

## Patient Family Advisory Councils



*Image:* Watercolor image of flower petals displaying 10 Mass General PFACs.  
Artwork by Patient/Family Advisor Stuart Murphy.

## 2022-2023 Annual Report



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# Introduction

## 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 a *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 grown 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 develops new ways of delivering care, so too, the PFAC program continues to bloom to match the moment.

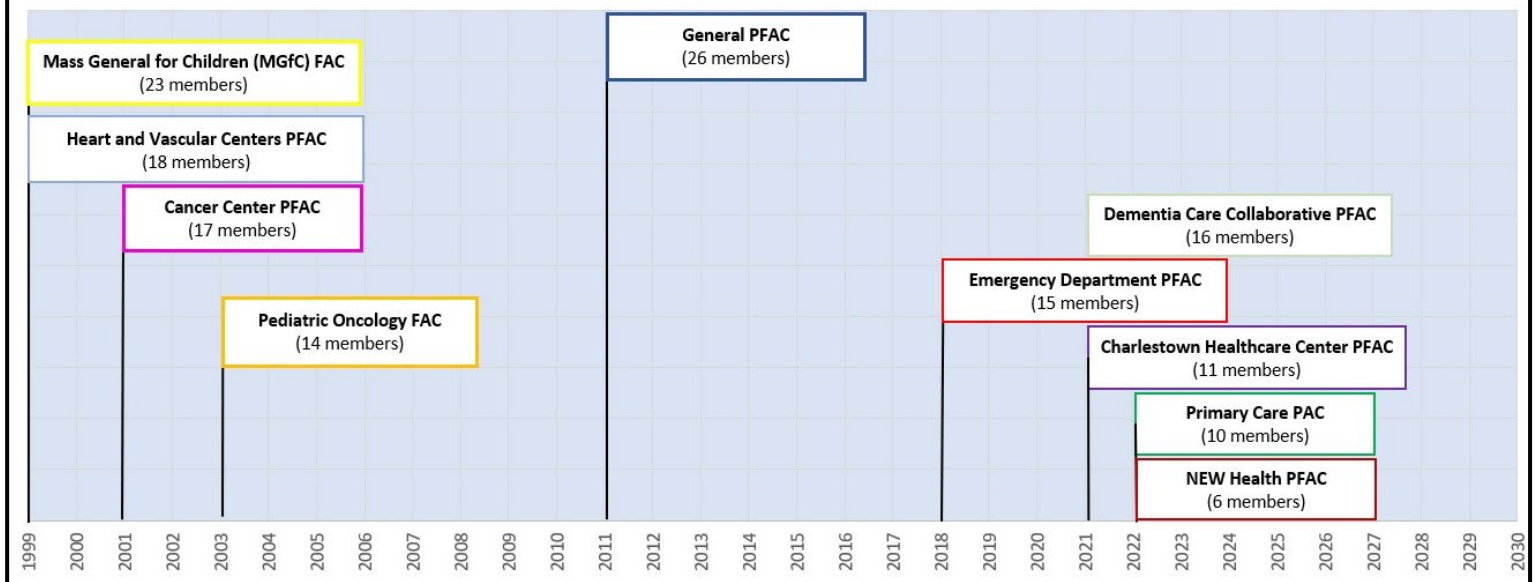
**This report presents the robust contributions of Mass General PFACs over the past year.** Through the COVID-19 pandemic, leadership changes, addition of new Advisory Councils, comings and goings of members, the PFACs have continued to blossom, participating in committees and project engagements.

**Mass General currently has 10 Patient and Family Advisory Councils (PFACs).** In our pediatric population, we refer to them as Family Advisory Councils (FACs), and in the case of Primary Care, it is called a Patient Advisory Council (PAC). For consistency, across the report, we will use the term “PFAC” to encompass all 10 of the Councils.



**Patient and family advisors (PFAs)** as they will be referred to in this report, have expressed renewed interest in bringing their lived experiences to the ongoing work of improving care experiences. They are interested in deeply engaging in co-designing and co-producing improvement initiatives, at both operational and strategic levels of the organization. Mass General is committed to listening and finding innovative ways to weave the PFA voice into the development and design of programs, services, and initiatives across Mass General.

## Mass General PFAC Timeline and Current Membership



# MassGeneral for Children Family Advisory Council



## 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 - 2022-2023

- **Goal Setting** – Each year the parent and patient membership of the 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:
  1. **Focus on mental health of families and staff.**
  2. **Help to disseminate the F-Words curriculum throughout the hospital.**
  3. **Collaborate with MGfC Patient Experience and Quality & Safety teams to measure the impact of 2 PFA-led Ether Dome Challenge projects: support after discharge & resource app.**
  4. **Engage more families in FAC activities.**

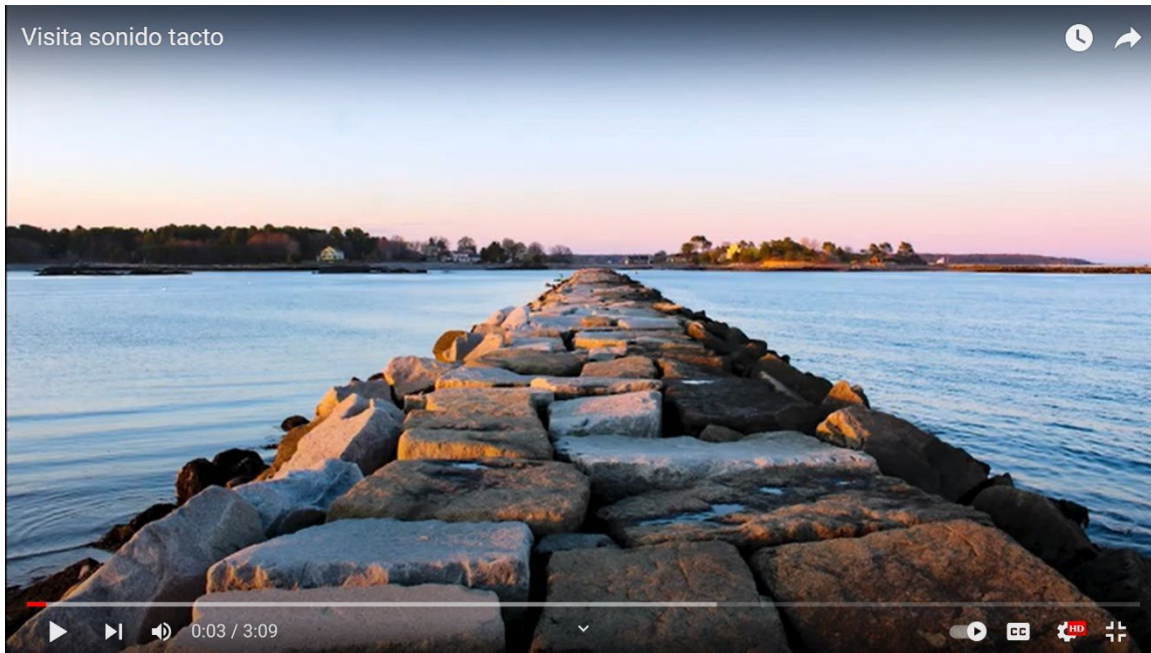
- **Ether Dome Challenge: “Support After Discharge” project** – Three PFAs have worked throughout the year with staff from the MGH Center for Innovation in Care Delivery and the Healthcare Transformation Lab to devise solutions to problems encountered by parents of children with complex medical needs after discharge from the hospital, most specifically which providers to contact for help with a medical issue and whether to go to the Emergency Department. They have surveyed providers and parents to gather data to craft possible solutions and consulted with experts in the field of patient experience. The project is ongoing.



- **Ether Dome Challenge: “Resource App” project** – One PFA and the PICU Nurse Director have worked throughout the year with staff from the MGH Center for Innovation in Care Delivery, the MGH Healthcare Transformation Lab, and the MGH Center for Innovation in Digital Healthcare to develop an app that will contain all the available information a parent needs when their child is admitted to the Pediatric Intensive Care Unit. The project is ongoing.



