnes
MJ Byrnes
Stephanie Casilla
Ben Crocker, MD
Terri Egan
Katie Engels
Dan Henderson, MD
Aaron Hoffman, DO
Leland Hull, MD
Jessica Hu, MD
Stephen Lynch
Jane Maffie-Lee, NP
Mary Anne Marshall, NP
Liza Mosley
Lori Newman
Barbara Anne Quaraglia



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Cancer Center Patient and Family Advisory Council



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 5:30 -7:30 PM. 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 24 active members, 15 alumni members, and 9 staff members. Members represent diverse perspectives and diversity in age, gender, diagnosis, treatment history, race/culture, and socioeconomic status. Current members represent at least ten different Cancer Center disease programs, as well as two different sites (Boston/Main Campus and Mass General/North Shore Cancer Center in Danvers).

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, three 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.

ACTIVITIES AND ACCOMPLISHMENTS - 2019-2020

Topics Reviewed by and Presented to the Cancer Center PFAC

The CC 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.

- **Visit to Charlestown Navy Yard Oncology Labs:** Presentations by several doctors describing their ongoing research endeavors.
- **GYN Medical Oncology's Approach to Practice:** David Spriggs, MD.
- **Overview and growth of the Supportive Care Services to continue to meet patient's needs:** Holly Chartrand
- **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.
- **Overview of MGHCC Virtual Visits:** Ephraim Hochberg, MD. and Steven Isakoff, MD.

Cancer Center PFAC Member Participation in Committees and Initiatives

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:

- **Patient Experience Council**
- **Care Redesign Projects**
- **Quality and Safety Committee**
- **Patient Education and Communications Subcommittee**
- **Survivorship Day**

CC PFAC members have participated in:

- **Interview process for oncology nursing leaders**
- **Review of patient satisfaction and quality data**
- **Design of programming and patient education efforts**
- **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.

CANCER CENTER PFAC MEMBERS

Patient/Family

Victoria Bond
Kevin Chan
Nia Chester
Lisa Cole
Bill Connors
Sarah Dagher
Jennifer Dreyer
Cindy Eid
John Gillis
Sandra Gillis
Maria Martell-Winthrop
Suzanne Sarafin
Leslie Waisnor
Robin Weisman
Peter Zschokke

Staff

Jill Allen
Mara Bloom
Barbara Cashavelly
Steve Herskovitz
Erika Rosato
Kevin Lynch
Nova Hodge
Jenna Gilberti
Devon Punch



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Emergency Department Patient and Family Advisory Council



EMERGENCY DEPARTMENT PFAC

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 - 2019-2020

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*.

Topics/projects reviewed:

- 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:

- 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

Patient/Family

Diane Cleary
Rosemary Marbach
Kevin Prophete
Fifi Reed
Diane Troderman
Ralph Verni
Beth Walsh

Staff

Maryfran Hughes (Co-chair)
Linda Kane
Cassie Kraus
Lindsey Krenzel
Jonathan Sonis (Co-chair)
Ben White



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Heart & Vascular Centers Patient and Family Advisory Council



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.

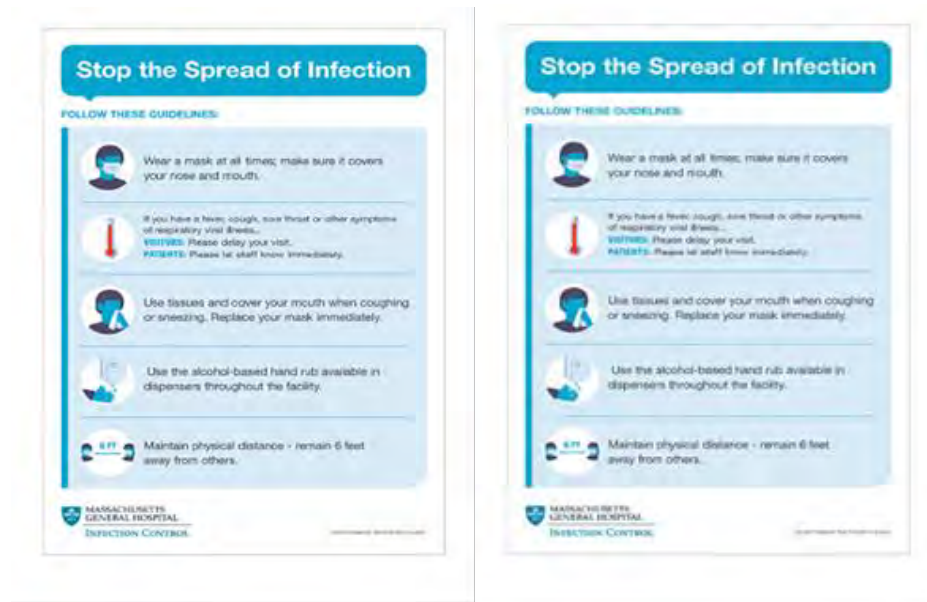
ACTIVITIES AND ACCOMPLISHMENTS - 2019-2020

