MASSACHUSETTS GENERAL HOSPITAL
PATIENT AND FAMILY ADVISORY COUNCILS
2012-13 REPORT
THE MGH MISSION

“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.”
Overview

The third oldest general hospital in the United States and the oldest and largest hospital in New England, MGH continues its tradition of excellence today. In 2013, MGH was ranked the number two hospital in America by *US News & World Report* based on the quality of care, patient safety and reputation in 16 different specialties. In 2003, MGH 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, the hospital was redesignated a Magnet hospital.

Massachusetts General Hospital is a 957-bed academic medical center, located in the heart of Boston, offering sophisticated diagnostic and therapeutic care in virtually every specialty and subspecialty of medicine and surgery. In addition, the hospital provides care and services in multiple health centers located within neighboring communities, including Back Bay, downtown Boston, Chelsea, Charlestown, Danvers, Everett, North End and Revere, as well as at MGH West and the North Shore Medical Center. The hospital also holds concurrent Level 1 verification for adult and pediatric trauma and burn care.

Each year MGH:

- Admits 48,493 inpatients
- Handles 1.5 million outpatient visits
- Records 95,765 emergency room visits
- Performs 41,304 operations
- Delivers 3,699 babies
- Translates medical information between English and 60-plus different languages
MGH also conducts the largest hospital-based research program in the United States with an annual research budget of nearly $775 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, MGH is the original and largest teaching hospital of Harvard Medical School, where nearly all MGH staff physicians have faculty appointments. Since the hospital’s founding, MGH 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 MGH

MGH 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 MGH.

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.
MGH General
Patient and Family Advisory Council
The General Patient and Family Advisory Council  
2012-13 Activities & Accomplishments

The General PFAC engaged in a strategic planning process this past year and identified objectives and tasks that will carry the group’s work through 2014.

- Our objectives are:

  1. To build a strong core structure
     - Design and implement a robust recruitment process
     - Standardize the orientation and onboarding process for new members
     - Educate the organization about PFACs and build brand awareness
     - Revisit PFAC roles and responsibilities

  2. To collaborate with other MGH PFACs
     - Establish a PFAC Chairpersons Council
     - Sponsor annual PFAC event
     - Invite members of other PFACs to attend learning initiatives

  3. To facilitate placement of PFAC members on committees
     - Identify committees
     - Develop advisor qualification process and training

  4. To report on successes and opportunities
     - Develop a robust method of collecting quantitative and qualitative data
     - Compile information into a comprehensive report
• Interviewed and selected two PFAC members to participate as members of the Quality Oversight Committee. Two year term started January 2013

• Developed “Visitor Tip Sheet” to enhance patient/visitor experience. These are available on all inpatient units, the Admitting department, Preadmission testing area and the Gray Family Surgical Waiting area.

• Identified learning initiatives to educate patient and family members about current organizational issues. These included a briefing of The Joint Commission visit held on July 23-July 27, 2012 by John Belknap, director of Corporate Compliance; Partners E-Care presentation by Andy Karson, MD, associate chief medical officer; Patient Experience Surveys by Rick Evans, senior director of the MGH Service Department, and Liza Nyeko, program manager, MGH Center for Quality and Safety.

• PFAC members provided feedback to Dr. Karson regarding participating on targeted workgroups to inform E-Care, such as the Patient Portal and education materials. They also got a commitment for future updates and opportunities to influence the process.

• PFAC members provided input in connection with Patient Safety Week, “Ask Us Tell Us,” theme. Two areas of particular interest are patient involvement in the safety reporting process and in ensuring accurate information in the medical record.

• Served as a resource to MGH and BWH staff presenting their Patient Centered Outcome Research Initiatives (PCORI) proposals on preventing hospital falls and safe transitions from hospital to home.

• Designed a Recruitment and General PFAC structure tool to learn more about the composition and operations of other MGH PFACs. The tool will be distributed internally and to other Boston area hospital PFACs.

• Sent representatives to the Statewide sponsored Health Care for All PFAC conference on May 17, 2013.

• Established PFAC Chairpersons Council to enhance collaboration among MGH PFACs, identify areas of commonality, and strategize about approaches for standardizing work.

• Attended a Diversity Collaborative Governance Committee meeting to get feedback on increasing the diverse membership of PFACs to better represent the MGH community.
• Provided input into the redesign of ID badges for Emergency Department staff to increase patient understanding of various clinical roles.

• Facilitated a PFAC member’s participation in a panel presentation about obligations to the patient held during the CRICO sponsored program, “Challenges of Training Surgical Residents in the New Millennium,” held on June 25-26 at Harvard Medical School.

