



MASSACHUSETTS
GENERAL HOSPITAL

Patient and Family Advisory Councils



2018-19 Annual Report



Massachusetts General Hospital Overview

- Founded in 1811, Mass General is the third oldest general hospital in the United States and the oldest and largest in New England.
- In 2019, Mass General was recognized as second of nearly 5,000 hospitals considered in the *U.S. News & World Report* ranking, and consistently has received top rankings over the years.
- Mass General patients rate their experiences very highly, with over 90% responding that they definitely would recommend Mass General to family and friends – a top percentage compared to hospitals nationally.
- The hospital consistently achieves high ratings from professional organizations, including the American Nurses Credentialing Center, the Society of Thoracic Surgeons, The Joint Commission, and the Leapfrog Group.
- Patients at Mass General have access to a vast network of physicians, nearly all of whom are Harvard Medical School faculty.
- Mass General clinicians and researchers are recognized domestically and internationally for their professional contributions.
- Mass General is a 999-bed academic medical center that offers sophisticated diagnostic and therapeutic care in virtually every specialty and subspecialty of medicine and surgery. In addition, the hospital provides care and services in multiple health centers located within neighboring communities.
- Mass General by the numbers annually:
 - Approximately 48,000 inpatient admissions
 - Nearly 1.5 million outpatient visits
 - More than 100,000 emergency room visits
 - More than 42,000 operations

PFACs at Mass General

- Within this large, complex environment of care, it is our mission that guides our individual and collective beliefs, decisions and actions—our work:

“GUIDED BY THE NEEDS OF OUR PATIENTS AND THEIR FAMILIES, we aim to deliver the very best healthcare 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 (PFACs) serve as one primary way for Mass General to realize the opening words of its mission statement, “Guided by the needs of our patients and their families. . . .”
- PFACs integrate and promote patient and family voices and experiences in the development of programs, services, and initiatives.
- PFAC members lend their expert thoughts and ideas by participating in regular PFAC meetings, participating in hospital committees, playing an active role in a variety of improvement efforts, reviewing educational materials, and providing feedback in many other ways.
- Mass General formed its first Patient and Family Advisory Council in 1999 and since that time several additional PFACs have formed:
 - General PFAC
 - Ambulatory Practice of the Future Care Alliance
 - Cancer Center PFAC
 - Emergency Department PFAC
 - Heart and Vascular PFAC
 - MassGeneral Hospital for Children (MGHfC) FAC
 - Pediatric Oncology FAC
- Mass General PFACs have evolved significantly over time and have made a difference. This report presents the robust contributions of Mass General PFACs over the past year.



Annual Joint PFAC Event

Partnering to Improve the Patient Experience

April 22, 2019

As a wonderful start to Patient Experience Week 2019, Mass General Patient Family Advisory Councils (PFACs) came together to share and celebrate the contributions of Patients and Family Advisors in helping to shape programs, services, and initiatives across the hospital.

Inga T. Lennes, MD, Senior Vice President, Service Excellence and Practice Improvement, provided welcoming remarks, highlighting the numerous PFAC contributions across the hospital over the past year and noting, “the breadth and depth of your involvement has evolved tremendously.”

Presentations and discussion focused on examples of patient and family partnerships with staff and clinicians in educational efforts to improve care experiences and create a welcoming environment. The Pediatric Family Advisory Council presented on the benefits of PFAC members and staff teaching as a team. The General PFAC spoke of the integration of PFAC members in an iCare video that was included in a year-end training of all current employees and continues to be included in ongoing new employee orientations and iCare Learning Labs. The Ambulatory Practice of the Future (APF) Care Alliance shared videos created to enhance the care and care experience of patients.

The assembled PFACs then engaged in a real-time partnership. All attendees consider what matters most to them in receiving care at Mass General. Selected responses were compiled in a poster created in honor of “What Matters to You?” Day. The group also engaged in interactive brainstorming about the future of patient and family partnerships at Mass General.



What Matters to our PFAC Members ... in receiving care at Mass General



"A constant caregiving team with knowledge of the patient as a person."

"An environment filled with kindness."

"Warm blankets in the E-R."

"Consistency between departments. Why do some clinics run soooo smoothly and others....not so well?"

"Honest expectation setting."

"Civility in all interactions."

"Trust."

"Genuine empathy."

"To feel understood."

"Ability to see my visit notes and labs online."

"That fabulous latte and muffin☺"

"Focused attention."

"Timeliness."

"Healthy food!"

"Saying I'm sorry when someone has made a mistake."



OFFICE OF PATIENT EXPERIENCE



Patient Experience

MGH Patient-Family Advisory Councils

partnering to improve the patient experience

—by Liza Nyeko, program director, Office of Patient Experience/CQS

As part of Patient Experience Week, MGH patient-family advisory councils (PFACs) came together, April 22, 2019, to share and celebrate the contributions of patient and family advisors in helping shape programs, services, and initiatives throughout the hospital.

Patient-family advisory councils are a true embodiment of our mission, which states, *"Guided by the needs of our patients and their families, MGH aims to deliver the very best health care in a safe, compassionate environment..."*

Inga Lennes, MD, senior vice president for Service Excellence and

Practice Improvement, highlighted the numerous contributions made by PFACs over the years, noting, "the breadth and depth of your involvement has evolved tremendously."

Discussion focused on the importance of patients and families partnering with staff and clinicians to improve the care experience and create a welcoming environment. PFAC members had the opportunity to engage in a real-time

partnership and an interactive brainstorming session about the future of patient and family partnerships at MGH.

For more information about PFACs or the recent joint meeting of all MGH PFACs, call Liza Nyeko at 617-643-5484.



At left: program director for the Office of Patient Experience/CQS, Liza Nyeko, presents at joint meeting of MGH patient-family advisory councils. Below: parent and member of the MassGeneral Hospital for Children Family Advisory Council addresses the gathering.



(Photos by Jeffrey Andree)





MASSACHUSETTS
GENERAL HOSPITAL

General PFAC



General Patient & Family Advisory Council

established 2011

Overview

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



“I’ve had the—I’ll call it a privilege—to be involved in some pretty high-end meetings of topics that normally a person not trained in the world of medicine would not be in, but my only role, my only expertise, was to be the voice of the patient.”

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

2018-2019 Topics – Feedback/Presentations

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

- **New Facility Design** – Architects for a large new Mass General building solicited input from members regarding future design of new spaces.
- **Addiction Consult Team (ACT) & Bridge Clinic** – Nursing Director, Substance Use Disorders/ACT and a Bridge Clinic Recovery Coach, and General PFAC staff member, provided an overview of their work, answered questions, and discussed ways members could contribute.
- **Ballot Question - Nurse/Patient Ratio** – Nursing Directors provided an overview of the ballot question regarding potential nurse/patient ratio mandates, answered questions, and shared how members could contribute.
- **Blum Patient and Family Learning Center initiatives and strategy** – General PFAC meeting was relocated to the Blum Center, where the Blum Center Director and staff discussed with members the Blum/General PFAC collaboration and future directions.
- **Center of Innovation Proposal** – Director, Center of Innovation and Staff Nurse/Inventor presented a bathroom harness design to help prevent falls. Members provided input on the concept and design, and various potential ways the harness could be utilized.

“We’re exposed to a lot of different medical techniques, research and challenges here. And being a part of that, trying to be a part of the solution, I think, is — I know is — very rewarding.”

- **International Collaborations - Cancer Center** – Program Director, International Programs and Advisory Services, and General PFAC staff member, provided an overview of Mass General’s international collaborations focused on assistance with building hospitals and services.
- **Radiology Report Language** – Vice Chairman for Radiology Finance and Quality presented a proposal to make the language in radiology reports that patients may view less confusing and solicited member perspectives about the proposal.
- **Serious Illness Conversations - Documentation & Engagement Materials** – Medical Director for the Mass General Continuum Project provided an overview of the work to promote earlier, more frequent, and better conversations about serious illness, and solicited feedback about documenting these conversations in the electronic medical record as well as about patient/family engagement materials.



