



**Massachusetts General Hospital**  
Founding Member, Mass General Brigham

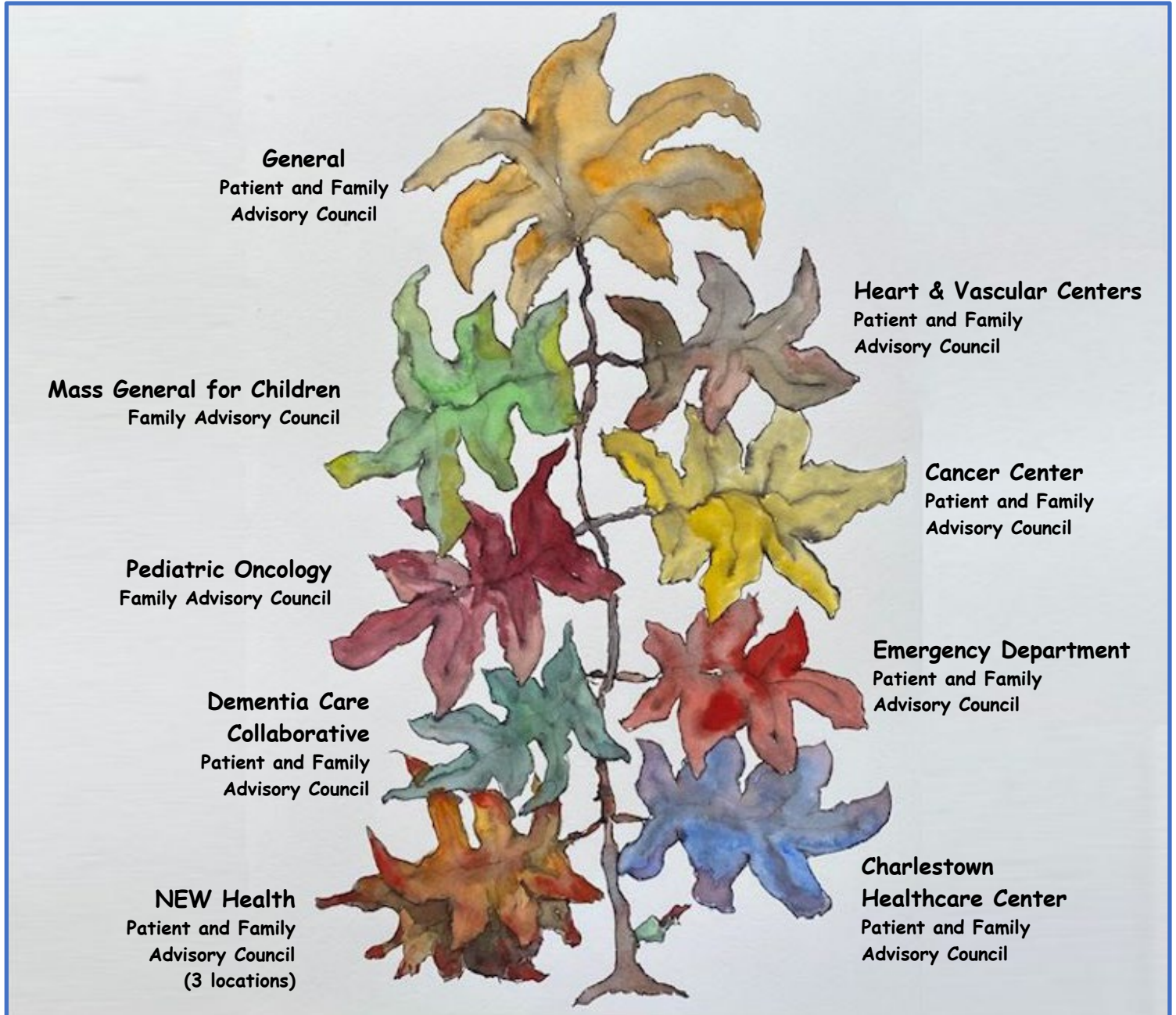


## *2021-2022 Annual Report*





# Introduction



*Image:* Watercolor image of a branch, each leaf expressing its own hue, representing the unique focus of each PFAC, one large leaf at the top representing the GPFAC, four slightly smaller leaves representing PFACs established 1999 -2003, three still smaller leaves, representing newer PFACs established 2018-2021, one leaf with 2 behind, representing the 3 locations of the newest PFAC, NEW Health, forming in 2022, and one bud, hinting future growth. Graphic by GPFAC 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. . .”

The Mass General PFAC program has developed significantly over time, bringing together Mass General patients, family members, staff, and clinicians in an ongoing effort to collaboratively improve care and care experiences. As Mass General evolves with new ways of delivering care, so too, the PFAC program continues to evolve to match this moment. The program has experienced leadership changes, addition of new Advisory Councils, comings and goings of members/advisors, and increased collaborations that integrate, elevate, and amplify the patient and family voice in the development and design of programs, services, and initiatives across Mass General.

This report presents the robust contributions of Mass General PFACs over the past year. Symbolic of this moment, the theme of this year’s annual report is “Leaves of Change.”

### Current Mass General Advisory Councils include:

1. General Patient and Family Advisory Council
2. Cancer Center Patient and Family Advisory Council
3. Charlestown Healthcare Center Patient and Family Advisory Council
4. Dementia Care Collaborative Patient and Family Advisory Council
5. Emergency Department Patient and Family Advisory Council
6. Heart and Vascular Centers Patient and Family Advisory Council
7. MassGeneral Hospital for Children (MGHfC) Family Advisory Council
8. Pediatric Oncology Family Advisory Council
9. NEW Health Patient and Family Advisory Council (*Forming*)





# General Patient and Family Advisory Council



*Image: Watercolor of leaf highlighting General PFAC. 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.

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**Patient:** My stay at Mass General was absolutely first rate and all the staff members contributed to making that possible. They all took personal ownership of their time and assistance and were a great help to me and my family. They are a first-rate team, second to none, in my opinion. My nurses gave all the compassion and support they could possibly provide.

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### ACTIVITIES AND ACCOMPLISHMENTS - 2021-2022

#### Topics Reviewed by and Presented to the General PFAC

During the past year, the General PFAC continued its practice, as in previous years, of reviewing topics sent to it for comment and guidance. Requests came in from across the system from truly diverse members of the Mass General staff. At our monthly meetings, members of the General PFAC gathered in our now-familiar virtual operating mode via Zoom. This format provided us the opportunity to continue to address the many topics presented to us.