• A PFAC member was selected to serve on a joint MGH-BWH PCORI Research Steering Committee. The goals of this three-year research project are to improve patients’ experiences when they are discharged from the hospital.

• Contributed a “Fielding the Issues” article for the June edition of the hospital’s Caring Headlines newsletter that provided both an update to the MGH community on current PFACs and contacts for recruitment and information.
Patient Family Advisory Councils (PFACs)

Question: How many Patient-Family Advisory Councils (PFACs) are there at MGH?

Jeanette: Currently, we have five Patient-Family Advisory Councils:
- The Cancer Center
- Mass General Hospital for Children
- Ambulatory Practice of the Future
- Institute for Heart, Vascular, Stroke Care
- The General Council

These councils provide a formal mechanism for patients and families who want to take an active role in improving the patient experience. Council members are sounding boards for new ideas; they participate in committees, working groups, staff orientation and education; they make recommendations for improvement and collaborate with MGH leadership on patient- and family-centered initiatives.

Question: Can you give me an example of some of the projects they've been involved with?

Jeanette: In January, two PFAC members were invited to join the Quality Oversight Committee. Family members sit on the Pediatric Quality and Ethics Committees. There is patient-family representation on the Cancer Center Quality and Safety Committee and the Patient Education Committee.

PFAC members have presented at the annual nursing conference of the Institute for Heart, Vascular, and Stroke Care, at the annual conference of the Institute for Patient- and Family-Centered Care, at the 2013 Health Policy Conference in Washington, DC, and at pediatric grand rounds.

Members have had input into the MGH Visitor Tip Sheet, the selection of artwork for the ICU waiting areas, Innovation Unit Family notebooks, care re-design discussions, and serving as family faculty for the Ambulatory Practice of the Future.

Question: How does one become a member of a PFAC?

Jeanette: Most PFAC members are referred by clinicians. Some respond to mailings. Candidates complete an application and are interviewed by other members of the council or the chairperson. All candidates must have healthcare experience at MGH. It's important that members be able to interact with different groups, have good listening skills, and be able to commit to an agreed-upon schedule of meetings (usually monthly).

Question: If I know a patient or family member who's interested, how can I refer them?

Jeanette: The General PFAC is currently recruiting members. You can send an e-mail to pscpfac@partners.org, or contact co-chairs, Robin Lipka-Orlando, RN, at 617-726-3370, or Rick Evans at 617-724-2838.

The Institute for Heart, Vascular, and Stroke Care PFAC is also looking for members. Contact Judy Silva, RN, at 6-1437, or Lin-Ti Chang, RN, at 3-2995.

To learn more about the Cancer Center PFAC or to get involved, contact the Blum Cancer Resource Room at 617-724-1822 or drop-by the Blum Cancer Resource Room onYawkey 8C.

For information about the MGHfC PFAC, send an e-mail to fac@partners.org.
Tips for Your Visit at MGH

We would like to partner with you to ensure a safe and comfortable healing environment for all our patients and families. Visitors will not be discriminated against based on race, color, national origin, sex, religion, sexual orientation, gender identity or expression, or disability. Different sex and same sex couples/parents will have equal visitation rights.

AGE OF VISITORS
Children are permitted to visit with adult supervision. Some units may have additional guidelines for children.

VISITORS HEALTH
To protect the health of our patients, units may ask questions about your immunization status. If you have fever, flu-like symptoms or other symptoms of infection, you should refrain from visiting.

HAND HYGIENE
Please use Cal Stat before entering and when exiting patient rooms.

NUMBER OF VISITORS
In order to promote rest, healing and privacy, family and friends are encouraged to schedule their visits. Due to physical space constraints on some units, it is advised to limit visitors at the bedside to two at a time. Many units have family waiting areas or lounges. Special requests for visiting should be discussed with the patient’s nurse.

QUIET HOURS
During posted Quiet Hours, you are encouraged to speak in a quiet tone and place cell phones on vibrate. During these hours, lights on the floors will be dimmer and doors may be shut.

ACCESS CONTROL
Some patient areas have controlled access to keep patients safe. Instructions for accessing these units are posted and usually involve pressing a doorbell to gain entry and exit from the area.

OVERNIGHT VISITS
Some patient areas have couches in the room for sleeping that accommodate one person. Semi-private rooms usually cannot accommodate overnight visitors. Unique situations should be discussed with staff.

VISITOR BELONGINGS
You are responsible for keeping cell phones, computers and other belongings in your presence at all times. Some units may have special considerations as to what may or may not be brought onto the unit for infection control or safety reasons. Please check with the patient’s nurse.