Topics Reviewed by and Presented to the Heart and 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:

- **Ballot Question - Nurse/Patient Ratio** – Nursing Directors provided an overview of the ballot question regarding potential nurse/patient ratio mandates, answered questions, and shared how members could contribute.
- **Center of Innovation Proposal** – Hiyam Nadel, RN, Director, Center of Innovation and Staff Nurse/Inventor, presented a bathroom harness design to help prevent falls. Members provided input on the concept and design, and various potential ways the harness could be utilized.
- **Patient Gateway** - Mike Paquette, Clinical Business Analyst for MGH eCare Support, presented on the details of Patient Gateway and new enhancements.
- **Vascular Surgery and the Fireman Vascular Center (FVC)** – Chief, Matt Eagleton, MD, presented an overview of Vascular disease as well as the virtual FVC which will join the Heart Center in the new building.

- **COVID-19 Overview** – Suzanne Algeri, RN, Associate Chief Nurse, provided a high-level overview of the Pandemic including a snapshot of the data being used to inform decisions. Cindy Sprogis, Senior Project Manager, provided an update on the communication efforts currently underway



Heart and 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*.

- **WeSolve Inpatient Experience Sessions** – Consortium for Affordable Medical Technologies (CAMTech) facilitated a series of 3 sessions focused on enhancing inpatient experience – six General PFAC members participated in these sessions.
- **Facility Design** - Architects for the large new inpatient building facilitated sessions with interdisciplinary clinicians and staff and PFAC members - included four General PFAC members.

HEART AND VASCULAR CENTERS PFAC MEMBERS

Patient/Family

Charlie Conn
Teri Fryer
Tom Fryer
Phil Geary
Susan Gerry
Pat Hollenbeck
Denise Mallen
Tom Quirck
Matt Smith
Sarah Strobe
David Wooster

Staff

Suzanne Algeri
James Breed
Marie Elena Gioiella
Judy Silva
Cindy Sprogis
Carolyn Velez



MASSACHUSETTS
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MassGeneral Hospital for Children Parent and Family Advisory Council



MassGeneral Hospital for Children Parent and Family Advisory Council

Established in 1999

OVERVIEW

The MassGeneral Hospital for Children (MGHfC) Parent and Family Advisory Council (PFAC) is integral to the Pediatrics Department, providing input and guidance around clinical practice, program planning and education, and the family experience. This council is the longest standing active advisory group of parents and families at MGH. It has a particular focus in helping the MGHfC care teams' practice with a family centered perspective.

MISSION

The Parent and 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 MGHfC.

ACTIVITIES AND ACCOMPLISHMENTS - 2019-2020

Goals and Progress Made

Transitions—Work with the team on the pediatric wards, Ellison 17 and 18, dedicated to improving inpatient transitions to adult care which is led by Nursing Director Lori Pugsley.

Progress: Two parent members of PFAC continue to be members of the committee that has been formed, offering their insights on the committee.

Patient Experience—Members of the PFAC sit on the Inpatient Patient Experience Committee and on the Ambulatory Patient Experience Committee.

Progress: In collaboration with the parent member a Healthstream video was finalized and published this past year. This training session which has been assigned to all ambulatory staff at MGHfC focuses on helpfulness and courteousness and handling difficult situations.

Neonatal Intensive Care Unit: A new member of the committee who had been a parent in the Neonatal Intensive Care Unit (NICU) met with Nursing Director of the NICU to help focus efforts

on the parent and patient experience in the NICU. She is putting together a presentation recapping the parent experience in the NICU from her personal parent perspective and as a healthcare architect/designer perspective. This parent is now a member of the Building Healthy Brains Committee of the NICU. As well, two parents met with Child Life representative, Ashley Reardon in a feedback session regarding introducing child life services into the NICU.

