



MASSACHUSETTS
GENERAL HOSPITAL

“Guided by the needs of our patients and their families...”



2017-18
Patient and Family Advisory Council
Annual Report

MASS GENERAL MISSION

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

MASS GENERAL OVERVIEW

Founded in 1811, Mass General is the third oldest general hospital in the United States and the oldest and largest in New England. Mass General continues its tradition of excellence today. Massachusetts General Hospital has been ranked among the top five hospitals in the United States by *U.S. News & World Report* ever since the rankings began.

Mass General is recognized as #4 out of nearly 5,000 hospitals considered in the ranking. Mass General is the only hospital ranked in all 16 specialties considered by *U.S. News & World Report*, a testament to the breadth and depth of our expertise. Mass General patients rate their experiences with us very highly, with nearly all indicating they would be very likely to recommend us to others¹. We also consistently achieve high ratings from professional organizations. We have been recognized by:

- The American Nurses Credentialing Center for our excellence in nursing as a Magnet[®] hospital
- The Society of Thoracic Surgeons for our excellence in cardiothoracic surgery
- The Joint Commission for our excellence in stroke care with a Comprehensive Stroke Certification
- The Leapfrog Group for our quality and safety with an “A” grade in 2018

In addition, our clinicians and researchers are recognized at home and internationally for their contributions.

Patients at Mass General have access to a vast network of physicians, nearly all of whom are Harvard Medical School faculty and many of whom are leaders within their fields. In addition, MassGeneral Hospital for Children provides a full range of pediatric health care services, from primary care to leading-edge treatment of complex and rare disorders.

Mass General is a 1,035-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, including Back Bay, downtown Boston, Chelsea, Charlestown, Danvers, Everett, North End and Revere, as well as at MGH West and the North Shore Medical Center. The hospital also holds concurrent Level 1 verification for adult and pediatric trauma and burn care. The MassGeneral Hospital for Children, Mass General provides a full range of pediatric health care services, from primary care to leading-edge treatments of complex and rare disorders. The hospital holds concurrent Level 1 verification for adult and pediatric trauma and burn care.

Mass General annually:

- Admits approximately 49,500 inpatients
- Handles nearly 1.7 million outpatient visits
- Records more than 108,000 emergency room visits

Mass General and Brigham and Women's Hospital are the founding members of Partners HealthCare, an integrated health care delivery system that includes community hospitals, primary care and specialty physicians, specialty facilities, community health centers and other health-related entities.

Mass General has long been a leader in successfully bridging innovative science with state-of-the-art clinical medicine. Mass General conducts the largest hospital-based research program in the United States, with an annual research budget of more than \$912 million. This funding drives discoveries and breakthroughs in basic and clinical research, which translate into new and better treatments that transform medical practice and patient care.

In addition, Mass General is the original and largest teaching hospital of Harvard Medical School, where nearly all Mass General staff physicians have faculty appointments. Since the hospital's founding, Mass General has been committed to training and mentoring the next generation of international leaders in science and medicine, providing a wealth of opportunities for physicians, nurses, and other health professionals. These clinicians, in turn, lend fresh and innovative perspectives on how to treat and care for patients.

Mission Driven

Within this large, complex environment of care, it is our mission that guides our individual and collective beliefs, decisions and actions—our work. Rewritten in recent years with direct input from patients and families, this statement of purpose provides the foundation for the hospital’s patient- and family-centered approach to care:

“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.”

The hospital’s Patient and Family Advisory Councils (PFACs) serve as a primary vehicle for incorporating the patient and family care experience into our planning and day-to-day hospital operations.

PFACs at Mass General

Mass General formed its first Patient and Family Advisory Council seventeen years ago, with the launch of the MassGeneral Hospital for Children (MGHfC) Family Advisory Council in 1999. Following their lead, other high-volume specialty areas launched their own service-specific PFACs: MGH Cancer Center in 2001 and the MGH Heart Center in 2007, and the hospital formed a General PFAC in 2011. In addition, the hospital’s Ambulatory Practice of the Future operates a Care Alliance. These PFACs represent the hospital’s most widely used clinical services and represent a large proportion of the care provided at Mass General.

The hospital, patients and families have found it beneficial to operate multiple, targeted PFACs, each bringing voice to a specific patient and family experience,

environment of care, and/or priority area for the hospital. These PFACs are optimally situated to impact the delivery of care for their respective and unique patient populations. Collectively, they are positioned to influence hospitalwide initiatives, with the added benefit of bringing multiple, authentic and highly relevant perspectives to the table, and ultimately, to the hospital's governing body, the Board of Trustees.

The PFACs continue to direct and shape the patient experience at Mass General by participating on key service-based and hospitalwide committees, reviewing educational and other materials for patients and families, lending their wisdom and voice to staff orientation sessions and educational offerings, bringing forward new ideas for services and service enhancements, reviewing blueprints and plans for new patient facilities, and so much more. Above all, they bring an experience and perspective to the table that no others can replicate, and for that we are all the better.

General PFAC

established 2011



“Guided by the needs of our patients and their families...”

General PFAC

established 2011

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.

Over the past year, the General PFAC (G-PFAC) has engaged in numerous partnerships, collaborations, and activities driven by its mission and established annual goals:

1. Promote G-PFAC member participation on committees across Mass General, so as to facilitate integration of the patient/family perspective in services, programs and initiatives.
2. Expand awareness of the G-PFAC across the Mass General.
3. Align G-PFAC activities with the strategic imperatives of the hospital - Clinical Care, Research, Community, and Education; include focus on 2018 organizational goals and additional priorities.
4. Enhance G-PFAC member understandings of Mass General infrastructure and operations, by inviting leaders and representatives to G-PFAC meetings.
5. Continue to recruit new G-PFAC members who represent the diverse population of the patients served by Mass General.

G-PFAC member participation on Mass General and Partners committees, task forces, and initiatives continues to be strong and has expanded over time. The G-PFAC also has received regular requests for feedback from across the organization and system and provided the patient/family perspective on many areas of strategic priority, by welcoming guests to monthly meetings and providing input remotely. The G-PFAC engaged in multi-pronged efforts to advance organizational and community awareness of the work of PFACs, and the power of the patient and

family voice. This past year the G-PFAC introduced several new patient, family, and staff members and continues to be led by patient and staff member co-chairs. The G-PFAC continues to use a best practice of assigning buddies to help guide new members into the role of G-PFAC membership. New G-PFAC patient and family members participate in the Mass General Volunteer Services orientation allowing for enhanced engagement throughout the organization.

In the spring of 2018, the G-PFAC was recognized by Mass General leadership with a Partners in Excellence (PIE) award for its hard work and commitment to advancing the care experience of patients and family members.

2017-2018 Topics – Presentations/Feedback

Through targeted requests and monthly meetings, the G-PFAC reviewed, provided feedback on, and learned about a spectrum of topics spanning Mass General settings and strategic imperatives. These topics included the following:

- Biobank/All of Us
- Digital Health
- Disparities & equity in healthcare
- Empathy in the patient/provider relationship
- Health care experience abroad
- Kind Care Bundle proposal
- Patient Generated Health Data (PGHD) Connect
- Planning for the future - Continuum engagement materials
- Primary Care/Specialty Care referrals – Infectious Disease
- Sepsis & Hospital Acquired Infections
- Spiritual Care
- Trauma Informed Care
- 2019 Quality and Safety Goal setting process
- Spaulding Rehabilitation Hospital - tour and learnings

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

G-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.

- Blum Patient & Family Learning Center
 - A working committee of several G-PFAC members focuses on a variety of aspects of patient education and collaborates closely with the Blum Patient & Family Learning Center.
- Anesthesia Quality and Safety Committee
- Bio Bank Committee Advisory Council
- Engagement Advisory Committee – Continuum Project
- Kitty Hawk Task Force Advisory Council
- Quality Oversight Committee
- icare model focus group
- icare interviews for video to be used for hospital-wide trainings
- Partners Patient Experience Leadership Committee
- Partners Patient Experience Summit 2018 - session development and panel participation
- Partners Telehealth Committee
- Patient Perspective on Perioperative Care (P3C) Committee
- Patient Safety Awareness Week
- Simulation- Managing Patient Discharge Expectations

Additional Activities

- G-PFAC patient/family and staff members participated in multiple national conferences and forums and shared learnings:
 - 8th International Conference on Patient and Family-Centered Care: Promoting Health Equity and Reducing Disparities, Institute for Patient and Family Centered Care (IPFCC), Baltimore, MD
 - Nurturing the Core Competencies of Effective PFAC Advisors, IPFCC, webinar

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- Improving Diversity in Patient and Family Advisory Councils, IPFCC, webinar.
 - Beryl Institute Patient Experience Conference 2018, Chicago, IL
 - Prepared materials in support of increasing PFAC member participation on hospital committees: Patient Advisor Position Description, Preparing to Collaborate with Patient/Family Advisors, PFAC Member Understandings and Expectations.
 - Hosted G-PFAC tables in the White lobby to raise awareness across the Mass General community about the G-PFAC and the role of PFACs, as well as to identify potential new members.
 - Increased exposure of G-PFAC on Mass General social media sites, including Facebook and LinkedIn, and internal and external Mass General websites. Published articles in primary Mass General Hospital and Physicians Organization publications.
 - Produced compilation of G-PFAC member biographies, including information about each G-PFAC member—shared internally with the group as a way for members to get to know each other better and to build rapport.
 - Enabled capacity for remote participation in monthly meetings, as needed if members are not able to be present in person.
 - Created a PFAC emblem.
 - Facilitated quarterly meeting of Mass General PFAC Chairs.
 - Successfully hosted joint Mass General PFAC event in November 2017 featuring PFAC member panel discussions facilitated by Dr. Annie Brewster, Health Story Collaborative Founder and Executive Director. The evening provided opportunity for all PFAC members to come together, for senior leaders to thank PFAC members for their contributions, to raise awareness of PFACs across the organization, and to highlight the power of the patient/family voice. Perspectives shared at the Joint PFAC meeting:

“When I was in a room with people who are running that department, they took me seriously. They listened to what I had to say in terms of representing myself as a person, as a patient, and then, representing other patients, and it felt amazing to be able to have that voice . . .I think it speaks volumes to the culture that has been created here.”

“One of the great things about the Family Advisory Council is that they provide for systemic change. And I get to talk to residents on their first day, and tell them about what it’s like to be the parent of a chronically ill child. And I get to talk to nurses, and I get to talk to front desk staff, and hopefully I get to change things systemically.”

“Our PFAC members have amazing stories to tell, which inform us on every level about how best to achieve our mission.”

“PFAC members are sought to serve as active members on committees and initiatives of strategic performance to share their ideas about how to best shape programs and service and to enhance the care experience.”

- Collected feedback on G-PFAC collaborations over the past year. Below are some of the comments reflecting these collaborations:

“[PFAC member’s] perspective and thoughtful contributions have been absolutely invaluable.”

“Sometimes the priorities of our patients are different than those of the caregivers, and it's important to know this.”

“Their feedback is always very helpful in improving the content of staff/leadership service trainings and coaching services.”

“Members provide us with valuable insight about their knowledge, attitudes, behaviors, beliefs, and information needs on particular health topics. Their perspectives allow us to make improvements to the patient education materials we work on for hospital departments.”

G-PFAC Members

Executive Committee

Julie DeCosta
Patient Co-Chair

Liza Nyeko
Staff Co-Chair

Robin Lipkis-Orlando
Staff

William Kieffer III
Patient Member-at Large

Members

Evelyn Abayaah (staff)

Diann Burnham (staff)

Robert Chen

Hilary Deignan

Catherine Duffek

Ann Galdos

Melissa Hoyt

Susan Keshian

Stuart Murphy

Kim Northrop (staff)

Jerry Pallotta

Daniel Ranti (retired)

Matt Reid

Elsir Sanousi (staff)

Lisa Scheck (staff)

Melissa Shea

Alexa Sherrill

Joyce Smith

Carrie Stamos

Kathy Verni

Joy Wu

General PFAC Bylaws

Article 1. Overview

The Massachusetts General Hospital General Patient Family Advisory Council (GPFAC) provides a formal communication vehicle for patients and families to take an active role in improving the patient experience at Mass General. The GPFAC focuses on representing the patient voice in providing feedback to departments, services, programs, and practices across Mass General so as to enhance the patient and family experience.