SMOKING
You are not permitted to smoke while on hospital property.

PETS
Therapy dogs are approved by the MGH Volunteer department. Service animals are permitted to accompany and assist their handlers while the handlers are at the MGH. No other animals other than service animals or pet therapy dogs are allowed in the MGH patient care and/or common areas.

FOOD
Before bringing food from the outside for a patient into a patient’s room, please check with the patient’s nurse. Guest trays may be available for ordering through the Nutrition and Food Services department for a fee.

If you have any feedback regarding this document, please contact mghpatientadvocacy@partners.org.
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<tr>
<th>Domain</th>
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<tr>
<td><strong>PFAC Composition</strong></td>
<td>How many patient/family members serve on your PFAC?</td>
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<td>How many MGH staff members/divisions serve on your PFAC?</td>
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<td>Please comment on PFAC member diversity.</td>
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<td><strong>Recruitment</strong></td>
<td>How do you go about recruiting new members?</td>
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<td>Is your recruitment process systematic or informal?</td>
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<td>Do you have an application form for recruitment?</td>
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<td>If so, are you able to share with us?</td>
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<td>Do you have a PFAC brochure?</td>
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<td><strong>Terms</strong></td>
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<td>If so, please specify term limits</td>
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<td><strong>Orientation</strong></td>
<td>Do PFAC members have MGH badges?</td>
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<td>If so, what do the badges state (e.g. volunteer; patient advisor)?</td>
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<td>Do PFAC members go through MGH volunteer training?</td>
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<td>Is there a PFAC-specific orientation process?</td>
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<td>Is orientation process systematic or informal?</td>
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<td><strong>PFAC Structure</strong></td>
<td>Who Chairs the PFAC?</td>
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<td>Are PFAC Chairs patients and/or MGH staff?</td>
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<td>Are there PFAC Chair term limits?</td>
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<td>If so, please specify term limits</td>
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<td><strong>Meeting Structure</strong></td>
<td>What is the PFAC's meeting frequency?</td>
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<td>How long are meetings?</td>
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<td>What is the format of meetings?</td>
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<td>(e.g. presentations, workgroups, networking, other)</td>
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<td>Is a quorum necessary for meetings to take place?</td>
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<td>Do PFAC members vote on topics?</td>
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<td>If so, is there a quorum for voting to take place?</td>
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<td>Who facilitates meetings?</td>
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<td>(e.g. PFAC Chairs; members)</td>
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<td>How are minutes taken?</td>
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<td>(e.g. designated PFAC member, recording, minutes not taken)</td>
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<td><strong>PFAC Focus Areas</strong></td>
<td>How are the PFAC’s primary areas of focus selected, and how are goals set?</td>
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<td>What have been the primary focus areas over the past two years?</td>
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<td>What has been the key achievement thus far for your PFAC?</td>
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<td>What has been the most challenging area for your PFAC?</td>
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<td>How is progress towards established goals tracked?</td>
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The MGH General Patient and Family Advisory Council Membership

Co-Chairs:
Robin Lipkis-Orlando, RN
Director of Patient Advocacy
Rick Evans
Sr. Director Service Improvement

Staff Members:
Kay Bander
Volunteer
Bessie Manley, RN
Nurse Director, Phillips House 22

Linda Kane, LCSW
Office of Patient Advocacy
Liza Nyeko
MGH Center for Quality & Safety

Karen Konnor, LICSW
Social Service
Steve Reardon, MPH
Office of Patient Advocacy

Patient/Family Members:

Patrick Brannelly
Susanne Goldstein
Win Hodges
Sue Lunn
Kathy Varela
David Wooster
Article 1. Overview

The MGH Patient and 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 MGH. The council will focus on discovering what programs and practices represent the most successful patient and family experience within MGH 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 administrators of the hospital.

Article 2. Mission Statement

Guided by the MGH 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 MGH by collaborating with existing Patient and Family Centered Councils and focus groups.

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

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 MGH and make recommendations for improvement.

Section 6. Educate: Collaborate with MGH staff to facilitate patient and
family access to information. Influence and participate in MGH staff orientation, patient/family education, discharge/transition planning.

Section 7. Evaluate: The role of Patient and Family Advisory Councils in improving outcomes for patients and families.

Article 3. Structure and Membership

The PFAC will consist of 10-15 members representing the diversity of the MGH community. Up to 6 MGH 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 4. Nomination and Application Process

Recruitment of patient and family council members is initiated by referral from all disciplines including MGH 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, Maxwell & Eleanor Blum Patient & Family Learning Center, Diversity Council, community at large, and the Office of General Counsel.