Pediatric Pain—Engage with the Pediatric Pain team, learn how they function and provide parent feedback based on the patient experience.

Progress: A letter written by the PFAC members in reaction to the presentation on the Pediatric Pain Team was sent to the Exec leadership of the Department of Pediatrics. There is work in progress in the Department incorporating this response.

MGHfC Marketing and Awareness—Continue to collaborate with MGHfC leadership, marketing, web design and editor around using patient stories to enhance awareness of MGHfC and differentiate it from other hospitals in the city.

Progress: A proposal was made to promote MGHfC along the Boston Marathon route to increase awareness of MGH's pediatric capabilities. A plan was put together that parents and staff would volunteer to hold signs along the Boston Marathon route. The signs would express inspirational messages, consistent with MGH/MGHfC Brand. Discussion of a tent and fliers had just begun among the PFAC members. A banner could be placed at mile 20, a private home, that would promote MGHfC. Purveyors of materials had been identified and all costs were covered. Discussion and coordination with internal departments and development were underway when the project was canceled due to COVID-19 and the race also being canceled. Much was put into place which can be picked up in a subsequent year.

A committee to create mechanisms by which parents can offer stories to MGHfC for possible use in social media and marketing efforts continues to meet.

Topics Reviewed by and Presented to the MGHfC PFAC

During *monthly meetings and through targeted requests*, the MGHfC PFAC reviewed, provided feedback on, and learned about a variety of topics spanning settings and strategic imperatives. With the onset of the Pandemic and discontinuation of in person meetings, the meetings in March and April were not held. We restarted in May using the ZOOM platform and had a record number of attendees. We have continued our monthly meetings via ZOOM with good attendance.

The presentations have included:

What Matters to You: Dr. Lindsay Carter, Medical Director of the Inpatient General Care Units,

presented to the group on the IHI initiative. A member of the PFAC volunteered as a member of this new group reviewing activities for this initiative.

Acute Psychiatric Services: Dr. Abby Donovan, Associate Director of Acute Psych Services in the ED presented to the PFAC on the opportunities in the APS to make it more family centered as a physical reorganization progresses to make the unit contiguous rather than separated. They will be looking for parents to join them in a reorganization committee which they plan on establishing.

Boston Strong: The Boston STRONG project is one in which researchers at MGH are looking at teeth of children to see evidence of trauma in their lives. Specifically, they are interested to procure teeth from children who had lived through the Boston Marathon to see if there was evidence of that trauma present in their teeth. They sent our parents a good deal of written material that explained their project and asked our members to read for clarity. PFAC members gave their perspective on the best way to present the information and research so that parents in general would understand and then sign up for the program.

MGHfC Editor: Briana Beckvold, MGHfC Editor for patient educational materials presented to the group to verify that the system for review of patient education materials works for parents.

Patient and Family Story Project: To grow MGHfC awareness and highlight the patient experience, the FAC worked with the MGHfC digital, marketing, public affairs, and patient education teams to create a patient stories page within massgeneral.org/children. This is meant to be a way to highlight patient stories at MGHfC, which can also be shared elsewhere (such as social), as well as provide a way for patients and families to signal interest in sharing their stories, rather than just relying on clinicians or other MGHfC team members to identify patients to reach out to. The page was originally created on the previous version of massgeneral.org, but was rebuilt along with the relaunch of the redesigned site late last year. After feedback from the PFAC, the page now includes standardized patient story titles to make them easier to identify on the website. Prior to the pandemic, this page as well as a few patient stories from this page, were featured as part of Facebook social ads for MGHfC (though all campaigns were paused due to COVID-19 and subsequent budget restrictions). Next steps include standardizing the story submission process (offering additional details for patients and families who click the “share your story” button), adding social links to the patient stories page and the individual story pages to encourage visitors to stay connected with MGHfC, and continuing to add new patient stories to this page as well as share them out from the MGHfC Facebook account.

COVID-19 Updates: Brian Cummings, Vice Chair and Medical Director of MGHfC has provided monthly updates once the PFAC restarted to meet in May. Updates have included pathophysiology and biology of COVID-19 as well as information regarding changing requirements and policies at MGHfC. The committee was asked for their perspective on some of these and how best to present information on these as well as other related topic to patients and their families.

Parents and Patients as Educators

Intern Orientation: Parents continue to be an integral part of intern orientation. In an annual “Meet and Greet”, this time done by ZOOM, the parent co-chair of MGHfC PFAC presented on issues important to PFAC members.