- **Structural Equity Policy Review** – Elena Olson, Executive Director, Center for Diversity and Inclusion. Elena provided an overview of policies through a structural equity lens, with the goal of identifying and reconciling structural racism through the review of administrative, human resource, and clinical policies. The General PFAC engaged in an active conversation — asking questions and providing feedback. The recommendation to invite PFAC members to participate in this process was offered.

- **Center for Telehealth** – Marcy Simoni, Director of Telehealth Strategy and Regulatory Affairs; Benji Meller, Program Director of MGPO, and Reniery O’Hara, Software Engineer. The General PFAC was updated on the Center’s current initiatives that offer patients equitable digital access to more affordable, accessible, and efficient ways of receiving care (i.e., subsidized access to digital equipment, Wi-Fi, etc.). Members shared their personal telehealth experiences, provided feedback, and engaged in an enthusiastic discussion.
- **Center for Perioperative Care (CPC)** – Mary Cramer, Executive Director, Organizational Effectiveness & Chief Experience Officer; Caroline Horgan, RN, Nurse Director, CPC; Sharon Bouyer-Ferullo, Perioperative Staff Specialist. The General PFAC was updated on the CPC’s current work and initiatives. Questions were asked and feedback was provided by members.
- **10-Year General PFAC Anniversary** – Debbie Burke, RN, DNP, MBA, NEA-BC, Sr. Vice President Patient Care and Chief Nurse; Inga Lennes, MD, MPH, MBA, Sr. Vice President Ambulatory Care and Patient Experience; Liz Mort, MD, MPH, Sr. Vice President Quality & Safety, and Robin Lipkis-Orlando RN, Director, Office of Patient Advocacy. MGH Leaders marked the General PFAC’s 10-year anniversary by sharing their experiences collaborating with the General PFAC over the past decade. Much appreciation for the value and work of the General PFAC was expressed during this celebratory gathering.
- **Conversation with New Chief Information & Digital Officer (CIDO)** – Jane Moran, MBA, CIDO, Mass General Brigham and Lee Schwamm, MD, Executive VP MGH Neurology & Director of MGH Center for Telehealth. The General PFAC was introduced to the new CIDO who presented an overview of her background and areas of focus at MGB in the coming months. Members asked questions and offered feedback on their experiences using various technology platforms at MGH.
- **Behavioral Health Conversation** – Joy Rosen, MS, VP, Behavioral Health. The General PFAC received an update on the challenges and initiatives in behavioral health care at Mass General. Members expressed strong support of this work and for increasing Mass General’s overall capacity to provide enhanced behavioral health care services to patients and families.
- **Health Care Transformation Lab & Center for Innovation in Care Delivery (CCD)** – Paula McCree, Managing Director, Healthcare Transformation Lab, and Hiyam Nadel, RN, MBA, BSN, CCD Director. The General PFAC received an overview of the programs focused on improving health care delivery and innovation at MGH, including the Ether Dome Challenge (EDC) contest that seeks to find solutions to pain points in the delivery of patient care at MGH. Members engaged in a robust discussion and provided feedback on their patient care experiences.
- **Interpreter and Translation Services** — Christopher Kirwan, Clinical Director, Interpreter Services. The General PFAC was given an in-depth overview of the interpreter and translator services provided to patient and families at Mass General. Members engaged in a lively discussion, provided feedback on their experiences, and offered its strong support for these services.
- **Hospitalist Photography Project** – Cindy Cooper, MD, Core Educator Faculty, Department of Medicine and Susan Edgman-Levitan, Executive Director, Stoeckle Center for Primary Care Innovation. An overview of the “Patient Photo Project” was provided to the General PFAC for discussion and feedback. Several members shared personal and family experiences with inpatient care and offered enthusiastic support of this initiative along with suggestions for enhancing it.

- **MGB Human Research and Affairs Institutional Review Board (IRB)** – Martha Jones, Vice President Human Research and Affairs Division MGB. The General PFAC received an overview of the IRB’s current work and proposal for including community (non-scientific) members such as PFAC members in its work. Members asked questions and offered support for this proposal. Some members later applied to become community members.
- **Infection Control Updates: COVID and Hand Hygiene** – Amy Courtney, RN, MPH, Director of Infection Control. The General PFAC was given an overview of the goals, structure, and responsibilities of the department. Several initiatives were discussed, including a clinical update on the COVID pandemic, and the “Hy5” Hand Hygiene initiative to encourage hand hygiene compliance across Mass General.

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**PATIENT:** Your staff, both in ICU and then in my regular room after it for recovery, were amazing people. I know they’re overworked, and they’ve had a hard few years. You wouldn’t know it. Everybody has a good attitude and is more than helpful and ready if you need to push a button. I really appreciate the care I got.

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## General PFAC Member Participation in Committees and Initiatives

In addition to attending monthly General PFAC meetings, General PFAC members participate in ongoing *committees, task forces, and initiatives* across the hospital and system, providing the *patient and family voice and perspective within interdisciplinary groups*. Participation takes place both in-person and virtually via online platforms.

- **ADVOCATE Advisory Committee (Advancing Digital and Virtual Opportunities for Care Access Translates to Equity)** – A General PFAC member serves on this committee focused on improving digital access services and resources (i.e., subsidizing the cost of equipment, providing Wi-Fi access, etc.) for those not digitally-enabled.
- **Annual Patient Experience Award Judges** – Each year, clinicians and staff submit patient experience award nominations on behalf of colleagues (individuals and teams) that have demonstrated excellence in **icare** elements (communicate, advocate, respect, empathy). For the fourth year in a row, several dedicated General PFAC members served as judges, reviewing, and voting on nominations, and participating in the virtual awards ceremony.
- **Blum Patient & Family Learning Center / General PFAC Education Sub Committee** – A working sub-committee of several General PFAC members collaborates closely with the Maxwell and Eleanor Blum Patient and Family Learning Center, reviewing patient educational materials using plain language review and sharing the patient and family voice in facilitated discussions on a variety of topics.





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**Council on Disability Awareness Co-Chair:** Having patient representation in both, the General PFAC and Council on Disabilities Awareness, has allowed us to bridge efforts where we are able to share ideas and collaborate on initiatives to create a welcoming, accessible, and inclusive hospital environment. General PFAC members have been an invaluable resource in providing feedback from the patient perspective.

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- **Council on Disability Awareness** – Two General PFAC members serve on an interdisciplinary council consisting of representatives from across the hospital, advising on disability access and moving beyond compliance mandates to provide a supportive and welcoming environment for all.
- **Equity Policy and Practice Review Committee** – A General PFAC member serves on this committee which is in the process of reviewing Mass General policies and practices for structural racism that may be embedded in these policies and practices.

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**General PFAC Sub Committee** – Several General PFAC members serve on a sub-committee that provides a deeper review of structural equity, viewing it through the patient and family lens to support equitable access to health care services at Mass General.