- **Mindfulness Meditation Videos in Spanish** – Last year, Miri Bar-Halpern, a parent member who is also a clinical psychologist developed 7 mindful meditation audios that are available on the MGfC website and YouTube channel that are used by parents and providers alike. The videos have now been translated into Spanish. Thus far, the videos in English have been viewed on YouTube 1,268 times and the ones in Spanish have been viewed 222 times.



- **Patient Experience Working Group** – 2 FAC parents collaborated with a diverse group of hospital stakeholders to generate lists of tactics departments can use to increase courtesy and helpfulness of front desk staff.
- **F-Words in Childhood Disability** – Mara Yale, FAC parent and head of the Pediatric Stroke and Brain Education program at MGfC spearheaded an effort, along with support from FAC, to bring [CanChild F-Words in Childhood Disability](#) trainings to key departments and teams at the hospital. Several FAC parents joined the training that were developed and presented by the CanChild team at McMaster University in Canada.
- **Family Advisory Council Grand Rounds** – In May, the Family Advisory Council sponsored its 13<sup>th</sup> annual Grand Rounds in which it again highlighted a partnership between providers and parents. Family Advisory Council parent Mara Yale, PhD discussed the Pediatric Stroke and Brain Injury Education program she leads. She was joined by Drs. Patricia Muscolino and Brian Wishart. The team presented the Pediatric Stroke Team’s implementation of ‘F-words in Childhood Disability’ an approach that focuses on function, family, fitness, fun, friends, and future.

- **Wayfinding at Newton Wellesley Hospital** – Parents on the Family Advisory Council provided feedback to the MGfC Quality and Safety team who developed wayfinding instructions to help parents find their way to pediatric primary and sub-specialty care at Newton-Wellesley Hospital.

## NEW Wayfinding instructions for MGfC Pediatric practices at NWH!

### Parent Contributors

- Kerstin Der
- Lynnette Lovasco
- Lacy Smith
- Mara Yale



When patient comments began coming in regarding difficulty finding the MGfC specialty practices at NWH, parents provided invaluable insight and concrete instruction suggestions. These instructions are now available in Patient Gateway for all MGfC NWH appointments. We are now working to expand wayfinding instructions for all MGfC practice locations.

Parent suggestions targeted readability, reading comprehension level, consideration for appearance on mobile digital devices, and including landmarks

- ✓ Bullet points instead of paragraph format
- ✓ Shorten sentences and parse into smaller steps
- ✓ Include landmarks inside the building

### ***New MGfC Pediatric Wayfinding language for NWH:***

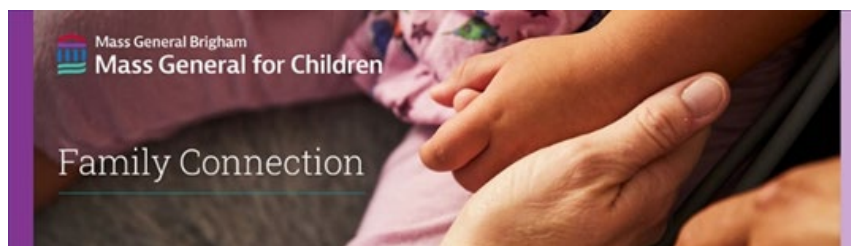
- *Enter the hospital campus from Washington St. (Rt. 16) via the East Entrance (turn at the traffic light onto the hospital road).*
- *Once you turn off Washington St., take an immediate right turn to park in the (insert "P" symbol) Visitors Garage.*
- *Enter the White building and take elevators/stairs to the 3<sup>rd</sup> floor.*
- *Follow signs to the Main Hospital/West Lobby. You will pass the florist and gift shop.*
- *When you reach the West Lobby, turn left before the Information Desk and proceed down the hallway.*
- *At the end of this hall, take a right and follow signs to the South Elevators, which will be on your left.*
- *Take the South Elevators to the 6<sup>th</sup> floor and you will see the Pediatric Ambulatory Clinic straight ahead to the left.*

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- **Joint PFAC event** – FAC members attended the Joint PFAC event titled 'A Conversation with Dr. William Curry, Chief Medical Office, MGH/MGPO and participated with him and other hospital leaders in a conversation about a shared vision to continually improve the patient and family experience.
- **Annual Social Gathering** – In July 2023, FAC members met for our annual social gathering, a practice we have not undertaken since the pandemic. Given the fact that most of our meetings are now virtual, the original intention of fostering stronger social connections between FAC members is even more important. A good time was had by all!
- **Magnet Event** – Lynnette Lovosco, PFA, participated in a session with outside Magnet appraisers, community organizations, and patients and parents to discuss how participants have worked with MGH nurses. Magnet is the highest recognition bestowed on healthcare organizations for excellence in nursing.



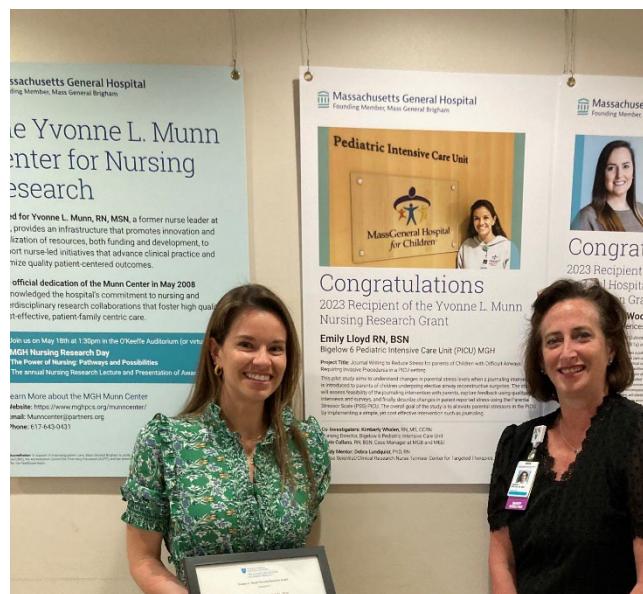
- **Patient Education Documents** – FAC parents continued to review patient education documents developed by the MGfC editor for clarity and relevance to the wider MGfC parent and patient community.
- **Parent Connection** – The MGfC editor and FAC continued to publish Parent Connection, the hospital’s parent-facing newsletter featuring staff profiles, events, upcoming talks of interest to parents and patients and a quarterly spotlight on Family Advisory Council activities.



March 2023

Your connection to news, stories, events and more at MGfC

- **Yvonne Munn Nursing Research Grant** – Emily Lloyd RN, BSN, Family Advisory Council staff member, won the Yvonne Munn Nursing Research Grant for her proposal addressing the effectiveness of journaling to reduce stress in the PICU setting. Emily’s co-investigator is fellow FAC member Kim Whalen, RN, MS, CCRN, Nurse Director of the PICU. Emily and Kim were inspired by the work of Faith Wilcox, a FAC parent who had used journaling to reduce stress when her child was hospitalized. Faith created Journals of Hope, a program that donates journals throughout the inpatient departments, including the PICU.



- **New Physician in Chief** – Joanne Wolf, MD, new Physician in Chief at MGfC joined the January meeting to introduce herself, discuss her commitment to the importance of parent and patient engagement, and learn about FAC activities.

## 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.
- **Parents of Children with Complex Medical Needs** – Justine Dellaria, LICSW and Sandra Clancy presented research highlighting the mental health challenges faced by many parents of children with complex needs and an integrated behavioral health approach that some parents have found beneficial.
- **Acute Hospital Care at Home for Pediatric Patients** – Dr. David Levine and Martie Carnie, Senior Patient Experience Coordinator, discussed efforts to expand the MGB hospital at home initiative to pediatric patients, a randomized clinical effectiveness trial he is conducting, and solicited feedback from FAC parents on his work.
- **Reflective Practice** - Robert Meyer MD and Susan Hata MD, Co-Directors of Wellness for MGfC oversaw an interactive session in which FAC members (providers, staff, and parents) reflected on their experiences of care at the hospital and discussed in small groups. This session is like ones offered to provider groups throughout the hospital.
- **Mental Health of Caregivers** – Nancy Rotter PhD, Director of Psychology and Child and Adolescent Psychiatry discussed her efforts to integrate behavioral and mental health supports for parents/caregivers within several departments. Specifically, she discussed screenings for food allergy anxiety within patients and parents in the Food Allergy Department.