Our vision is to achieve a level of care where patient and family involvement is expected and welcomed by all. We will achieve this through collaborative efforts between patients, families, staff, physicians, and administration of the hospital.

Article 2. Mission Statement

Guided by the Mass General Mission, Credo and Boundaries, the GPFAC is dedicated to ensuring that our patients and families have a successful, compassionate, and supported healthcare experience.

Article 3. Goals

Section 1. Advise: Work in an advisory role to enhance patient and family centered care initiatives at Mass General.

Section 2. Support: Support Mass General staff and leadership in enhancing patient and family-centered focus. Act as a sounding board for implementation of new programs and review and enhance existing programs across Mass General.

Sections 3. Participate: Encourage and solicit patient/family member representation on committees and work groups per requests from across the organization.

Section 4. Inform: Proactively identify opportunities for patients to influence and participate in educational initiatives.

Section 5. Represent: Bring forward patient and family perspectives about the healthcare experiences at Mass General and serve as a central resource for the voice of the patient and family.

Section 6. Evaluate: Assess the role of the GPFAC in improving experiences for patients and families.

Article 4. Structure and Membership

The GPFAC will consist of at least 16 patient/family members ideally representing the diversity of the MGH community. Up to eight MGH staff members also may serve on the GPFAC. The GPFAC will include a Patient/Family Co-Chair, a Staff Co-Chair, Patient/Family Vice Chair, and an Executive Committee, as provided for in Articles 7 and 8. Patients or family members should co-lead the GPFAC. The structure of the GPFAC may change over time.

Article 5. Nomination and Application Process

Section 1. Recruitment

Recruitment of patient and family GPFAC members is initiated by referral, solicitations through targeted mailings, and/or conversations with potential candidates.

Section 2. Membership Criteria

Members are selected based on the following criteria:

- Experience as a patient or family member at MGH
- Ability to represent patient care experience
- Willingness to work in an advisory role
- Good listening skills
- Ability to interact well with differing groups of people
- Respect of others' perspectives

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- Ability to participate in a consistent and agreed upon schedule of meetings,
 - Ability to participate in subcommittees and in hospital committees, meetings, and/or workgroups, strongly preferred
 - Commitment to serve for a two-year term with potential to renew at the end of the term

Section 3. Membership Selection

Applications are sent to identified prospective members. Applicants are screened by staff, and those identified as viable candidates are then interviewed by selected GPFAC members and staff. 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 GPFAC as to their selection.

Section 4. Terms of Appointment

- GPFAC patient/family members are appointed for a term of 2 years.
- GPFAC patient/family members may request to be reappointed for an additional term of two years, with total consecutive years not to exceed 6.
- GPFAC patient/family members who have completed the 6 year term may apply to become a member again after a hiatus of 1 year. GPFAC members who are selected to join again become eligible, as any GPFAC member, for another 2 year term. A member shall not serve more than a total number of 8 years.
- Resignations will be submitted in writing or via e-mail to the Co-Chairs.
- Vacancies may be filled during the year as needed.

Article 6. Roles and Responsibilities of Members

Section 1. Roles and Responsibilities for Patient/Family Members

- Attend each GPFAC meeting or, whenever possible, notify a Co-Chair in advance, if unable to attend.
- Prepare and engage thoughtfully and constructively with respect to the issues and ideas discussed during each session.
- Proactively drive improvement and bring creative ideas for change.
- Respect the unique background and perspective of each member.
- Be realistic and mindful of the hospital's budgetary constraints.

Section 2. Roles and Responsibilities for Staff Members

- Attend each GPFAC meeting or, whenever possible, notify one of the co-chairs, in advance, if unable to attend.
- Identify, invite, vet and/or orient potential GPFAC patient and family members.
- Align with and facilitate GPFAC subcommittees.
- Facilitate discussions and engage all members.
- Provide reports to the GPFAC of progress on ongoing projects and any hospital initiatives of interest to the group.
- Minimize potential barriers to achieving established goals.
- Be an advocate for the GPFAC.

Article 7. Roles and Responsibilities of Officers of the GPFAC

Section 1. Patient/Family Member Co-Chair

- Attend and preside at each GPFAC meeting.
- In collaboration with the Executive Committee, develop and implement strategic initiatives of the GPFAC.
- In collaboration with the Executive Committee, set agendas for meetings.
- In collaboration with the Executive Committee, manage the patient and family member recruitment process.
- Manage communications with GPFAC members, including distribution of agendas, minutes, any additional materials.
- Work with staff Co-Chair in communicating activities of the GPFAC to Mass General leadership.
- Work with staff Co-Chair in serving as an advocate for PFACs across Mass General and Partners.
- Represent Mass General PFACs in the health care community, as appropriate.
- Participate in PFAC Chairs meeting.
- Participate in planning of annual PFAC meetings.

Section 2. Staff Co-Chair

- Attend and preside at each GPFAC meeting.
- In collaboration with the Executive Committee, develop and implement strategic initiatives of the GPFAC.
- In collaboration with the Executive Committee, set agendas for meetings.
- In collaboration with the Executive Committee, manage the patient and family member recruitment process.
- Work with Patient/Family Member Co-Chair in managing communications with GPFAC members.
- Communicate activities of the GPFAC to Mass General leadership, and serve as a liaison with Mass General staff.
- Serve as an advocate for PFACs across Mass General and Partners.
- Represent Mass General PFACs in the health care community, as appropriate.
- Participate in PFAC Chairs meetings.
- Participate in planning of annual PFAC meetings.
- Check in at least quarterly with former GPFAC members serving on Committees throughout the hospital, to ensure seamless transition and positive participation in the Committees, and act as liaison between former GPFAC members and Committee Chairs as needed.

Section 3. Vice Chair

- Support the GPFAC Co-Chairs in ongoing activities, as described above.
- Serve as Co-Chair of GPFAC meetings, as necessary.
- Support documentation and measurement of the successes of the GPFAC.

Section 4. Secretary

- Record minutes of each GPFAC meeting.
- Record minutes of each Executive Committee meeting.
- Provide minutes to Co-Chairs, and/or designated Executive Committee

member(s) in a timely manner, for their review, prior to distribution to members of the GPFAC.

Section 5. Immediate Past Patient/Family Member Co-Chair

- Upon completion of the term as Co-Chair, the patient/family member would serve as Immediate Past Co-Chair for a term of 1 year.
- This position would be exempt from the maximum 6 consecutive year term limit, and 8 total year limit.

Article 8. Executive Committee of the GPFAC

Section 1. Membership

- The Executive GPFAC Committee will consist of the Patient/Family Member Co-Chair, the Staff Co-Chair, Vice-Chair, Secretary, and staff members, and may include a selected GPFAC member at large. The total membership shall not exceed 7.

Section 2. Duties and Responsibilities

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

Article 9. Terms of Officers

The terms of GPFAC Officers will be as follows:

- The term of the GPFAC patient/family member serving as Co-Chair is not to exceed 2 years.
- The term of the Vice Chair shall be 2 years, directly preceding the assumption of the role as Patient/Family Co-Chair.

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- The term of the Secretary shall be 2 years, subject to renewal for 2 subsequent 2 year terms.
 - The term of the Immediate Past Co-Chair shall be 1 year, directly following the term as Co- Chair.
 - Vacancies will be filled as necessary, as provided for in Article 5, Section 3.

Article 10. Activities of the GPFAC

The GPFAC will engage in the following activities:

- Represent the patient voice across Mass General, as requested, and seek opportunities to do so.
- Provide targeted feedback to departments, services, programs and practices across Mass General.
- Participate in a variety of hospital committees and workgroups, as a whole, and individually as members.
- Provide regular updates to the MGH leadership and annual progress reports to the Department of Public Health (DPH).
- Promote awareness and recognition of the functions and importance of PFACs across the hospital, system, and healthcare community.

Article 11. Orientation and Training

Section 1. Mass General Orientation and Training

All selected GPFAC patient and family applicants will receive orientation and training as to the mission and goals of Mass General, Training will include hospital regulatory and privacy issues, and through this training, GPFAC members will commit to adhering to MGH guidelines and Health Insurance Portability and Accountability Act (HIPAA) standards and guidelines. The Volunteer Department of MGH will provide the Mass General orientation and training.

Section 2. GPFAC Orientation

All selected GPFAC patient and family applicants will receive orientation specific to the GPFAC, including review of the bylaws.

Article 12. Confidentiality

GPFAC members must not discuss any personal or confidential information revealed during GPFAC meetings outside of the GPFAC meetings. GPFAC 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

Meetings will be held monthly. Each meeting will be 1 to 2 hours in length.

Section 1. Agenda

Meeting agenda will be set by the Executive Committee and will be distributed to the membership prior to each meeting, along with any pertinent materials for discussion during the meeting.

Section 2. Meeting Minutes

The Secretary will take minutes of each GPFAC meeting and Executive Committee meeting. Council minutes will be retained for a minimum of 5 years.

Section 3. Attendance

It is expected that the members of the GPFAC will make every attempt to attend each meeting held. Teleconference call in is acceptable when physical presence cannot be achieved. Participation by every member is expected. Confirmation of attendance is requested for each meeting. If a member is not able to attend 3 consecutive meetings, the Co-chairs will contact the member to discuss their commitment to the GPFAC.

Article 14. Termination

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

Article 15. Bylaws

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

MassGeneral Hospital *for* Children FAC

established 1999



“Guided by the needs of our patients and their families...”

Massachusetts General Hospital for Children

established 1999

FAC Goals for 2018

- Work with hospital leadership and personnel to improve the processes through which patients transition from pediatric to adult healthcare at MGHfC and MGH
- Continue to use patient stories and draw from patient experiences to enhance patient and staff education at MGHfC
- Engage with MGHfC's patient experience workgroups, by serving on committees and collaborating in activities, to enhance the patient experience at MGHfC
- Learn more about and engage with the Pediatric Pain Service, to improve patient understanding of pain management service at MGHfC

Presentations and Feedback

- Dr. Ronald Kleinman, MD (Physician-in-Chief, MGHfC) outlined the Department of Pediatrics strategic goals for the year and heard about areas of priority for parents.
- Michael Pistiner, MD (Director of Food Allergy Advocacy, Education and Prevention at MGHfC) presented his recent efforts and received feedback about how parents and patient participation could enhance that work.
- Deborah Wachenheim (Director of Dissemination at OpenNotes) discussed the work of the non-profit whose mission is to enable patients to have more access to their medical records.
- Christine Griffin (MGH Director of Health Information Management/Privacy Officer) gave a power point presentation on the new Partners Patient Gateway access policy for adolescents and their parents as well as the process

by which patients can achieve a waiver from the policy. FAC parents provided feedback about the drawbacks of the policy in terms of limiting access to important medical information.

- Robin Lipkis-Orlando and Jennifer Repper-DeLisi from the Office of Patient Advocacy visited FAC to explain their roles and the programs that are run through their office.
- Liz Mover (MGH nurse in the Medical ICU) presented on Operation House Call, run through The Arc of Massachusetts. This program enables young medical professionals to visit patients in their homes and teaches essential skills to enhance the health care of persons with autism and other intellectual and developmental disabilities.
- Sandra Clancy (Co-Chair of FAC) asked FAC members for feedback on a medical education collaboration between MGHfC and Cleveland Clinic's Children's Hospital. Two hospital teams are creating curricula to train residents in pediatric palliative care using videos from the Courageous Parents Network featuring parents of children with serious illness discussing their hospital experiences.