- **Harvard Medical School Course** – A General PFAC member along with the Staff Co-Chair of the General PFAC, spoke to a Harvard Medical School Class on what PFAC’s do and shared practices for measuring the success of PFAC’s through survey data.
- **Health Care Transformation Lab (HTL) and Center for Innovation / PFAC Ether Dome Challenge** – All members of the General PFAC were invited to participate in a pilot patient- and family- centered “Ether Dome Challenge” – an open innovation contest designed by HTL in collaboration with Harvard Business School that uses crowdsourcing to solicit and identify ideas to be developed. Previously conducted with Patient Care Services and other care provider groups, it was always the HTL Director’s dream to launch a contest with patients and family members. Launched this year with the tagline “Nothing about us, without us,” the PFAC Ether Dome Challenge (EDC) has been very engaging, with General PFAC members offering several ideas for enriching the patient and family experience.
- **Mass General Brigham Home Care PFAC** – A General PFAC member serves on this PFAC that meets monthly to review and provide feedback on the care parameters established for home care following surgery and/or rehab in the nursing, occupational, and physical therapy areas of practice.
- **Mass General Brigham Patient Experience Leadership Committee** – A General PFAC member serves on a system-level committee consisting of patient experience leaders from hospitals and Physician Organizations across the system that focuses on patient experience strategies and initiatives to enhance the patient experience.

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**Director, Healthcare Transformation Lab:** In the Healthcare Transformation Lab, our goal is to improve the experience and value of healthcare for both patients and providers, so working directly with Mass General patients and families is invaluable. Given their commitment to the Mass General and its mission, the members of PFAC have been ideal partners in our work.

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- **Mass General Brigham Patient Voice** – Several General PFAC members have applied to serve in a patient focus group that will provide patient/family perspectives to Mass General Brigham leaders as digital health enhancements are made to care delivery.

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**GPFAC Collaborator:** My collaborations with GPFAC members have demonstrated the value of incorporating the voice of our patients and family members into our work.

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

### 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 GPFAC 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. Photos do not represent the entire membership.

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**GPFAC Member:** Serving on the GPFAC at Mass General for nearly 7 years has been tremendously rewarding. I have received mostly exceptional care at Mass General for 33 years. I have always valued the excellence of the institution. When I had the opportunity to join the GPFAC, I was eager to get involved in what makes this institution great - its focus on patients. My expectations of what I could do as a GPFAC member has been consistently surpassed. A volunteer group comprised of patients at a large organization could easily be marginalized, but I have consistently found that our knowledge is sought out and taken seriously. We are a valued part of Mass General. I find that amazing.

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## GENERAL PFAC MEMBERS

### Patient/Family

Neelesh Ajmani  
Michelle Anderson  
Stephen Brown  
Bob Chen  
Linda Cline  
Josselyn Sofia Vergara Cobos (>May '22)  
Julie DeCosta, Co-Chair  
Hilary Dignan  
Catherine Duffek  
Melissa Hoyt  
Susan Keshian  
William Kieffer  
Linda Lanton  
Cynthia Lo  
Stuart Murphy  
Rhonda Pieroni  
Fifi Reed  
Matt Reid  
Joyce Smith  
Paul Smith  
Carrie Stamos  
Lisa Stein  
Tracy Talbott

### Staff

Evelyn Abayaah  
Robin Lipkis-Orlando  
Liza Nyeko, Co-Chair (>April '22)  
Elsir Sanousi

### New Staff (May '22 Start)

Margaret Martin, Secretary  
Helen Scarr, Co-Chair  
Jamie Tirrell Hassey



# Cancer Center Patient and Family Advisory Council



*Image: Watercolor leaf highlighting Cancer Center PFAC. 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 Cancer Center (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 CC 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 virtually on the second Wednesday of each month from 5pm - 6:30pm. Meeting minutes and materials are stored electronically.

#### 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).



## 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, and 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. 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.



*Image:* Photograph of several Cancer Center PFAC members at July meeting and celebration for those completing their terms

## 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 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 - 2021-2022

### 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. Topics reviewed included:

- **Irving Symposium:** Nir Hacoen, PhD, Rachel Mastone
- **Cancer Center Development Updates:** Jenn Ryan
- **Radiation COVID and Marketing Initiatives:** Steve Herskovitz
- **New Building Updates and Previous PFAC Feedback Integration:** Sarah Markovitz
- **The CROWN Act & Hair Loss Products for Women of Color:** Dianne Austin and Lisa Leung-Tat
- **Racism in the Chemo Infusion Unit:** Leah Gordon, NP and Beбина Shrestha
- **Leaders Committed to Change (LC2C):** Margaret Soriano, CN, Cassandra McIntyre, RN, Lisa Leung-Tat, Marie Borgella, RN
- **State of the Cancer Center:** David Ryan, MD.
- **Radiology Updates:** Natalie Egan and Jeremy Herrington
- **Sickle Cell Disease Program:** Sharl Azar, MD, and Ellen Silvius, RN
- **The Peoples' Heart – Health Equity x Art Program:** Daniel Chonde, MD, PhD
- **Value in a Healthcare Setting:** Effie Hochberg, MD
- **CANVAX Study:** Vivek Naranbhai, MBChB, PhD, DPhil
- **Sexual Health Program Overview:** Lorraine Drapek, NP
- **Mind-Body Medicine Program Overview:** Giselle Perez-Lougee, PhD
- **Caring for a Cure:** Molly Higgins, RN, Laura White, RN, Christine Weiand, RN
- **Lifestyle Medicine Program Overview:** Amy Comander, MD

## 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

### Patient/Family

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

### Staff

Mara Bloom  
Steve Herskovitz  
Nova Hodge  
Kellyann Jeffries  
Lisa Leung-Tat  
Devon Punch  
Erika Rosato  
Kassie Sweeney



**Massachusetts General Hospital**  
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# Emergency Department Patient and Family Advisory Council



*Image: Watercolor leaf highlighting Emergency Department PFAC. 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 Mass General Emergency Department PFAC is going to work on making those days *better*.

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**Parent of ED Patient:** I was not the patient but the mom (of the college aged patient) who ended up in your ER after making some poor choices during a night out with her friends. Although she was "resting" very comfortably during her entire stay, I was wide awake in worry. Both she and I were treated with dignity and respect. The nurses, doctors, and entire staff in the ER were kind, sweet and amazing. It broke my heart to see how they were treated by other patients.... I was completely impressed how each and every member of your staff handled themselves and the patients. Thank you again (from a mom that hopes to never be in you ER again).