- **Phone Access and Encounters** – Practice Improvement Division Senior Program Manager engaged members in conversation about their experiences with accessing outpatient practices by phone. Members provided feedback on areas of strength and opportunity.
- **Respect/Courtesy-Ambulatory Practices** – Members provided feedback to questions regarding the extent to which they are treated with respect and courtesy in the ambulatory practice encounters.
- **Supporting Decisions about Cancer Screenings for Older Adults - PCORI** – Health Decision Sciences Center Directors provided an overview of their work on a Patient-Centered Outcomes Research Institute (PCORI) grant focused on decisions about colorectal cancer screening in older adults, and solicited member perspectives.
- **Fall-Related Injury Severity Perceptions** – Researchers from a joint Mass General/Brigham and Women's Hospital effort solicited member perspectives about the severity and quality of life impact of various types of falls.
- **Research Direct Patient Contacts** – Director of Patient Engagement in Research, Director of Human Research Affairs, and Chief Medical Information Officer engaged members in conversation about different ways of inviting patients to participate in research, and solicited their feedback.
- **Chief Nurse & Senior VP of Patient Care Services** – Chief Nurse & Senior VP of Patient Care Services visited with members to discuss PCS strategic initiatives, challenges, and opportunities, and to engage in dialogue with members.
- **Hospital Medicine Care Team Information Cards** – Members provided feedback on information cards developed by Hospital Medicine to help clarify the roles of hospitalists and care team members.
- **Discharge Call Experiences** – Members responded to questions about the calls placed to patients in follow-up to their inpatient visits, and aspects of those discharge calls that they found important.

- **Partners Stroke Clinical Collaborative Materials** – Members provided feedback on patient/family education materials created through a Partners Stroke Clinical Collaborative.
- **Team-based Care Patient Expectation Materials** – Members provided feedback on posters designed for the ambulatory exam room to set expectations and provide information about team-based care.
- **Primary Care Phone Tree** – Members provided feedback on proposed menus of responses to phone calls placed to primary care practices.
- **Integrated Care Management Program (iCMP) Brochure Review** – Members provided feedback on a brochure produced by Partners to be used across hospitals and entities to describe iCMP services.
- **2020 Quality and Safety Goals**– Members provided input to the 2020 Quality & Safety Goal setting process, along with stakeholders across the hospital.

“I have learned that having patients’ and families’ perspectives on decisions that we believe are right from the clinical and hospital perspective is helpful to guide and validate whether we’re moving in the right direction.”

Participation in Mass General Committees, Task Forces, and Initiatives:

General PFAC members continued to participate in ongoing committees, task forces, and initiatives across the hospital and system, providing the patient/family perspective within and across interdisciplinary groups:

- **Blum Patient & Family Learning Center/General PFAC Education Committee** – A working committee of several General PFAC members collaborates closely with the Blum Patient & Family Learning Center to review educational materials using plain language review and facilitated discussion.
- **Quality Oversight Committee** –Senior leadership committee reviewing quality and safety topics- includes two General PFAC members.
- **Partners Patient Experience Leadership Committee** –Partners committee consisting of patient experience leaders from hospitals and entities across the system-includes one General PFAC member.
- **Patient Experience Leadership Committee (PELC)** – Committee consisting of leaders from across Mass General Hospital and Physicians Organization who focus on the patient experience in various capacities-includes one General PFAC member.
- **Judges - Annual Patient Experience Awards** – Each year clinicians and staff submit patient experience award nominations for colleagues who have demonstrated icare (communicate, advocate, respect, empathy) excellence. In 2019, seven General PFAC members served as judges for the first time, reviewing and voting on nominations.
- **Partners Telehealth Committee** –Partners committee focused on the advancement of telehealth services across the system - included one General PFAC member.

- **Partners Quality and Safety Symposium presentation** –General PFAC member presented with the Director of the Blum Center on the General PFAC Education Committee’s collaborative review of educational materials.
- **Partners Patient Experience Summit 2019- session development and presentations**
 - **Outpatient Behavioral Health: Saving Lives in a Different Way** – Breakout session of the Summit featured one General PFAC member sharing personal experiences and perspectives.
 - **Partnering with Patients and Families across Ambulatory Care** –General PFAC member helped to organize this session including presentations and a panel of PFAC members; another member spoke on the panel about reviews of educational materials via the Blum Center collaboration.
- **Engagement Advisory Committee – Continuum Project** – The Continuum Project is an organization-wide initiative focused on living well with serious illness and introducing earlier, better, and more frequent serious illness conversations. One General PFAC member participates in this interdisciplinary committee focused on engaging patients and family members.
- **Facility Design focused interdisciplinary sessions** – Architects for the large new inpatient building facilitated sessions with interdisciplinary clinicians and staff and PFAC members - included four General PFAC members.
- **Marketing Team Retreat Presentation** – General PFAC member participated in and shared a personal story during a Marketing team retreat.
- **Mass General Website Design** –Marketing team members met with five General PFAC members individually to solicit input on proposed redesign of the Mass General website.
- **WeSolve Inpatient Experience Sessions** –Consortium for Affordable Medical Technologies (CAMTech) facilitated a series of 3 sessions focused on enhancing inpatient experience – six General PFAC members participated in these sessions.
- **What Matters to You? Day Participation** –In honor of What Matters to You? Day, celebrated internationally, Mass General hosted an event featuring a variety of presentations and tables demonstrating how Mass General integrates this concept across areas on an ongoing basis. PFACs members hosted a table during this event.
- **Boston Globe Article Interview** –Boston Globe reporter interviewed one General PFAC member about experiences with quietness of the inpatient hospital environment and shared vs private rooms.
- **Spaulding Visit & Sharing of General PFAC Practices** – General PFAC member and Office of Patient Experience Administrative Intern visited Spaulding Rehabilitation Hospital to share PFAC structures and processes.
- **Council on Disability Awareness** – Interdisciplinary Council consisting of representatives from across the hospital focused on disability access and awareness and creating a welcoming environment for all – includes two General PFAC members.

Additional

- Increasing number of requests from across the hospital and system for PFAC member participation and feedback.
- Expansion of the breadth and depth of PFAC member involvement.
- Continued facilitation of cross-PFAC leader dialogues.
- Compilation of advancing patient and family partnerships toolkit.
- 100% term renewal among those members with 2-year terms coming to an end.

Membership



Patient/Family

Stephen Brown
Bob Chen
Julie DeCosta (Co-Chair)
Hilary Deignan
Catherine Duffek
Ann Galdos
Melissa Hoyt
Susan Keshian
Bill Kieffer
Stuart Murphy
Jerry Pallotta
Rhonda Pieroni
Fifi Reed
Matt Reid
Joyce Smith
Paul Smith
Carrie Stamos
Lisa Stein
Kathy Verni

Staff

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



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Ambulatory Practice of the Future



Ambulatory Practice of the Future

established 2010

Brief Overview/Background

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

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

Our efforts play an important role in managing challenges that are part of the current healthcare environment.

Mission

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

Activities

2017-2018 Presentations/Feedback

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

- Quarterly to bi-annual Newsletter
- Use of Vidscrips with patients
- Urgent care access vs. same day practice visits
- Health coaching
- Onboarding of new clinical staff via staff highlights
- Referrals through Patient Gateway
- End of life care conversations
- Direct Scheduling
- Discussed how the Care Alliance operates as a PFAC for the Center for Innovation in Digital HealthCare
- Discussed the use and implementation of HealthWeb Navigator

Participation in Mass General Committees, Task Forces, and Initiatives

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

Newsletter: “The Link”

Our quarterly Newsletter continues to be a primary means by which the APF connects with their patient population. It is a two-page summary written and edited by the Care Alliance that describes ongoing initiatives by the APF, seasonal health related topics, and any information regarding new team members of the APF. The Newsletter is distributed to every active patient gateway member in the APF.

Vidscrips

Our Care Alliance team members have been using the Vidscrip platform for multiple years. It is another avenue in which the APF can connect with their patients in a digital way. We have created content that ranges from how to sign up on patient gateway to stress management techniques.

“Patient and Family Advisory Council contributions are vital to elevating and integrating the patient and the family voice into our ongoing work across the hospital.”

Additional Activities

- Presented on vidscrips at the Annual PFAC meeting in April
- Recruited 2 new members to the APF
- Facilitated relationship with APF’s Health coach to establish a “coaches corner”—Increased awareness of what health coaching can offer

Members

Parents/Patients

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

Staff

Adriana Mesa Balbin
Tina Byrnes
MJ Byrnes
Lakeya Bryant
Stephanie Casilla
Ben Crocker, MD
Terri Egan
Katie Engels
Dan Henderson, MD
Aaron Hoffman, DO
Jessica Hu, MD
Stephen Lynch
Jane Maffie-Lee, NP
Mary Anne Marshall, NP
Liza Mosley
Lori Newman
Emily Shipp
Glenda Shuel
Donna Winderl-Malyak



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Cancer Center PFAC



Cancer Center Patient & Family Advisory Council

established in 2001

Overview

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

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

Mission

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

Issues & Activities:

Council Operations

The CC PFAC meets on the second Wednesday of each month from 5:30 -7:30 PM. Meeting minutes and materials are stored electronically for at least five years. Council minutes and a summary of the council's accomplishments are provided to the hospital's governing body.