## 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.

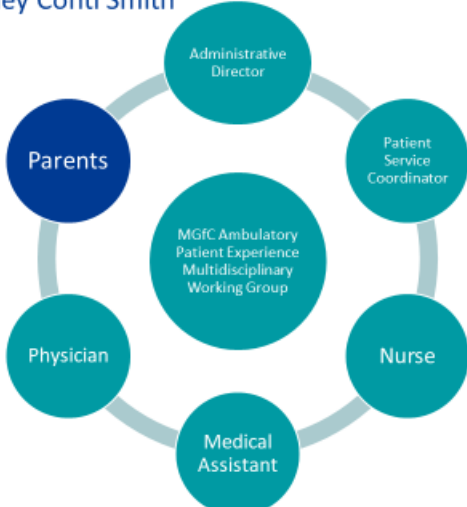
- **Pediatric Ethics Committee** – One parent member of FAC sits on this Committee that provides guidance on ethical dilemmas that present themselves in the hospital setting.

- **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 PFAs as members.

### MGfC Patient Experience Multidisciplinary Working Group

**Parent Members**

- Courtney Chisholm
- Lynnette Lovasco
- Ashley Conti Smith



- ✓ **Parents** attended working group meetings to identify barriers and contributing factors to optimal patient experience regarding courtesy and respect and generate ideas for changes and improvements
- ✓ From these discussions, MGfC Quality and Safety developed 24 tactics for ambulatory specialties to implement in their practices to improve patient experience courtesy and respect scores in 3 focus areas
- ✓ 15/15 (100%) Ambulatory Specialties implemented at least 1 tactic
- ✓ **MGfC Ambulatory patient experience scores for courtesy and respect increased in all 3 target areas!**

Pediatric Quality and Safety | Confidential—do not copy or distribute 1

- **Pediatric Quality and Safety Committee** – Multidisciplinary committee that oversees quality and safety efforts at MGfC has one parent member.
- **Ether Dome Challenge Working Groups** – Four FAC members serve on two EDC Working Groups, meeting one time per month for a year to provide patient experience perspectives on problems families often have post-discharge and information families need during a PICU stay.
- **FAC Membership Committee** – 2 PFAs review applications and weigh in on membership decision.

### Additional Activities & Accomplishments

- Recruited 3 new PFAs and one new staff member.
- Two new PFAs on the Membership Committee.
- One PFA has begun working with the Pediatric Stroke Team to explore the possibility of improving screenings for children with Cortical Visual Impairment.
- One PFA is planning to work with the MGfC Child Life team to develop activities for children that they can take home with them post-discharge.



### MASSGENERAL FOR CHILDREN FAC MEMBERS

#### **Patient/Family Advisors (PFAs)**

Seta Atamian  
Miri Bar-Halpern  
Ashley Conti Smith  
Kristin Der  
Roxanne Hoke-Chandler  
Robert Lillianfeld  
Lynette Lovosco  
Erin Quinney  
Sarah Romano  
Lacey Sakash  
Ann Skoczenski  
Lacey Smith  
Faith Wilcox, parent co-chair  
Mara Yale

#### **Staff**

Rebecca Aures  
Sandra Clancy, staff co-chair  
Brian Cummings  
Hillary Ellis  
Esther Israel  
Emily Lloyd  
Sandra Dodge McGee  
Anne Bouchard Pizzano  
Lori Pugsley  
Kim Whalen

# Heart and Vascular Centers Patient and Family Advisory Council

**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, focused on clinical practice, programs, patient safety and innovation. This has been a long-standing group of very active PFAs (Patient/Family Advisors) 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.

## ACTIVITIES AND ACCOMPLISHMENTS - 2022-2023

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

#### Presentations

- **PFAC Ether Dome Challenge Overview** – Paula McCree and Hiyam Nadel, RN
- **Patient Experience Staff Recognition Initiatives** – Cindy Sprogis
- **Discharge Lounge and Auxiliary Space Updates** – Sue Algeri, RN and Kyan Safavi, MD
- **Vascular Surgery Updates** – Matthew Eagleton, MD
- **Anticoagulation and Periphery Arterial Disease** - Anahita Dua, MD, MBA, FACS
- **Stanford University Care Coordination** – Marcello Chang, MD and Joy Cai



“The Heart and Vascular Patient Family Advisory Council provides the opportunity for regular and ongoing feedback from patients and family members to Hospital Staff on continuous improvement in care delivery. Including nurses, doctors, and clinicians in regular discussions with patients and family members, ensures there is an opportunity for hospital staff to solicit and receive feedback on the experience they deliver, as well as providing a sounding board on new ideas to improve the patient experience. The Heart and Vascular Team should be commended for really listening to their patients' experiences and working to make them even better!”

–Heart and Vascular PFA

### 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 were not limited to:

- **New Facility Design:** (2021 – ongoing): Architects for a large new Mass General building solicited input from PFAs regarding future design of new spaces.
- **Cambridge Street Project: (December 2022 – April 2023):** Provided feedback for Patient Infotainment Design for new buildings.
- **Annual Patient Experience Awards: (January 2023) –** Members were asked to participate as judges to review nominations and cast their votes.
- **Recruitment Efforts:** Recruited two new members and in process of seeking additional new members of diverse backgrounds (2022 – present); PFAC member participated in the interviewing process.
- **Bylaws:** Developed Bylaws aligned with the General PFAC's, appointed additional committee co-chair, and recruited two new staff members to join Executive Leadership group.
- **Ether Dome Challenge:** (June 2022 – present) – Members were encouraged to submit suggestions for innovative patient experience improvements. PFA Jonathan Parziale's submission, “Information Gathering Prior to Appointment,” received a significant score from the three judges and was recognized as one of three runner ups of the PFAC Ether Dome Challenge.

“Serving on the Heart and Vascular PFAC has provided me the opportunity to learn about and support the goals for excellence in service and care, and to provide feedback as a voice of the patient to improve the patient experience for others. The time spent has been a fulfilling and rewarding way to pay forward the gift of excellent care I received as a patient.”

–Heart and Vascular PFA



“I've been impressed with the collaboration between PFAs and staff in the Heart and Vascular PFAC. Discussions are often lively, with each person bringing a unique perspective. I can see how passionate everyone is about improving patient experience and working to make that a reality. Being a PFA of this PFAC has also afforded me other opportunities, such as participating in this past year's Ether Dome Challenge. It was an honor to be selected and to serve with this group. I look forward to what we accomplish next.”

*–Heart and Vascular PFA*



## HEART AND VASCULAR CENTERS PFAC MEMBERS

### Patient/Family Advisors (PFAs)

Teri Fryer  
Tom Fryer  
Phil Geary  
Susan Geary  
Pat Hollenbeck  
Denise Mallen  
Jonathan Parziale  
Stuart Rothman  
Matt Smith  
Sara Strobe  
Hiromi Towle  
David Wooster, PFA co-chair

### Staff

Gigi Aguasvivas  
Suzanne Algeri  
Michelle Anastasi  
LaVern Delaney  
Miguel Ferry  
Jonathan Ludmir  
Asishana Osho  
Cindy Sprogis  
Carolyn Velez, staff co-chair

# Cancer Center Patient and Family Advisory Council



**Established in 2001**

## OVERVIEW

As an advisory council to Cancer Center administration and staff, the Cancer Center 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 Mass General by participating in organization-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 to enhance their entire experience at the Massachusetts General Cancer Center.

## COUNCIL OPERATIONS

The Cancer Center PFAC meets virtually on the second Wednesday of each month from 5pm - 6:30pm and aims to hold in person gatherings at least twice per year. Meeting minutes and materials are stored electronically.





## MEMBERSHIP

The Cancer Center PFAC currently consists of 13 active Patient/Family Advisors (PFAs). In July of 2022 we honored several PFAs in transition, conducted interviews, and selected 5 new PFAs to join our 8 alumni PFAs, who have all committed to a 2-year term. Additionally, the council includes 4 staff members that collaboratively organize and lead the council. PFAs 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 diverse sites of care (Boston/Main Campus, Mass General/North Shore Cancer Center in Danvers, and Mass General Cancer Center at Mass General Waltham).