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## 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 Capacity
- Social Resources
- Office of Patient Advocacy
- Alternative Care Pathways
- Stigmatizing Language
- Website Content Review
- A Day in the Life
- ED Patient Texting Program

#### Previous topics/projects reviewed by the ED PFAC have included the following:

- Center for Disaster Medicine
- 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
- 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

**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**

Several patient/family members participate 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**

Penny Blaisdell  
Chris Kazlauskas  
Rosemary Marbach  
Kevin Prophete  
Fifi Reed  
Ralph Verni  
Beth Walsh

**Staff**

Jennifer Andonian Shearer  
Denise Flaherty  
Cassie Kraus (co-chair)  
Lauren Lapointe  
Ines Luciani-Mcgillivray  
Jonathan Sonis (co-chair)  
Robert Seger  
Ben White



**Massachusetts General Hospital**  
Founding Member, Mass General Brigham

# Heart and Vascular Centers Patient and Family Advisory Council



*Image: Watercolor leaf highlighting Heart and Vascular Centers PFAC. Graphic by General PFAC member Stuart Murphy.*





## HEART and VASCULAR CENTERS PFAC

Established in 1999

### OVERVIEW

The MGH Heart and Vascular Centers Patient and Family Advisory Council continues to be an important and integral group that provides input to and feedback on 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 perspective 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 Mass General Heart and Vascular Centers.

### MISSION

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

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***H&V Centers PFAC Member:*** Volunteering on the Heart & Vascular Centers PFAC brings a far-reaching shower of benefits to so many: the PFAC members, patients, families, hospital professionals, and the hospital community, itself. The work we do provides significant positive advancement in the delivery of healthcare services for patients and increased comfort to their families. I have grown to learn that even the smallest tasks we were asked to do can make a real difference to the lives of people.

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### ACTIVITIES AND ACCOMPLISHMENTS - 2020-2021

#### Topics Reviewed by and Presented to the Heart and Vascular Centers PFAC

##### Presentations

- **MGB System Integration Overview** – Jeff Weiss, Chief Strategy & Transformation Officer
- **MGB Capacity Challenges (trends & ongoing efforts)** – Kyan Safavi, MD, Donna McEachern, RN
- **Office of Patient Advocacy** – Robin Lipkis-Orlando
- **Cardiac Surgery** - Thor Sundt, MD, Chief of Cardiac Surgery

## PFAC Member Participation in Committees and Initiatives:

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

- **New Facility Design:** (2021 – ongoing): Architects for a large new Mass General building solicited input from members regarding future design of new spaces.
- **Autopsy Consent Form:** (Oct 2021) – Members were asked to review autopsy consent form and to provide feedback.
- **Annual Patient Experience Awards:** (January 2022) – Members were offered the opportunity to serve as judges in reviewing the nomination submissions.
- **Vascular Center Patient Report Card:** (March 2022) – Members provided input on the Vascular Center Patient Report Card.
- **Patient Experience Summit:** (June 2022) – Members were encouraged to attend and to participate in the Spring Summit.
- **Stent Summit:** (June 2022) – Members were asked to join the Stent Summit hosted Matt Eagleton, MD, Vascular Chief of Surgery.
- **Ether Dome Challenge:** (June 2022 – present) – All members of the Heart and Vascular Centers PFAC were invited to participate in a pilot of a patient/family- centered “Ether Dome Challenge,” an open innovation contest designed by the Health Care Transformation Lab (HTL) and Center for Innovation in collaboration with Harvard Business School that uses crowdsourcing to solicit and identify ideas to be developed. Previously conducted with Patient Care Services and other care provider groups, HTL wanted to have an EDC challenge that generated ideas from patients and families. Members offered ideas for enriching the patient and family experience.
- **Recruitment Efforts:** - Recruited one new member and in process of seeking additional new members of diverse backgrounds (2022 – present). Also recruited two new staff members.

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**H&V PFAC Member:** Since joining the Heart and Vascular PFAC in December 2017, I have been so impressed with the engagement and participation of our members. Hearing feedback from them on ways we can improve the patient experience and the way care is provided from both an inpatient and outpatient perspective has been extremely helpful. Our member insights are so valuable, and they help to better inform the important work we do within the Heart and Vascular Center. It is a privilege to be a part of this special group.

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### Patrick Hollenbeck

PFAC Member Pat Hollenbeck has attended the Eastman School of Music and graduated with Honors from the New England Conservatory. He has been closely associated with the Boston Pops since last century. He plays in the percussion section where he has performed and recorded under Keith Lockhart and John Williams and has multiple accolades and orchestration credits.



In 2009 someone obtained a Pat Hollenbeck voodoo doll, resulting in his having a stroke. After a two-year rehab period, he made a full recovery. He is indebted to the world-class care he received at Mass General and considers it an honor and a privilege to be a member and key contributor to the Heart and Vascular Centers PFAC.



### HEART AND VASCULAR CENTERS PFAC MEMBERS

#### **Patient/Family**

Charlie Conn  
Teri Fryer  
Tom Fryer  
Phil Geary  
Susan Geary  
Pat Hollenbeck  
Sr. Jon Julie Sullivan  
Denise Mallen  
Jonathan Parziale  
Tom Quirk  
Matt Smith  
Sara Strobe  
David Wooster

#### **Staff**

Carolyn Velez, Chair  
Suzanne Algeri  
Michelle Anastasi  
Glenn LaMuraglia  
Cindy Sprogis  
Miguel Ferry



# MassGeneral for Children Family Advisory Council



*Image: Watercolor highlighting Mass General for Children FAC section. Graphic by General PFAC member Stuart Murphy.*





## MassGeneral 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 for Children (MGfC). 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 MGfC 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 - 2021-2022

- **Goal Setting** – Each year the parent and patient membership of the Family Advisory Council vote on four goals to pursue for the upcoming year. The goals are chosen based on members' experiences of care in the hospital. This year we selected the following topics – support after discharge; focus on mental health of families and staff; create more mindfulness audios and better distribute the ones we have; continue developing a parent newsletter.
- **Support after discharge**– The three FAC parents and the Co-Chair formed a subcommittee to discuss problems parents had been experiencing post discharge. Together they developed a problem statement and presented it to the FAC. At the same time, staff, and leadership in the Pediatric Intensive Care Unit (PICU) undertook a quality improvement initiative to address the same issue. The three FAC parents have joined this effort and are active participants in the project.
- **Patient Education** – Matt McGuinness, one of our parent members, is in the process of transforming a patient education document about partial dose injections into a video-based learning module to help parents understand better how to administer these injections.