Patient and Staff Education

- Four FAC parents completed video interviews in which they articulated why they chose MGHfC for their child's care and why they serve on the FAC. MGHfC web development and marketing personnel are in the process of making the interviews available on the FAC website.
- Two FAC parent members collaborated with Sharon Badgett Lichten (Senior Organizational Development Specialist in Service Excellence at MGH and MGPO Practice Improvement Division) to develop and present three staff training sessions. The sessions, hosted by the MGHfC Quality and Safety Team, focused on providing staff with skills in the areas of courtesy and helpfulness.
- FAC developed and hosted a Grand Rounds in collaboration with three members of the Pediatric Radiation Oncology Team, a fourteen-year-old patient and his parents. The Grand Rounds featured the MGHfC staff describing their role in the Peer Mentor Program which matches patients who have undergone proton beam radiation therapy without sedation with

patients who wish to do the same. The Peer Mentor Program was developed by a nurse in Pediatric Radiation and the patient.

- Two MGHfC patients (ages 13 and 14), along with their parents who are FAC members, spoke to incoming medical interns to provide their experiences of bedside rounding. The adolescents noted that they appreciate when doctors call them by their names and include them in discussions about their healthcare.

FAC Parents Activities Throughout the Hospital

- Two FAC parents joined hiring committees for Nurse Director positions. They participated in assessing resumes, interviewing candidates and writing reports to the MGH Nursing Director. The positions were for Nurse Director of OB-GYN and Nurse Director of Ellison 17 and 18.
- FAC members attended a Joint PFAC event hosted by the MGH PFAC that featured a panel of patients who spoke about their experiences at MGH. A FAC parent member participated on the panel.
- FAC staff and parents participated in the Ellison 17 and 18 Santa's Workshop, a hospital tradition in which parents of patients who will spend the holidays in the hospital choose gifts for them from a collection displayed on the wards. FAC members wrapped the gifts and interacted with parents who were choosing gifts for their children.
- Several parent members of the FAC met in December with several members of the MGHfC Pedi Cancer Center PFAC to collaborate on a statement for MGHfC Leadership around the need for single rooms on the wards.
- In response to a request from the MGHfC Residency Program Leadership, FAC parents provided their perspectives on the benefits of bedside rounding. The feedback was included as the residency program made changes to the process of bedside rounding.
- Four FAC members formed a committee to work with MGHfC Leadership to use FAC patient stories to enhance awareness of and differentiate MGHfC. They presented 'Using Patient Stories and Experiences to Increase Awareness

and Differentiate the Hospital' to the MGHfC Executive Group. A working group has been formed to carry out the suggestions.

- Two FAC parents staffed a table at the 2018 New Intern Meet and Greet Event to introduce FAC and its activities to entering interns.
- FAC parents continued to pilot a 'Secret Shopper' form developed by MGHfC Quality and Safety Team that allows parents to fill out an on-line patient experience survey after ambulatory visits. The survey results are shared with ambulatory practice leadership to help target areas that need improvement.
- Supported Department of Nursing's successful Magnet Redesignation
- FAC PICU nurse Eleanor McLaughlin initiated the PICU Adolescent Rounding project that was inspired by her work on the FAC. The project offers teens and young adults in the PICU the opportunity to take part in bedside rounding. The project was included in the 2017 MGH application for Magnet Nursing status.

Research

FAC was invited by Elsie Taveras, MD (Chief, Division of General Academic Pediatrics) to write a letter of support for her grant proposal titled "Implementation of Childhood Obesity Treatment Innovations to Improve Outcomes of Low-Income Children: The Connect for Health II Study." FAC parents' role in the project would be to inform the proposed implementation, to guide adaption of family educational materials, and to provide feedback on culturally- and family-oriented strategies and experiences that will be beneficial to the success of implementation.

Awards

The Co-Chairs of the FAC traveled to Washington DC on November 3, 2017 to attend a conference and award ceremony sponsored by the Institute for Patient and Family Centered Care. They received a Partnership Award for 'Wendy's Welcome,' a cartoon animation video that introduces pediatric patients to the MGHfC Emergency Department. The award recognizes innovative partnerships among patients, families and health care professionals.

Massachusetts General Hospital for Children FAC Members

Parents/Patients

Seta Atamian
Lisa Cimino
Darcy Daniels (Co-Chair)
Michael Doiron
Charlene Harper
Roxanne Hoke-Chandler
Cindy Matuszewski
Matthew McGuinness
Eve Megargel
Janice Morris
Elizabeth Mover
Alix Nozzolillo
Kelli Purchase
Erin Quinney
Kathleen Rufo
Randi Stempler
Faith Wilcox

Staff

Sharon Badgett-Lichten
Barbara Cashavelly
Monic Chardin
Sandra Clancy (Co-Chair)
Anne Fonseca
Kate Gerne
Peter Greenspan
Esther Israel
Karen Manning
Jessica Mascola
Sandra Dodge McGee
Anne Bouchard Pizzano
Alexandra Sobran
Kimberly Whalen

Family Advisory Council Charter/By-laws

1. Mission Statement:

The MassGeneral Hospital *for* Children's Family Advisory Council (FAC) is dedicated to fostering the partnership of family members, children, and professionals working together to ensure a climate of responsiveness to the needs of children and their families.

2. Purpose:

- 2.1. Work together with the administration and staff of MassGeneral Hospital *for* Children (MGHfC) to promote family-centered care;
- 2.2. Collaborate with the MGHfC staff in improving the quality of health care provided to children and their families in both inpatient and outpatient settings;
- 2.3. Foster engagement among patients, families and professionals;
- 2.4. Act as an advisory resource to MGHfC leadership on issues of planning, equipment, evaluation of programs and services, policies and new facilities;
- 2.5. Act as an advisory resource to MGHfC giving input to teaching documents generated by the hospital regarding families;
- 2.6. Promote a positive relationship between MGHfC and the community;
- 2.7. Contribute to the educational process of professionals at MGHfC.

3. Membership Committee:

- 3.1. Members of the Membership Committee will be appointed by the MGHfC Associate Chief, Department of Pediatrics;
- 3.2. The Membership Committee will consist of three current FAC family members and two MGHfC staff members;
- 3.3. Members of the Membership Committee will track family membership and actively recruit new family members.

4. Membership:

- 4.1. Family membership is by application to the Membership Committee;
- 4.2. Family membership consists of up to twenty-one people whose children have received care at MGHfC or are patients sixteen years or older who have received care at MGHfC;
- 4.3. There will be one staff Co-Chair and one family Co-Chair;

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- 4.4. The MGHfC 's Medical Director, Associate Chief Nurse of Pediatrics, Executive Director, and Inpatient Director of Quality and Safety will be ex-officio members;
 - 4.5. The MGHfC Inpatient Director of Quality and Safety will be allowed to vote in times where a tie-breaking vote is required.
 - 4.6. The MGHfC will have four rotating staff members of the Council;
 - 4.7. Other MGHfC staff will attend meetings as needed given the Council's goals and receive meeting minutes approved by the Council to have knowledge regarding the agenda and on-going work.
5. Family Membership:
 - 5.1. Each September the Co-Chairs will contact the family members of FAC to ensure they will be able to carry out their responsibilities for the coming year;
 - 5.2. The family Co-Chair of FAC will serve a two-year term;
 - 5.3. Any Council member that misses four consecutive meetings will be contacted by the Council Co-Chairs to determine whether they will be able to continue to serve;
 - 5.4. If a Council member cannot fulfill his/her commitment to the Council, they can resign in writing.
6. Membership Responsibilities:
 - 6.1. Participate in the formation and evaluation of FAC yearly goals and objectives and be an active participant in Council activities;
 - 6.2. Prepare for and attend meetings;
 - 6.3. Be an advocate for all patients and families by identifying and representing their needs and concerns;
 - 6.4. Maintain patient confidentiality according to HIPPA guidelines at all times;
 - 6.5. Consider serving on other MGHfC committees when requested;
 - 6.6. Support the MGHfC publicly;
 - 6.7. Notify the Co-Chairs if unable to attend meetings;
 - 6.8. For family members, agree to undertake MGH Volunteer Department orientation and become an official MGH Volunteer;
 - 6.9. MGHfC staff members will act as the hospital liaisons to the Council.

7. Co-Chair Responsibilities:

7.1. Establish goals and objectives of the Council with the membership annually;

7.2. Complete an annual progress report to be submitted to the Chief of Service, Department of Pediatrics; Chief of Pediatric Surgery; Vice-President of Pediatrics; and Chief Nurse, MGH;

7.3. Set meeting agendas and schedules;

7.4. Represent the goals and objectives of the FAC with any correspondence approved by the membership with hospital administration and staff;

7.5. 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;

7.6 Liaison with six Patient and Family Advisory Councils at MGH and represent the work of the FAC.

8. MassGeneral Hospital for Children Responsibilities:

8.1. Work collaboratively with the FAC to promote the best possible family-centered practice at the MGHfC;

8.2. Work together with the FAC in policy-making, planning and evaluating of programs and services;

8.3. Review and respond to recommendations of the FAC in a timely manner;

8.4. Offer new member orientation to the MGHfC structure, decision-making process, committee structure, and HIPPA regulations;

8.5. Provide meeting space and refreshments;

8.6. Provide free parking for FAC meetings and work in hospital;

8.7. Provide financial support for approved FAC activities based on submitted proposals.

8.8. 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;

9. Quorum:

9.1. For voting, a quorum represents at least 7 members, one of whom must be a staff member, and two more parent members than staff members are needed for any vote to be official. If there is not a quorum at a meeting, the vote will be taken via email and the votes of eight family members are required for the vote to be official.

10. Amendments:

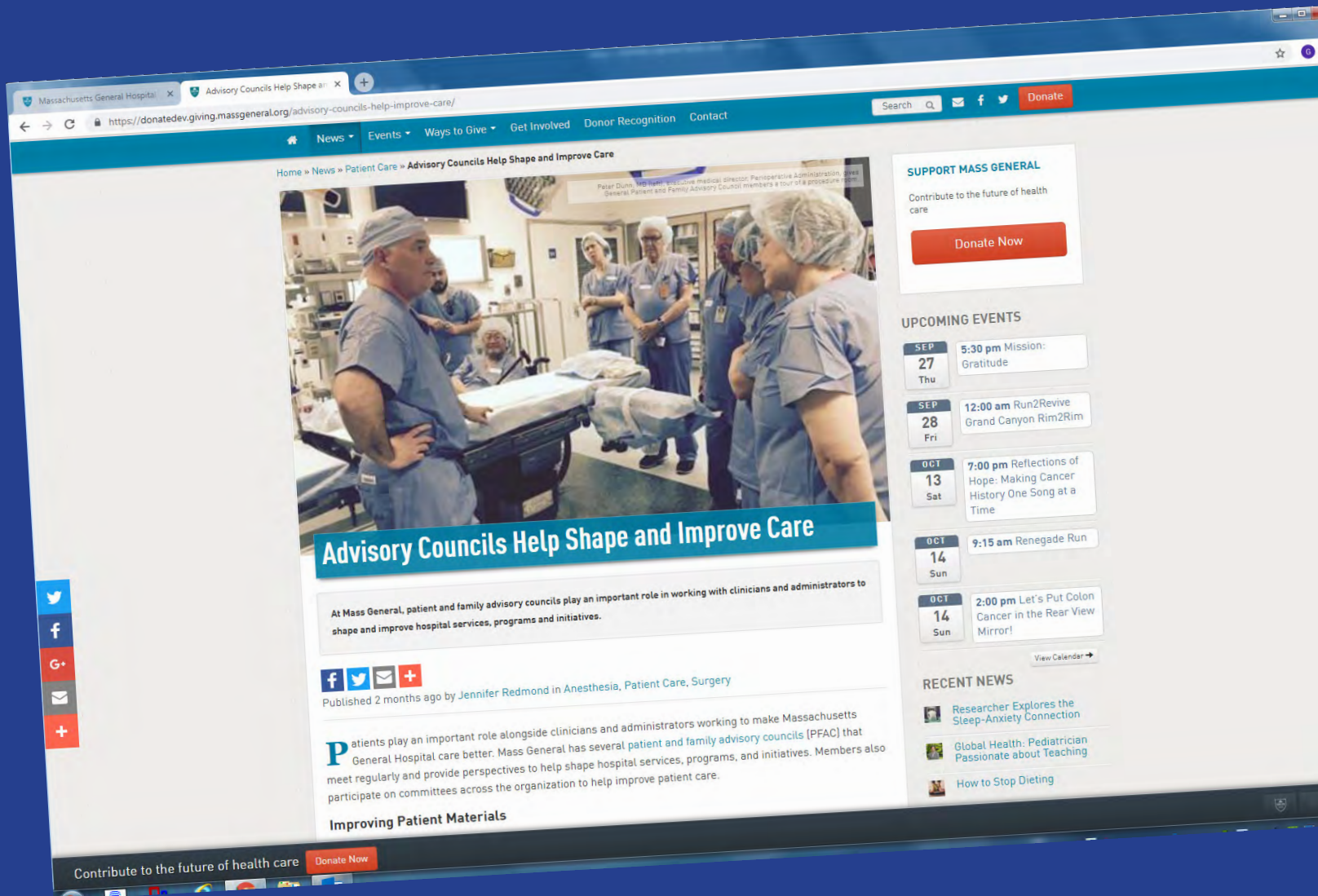
10.1 The process to amend the FAC By-Laws is as follows:

- Council member submits suggested revision in writing.
- Revisions are sent out to members and discussed at a Council meeting.