Staff members of the Cancer Center PFAC include the Director of Advanced Practice Oncology Providers, Cancer Center Administrative Director, Cancer Center Senior Administrative Manager, an Oncology Social Worker, and a project/program manager.



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*"Words cannot express how honored I feel to be part of PFAC these past 5 years! Please include me in giving thanks to the brilliant doctors who gave up their valuable time to spend time with us last evening. This is my second time visiting the research center. Like before, I remain hopeful, that progress will be made, particularly for pancreatic cancer."*

*– Cancer Center PFA*

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## ACTIVITIES AND ACCOMPLISHMENTS - 2022-2023

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

During monthly meetings and through targeted requests, the Cancer Center PFAC reviewed, provided feedback on, and learned about a variety of topics and strategic initiatives. Our year opened with introductions and an open discussion with the council about interests and goals for the year. With input from the council and themes of interest in Equity, Diversity, Caregiver Support, Supportive Care, Process Improvement, and Healthcare Delivery in a changing environment, our monthly agendas took shape and were as follows:

- **Supportive Care Program:** Jeff Peppercorn, MD and Amy Comander, MD
- **Integrated Network Services/Cross Site Scheduling:** Courtney McLeish
- **New Patient Scheduling Decision Tree:** Judie Panagiotopoulos
- **Cancer Center Equity Colloquium:** Brenda Lormil, NP, Colin Weekes, MD
- **Patient Journey Beyond the Primary Team:** Kellyann Jeffries, NP, Marissa Lauria, NP
- **Charlestown Navy Lab/Center for Cancer Research Discussion and Tour:** Daniel Haber, MD, Ph.D., Raul Mostoslavsky, Christopher Ott, Ph.D., Shyamala Maheswaran
- **Psychiatric Oncology:** Jamie Jacobs, Ph.D.
- **Early Detection Program:** Lecia Sequist, MD
- **CAR-T:** Matthew Frigault, MD
- **State of the Cancer Center:** David Ryan, MD.
- **An Integrated Health Care System: What's in it for us?:** Dr. William Curry, CMO, MGH/MGPO"

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*"Each time I experience such welcoming hosts and presentation of research, I am inspired by each doctor-scientist's passion and knowledge, proud of MGH's amazing achievements, and hopeful for treatments that will improve the quality of cancer patients' lives, and maybe even cure cancer for many. I am grateful for the time they took out of their evening to introduce us to the Center for Cancer Research and sharing their own research. The discussion about the integration of AI into medical research was fascinating. Thank you for this amazing opportunity!!"*

– Cancer Center PFA

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### Participation in Committees and Initiatives

- **The Continuum Project – Serious Illness Conversations Focus Group:** Susan Edgman-Levitan requested PFAs engage with a focus on improving serious illness conversations and helping patients/families understand the importance of patients having a health care proxy. Peter Zschokke & Leslie Waisnor from Cancer Center PFAC served on this group.

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*"It was such an enjoyable time and gathering in person was great. Appreciate all who helped plan and set up reception. Everything was beautifully done."*

*– Cancer Center PFA*

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*"Thanks and appreciation for this special evening. I am honored to be a part of this special group of people!"*

*– Cancer Center PFA*

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### CANCER CENTER PFAC MEMBERS

#### **Patient/Family Advisors (PFAs)**

Shawn Campinha  
Kevin Chan  
Sarah Dagher  
Cindy Eid  
John Gillis  
Sandra Gillis  
Diane Moes  
Joanne Rowley  
Suzanne Sarafin  
Theresa Shea  
Leslie Waisnor  
Katherine Wharton  
Peter Zschokke

#### **Staff**

Colleen Anderson  
Jennifer Grasso  
Nova Hodge  
Kellyann Jeffries  
Lisa Leung-Tat

# Pediatric Oncology Family Advisory Council



**Established in 2003**

## OVERVIEW

The Pediatric Oncology Family Advisory Committee (FAC) has confronted significant challenges and transitions over the past year. While this group has been integral to the Pediatric Oncology clinical service for many years, changes in the medical practice provided an opportunity to pause and review the current program. This group of parents have provided input around clinical practice, program planning, and patient safety, for many years. This has been a long-standing active group since 2003 with a changing membership to reflect the needs of the parents and the practice. Historically, parents of children receiving cancer treatment and parents of those children who have completed treatment joined 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.

With the closure of Tufts Medicine's Pediatric Hematology- Oncology program and the additional influx of non-oncology patients coming to the clinic for infusion support, the population we serve is different. Staff identified the need to be more inclusive in our Advisory Council, which in turn will change the focus of our group. As such, in October 2022, we decided to "pause" and spend time reflecting as a clinical practice on the goals of the current Family Advisory Council and the needs of our practice in the context of our current patient population. The months that followed have included many ongoing conversations related to the goals and composition of the Council.

## 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 - 2022-2023

### Topics Reviewed by and Presented to the Pediatric Oncology FAC

In the early fall, meetings continued to be held virtually to ensure the continued safety of our members due to hospital policy and health concerns related to the COVID-19 pandemic. The focus was as follows:

- **Tufts Medicine's Pediatric Hematology- Oncology Program Closing:** Discussion of onboarding of the many Tufts Children's patients into the Pediatric Hematology-Oncology practice.
- **Diversity and Racial disparities in Health Care:** and opportunities for enhancement to our clinical program in this arena.
- **Patient/Family Survey:** completed with 75 patients/families in outpatient clinic to assess patients' experiences looking at variables of language, diagnosis, and frequency of visits. Presented to clinical staff in September 2022, with plans for a working group to be established to address results and actions plans based on survey results.

**Family Advisory Council Meetings Paused:** The FAC suspended meetings in November 2022, and has not met as a committee since then. We are gearing up to resume our program, after adding new members to reflect a greater diversity of patients, families, treatment experiences, and providers.

**Pediatric Oncology FAC Celebration Dinner:** In February 2023, with the pandemic less of an acute concern, we hosted a Celebration Dinner to honor the current membership, including some recent past active members. This was the first opportunity for the Family Advisory Council to convene in person since early 2020, and a wonderful way to recognize the commitment and accomplishments of a Council dedicated to the Pediatric Oncology program and enhancing patient and family-centered care.

### PEDIATRIC ONCOLOGY FAC MEMBERS

#### Patient/Family Advisors (PFAs)

Dawn Regan, co-chair  
Mary Cincotta  
Michael Doiron  
Tim Dunne  
Susan Jacobson  
Chau Nguyen  
Sandra Santoro  
Jerry Schindler  
Janice Theriaque  
Tarah Zedower

#### Staff

Elyse Levin-Russman. staff co-chair  
Alison Friedmann  
Patti Scott

# General Patient and Family Advisory Council

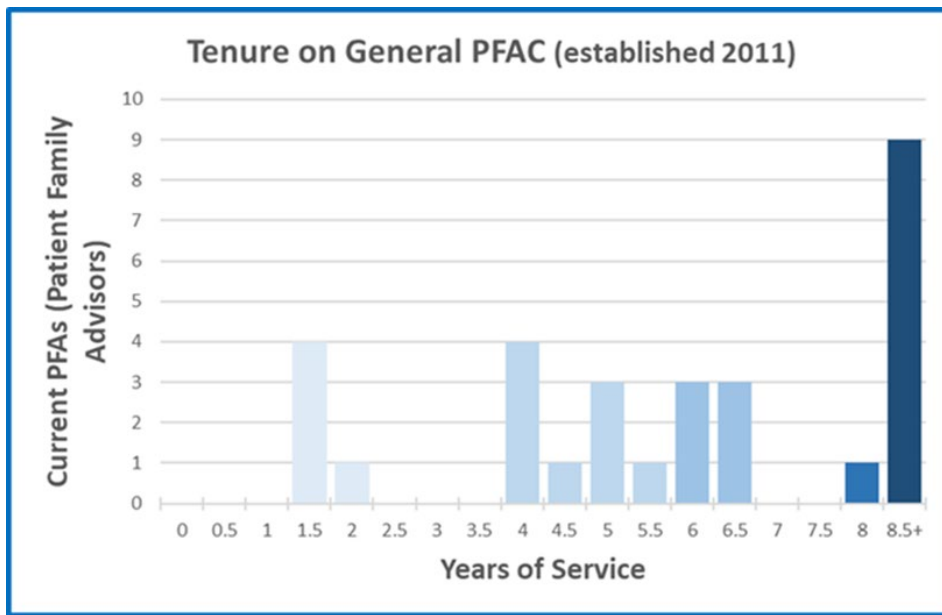
**Established in 2011**

## OVERVIEW

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



## ACTIVITIES AND ACCOMPLISHMENTS - 2022-2023

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

Through the past year, the General PFAC continued its practice of engaging with leadership and reviewing a wide variety of topics. This year's topics spanned strategic imperatives, services, and settings, along with coordinating joint MGH PFAC meetings, ensuring consistency and sharing of best practices. Requests for comment and guidance came from a variety of Mass General and Mass General Brigham staff and providers. At monthly meetings, PFAs gathered virtually, and once in person. The monthly meeting format provided the opportunity to address many topics, including:

- **Patient & SLP Collaboration** – Jaime Tirrell Hassey, M.S, CCC-SLP, Speech Language Pathologist at the MGH Chelsea HealthCare Center, shared ongoing efforts to meet families “where they are” in Speech Language Pathology. Information was also shared on the Chelsea HealthCare Center and how the PFAC could become more involved in the community.
- **Pharmacy and Therapeutics Safety** – Christopher Fortier, PharmD, Chief Pharmacy Officer, and Jacqueline MacCormack-Gagnon, PharmD, Director of Medication Use Policy and Informatics provided an overview of the Pharmacy department sharing key challenges. They shared information on current medication shortages, home medication, and medication compliance and accommodations. PFAs shared their concerns across a range of medication topics.
- **MGB Innovation and Strategy** – Jeff Weiss, MGB Chief Strategy and Transformation Officer updated the PFAs from all MGH PFACs, on the 5 MGB Strategic Priorities. Some of the work he shared included optimizing all resources effectively, ramping up “hospital at home,” and investing in and retaining outstanding people. PFAs offered concern regarding growing destination medicine when capacity continues to be an issue. He shared information on how UPMC is a good example of a system growing margins, working two strategies at once, while improving financial performance and care delivery.
- **MGH Center for Immigrant Health (CIH) Overview** – Fiona Danaher, MD, CIH Director, provided an overview and history of CIH, which began as a volunteer effort and grew into a program with limited funding. PFAs were interested in how they could help, including immigrant health advocacy work, asking for a list of bills to support. CIH website and links were shared to help educate the PFAs, who profoundly thanked Dr. Danaher for the important work being done.

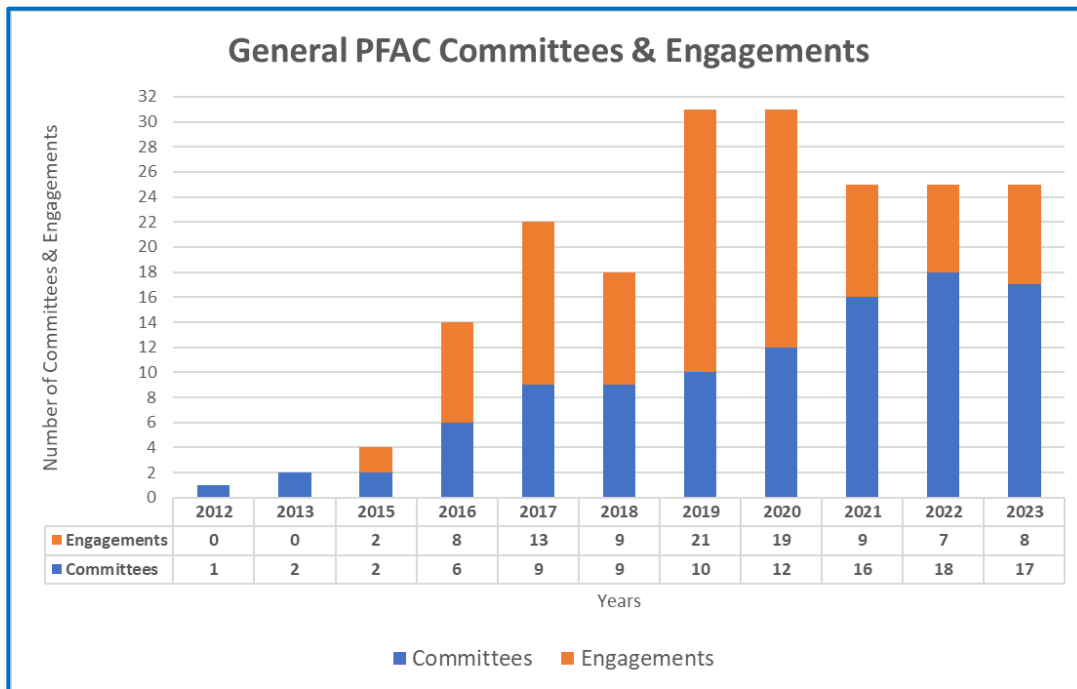


- **MGH Community Health Worker (CHW) Model** – Sarah Oo, MSW, Senior Director, Community Health Improvement, shared the CHW model. PFAs deepened their learning of the CHW model and were invited to visit MGH Chelsea to meet the team and help champion the program.
- **Blum Center Overview, Initiatives, and Strategy** – Brian French, RN, Director of the Blum Center, and Amy Quach Sam, Health Education Project Specialist, both work regularly and closely with the General PFAC. They provided an update to the General PFAC and asked how the Blum Center could increase visibility of programs to patients, recruit more volunteers, and raise its profile. PFAs provided ideas, including referring newly diagnosed patients to Blum Center through Patient Gateway messages to connect them with educational content related to the diagnosis, and sharing the Blum Center Patient Story Kiosk in several high traffic areas of the hospital. A suggestion was also made to ensure the Blum Education Center is part of the Ragon Building first-floor design, centering patients/families from the moment they enter.
- **An Integrated Health Care System: What’s in it for us?** – William Curry, MD, Chief Medical Officer, MGH/MGPO, was the guest speaker at the second Joint PFAC meeting, which was held in person. Dr. Curry shared his thoughts regarding the ongoing Mass General Brigham (MGB) integration and its impact on MGH. In addition, he shared specific examples of clinical service integration across all health system facilities that improved efficiency and communication, such as Radiology and Emergency Medicine. Dr. Curry acknowledged that transitions require strong change management efforts, and he invited questions and comments from participants. He was very appreciative of PFAs and their contributions.
- **“Got Help as Soon as Wanted” – Unit Responsiveness Project** – Helen Scarr, Senior Advisor, Patient Experience, shared an overview of the Unit Responsiveness Project, which included observations and staff interviews. Information from interviews was used to determine best communication practices – communication flow, escalation and closing the loop. Data and survey metrics were shared, and members offered a variety of ideas on what could be impacting the metrics. PFAs were asked to review the unit guide and share improvement suggestions. They will be invited to co-produce a patient-facing document to guide patients in ways to best-communicate their needs to staff.

## Participation in Committees and Initiatives

In addition to attending monthly General PFAC meetings, PFAs participate in ongoing committees, projects, and workgroups across the hospital and system, providing the patient and family voice and perspective within interdisciplinary groups. Participation is both in-person and virtual.

The chart below highlights that PFAs participated in fewer engagements (projects/workgroups) and spent more time in their roles as advisors for standing committees. Now 3 years out from COVID, the General PFAC has renewed its focus on weaving PFAs into more projects and initiatives across the organization.



PFAs have been engaged in the following committees, projects and workgroups:

- **ADVOCATE Advisory Committee (*Advancing Digital and Virtual Opportunities for Care Access Translates to Equity*)** – One PFA 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 Awards** – Annually, clinicians and staff submit patience experience award nominations on behalf of colleagues (individuals and teams) that have demonstrated icare (communicate, advocate, respect, empathy) excellence. For what is now the fourth year, General PFAC members served as judges, reviewing nominations, and voting on nominations. Members also attend the award 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.

- **Continuum Project** – Two PFAs from the General PFAC joined an ongoing workgroup that provides feedback on a palliative care toolkit and the Continuum Project website. Other members of the workgroup include 3 PFAs from other Mass General PFACs and people who have a family member engaged with palliative care. The PFAs shared the materials at a General PFAC meeting. The Continuum project will start to offer more patients this opportunity in the future. Participants find this project very fulfilling, and their input valued.