- **Focus on mental health of families and staff** – At our parent members’ suggestion, Roxan del Valle, spiritual care provider and member of FAC, developed a once per week spiritual care zoom session for parents and patients in the PICU and NICU at which members reflect up themes such as hope, loss and resilience.
- **Develop more mindfulness audios** – Last year, FAC parent member Miri Bar-Halpern created five mindfulness meditation audios for parents. With the help of staff, she created a patient education document that contains QR codes so that parents can access them while in the PICU. The patient education documents are now available throughout the hospital, in both in-patient and out-patient settings. The audios have been downloaded 631 times, by staff, patients, and parents. Given their success, Miri is developing more this year.
- **Create parent newsletter** – The Family Advisory Council is working with MGfC editor Briana Beckvold to develop a parent newsletter. It will be called Family Connection. A draft of the first edition has been reviewed by current FAC members to extremely positive reviews.

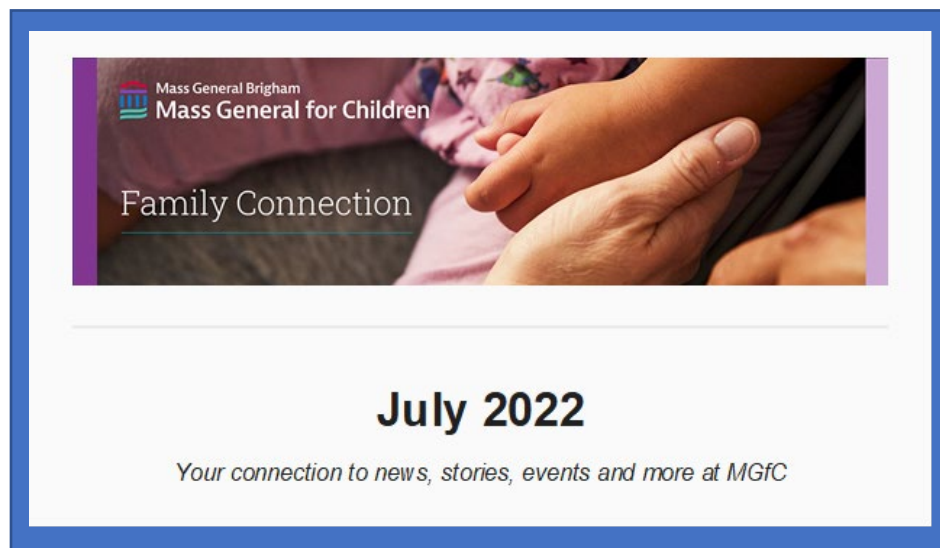


Image: Parent Newsletter Banner

**Annual Family Advisory Council Grand Rounds** – In this Grand Rounds, FAC parent member Dr. Miri Bar-Halpern, clinical psychologist, and several staff presented “Trauma and Healing During Covid 19: Provider and Parent Perspectives and Research.” Bar-Halpern spoke of her own experiences in the PICU with her two children, as well as research on trauma in the critical care setting. Kim Whalen, Nurse Director of the PICU, discussed the trauma PICU staff faced during the Covid 19 pandemic and their ensuing burnout. Sarah Taddei, PICU Social Worker, talked about the field of trauma-informed care, while Roxan del Valle, Spiritual Care provider, informed the audience about her work in helping patients and staff to remember that spirituality focuses on healing and the creation of meaning to combat trauma.

- **Journals of Hope** – This program, created by FAC Co-Chair Faith Wilcox, has continued to grow since its inception five years ago. Patients and family members in the following areas of the hospital are offered journals and writing prompts in English and Spanish, with many other languages in the wards, PICU, NICU, and Radiation Oncology. Furthermore, a PICU team has formed to research existing literature about the effects of journaling in the critical care setting. In addition, starting soon, each family whose child will undergo laryngotracheal reconstruction (LTR) surgery will receive a packet including a journal and prompts. The team will assess the family members stress levels before and after journaling.
- **Gifts from the Heart** – FAC parent member, Lacey Sakash, organized a toy drive during the holiday that donated 450 toys to the hospital.

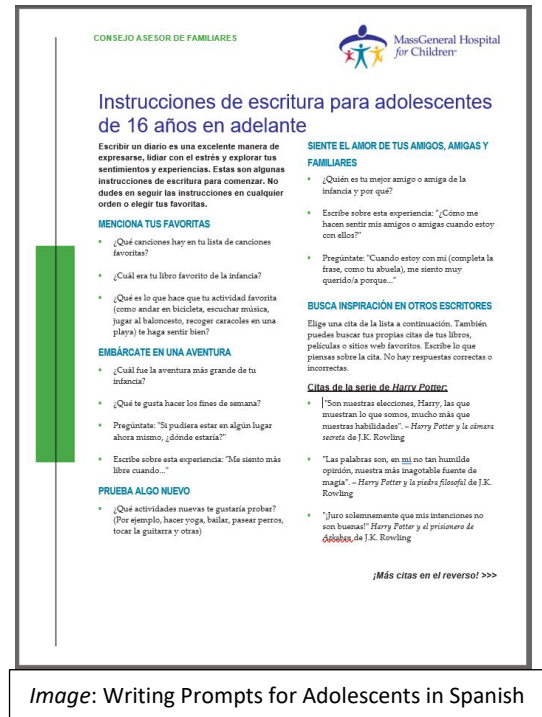


Image: Writing Prompts for Adolescents in Spanish

## Topics Reviewed by and Presented to the MGfC FAC

- **Parental Mental Health in the Neonatal Intensive Care Unit (NICU)** – Victoria Grunberg, PhD, Department of Psychiatry, and Giselle Vitcov, Research Coordinator in NICU, presented their research in the MGfC NICU on parents' emotional distress and mechanisms they've devised to promote resiliency, coping and relationship functioning.
- **Hospitality Homes** – Darcy Daniels and Denise Duclos spoke to FAC about Hospitality Homes that offers housing to patients at Boston hospitals who travel from far distances to receive care.
- **Checking in for Surgery Video** – Briana Beckvold, MGfC Editor, and Yolanda Gonzalez, Administrative Director for Pediatric Surgery, presented a video made a few years ago that walks families through the pre-surgery process. FAC members provided feedback on ways to improve and update the video.
- **Diversity, Equity, and Inclusion** – Dr. Emily Kung updated FAC on the most recent activities of the MGfC Diversity, Equity, and Inclusion Committee.
- **MGfC Physician-in-Chief annual presentation** – Dr. Ron Kleinman presented the Department of Pediatrics annual goals to the FAC, a practice started many years ago to allow our group to align our goals with those of the Department.