10.2 The Council will vote on the amendments and approve through majority vote.

MGH Cancer Center PFAC

established 2001



“Guided by the needs of our patients and their families...”

MGH CANCER CENTER

established 2001

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.

Objectives

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, communications to patients and families, program development, the Cancer Center's ongoing evaluation of the quality of care and other important initiatives.

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, 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.

2017-18 Activities and Accomplishments

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. This year, the committee prioritized the following objectives:

- Enhance communication to patients and families about Cancer Center programming and resources
- Minimize delays and increase efficiency of patient care
- Improve survivorship programming

The accomplishments below represent areas that demonstrate the impact of the PFAC on the Cancer Center's patient experience, in accordance with the goals mentioned above:

- ***Quality, Safety and Value in the Cancer Center***- Therese M. Mulvey, MD and Meg Soriano, RN presented on the robust safety culture in the Cancer Center and new initiatives targeted at improving the quality of care provided to patients. Patient Reported Outcome Measures (PROMs) measure health from the patient perspective through an Epic questionnaire presented on an iPad at check-in. The committee discussed the positive impact this could have on caring for the whole patient and managing symptoms and issues.
- ***Telemedicine***- Benjamin Meller and Kaitlin Bilodeau from the MGH/MGPO Center for TeleHealth provided an overview of the history of telemedicine at MGH and the rapidly expanding scope of practice within the department. As telehealth expands into the Cancer Center, PFAC members gave feedback on the types of visits appropriate to telemedicine and which are important to remain in person. There was conversation related to the relationship formed between a patient and their entire healthcare team and how it could be altered by the introduction of telemedicine.
- ***Distress Screening***- Joseph Greer, PhD, Lourdes Barros, LICSW and Carlos Fernandez-Robles, MD discussed the Cancer Center's plan to implement distress screening in outpatient oncology practices. They presented a plan to

regularly screen patients for psychosocial distress utilizing an Epic questionnaire developed to identify patients that may need additional support and direct them to available resources.

- **Virtual Support Groups-** Justin Jordan, MD presented on a pilot program to make support groups more accessible to all patient populations by expanding to an electronic platform. This initiative was a result of the 2017 Cancer Center Ether Dome Challenge in which PFAC members were active participants. The committee shared their experience with support groups and gave insightful feedback to the challenges anticipated with moving to remote attendance. There was a meaningful discussion about the emotional ties that form within the support group settings and advice on how to cultivate the same dynamic in a virtual space.
- **MIT Project Updates-** Beth Souza returned to PFAC to provide an update on the MGH/MIT collaborative schedule optimization program (OptIn) designed to reduce patient delays in Infusion. In a previous meeting, PFAC members were asked for feedback on best methods to communicate this new change to our patients and asked their thoughts/concerns with the new process. This update showed how over a six-month period, the infusion unit capacity has increased to accommodate more patients in a more efficient manner.
- **Cold Cap-** Steven Isakoff, MD presented details on the newly approved scalp cooling technologies and his ongoing work to bring a scalp cooling program to the Cancer Center. Cold Cap therapy aims to minimize chemotherapy-induced hair loss by reducing blood flow to the hair follicle. PFAC members were very involved in giving feedback on their own experience with hair loss throughout treatment and provided insight into the lack of control associated with chemotherapy-induced alopecia.
- **Understanding Immunotherapy Side Effects-** Kerry Reynolds, MD and Alexandra-Chloé Villani, PhD were joined by the families of former patients to facilitate a meaningful and emotional discussion regarding the complications associated with immunotherapies and how MGH is partnering across departments and divisions to help manage complications and side effects. The

families shared their experience navigating the complications associated with immunotherapy, and Dr. Reynolds sought feedback from the committee on how to best communicate severe toxicity to patients.

- ***Smokefree Support Services***- Elyse Park, Irina Gonzalez and Laura Malloy reviewed the smoking cessation services available to oncology patients. The Mass General Cancer Center Smokefree Support Service provides free, phone-based, one-on-one quit-smoking counseling for all MGH Cancer Center patients.
- ***Cellular Therapy Service***- Matthew Frigault, MD presented on the rapidly growing cellular therapy (CAR-T) service within the Cancer Center and the various clinical trials offered at MGH. Cellular therapy is a new form of treatment in which a patient's cells are extracted and genetically engineered to identify and target cancers. Dr. Frigault facilitated a collaborative discussion on how new research and technologies are influencing the way clinicians care for patients while they undergo treatment and moving forward.
- ***Chaplaincy: Spirituality & Mindfulness***- Katrina Scott reviewed the various services offered to patients from the Chaplaincy program at MGH. Patients are provided with spiritual care for all traditions, religions and cultural beliefs. In an informal "ask the chaplain" forum, the committee and Katrina discussed the benefits chaplaincy involvement can offer patients and families in addition to the versatile exercises used to approach spirituality at MGH.
- ***Waltham Radiology Expansion Project***- Jeremy Herrington from the Department of Radiology presented on the ongoing efforts to expand available services offered in the Waltham location. The expansion plan will increase the availability of current imaging services offered and introduce standard interventional radiology procedures to the location. PFAC members were asked about their experience with radiology across locations and provided advice on what additional services best serve oncology patients.
- ***Cancer Center Updates***- Mara Bloom, Executive Director, MGH Cancer Center provided an update on Cancer Center growth strategies, international partnerships and the ongoing efforts to develop a supportive care program. As

the Cancer Center looks forward, there is a focus on aligning strategies with the patient experience and providing care that supports all patient needs.

- **Overview of Oncology Resources-** Ellen Forman, LICSW, Greta Gaeta, LSW and Patrina Jacob updated PFAC on the various resources accessible for patients in the Cancer Center and the appropriate pathways for navigating patients to available support. The presenters were interested in feedback from PFAC members on how to raise awareness of these resources and the best way and time to communicate with patients.
- **Patient Access Initiatives-** Courtney McLeish presented ongoing Cancer Center initiatives to improve the patient experience and increase the accessibility of both the administrative and clinical teams. These include providing next day new patient access, decentralizing the call center to deliver one touch resolution for routine administrative concerns and restructuring the after-hours patient call service. There was a lively discussion on the various ways patients interact with the Cancer Center and how administration can help provide a consistent patient experience through each available point of contact.
- **Role of Nursing in the Cancer Center-** Erika Rosato, Nursing Director of Ambulatory Oncology Clinical Services and KellyAnn Jeffries, Nursing Director of Advanced Practice Clinicians provided an overview of the Cancer Center collaborative and integrated nursing leadership structure that reaches across the continuum of care. PFAC members shared their experiences interacting with nursing and the prominent role oncology nurses take in the care of the patient.
- **Conferences:** As part of its mission to educate others about the value and role of PFACs, members participated in several external forums. During FY2018, members participated in the following forums:
 - MGH Annual Joint PFAC Meeting- *November 2017*
 - The World Innovations Forum- *April 2018*
 - 2018 Survivorship Conference: Own Your Story: Creating Meaning from Your Cancer Experience- *June 2018*

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- ***Committee and Subcommittee Participation:*** PFAC members also participate in a variety of Cancer Center committees and subcommittees. This ensures that the patient and family member perspective is well integrated into the fabric of the Cancer Center. PFAC representatives on these committees provide periodic updates during the monthly council meetings. PFAC members participated in the following committees during FY2018:
 - PFAC Task Force on Enhancing Patient Connection to Cancer Center Supportive Care Resources
 - Cancer Center Quality & Safety Committee

Looking Forward

As FY19 begins, many of the committees and activities listed above will continue. Cancer Center staff and leadership seek out the opinions and perspectives of CC PFAC members as staff are increasingly aware of PFAC's diversity of experience and perspectives that can make an excellent initiative or program even better. CC PFAC members also contribute to the Mass General Cancer Community information learned, from personal experience or active learning and participation, to guide the Cancer Center in new directions to continually improve the patient experience.

Pediatric Oncology FAC

established 2003

The Voice of the Patient

Patient-family advisory councils come together

—by Liza Nyeko, Office of Patient Experience/MGH Center for Quality & Safety

MGH patient-family advisory councils (PFACs) came together, November 14, 2017, in O’Keeffe Auditorium to celebrate the voices of patients and families and highlight their contributions to enhancing the care experience. Founder and executive director of Health Story Collaborative, Annie Brewster, MD, facilitated two panel discussions, demonstrating the power of storytelling to effect change.

Said senior vice president for Performance Improvement and Service Excellence, Inga Lennes, MD, “Stories are the things that motivate us. They fuel change. Our PFAC members have amazing stories that inform our efforts to advance our mission.”

Former senior vice president for Patient Care, Jeanette Ives Erickson, RN, thanked PFAC members for, “the incredible work that is happening because of your commitment to advise and improve the care we deliver.” She cited examples of their input into key initiatives, designing new buildings and services, developing educational programs, and participating on hospital committees. Ives Erickson introduced her successor, Debbie Burke, RN, who’s been a member of the Cancer Center PFAC and the Pediatric Oncology FAC for years. Said Burke, “We’re going to need your help in the years ahead to remind us of what’s most important—you and your families.”

One panel focused on the unique relationship between patient, provider, and parent through the accounts of Tarrah Zedower, of the Pediatric Oncology FAC, and Howard Weinstein, MD, chief of Pediatric Oncology. Together, they told the powerful story of one care journey and the importance of trust and partnership.

Another panel, comprised of members of the other six PFACs, shared stories of coping with medical conditions, finding strength in the patient-family-provider relationship, and contributing to hospital efforts to improve the care experience. Matt Reid, General PFAC; Paul O’Leary, Ambulatory Practice of the Future Care Alliance; Darcy Daniels, Pediatric FAC; Michael Bider, Heart and Vascular Center PFAC; Ann Buckley, Cancer Center PFAC; and Kim Nunnari, Cystic Fibrosis PFAC, all shared stories.

Said Reid, “When I was in the room with people who run that department, they took me seriously. They listened in terms of me representing myself as a person, as a patient, and then representing other patients. It felt amazing to be able to have that voice... That speaks volumes about the culture that has been created here.”

For more information about patient-family advisory councils, contact Liza Nyeko at 617-643-5484.



Panelists, Tarrah Zedower, of the Pediatric Oncology FAC, and Howard Weinstein, MD, chief of Pediatric Oncology, share their journey together.

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“Guided by the needs of our patients and their families...”

Pediatric Oncology FAC

established 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.

OBJECTIVES

- Build a consistent and committed membership
 - Continue a vigorous recruitment process including promoting diversity amongst members.
 - Develop an orientation program in collaboration with Mass General's Volunteer Services program for all members joining the Committee.
 - Increase awareness of the value of the Family Advisory Committee's role within the clinic's operations and programs.
 - Enhance the Advisory Committee member's role as a change agent within the practice.
- Collaborate with other PFAC's and integrate into the infrastructure of Advisory Committees at Mass General
 - Co-Chairperson (Mass General staff member) will attend Chairpersons Council.
 - Family Advisory Committee members will have the opportunity to participate in professional conferences within the region for education and collaboration.