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“The Continuum Project allowed PFAs to engage in discussions on how to best support families in talking about serious illness, palliative care, and end-of-life planning, in a meaningful way. By participating in the conversations and reviewing the materials, we were able to provide feedback on how we as patients and families would most like to be engaged on these difficult topics.”

- PFA, Continuum Project Participant

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- **Council On Disability Awareness (CODA)** – Two PFAs 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** – One PFA 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.
- **Equity Policy and Practice Review Committee – General PFAC Sub Committee** – Several PFAs 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.
- **Hospitalization through a Disability Lens** – Three PFAs from the General PFAC are part of a collaboration between the General PFAC, CODA, and Patient Care Services. The goal is to reduce care experience disparities and optimize patient safety, quality and overall experience of patients with disabilities throughout their hospitalization. The group is co-designing interventions to improve admission to the unit for patients with disabilities.

- **Input in Care** – Improving the ‘Had enough input/say in care’ NRC metric has been identified as one of Mass General’s FY23 priorities. A process improvement initiative was launched around optimizing the use of the whiteboards within each patient room to ensure patients have input/say in their care and foster active engagement. One PFA has been engaged in this work and has helped design a patient feedback survey to measure the initiative’s impact.
- **Institutional Review Board (IRB)** – The IRB is a formal committee required by the FDA of all organizations involved in biomedical research involving human subjects. It is designed to review and monitor biomedical research to protect the rights and welfare of human subjects. One PFA serves as a non-scientific member of the IRB for ongoing reviews and monitoring of research studies.
- **Health Care Transformation Lab (HTL) and Center for Innovation / PFAC Ether Dome Challenge** – All PFAs 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, which 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 PFAs offering several ideas for enriching the patient and family experience, and 3 PFAs advancing to the second round.



Winners, Runner Ups, Final Round participants (not pictured, Linda Cline/ Catherine Duffek) **Back row:** MGH leaders, including Sandy Clancy, MGfC PFAC, staff co-chair.



**Pictured from Left:** Debbie Burke, RN, Chief Nurse, Inga Lennes, MD, SVP, Ambulatory Care and Patient Experience, Linda Cline and Tracy Talbott, who advanced to the final round, and Eric Isselbacher, MD, HTL Director.

“The Ether Dome Challenge provided a fantastic and meaningful opportunity for patient voices to be heard. Identifying areas for improvement and getting to work with staff to find creative solutions felt satisfying, meaningful, and fun!”

– PFA, Ether Dome Participant

- **Mass General Brigham Home Care PFAC** – One PFA serves on this MGB PFAC that meets monthly to review and provide feedback on the care parameters established for home care following surgery and/or rehab in nursing, occupational, and physical therapy areas of practice.
- **Phillip & Susan Ragon Building (Cambridge St Project) Patient Infotainment** – One PFA served on a 5-month taskforce that met with 2 potential tech partners. These interactive surfaces are used to display care information (food restrictions, meds, accommodations, etc.), education, and entertainment. Participants interacted with both platforms, advised on critical features of the design, and ultimately informed the final decision of which partner will move forward for the Ragon Building.
- **Quality Oversight Committee** – Two PFAs serve on the Quality Oversight Committee led by the Chief Quality Officer and including the Mass General quality directors. The committee shares statistics and gives updates on a broad cross-section of hospital initiatives to improve quality and safety.

## Additional Accomplishments

- **Updated General PFAC Bylaws** – The General PFAC bylaws were reviewed and updated by members of the Executive Committee, approved by the General PFAC, and shared with the other Mass General PFACs to use as a guide in updating or developing their own.
- **2 PFAs transitioned from the group to attend medical school** – 2 PFAs who had made significant contributions to the PFAC had to step down when each of them started medical school. We are very proud of their continuing accomplishments.
- **Robin Lipkis-Orlando, RM, MS Excellence in Patient Advocacy Award** – established in honor of Roblin's retirement as MGH Director of Patient Advocacy after serving over 40 years at MGH. This annual award will honor Robin's tenure as an outstanding Mass General employee who embodies the characteristics of a strong patient advocate for patients, families, colleagues, and communities. The award winner will be honored during Patient Experience Week each year and includes a \$500 prize, provided by an anonymous donor.
- **Established Emerita/Emeritus member status** – The General PFAC developed criteria and approved the establishment of a new membership category of emerita/emertus. Robin Lipkis-Orlando was invited to be the first emerita member.
- **Continued consultations** with areas looking to form a PFAC or partner with patients/families.





Image: Photo montage of several General PFAC advisors. Photos do not represent the entire membership.

## GENERAL PFAC MEMBERS

### Patient/Family Advisors (PFAs)

Neelesh Ajmani  
Michelle Anderson  
Stephen Brown  
Bob Chen  
Linda Cline  
Julie DeCosta, co-chair  
Hilary Dignan  
Catherine Duffek  
Melissa Hoyt  
Susan Keshian  
William Kieffer  
Cynthia Lo  
Stuart Murphy  
Rhonda Pieroni  
Fifi Reed  
Joyce Smith  
Paul Smith  
Carrie Stamos  
Lisa Stein  
Tracy Talbott

### Staff

Evelyn Abayaah  
Robin Lipkis-Orlando  
Margaret Martin, Secretary  
Elsir Sanousi  
Helen Scarr, staff co-chair  
Jamie Tirrell Hassey

### Emerita/Emeritus

Robin Lipkis-Orlando (since 2023)

# Emergency Department Patient and Family Advisory Council

Established in 2018



## OVERVIEW

Because of the unique nature of Emergency Department (ED) care, patient and family experience is a challenge in the MGH ED. Growing patient volume, overcrowding and ongoing renovations, make providing outstanding patient experience increasingly difficult.

For many, the ED represents a point of “first contact” with MGH. Despite the noted challenges, 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. Challenging communication, overcrowding, and a constrained physical environment make those days worse.

The Mass General Emergency Department PFAC is working on making those days *better*.

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“I was waiting in the Emergency Room, which, all together, was 5 or 6 hours. I couldn't help but watch a lot of the care providers waiting on other patients. I was very, very impressed, how patient they were, and how much compassion they had. I forgot what it was like in an Emergency Room, and what they had to deal with, and I was just very impressed and want to thank them again.”

– ED PFA



## ACTIVITIES AND ACCOMPLISHMENTS - 2022-2023

### 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 2022/2023, areas of focus for the ED PFAC included:

- ED Capacity
- Stigmatizing Language
- Website Content Review
- A Day in the Life
- Ether Dome Challenge
- ED Patient Texting Program
- ED to Community Hospital Transfers Program
- Virtual Observation Unit (VOU) and Medical Response Program (MRP)
- Patient Safety
- Ambulatory Referrals
- Clinical Decision Unit (CDU) and Austin Building Construction
- New hospital mask policy

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

- ED Welcome Video
- ED Comfort Menu
- ED Signage
- 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 (Transition to NRC)
- 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
- Alternative Care Pathways
- Urgent Treatment Area patient experience
- Pediatric & Psychiatry population volumes



## Emergency Department PFAC Member Participation in Committees and Initiatives

Several patient/family members participate in initiatives including:

- **Community Hospital Transfer Program:** Providing marketing ideas for the ED to Community Hospital Transfers Program.
- **Patient Texting Program:** Reviewing current messaging for Patient Texting Program and suggesting edits.
- **PFAC Ether Dome Challenge** – All PFAs were invited to participate in the first Patient and Family “Ether Dome Challenge” – an open innovation contest designed by the MGH Health Transformation Lab that uses crowdsourcing to identify improvement ideas to be developed. Emergency Department PFA Penny Blaisdell was selected as one of 3 runner ups, with her idea, ““Patient Education about the Patient Gateway Features.” Penny was asked to say a few words about her submission at the Awards presentation and Celebration in December 2022. She identified a need for clearer directions on sharing records, and information on why an account becomes "inactive" and “not visible.”