Membership

The CC PFAC currently consists of 26 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 ten different Cancer Center disease programs, as well as two different sites (Boston/Main Campus and Mass General/North Shore Cancer Center in Danvers).

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

Qualifications for Membership

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

Membership Requirements and Training

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

PFAC Member Recruitment

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

CC PFAC Leadership

By choice, the CC PFAC has no formal chair or elected officers. Currently the meetings are facilitated by Cancer Center leadership. Agenda items are prioritized by staff members based on topics discussed at

CC PFAC meetings and requests from Cancer Center and MGH-wide staff that wish to consult the council.

Roles and Activities

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

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.

2018-2019 Topics – Presentations/Feedback

Activities and Accomplishments: Fiscal Year 2019

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.

- Continuum Project: Juliet Jacobsen, MD
- Nursing Bill, Ballot Question #1: Julie Cronin, Nurse Director, Infusion Center.
- New Patient Satisfaction Surveys
- Cancer Center at Newton Wellesley Hospital Launch
- 3.0 PX Innovation
- New Building Presentation with NBBJ
- Radiology Updates; Jeremy Herrington, Director of Clinical Operations, and Mary-Theresa Shore, Sr Director of Clinical Operations; Department of Radiology

- Cancer Center Genetics: Decision Aid feedback; Kristen Shannon, Director and Erica Blouch, Genetics Counselor, (20 minutes)
- Medical System with Juliet Jacobsen, MD, Medical Director, Continuum Project
- Termeer Center and Phase I Research
- Chaplaincy Program: Donna Blagdan, Chaplain
- MeWe Nutrition - What's good for ME is good for WE: Annie Abbruzzese and Maria Kasparian, Executive Director of Edesia Nutrition
- Peer Matching Program: Nova Hodge
- Young Adults support group and program
- Lifestyle Medicine Clinic: Betsy O'Donnell, MD
- Patient Education materials review for the serious illness care program: Juliet Jacobsen, MD, Palliative Care Services, Medical Director, Continuum Project
- Health insurance needs of Cancer Survivors: Elyse R. Park, Ph.D., MPH, Associate Director of Survivorship Research and Psychosocial Services for the Mass General Cancer Center Survivorship Program

Participation in Mass General Committees, Task Forces, and Initiatives:

Cancer Center PFAC members continued to participate in ongoing committees, task forces, and initiatives across the hospital and system, providing the patient/family perspective within interdisciplinary groups considering a variety of topics.

- MGH American Cancer Society Research Grant, Two members volunteered to review proposal abstracts and share their perspective at review meeting; February 14, 2019
- Workshop in Supportive Oncology, January 15, 2019
- NBBJ Building Planning workshops; attend two workshops that are 4 hours
- Cancer Center tour video
- Genetics Decision Aid; The Genetics Team are seeking a few individuals from PFAC who can give continued feedback over the next ~12 months on the decision aid we are creating at MGH.
- Partners Patient Experience Summit 2019 - session development and panel participation
- Friends of the Cancer Center Annual Fundraiser event
- Attended Annual MGH all PFAC Networking Dinner
- What Matters to You Day Inaugural Event, June 5, 2019, participated at table for one hour
- Survivorship Conf June 15, 2019:

Members:

Patients/Family

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

Staff

Jill Allen
Mara Bloom
Barbara Cashavelly
Lisa Goggin
Steve Herskovitz
Nova Hodge
Kevin Lynch
Courtney McLeish
Devon Punch
Erika Rosato



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Emergency Department (ED) PFAC



Emergency Department (ED) Patient and Family Advisory Council

established in 2018

Background

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 Statement

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

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

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

Issues & Activities

2019 Topics for Presentation/Feedback

Through quarterly meetings (first meeting January 2019, subsequent meetings April 2019 and July 2019) and additional ongoing targeted requests and projects, the MGH ED PFAC has contributed throughout a wide spectrum of ED patient experience initiatives.

Topics/projects reviewed by the ED PFAC have included the following:

- ED Welcome Video
- ED See What Our Patients Are Saying About Us poster
- Attending informational business cards
- ED Comfort Menu
- ED signage
- Clinical Decision Unit (CDU) redesign
- Geriatric ED care
- Emergency Medicine intern orientation
- ED Code of Conduct

Presentation topics have included the following:

- 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

Participation in MGH Committees/Task Forces:

While the ED PFAC is brand new, several patient/family members have already participated in initiatives including:

- Providing public comment for Determination of Need for future ED expansion
- Participation in What Matters to You event
- Emergency Medicine resident conference

Members



Patient/Family Participants

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

Staff

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



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Heart and Vascular Centers PFAC



Heart and Vascular Centers Patient and Family Advisory Council

established 1999

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

Mission Statement

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

2018-2019 Quarterly Meetings were devoted to these important topics:

- **Dr. Jag Singh, Associate Chief, Cardiology Division:** Discussion regarding virtual cardiology visits—face to face meetings between a patient and a clinician via video chat, serving as an adjunct and not a substitute for in hospital appointments
- **Gina Livingston-Smith, NCIDQ, EDAC, Healthcare Designer & Experience Specialist and Terry Huang, Healthcare Consulting Strategist & Design Researcher:** Architects for a new building planned at Mass General, solicited input from patients and families regarding aspects of their healthcare journey that are or are not working well. Council members had an opportunity to inform future design of spaces, services, amenities, process, etc., at the hospital, particularly valet parking, wayfinding, waiting areas/procedures, and in-patient rooms.
- **Dr. Willian Curry, Jr., Neurosurgeon and Breen Power, Program Director, Neuroscience Institute:** Presentation on the department of Neuroscience, ranked among the best in the nation, and consistently among the top 10 institutions receiving neurosciences funding from the National Institutes of Health.
- **Jared Jordan, RN, Staff Nurse/Nurse Entrepreneur and his mentor Hiyam Nadel RN, MBA:** Shared work on a bathroom harness design to help prevent falls, an example of work being done as part of the Innovation Program at MGH. The program is designed to foster a “Culture of Innovation” by offering Idea Grants of \$5,000 to direct care providers, to support initiatives that enhance care and patient safety.

- **Cyndi Sprogis, Office of Patient Experience:** Presented the hospital's iCare Model and recognition program, designed to foster a Welcoming Environment at Mass General in which every hospital employee contributes to shaping the patient experience. "CARE" stands for Communicate, Advocate, Respect and Empathize.
- **Dr. Matthew Eagleton, Chief of Vascular Surgery/ Vascular Center:** Discussion on vascular and endovascular surgery and vascular center (upcoming)

Ad Hoc meetings: Teri and Tom Fryer and David Wooster and members of the Cancer Center PFAC participated in two (four-hour) sessions with the architectural firm, NBBJ, related to the Cambridge Street Project. The meetings were facilitated with an effort to understand the aspects of their health journey that were or were not working well. Goal was "to envision their ideal healthcare experience."

MGH Heart and Vascular Centers PFAC Members

Patient and Family

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

Staff

Sue Algeri
Marie Elena Gioiella
Judy Silva
Cynthia Sprogis



MASSACHUSETTS
GENERAL HOSPITAL

Massachusetts General Hospital for Children FAC



Massachusetts General Hospital for Children Family Advisory Council

established 1999

Mission Statement

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

Goals for 2018-2019 and Progress Made

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

Progress: Two parent member of FAC have joined the committee that has been formed, will offer their insights on the committee and report back to FAC.

Patient Experience—Collaborate with team on Ellison 17 and 18 lead by Nursing Director Lori Pugsley to create a document in EPIC that will prompt providers to check on Family Wellness called a Family Care Plan.

Progress: Committee has been formed, on which sits one FAC parent, and has met one time to generate a list of current wellness programs and ideas for the future. Committee members are evaluating the feasibility of ideas proposed.

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

Progress: Mike Leeman, MD, Medical Director of the Pediatric Pain Service, joined a FAC meeting, heard parent feedback and engaged in discussions about how to improve the service. FAC members wrote a letter to the Department of Pediatrics suggesting changes to the pain service.

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

Progress: A committee has formed to create mechanisms by which parents can offer stories to MGHfC for possible use in social media and marketing efforts. This committee will report back to FAC on its progress.

Presentations and Feedback

Transition: Alexy Arauz Boudreau, Associate Director, Population Health Management, MGHfC updated the group on the hospital's current comprehensive plan improve the process by which patients transition from pediatric to adult medicine.

State Ballot Question: Kim Whalen, PICU Nursing Practice Specialist, presented to FAC about Massachusetts Ballot Question #1 which sought to impose new limits on the number of patients any one nurse could be assigned at a time.