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- Document initiatives and successes to organizational leadership
 - Provide periodic reports to practice leadership.
 - Compile a yearly report detailing annual activities.
 - Promote new programs and successes in Mass General publications throughout the year.
 - Identify opportunities for collecting additional data for evaluation and action.

The Pediatric Oncology FAC holds meetings five times annually with additional meetings scheduled when the group or subgroup is working on a specific project. There is a clear understanding of the competing demands of families when a child has cancer – including the needs of other children in the family, work, and requirements of treatment for the sick child. All of these factors will impact the ability of a parent to attend in person meetings of the Advisory Committee. Opportunities to call into meetings or Facetime have been made available to members, so to offer flexibility and promote members' inclusion in the group. This year the group honored 3 members of the Committee who departed, two after many years of service. Subsequently, the Family Advisory Committee also welcomed two new parents to the group who brought with them valuable experience and perspectives related to their child's care in the practice. Clinical staff participation remained constant.

Activities and Issues

- Family Advisory Committee members hosted a lunch in the Pediatric Oncology Clinic for patients and families in honor of National Childhood Cancer Awareness month. Information about childhood cancer and clinic programs was available along with gold shoe laces donated by Go 4 the Goal for all the children. Advisory Committee parents met with newer families for camaraderie and support.
- Pediatric Oncology FAC members joined with the other MGH PFAC's for The Voice of Mass General PFAC's, a joint program of all the MGH Advisory Committees. Featured speakers were Tarrah Zedower, member of our FAC along with Dr. Howard Weinstein, Chief of Pediatric Oncology who shared their stories about the partnership between patient/family/provider in a child's cancer journey.
- In early December 2017, the FAC met with Emergency Department Leadership to review the initiatives the ED has taken to improve the patient and family experience for Pediatric Oncology families. This meeting was part of the continuing dialogue between families and ED staff to address the challenges children experienced around port-a-cath access in the ED. As result of these discussions, standards of nursing practice have been established in the ED, new protocols established for accessing assistance from inpatient nursing if needed, and efforts to improve the competencies and comfort of the nursing staff with pediatric port access.
- Pediatric Oncology FAC members helped staff develop an information sheet for families to address issues of scheduling appointments, importance of timely arrival and the impact on the clinic operations. FAC members reviewed the content and messaging before distribution to families of children receiving care in the clinic.
- Pet Therapy started in the Pediatric Oncology outpatient clinic in February 2018. This was the result of an intensive initiative by members of the FAC advocating for the inclusion of the program with the clinic practice. There was ongoing collaboration with MGH Volunteer Services to bring this program to fruition. Pediatric Oncology became the 1st outpatient service to offer Pet Therapy. It has proven to be an enormously popular and successful program.

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- A subgroup of Pediatric FAC members joined with a group from the Mass General Hospital for Children's FAC to develop a position statement about the need for private rooms on the inpatient Pediatric service. The group detailed a list of challenges when children must share rooms, which was submitted to Dr. Ronald Kleinman, Chief of Pediatrics at Mass General Hospital for Children. As expansion of hospital inpatient beds is being addressed through new building and re-allocation of resources, the group felt that it was timely to articulate their position.
 - Michael Doiron, a member of the FAC, attended ACCO Children's Cancer Association Advocacy Days in Washington DC with support of the FAC and Pediatric Oncology. Mike met with the staff of his local legislatures to lobby for the passage of the STAR Act, The Childhood Cancer Survivorship, Treatment, Access and Research Act and participated in advocacy activities throughout the two-day program. He shared the inspiration he gained from his participation with our FAC at a subsequent meeting.
 - The Parent to Parent POPS program continues to be evaluated with the Family Advisory Committee. The FAC reviewed obstacles for engaging parents at various points in a child's treatment, and discussed strategies to promote the program. Moving this program to an online portal that is secure will continue to be discussed as a next step in advancing family participation.
 - The FAC continues oversight of the tracking of Patient Experience Data and offers input for clinical and operational improvements.
 - Pediatric Oncology FAC members provide regular feedback about programs held. The group also addresses the development of new psychosocial care programs for family support, education and creating connections between families during their child's cancer treatment. Building opportunities for linkages and support are central the value of services offered.

Pediatric Oncology Family Advisory Committee Membership

Co-Chairs

Dawn Regan, FAC Parent

Elyse Levin-Russman, LICSW, OSW-C, Clinical Social Worker

Parent Members

Claudia Cardona

Mary Cincotta

Susan Jacobson

Mary Koperski

Paula Marshall

Peter Palamidis

Jerry Schindler

Janice Theriaque

Tarrah Zedower

Staff Members

Mary Huang, MD

Pediatric Oncologist

Heidi Jupp, RN, CPON

Pediatric Oncology Nurse

Ellen Silvius, RN, BSN

Ambulatory Nurse Manager

Pediatric Oncology 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 insuring that the physical environment of the clinical areas are responsive to the needs of children and their families.

Membership

The goal of membership is to have 75% 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 members of the Pediatric Oncology health care team. Currently there are 14 members of the Family Advisory Committee – 10 parents and 4 clinical staff. The clinicians are the Clinical Social Worker as co-chairperson, a Pediatric Oncologist, a Pediatric Nurse and the Ambulatory Nurse Manager. 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 be able to consider issues beyond one's own child's 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 so as 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 a minimum of five times annually, with a schedule provided at the beginning of each year. Meetings are held on a work day evening from 6:30 - 8:30 PM. The day of the week is rotated to accommodate the varied schedules of parent members.
- 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 will notify one the co-chairs if unable to attend a meeting.
- Members are expected to participate in each meeting, 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 and Pediatric Oncology staff member will serve as Committee Co-Chairs.
- Parents will make a one year commitment to this role, with the option to continue for an additional year.
- Work collaboratively with the FAC to provide annual Committee goals and objectives.
- 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.

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- 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.

MassGeneral Hospital *for* Children's Cancer Center's Responsibilities

- Attend each FAC meeting.
- Communicate activities of the FAC to the Chief of Pediatric Hematology Oncology as well as the treatment team.
- Work collaboratively with the FAC to promote the best possible family centered practice.
- Ensure respectful collaboration in policy making, program planning and evaluation
- Review and respond to recommendations of the FAC in a timely manner.
- Provide free parking for FAC meetings.
- Provide suitable meeting space and dinner with each evening meeting.
- Offer new member orientation in collaboration with the MGH Volunteer Services program.
- Retain FAC minutes for a minimum of five years.
- Provide minutes and annual reports to the Hospital's governing body, as requested.

Amendments to the By-laws

- Committee members should request item added to the agenda.
- Revisions are sent out prior to the meeting, with discussion at the FAC meeting.
- The Committee will vote on the amendments and approve through a majority vote.

MGH Heart and Vascular Centers PFAC

established 2007



“Guided by the needs of our patients and their families...”

MGH Heart and Vascular Centers (HVC)

established 2007

Mission

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

The 2017-2018 quarterly meetings were devoted to these important topics:

- New Cardiology Programs/Recent innovations in patient care delivery
- Joint PFAC event: The Voice of MGH Patients and Families
- Transitions in Outpatient Cardiology
- Reviewing plans for new Electrophysiology Lab
- Massachusetts Nurse-Patient Assignment Limits Initiative

September 5, 2017

Sue McDermott NP, Lead NP and Rory Weiner MD Inpatient Medical Director presented a restructuring of the Cardiology Division at MGH with the goals to improve patient care, further research and education and community outreach. They introduced the concept of the Cardiology Service Model on Ellison 10 and 11 where there would be 2 dedicated Cardiologists covering the entire unit and would be present and available all day. They would communicate with the primary cardiologist and collaborate with nurses, NPs and residents. This would provide increased continuity over weekends, reduced length of stay and sub-specialty care with prompt consultations.

They acknowledged challenges such as maintaining continuity with primary cardiologists. Our members voiced concern about not seeing their primary cardiology but were reassured that primary cardiologists are expected to see patients in the hospital and be present/communicate major decisions.

At the time of this meeting, patients feel that they are at the center of the care plan and well communicated to and informed. They understand that this frees up cardiologists not on service to provide access to patients (new and existing) in the outpatient (ambulatory environment)

Sue McDermott gave an overview of the role of Cardiology Nurse Practitioners within the New Service Model

- All Cardiology Services have a team of Nurse Practitioners supporting them. (General Cardiology, Heart Failure, Interventional Cardiology and Electrophysiology)
- Nurse Practitioners will assist in managing your care while in the hospital.
- They will help expedite treatments, med changes and testing and provide continuity.

Emergency Room Response:

Sue informed the members that there is now a Nurse Practitioner rapid response system for patients in the emergency room who have been recently discharged (within 30 days) following heart attack, stent procedure, heart failure admission or Afib admission.

- Automatic notification once a patient registers in the ED.
- Rapid evaluation and assessment by NP and MD regarding admission or discharge.
- If a patient is discharged from the ED the NP will expedite an outpatient follow up appointment.

Members also supported the addition of RNs to each service across the Heart Center who can respond to calls from patients, families, and home care providers in a timely

fashion, assist in prescription refill process and clarify medications and patient education.

September 5, 2018

Ami B. Bhatt, MD, FACC, Director, Outpatient Cardiology and Susan McDermott, NP, Lead Cardiology NP presented on the changes and transitions in outpatient cardiology. Outpatient cardiology is now located on Yawkey 5. They are working to improve wait time for appointments, offer more convenient follow-up options and the overall patient experience. PFAC committee was asked to provide their opinion on “Skype visits”, allowing patients to telecommunicate for follow up appointments which would eliminate the need to visit the office for test results or routine follow up.

The committee was in favor of Skype visits. They also provided great feedback on how to best make patients aware of the availability of skype appointments. Examples: Simply asking patients if they have access to skype/have interest in a virtual appointment; post signs on the units; provide an option in Patient Gateway to select a virtual appointment.

Many committee members expressed the convenience and timeliness of Patient Gateway. The independence has provided patients with an alternative to hospital visits or direct doctor communication. They appreciate being able to book appointments online or submitting questions and receiving a phone call, email or text back with an answer from a physician or NP.

Sue McDermott NP spoke about the initiative to have follow up visits within 2 weeks of discharge to review medications and symptoms. The appointment will be arranged prior to discharge and the visit would be with the primary cardiologist or his/her NP. Members felt this was a positive change and felt fine about seeing an NP. They said that the provider being an NP or MD was not as important as knowing and trusting the provider and feeling known by them as well.

Urgent Visits were discussed as well. These would be available for patients who call the office with issues of symptoms requiring evaluation. There will be appointment availability for these patients to be seen by a Cardiology Nurse Practitioner within 24 hours of the phone call. And in the meantime, the NP would be able to adjust medications and/or order tests and arrange for ongoing evaluation if needed.

November 14, 2017

The Voice of MGH Patient and Family Advisory Council Members

This event was attended by all members of MGH PFACs with the focus on the sharing of patients' stories from different PFAC's. Michael Bider III from our Heart and Vascular Center PFAC told the compelling and sometimes humorous account of recognizing the symptoms (or not) of a heart attack and his journey to MGH from and outside hospital via a medical helicopter. From there, to the Cardiac Catheterization Lab for a procedure to open his artery to his recovery at MGH and home. He spoke about being a PFAC member and having the opportunity to share experiences and ensure that we include the voice of patients in the care we provide.

December 4, 2017

This meeting was our annual Holiday celebration. Marie Elena reviewed the Hospital Wide PFAC event with members and we thanked Michael Bider II for his excellent presentation. After over 13 years, Theresa Gallivan RN, Associate Chief Nurse announced that she was stepping down from her leadership role in the HVC PFAC. Sue Algeri, RN Associate Chief Nurse was introduced as a new leadership member.



March 6, 2018

Patrick Ellinor MD, Director of Cardiac Arrhythmia Service, Conor Barrett MD, Clinical Director, Sharon McKenna RN, Nursing Director, Cardiac Invasive Labs and William Cullen, MPA, Administrative Manager presented on the plans for the new Electrophysiology lab, expected start date of October 2018.