### EMERGENCY DEPARTMENT PFAC MEMBERS

#### Patient/Family Advisors (PFAs)

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

#### Staff

Jennifer Andonian Shearer  
Olivia Clark (staff co-chair)  
Amanda Drapcho  
Denise Flaherty  
Ines Luciani-McGillivray  
Jonathan Sonis (staff co-chair)  
Robert Seger  
Ben White

# 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 relatively new PFAC whose Patient Family Advisors (PFAs) include people living with dementia (PLWD), family and caregivers of PLWD, along with a Spanish-speaking professional from the community. In addition, the PFAs are joined by staff from the **Division of Palliative Care and Geriatric Medicine**. The goal of the DCC PFAC is to offer advice from the PFAs 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.

## Goals

- 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.
- 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 on, and learned about a variety of critical topics. These included:

- **Introductory PFAC Training for new PFAC members** – Reviewed the tenants of the PFAC, PFA responsibilities, and received their feedback as they attended all meetings.
- **The Hospital Environment** – Nancy Kelly, NP, and Susan Rowlett, Director of the Dementia Caregiver Support Program, shared the strengths and weaknesses of the physical environment at Mass General Hospital. PFAs shared their experiences and their advice to improve the environment and to improve patient safety.
- **State Dementia Legislation** – Maura Kennedy, Director of the Geriatrics in the Mass General Emergency Department, shared the required State Operational plan for dementia care at Mass General that was due October 1, 2022. PFAs' feedback will impact actions for this plan for 2023 and future years.
- **Better Care and Better Communication at Mass General** – Led by Dr Joanna Paladino, Researcher, Mass General Mongan Institute Center for Aging and Serious Illness, discussed the action plans for patient feedback and care at Mass General. This session helped Dr Paladino lead the effort to improve communications for staff and patients in the hospital.
- **Driving Safety for People Living with Dementia** – Amanda Gold, OT, from the Newton Wellesley Drive Safe program, discussed how they work with caregivers and patients with dementia. PFAs talked about ways to take away the keys and how to expand this program.
- **New Alzheimer's Drugs** – Director of Research, Christine Ritchie, from the Division of Palliative Care and Geriatric Medicine, discussed and received PFAC members thoughts on the new Alzheimer's drugs that have been approved by the FDA and Medicare.

## PFAC Member Participation in Committees and Initiatives:

Dementia Care Collaborative PFAs participated in the following outside committee:

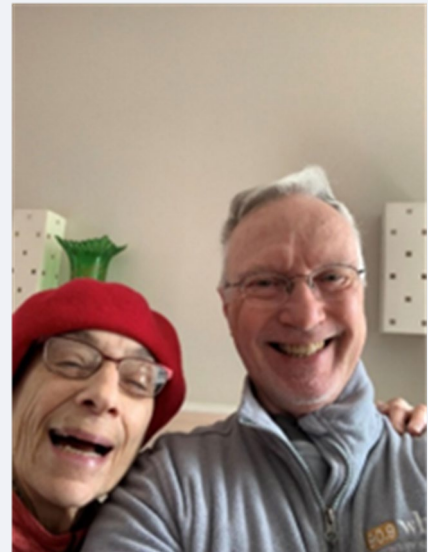
**IHI Expert Panel** – Member participated on the Institute for Healthcare Improvement’s expert panel to review a research study on cognitive testing for dementia.

### Patient Family Advisors, Greg Anderson and Helen Samuels

#### Our Path, Hand in Hand...

Our journey along the dementia care path began about seven years ago, when Helen was diagnosed with Alzheimer’s disease. It was the little things we noticed together that were early signs of diminishing cognitive abilities. For us, the disease became the accumulation of many small things that added into an overall picture that was hard to confront, both rationally and emotionally. At first, we tried to walk this path alone, feeling that, together, we could adapt and accommodate whatever changes were manifest. Ultimately, however, we recognized that engaging with the resources and deep expertise at Mass General was best for both of us. For my wife, who has done her own professional research, the blend of clinical and collaborative/social care was important for her care and complemented her core value to contribute to the growing body of knowledge through research. The DCC has opened many doors and perspectives for us.

Perhaps the most important door that the DCC opened for us is the sense of belonging. In our journey - especially during the darkest period of COVID – the DCC reduced the feelings of isolation and loneliness. For us, the notion of belonging and socialization has been such a strength; we know that we have so many wonderful people in our corner. Knowing that there are wonderful staff who are always willing to listen, to bolster our spirits, and to lend a guiding and gentle hand is so reassuring as we move farther down this path.



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“ The Dementia Care Collaborative is a really great service, and we just hope that they continue to get the funding they need to make the significant difference in the care my mother is receiving, as well as those of us who love her and care for her. We thank them for their support. Wonderful organization.”

– Caregiver

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## DEMENTIA CARE COLLABORATIVE PFAC MEMBERS

### Patient/Family

Greg Anderson  
Helen Samuels  
Mike Belville  
Leonor Buitrago  
Scott Hanson  
Barbara Ivery  
Ellen DeGenova  
Marty Gilpatrick  
Judy Johanson  
Bob Kagey  
Stan Leven  
Bernice Osbourne  
Mary Walsh

### Staff

Todd Rinehart  
Christine Ritchie  
Judy Willett

# Charlestown HealthCare Center Patient and 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 our personalized healthcare.

The MGH Charlestown Healthcare Center developed the Patient Family Advisory Council (PFAC) 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 patient, family, and providers to collaborate on innovations and optimization of the care experience for all.

"Always the best! Best site for care. Spotless, excellent knowledgeable staff. Staff always friendly, courteous, appointments are always on time, easy to get appointments, just exceptional all the way around. Kudos to all!"

*– Patient, Charlestown Healthcare Center*



## ACTIVITIES AND ACCOMPLISHMENTS - 2022-2023

### 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:

- **Community Garden Grant** – Carolina Abuelo, MD and Linda Forsythe, MD
  - Presentation on funding for the Community Garden Grant to patients and families.
  - Goal is to continue to help the community get healthier.
  - Followed by discussion with PFAs for suggestions and ideas.
- **Health Center and Community** – Claire Conlan and Jim Morrill, MD
  - Presentation on role of the Health Center and Community and leadership restructure.
  - Goal is to be true to the community health center model, keeping patients healthy at baseline.
  - Followed by discussion, with PFAs for suggestions and ideas.
- **Navigation Department** – Branden Washington, Community Health Programs Manager, Certified Community Health Worker
  - Presentation on role of the Health Center Navigation Department
  - Provided information on how to refer to the program and assistance with many needs such as Mass Health applications, PT1 transportation.
- **Community Care Vans** – Priya Sarin Gupta, MD MPH, Medical Director of Community-Based Clinical Programs
  - Presentation on role of Community Care Vans
  - Provided information on services provided in care vans: flu vaccines, COVID vaccines, blood pressure screenings, substance use disorder care visits, etc.
  - Followed by Q&A by members of PFAC.
- **Mass General Brigham (MGB) Branding** – Presented presentation on MGB Branding with interactive surveys; PFAs provided input on re-branding at the healthcare center.

“A wonderful experience. A gem in my Charlestown neighborhood.”

– *Patient, Charlestown Healthcare Center*

### Additional Activities/Accomplishments

- **Mass General Joint PFAC meeting** - PFAs were invited to join the Mass General Joint PFAC meeting on June 14, 2023. Dr. Curry presented the value of integrated healthcare delivery systems with discussion.

“Love my primary care doctor. He is a wonderful doctor. I live an hour away, but I continue to go to Charlestown because of him. He has helped me so very, very much. I am extremely grateful. I am clean from opioids for over 10 years because of his help, and 1 or 2 therapists on the 3rd floor. Forever thankful.”

– Patient, Charlestown Healthcare Center

“My visit to the Charlestown MGH Health Center was a positive and helpful experience. That has usually been the case over the 30+ years I have been coming to the health center. It is why I keep coming back. The quality of care and professionalism from staff is and has been of the highest order.”

