2015

MASSACHUSETTS GENERAL HOSPITAL

PFAC ANNUAL REPORT
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. In 2015, Mass General was ranked the number one hospital in the country by US News & World Report based on the quality of care, patient safety and reputation in 16 different specialties. In 2003, Mass General became the first hospital in Massachusetts to receive the highest honor for nursing excellence awarded by the American Nurses Credentialing Center: Magnet designation. In 2008 and 2012, the hospital was redesignated a Magnet hospital. Patients and families help to advance the hospital’s mission, sitting on many hospitalwide committees, such as Quality Oversight and the Mass General Council on Disabilities Awareness, and they play an active role in a multitude of care improvement efforts, from selecting the hospital’s information system to designing new buildings ... and more.

Mass General is a 999-bed academic medical center that offers sophisticated diagnostic and therapeutic care in virtually every specialty and subspecialty of medicine and surgery. The hospital’s five multidisciplinary care centers—known worldwide for innovations in cancer, digestive disorders, heart disease, transplantation and vascular medicine—unite specialists across the hospital to offer patients comprehensive, state-of-the-art medical care. 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.

In FY ’14, Mass General:

- Admitted more than 49,000 inpatients
- Handled nearly 805,000 outpatient visits
- Recorded more than 102,000 emergency room visits
- Delivered more than 3,900 babies

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 $760 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.”

Our 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 fourteen 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 Hospital PFAC
General Hospital PFAC

The MGH General Hospital PFAC was formed in 2011 to advance the patient experience and promote patient and family member involvement in all aspects of the operation of the hospital. The General Hospital PFAC has an enterprise-wide focus, looking at operations and services across the continuum from inpatient through to all outpatient services. The General Hospital PFAC also strives to help the hospital achieve its four key missions – patient care, education, research and community service and also supports the Mass General in meeting its strategic goals and initiatives.

The council is comprised of a dedicated group of patient and family members who have experienced many different aspects of care and services at Mass General and who volunteer their time to make that care even better with their expertise and input. Additionally, other key stakeholders from hospital staff also sit on the council. The council is co-chaired by a patient member and hospital administrator and meets monthly throughout the year.
Activities and Outcomes

- Led a recruitment effort that resulted in the identification and placement of over 50 new members to the hospital’s array of PFACs – the largest such effort ever conducted at Mass General.

- Created and implemented a uniform process for the orientation and onboarding of new PFAC members.

- Conducted outreach to key areas of the hospital to promote the creation of new PFAC’s. Interest is currently being pursued at the Charlestown Health Center, The Research Institute and in GI.

- Provided input into key elements of the Partners eCare system – especially in the development of patient facing aspects such as the new patient portal.

- Provided feedback into the naming and positioning of the new patient portal as it is rolled out.

- Met with and provided feedback on enhancements to the hospital’s interpreter services program.

- Met with and provided feedback to the MGH program to address the needs of patients with disabilities.

- Met with leaders of Telehealth program and provided feedback on the incorporation of technology in communications between the patient and physician, both from an individual and employer perspective.

- Provided guidance to the hospital’s strategy to reduce administrative burden on physicians – allowing them to devote more hours to direct patient care. Placed two members on the hospital task force that is guiding this work.

- Supported the participation of two patient advisors on the hospital’s Quality Oversight Committee and coordinated the recruitment and turnover of a new advisor to the committee.

- Provided feedback on a Partners-level research study to assess attitudes of patients and physicians on increased transparency of patient ratings and comments.

- Recruited and placed a patient advisor on the Partners system Patient Engagement Steering Committee.
• Facilitated regular meeting of the Chairpersons of all of Mass General’s PFAC’s and assisted with coordination of efforts across all groups.

• Sponsored an annual joint PFAC meeting of all of Mass General’s patient advisors with the hospital’s CEO to discuss major hospital priorities and initiatives.

• Presented on PFACs and PFAC development at the national Institute for Healthcare Improvement meeting in Orlando, FL in December of 2014.

• Presented at the Massachusetts state PFAC Conference in Worcester in April of 2015.

• Participated in an interview about PFAC’s with Kaiser Healthnews that was published widely across the US, including in USA Today.

• Provided feedback into education materials and programming for both patients and providers about post-acute levels of care to assist with better patient placement, more informed decision making and reduced length of stay.

• Formed and launched PFAC work groups addressing access to care, patient experience, behavioral health, PFAC integration into hospital operations and coordination of care.

• Informed and enhanced the hospital’s program to improve the patient experience and the ratings given by patients to the hospital about care.
# General PFAC Members

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<tr>
<th>Patient and Family</th>
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<tr>
<td>Kay Bander</td>
<td>Rick Evans (Co-Chair)</td>
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<td>Emily Bider</td>
<td>Robin Lipkis-Orlando</td>
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<td>Patrick Brannelly</td>
<td>Linda Kane</td>
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<td>Carrie Stamos</td>
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<td>David Wooster</td>
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General PFAC Bylaws

Article 1. Overview

The Mass General Patient Family Advisory Council (PFAC) will provide a formal communication vehicle for patients and families to take an active role in improving the patient experience at the Mass General. The council will focus on discovering what programs and practices represent the most successful patient and family experience within Mass General and will help to replicate and share those best practices across the entire community.

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 PFAC 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 the Mass General by collaborating with existing Patient Family Centered Councils and focus groups.

Section 2. Support: Staff and Mass General leadership in their patient –family centered activities and initiatives. Act as a sounding board for implementation of new programs and existing programs across the Mass General.

Sections 3. Participate: Provide patient/family member representation to committees and work groups including, but not limited to patient safety, quality improvement, facility design, service excellence, ethics and education.

Section 4. Identify: Identify existing best practices in patient- and family-centered care and explore ways to share and replicate those across the organization.

Section 5. Represent: Patient and family perspectives about the healthcare experience at the Mass General and make recommendations for improvement.

Section 6. Educate: Collaborate with Mass General staff to facilitate patient and family access to information. Influence and participate in Mass General staff orientation, patient/family education, discharge/transition planning.
Section 7. Evaluate: The role of Patient Family Advisory Councils in improving outcomes for patients and families.

Article 4. Structure and Membership

The PFAC will consist of 10-15 members representing the diversity of the Mass General community. Up to 8 Mass General staff members may also serve on the PFAC. The structure of the Council may change over time and patients themselves may lead the Council as appropriate.

Article 5. 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 providers and professional staff.

Section 1. Membership Recruitment: Sources of recruitment may also include Office of Patient Advocacy, Development Office, Volunteer Office, Blum Patient and Family Learning Center, Diversity Council, Community, and Office of the General Counsel.

Section 2. Membership Criteria: Members are selected based on the following criteria:

- Current experience as a patient or family member at Mass General
- 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
- Ability to participate in a consistent and agreed upon schedule of meetings and potential subcommittee efforts
- Commitment to serve for a two-year term with potential to renew or step down at the end of the term

Section 3. Membership Selection: Applications forms are sent to prospective members and, once selected, the applicant receives an acknowledgement letter from staff of the PFAC and a thank you letter is sent to the referring Mass General staff member.

Section 4. Terms of Appointment:

- Members of the PFAC select and grant two-year terms to council members
- Council members may request to be reappointed
- Resignation will be submitted in writing or via e-mail to the Mass General PFAC
- Vacancies may be filled during the year as needed
Article 6. Roles and Responsibilities

Section 1. Roles and Responsibilities for Patient /Family Members:
- Attend each PFAC meeting or notify a staff member in advance if unable to meet
- Engage thoughtfully and constructively around the issues and ideas discussed during each session
- Be proactive in driving improvement and bring creative ideas for change
- Be respectful of 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/Employee Members:
- Attend each PFAC meeting
- Prepare meeting agendas
- Identify, invite, vet and orient potential PFAC patient and family members
- Facilitate discussions and engage all members
- Provide a report back to the PFAC of progress on ongoing projects and any hospital changes of interest to the group
- Assist with operations behind the scenes (ie. book rooms)
- Minimize potential barriers to achieving established goals
- Be an advocate for the utility, spread, and patient engagement of PFACs.

Section 3. Roles and Responsibilities of Chair/Co-Chair:
- Attend each PFAC meeting
- Communicate activities of the PFAC to the leadership of Mass General
- Co-Chair will support duties of Chair in his/her absence

Article 7. Outputs of the PFAC
- The PFAC will provide regular updates to the Mass General leadership and annual progress reports to DPH
- The PFAC shall engage in a variety of information gathering activities such as open discussion with patients and family members, including focus groups, surveys, open forums.
- The PFAC may engage in educational and policy making forums
- The PFAC may serve as community liaisons, engaging other patients and families in various programs as necessary.
- Members of the PFAC may also serve on other committees as appropriate across the hospital system
Article 8. Orientation and Training

All selected patient and family applicants will receive orientation and training as to the mission and goals of the institution and the advisory council, as well as hospital regulatory and privacy issues. The Volunteer department will provide orientation.