Patient Education Material: PFAC parents continue to work with the MGHfC Editor by reviewing patient education material and providing the parent perspective.

FAC Grand Rounds: In anticipation of the annual MGHfC FAC Grand Rounds in April, the PFAC had worked with Suzanne Koven to develop a discussion around “Writing as Healing” as a theme. Plans were put together for a panel including Dr. Koven, a resident, and a parent to describe their experiences with journaling. Unfortunately, it was canceled due to COVID.

Additional Activities

Journals of Hope Program: Faith Wilcox, parent member of the FAC, offers a program in which she visits the pediatric wards for two hours each week and provides journals and writing prompts to parents, family members, and patients. The goal is to help individuals to reduce stress, celebrate victories, and honor their grief. Since the inception of Journals of Hope in January 2019 until the program had to be paused because of the pandemic in mid-March 2020, Faith has spoken with 713 individuals of which 607 have selected journals and expressed interest in writing, an eighty-five percent rate of success. To fund Journals of Hope, Faith has raised \$3,400.00. Matt McGuinness and his employer, Harvard Pilgrim, generously contributed to this program as well. Faith looks forward to continuing the Journals of Hope program in the future.

MGHfC Facebook: The annual FAC Grand Rounds was featured in a story and photograph on MGHfC Facebook.

Website: FAC continued to work with MGHfC Senior Manager of Digital Strategy and Web Development to ensure that FAC’s webpage is up-to-date and reflective of the group’s activities.

Social Media: MGHfC Editor continued the practice of profiling a FAC parent in Totline, MGHfC’s online publication.

MGHfC PFAC Member Participation in Committees and Initiatives

PFAC members continue to *participate in ongoing committees, task forces, and initiatives* at MGHfC, providing the *patient/family perspective within interdisciplinary groups*.

- **Family Wellness Committee**
- **Ellison 17 and 18 Transitions Committee**
- **Inpatient Experience Committee**
- **Outpatient Experience Committee**
- **Ethics Committee**
- **MGHfC Advisory Board**
- **MGH Gun Violence Prevention Committee**



MGHfC PFAC MEMBERS

Patient/Family

Seta Atamian
Lisa Cimino
Mike Doiron
Charlene Harper
Roxanne Hoke-Chandler
Ana Mastrocola
Matthew McGuinness **(Co-Chair)**
Eve Megargel
Janice Morris
Colleen Newland
Alix Nozzolillo
Yara Osler
Kelli Purchase
Erin Quinney
Ann Skoczenksi
Randi Stempler
Faith Wilcox

Staff

Barbara Cashavelly
Sandra Clancy **(Co-Chair)**
Brian Cummings
Kate Gerne
Esther Israel
Karen Manning
Jessica Mascola
Sandra Dodge McGee
Anne Bouchard Pizzano
Alexandra Sobran
Kim Whalen



MASSACHUSETTS
GENERAL HOSPITAL

Pediatric Oncology Family Advisory Committee



PEDIATRIC ONCOLOGY FAMILY ADVISORY COMMITTEE

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 - 2019-2020

Topics Reviewed by and Presented to the Pediatric Oncology FAC

Through meetings which are held on site at Mass General 5 times a year and remotely/electronically as an on needed basis, the Pediatric Oncology Family Advisory Committee *reviewed programs and issues impacting the Pediatric Oncology clinic*. With the presence and risks associated with coronavirus, our meetings became virtual as of March 2020 and expected to continue in a zoom format throughout the year.

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:

- **An educational series for pediatric oncology cancer survivors**, developed in collaboration with the treatment team.

- **Impact of child's cancer treatment on siblings**

- **Completion of revised Family Guide** for pediatric oncology families

- **Identifying opportunities for grants** to support patient/family programs

- **Programming for National Childhood Cancer Awareness month**

- **Diversity and disparities** in health care

- **Emergency Department care of Pediatric Oncology patients** including Port a Cath access. FAC met with Pediatric Emergency Department leadership staff prior to the pandemic

- **Review of Patient Experience data**

- **Program planning** including Kaleidoscope (expressive arts program) and Celebrating Amazing Moms (parent support program)

- **Review of Pediatric Hematology-Oncology website** and plans for surveying usage by families

- **Development of a new virtual support program** for parents (Conversations in Challenging Times) which began soon into the coronavirus pandemic