Annual presentation of goals of Department of Pediatrics, MGH: Dr. Ronald Kleinman, Physician-in-Chief, MGHfC presented the annual goals of the Department of Pediatrics. Sandra Clancy, Chair of FAC, presented the group's yearly goals. Discussion ensued about shared priorities and plans for future collaboration.

PICU follow-up Clinic: Sarah Murphy, MD apprised FAC of her work in the PICU follow-up clinic in which she cares for children who have been patients in the PICU. Dr. Murphy addresses patients' symptoms and parents' concerns, as well as conducting research on adverse effects on children of PICU stays.

Pediatric Pain Service: The Medical Director of the Pediatric Pain Service at MGHfC explained how his service functions to ensure that patients' pain is addressed in a family and child-centered manner. Parents shared their experiences of the pain service, noting that inpatient procedures are often performed by providers trained in adult medicine who, while providing safe and high-quality care, lack training in communicating with children and families. The group discussed ways to address this situation.

Parents and Patients as Educators

FAC Grand Rounds: The group sponsored its annual Grand Rounds session on April 30, 2019. From participating in the staff hiring process to discussing the difficulties of communicating with a child's medical team when a couple is divorced, the parent members highlighted their efforts to further family-centered care and communication initiatives throughout the hospital. This work is a way for members to give back to the caregivers who treated their children.

New England Pediatric Hospital Medicine Conference: Four FAC parents participated in a Serious Illness Conversations Workshop in which they helped facilitate small group sessions and participated in role plays on difficult conversations in healthcare.

Intern Orientation: Two FAC parents and their adolescent children (patients at MGHfC) participated in an intern orientation session on the topic of bedside rounding. The children expressed why they find bedside rounding helpful in their care and interns asked them questions. Topics that arose included the importance of providing full information in advance of painful procedures, good communication, and speaking to adolescents in a developmentally appropriate manner.

Joint PFAC Event: Two members of FAC, Janice Morris (parent) and Sharon Badgett-Lichten (Senior Organizational and Executive Coach, MGH) presented a staff training they developed on helpfulness and courtesy. In this innovative program, front desk staff were provided coaching on how to diffuse difficult encounters with patients. Feedback from the participants pointed to the benefit of having a parent who shared her experiences of care as a facilitator.

HealthStream Project: Members of MGHfC's Quality and Safety team who serve on FAC, along with a FAC parent, developed (in conjunction with Partners Healthcare) an educational video based on a staff training they created on helpfulness and courtesy. The video will be part of the Partners Health stream library and will be available as part of on-line orientation.

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

Additional Activities

Marketing and Branding: Four parent members of the FAC and the Co-Chair gave a power point presentation to the MGHfC Executive Leadership Group outlining a strategy to use patient stories in marketing efforts to increase awareness of the hospital and differentiate it from others in the city.

Journals of Hope Program: Faith Wilcox, parent member of the FAC, initiated a program in which she visits the pediatric wards for two hours each week and provides journals and writing prompts to parents, family members and patients. Seventy-five percent of those to whom she offers a journal accept and express appreciation. The aim of the program is to reduce stress and promote coping while a family is in the hospital.

Patient Centered Outcomes Research Institute (PCORI) grant presentation: Members of the team conducting a research project titled *Dissemination and Implementation of Effective Childhood Obesity Treatment* explained their project and heard from FAC members about best ways to communicate with the parents enrolled in the research project (phone, texting, social media).

Why I Chose MassGeneral Hospital for Children Video Project: Four parent members of FAC provided two-minute interviews explaining why they chose MGHfC for their children's care. The videos are available on the MGHfC website.

New Parent Co-Chair: FAC voted in a new parent Co-Chair, Matt McGuinness, and Darcy Daniels stepped down from her two years of service.

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

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

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

Committees on which MGHfC Family Advisory Council members serve

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

The screenshot shows the Facebook profile of MassGeneral Hospital for Children. The page header includes the Facebook logo, the name "MassGeneral Hospital for Children", a search bar, and navigation links for "Sandra", "Home", "Find Friends", and "Create". On the left is a sidebar menu with links: "Home", "About", "Posts" (highlighted), "Photos", "Videos", "Events", "Community", and "Reviews". The main content area displays two posts. The top post, dated May 17, features the hospital's logo and text about the annual Grand Rounds session sponsored by the Family Advisory Council. Below the text is a photograph of six people standing in front of a modern building. The bottom post, dated July 25 at 11:53 AM, also features the hospital's logo and text about a study for sunflower syndrome, quoting Emma Paven and mentioning The Boston Globe.

MassGeneral Hospital for Children
May 17 · 🌐

On April 30, #MGHfC's Family Advisory Council sponsored their annual Grand Rounds session. From participating in the caregiver hiring process to developing a journaling program for adolescents and families, the 19 parent members highlighted their efforts to further family-centered care and communication initiatives throughout the hospital. This work is a way for members to give back to the caregivers who treated their children.



MassGeneral Hospital for Children
July 25 at 11:53 AM · 🌐

"I have felt so alone in this for so many years," she said to [The Boston Globe](#). "I never saw anyone else do it."

Emma Paven and other teens with sunflower syndrome, a rare form of epilepsy caused by reaction to the sun or bright lights, is hoping, after years of misdiagnosis and misunderstanding by the medical community, that a new [MassGeneral Hospital for Children](#) study will find answers to and relief from the debilitating condition.

Members of Family Advisory Council

Parent Members

Seta Atamian
Lisa Cimino
Darcy Daniels
Mike Doiron
Roxanne Hoke-Chandler
Ana Mastrocola
Matthew McGuinness (Co-Chair)
Eve Megargel
Janice Morris
Elizabeth Mover
Alix Nozzolillo
Yara Osler
Kelli Purchase
Erin Quinney
Ann Skoczenksi
Randi Stempler
Amanda Vincent
Faith Wilcox

Staff Members

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



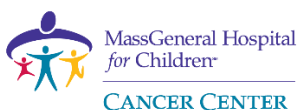
MASSACHUSETTS
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Pediatric Oncology FAC



Pediatric Oncology Family Advisory Committee

established in 2003



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.

Issues and Activities

2018-2019 Topics – Presentations/Feedback

Through meetings which are held on site at Mass General 5 times a year and remotely/electronically as an on needed basis, the Pediatric Oncology Family Advisory Committee reviewed programs and issues impacting the Pediatric Oncology clinic. The FAC provided guidance to clinical staff around operations and program development and addressed an array of issues which have impacted patients and families throughout their treatment trajectory. These topics included the following:

- Collaborating with community cancer programs to provide services to families
- Creation of a letter from Parents to Parents at the time of a child's diagnosis
- Diversity and disparities in health care
- Emergency Department care of Pediatric Oncology patients including Port a Cath access
- End of Treatment celebrations and transitions in care
- Family Guide including family voices addition
- Engaging parents in programs and services for mutual support and camaraderie
- National Childhood Cancer Awareness Month

- Parent to Parent Support mentoring program
- Patient Experience data
- Patient/Family programming including Celebrating Amazing Moms, MGH Marathon and Family Day Boston Children's Museum
- Physical therapy services (new) for Pediatric Oncology patients
- Physician patient/parent communication with Sharon Badgett-Lichten of the Patient Experience office
- Private rooms for inpatient Pediatric Oncology patients
- Quality and Safety pediatric initiatives
- Report from the Chief – update on cancer research and MGH services by Dr. Howard Weinstein
- Sibling week in Pediatric Oncology
- Training/orientation of new staff – Dr. Lauren Boal (Pediatric Oncologist) and Julie Upadhyay, MPH (Social Work intern)
- Website redesign – meeting with Brian Burns of the MGH Integrated Marketing program
- What Matters to You initiative



Additional Activities

- Member was funded to attend the ACCO (American Childhood Cancer Organization) Advocacy Days in Washington DC in April 2019. He shared experience of meeting with congressional representatives to advocate for passage of Childhood Cancer Research bill.
- Enabled capacity for remote participation in monthly meetings, for those members who were not able to be present in person.
- MGH staff Chairperson attended quarterly meeting of Mass General PFAC Chairs
- Joined with the other Mass General PFAC's in a networking event held in April 2019. The evening provided opportunity for all PFAC members to come together, celebrate Patient Experience Week and share mutual goals and initiatives.