Article 9. Confidentiality

PFAC members must not discuss any personal or confidential information revealed during a council meeting outside of these sessions. Council members must adhere to all applicable HIPPA standards and guidelines. If an advisor violates these guidelines, a staff member will remind them of the guidelines. Ongoing violations may result in repeating HIPPA training or reevaluation of membership status.

Article 10. PFAC Meetings

Meetings will be held monthly on a day and time that best meets the schedules of members. Each meeting will be 1 1/2 hours in length.

Section 1. Agenda: Meeting agenda will be set by the designated staff/employee member and distributed to the membership prior to each session.

Section 2. Meeting Minutes: The designated staff/employee will distribute the minutes in a timely manner to all PFAC staff and patient/family members. Council minutes will be retained for a minimum of 5 years.

Section 3. Attendance: It is expected that the members of the council will make every attempt to attend every session during their term. Teleconference call in is acceptable. Participation by every patient will provide the most effective meeting and make the most impact on the patient experience at Mass General. However, if a member is not able to make one or more sessions, notification to a staff member as soon as possible is expected in order to make any needed adjustments prior to the group meeting.

Section 4. Inclement Weather: Business meetings will be cancelled if the City of Boston declares a snow emergency and driving to and/or from the Boston areas becomes unsafe. Council members will be notified in a timely manner.

Article 11. Termination

The Chair and Co-Chair of the PFAC reserve the right to dismiss any member who is not compliant with the rule and bylaws.
Jane Maier was among a select group of patients invited in early 2012 to help Partners HealthCare, Massachusetts’ largest health system, pick its new electronic health record system — a critical investment of close to $700 million. The system, which is now being phased in, will help coordinate services and reshape how patients and doctors find and read medical information. The fact that Partners sought the perspective of patients highlights how hospitals increasingly care about what their customers think.

"It's such a great experience," Maier said. "They treat us as a member — a partner — in their review process."

Patient advisory councils, like the one Maier belongs to, often serve as sounding boards for hospital leaders — offering advice on a range of issues. Members are usually patients and relatives who had bad hospital experiences and want to change how things work, or who liked their stay and want to remain involved.
For Maier, it all started in 2009 when she had surgery at Brigham and Women's Faulkner Hospital, a Partners facility. Her husband wrote to the hospital's CEO, praising her experience. The couple was then invited to speak at a hospital leadership retreat, sharing with top executives both the good and the not-so-good, and Maier was recruited to serve on a new patient advisory panel.

This hunt for patient perspective, which is becoming more and more common, is fueled in part by the health law's quality-improvement provisions and other federal financial incentives, such as the link between Medicare payments and patient satisfaction scores. "It's a change in culture," said Jayne Hart Chambers, senior vice president for quality at the Federation of American Hospitals, which represents for-profit hospitals.

Data from 2013 suggested that 40% of hospitals had some kind of patient council, said Mary Minniti, a program and resource specialist at the Institute for Patient and Family Centered Care, a Maryland-based non-profit organization. Though councils appear to have become more common in the past few years, experts say it's too early to know whether they typically improve hospital practices.

"A lot of hospitals right now are very concerned because of the direction of [Medicare] payments," said Carol Cronin, executive director of the non-profit Informed Patient Institute, an advocacy group. "They're very concerned about patient experience and patient satisfaction."

But it's not just federal incentives. Patients have greater expectations as they shoulder larger shares of health care costs, said Richard Evans, chief experience officer at Massachusetts General Hospital, another Partners facility. This, he added, leads hospitals to focus on customer service.

Cronin, who has had a family member stay for an extended time in the hospital, volunteers on the patient advisory council at Johns Hopkins Hospital in Baltimore. She was struck, she said, by the "meaty" topics the group addresses. Hopkins' medical researchers have even pitched their projects to the council to find out what patients and families think are worthy of scientific investigation.

To have an impact, though, these groups can't operate in isolation.

Patient and family advisory councils are useful if they have the ear of hospital leaders, Minniti said. But the groups also have to be integrated into decision-making. Andy DeVries joined the first patient advisory council at Michigan's Spectrum Health about 10 years ago, after he was hospitalized with life-threatening injuries from a motorcycle accident.

"Initially, nobody knew who we were and we had to sell ourselves," said DeVries, who serves on one of Spectrum Health's 13 patient groups. Now, by contrast, his group offers input "anytime there's something new that involves patient or family care," adding that the panel of patient advisers has tackled issues ranging from beefing up the
facility's security to how the hospital should give patients billing information. He even has worked with the human resources department on what to look for when hiring doctors and nurses.

Such feedback led to marked increases in patient satisfaction scores, said Deborah Sprague, Spectrum Health's program manager for patient and family services. For instance, she said, a member of the orthopedics and neuroscience patient council noticed slow responses when he pushed the call button in his hospital room, a problem staff hadn't noticed. The council worked with hospital employees to speed up response times. After the fix, positive patient assessments of the hospital jumped.

Maier, from the Faulkner council, recalled a time when hospital executives asked for help with patient complaints regarding nighttime noise levels. Late-night talking by staff was keeping patients awake.

The group discussed potential nighttime "quiet times" and other strategies to minimize noise without keeping doctors from doing their jobs. Once changes were made, patient satisfaction scores went up, Maier said — and a council member noticed a definite improvement the next time he was a patient.

But even as the role of patient advisory committees grows, recruiting members continues to be a challenge. Finding people from diverse backgrounds with both inclination and time can be tricky, Cronin said. As a result, council members are often "middle-aged and older, white and English-speaking, and a lot of women," said Deb Wachenheim, health quality manager at the Massachusetts-based advocacy group Health Care For All.

For some hospitals and health systems, though, these panels are just the beginning. Massachusetts General puts patients on various policy-setting committees, and Faulkner has a non-voting patient board member.

"As we continue to evolve," Maier said, "the hospital looks to us more and more."

*Kaiser Health News is an editorially independent program of the Kaiser Family Foundation*
MGH Heart Center and Vascular Center PFAC
MGH Heart Center and Vascular Center PFAC

In order to highlight the unique strengths of the Corrigan Minehan Heart Center and Fireman Vascular Center individually, in February 2015, a change in the organizational framework of the core components of the Institute for Heart, Vascular and Stroke placed a greater emphasis on what each Center offers to patients. Accordingly, the Institute Patient and Family Advisory Council (PFAC) was renamed the Heart Center and Vascular Center (HVC) PFAC.

A key focus for 2014-15 has been to increase the visibility and utilization of the Heart Center and Vascular Center PFAC across the Corrigan Minehan Heart Center and Fireman Vascular Center and to strategize diversity of PFAC representatives.

Goals

- Represent patient and family voice and perspective in the implementation of new Heart Center and Vascular Center programs and initiatives and improvement of existing programs.
- Extend the reach of Heart Center and Vascular Center PFAC beyond monthly meetings including Patient Centered Outcomes Research Institute, Partners eCare, Quality and Safety Committee, etc.
- Participate in the review and revision of Patient Education materials and Care Redesign processes.
- Provide input and ongoing evaluation of Innovation Units and related initiatives.
- Influence and participate in the education of Staff, including Physicians, Nurses and Support Staff.
- Recruit new Council Members who will continue to represent the diverse interests and concerns of all patients across the Institute care continuum.

In terms of membership, we welcomed returning member Sara Strope, who recently relocated back to Boston from the West Coast and new members Charlie Conn, Matt Smith and Paul Simard, Jr. We thank the commitment and contributions made by exiting members Bob Brunelle, Marie Therese Daniels and Lin-Ti Chang, RN, Staff Specialist (member and key program supporter since inception of the Heart Center PFAC February 2007).
Activities and Outcomes

The Heart Center and Vascular Center PFAC has achieved several noteworthy outcomes. In addition, members participated in, and provided valuable input to an array of activities beyond those addressed in the standing monthly meetings including:

**ENHANCING PATIENT- AND FAMILY-CENTERED CARE**

- Dialogued with Mass General Patient Care Services Clinical Support Services Team (October 7, 2014).

  Patient Care Services Clinical Support Services Team provided an overview of the Operation Associate (OA) role and patient experience on inpatient units. Innovation initiatives with the use of technology for communication and responsiveness to patient needs were shared.

  **HC and VC PFAC Input and Recommendations:**

  - Introduce unit-specific OA and his/her role during inpatient admission and inform patients that the OA will be the voice they hear responding to them
  - Since the OA plays such a great role in patient satisfaction, add OA’s name to the white board, this would explain who was responding to their call
  - Notify patients when fire alarms are going to be tested, very stressful to be in a bed with alarms going off not knowing it it’s a true emergency situation
  - Inform patients of any construction going on near or on the unit

- Dialogued with Nursing Leaders of the Innovation Unit Journey: Bigelow 14 Vascular Surgery (August 5, 2014)

  S. Bouvier, RN, Nursing Director shared Bigelow 14, 27-bed Vascular Surgery Unit Phase 1 implementation of the Innovation Units by changing the way we deliver care with the following key interventions including Attending Registered Nurse (ARN), Hourly Safety Rounding, Quiet Hours, Multidisciplinary Rounds and Bedside Report.