The reasons for the new lab:

- Patient capacity has outgrown the current lab
- Equipment is outdated
- Lack of patient privacy
- Old equipment makes integration of new technologies challenging
- Limited capacity for urgent procedures causing increased wait times

Committee members enjoyed seeing the new blueprints and plans and agreed with the need for a new lab, larger space and new equipment. A new lab will allow MGH to provide top service and continue growing with ever-changing procedures and equipment.

Additional recommendations from the PFAC Committee:

- The ability to leave the waiting area and be notified of changes (Cell phone, text message, pager)
- Additional seating added to the area around Blossom Café.
- A clear separation between the waiting area and the Admitting Department.
- TV/computer use while in the waiting room.

June 5, 2018

Tara Tehan RN, Nursing Director, Neuroscience ICU, Julie Cronin RN, Nurse Practice Specialist, Oncology and Jen Gil RN, Staff Nurse, Neuroscience ICU presented information regarding the Massachusetts Nurse-Patient Assignment Limits Initiative (November ballot question).

The Massachusetts Nurses Association is advancing a ballot initiative to mandate minimum nurse staffing levels in all units, at all times, in all hospitals, with no flexibility regardless of local circumstances. The initiative would increase hospital costs, impose mandated, “at-all-times ratios” between registered nurses and patients, require hospitals to comply with the ratios without reducing staffing levels of other non-RNs (other health care workers, service, maintenance, administrative, etc.), require implementation of a patient acuity system, and impose a \$25,000 per-violation, per-day fine on providers that do not comply. Ratios are costly, with no guarantee of improved quality, and run counter to reform where payment is tied to quality and patient satisfaction. Committee members asked many questions and had great feedback.

MGH Heart and Vascular Centers PFAC Members

Patient and Family

Michael C. Bider, III

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

Cindy Sprogis

MGH Heart Center and Vascular Center 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 HVC 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

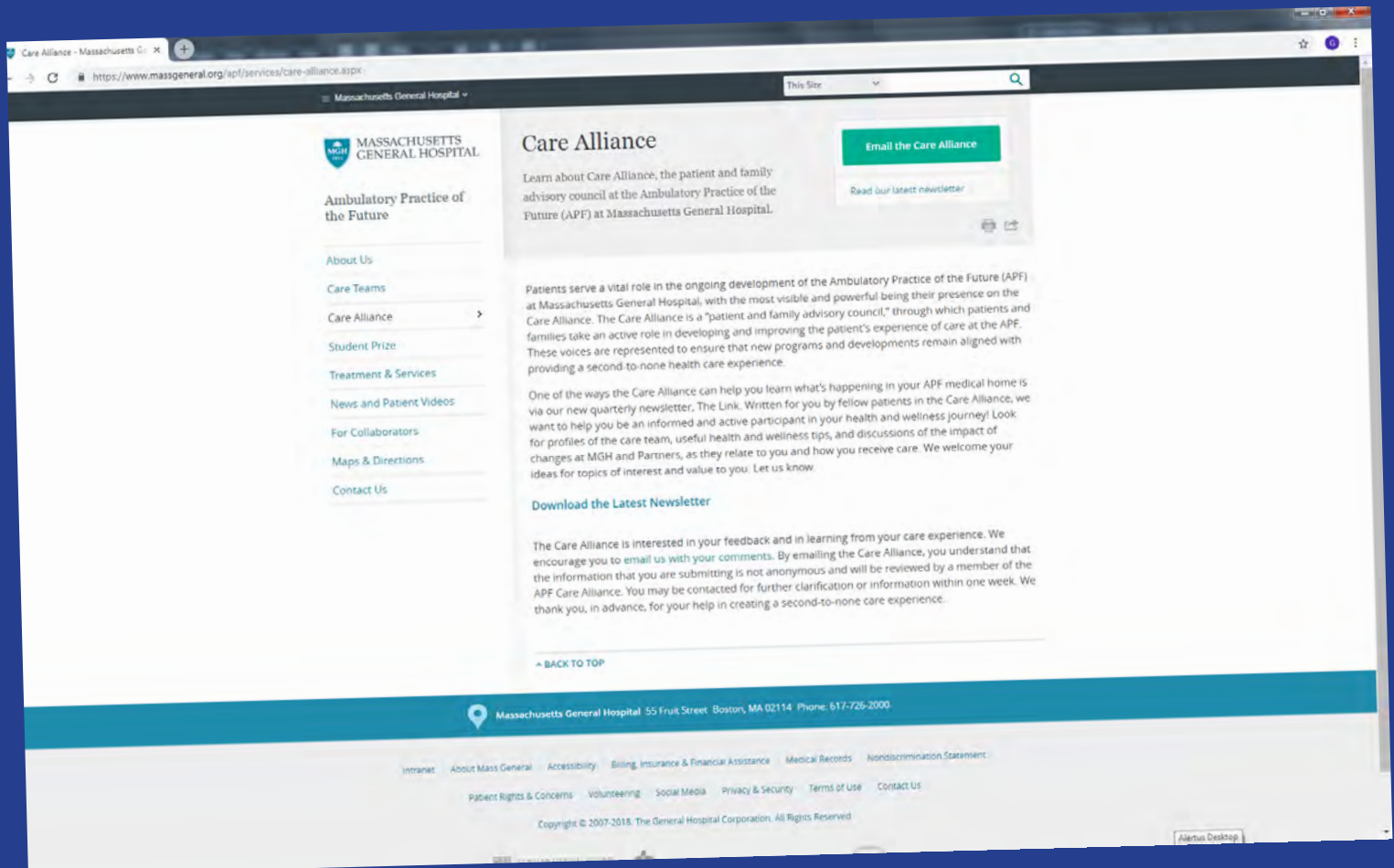
Members attend quarterly meetings with dinner

Location: MGH Trustees Boardroom

Time: 5:30 PM to 7:00 PM

APF Care Alliance

established 2010



“Guided by the needs of our patients and their families...”

APF CARE ALLIANCE

established 2010

BACKGROUND

The Ambulatory Practice of the Future (APF) delivers primary care services to Mass General employees and their adult dependents. The APF has proven to be an innovator and leader among practices, differentiating itself by delivering patient-centered care in a team-based setting.

The Care Alliance (CA) is the APF's Patient and Family Advisory Council. It is a partnership of patients, family members, and providers, which promotes the voice of the patient, innovation, and the optimization of the care experience for all. It was founded several months before the APF practice opened in August 2010, to guide it from the start.

The APF staff members value partnership and transparency with patients and each other. The APF feels so strongly about transparency that it has service-marked TransCAREncySM for use by the MGH community. This term means promoting transparency in all the ways that the APF cares for its patients. Patients are asking for more from their relationships with their care teams and for better access to the information created about their care (this ranges from providing them with their visit notes and other medical information, to easier-to-understand billing statements, to greater collaboration between ambulatory and inpatient care teams and care plans).

The practice partners with patients by offering electronic communication, unrestricted access to test results and visit notes, and continuous care, as well as health coaching to help patients better manage and achieve their health, life-balance, and wellness goals. The CA proactively partners with staff to ensure that

the care experience is rewarding for patients, patients' families, and staff, as well as to promote values that define the APF and support those values while the practice expands.

During the developmental phases of the practice, the APF relied on substantial patient- and family-member input for planning the practice and for creating the structure necessary for APF and the CA to support each other. As the practice grew initially, it called on the CA to help monitor implementation of the patient-centered model while generating and supporting opportunities to promote innovation. As demands and pressures on staff increased, patients on the CA worked more pro-actively, surveying patients about their care experience and circling back to them with survey results and the APF's reaction to their suggestions.

The need to communicate information to patients remains important as a way to help them become more engaged in their own health care. The CA assesses means of communicating with patients and has made progress toward utilizing new venues, including social media, to deliver information to APF patients and the Mass General community. We believe that keeping patients better informed about relevant clinical information, as well as practice- and hospital-based news, is vital, especially in anticipation of continued organizational change. Doing so will further APF's goals to offer care that is based on transparency and partnerships.

Communication is a two-way street. Hospital-wide surveys, like CG-CAHPS, are one way that patients provide feedback about their care experience. Delivered at the practice level, these scores reflect patient satisfaction about various functions and services, for example: wait times, physician knowledge of patient history, willingness to refer to others, receiving coordinated care, having access to care team, having enough time during an appointment to cover all their issues, feeling respected by clinicians and team members, ease of understanding physicians' explanations of conditions and treatments, etc. The practice takes the results of these surveys very seriously and works hard to improve care.

Since the practice opened, the CA has been an integral part of the APF. The CA is excited by the continued opportunities to work with an open, supportive, and caring staff to promote the innovative patient-centered model of care with APF patients and the larger Mass General community. We also believe our efforts play an important role in helping to manage the changes and challenges that are part of current health care.

Reflections on Eight Years of the Care Alliance

Pre-APF: Patients were members of the APF Development Team and served as strong advocates in the design of APF and its model of care years before APF opened its doors.

Years 0-2: The Care Alliance was founded in April 2010, several months before the APF opened. The name Care Alliance (as opposed to Patient and Family Advisory Council) was selected to reflect a partnership of providers with patients and families. The Care Alliance (CA) membership was established to be roughly equivalent in numbers of providers and patients/family members and to be chaired by patients. Patient members wrote the by-laws for the CA. It was understood from the outset that there would be a ramp-up period for the practice to add patients and convert concepts into operations. The CA provided valuable feedback to this process, with ample opportunity for patient and family members to add value to the transformation. The chairs of the Care Alliance attended staff meetings and managed CA meetings and their agendas. Attendance at staff meetings allowed the chairs to offer immediate input as operational concepts such as patient and staff scheduling were discussed.

Years 2-3: As the practice grew, development turned into fine-tuning. The budgetary and operational support for a practice exploring a new way of delivering care evolved to become the same as that for all primary care practices. With budget cuts and hiring restrictions, the pressure on providers and staff increased. The CA monitored available practice outcomes with staff. Staff also asked the CA to explore ways to assess and understand patient engagement and the patient experience at APF.

Years 3-4: In response to continued budget cuts, patient and family members of the Care Alliance took responsibility for projects like developing and executing APF patient feedback surveys, and promoting the use of the uniquely transparent patient portal, iHealthSpace. A former chair worked with practice leadership to explore opportunities for innovators and the APF to jointly test innovative technologies and procedures. As patient panels continued to grow, so also did pressure on a staff trying to maintain the values that differentiate APF from other primary care practices. As a result, staff has had far fewer resources to invest in CA projects.

Year 5: The CA remained mindful of the ever-changing nature of health care and the very real limits on everyone's time. The CA streamlined its meeting structure and simplified its role to focus on brief, important communications to the APF patient population. The importance of using multiple communication vehicles became evident, and social media was added as a way to provide an easily accessible communication link between staff and patients, to keep patients better informed about relevant clinical news, information, and changes at APF, as well as broader Mass General changes impacting APF (e.g., EPIC and MyChart).

Year 6: The CA reinvented its role in advocating for the excellence of the practice throughout Mass General and health care at large; built relationships and community between staff, patients and PFAC; and created innovative communication practices to better enhance APF's patients' experience and become an effective Voice of the Patient.

Year 7: The CA continued to evaluate its goals and role in communicating with patients, and is striving to implement a comprehensive menu of communication tools. We have also invited new CA members whose strengths in data, patient information, media, and more help us to find solutions to being a relevant voice to our patients.

Year 8: The CA progressed its mission as the bridge between the voice of the patient and the providers at the APF. We have included services the APF can provide for their patients in the quarterly newsletter while looking to expand the CA's membership to prepare for a new chapter in working with the APF.

As the year comes to a close, the practice continues to keep their doors open to new employee patients and their adult dependents. In a hospital system where many, if not most, primary care practices are closed to new patients, it's exciting that the APF has hired new clinicians and expanded access ranging from PCP to health coaches. This new capacity, which brings new staff, patients, and energy signals growth and opportunity for the practice, but is also a change from the tight-knit, intimate nature of the original team.

The healthcare environment continues to be challenging for primary care. The uniqueness of the APF does not prevent/protect it from the impact of time and income pressures—pressures that may be compounded given that the majority of our patients are dealing with them during their work hours, as employees. And while the APF is a practice committed, from inception, to team-based care and an extraordinary experience for patients, these commitments need constant attention and energy. As such, the practice and CA try to be protective of our commitment and temper the impact of pressures like reduced budgets, increasing patient panels, laborious medical record-keeping, and limited time resources.