– Patient, Charlestown Healthcare Center

### CHARLESTOWN HEALTHCARE CENTER PFAC MEMBERS

#### Patient/Family Advisors (PFAs)

Nancy Erhard  
Shane Fisher  
Aileen Gorman  
Gowri Nagaraj  
Jane O’Neil  
Chris Turunen  
Gabrielle Vacheresse

#### Staff

Susan FitzMaurice, staff co-chair  
Jennifer Marino, staff co-chair  
Muriel Montecinos



# Department of Internal Medicine (DGIM) Primary Care Patient Advisory Council (PAC)

**Established in 2022**

## OVERVIEW

The Division of General Internal Medicine (DGIM) at Massachusetts General Hospital encompasses more than 350 general medicine physicians with world-renowned programs in teaching and training, research, clinical practice, hospital medicine, consultative medicine, global health, innovation, and scholarship.

The DGIM is an integrated, coordinated group that works across clinical areas to develop innovative new programs addressing health care needs in clinics, hospitals, patients' homes, and the community. Primary Care Practices fall under DGIM and Mass General provides comprehensive primary care and medical specialty services to 200,000 adult and pediatric patients in 23 locations throughout Greater Boston. Our primary care physicians are highly trained and board-certified in family medicine, internal medicine, pediatric medicine and/or geriatrics, and serve on the faculty of Harvard Medical School.

The DGIM Primary Care Patient Advisory Council (PAC) was formed in 2022. The PAC has started by recruiting five MGH employees who receive their primary care at MGH practices, to serve as patient advisors with the intention to expand membership to non-employees in 2023. Having members who are part of the MGH family and understand the intricacies and complexity of our primary care practices is key in driving positive change and improvement and because our system is hoping to provide primary care for all MGB employees in the future.

## MISSION

The mission of the MGH DGIM Primary Care PAC is centered in the words of the MGB Mission Statement, "Guided by the needs of our patients and their families." As one of the world's foremost academic medical centers, our focus is not just on delivering excellent care, but also on improving the quality and delivery of primary medical care at each of our practices and health centers. To accomplish this, we will integrate the employee, patient, and family voices to continuously innovate and improve on the primary care experience.



### List of Primary Care Practices

<b>Assembly Row</b>
<b>Back Bay</b>
<b>Beacon Hill</b>
<b>Bulfinch Medical Group (BMG)</b>
<b>Charlestown Adult Medicine</b>
<b>Chelsea Adult Medicine</b>
<b>Chelsea Urgent Care</b>
<b>Downtown</b>
<b>Everett Family Practice</b>
<b>Internal Medicine Associates (IMA)</b>
<b>Mass General Medical Group (MGMG)</b>
<b>Primary Care Associates (PCA)</b>
<b>Primary Care Boston</b>
<b>Bridge to Access (B2A)</b>
<b>Revere Adult Medicine</b>
<b>Revere Broadway</b>
<b>Revere Meds/Peds</b>
<b>MGH West Medical Group</b>
<b>Transgender Health</b>
<b>NEW Health</b> (North End, Charlestown, and Charlestown High School)
<b>Concierge Medicine</b>

## ACTIVITIES AND ACCOMPLISHMENTS - 2022-2023

### Topics Reviewed by and presented to the Primary Care PAC



The PAC's began its inaugural year by establishing three key improvement areas:

- Patient access to care
- New patient onboarding experience
- Patient-Provider communication through Patient Gateway, the MGB patient portal

These 3 focus areas were the topics of discussion in this first year of the PAC meetings.

### Engagements

- **MGH Primary Care Welcome Letter Template** – The goal is to align welcome letter content across all primary care practices.
- **MGH Primary Care Patient Packet Template** – The goal is to create a comprehensive onboarding patient packet covering the most relevant information for all patients across all primary care practices.
- **Patient Reassignment Letter** – The goal is to set patient expectations amidst the frustration of some patients who are being reassigned to new primary care providers due to the national primary care provider shortage, COVID, or the shutdown of some practices.

### Additional Accomplishments

Took part in the first in-person joint PFAC meeting (since COVID) which was held on 6/14  
Reviewing GPFAC by-laws draft to ensure the PAC's by-laws will be aligned.

## PRIMARY CARE PATIENT ADVISORS (PAs)

### Patient Advisors

Juliane Brooks  
Vanessa Merker  
Abigail Scherrer  
Jill Smith  
Rosa Torres, patient co-chair

### Staff

Haneen Bou-Ayash  
Susan Edgman-Levitan, staff co-chair  
Greg Kane  
Amelia Lundkvist  
Kimberly Russell Holm

# 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

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

# PFAC Values



*Image:* Watercolor image of flower petals displaying PFAC values: Respect, Commitment, Passion, Equity, Inclusion, Collaboration. Image by PFA Stuart Murphy.

# Appendix – PFAC Bylaws

## **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 share their time and ideas by participating in ongoing General PFAC meetings, committees and initiatives across the organization, by conducting reviews, and generally by serving as an advisory resource.

#### **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 consistent compassionate care experiences.

### **Article 3. General 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 COVID pandemic.
- Promote General PFAC member participation on committees and initiatives across the hospital/system, to facilitate the integration of the patient/family perspective in shaping services, programs, and initiatives.
- Continue to recruit General PFAC members who represent the diverse population of patients and family members served by Mass General.
- Continue to expand awareness of the General PFAC across the hospital/system.
- Enhance General PFAC member understandings of the hospital/system infrastructure and operations, to facilitate capacities to contribute as Advisors.
- Advance and support high quality, coordinated communications between patients and their care team members.

### **Article 4. Overarching Structure and Membership**

The General PFAC shall consist 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.
- Represent the diversity of the Mass General patient populations served, including diversity of race, ethnicity, culture, sexual orientation, disability, etc.
- Comfort with sharing ideas and experiences in a group setting.
- Respect for diverse backgrounds, viewpoints, perspectives, and the ability to interact positively with a diverse group of individuals.
- Aptitude for active listening.

- Ability to advocate effectively for the needs and priorities of patients and families.
- Enthusiasm for serving in an advisory role through participation in organizational committees and initiatives.
- Ability to participate in a consistent and agreed upon schedule of virtual and/or in-person meetings.
- Commitment to serve for a 2-year term with potential to renew at the term end.
- 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 14.
- Resignations should be submitted in writing or via e-mail to the Co-Chairs.
- Granting appointments is ongoing, with vacancies filled during the year, as needed.

### **Section 5. Member Emerita/Emeritus**

- Members who have served 10 or more years and who are retiring from the General PFAC, are eligible to be considered for an appointment as a General PFAC Member Emerita/Emeritus. Such approval is made by the Executive Committee.
- Members appointed as Emerita/Emeritus are required to abide by all HIPAA laws and MGH Confidentiality Agreement.
- Member Emerita/Emeritus status is an honorary, non-voting role, allowing members to step down as active members, while remaining connected to the General PFAC in an advisory role for specific initiatives, as their time and interest permits. This membership appointment may receive additional privileges, as identified by the Executive Committee.



## **Article 6. Roles and Responsibilities of Members**

### **Section 1. Roles and Responsibilities of Patient/Family Members**

- Attend each General PFAC meeting, virtually or in-person, or notify a Co-Chair in advance (barring prohibitive circumstances), if unable to attend.
- Prepare and engage thoughtfully and constructively with respect to issues and ideas discussed during General PFAC meeting and all additional committees attended.
- Respect the unique background and perspective of each member.
- Represent General PFAC positively on all organizational committees and initiatives attended.
- As appropriate, serve as a mentor for newly appointed General PFAC members.

### **Section 2. Roles and Responsibilities for Staff Members**

- Attend each General PFAC meeting, virtually or in-person, 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 General PFAC goals and strategic initiatives.
- 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 members 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, selected staff members, and may include selected General PFAC members at large. The total membership shall not exceed 8.

### **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 Co-Chair term is not to exceed 10 years.
- The Secretary term 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 that includes Mass General history, overview, mission and goals, and hospital regulatory and privacy issues. 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, virtually or in person. 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 members prior to each meeting, along with minutes of the previous meeting(s) and any pertinent materials for discussion during the meeting.

### **Section 2. Meeting Minutes**

The Secretary records minutes of each General PFAC meeting. Minutes are retained for a minimum of 5 years.

### **Section 3. Attendance**

It is expected that 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 will 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 shares 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 non-compliant with the responsibilities as set forth by the bylaws, or whose behaviors do not align with the Mass General Patient Code of Conduct.

### **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.