  **HC and VC PFAC Input and Recommendations:**

  - Underscore the role of the ARN in assisting patients/families navigate their hospital stay and raising awareness of available resources and opportunities.
• Dialogue with Associate Chief Nurse on Hourly Rounds and Nurse Staffing Ratio (August 5, 2014)

K. Whitney, RN, Associate Chief Nurse, shared an overview of Mass General Hourly Rounding core components of 4 Ps (Presence, Personal Hygiene, Pain, Position). Tactics including Hourly Safety Rounding Magnet and overlay on inpatient White Boards, and Nurse Leader rounding and validation were discussed. Shared impact on patient care outcomes including decreased fall rates, pressures ulcers, patient call requests and fewer steps taken by nurses.

**HC and VC PFAC Input and Recommendations:**

• Hourly Rounding (HR) is very important since many patients may not wish to “bother” staff by using nurse call bells.
• Given more family members are working and unable to have a long or frequent visits, HR will be reassuring to family members that their love ones are being cared for.
• Recommendation to provide individualized messaging for HR, prompt patients the purpose of HR, enhance the visibility of the whiteboard for patients to view, educate family members of the whiteboard and HR and personalize the whiteboard.

• Revisited with My Health Check ✓ Team: 6-Month Follow Up (November 4, 2014)

**Heart Center and Vascular Center PFAC Input and Recommendations:**

• To include in the survey – if patient has a computer or other type of technology
• To include Apps recommended and approved by the Mass General to enhance success of this program.

• Dialogued with Drs. C. DiGiovanni and B. Lubberts on PFAC partnership and engagement to strengthen the PCORI Study: Evaluating Venous Thromboembolic Disease (VTED) in Patients Post Foot and Ankle Surgery (April 7, 2015)

**Heart Center and Vascular Center PFAC Input and Recommendations:**

When at a physician office visit, what are possible ways of letting patients feel that they are equal partners in making decisions about their treatment?

• Consider and understand alternatives. Give them a decision aid tool, e.g., consider a list of questions to guide patients.
• Time is an important factor in deciding what to choose
• Some people learn by reading, talking or hearing. (Let the patient choose type of modality)
Education material should be available for everyone and meet educational level (everyone should understand and the patient should make a choice in what kind of education material he or she would like to receive).

How do we deliver the outcomes to the patients? This is difficult. It should be sufficient for everyone. Knowing the patient is key.

Education should not only be provided during the visit with the clinician but beyond.

Provide patients with adequate time to make a good decision. For example, provide information about the decision for anticoagulant therapy before the surgery.

Give patient the permission to choose when possible.

Patient partners—how to keep them involved for 4 years?

Let them know how important they are. Give them recognition. Let them know that they help other patients.

Best way to communicate about randomization: (1) no treatment, (2) on aspirin or (3) on anticoagulant.

- Explain to potential study participants that benefit is currently unknown to Foot/Ankle Surgeons.
- When we have patients enrolled in the study, what is the best method of communication with them? Email? Phone calls?
- If there is a back and forth discussion anticipated, the telephone is always the best and most effective. However, for notifications, e-mails are more time efficient and a record is kept.
- I think the best method to communicate with people in the study is by phone call. It is always possible to leave a message and phone number to respond. I personally am not at a computer every day so e-mail is not the best way for me.

What are some ideas you might have to prevent loss of follow up for patients who have agreed to participate in the study?

- Assigning one person to follow up and giving that one person the responsibility to coordinate all activities and to follow up should be the most effective.
- Some ways to keep participants in the study over the long haul is to send them some ideas of what is happening with the research itself...what is being identified, are there articles that are not only appearing in medical journals but are available for them to read to understand the need for research.
- I think it's helpful if you give them some praise for being a partner and perhaps take a group picture for "Caring" periodically so they know they matter.

Do you think study participants are willing to have two additional visits (30 minutes per visit) in the hospital at 6 and 12 months, even if they did not have a VTED event or experienced adverse effects?
• I think any person who is involved in any study would certainly not mind coming back for second visits.
• If people are engaged in the partnership and feel good about the way things are going an extra visit or two does not seem unreasonable if you identify WHY the extra visits are needed. Most of the people in our PFAC are very supportive of these new ventures and many of us have benefited from the fact that we have had procedures that once were brand new ideas that needed to be tested before they became approved so I think we would come.

ENHANCING STAFF EDUCATION

• Guest Speaker and Participation in Institute Annual Nursing Conference “Complex Issues in Heart, Vascular and Stroke Patients” (October 29, 2014)

Heart Center and Vascular Center PFAC Member (D. Wooster) shared his patient experience on Amyloidosis Heart Failure: Heart and Stem Cell Transplant and Rehabilitation.

Staff feedback and identify specific changes in clinical practice:

• I am much more aware of the differing types of amyloid and should be better equipped to answer patients’ questions.
• I will be more supportive to our amyloid population in terms of helping to explain care trajectory.
• Patient witness was helpful in knowing that the personal touch is what really means something and is carried with the patient in addition to the medical care.
• David’s description of his experience will remain as a constant reminder of the patient perspective during long hospitalizations as well as the strong element of denial that patients might have. I enjoyed his talk and am so thankful that he was able to be here (both at the conference and alive) to tell his story.

ENHANCING PATIENT COMMUNICATION, SERVICE AND DEVELOPMENT


Reviewed draft templates: (1) How Can I Manage Stress?, (2) Preparing for an Exercise Tolerance Test, and (3) Prescription Pad for Your Health Education

Heart Center and Vascular Center PFAC Input and Recommendations:

• Have all patient education documents available in languages beyond English
• Edit title “Prescription Pad for Your Health Education” to “Information Pad to Help You Better Understand Your Health Conditions”
• Remove (#s) on “Prescription Pad for Your Health Education”; may be helpful for clinicians but too distracting for patients
Like “How can “I” Manage Stress?; use of “I” stress “You”
Consider including the Exercise Tolerance Test departmental phone # on the header instead of a general # at the footer
Parenthesis (Stress Test) aside “Exercise Tolerance Test” as known by many patients
Recommend documents to be available on the website
Consider any procedural information be available ahead of time or incorporate in patient visit workflow. For example, per physician recommendation, patient education can be given to patient at the front desk during scheduling process
Okay with abbreviated title on the upper left corner to utilize that space
Use the prescription pad with sub-headings categories for more detail information that personalized to patient needs

- Recommended Strategies for Heart Center and Vascular Center Community Outreach Initiatives (May 5, 2015)

**Heart Center and Vascular Center PFAC Input and Recommendations:**

- Facilitate “MGH TV” educational program for patient waiting for appointment.
- Reach out to Brian French, Director, The Maxwell & Eleanor Blum Patient and Family Learning Center, and Joan Quinlan, Executive Director, MGH Center for Community Health Improvement.
- Partner with AARP (American Association of Retired Persons).
- Reach out to Mass General Network Development and Munn Center nursing research program.

- Met with Annabaker Garber, Director of Patient Care Services Informatics, and recommended strategies to communicate Mass General transition to EPIC with patients and families (July 7, 2015)

What questions do PFAC members have about Epic?

- Is record available everywhere? – Care Everywhere = feature where you give permission for MD to pull record to other users.
- Confidentiality concerns – key driving factor of Epic is interoperability – keeping it standardized and safe. Balance = protection of information and allowing people to get to it; the right usage of it
- What is the MD point of view for communication? Previous to go live MD’s worried they would spend all time doing emails. Actually the asynchronous communication is more effective/efficient
- How will patients learn about record? Open Notes Movement – notes available for patient to read. Finding = strengthens relationship with the patient
How should we communicate the transition with patients and families?

- Phase 1 of communication: “This is coming: How will it affect me?” Common questions and answers
- Phase 2: Ramping up December – April. Letting patients know it’s coming as we get closer. Patient experience impact: a lot more people in the hallways, period of time when things will seem slower than usual
- Consider current patient gateway – can we differentiate types of messages and email notification.
- Ensure the right amount of email – not too many. Short video – patient visit and how it will change
- Where should we share this? Websites/TV boards in waiting rooms
- Importance of setting the stage of Quality and Safety – not ignoring our priority, but recognize how we may shift and experience delays during ramp up. Goal = enhance quality and safety checks. Patient will benefit from having all information in one place. Remove redundant messages.
- Language issues – multilingual patient education materials purchased
- What about patients that aren’t interested in looking/want MD to tell them everything? How do we reach these folks? Patient can assign a proxy to look at record/communication; printed visit summary report.

Heart Center and Vascular Center PFAC Input and Recommendations:

Make it clear to patients that electronic communication is not a requirement; phones still work!