Members

Parents

Dawn Regan (Co-Chair)
Claudia Cardona
Mary Cincotta
Michael Doiron
Susan Jacobson
Mary Koperski
Paula Marshall
Peter Palamidis
Jerry Schindler
Janice Theriaque
Tarrah Zedower

Staff

Elyse Levin-Russman, MSW, LICSW (Co-Chair)
Mary Huang, MD
Heidi Jupp, RN
Ellen Silviu, BSN, RN



Bylaws



General PFAC Bylaws

Article 1. Overview

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

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

Article 2. Mission Statement

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

Article 3. Goals

1. Promote General PFAC member participation on committees and initiatives across the
2. hospital/ system, to facilitate integration of the patient/family perspective in shaping services, programs and initiatives
3. Expand awareness of the General PFAC across the hospital/system
4. Align General PFAC activities with the strategic imperatives of the hospital/system
5. Enhance General PFAC member understandings of the hospital/system infrastructure, and operations to facilitate capacities to contribute as Advisors.
6. Continue to recruit General PFAC members who represent the diverse population of the patients served by Mass General.

Article 4. Overarching Structure and Membership

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

Article 5. Membership

Processes:

Section 1. Recruitment

Recruitment of patient and family General PFAC members is initiated by referral, website application, targeted information dissemination, and interest otherwise expressed by potential candidates.

Section 2. Membership Valued Qualities

Members are selected with consideration of the following criteria:

- Recent experience as a patient or family member at Mass General
- Comfort with sharing ideas and experiences in a group setting
- Embrace of diverse backgrounds and viewpoints, respect for others' perspectives, and ability to interact well with a diversity of individuals.
- Aptitude for active listening
- Ability to advocate effectively for the needs and priorities of patients and families
- Enthusiasm about work in an advisory role through participation in organizational committees or initiatives
- Ability to participate in a consistent and agreed upon schedule of meetings
- Commitment to serve for a 2-year term with potential to renew at the end of the term
- Support of Mass General's Mission
- Passion about making a difference

Section 3. Membership Selection

Applications are available on the Mass General website, and otherwise shared with identified prospective members. Applications are reviewed on an ongoing basis. Applicants are screened and subsequently interviewed, as deemed appropriate, by General PFAC Co-Chairs and/or Executive Committee members and/or designated individuals. Those who are identified as top candidates by interviewers will be reviewed by the Executive Committee, and subsequently notified by the Co-Chairs of the General PFAC as to their selection.

Section 4. Terms of Appointment

- General PFAC patient/family members are appointed for a term of 2 years, commencing upon the date of their selection.
- General PFAC patient/family members may request to be reappointed for additional terms of 2 years, upon mutual agreement between General PFAC Executive Committee and the member, with total consecutive years not to exceed 8.
- Resignations should be submitted in writing or via e-mail to the Co-Chairs.
- Appointments are granted on an ongoing basis, and vacancies may be filled during the year as needed.

Article 6. Roles and Responsibilities of Members

Section 1. Roles and Responsibilities of Patient/Family Members

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

Section 2. Roles and Responsibilities for Staff Members

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

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

Section 1. Patient/Family Member and Staff Co-Chairs

- Attend and preside at each General PFAC meeting.
- In collaboration with the Executive Committee, develop and implement goals and strategic initiatives of the General PFAC.
- In collaboration with the Executive Committee, set agendas for meetings, and respond/outreach to potential General PFAC presenters and visitors.
- In collaboration with the Executive Committee, manage the patient and family member recruitment process.
- Manage communications with General PFAC members, including distribution of agendas, minutes, and any additional materials.
- Communicate activities of the General PFAC to Mass General leadership.
- Serve as an advocate for PFACs across Mass General and Partners.
- Represent Mass General PFACs in the health care community, as appropriate.

- Facilitate PFAC Chairs meeting.
- Facilitate planning of annual PFAC meetings.
- Prepare annual General PFAC report in collaboration with additional designated General PFAC members, as appropriate.

Section 2. Secretary

- Record minutes of each General PFAC meeting.
- Provide minutes to Co-Chairs, and/or Executive Committee member(s) in a timely manner, for their review prior to distribution to members of the General PFAC.
- Maintain minutes for a minimum of 5 years as provided for in Article 13, Section 2.

Article 8. Executive Committee of the General PFAC

Section 1. Membership

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

Section 2. Duties and Responsibilities

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

Article 9. Terms of Officers

The terms of General PFAC Officers are as follow:

- The term of the Co-Chair is not to exceed 6 years.
- The term of the Secretary shall be 2 years, subject to renewal for 2 subsequent 2-year terms.
- Vacancies will be filled as necessary.

Article 10. Orientation and Training

Section 1. Mass General Orientation and Training

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

Section 2. General PFAC Orientation

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

Article 12. Confidentiality

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

outside of these forums. General PFAC members must adhere to all applicable HIPAA standards and guidelines. If a member violates these guidelines, the Co- Chairs will remind them of the

guidelines. Repeated violations may result in repeating HIPAA training or reevaluation of membership status.

Article 13. PFAC Meetings

General PFAC meetings are held monthly. Each meeting is scheduled for 2 hours in length.

Section 1. Agenda

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

Section 2. Meeting Minutes

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

Section 3. Attendance

It is expected that the members of the General PFAC will make every attempt to attend each monthly meeting. Remote participation is acceptable when physical presence is not possible. Participation by every member is expected and welcomed. Notice of inability to attend is requested for each meeting. If a member is not able to attend 3 consecutive meetings, the Co-chairs contact the member to discuss their commitment to the General PFAC.

Article 14. Termination

The General PFAC Executive Committee reserves the right to dismiss any member whom the committee deems not to be compliant with the responsibilities as set forth by the bylaws.

Article 15. Bylaws

The bylaws of the General PFAC shall be reviewed at least every 3 years. These bylaws are reviewed by the Executive Committee of the General PFAC and accepted via a voting process in which at least 75% of the members of the General PFAC participate. The bylaws may be amended as necessary by the members of the General PFAC, as stated herein.

Updated: August 2019

Ambulatory Practice of the Future Bylaws

Article I. Name.

The name of the Patient–Provider Advisory Council (PFAC) of the Ambulatory Practice of the Future (APF) is the “APF Care Alliance,” also referred to as the “Care Alliance.” The APF Care Alliance is a self-governing entity of the Ambulatory Practice of the Future (a primary care practice) and Massachusetts General Hospital, currently operating at 101 Merrimac Street, Suite 1000, Boston, Massachusetts 02114.

Article II. Mission.

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

Article III. Goals.

The APF Care Alliance is dedicated to assuring the delivery of the highest standards of comprehensive and compassionate health care by the APF, a primary care practice of Massachusetts General Hospital. This is accomplished by working in active partnership with health care providers to:

- strengthen communication and collaboration among patients, family members and providers
- promote patient and family advocacy and involvement
- propose and participate in programs, services, and policies

Article IV. Members.

Section 1. Roles and Responsibilities.

Advise: Work in an advisory partnership role to enhance the patient and staff experience of primary care at the APF.

Support: Act as a sounding board for implementation of new and innovative APF initiatives and improvement of existing programs.

Participate: Attend and participate in Care Alliance meetings with good listening skills and respect for the positions and opinions of others.

Identify: Seek opportunities to be innovative and be proactive in driving improvement of the service and practice of healthcare delivery at the APF.

Represent: Bring patient, family, and staff perspectives on the APF experience to enhance the healthcare experience of all stakeholders.

Educate: Share lessons learned in the APF practice with other primary care practices within Partners Healthcare Services and with the broader medical community.

Evaluate: Review the annual accomplishments of the Care Alliance against goals set at the beginning of the year.

Section 2. Membership Eligibility.

Patients, family members, and staff from APF are eligible to be members of the Care Alliance. Members should be committed to working in partnership with all APF staff to represent the needs of patients and families and to provide input in the development of programs and policies that address health care challenges within the APF practice.

Section 3. Membership Categories.

The Care Alliance will consist of Active, Emeritus and Staff Members as follows:

Active Members. The Care Alliance will be made up of a broad base of up to 12 APF patient or family Members (at least two-thirds patients) and serve on a volunteer basis.

Active Members serve for a two-year term, renewable every other year, for a maximum of three terms. Individuals will be polled for their preference for continued membership at the anniversary of each term renewal.

Active Members are expected to participate in all regular meetings and such special meetings as may be called from time to time. One active patient or family member serving on the Care Alliance is welcome to attend any staff meeting when appropriate and by prior invitation of APF Leadership. It is hoped, but not expected, that some Members will consider opportunities for involvement in special projects initiated by the APF or the APF Care Alliance. All Members must be in compliance with the requirements for Care Alliance participation and active volunteer status. Non-employee members must go through the Volunteer Orientation and Training, which includes a CORI background check, as well as HIPPA, safety and security training.