The CA's vision during 2017 and 2018 was to expand reach out to the patients via new channels. With the addition of VidScripts and the continued newsletter, we have been looking to make the patient experience more personal and open. As we continue this expansion into uncharted patient outreach, we continue to look for new and exciting methods of delivery to help reach as many patients as possible.

In addition to its broad purpose of engaging patients, supporting staff, and contributing to practice outcomes, the CAs identified the following specific 2019 priorities, developed in response to staff, leadership, and Care Alliance member input:

- Continue the newsLetter with potential expansion into social media with the help of health coaches
- Construct a prospective piece of the care alliances in it's 8 years since inception and it's role in the APF
- Expand the Care Alliance team to add 2 new members

2019 GOALS

1. Build a strong, effective team to represent the voice of the patient and make an impact on patients and practice.
 - We have gone through preliminary interviews for potential candidates whose skills will differ from the current care alliance team allowing us to expand our ideas and creativity
 - We continued to encourage staff to recommend patients who are family members or workers here at the Hospital to allow for better schedule management of our meetings and have the maximum number of Care Alliance member present at each meeting
2. Introduce a patient newsletter
 - The LINK continues on a quarterly basis, being distributed through gateway every 3-4 months
 - Logistical barriers continued to limit full distribution to the APF's patients however feedback from staff and colleagues has been positive
 - We hope to expand content by adding in profiles of Care Alliance staff members
3. Assist in creation/administration of supplemental surveys to gather information on patients' care experiences
4. Create Vidscrips (short, single-topic videos about health conditions and treatments)
 - We have created multiple videos for the APF about which we are now awaiting metrics.
 - Videos have been posted, but there is not accurate way to determine length of view until recently, however we are still awaiting these results. Due to this, we have held on creating more content until we can better understand how this tool can assist the APF

APF CARE ALLIANCE MEMBERS

The CA leadership remains patient-driven. In 2018, CA leadership shifted with the promotion of Jarrett Maggio to join Julie Martin as a co-chair, as Paul O’Leary stepped down from his position. Robert Evans has been relinquished of his position on the Care Alliance. Bi-monthly meetings with CA meeting continued which allowed for more growth between meetings. Patient members facilitate meetings on a rotating basis and communicate between meetings to brainstorm and work on action plans. The CA continues to use Rapid Action Teams, when necessary, to deliver urgent, pragmatic, problem/opportunity focus that produce action-oriented results. CA members have an open invitation to attend weekly APF staff meetings to understand current staff concerns and provide additional patient perspectives. APF Leadership is active, supportive and easily accessible to CA members.

Patients

Jarrett Maggio (*Co-Chair*)
Julie Martin (*Co-Chair*)
Nancy Davis
Ann Erwin
Paul O’Leary

Staff

Adriana Mesa Balbin
Lakeya Bryant
MJ Byrnes
Tina Byrnes
Cindy Casilla
Ben Crocker
Terri Egan
Katie Engels
Emily Finn
Annie Helgason
Dan Henderson
Aaron Hoffman
Jessica Hu
Cassandra Laine
Jane Maffie-Lee
Stephen Lynch
Mary Anne Marshall
Lori Newman
Glenda Shuel
Milly Teixeira
Donna Winderl-Malyak

AMBULATORY PRACTICE OF THE FUTURE: CARE ALLIANCE BY-LAWS

Article I. Name

The name of the patient/provider advisory council of the Ambulatory Practice of the Future (APF) is the APF Care Alliance, sometimes also referred to as the Care Alliance. The APF Care Alliance is a self-governing entity of the Ambulatory Practice of the Future 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 Ambulatory Practice of the Future, 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 a proactive 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 Active Members (at least two-thirds patients) and serve on a volunteer basis. Each of the APF's three care teams, when operational, will be represented by up to four patient or family Active Members.

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 when their terms are up.

Active Members are expected to participate in all monthly 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 should attend each staff meeting. It is hoped, but not expected, that some patient or family Active Members will consider opportunities for involvement in special projects initiated by the APF or the APF Care Alliance. All Active Members must be in compliance with the requirements for Care Alliance participation and active volunteer status. Nonemployee 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. Emeritus Members must be in compliance with the requirements for Care Alliance participation and active volunteer status. The Founding Emeritus Member Winthrop M. Hodges is eligible to serve as Chair Emeritus for such period as he chooses to serve. Upon his resignation, an eligible successor may be nominated by a majority of the Care Alliance to serve for two years. Only one Chair Emeritus may serve concurrently.

Chair Emeritus Members may be re-nominated in the event no other eligible Member chooses to serve in that capacity. In the event the serving Chair Emeritus resigns before the end of their two-year term, the Care Alliance may at its discretion but is not required to nominate any Eligible Member to serve the remainder of the incumbent Member's term.

Staff Members: With the exception of the APF Director and Associate Director, 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. Co-Chairs

Section 1. Duties

The Care Alliance has two 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 one or both of the co-chairs is specifically requested.

Section 2. Nomination Procedure

Candidates for the Co-Chair position will be nominated by Care Alliance members and must have at least two years of experience as an Active Member.

Section 3. Election Procedure

A new Co-Chair will be elected every two years, requiring the affirmative vote of two thirds cast by Active and Staff voting members. The new Co-Chair will be announced during the December Care Alliance meeting.

Section 4. Term

The standard term for 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 the Co-Chair is elected, unless otherwise specified.

Section 5. Vacancies

A Co-Chair may resign from office at any time by submitting written notification to the Director of the APF and the other Co-Chair. 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.

Section 6. Termination

A 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 co-chair by a vote of two thirds of the Active 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 every two years 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 will attend their first Care Alliance meeting on the same date and will be oriented to the Care Alliance together. Every two years patient or family members will be offered the option to continue as an Active Member for another two years, become an Emeritus Member or resign from the Care Alliance.

Section 2. Application Process

An Active Member applicant may submit a membership application to the Care Alliance for review at any time. Nominations may be made by staff members or patient or family members and nominees will be interviewed by a minimum of one staff member, one Co-Chair, and one patient or family member, jointly or separately. Upon completing the application review and interviews, the interviewers will present the nominees at a Care Alliance meeting and a vote will decide whether an offer of membership should be extended to the applicant. A new Active Member's term of membership will commence at the next Care Alliance orientation meeting following his or her acceptance to 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. The member must submit a request, in writing, to the Co-Chairs, stating the reason for the request and the length of the leave. The Co-Chairs will determine if the request will be accepted. Members on an approved leave are required to contact the Care Alliance Co-Chair prior to the expiration date of granted leave, ensure volunteer status is current, and attend the first monthly meeting after the leave ends, or request a one-month extension. A position will be held for a member on leave of absence for three months or less. If a member cannot return at the end of the three-month period, plus the one month extension if granted, he or she will be asked to resign and wait for an open seat to become available when next again able to fulfill the service requirements.

Section 4. Resignation

An Active or Emeritus Member may resign from the Care Alliance by filing a letter of resignation with the 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 explanation will be considered to have resigned.

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 Active and Staff voting members via electronic vote. 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 each month at the APF practice, unless otherwise planned, presuming the presence of a quorum. 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 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

An official meeting will require the presence of a minimum of a Co-Chair, two patients and a minimum of four Staff Members to be called to order.

Section 4. Voting

Only Active and Staff Members may vote on official Care Alliance business when voting is required. All issues to be voted on shall be decided by a simple majority vote of those Care Alliance members present at the meeting. In addition, election or termination of Co-Chairs and approval of revisions to bylaws require a vote of Active 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 vote, all voting members will be asked to recast their votes. Three consecutive tie votes results in the motion being tabled indefinitely. A request for consensus of Active, Staff and Emeritus Members may be conducted to approve items such as annual goals, ending a meeting early, or scheduling a retreat. Consensus on these issues shall be decided by a two-thirds majority of

those Care Alliance members present at the meeting.

Article VIII. Confidentiality

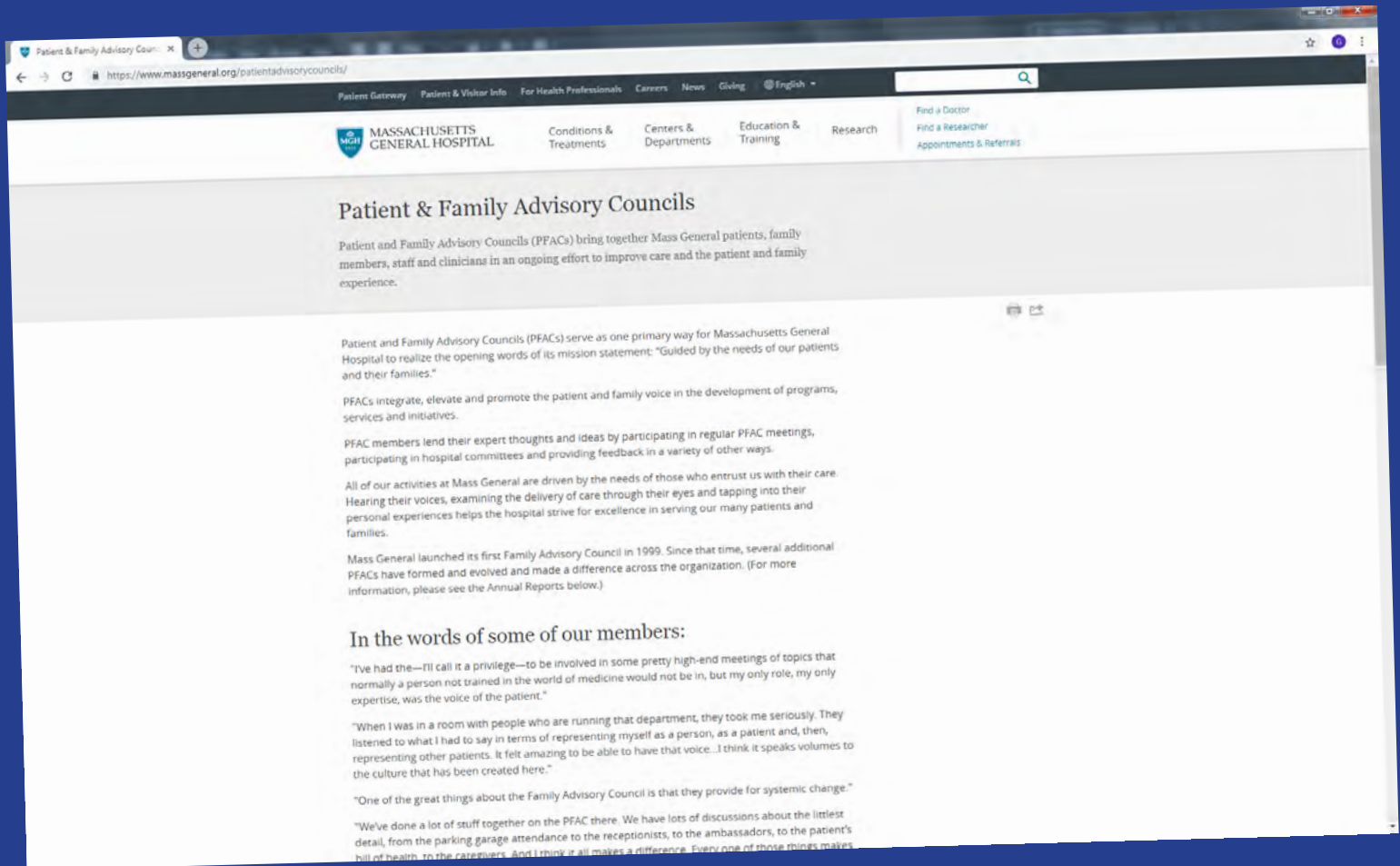
Care Alliance members must not discuss any personal or confidential information revealed during a council meeting or related project committee meetings. Care Alliance members must adhere to all applicable HIPPA standards and guidelines. Violations may result in repeated HIPPA training or a re-evaluation of membership status.