STRENGTHENING AND ENHANCING AWARENESS OF MGH HEART CENTER AND VASCULAR CENTER PFAC

- Participation in Partners Marketing Patient Portal Design Survey (August 8, 2014)
  - Five HC and VC PFAC members (M. Bider III, T. Fryer, Sr. J. J. Sullivan, S. Geary and P. Geary completed the survey to guide and ensure the new Partners patient portal login page will be simple, clear, attractive and patient user friendly.
- Participation in 19th Annual Kenneth B. Schwartz Compassionate Healthcare Dinner (November 20, 2014)
  - D. Wooster and his wife, L. Wooster (former Institute PFAC Member) joined the Mass General Leaders to support the Schwartz Center’s mission of promoting compassionate caregiving, networking and raise funds for its programs.
• Featured in The Boston Globe “Shaping the Delivery of Care” (December 18, 2014)
  
  • Tom Fryer, 67, a retired financial services professional and a Mass. General patient, had his blood drawn for new Research Biobank while at the hospital for another appointment. Now Fryer is serving on a Partners advisory committee that recruits other patients. “It’s a longer-term effort,” he said. “You’re doing something that’s pretty neat, trying to develop a better world and a better life for our children.”

• Participated in Mass General Volunteer PFAC Orientation (January 20, 2015 & June 2, 2015)
  
  • Three HC and VC PFAC members attended Jan 20th Mass General Volunteer PFAC Orientation (S. Strope, M. Smith and C. Conn).

• Participation in celebration of Mass General Nurse Recognition Week “Understanding Biases Can Make You a Better Caregiver and Co-Worker” (May 5, 2015)
  
  • Three HC and VC PFAC members joined Mass General nurses in celebration of Mass General Nurse Recognition Week (S. Geary, P. Geary and Sr. J.J. Sullivan)
  
  • A personal note of appreciation for nurse’s dedicated service to us all. At Mass General, Jean Watson, RN, PhD, defined caring as “a quality that is based on human values and a concern for the well-being of others” and a caring occasion as “the moment when a nurse and another person come together in such a way that an occasion for human caring is created. Both, when aware that a caring occasion exists, are influenced by the choices and actions within the relationship, and it becomes transpersonal and the event of the moment expands the limits of openness and has the ability to expand human capabilities.” I have experienced this (Patient Member T. Quirk)

• Update in Heart, Vascular and Stroke Care in Women 2014” sponsored by the Institute HVS (May 3, 2014)
  
  • Three Heart Center & Vascular Center PFAC members (T. Fryer, S. Geary and Susan’s daughter Noelle) learned differences between men and women with cardiovascular disease, vascular disease and stroke.

• Participation in Health Care for All (HCFA) (May 12, 2015)
  
  • New member, M. Smith, attended HCFA Statewide PFACs conference: First 5 years and looking to the future.
• Survey Participations
  • Partner’s Marketing naming survey (November 2014)
  • Vidscrip feedback (November 10, 2014)
  • Naming of Patient Portal Survey for Partners Marketing (November 12, 2014)

• Participation in Other Activities
  • T. Fryer represents Community Advisory Panel for the Partners HealthCare Biobank in July 2014 to present
  • D. Wooster stepped down from the Quality Oversight Committee (January 2013 – 2015)
  • D. Wooster represents the Patient Portal Committee in July 2014 to present
  • Featured December 23, 2014, newspaper article, “Clinicians and patients agree: Partners eCare is all about better care”

Excerpt: from D. Wooster “The tools that will be available through the patient portal – the idea of giving my doctor information rather than just receiving lab results and information – is very exciting. It will allow patients to be better educated and access more health and wellness information, and it will allow me to take full advantage of this heart I’ve received.”

• Heart Center and Vascular Center PFAC endorsement Letter of Support of the PCORI Study: Evaluation Venous Thromboembolic Disease (VTED) in Patients Post Foot and Ankle Surgery (January 2015)
• Electronic input on Patient Education “Caring for Your Heart” (April 2015)
MGH Heart Center and Vascular Center PFAC Members

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<th>Patient and Family</th>
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<tr>
<td>Michael C. Bider III</td>
<td>Heidi Bas</td>
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<td>Bob Brunelle</td>
<td>Janet Caruso</td>
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<td>Charlie Conn</td>
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<td>Denise Mallen</td>
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<td>Paul Simard Jr.</td>
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<td>Sara Strope</td>
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<td>Sr. Jon Julie Sullivan</td>
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<td>David Wooster</td>
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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 the 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 one-year term to council members
- At the end of a one-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.
### Roles

#### MGH HVC
- MGH HVC Co-Directors, Program leadership and staff

#### MGH HVC PFAC Members
- Mass General staff
  - Mass General staff will be appointed by the MGH Heart Center CoDirectors 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

### Responsibilities

#### MGH HVC
- 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

#### 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

#### Mass General staff
- Communicate HVSC PFAC activities to the leadership of the executive committees of the MGH HVC
- Communicate with MGH HVC staff re council recruitment
• Review new council member 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 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 Patient and Family

• Complete Mass General volunteer program application and on-site orientation (which will occur at PFAC meeting for subsequent new members)
Attendance

Members attend monthly meetings on the first Tuesday of each month

- Location: Mass General Yawkey Center for Outpatient Care in Yawkey 2-220
- Time: 5:30 PM to 7:00 PM

Reappointment

MGH HVC PFAC Staff will remind Council Members for reappointment of members at the end of their term.
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 7 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 Associate Chief Nurse, Cancer Center Nursing Director, an Oncology Social Worker, two 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 Mass General, 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 Mass General 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 Mass General-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.
Activities and Outcomes

The PFAC has had many accomplishments over the past year. The following accomplishments represent areas that demonstrate the impact of the PFAC on the Cancer Center’s patient experience:

- **Advice and Feedback:** A major role of the PFAC is to serve in an advisory role to leadership and staff in an effort to continually improve the patient experience. During FY15, PFAC members provided guidance for many programs and initiatives including: Inpatient Nutrition Services, Psychiatric Oncology Teleconsult Program, Cancer Center Survivorship Conference, Peer Guide Program and many others.

- **Education:** A major role of the CC PFAC is to enhance education of patients and families, staff and faculty about the human experience of living with cancer. PFAC members participate in several “Meet the Patient” forums throughout the year with fellows, residents, support staff, and nurses as a way to educate faculty and staff about patient and family member needs and viewpoints. CC PFAC members also participate in the monthly staff Cancer Center orientation. These forums have been highly successful and provide a venue for faculty and staff to ask difficult questions about how patients and family members cope with a cancer diagnosis. The PFAC also participated in the annual Mass General PFAC meeting which includes all Mass General PFACs; this is a forum during which CC PFAC has the opportunity to network and share experiences with the other Mass General PFACs. PFAC is also extensively involved in the development of the annual Cancer Center Survivor’s Conference, including selection of speakers and panelists, and special guests. During FY2015, CC PFAC members helped the Survivorship Conferences facilitators brainstorm a list of interesting topics for the 2015 conference.

- **Quality and Safety:** PFAC members continue to play an active role in the quality and safety efforts of the Cancer Center. A PFAC member serves on the monthly Quality and Safety Committee. This committee reviews safety incidents and develops performance improvement initiatives to promote quality and safety. PFAC members also participate in quality rounds, a team based rounding process to educate and promote awareness about quality and safety. The Cancer Center was also asked to participate in the Mass General Quality and Safety Committee, which provides even greater perspective to our Council about quality and safety across the Mass General. During this year, PFAC members reviewed and gave input on a Cancer Center booklet created for patients that outlines guidelines for the safe handling of oral chemotherapy.

- **Virtual Visits:** The Breast Oncology Center launched a virtual visit pilot in early 2014. The virtual visit program allows the physicians and nurse practitioners to conduct select visits with patients from the patient’s home using a secure video connection from the patient’s computer or iPad. This saves the patients the expense and hassle of traveling to Mass General but still provides the opportunity to check in with their provider. The TeleHealth/Cancer Center team approached the CC PFAC for feedback on the program, their process for enrolling patients in the virtual visit program/getting patients ready for their visits, and the instructional materials they had drafted.
CC PFAC members had a lot of helpful feedback for the team on how to message this to patients and in which circumstances a virtual visit may be especially helpful.

- **Cancer Center iPad Program:** The Cancer Center will soon be piloting the use of iPads for the Breast Oncology and Lymphoma disease centers. A demo of the application was created for the CC PFAC to test. To operationalize this project, the FF PFAC suggested the best location to pilot would be in the multi-disciplinary clinic exam rooms, as patients will often spend much of their day waiting in these rooms and this will also offer better control of the iPad distribution. The CC PFAC was able to provide extensive feedback on the content of the app, making suggestions to include parking garage maps, information about accessing social workers, and to rephrase or remove information regarding cancer prevention.

- **Wellist:** Wellist is an online service that helps to connect cancer patients with the services they/their caregivers need by creating a “Wellistry” that is somewhat similar to a bridal registry but includes many services as well as items. Two members of the Wellist team joined a CC PFAC council meeting to demo the new product and brainstorm some ideas on how to enhance the product. CC PFAC members thought this was a great idea, and members offered numerous suggestions that have been incorporated into the product since this session.