- **Pediatric Pain Team Update** – Drs. Jeanne MacDonald and Esther Israel provided an update about efforts to improve the pediatric pain team by forming a multidisciplinary group including a board-certified pain doctor, nurses, psychiatrists, and child life experts. The department is committed to pursuing this initiative.
- **Mental Health of Parents of Children with Complex Medical Conditions** – Dr. Emmanuel Aryee, Research Fellow at Mass General for Children, presented his article “Parents of Children with Complex Medical Needs: Mental Health Challenges and Financial Burden,” outlining his survey research of 70 parents and soliciting feedback from FAC members about how they’ve overcome challenges they’ve faced.
- **Pediatric Stroke Team presentation** – Mara Yale and Dr. Brian Wishart of the Pediatric Stroke Team presented their work, focusing on resources assembled for parents, including a monthly video presentation on topics relevant to parents that is now viewed by participants around the world.

## MGfC FAC Member Participation in Committees and Initiatives

FAC 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** – One parent member of FAC sits on this Committee that provides guidance on ethical dilemmas that present themselves in the hospital setting
- **Pediatric Ambulatory Patient Experience Committee** – A working group that is made up of several stakeholders to examine ways to improve patient experience results around front desk courtesy and respect has 2 FAC parents as members
- **Pediatric Quality and Safety Committee** – Multidisciplinary committee that oversees quality and safety efforts at MGfC has one parent member
- **Pediatric PICU Journaling Committee** – Committee tasked with researching the effects of providing journals to parents in the PICU setting has one FAC parent

## Additional Activities & Accomplishments

- Members participated in interviews for a Nurse Director candidate.
- Members participated in a Joint PFAC event during which they were able to ask questions of Joel Weiss, Chief Strategy and Information Officer for MGB.
- Our members received quarterly updates about the results of the hospital’s patient experience surveys from member Dr. Esther Israel, Quality Chair of the Department of Pediatrics.
- Our membership is participating in the first ever Ether Dome Challenge open to parent and patients.
- Montreal Children’s Hospital contacted FAC leadership to learn more about our activities as they enhance their patient and parent partnership efforts.
- Videos that FAC parents had made titled “Why I Chose MGfC for My Child’s Care” were featured on the main MGfC website.



- After more than two years of zoom meetings, FAC held two in-person meetings in the summer of 2022. The group gathered at tables on the Bulfinch Lawn.



**MASSGENERAL FOR CHILDREN FAC MEMBERS**

**Patient/Family**

Seta Atamian  
Miri Bar-Halpern  
Ashley Conti Smith  
Roxanne Hoke-Chandler  
Robert Lillianfeld  
Lynette Lovosco  
Matthew McGuinness  
Erin Quinney  
Sarah Romano  
Lacey Sakash  
Ann Skoczenski  
Lacey Smith  
Sandra Soto  
Randi Stempler  
Faith Wilcox (Co-Chair)

**Staff**

Briana Beckvold  
Barbara Cashavelly  
Sandra Clancy (Co-Chair)  
Brian Cummings  
Roxan Del Valle  
Hillary Ellis  
Esther Israel  
Emily Lloyd  
Sandra Dodge McGee  
Anne Bouchard Pizzano  
Lori Pugsley  
Carmen Vega-Barachowitz  
Kim Whalen  
Glynis Wood



MASSACHUSETTS  
GENERAL HOSPITAL



MASSACHUSETTS GENERAL  
PHYSICIANS ORGANIZATION

# Pediatric Oncology Family Advisory Council



*Image: Watercolor leaf highlighting Pediatric Oncology FAC. 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.

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**FAC Member:** "The opportunity to share ideas and work on projects has brought meaning to my experience as a parent of a child with cancer. I am grateful the team of care providers wants my input and values my suggestions."

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### 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. The Pediatric Oncology Family Advisory Committee continued to review programs and

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**FAC Member:** "It has been important for me to contribute to this Committee and help other families as they go through their child's cancer treatment. The Pediatric Oncology team took amazing care of our child and family, and we can pay it forward by giving our support to the practice."

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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 group meets every other month in the evening and breaks for the summer. There are a total of 5 scheduled meetings per year, and additional subcommittees meet to address specific initiatives. The topics addressed this year included:

- Identifying topics to be addressed in the parent support/informational series entitled, *Conversations in Challenging Times*
- Onboarding of the many Tufts Children’s patients into the Pediatric Hematology-Oncology practice
- Diversity and racial disparities in health care and opportunities for equity enhancements to our clinical program
- Survey completed with 75 patients/families in outpatient clinic to assess patients’ experiences looking at variables of language, diagnosis, and frequency of visits. Survey is being used to inform clinical staff on needed improvement work and to guide the development of a working group to focus on improvement opportunities.
- Programming for National Childhood Cancer Awareness month
- Review of Family Guide translated this year into Spanish for clinic families
- Consideration of changes to Pediatric Oncology website and how best to implement
- Report from the Chief – update on coronavirus in pediatric oncology and changes in clinic practice

### Additional Accomplishments

- A member was funded to attend the ACCO (American Childhood Cancer Organization) Advocacy Days which was held virtually in April 2022. She shared experience of meeting with congressional representatives to advocate for passage of Childhood Cancer Research initiatives

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**FAC Member:** “I love working with other parents to optimize the care and experience of children receiving cancer care. This is a wonderful group of parents, and I am honored to be a part of this group.”

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## PEDIATRIC ONCOLOGY FAC MEMBERS

### Patient/Family

Dawn Regan (Co-Chair)  
Mary Cincotta  
Michael Doiron  
Tim Dunne  
Susan Jacobson  
Chau Nguyen  
Janine Robinson  
Sandra Santoro  
Jerry Schindler  
Janice Theriaque  
Tarrah Zedower

### Staff

Elyse Levin-Russman, MSW, LICSW (Co-Chair)  
Alison Friedmann, MD  
Patti Scott, RN





**Massachusetts General Hospital**  
Founding Member, Mass General Brigham

## Dementia Care Collaborative Patient Family Advisory Council



*Image: Watercolor leaf highlighting Pediatric Oncology FAC. Graphic by General PFAC member Stuart Murphy.*



## Dementia Care Collaborative Patient Family Advisory Council

Established **September 2021**

### OVERVIEW

The Dementia Care Collaborative(DCC) Patient Family Advisory Council has provided unique input into the functioning of the DCC and the Dementia Caregiver Support Program along with opportunities to foster a more dementia-friendly environment across Mass General. Their feedback has guided Mass General stakeholders of Age-Friendly Care in issues related to clinical practice, program planning and patient safety. This is a new PFAC whose members are people living with dementia (PLWD), family and caregivers of PLWD, along with a Spanish-speaking professional from the community. The goal of the DCC PFAC is to offer advice from Council's lived experiences on specific dementia related topics and to enhance the patient and family's experience at Mass General.