Article IX. Amendment Procedure

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

Adult Cystic Fibrosis PFAC

established 2012



"Guided by the needs of our patients and their families..."

Adult Cystic Fibrosis PFAC

established 2012

The MGH Adult Cystic Fibrosis PFAC was established with the purpose of serving as an advisory resource in conjunction with the center staff in order to enhance the quality, safety and experience of care for adults with cystic fibrosis.

Until recently, cystic fibrosis has been viewed primarily as a pediatric disease. Advances in research and new medications which have been developed in the past two decades have increased life expectancy and now half of all patients living with this genetic disease are over the age of 18. Because it is a life-long disease, patients have a unique and rich perspective to offer as members of the PFAC

The MGH Adult Cystic Fibrosis Center treats approximately 200 individuals. Patient members of the PFAC must be over 18 years of age, followed at the MGH center (or a family member of a patient) and are selected on the basis of communication/interpersonal skills, background experience, as well as problem solving and analytical ability.

In addition to patient members, the PFAC is comprised of up to 5 clinic staff and one representative from the MA/RI Chapter of the Cystic Fibrosis Foundation. In 2018 it was necessary to change the meeting day from the second Tuesday to the second Friday of each month to accommodate inclusion of a member of physician staff.

Accomplishments

1. Our PFAC provided input to clinic staff and Pulmonary Administration into the change in level of patient satisfaction with care after a clinic staffing decrease 2 years ago. Patients were experiencing unreturned phone calls, lack of

continuity between inpatient and home care and unacceptable length of time for prescription refills/prior authorizations after staff cuts. We met with administration several times to provide insight and outline the changes in quality of care.

2. The attending physician staff were included in meetings on an alternating basis to better involve all levels of clinic staff.
3. We assisted in developing plan to address issue of last minute cancellations/no-shows, which negatively impacts the clinic budget and ultimately patient care. Clinic staff sent out letters explaining the importance of ample notification for appointment cancellations/changes.
4. The PFAC continues to liaise with the MA/RI chapter of the Cystic Fibrosis Foundation to promote communication between clinic/foundation/patients in order to keep up to date with the latest research developments, local fundraising efforts and news.
5. We have assigned Facebook postings to members on a rotating basis with updated to keep patients engaged in clinic goings-on. Information from staff as well as patient-to-patient communication enhances patient engagement. This has been very helpful in terms of important information regarding drug recalls, clinic closures due to weather etc. Patients are able to communicate and offer suggestions and advice to common questions.
6. We set goals for the coming year which include working on survey to assess patient needs (parking assistance etc.), continuing to develop use of PFAC to improve patient care/experience, add Go-to-Meeting as communication option and improving communication with Administration of Pulmonary to provide dialog and feedback on staffing and patient care.
7. Provided budget for use of discretionary fund for PFAC to purchase supplies and a web camera for meetings. Educational materials for new patients/patients transitioned from the Pediatric CF Center are provided with positive feedback.

-
8. Due to additional MD staffing/clinic times, we have changed our meeting day/time to allow maximum staff participation, in keeping with our continued goal of receiving and providing feedback from all clinic staff.
 9. We have updated information and teaching sheets for patients (e.g., What to Expect During an Admission, PICC line placement) to better serve all aspects of CF care, both inpatient and outpatient.

Outcomes

1. A part-time Medical Assistant position created to alleviate some of the work burden of the clinic RN.
2. Our close relationship with CFF of MA/RI promoted good communication which has kept us up to date on fundraising efforts, new policies, NACFC news and up to date research. This is especially important as new drugs are being developed and become available.
3. Patients have been kept up to date on clinic matters and important news (i.e. drug recalls, Listeria outbreak) via Facebook, enabling patients to make informed decisions that impact their health.
4. Since our inclusion of clinic physicians, we have had better communication with entire clinic staff, which benefits both patients and physicians. Physician staff has expressed that they enjoy the interaction with the committee and are able to provide a perspective unique to their position to the committee.
5. Minutes distributed to absent members and Administration in order to keep everyone up to date, regardless of ability to attend or call in to meetings. This helps reduce time spent reviewing past meetings at the start of our meeting and makes the best use of our time together in addition to keeping the Pulmonary Administration in the loop of our clinic, since we are in an off-site building.

ADULT CYSTIC FIBROSIS PFAC MEMBERS

Patients

Kim Nunnari, Co-chair
Brian Armstrong
Sean McCarthy
Meg Kiley-Murray
Sheila Tines

Staff

Lindsay Bringhurst, RN
Abby Folger
Gretchen Garlow
Suze Avignon
Caitlin Miller
Isabel Neuringer
Christopher Richards
Leonard Sicilian

Adult Cystic Fibrosis PFAC Bylaws

Article 1- Name and Purpose

Section 1. Name

The name of this organization shall be the Patient and Family Advisory Council (PFAC) of the Adult CF Program at Massachusetts General Hospital.

Section 2. Purpose

The Patient and Family Advisory Council (PFAC), established in 2012, serves as an advisory resource committee in partnership with the MGH Adult CF Program. Its purpose is to provide a diversity of perspectives in matters relating to the provision of medical care to adult patients with cystic fibrosis in an effort to enhance quality, safety, experience of care and the value of clinical research.

Section 3. Major Goals

- A. To improve the quality of life for people with cystic fibrosis.
- B. To offer ideas and suggestions regarding policy and practice that affect patient-centered care.
- C. To review recommendations and concerns as identified by patients, caregivers, staff, physicians or administration
- D. To serve as an educational role, as needed or requested, regarding patient/caregiver perception of care and services.
- E. To assist in the planning of new services as requested by the MGH Adult CF Center clinical staff.
- F. To serve as advocates for the patients and caregivers in order to assist our center in becoming one that provides excellent clinical care.
- G. To use its best efforts to quantify the impact of the PFAC on the MGH Adult CF patient population.

Article 2- Membership

Section 1. Selection Criteria for Patients

- A. Membership will consist of adult patients and family members of adults with cystic fibrosis who are receiving CF care at MGH Adult CF Center who have voluntarily agreed to be a member.
- B. Members must be receiving care at the MGH Adult CF Program.
- C. The following are important factors that are considered when considering membership to PFAC participation:
 - Communication Skills
 - Interpersonal Skills
 - Background, Training and Experience
 - Problem Solving
 - Analytical Ability
- D. Minimum age for participation in the Adult CF PFAC is 18 years.

Section 2. Other members

- A. Membership will consist of up to five staff members from the MGH Adult CF Program.
- B. Membership will consist of one representative from the New England Chapter of the CF Foundation

Section 3. Terms of Service

- A. Members shall serve a 12-month term beginning September 1st of each year and may be re-invited to participate.
- B. Members joining the PFAC after September 1 shall complete their term on the following September 1st.

Section 4. Duties of Members

Regular attendance is vital to the purpose of the Board. Each member is strongly encouraged to participate in all PFAC meetings and any appointed Task Group

conference calls/emails. If any member cannot participate in a conference call, they are to communicate with board members for an update and review meeting minutes.

Article 3- Meeting Roles

Section 1. Roles

Leader, Recorder and Timekeeper. The role of facilitator will be filled by Adult CF Clinical Social Worker and Adult CF Nurse Coordinator.

Section 2. Selection

Volunteers for each role will be requested at the beginning of each meeting. All roles will be rotated among PFAC members at each meeting. Everyone will be invited to take a turn in each role.

Section 3. Duties and Responsibilities:

- A.** Leader- The leader shall preside during the meeting of the PFAC for which he/she has volunteered and shall have the authority to enforce the bylaws. The specific roles of leader are noted:
- Open the meeting
 - Review the agenda for revisions and time
 - Review roles and who is doing what (timekeeper, recorder, facilitator)
 - Move through the agenda one item at a time
 - Keep the team focused
 - Establish an appropriate pace
 - Facilitate discussions
 - Manage participation
 - Help the team use appropriate decision-making methods
 - Help the team evaluate the meeting
- B.** Recorder- The recorder is responsible for the minutes which shall include high level discussions, their results and next steps and a list of ideas for

the next meeting agenda. In addition, the following shall be incorporated into the minutes when appropriate:

- Improvement tools such as lists, tables, etc. to track meeting
- Lists of further steps for specific agenda items

C. Timekeeper- The timekeeper ensures adequate time allotments per agenda item. They shall:

- Move the team along by keeping track of time during the meetings
- Alert the team when the allotted time is half over
- Announce when 1 minute is left
- Announce when time is up and if needed reconsideration of the allotted time or revision of the agenda is needed

D. Facilitator- The facilitators (Adult CF Clinical Social Worker or Nurse Coordinator) shall ensure that each board member has a chance to participate in discussions. The facilitator also shall:

- Remind the leader and team when conversations are not consistent with the agenda
- Point out when members are not following ground rules
- Manage conflict and provide direct feedback to member participation.

E. At times, carrying out these roles may provide access to confidential information. In agreeing to participate on the PFAC, members also agree to keep such information within the confines of the group.

Section 4. Terms of Office

Each role will rotate from one meeting to the next, with the exception of the role of facilitators.

Article 4 - Task Groups

Section 1. Task Groups

The whole board may form specific and various Task Groups.

Section 2. Powers, Duties and Responsibilities

Powers, duties and responsibilities of the Task Group shall be assigned by the Board.

Section 3. Membership

Non-Board members may serve on Task Groups at the consent of the full Board.

Section 4. Authority

The authority of any Task Group is to advise the full Board on issues as assigned.

Article 5 - Orders of Business and Schedule of Meetings

Section 1. Meeting Schedule

- A. PFAC meetings shall be held on the 2nd Tuesday of each month from September to June. CF infection control practices will be followed. For this reason, one patient will be invited to attend each meeting in person, the other participants will participate by conference call. There shall be no meetings during the months of July or August. *Update 8/2018: Meeting schedule changed to the 2nd Friday of each month.*
- B. Participation will be by group meetings, conference calls or internet communication.
- C. A minimum of 2 patient members and 1 clinical staff member is required to conduct a meeting.
- D. The meeting shall last no longer than 90 minutes.

Section 2. Agenda Development

The PFAC members will develop meeting agendas at the end of the previous

meeting. Any member wishing to include an item on the agenda has the responsibility to draft and present the agenda items to the Council for approval and inclusion.

Section 3. Agenda Distribution

The agenda shall be published by the Adult CF Clinical staff and distributed to members via group email one week prior to the meeting.

Section 4. Meeting Records

The designated Recorder shall post the minutes of the PFAC meeting within one week after the meeting. All minutes and board correspondence shall be posted to the PFAC via group email.

Article 6 - Parliamentary Authority

Section 1. Guidelines of Authority

The PFAC is advisory in nature and will not have direct authority over policy, procedure or practice. Any authority will be given by the MGH Adult CF Program. The PFAC cannot enter into any agreements or bind MGH in any fashion. Any events organized or statements issued by the PFAC on behalf of MGH are done so with prior approval of MGH Administration in coordination with the MGH Adult CF Program staff.

Section 2. Establishing a Majority

For administrative decisions, such as recommendations to remove a member or changing the bylaws, a majority is established by a majority of all members of the Board. For other matters, a majority is established by a simple majority of all members present.

Section 3. Advising the Director

The Board shall vote on any issue requiring advice to the Director. Consensus is not required. The MGH Adult CF Program staff shall assist the board in communicating the Board's advice and presenting it to the Program Director.

Section 4. Minority Reports

On any issue resulting in advice to the MGH Adult CF Program Director, if there is not consensus among all members of the Board, minority members are encouraged to submit minority reports for the Director's consideration.

Article 7. Amendment Procedures

Section 1. Bylaw Changes

Any article of these bylaws may be added, deleted or amended by a majority vote of at least 2/3 of the membership of the Board and finalized when all Advisory Council members have been notified of proposed changes in writing.

Section 2. Effective Date

The bylaws of the Adult Advisory Board shall become effective as adopted by a two-thirds majority vote of the Board on June 12, 2012.



MASSACHUSETTS
GENERAL HOSPITAL

55 Fruit Street
Boston, MA 02114
(617) 726-2000
www.massgeneral.org