- **Safe Handling Oral Chemotherapy Guidelines & Booklet:** The CC PFAC continually provides vital feedback on patient education materials and literature. In recent months, the Cancer Center Marketing and Communications team, in collaboration with the Cancer Center Quality and Safety Committee, has revised and improved the patient education surrounding the safe handling of oral chemotherapies. 20-30% of chemotherapies are administered at home even though these regimens are just as toxic as those administered in the hospital or an outpatient setting. From a quality and safety perspective, proper preparation and storage of these drugs at home is a large part of the cancer therapy itself. The CC PFAC offered advice from their personal experiences and contributed to the Safe Handling Booklet and provided additional ideas for patient education including short videos, revised discharge sheets and in-clinic demos.

- **Cancer Center Survivorship Program:** Dr. Jeffrey Peppercorn met with the CC PFAC to present information on the re-vamped Survivorship Program, and to seek feedback on the content and accessibility of the individual programs involved. Suggestions offered by the CC PFAC members surrounded the issue of accessibility and promotion of the program, requesting the implementation of an robust communications campaign to inform patients and families. The Survivorship Program will aim to act as an embedded clinic, partnering with programs in lifestyle medicine, specialized PCP care, the implementation of “Bridge Visits”, and more. Partnering with the CC PFAC, the Survivorship Program will plan to create and launch a communications campaign over the next year.

- **Support Staff Luncheon:** On June 17th, PFAC members met with support staff from the Cancer Center during the Annual Support Staff Luncheon. The luncheon serves as an opportunity to recognize the work of support staff as well as promote discussion between support staff and
patients to foster a mutual appreciation and friendly atmosphere in the Cancer Center. PFAC members and support staff exchanged emotional stories of their backgrounds and Cancer Center experiences, cultivating a greater understanding of the perspectives of one another. As the luncheon ended, it was evident that this exchange created an empowering environment in which support staff felt appreciated by patients, motivated to continue to provide exceptional service at the front-end, and that they, too, were making a difference in patient care. The PFAC members present at the luncheon were delighted to share their stories and left with a sense of gratitude for their support staff.

- Cancer Center Patient Experience Council: A few years ago, the Cancer Center launched its first Patient Experience Council. This is a multi-disciplinary committee including physicians, nursing, administration, communications, social work, CC PFAC representation, and Mass General’s Service Excellence Department. The goal of the committee is to provide a process for continual improvement of the patient experience. The council uses the Press Ganey survey as a way to understand the current state of patient satisfaction. Three subcommittees have been formed, including patient education, service expectations, and survey review. The council has published patient satisfaction targets and is launching a leadership/staff training program, service recovery program, and is facilitating enhanced patient education methods, including exploring new technologies.

- Cancer Center Space Planning Process & Mass General West: In 2012, the Cancer Center led a master space planning initiative and CC PFAC members provided input during a session with NBBJ, the architectural firm. During FY14, CC PFAC members continued to provide feedback to Cancer Center leadership and architectural firms pertaining to key Cancer Center space initiatives. In August 2013, Steffian Bradley Architects presented the draft of the space plans for MG West to PFAC and conducted a feedback session. CC PFAC’s feedback was considered and much of it was incorporated into the final designs. In May 2015, just two months before the opening of MG West, the MG West leadership team joined a council meeting to update members on the opening of MG West including the provider schedules, services available and the communication plan surrounding the opening of the center.

- Conferences: As part of its mission to educate others about the value and role of PFACs, members participated in several external forums. During FY2015, members participated in the following forums:
  - World Congress, Patient Engagement Summit: September 2014
  - Undergraduate Seminar at Harvard College: Fighting Cancer with the Mind, March 2015
  - Annual PFAC/Residents and Fellows Annual Meeting, April 2015
  - Massachusetts PFAC Conference: Celebrating the First Five Years and Looking to the Future, May 2015
  - Meet the Patients: A Conversation with Support Staff and Cancer Center Patients, June 2015
• **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 FY2015:
  
  • Cancer Center Quality Committee
  • Cancer Center Quality Rounds
  • Cancer Center Patient Experience Council
  • Cancer Center Patient Education and Communications Subcommittee
  • Cancer Center Illuminations Art Program
  • Cancer Center Network for Patients and Families
  • Friends of the Massachusetts General Hospital Cancer Center
  • Mass General Patient and Family Advisory Council
  • Mass General Quality Committee
  • The Professional Friends of the MGH Cancer Center

**Looking Forward**

As FY16 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.
# MGH Cancer Center Members

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<th>Patient and Family</th>
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<tr>
<td>Laura Allen</td>
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<td>Katherine Baker</td>
<td>Mara Bloom (Co-Chair)</td>
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<td>Ann Buckley</td>
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<td>Eric Buckley</td>
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<td>Bill Starratt</td>
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1) Mission Statement and Purpose

Mission Statement

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

Purpose

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

2) Membership

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

Qualifications

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

Selection

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

- Completion of an application form created specifically for the Cancer Center PFAC.
- PFAC staff leadership reviews membership applications, evaluates candidates based on the above qualifications, interviews each candidate via telephone or, preferably, in person and makes final membership selections.
The recruitment process takes place every two years and can be initiated in the interim as needed.

Terms

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

Alumni Members

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

Officers/Chairs

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

3) Orientation

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

4) Roles

PFAC members advise on a range of Cancer Center initiatives that impact patient care. In addition to the monthly PFAC meetings, PFAC members may serve on Mass General or Cancer Center committees or PFAC subcommittees formed to accomplish PFAC goals.

Key areas of focus for PFAC members include: operational improvement, patient education and communication, review of patient satisfaction and quality efforts, and program planning. Members are also invited to serve in an educational and advisory capacity annually via scheduled meetings with the oncology fellows, Cancer Center support staff and nursing staff. Participation in subcommittees is encouraged but not mandatory.

5) Responsibilities

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

6) Logistics

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

The Pediatric Oncology Family Advisory Committee (FAC) has been a long standing, active group since 2003. Parents of children receiving cancer treatment and parents of those children who had completed treatment were joined by a multidisciplinary team of clinical professionals to collaborate with the common goal of providing excellence in pediatric oncology care.

In January 2014, the Pediatric Oncology Family Advisory Committee began the work of integrating with the other Advisory Committees within MGH. The Pediatric Oncology FAC formalized its mission statement and created bylaws. It developed new goals and plans for the upcoming year. It clarified the requirements of membership, and reviewed its current membership, setting in motion plans to expand its current group. This process proved inspiring to the Committee. Defining their mission provided the FAC focus and definition, and reaffirmed the value of the work of the Committee.

Objectives

1. Build a consistent and committed membership
   - Initiate a vigorous recruitment process, including promoting diversity amongst members
   - Develop an orientation program for all members joining the Committee
   - Increase awareness of the value of the 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

2. Collaborate with other PFAC’s and integrate into the already establish infrastructure of Advisory Groups at MGH
   - Co-chairperson (MGH staff member) will attend Chairpersons Council
   - Advisory Committee members will have opportunities to participate in professional conferences within the region for education and collaboration

3. Document initiatives and successes to organizational leadership
   - Provide periodic reports to practice leadership
   - Compile a yearly report detailing annual activities
   - Identify opportunities for collecting additional data for evaluation and action

The Pediatric Oncology FAC holds quarterly meetings with additional meetings scheduled when the group or a subgroup is working on a particular project. There is a clear understanding of the competing demands of families when a child has cancer—family, other children, work and of course, treatment, all impact the ability of any member to actively engage in the Advisory Committee.
Specific activities and issues throughout the 2014-2015 year included:

- Tracking of Patient Experience Data and input offered by the Committee around clinical improvements
- Issues related to caring for pediatric patients in the Emergency Department. Specifically, problems with port-a-cath access due to there not being specific pediatric nurses in the MGH ED. Training program initiated with the ED physicians and further discussion between nursing administration about improving the competencies of the ED nurses in this arena.
- In an effort to involve the chief of Pediatric Oncology more directly with the Committee, Howard Weinstein, MD, attended the fall Board Meeting in September 2014 to provide practice updates and begin an ongoing dialogue with the FAC.
- Developed a questionnaire distributed to Adolescent and Young Adult patients to assess educational needs around diagnosis and treatment planning. This study is ongoing at this time as we continue to collect data.
- In an effort to involve the chief of Pediatric Oncology more directly with the Committee, Howard Weinstein, MD, attended the fall Board Meeting in September 2014 to provide practice updates and begin an ongoing dialogue with the FAC.
- Initiation of a Parent to Parent support program for newly diagnosed pediatric oncology parents. Program named MGH POPS (Parents offering parents support). A subcommittee of members with the staff Co-Chairperson had conference calls with other well established programs to guide us in our development. Recruitment and training of volunteers will begin late fall/early winter.
- Family Advisory Committee members provided guidance about the development of psychosocial care programs for patients and families throughout the year. Elyse Levin-Russman, LICSW, OSW-C, Co-Chairperson of this Committee, presented at the Association of Pediatric Oncology Social Workers annual conference in Whitefish, Montana in May 2015 on “Developing and Sustaining a Family Advisory Committee in Pediatric Oncology”. Members of the Committee participated in the seminar through video interviews embedded in the power point presentation.
Pediatric Oncology FAC Members

**Parents**

Joseph Barnes (Co-Chair)
Nancy Barnes
Mary Cincotta
Patricia Flaherty
Kim Kayajan
Agatha McEachern
Michelle McKiernan
Dawn Regan
Garry Waldeck

**Staff**

Mary Huang, MD
Heidi Jupp, RN
Elyse Levin-Russman, LICSW, OSW-C (Co-Chair)
Ellen Silvius, RN, BSN
Pediatric Oncology FAC By-Laws

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

Mission Statement
Massachusetts General Hospital for Children’s Cancer Center Family Advisory Committee (FAC) is committed to fostering a partnership between families and caregivers to promote excellence in the care of children with cancer.