### 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.

- Influence & align DCC 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 DCC PFAC member participation on committees and initiatives across the hospital/system, so as to facilitate integration of the patient/family perspective in shaping dementia services, programs, and initiatives.
- Continue to recruit DCC PFAC members who represent the diverse population of the patients served by Mass General and the community.
- Enhance DCC PFAC member understandings of the hospital/system infrastructure, and operations to facilitate capacities to contribute as Advisors.
- Continue to expand awareness of the DCC PFAC across the hospital/system.
- Advance and support high quality, coordinated communications between patients and their care team members.

## ACTIVITIES AND ACCOMPLISHMENTS - 2021-2022

### Topics Reviewed by and Presented to the Dementia Care Collaborative PFAC

During our every other month meetings, the DCC PFAC reviewed, provided feedback, and learned about a variety of topics spanning the emergency department, inpatient service, and ambulatory clinics. These topics included:

- **Introductory PFAC expectations and answering** – “What has been your experience with caregiving or living with dementia?” Tremendous shared learning occurred.
- **Complete review of all the DCC programs** – PFAC members learned and gave feedback about the Dementia Caregiver Support Program (CGSP) and the Memory Care Initiative, Age Friendly Hospital Initiatives, such as the ID cards for caregivers and people living with dementia. The CGSP offers educational programming every month for patients, caregivers, and the community. CGSP also offers clinical one-on-one sessions and Caregiver Support Groups and Fundamental Skill classes.



- **Mass General’s current activities to support Caregiver resiliency** – The topics covered and received feedback on were: Resiliency: Psychology well-being for caregivers; Capacity to spring back into shape; What contributes to caregiver resiliency; Learning to manage challenging behaviors and reducing stress.
- **Dementia Research Presentation** – Director of Research, Christine Ritchie, from the Division of Palliative Care and Geriatric Medicine, engaged members in conversation about different ways of inviting patients to participate in dementia and caregiver research, and solicited their feedback.
- **Mass General Emergency Department** – Director of Geriatrics in the ED, Dr. Maura Kennedy, joined the PFAC to discuss the goals of care for older patients and shared our future plans. Members gave direct and useful feedback about their experiences in the Mass General Emergency Department.



“After the Storm”

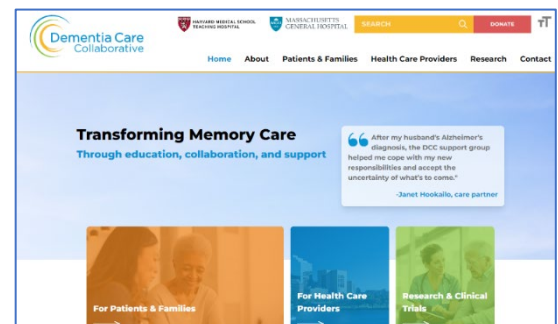
“Understanding that it is crucially important to make time to recharge my spirits has finally sunk in. Picking up my paint brushes again for the first time since my husband’s diagnosis has been a big step in being a caregiver.”

– Janet Hookailo, Painter and caregiver

## PFAC Member Participation in Committees and Initiatives:

- **IHI Expert Panel** – Member participated on the Institute for Healthcare Improvement’s expert panel to review a research study on cognitive testing for dementia.
- **UMass Continuity of Care** – Member participated as a volunteer staff person at UMass Memorial Hospital in the Department of Family Medicine on the issues of access and coordination of continuity of care for discharged patients.
- **UMass Medicare Advantage Program** – Member participated as volunteer staff person at UMass Memorial Hospital Department of Family Medicine, working with their Medicare Advantage program on utilization and data tracking issues.
- **DCC Website** – The DCC PFAC, also, helped to create the DCC website: [www.Dementiacarecollaborative.org](http://www.Dementiacarecollaborative.org).

**Caregiver:** I was with my mom who had recently turned 100 and has dementia issues. The care and respect they showed my mom was heart-warming. Additionally, they took the time to care about me and checked in to make sure I was comfortable. From the bottom of two grateful hearts - thank you.



## DEMENTIA CARE COLLABORATIVE PFAC MEMBERS

### Patient/Family

Rick Anderson  
Greg Anderson  
Helen Samuels  
Mike Belville  
Greg Culley  
Ellen DeGenova  
Marty Gilpatrick  
Judy Johanson  
Bob Kagey  
Stan Leven  
Bernice Osbourne  
Mary Walsh

### Staff

Todd Rinehart  
Christine Ritchie  
Susan Rowlett  
Judy Willett



# Charlestown HealthCare Center Patient and Family Advisory Council



*Image: Watercolor leaf highlighting Charlestown Patient Family Advisory Council (CPFAC). Graphic by General PFAC*



## MGH Charlestown HealthCare Center Patient Family Advisory Council

Established in 2021

### OVERVIEW

MGH Charlestown HealthCare Center is designed to bring the hospital's world-class services conveniently to neighborhood residents and has become a solid community resource. Our healthcare services are among the best in the nation, as are our outreach programs. Today, Charlestown is celebrated for its rich cultural diversity and is a great place to live, work, and raise a family.

MGH Charlestown offers Massachusetts General Hospital's quality healthcare services in a patient-centered and family-focused manner. We listen closely to our patients and make them active partners with us in delivering personalized healthcare.

The MGH Charlestown HealthCare Center developed the Charlestown Patient Family Advisory Council (CPFAC) in 2021. Our primary goal is to integrate and promote patient and family voices and experiences in the development of programs, services, and initiatives.

### MISSION

The mission of the MGH Charlestown HealthCare Center PFAC (CPFAC) is centered in the words of the MGB Mission Statement, "Guided by the needs of our patients and their families." To accomplish this, we will integrate the patient, family, and provider voices to promote innovation and the optimization of the care experience for all.

### ACTIVITIES AND ACCOMPLISHMENTS - 2020-2021

#### Topics Reviewed by and Presented to the MGH Charlestown Healthcare Center PFAC

During monthly meetings and through targeted requests, the CPFAC reviewed, provided feedback on, and learned about a variety of topics spanning settings and strategic imperatives. These topics included:

- **Restorative Justice Policy** – The goal of this policy is To create a process for patients who have caused harm by violating Health Center or MGH/MGB rules or norms to remain in care at the Health Center.
- **Elizabeth Dellaporta, Fitness Instructor & Health Coach** – This presentation provided an overview of wellness opportunities offered to patients and families, followed by a discussion with CPFAC Advisors.