Emeritus Members. Care Alliance members who have served three terms as Active Members may become Emeritus Members. Individuals will be polled for their preference for continued membership annually. Emeritus Members will continue to receive materials distributed to the Care Alliance and are expected to attend Care Alliance meetings. Emeritus Members may continue to represent the Care Alliance on committees and projects but do not count toward quorum purposes in meetings or are eligible to vote. Emeritus Members must be in compliance with the requirements for Care Alliance participation and active volunteer status and are eligible to serve on committees or projects as requested by the Care Alliance Chair/Co-Chairs.

Staff Members. With the exception of the APF Director, Nurse Director and Practice Manager, staff members may attend Care Alliance meetings on a rotating basis.

Section 4. Other Membership Categories.

From time to time, the Council may develop other membership categories to fit with the needs of the APF and the mission of the Care Alliance.

Article V. Chair/Co-Chairs.

Section 1. Duties.

The Care Alliance has a Chair or Co-Chairs, whose roles are to work in partnership with APF leadership to guide Care Alliance goals and objectives; ensure the Care Alliance is following its mission and bylaws; set the meeting agenda; lead or appoint a patient Care Alliance member to facilitate monthly meetings; provide leadership for Care Alliance members; and serve on certain APF committees where the Chair or Co-Chairs are specifically requested.

Section 2. Nomination Procedure.

Candidates for a Chair/Co-Chair position will be nominated by Care Alliance members and must have at least one year of service as a Member. Exceptions may be made on a case-by-case basis requiring a two-thirds affirmative vote cast by Care Alliance and Staff voting members.

Section 3. Election Procedure.

A new Chair/Co-Chair will be elected or eligible for re-election every two years, requiring a two-thirds affirmative vote cast by eligible Care Alliance and Staff members.

Section 4. Term.

The standard term for Chair/Co-Chair will be two years. The terms of the Co-Chairs will be staggered. The term of office will begin the January 1st after a Co-Chair is elected, unless otherwise specified.

Section 5. Vacancies.

A Chair/Co-Chair may resign from the Care Alliance at any time by submitting written notification to the Director of the APF and the other Co-Chair when applicable. The Care Alliance may choose to elect a replacement to complete the term of that Co-Chair or to leave the position vacant until the next scheduled election. A Chair resigning from the Care Alliance will continue to serve until a new Chair is nominated and elected requiring a two-thirds affirmative vote cast by eligible Care Alliance and Staff members or an interim Chair may be appointed by the Director of the APF until an election can be scheduled.

Section 6. Termination.

A Chair/Co-Chair who is not fulfilling the role as outlined in Article V, Section 1, or is not fulfilling the role of an Active Member outlined in Article IV, section 2, and having been given appropriate notice and an opportunity to fulfill the requirements, may be removed as Chair/Co-Chair by a two-thirds vote of the Care Alliance and Staff voting members via electronic vote. The APF and the Care Alliance reserve the right to terminate any volunteer who does not uphold APF professional behavior standards.

Article VI. Membership Procedures.

Section 1. Membership Application.

Patient and family members will be recruited as needed to fill vacant positions. Patients or family members of the practice are welcome to approach staff members to indicate their interest in serving on the Care Alliance. Any APF patient or family member may apply to be an Active Member of the Care

Alliance. Membership is granted after completion of a membership application process set forth in Section 2 below. All new members may attend Care Alliance meetings once elected and will undergo an orientation to the Care Alliance with the Chair/Co-Chairs and APF leadership as soon as reasonable after their election. Every two years members will be offered the option to continue as a Care Alliance Member for another two years, become an Emeritus Member if eligible or resign from the Care Alliance.

Section 2. Application Process.

An applicant may submit a membership application to the Care Alliance for review at any time. Nominations may be made by staff members, patient or family members and nominees will be interviewed by a minimum of one staff member, one Chair/Co-Chair, and one patient or family member. Upon completing the application review and interviews, the interviewers will present the nominees at either a Care Alliance regular or special meeting. An affirmative two-thirds vote cast by Care Alliance and Staff voting members will determine whether an offer of membership should be extended to the applicant. A new Member's term of membership will commence at the next Care Alliance orientation meeting following his or her acceptance to join the Care Alliance.

Section 3. Leave of Absence.

An Active or Emeritus Member may request a leave of absence from the Care Alliance at any time during their term when unusual or unavoidable circumstances require that the member be absent from meetings and from working on APF committees and/or projects for up to four months. The member must submit their request in writing to the Chair/Co-Chairs, stating the reason for the request and the anticipated length of the leave. Members on approved leave are required to contact the Care Alliance Chair/Co-Chair one month prior to the expiration date of granted leave, ensure volunteer status is current, and attend the first monthly meeting after the leave period ends. If a member cannot return at the end of the four-month period, he or she will be asked to resign and resubmit an application when they are eligible, willing and able to resume service.

Section 4. Resignation.

An Active or Emeritus Member may resign from the Care Alliance by filing a letter of resignation with the Chair/Co-Chairs and the APF Director, effective on the date specified in the notice of resignation. Patient or family members who miss three meetings in a row without communication to the Chair/Co-Chair of the Care Alliance will be considered as no longer eligible to serve.

Section 5. Termination.

Care Alliance members who are not fulfilling the role of an Active Member as outlined in Article IV, Section 2, having been given appropriate notice and an opportunity to fulfill the requirements, may be terminated from the Care Alliance, by a vote of two-thirds of the Care Alliance and Staff voting members via anonymous poll. The APF and the Care Alliance reserve the right to terminate any volunteer who does not uphold the APF's professional behavior standards.

Article VII. Meetings.

Section 1. Regular Meetings.

Regular meetings of the Care Alliance will be held on the third Thursday of alternating months at the APF practice, unless otherwise planned, presuming the presence of a quorum and conducted per Roberts Rules of Order. Care Alliance meetings are open to all interested staff members. Agendas will be distributed prior to each meeting and minutes will be maintained on file for a minimum of five years as part of the APF Care Alliance operations protocol.

Section 2. Special Meetings.

Special meetings may be called by the Chair/Co-Chairs as they deem necessary. Care Alliance members will be given at least five business days' notice of the special meeting schedule and agenda.

Section 3. Quorum.

Meetings require the presence of a minimum of four Care Alliance members to include a Chair/Co-Chair and a minimum of four Staff Members to be called to order and to constitute a quorum for official business to be conducted.

Section 4. Voting.

Only Care Alliance and Staff Members may vote on official Care Alliance business when voting is required. Election or termination of Chair/Co-Chairs and approval of revisions to bylaws require a vote of Care Alliance and Staff voting Members. Such votes may be counted by being present at meetings, submission of an absentee ballot, or submission of an electronic ballot. In the event of a tie, all voting members will be asked to recast their votes. Three consecutive tie votes results in the motion being tabled indefinitely.

Article VIII. Confidentiality.

Care Alliance members must not discuss any personal or confidential information revealed during a council meeting or related project committee meetings. Care Alliance members must adhere to all applicable HIPPA standards and guidelines. Violations will result in a re-evaluation of membership status at the discretion of the Chair/Co-Chairs and Practice leadership.

Article IX. Amendment Procedure.

These bylaws may be amended at any regular meeting of the Care Alliance by a two-thirds affirmative vote of the members present, provided that the amendment has been submitted in writing at the previous regular meeting.

Cancer Center PFAC Bylaws

Revised January 2014

Mission Statement and Purpose

Mission Statement

The Massachusetts General Hospital Cancer Center Patient and Family Advisory Council ensures that the voices of cancer patients and their families are represented in all aspects of cancer care at the Massachusetts General Hospital.

Purpose

To act in an advisory capacity to MGH Cancer Center staff, services and programs regarding topics that affect the quality of the patient experience at MGH.

Membership

Membership of the council is comprised of current and former patients of the MGH Cancer Center, their family members, and MGH staff and physicians as selected by Cancer Center leadership. The council will be comprised of 25-35 members and at least 50% of council membership shall be current or former MGH Cancer Center patients or their family members. The council's qualification and selection process reflects its commitment to PFAC membership being representative of the community served.

Qualifications:

- Cancer treatment history for themselves or a family member. General guidelines: patients currently receiving treatment or having completed treatment, inclusive of chemotherapy, clinical trials, radiation, proton therapy and surgery.
- Ability to represent the perspective of patients and family members and understand cancer issues beyond one's own cancer experience.
- Represent diverse perspectives and backgrounds.
- Ability to work as a team player and to take initiative.
- Ability to make the time commitment for meetings and subcommittee efforts.