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

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

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

Membership Qualifications

- There will be an open enrollment process for participation in the Family Advisory Committee. Parents who are interested in joining should speak with the Clinical Social Worker who can provide information about the Committee. Additionally, parents can be recommended by staff for participation. In those cases, the Clinical Social Worker will contact the identified family member to discuss membership in the FAC. Information about the Committee will remain available in the Pediatric Oncology waiting area.
- Parents should have a child currently in treatment or be followed in the Pediatric Oncology practice for ongoing follow up care.
- Individuals participating should possess the ability to represent the perspective of the patients and family members and be able to consider issues beyond one’s own cancer experience.
- Ability to work collaboratively amongst a team of parents and clinical staff members.
- Ability to make a time commitment for meetings and special projects, as they arise.
- Represent diverse perspectives and backgrounds 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 quarterly, with a schedule provided at the beginning of each year.
- Additional meetings, either in person or via conference calls, may be added to address special projects or input from the Committee that needs to be obtained before the next scheduled meeting.
- Members are expected to participate in the quarterly meetings, and make a reasonable attempt to participate in meetings outside the quarterly schedule.
- Participate in MGH Pediatric Oncology community programs such as Fall for the Arts and Winterfest to provide a presence for the Committee and serve as a point of contact for other parents.
- Members will maintain patient confidentiality according HIPPA guidelines at all times.
Co-Chairpersons Responsibilities

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

MassGeneral Hospital for Children’s Cancer Center’s Responsibilities

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

Amendments to the By-laws

- Committee members should request the 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.
MassGeneral Hospital for Children FAC
MassGeneral Hospital for Children FAC

Mission Statement
The MassGeneral Hospital for Children's Family Advisory Council (FAC) is dedicated to fostering the partnership of parents, children, and professionals working together to ensure a climate of responsiveness to the needs of children and their families in all areas of care delivery within Massachusetts General Hospital.
Accomplishments and Outcomes

- **Round table discussion with 20 ambulatory nurses.** 5 FAC parents participated in a discussion centered on the topic of wait times. Feedback from parents was that it was helpful to understand factors that contribute to long wait times. Staff noted that they will institute new policies to mitigate wait times.

- **Discussion with Medical Director of the Child Protection Team at MGHfC** who presented a talk about the role of her team in caring for children, answered questions from parents and staff, and received feedback from parents about their experiences of care at the hospital.

- **Head of Quality and Safety at MGHfC presented to FAC** about hospital’s efforts in this area and explained the hospital’s efforts to improve the patient experience. Parents articulated their priorities in this area.

- **Patient Experience efforts.** Brenda Miller, Nursing Director of the Pediatric Wards, presented to the FAC on the topic of the patient experience on Ellison 17 and 18, soliciting their feedback on issues such as food service and discharge planning.

- **Staff Helpfulness Trainings designed to improve MGHfC’s CGCHAP scores.** 3 FAC parents co-facilitated 3 separate staff helpfulness trainings that had been developed by the Mass General Service Excellence Department. These parents presented a talk about the meaning of helpfulness and courteousness, their experiences with helpful and courteous staff and participated in a role play in which staff simulated difficult clinical scenarios with patients. Survey results from staff indicate that parent participation was overwhelmingly approved.

- **New intern orientation.** 4 FAC parents spoke at an orientation on bedside rounding. These parents shared their experience with bedside rounding with their children, explained to interns why it is important to them to have questions answered on rounds.

- **Provided feedback on patient Facesheets.** Staff from Mass General Service Excellence Department attended a FAC meeting and shared ‘patient facesheets,’ documents that include photographs and descriptions of staff who take care of patients on the wards. This material is given to patients so they can easily identify staff who are caring for them. FAC parents provided feedback.

- **National Patient Safety Week.** One FAC parent participated in a Mass General-wide event for National Patient Safety Week. The theme was Speak Up for Safety and focused on communication to ensure patient safety. The title of the presentation was “Overcoming Barriers to Effective Communication.”

- **MGHfC Medical Home initiative.** As part of a process to have MGHfC primary care certified as a medical home, 2 members of the MGHfC Medical Home Initiative spoke at FAC and solicited parent feedback about what they like and would like to change about their primary care offices.

- **FAC hosted an ice cream social** on the Pediatric Wards in order to raise awareness among staff, parents and patients and provide them with an opportunity to connect and engage with one another.

- **The FAC hosted a tea and cupcake event** in the Pediatric NICU and the PICU in order to raise awareness and to provide an opportunity for respite and relaxation to parents and staff there. The theme was “Welcome Spring.” The event was well-attended by staff and parents.
• **Animated Video for Children Waiting in the Emergency Department.** One FAC parent and one FAC Co-Chair formed a committee in order to develop patient material for children who are waiting to be seen in the Emergency Department. The material will take the form of an animated video in which a fictional patient takes patients on a tour of MGHfC. A summer intern has been hired to make the video and a pediatric patient is consulting on the project.

• **FAC had a yearly goal-setting session.** Their goals are: develop a parent-to-parent network; continue developing patient and staff education materials; develop a relationship with the office of Patient Advocacy; make outreach to the MGHfC Health Centers for new FAC members; mentor other PFACs; have more parents on hospital committees; identify our top priorities; develop case scenarios.

• **Institute for Patient and Family Centered Care’s (IPFCC) Training in Cambridge in November, 2014 3 members.** 2 parents and 1 FAC Co-Chair attended this event. They were part of a team that consisted of a PICU nurse, a hospitalist, and a resident, for a total of 6 MGHfC participants. Our main goal coming out of the training was to align FAC efforts with MGHfC’s Patient Experience and Quality and Safety efforts.

• **NICU Peer To Peer Support.** One FAC parent and one FAC Co-Chair met on a regular basis throughout the year with a NICU team that included a social worker, a nurse, Nursing Director of NICU and Clinical Director of Social Work. This team developed a program in which a former NICU parent will co-facilitate bi-weekly support groups that currently take place in the NICU that are facilitated by a social worker and a nurse. Developed an orientation package for parent facilitators. Program is now underway.

• **Family-Centered Grand Rounds.** FAC developed and hosted a Family-Centered Grand Rounds titled, “There is No Us and Them: Staff Reflect on their Experiences of Having a Child Cared for at MGHfC” in which two physicians and one Nursing Director shared their insights and answered questions.

• **Committee Memberships:**
  - FAC parent members joined the following hospital committees:
    - MGH Quality Oversight Committee
    - MGHfC In-Patient Experience Committee
    - MGHfC Out-Patient Experience Committee
    - State of Massachusetts Health Care for All PFAC
    - Committee formed to consider use of equipment in the Neonatal Intensive Care Unit allowing parents who are at home to view their babies while they are in the hospital
    - MGHfC Discharge Committee
    - FAC parents continued to serve on the following committees:
      - Pediatric Ethics Committee
      - MGHfC Advisory Board
      - MGHfC Quality and Safety

• **Holiday Toy Store.** 5 FAC parents and several staff participated in a holiday ‘toy store’ event at MGHfC in which they wrapped presents for children who were in the hospital during the winter holidays.
• FAC parent Co-Chair presented a talk to FAC about an MGHfC event in which she and her daughter participated that brought families of children who had had kidney transplants together for information sharing.

• Several FAC parents participated in an Mass General Volunteer Orientation in which they became formal Mass General Volunteers and received volunteer badges.

• Several FAC parents attended MGHfC Education Day, an event in which MGHfC Faculty lectured on topics such as Pediatric Allergies, Pediatric Sports Injuries, and Pediatric GI issues.

• FAC Co-Chair met with MGHfC’s Medical Director of Quality and Safety in order to develop a list of ways FAC parents could participate in the hospital’s Quality and Safety and Patient Experience efforts.

• FAC parent to introduce Peter Slavin at event. FAC parent members was chosen to welcome the audience and introduce Peter Slavin as he presents the Mass General Strategic Plan to the Mass General Joint PFAC dinner which consists of members of PFACs across the Mass General campus.

• Mentoring other PFACs. Sandra Clancy (FAC Co-Chair) and Rick Evans (Mass General PFAC Co-Chair) spoke with members of the Mayo Clinic PFAC in order to share our hospital’s best practices.