- **Shreedhar Paudel, MD MPH and Antonia Makosky, DNP MPH ANP-BC, Assistant Professor – School of Nursing: Co-Chairs of Antiracism, Equity & Inclusion Committee for the Health Center** – The Co-Chairs shared their committee’s charge, past initiatives and plans for future initiatives for patients and families. Discussion with CPFAC Advisors followed the presentation.
- **Charlestown HealthCare Center Services Overview** – CPFAC Advisors were given an overview of services offered at the HealthCare Center. Advisors were asked to take notes during the presentation on what services they liked and what service gaps they may see.
- **Jean Bernhardt and Jim Morrill** presented to discuss limitations in space and the impact of Covid restrictions, asking what patients and families see as gaps in the healthcare center’s physical environment.
- **Antonia Makosky updated PFAC Advisors as to progress of Art Project**, asking Advisors for feedback regarding this community project.

### Additional Accomplishments

- Advisors were invited to participate in the PFAC Ether Dome Challenge (EDC) with PFAC Advisors of other MGH PFACs.
- CPFAC Advisors were invited to the MGB Patient Experience Summit, June 2, 2022.

### CHARLESTOWN HEALTHCARE CENTER PFAC MEMBERS

#### Patient/Family

Aileen Gorman  
Lucie Ann Guerriero  
Gowri Nagaraj  
Chris Turunen  
Shane Fisher  
Nancy Erhard  
Gabrielle Vacheresse  
Jane O’Neil  
Gloria Ristaino

#### Staff

Tracy Waterhouse, RN (Co-Chair)  
Bridget Kearns, RN (Co-Chair)  
Jennifer Marino, BS





# Forthcoming Patient and Family Advisory Councils



*Image:* Watercolor leaves representing the forming PFAC and representing NEW Health 3 locations  
Graphic by General PFAC member Stuart Murphy.





## NEW Health Patient and Family Advisory Council

Forthcoming

### OVERVIEW

NEW Health is a federally qualified health center and an affiliate of Massachusetts General Hospital and Boston Medical Center. NEW Health is committed to improving the quality of health and life for the residents of Boston's North End, Waterfront, Charlestown, and the people we serve by providing high quality health care that is consumer oriented, culturally appropriate, neighborhood-based, affordable, and produces positive outcomes. NEW Health currently serves patients at three locations: North End (332 Hanover St), Charlestown (15 Tufts St), and Charlestown High School (240 Medford St).

### Mission Statement

The mission statement will be developed with input from stakeholders as part of the Advisory Council's development process in the coming months.

### PROPOSED ACTIVITIES

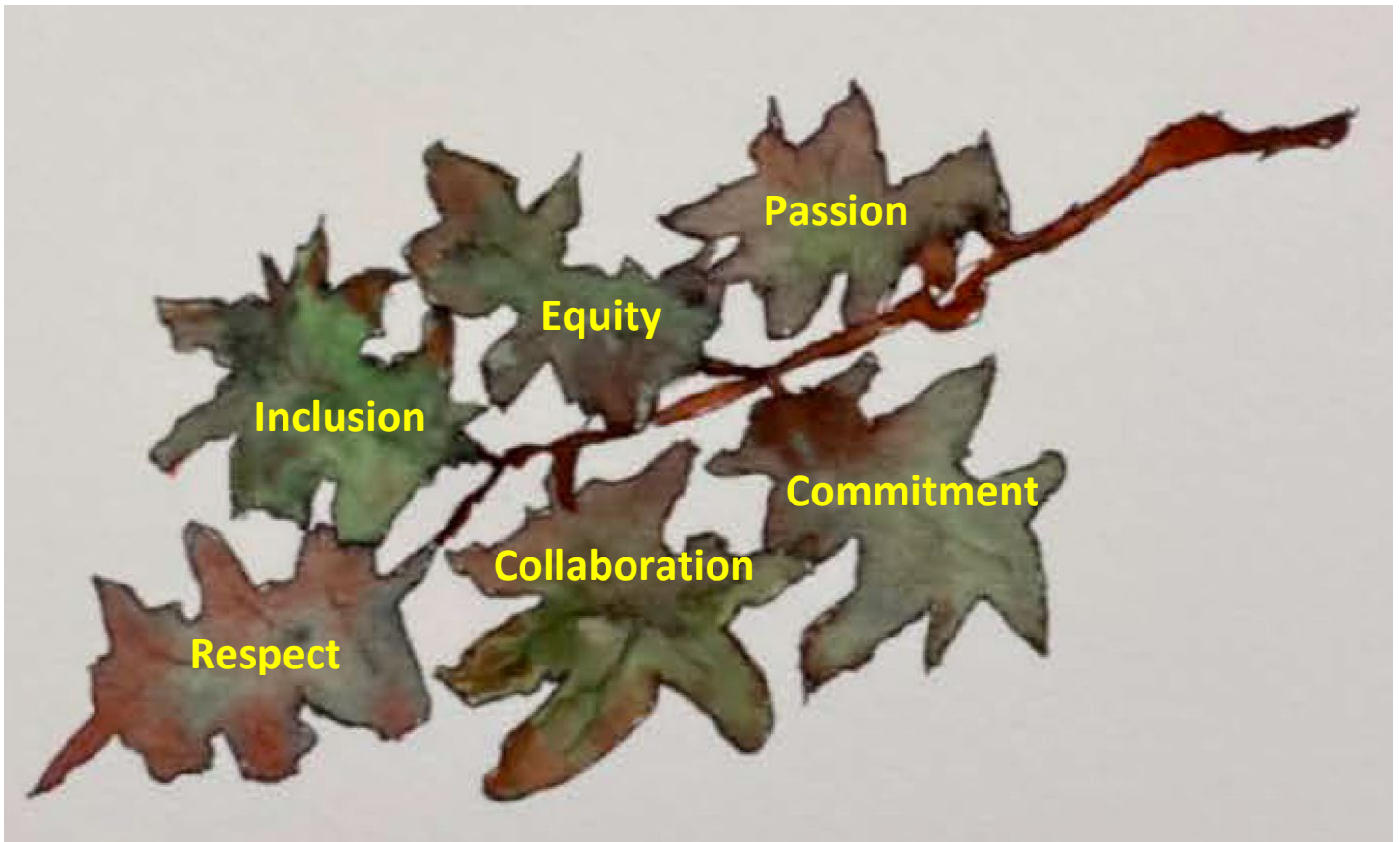
Members will lend their time and ideas by participating in ongoing PFAC meetings, by participating in committees and initiatives across the organization, by conducting reviews, and by serving as an advisory resource in multiple additional ways.





# Closure

## PFAC Values



*Image:* Watercolor image of leaves displaying PFAC values: Respect, Commitment, Passion, Equity, Inclusion, Collaboration. Graphic by General PFAC Members: Concept-Joyce Smith. Image-Stuart Murphy.





# 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*