- **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



Mass General Hospital Pediatric Oncology invites you to attend our

Survivorship Series

Information for parents, adolescents and young adults about issues after childhood cancer
Sessions will feature clinical experts and long term cancer survivors

Thursday, October 24, 2019 6:30 - 8:00 PM	What you Need to Know about Care after Treatment Mary Huang, MD Director, Long Term Follow Up Program Molly Tower, MS, PNP Nurse Practitioner, Long Term Follow Up Program Elyse Levin-Russman, MSW, LICSW, Clinical Social Worker
Thursday, January 16, 2020 6:30 - 8:00 PM	Fertility after Cancer Mary Sabatini, MD Director, Clinic for Reproductive Health and Cancer
Thursday, April 2, 2020 6:30 - 8:00 PM	School and Learning after Cancer Treatment Margaret Pulsifer, PhD Neuropsychologist, MGH Psychology Assessment Center Casey Evans, PhD candidate, MGH Psychology Assessment Center Elyse Levin-Russman, MSW, LICSW, Clinical Social Worker

All programs will be held in the Lawrence House Conference Room - corner of Grove and Cambridge Street
Light Dinner and Complementary Parking included

Additional Accomplishments

We recruited two new members (parents) this year who are reflected in the roster below. Our physician Clinical Director also joined our group as our new physician representative.

PEDIATRIC ONCOLOGY FAMILY ADVISORY COMMITTEE MEMBERS

Parents

Dawn Regan (Co-Chair)

Claudia Cardona

Mary Cincotta

Michael Doiron

Tim Dunne

Susan Jacobson

Paula Marshall

Chau Nguyen

Peter Palamidis

Jerry Schindler

Janice Theriaque

Tarrah Zedower

Staff

Elyse Levin-Russman, MSW, LICSW (Co-Chair)

Alison Friedmann, MD

Ellen Silvius, BSN, RN



PFAC Collaboration



A COLLABORATIVE PFAC THANK YOU

As the pandemic took hold during Spring 2020, Mass General PFACs joined together to create a [Thank You Video](#) to share with health care workers across the hospital community. Messages of thanks, hope, support, and encouragement were compiled to show appreciation for all during these difficult times.

"[Real courage is] when you know you're licked before you begin, but you begin anyway and you see through it no matter what." ~ Atticus, To Kill a Mockingbird.

Thank you for showing us
all what real courage
looks like

There are no words to express the gratitude that my family and I feel for the brave and unwavering dedication, care and support of MGH front line providers and staff. You are each a beacon of light in this dark and scary time of crisis. We send all good thoughts for you and your families to remain safe and healthy. Thank you!

Thank you for all that you do. Patients and families appreciate your hard work and dedication!



Thank you all for your selfless hard work. You offer the "gold standard" of medical care and do so with brilliance, love, kindness and humility.

Your example
inspires us to try to
help others
Thank you!



To all the wonderful providers and staff at MGH, thank you for all you do and sacrifice each day. You are confronted with the unimaginable and somehow you find the strength and courage to take on another day. Please know that each day you and your families are on my mind and in my prayers.

Thank you is not enough... what else would give you dedicated people a boost?

Indeed, our hospital staff and providers are true heroes!





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 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

- Promote General PFAC member participation on committees and initiatives across the hospital/ system, to facilitate integration of the patient/family perspective in shaping services, programs and initiatives
- Expand awareness of the General PFAC across the hospital/system

- Align General PFAC activities with the strategic imperatives of the hospital/system
- Enhance General PFAC member understandings of the hospital/system infrastructure, and operations to facilitate capacities to contribute as Advisors.
- Continue to recruit General PFAC members who represent the diverse population of the patients served by Mass General.

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, 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 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 8.
- 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 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 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.
- Communicate activities of the General PFAC to Mass General leadership.
- Serve as an advocate for PFACs across Mass General and Partners.
- Represent Mass General PFACs in the health care community, as appropriate.
- Facilitate PFAC Chairs meeting.
- Facilitate planning of annual PFAC meetings.
- 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.
- Maintain minutes for a minimum of 5 years as provided for in Article 13, Section 2.

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 6 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. PFAC members will be onboarded through the Mass General Volunteer Department onboarding process.

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 12. Confidentiality

General PFAC members must not discuss any personal or confidential information revealed during General PFAC meetings, through communications, or through the secure filing 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 13. PFAC Meetings

General PFAC meetings are held monthly. Each meeting is scheduled for 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. Remote participation is acceptable when physical presence is not possible. 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 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: August 2019