Selection:

Patient and family member representatives are nominated by a Cancer Center staff member, PFAC member or clinician as part of a formal recruitment process that is comprised of the following components:

- Completion of an application form created specifically for the Cancer Center PFAC.
- PFAC staff leadership reviews membership applications, evaluates candidates based on the above qualifications, interviews each candidate via telephone or, preferably, in person and makes final membership selections.

The recruitment process takes place every two years and can be initiated in the interim as needed.

Terms:

A term of Active Membership will consist of two years. After two years, members in good standing may renew for one additional two-year term. At the conclusion of a member's term of Active Membership, subcommittee membership may cease with the goal of rotating membership. If a council member takes a leave of absence due to illness, the duration of the leave is not encompassed in the term of Active Membership.

Alumni Members:

Council members who have completed their term of Active Membership may become Alumni members. PFAC alumni will receive an annual report each year and invitations to select events. Alumni members may be called upon to serve on ad hoc task forces and participate in subcommittee efforts as needed.

Officers/Chairs:

PFAC staff members act as the meeting facilitators and develop meeting agendas. PFAC does not have an elected council chair and each member plays an equal role in meeting facilitation, developing agendas and managing the flow of council meetings.

Orientation

PFAC members will be oriented to the role through a formal orientation process by current PFAC members and staff. All PFAC members will adhere to all Massachusetts General Hospital policies and procedures. PFAC members are MGH volunteers and will also be trained by the volunteer office.

Roles

PFAC members advise on a range of Cancer Center initiatives that impact patient care. In addition to the monthly PFAC meetings, PFAC members may serve on MGH or Cancer Center committees or PFAC subcommittees formed to accomplish PFAC goals. Key areas of focus for PFAC members include: operational improvement, patient education and communication, review of patient satisfaction and quality efforts, and program planning. Members are also invited to serve in an educational and advisory capacity annually via scheduled meetings with the oncology fellows, Cancer Center support staff and nursing staff. Participation in subcommittees is encouraged but not mandatory.

Responsibilities

Members commit to:

- Adhere to all MGH policies as reviewed in the PFAC orientation, including the non-solicitation policy and HIPAA privacy policy.
- Adhere to all volunteer policies as covered in the MGH Volunteer Department orientation.
- Fully participate in monthly meetings.
- Participate in other PFAC communications, subcommittees and activities as needed.
- Be active listeners.
- Advise and collaborate with the Cancer Center.
- Be respectful.

Logistics

- The council meets on a monthly basis.
- Minutes of the council meetings are taken by a PFAC staff member and will be maintained internally in an online file. They will be distributed to members monthly and available to members upon request.
- An annual report will be compiled for each fiscal year and will be available to council members for review.
- The annual report and meeting minutes will be transmitted to the hospital's governing body.

Heart Center and Vascular Centers PFAC Bylaws

Mission Statement

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

Goals

Advise:

- Work in an advisory role to enhance cardiovascular care at the MGH HVC

Support:

- Act as a sounding board for implementation of new MGH HVC programs, and improvement of existing programs

Participate:

- Provide input to improve the physical environment of care
- Provide representation on committees within the MGH HVC to represent the voice of the patient and families

Identify:

- Opportunities to promote wellness and prevention of heart, vascular and stroke conditions
- Patient- and family-centered care strategies
- New services, programs and/or communication, for consideration, that may benefit patients with heart, vascular and stroke conditions and/or the MGH HVC, itself
- New programs, efforts and/or mechanisms for consideration that would enable the MGH HVC patients to be able to give back to the Mass General community through either support, community or recognitions

Represent:

- Patient and family perspectives about the overall experience of care at the Mass General
- The MGH HVC in its commitment to listening to the voices of patients and families

Educate:

- Collaborate with Mass General staff to create, review, and revise MGH HVC educational materials and processes
- Influence and participate in the education of Mass General staff, including registered nurses, nurse practitioners, physicians and support staff

Membership

Nomination and Application Process

Recruitment of patient and family council members is initiated by referral from all disciplines including Mass General physicians, nurses, other healthcare professionals and staff. Invitation letters and application forms are then sent to potential participants.

Applicants are selected based on the following criteria:

- Current experience as a patient or family member at Mass General
- Ability to represent overall patient care experience
- Willingness to work in an advisory role
- Ability to participate in a consistent and agreed upon schedule of meetings and potential subcommittee efforts
- Commitment to serve for a one-year term with potential to renew or step down at the end of the term
- Once selected, the applicant receives an acknowledgement letter from staff of the MGH HVC
- PFAC and a thank you letter is sent to the referring Mass General clinician or staff member.
-

Term of Appointment

- Members of the MGH HVC PFAC select and grant two-year term to council members
- At the end of a two-year term, council members may request to be reappointed.
- Resignation will be submitted in writing or via email to the MGH HVC PFAC
- Vacancies may be filled during the year as needed.

Roles and Responsibilities

Membership consists of 16 to 20 members: patients, family members and Mass General staff. The three membership roles are described below.

a. MGH HVC:

MGH HVC Co-Directors, Program leadership and staff

- Referral of potential PFAC member candidates
- Provide new PFAC members with an overview of the MGH HVC's mission, programs and strategic initiatives
- Partner with the MGH HVC PFAC to improve the patient and family experience of care at the Mass General
- Provide financial support for monthly meetings and approved Council Member activities beyond the monthly meetings

b. MGH HVC PFAC Members:

Mass General Staff: Mass General staff will be appointed by the MGH Heart Center Co-Directors and Associate Chief Nurse.

Patient and Family: Includes patients and families representing diversity in age, gender, ethnicity and nature of heart, vascular and stroke conditions.

c. MGH HVC PFAC Members: All Members

- Maintain patient confidentiality according to Health Insurance Portability and Accountability Act (HIPAA) guidelines
- Advocate for all patients and families by identifying and representing their needs and concerns
- Establish goals and objectives of the MGH HVC PFAC at the beginning of each year
- Plan, facilitate and guide the work of the MGH HVC PFAC
- Prepare for and attend meetings
- Provide notification by email or phone in advance, if attendance is not possible at a given meeting
- Participate in meeting discussions and activities. Any pertinent information, ideas, and suggestions should be communicated at meetings or by email or phone
- Be willing to consider additional opportunities for involvement beyond the monthly meetings

d. Mass General Staff

- Communicate HVSC PFAC activities to the leadership of the executive committees of the MGH HVC
- Communicate with MGH HVC staff re council recruitment
- Review new council member
- Review new council member application(s) and participate in selection of new council member(s)
- Provide new members with an MGH HVC PFAC name tag and a binder which includes: Meeting Schedule, Staff and Member Contact List, Status Report, PHS Confidentiality Agreement, Caring Headlines Permission Form, Website page of MGH HVC & Blum Patient and Family Learning Center, Mass General Ground Floor Map & Directions to the Yawkey Center for Outpatient Care
- Send a reminder email to council members one-week prior to the monthly meeting including agenda and attached minutes from the previous meeting
- Provide copy of agenda, minutes and any handouts as required at each meeting
- Provide council members a copy of their signed Partners Healthcare System

- Confidentiality Agreement and Caring Headlines Permission Form
- Provide meeting space
- Provide complimentary parking and light dinner at each meeting
- Provide a PowerPoint slide presentation on the ongoing Council's activities and accomplishments as determined by the MGH

e. HVC Executive Committee

- Provide an annual progress report on Council's accomplishments during the preceding year to PCS for submission to Department of Public Health
- Retain Council minutes for a minimum of 5 years
- Transmit minutes and annual accomplishments to the hospital's Board of Trustees

f. Patient and Family

- Complete Mass General volunteer program application and on-site orientation

Attendance

- Members attend quarterly meetings with dinner
- **Location:** MGH Trustees Boardroom
- **Time:** 5:30 PM to 7:00 PM

MassGeneral Hospital *for* Children FAC Charter/Bylaws

Mission Statement:

The MassGeneral Hospital *for* Children's Family Advisory Council (FAC) 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 delivery within Massachusetts General Hospital.

1. Purpose:

- 1.1. Work together with the administration and staff of MassGeneral Hospital *for* Children (MGHfC) to promote Family-Centered Care;
- 1.2. Collaborate with the MGHfC staff in improving the quality of health care provided to children and their families in both inpatient and outpatient settings;
- 1.3. Improve patient, family and staff satisfaction;
- 1.4. Ensure an attractive environment that is responsive to the needs of children and their families;
- 1.5. Act as an advisory resource to MGHfC leadership on issues of planning, evaluation of programs and services, policies and new facilities;
- 1.6. Act as an advisory resource to MGHfC giving input to teaching documents generated by the hospital regarding families;
- 1.7. Promote a positive relationship between MGHfC and the community; and serve as a vital link between community at large;
- 1.8. Contribute to the educational process of new professionals as positive resources and teachers contributing to the mission of the MGHfC.