• Hospital Tours. FAC members received a tour of the new Ellison 18 playroom and the new Pediatric Emergency Department.

• Member Survey. 3 members of the FAC devised a survey for members to elicit feedback about meeting times, length of meetings, and members’ overall satisfaction with their experience. Members decided to trial shortening the length of monthly meetings from 2 to 1.5 hours. On a scale of 1 to 5, members rated their experience on FAC as 4.6.

• Presentation at Institute of Patient and Family-Centered Care Conference. The two FAC co-chairs, a parent and a staff member developed an abstract to give a presentation to the International Meeting of the Institute for Patient- and Family-Centered Care in July 2016 in New York City.
MassGeneral Hospital for Children
FAC Members

<table>
<thead>
<tr>
<th>Parents</th>
<th>Staff</th>
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<tbody>
<tr>
<td>Seta Atamian</td>
<td>Sharon Badgett-Lichten</td>
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<td>Debby Cartisser</td>
<td>Anne Bouchard Pizzano</td>
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<td>Lisa Cimino (Co-Chair)</td>
<td>Debra Burke</td>
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<td>Darcy Daniels</td>
<td>Monic Chardin</td>
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<td>Beth Garneau</td>
<td>Sandra Clancy (Co-Chair)</td>
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<td>Randi Goldman</td>
<td>Sandra Dodge McGee</td>
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<td>Jan Lanosa</td>
<td>Peter Greenspan</td>
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<td>Eve Megargel</td>
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<td>Janice Morris</td>
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<td>Erin Quinney</td>
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<td>Meagan Taylor</td>
<td>Peggy Settle</td>
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<td>Alexandra Sobran</td>
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Charter/By-laws

1. **Mission Statement:**
The MassGeneral Hospital for Children's Family Advisory Council (FAC) is dedicated to fostering the partnership of parents, children, and professionals working together to ensure a climate of responsiveness to the needs of children and their families in all areas of care delivery within Massachusetts General Hospital.

2. **Purpose:**
   2.1. Work together with the administration and staff of MassGeneral Hospital for Children (MGH/C) to promote Family-Centered Care;
   2.2. Collaborate with the MGH/C staff in improving the quality of health care provided to children and their families in both inpatient and outpatient settings;
   2.3. Improve patient, family and staff satisfaction;
   2.4. Ensure an attractive environment that is responsive to the needs of children and their families;
   2.5. Act as an advisory resource to MGH/C leadership on issues of planning, evaluation of programs and services, policies and new facilities;
   2.6. Act as an advisory resource to MGH/C giving input to teaching documents generated by the hospital regarding families;
   2.7. Promote a positive relationship between MGH/C and the community; and serve as a vital link between community at large;
   2.8. Contribute to the educational process of new professionals as positive resources and teachers contributing to the mission of the MGH/C.

3. **Membership Committee:**
   3.1. Members of the Membership Committee will be appointed by the MGH/C Associate Chief, Department of Pediatrics;
   3.2. The Membership Committee will consist of three current FAC members and two MGH/C Council members;
   3.3. Members of the Membership Committee will track membership terms and actively recruit new members.

4. **Membership:**
   4.1. Membership is by application to the Membership Committee;
   4.2. Membership consists of fifteen people whose children have received care at MGH/C or are patients sixteen years or older who have received care at MGH/C;
   4.3. Family members will serve as the Council Co-Chairs;
   4.4. The MGH/C’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 MGH/C Inpatient Director of Quality and Safety will be allowed to vote in times where a tie-breaking vote is required.
   4.6. The MGH/C will have four rotating staff members of the Council;
4.7. Other MGHfC staff will attend meetings as needed and receive meeting minutes approved by the Council to have knowledge regarding the agenda and on-going work.

5. Membership Terms:
5.1. Each year in September, the Council will seek to appoint three family members to serve a three-year term to the Council;
(Beginning with the Council in 2007, the 9 appointed family members will be appointed to one, two, and three year terms, the same with the 3 MGHfC staff);
5.2. Members can re-apply for appointment for up to six years. After this time, members can still be active on committees but must wait three years before reapplication to be a member of the Council;
5.3. Membership will elect in March a Council Co-Chair for a two-year term with co-chair election to follow six months later.
5.4. Any Council member that misses four consecutive meetings will be considered an inactive member unless the absence has been approved by the Membership Committee;
5.5. If a Council member cannot fulfill his/her commitment to the Council, they can resign in writing and a new member will be chosen to serve the balance of his/her term.

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. Agree to attend the Volunteer Program Initiation and Training as well as participate in the Volunteer Program;
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 in September;
7.2. Complete an annual progress report to be submitted in January to the Chief of Service, Department of Pediatrics, Chief of Pediatric Surgery, Vice-President of Pediatrics, MGH, Vice-President, Chief Nurse, MGH, Storybook Ball Committee Chair;
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.
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. A quorum represents 7 members, one of whom must be a staff member, needed for any official meeting.

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.
MassGeneral Hospital for Children Grand Rounds

January 13, 2015, 8am to 9am
O’Keeffe Auditorium

THERE IS NO US AND THEM:

MGHfC Clinicians Reflect on Lessons They Learned When Their Children Were Patients

Participants
Peggy Settle, RN
Paula Ranich, MD
Avi Traum, MD

In this Grand Rounds, a physician and a nursing director reflect upon what they have learned about the patient experience after their own children have been treated in the hospital. They will comment on how their experiences have changed how they think about their professional roles, how they communicate with their patients, and how other providers can adopt methods to improve the quality of care they give to their patients. In addition, they will consider how parents and patients can be empowered to partner with hospital staff. A child psychiatrist will consider how patients/parents and providers can collaborate best to care for children.
Family Advisory Council Tea in the Pediatric Intensive Care Unit
Family Advisory Council Tea in the Neonatal Intensive Care Unit
The Ambulatory Practice of the Future Care Alliance
Background

The Care Alliance, a partnership of patients, family members and providers, promotes innovation and the optimization of the care experience for all.

2015 marks the 5th Anniversary of the APF, an innovative primary care practice charged with caring for Mass General employees and their spouses/partners. APF remains committed to its patient-centered model of care and its team-based practice. Staff value partnership and transparency with patients and with each other. APF partners with patients by offering electronic communication, unrestricted access to test results and visit notes, along with continuous care and coaching to help patients better manage and achieve their health, life balance, and wellness goals. The Care Alliance (CA) proactively partners with staff to promote making the care experience equally rewarding for patients, their families, and staff, and to ensure that the values that define APF remain strong while the practice expands.

The initial needs of APF called for substantial patient and family member input into planning and implementing this patient-centered practice, along with creating the necessary structure for APF and the CA to support each other. Next, the initial growth in the practice called for a CA that could help monitor implementation of this patient-centered model while generating and supporting opportunities to promote innovation. As demands and pressures on staff increased, patients on the CA needed to work more pro-actively. We surveyed patients about their care experience and communicated back to patients both the survey results and how staff addressed their suggestions. The need to communicate information to patients remains increasingly important as a means to help patients become more engaged in their own health care. In looking forward, the CA sees itself streamlining its meeting structure and better utilizing multiple media, including social media to better communicate with APF patients and the Mass General community. We believe that keeping patients better informed about relevant clinical news, information and changes is important, especially in anticipation of EPIC and MyChart. Doing so will further APF’s goals to offer care that is based on transparency and partnerships.

2015 also marks the 5th Anniversary of APF’s Care Alliance (CA). The CA is actually older than the APF, founded several months before APF opened, to guide it from the start. The first patients were seen at APF in August 2010. The CA thought it fitting to celebrate five years by hosting a birthday party for APF staff at its August meeting. Win Hodges, Charter Member of the APF Development Team and CA Chair Emeritus, presented a toast.

The Care Alliance is happy to be such an integral part of The Ambulatory Practice of the Future. We enjoy the opportunity to promote this patient-centered model of care with such open, supportive and caring staff. We are excited about the new opportunities to promote this innovative model of care with APF patients and the larger Mass General community via social media. We believe our efforts play an important role in helping to manage the changes and challenges that are part of current health care.
Reflections on 5 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 remains mindful of the ever-changing nature of health care and the very real limits on everyone’s time. The CA is now in the process of streamlining its meeting structure and simplifying its role to focus on brief, important communications to the APF patient population. This involves rethinking both messages and media in light of the fact that current patient communication vehicles will be changing. The team is exploring ways to develop patient communications based on the principle that the key to reaching an audience is to use multiple media. We believe it is important to increase our use of social media to provide an easily accessible communication link between staff and patients in order to keep patients better informed about relevant clinical news, information and changes at APF, and any broader Mass General changes impacting APF (e.g., EPIC and MyChart). Doing so will further APF’s goals to offer care that is based on transparency and partnerships.
2015 Goals
We continue to focus on Patient Engagement, Staff Support, and Review of Practice Outcomes. The Care Alliance believes it is essential to inform patients about the unique nature of APF and how best to become a partner in their own healthcare. We also believe it is vital to obtain in-depth patient feedback to improve the care experience and stimulate innovation in the practice. APF’s patients are primarily Mass General employees and we are mindful of the impact of reduced budgets, increasing patient panels, and limited time resources on our patients, APF, the Care Alliance, and the entire Mass General community. As a result, we have embarked upon a serious self-review this year. Our 5th Anniversary has provided a timely opportunity to review what the role of the CA has been and what it now needs to be to best accomplish our continuing goals.
Accomplishments and Outcomes

- **iHealthSpace Flyer**: The CA promoted the use of APF’s patient portal, iHealthSpace by working with staff to create and distribute an information flyer.