2. Membership Committee:

- 2.1. Members of the Membership Committee will be appointed by the MGHfC Associate Chief, Department of Pediatrics;
- 2.2. The Membership Committee will consist of three current FAC members and two MGHfC Council members;
- 2.3. Members of the Membership Committee will track membership terms and actively recruit new members.

3. Membership:

- 3.1. Membership is by application to the Membership Committee;
- 3.2. Membership consists of fifteen people whose children have received care at MGHfC or are patients sixteen years or older who have received care at MGHfC;
- 3.3. Family members will serve as the Council Co-Chairs;
- 3.4. The MGHfC's Medical Director, Associate Chief Nurse of Pediatrics, Executive Director, and Inpatient Director of Quality and Safety will be ex-officio members;
- 3.5. The MGHfC Inpatient Director of Quality and Safety will be allowed to vote in times where a tie-breaking vote is required.
- 3.6. The MGHfC will have four rotating staff members of the Council;
- 3.7. Other MGHfC staff will attend meetings as needed and receive meeting minutes approved by the Council to have knowledge regarding the agenda and on-going work.

4. Membership Terms:

- 4.1. Each September the Co-Chairs will contact the parent members to ensure they will be able to carry out their responsibilities for the coming year.
- 4.2. Membership will elect in March a Council Co-Chair for a two-year term with Co-chair election to follow six months later.
- 4.3. Any Council member that misses four consecutive meetings will be considered an inactive member unless the absence has been approved by the Membership Committee;
- 4.4. If a Council member cannot fulfill his/her commitment to the Council, they can resign in writing and a new member will be chosen to serve the balance of his/her term.

5. Membership Responsibilities:

- 5.1. Participate in the formation and evaluation of FAC yearly goals and objectives and be an active participant in Council activities;
- 5.2. Prepare for and attend meetings;
- 5.3. Be an advocate for all patients and families by identifying and representing their needs and concerns;
- 5.4. Maintain patient confidentiality according to HIPPA guidelines at all times;
- 5.5. Consider serving on other MGHfC committees when requested;
- 5.6. Support the MGHfC publicly;
- 5.7. Notify the Co-Chairs if unable to attend meetings;
- 5.8. Agree to attend the Volunteer Program Initiation and Training as well as participate in the Volunteer Program;
- 5.9. MGHfC staff members will act as the hospital liaisons to the Council.

6. Co-Chair Responsibilities:

- 6.1. Establish goals and objectives of the Council with the Membership in September;
- 6.2. Complete an annual progress report to be submitted annually to the Chief of Service, Department of Pediatrics, Chief of Pediatric Surgery, Vice-President of Pediatrics, MGH, Vice-President, Chief Nurse and MGH.
- 6.3. Set meeting agendas and schedules;
- 6.4. Represent the goals and objectives of the FAC with any correspondence approved by the Membership with hospital administration and staff;
- 6.5. Appoint subcommittee chairs, who will be responsible for:
 - updates of the subcommittee work to the Council at regular intervals;
 - goals and objectives for the subcommittee;
 - annual reports of the subcommittee.

7. MassGeneral Hospital for Children Responsibilities:

- 7.1. Work collaboratively with the FAC to promote the best possible family-centered practice at the MGHfC;
- 7.2. Work together with the FAC in policy-making, planning and evaluating of programs and services;
- 7.3. Review and respond to recommendations of the FAC in a timely manner;
- 7.4. Offer new member orientation to the MGHfC structure, decision-making process, committee structure, and HIPPA regulations;

- 7.5. Provide meeting space and refreshments;
- 7.6. Provide free parking for FAC meetings and work in hospital;
- 7.7. Provide financial support for approved FAC activities based on submitted proposals.
- 7.8. Provide staff support person to:
 - take meeting minutes;
 - notify members of upcoming meetings with agendas;
 - distribute meeting minutes to the Council and others on the distribution list;
 - keep the FAC distribution list up to date;

8. Quorum:

- 8.1. A quorum represents 7 members, one of whom must be a staff member, needed for any official meeting.

9. Amendments:

- 9.1. The process to amend the FAC By-Laws is as follows:
 - Council member submits suggested revision in writing.
 - Revisions are sent out to members and discussed at a Council meeting.
- 9.2. The Council will vote on the amendments and approve through majority vote.



Pediatric Oncology FAC Bylaws

Overview

In 2003, the Massachusetts General Hospital for Children's Cancer Center launched its' initial Advisory Committee. Parents of children both currently receiving cancer treatment, as well as parents of children who had completed treatment joined with a multidisciplinary team of pediatric oncology providers to develop a framework for collaboration to inform clinic operations and program development. The committee quickly became an important voice in meeting the center's expressed goal of providing family centered care. Since its' inception, the Family Advisory Committee has seen changes in membership, as parents typically move off the Committee after several years of service. This has afforded the Committee the opportunity to move forward with new input while building upon past accomplishments.

Mission Statement

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.

Purpose

- Parents, patients and health care providers work together to improve the quality of care for children and their families during and after cancer treatment.
- Promote Family Centered Care as a central principle within the Pediatric Oncology practice.
- Optimize the patient and family experience.
- Provide guidance and input on family education and the development of resources to support patients and families.
- Act as an advisory resource on issues of planning and evaluation of programs, services and clinic operations.
- Contribute to ensuring that the physical environment of the clinical areas is responsive to the needs of children and their families.

Membership

The goal of membership is to have more than 50% of all committee members be parents of patients either currently in treatment for cancer, or those who have completed treatment. The remainder of the membership will include clinicians of the Pediatric Oncology health care team. The Clinical Social Worker will serve as the Co-Chair of the Committee. A Pediatric Oncologist and representative of the Nursing staff will maintain membership in the Advisory Committee. Other MGH Pediatric Oncology staff may attend a FAC meeting as needed.

Adolescents and young adults cared for within the Pediatric Oncology practice will be invited to participate in the FAC as needed. Specifically, patients will be included as ad hoc committee members, serving as subject experts and advisors on projects and new program development.

Membership Qualifications

- There will be an open enrollment process for participation in the Family Advisory Committee. Parents who are interested in joining should speak with the Clinical Social Worker who can provide information about the Committee. Additionally, parents can be recommended by staff for participation. In those cases, the Clinical Social Worker will contact the identified family member to discuss membership in the FAC. Information about the Committee will remain available in the Pediatric Oncology waiting area.
- Parents should have a child currently in treatment or be followed in the Pediatric Oncology practice for ongoing follow up care.
- Individuals participating should possess the ability to represent the perspective of the patients and family members and can consider issues beyond one's own cancer experience.
- Ability to work collaboratively amongst a team of parents and clinical staff members.
- Ability to make a time commitment for meetings and special projects, as they arise.
- Represent diverse perspectives and backgrounds to reflect the clinic's population.

Membership Terms/Responsibilities

- Members will be expected to make a two-year commitment with the option to renew after that time.
- No specific term limits have been set.
- Meetings will be held 5 times a year, with a schedule provided at the beginning of each year.
- Additional meetings, either in person or via conference calls, may be added to address special projects or input from the Committee that needs to be obtained before the next scheduled meeting.
- Members are expected to attend the meetings and make a reasonable attempt to participate in meetings outside the usual schedule.
- Participate in MGH Pediatric Oncology community programs to provide a presence for the Committee and serve as a point of contact for other parents.
- Members will maintain patient confidentiality according HIPPA guidelines at all times.

Co-Chairpersons Responsibilities

- A Parent with the Pediatric Oncology Clinical Social Worker will serve as Committee Co-Chairs.
- Parents will make a two-year commitment to this role with the option to continue for an additional year.
- Co-Chairpersons will define and distribute the meeting agenda.
- Follow up with Committee members in between meetings to address action items.
- Be available as the point of contact for family members who would like to discuss Committee participation.
- Develop an annual report with input from the Committee
- The role of recorder will be delegated by the Co-Chairpersons at each meeting on a rotating basis amongst other Committee members.

Mass General Hospital for Children's Cancer Center's Responsibilities

- Work collaboratively with the FAC to promote the best possible family centered care.
- Provide orientation and training of new FAC members.
- Insure respectful collaboration in policy making, program planning and evaluation.
- Provide orientation to new members of the FAC to include training around safety and privacy.
- Review and respond to recommendations from the FAC in a timely manner.
- Provide suitable meeting space, refreshments and parking with each meeting.
- Retain FAC minutes for a minimum of 5 years.



MASSACHUSETTS
GENERAL HOSPITAL

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