- **Brief Patient Survey**: Patient feedback is very important to APF and the CA. This year, we streamlined our second patient survey to offer a quick and easy means to solicit feedback from patients at the time of their visits. Patients and staff on the CA reviewed the surveys together and developed action plans to address patient concerns. The survey format remains consistent with our more extensive 2013 survey, in order to track changes over time.

- **Recruitment**: Staff and patients worked closely together to increase our patient membership. Staff approached potential patient candidates about the CA; patient members then reached out to these potential members to discuss the CA in more depth and to move the application process forward. We presently hope to add several new members before the end of the year.

- **Self Review**: After five years, members of the CA have taken the time to review what we have achieved. Our self-review process has helped us better understand the changing needs of this evolving primary care practice and the role the CA can play at various times.

- **Review of Practice Performance**

  Care Alliance patient members continue to provide feedback to APF staff and leadership about the patient experience at APF. Some examples from the past year include:

  - Reviewing CAHPS scores
  - Reviewing patient comments from CAHPS surveys to offer additional patient perspectives and make recommendations
  - Reviewing internal APF patient comments and concerns on our Brief Patient Survey
  - Reviewing clinical outcome, utilization, and cost data when available

- **Patient Perspectives**

  *EPIC and MyChart*: CA members continue to provide input on the development of Mass General’s patient portal. APF remains the only practice at Mass General (and, we believe, Partners Healthcare) to provide its patients with full transparent access to their outpatient medical records, and has been doing so since its doors opened in 2010. In line with what other institutions that have adopted similar pioneering moves have learned, we believe this policy contributes to APF’s strong patient satisfaction, engagement, and activation. APF has one of the highest penetration rates of patient portal use in outpatient care at Mass General, and the provision of full access to notes and medical information via the portal drives this success. Using both our own experiences and the results from our 2013 APF patient survey
about what APF patients like about the iHealthSpace patient portal, our Care Alliance has been in a unique position to promote full transparency in patient portals. On behalf of its patients, the APF Care Alliance expresses its deep concern and disappointment about having to step back from this crucial aspect of patient-centered care from the outset of Mass General’s emigration to the world of EPIC. Removing effective tools of self-care is counter-intuitive to Mass General’s mission of visionary, standard-leading health care in today’s world.

Research Recruitment: Patients on the CA met with Dr. Jeanhee Chung to provide their perspectives on recruiting patients for research studies.

• Conferences and Presentations

The Mass General PFAC encouraged our presence at the 2015 HCFA Conference by supporting the attendance of one of our patient members, Paul O’Leary, and by arranging for the poster presentation of our recent patient survey results. Our poster, Patient-centered Care: Full Inclusion and Full Infusion, (previously presented at the 2014 American Psychological Association’s Annual Convention in Washington D.C.) was highlighted at this HCFA Conference. The poster demonstrates APF’s strong patient-driven model, as evidenced in both our patient-driven survey process and the patient-driven care explicitly valued by survey respondents. The poster generated discussion among HCFA conference participants.
The CA leadership remains patient-driven; In 2015 CA leadership has been shared by two patient members, Rebecca Petersen and Stephanie Geohagen. Founding member Win Hodges, Chair Emeritus, provides valuable input from his extensive PFAC experience. Patient members facilitate monthly meetings on a rotating basis and communicate between meetings to brainstorm and work on action plans. Care Alliance patient 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. The CA is currently in the process of adding several new patient members. Several additional staff members (Ishani Ganguli, MD, Karen Esty, MA, Martha Pierce (Reception), Sarah Sherwood (Twine Health Coach), and Ana Panagiotidis (NP) now attend CA meetings when possible, and bring important new perspectives. For attendees who are new staff members, interaction with the CA underscores the value of adding patients to the process of orienting new staff. Steve Lynch, former Co-chair, continues to work closely with APF leadership on targeted technology projects and remains available for consulting with the CA as needed.
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 an pro-active 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 renominated 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 are 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 CoChair, 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 that the amendment has been submitted in writing at the previous regular meeting.
Welcome to iHealthSpace!

MAKE YOUR CARE EXPERIENCE EASIER, FASTER, AND BETTER

Go to: www.ihealthspace.org for quick and easy access to appointment requests, refilling meds, checking results, and messaging your provider during regular office hours for non-emergencies.

You can access iHealthSpace from either the APF website (https://apf.partners.org) or from www.ihealthspace.org. Save these links as favorites or icons on your computer or mobile device.

Easiest way to message your team/provider: Click “View Messages” from Quicklist, then click “Compose Message” to write and send your message.

Find helpful information about your health concerns: Click on the “MGH Primary Care Library” from Quicklist. Instead of googling, go to iHealthSpace for access to a great healthcare library!

Information sent via iHealthSpace for registered users:

- We will not send you junk email. Anything we send we consider specifically important to you!
- Test and lab results: These results will be sent to you via iHealthSpace instead of being mailed. You can view results as soon as they are available. APF will send you a notification via iHealthSpace as soon as we have read them.
- Important announcements (e.g., flu shot reminders, holiday hours, etc.)

Not a registered iHealthSpace user? Your results will continue to be mailed to you.

Not a computer user? You can assign a proxy for iHealthSpace use. See “Caregiver” section on the homepage.

GETTING STARTED: How to Enroll in iHealthSpace

Make sure you have your iHealthSpace Enrollment Code (the code in your new patient packet or given at the time of your visit). As a new patient, you should receive an email enrollment link in your email inbox. If not, check your spam folder for the enrollment link.

1. Sign on to: www.ihealthspace.org
2. Find New User box and click “Sign up” button
3. Provide the information requested, including your email address. You will need your enrollment code. You will also need to set your User Name and Password. These are case sensitive.

If this process doesn’t work, click the “Get Help” button, call the office (617-724-1100), or come in 10 minutes early for your next appointment and someone will help you.

TROUBLESHOOTING: 1) Access the help center by clicking the “Get Help” button on the iHealthSpace homepage, or 2) Call the office (617-724-1100) and we will help (or connect you with someone who can).

MESSAGE your team via iHealthSpace: DO NOT EMAIL your team. Email is not confidential, secure, or safe. HealthSpace messaging is more efficient and we can respond to your questions more quickly.

IHealthSpace Information Flyer developed by the Care Alliance
A Toast to The Ambulatory Practice of the Future on the Fifth Anniversary of its Opening

Congratulations on achieving this milestone. You are all fulfilling a vision that began in 2004. The Ambulatory Practice of the Future (APF) was founded on principles unique to the practice of primary care at MGH. You are engaging patients and families in a partnership for managing their own health care. Your patients are supported by your attentive listening, by complete transparency during visits, and by immediate access to all results, including visit summaries, via iHealthspace. Uniquely APF visit summaries include summaries of the visit discussions as well as the usual lists of health issues and medications. You are treating the whole patient by integrating emotional care (stress being the most common need) with exceptional physical care. Again, uniquely, coaching has been integrated into and is playing an important role in both.

Health management at APF has been vital to providing excellent care. Closely monitoring patients with Diabetes, Hypertension and COPD and using innovative tools such as Twine to monitor blood pressure and weight, has facilitated a timely response to developing problems for patients with more serious health issues.

By delivering care that is rewarding for both staff, as well as patients you are fulfilling one of the basic principles of the APF Vision. While staff members have differing responsibilities, you value the contribution of each member of the staff to the success of the practice. I don’t think any other Partners practice has each staff member facilitate a staff meeting! Your team approach, communicating and coordinating with one another, contribute not only to a confidence-building and rewarding experience for patients but also for yourselves.

You have incorporated patient perspectives in the operation of the practice through the Care Alliance. The Care Alliance has promoted the use of iHealthSpace by patients and families. Care Alliance surveys have provided proof of exceptional patient satisfaction. Since the APF patient population consists of hospital staff, such positive feedback is particularly high praise!

Your successful efforts have been recognized on more than one occasion. APF has received Service Excellence Awards in the Provider Explain and Staff Courtesy categories based on patient satisfaction research by the CGCAHPS. These skills are the very essence of partnership with patients and families. In addition, APF was among the first to achieve the highest level rating as a Modern Medical Home by the NCQA.

You should be very proud of what you have accomplished. Your hard work, your dedication, your commitment to delivering excellent care, to continuous improvement and to the principles of the APF vision are outstanding, especially in the face of an increasingly challenging hospital operating environment.

Congratulations!

Win Hodges, Charter Member, APF Development Team