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

- Current experience as a patient or family member at MGH
- Ability to represent patient care experience
- Willingness to work in an advisory role
- Good listening skills
- Ability to interact well with differing groups of people
- Respect of others’ perspectives
- 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: Application 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 MGH 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 MGH PFAC
- Vacancies may be filled during the year as needed

Article 5. 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 (i.e. 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 MGH
- Co-Chair will support duties of Chair in his/her absence
Article 6. Outputs of the PFAC

- The PFAC will provide regular updates to the MGH 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, and 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 7. 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.

Article 8. 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 9. 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 MGH. 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 10. Termination

The Chair and Co-Chair of the PFAC reserve the right to dismiss any member who is not compliant with the rules and bylaws.
Patient Advisor – Hospital Committee
Position Description

Summary
A Patient/Family Advisor is a designated representative from an existing PFAC who sits on hospital committees to provide input into patient care and organizational processes, and advocates for patient and family needs from a broad perspective.

Duties
- Attends meetings of designated committee(s).
- Reviews all materials for meetings beforehand.
- Offers input and feedback on committee areas of focus and agenda items from a patient and/or family perspective.
- Participates in work groups or projects generated by the designated committee as needed and appropriate.
- Reports back to the PFAC on the activities of the designated committee, as appropriate, and uses knowledge gained to help shape PFAC objectives and initiatives.

Qualifications
- Member of an MGH PFAC or related group for 2 years or more.
- Ability to speak to personal experience in a way that informs committee work and outcomes.
- Ability to advocate effectively for the needs and priorities of patients and families, as appropriate.
- Capacity to read and understand hospital reports necessary for the committee’s work.
- Comfort with speaking in front of a large, diverse leadership audience.
- Aptitude for active listening.
- Ability to respect and uphold confidentiality of meeting discussions.
- Availability to attend recurring scheduled meetings.

Orientation
- Review of the job description of the Patient Advisor role.
- Meeting with the Committee Chair to review:
  - Committee purpose and function
  - Expectations of committee members
  - Relevant reports and data
  - Term of service with the committee
  - Benefits of participation
- Review of the organization’s confidentiality policy and its requirements, vis-à-vis working with the designated committee.
- Review of at least 6 months worth of minutes and exhibits to allow for deeper understanding of the committee’s work.
- Successful completion of an orientation to the committee.
**MGH Cancer Center PFAC Mission**
The mission of the Mass General Cancer Center’s PFAC 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 staff and Cancer Center administration, the Cancer Center PFAC’s primary objectives are: to promote and support patient- and family-centered care; to provide staff education on the patient and family experience; and to expand the voices of patients and families throughout Mass General by participating in opportunities to join hospital-wide committees and engage with other PFAC councils.

The Cancer Center PFAC (CC PFAC) has an ongoing commitment to meet these objectives by, for example, advising Cancer Center leadership on Cancer Center initiatives such as space planning, communications to patients and families, website design, and the Cancer Center’s ongoing evaluation of the quality of care.

**Council Operations**
The CC PFAC meets on the second Wednesday of each month from 5:30 pm - 7:30 pm. Documentation of meeting minutes is stored electronically for a minimum of five years. Council minutes and accomplishments are provided to the hospital’s governing body.

**Membership**
The PFAC currently consists of twenty-five Active Members, fourteen Emeritus Members, and 8 staff members. Members represent diverse perspectives and experiences relative to age, gender, diagnosis and socioeconomic status. Current members represent approximately ten different Cancer Center disease programs, as well as three different sites (Boston Main Campus, Mass General/Danvers, and Mass General/Emerson). During FY 2013, the Cancer Center on boarded 13 new members.

Staff Members of PFAC include the Blum Cancer Resource Room director, Cancer Center executive director, Cancer Center executive assistant, Cancer Center associate chief nurse, Cancer Center nursing director, Cancer Center project manager, Cancer Center oncologist, and Service Excellence specialist.
Qualifications for Membership
To serve on a PFAC, patients and family members must have a history of receiving care at the Mass General 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.

Cancer Center PFAC members are asked to commit to attend monthly Cancer Center PFAC meetings and serve on Cancer Center PFAC-specific subcommittees, as well as committees throughout the Cancer Center and the wider hospital. Members are asked to make a two-year minimum commitment; there is no term limit at this time. Emeritus members maintain their involvement in CC PFAC activities, if available, but are not required to attend the monthly PFAC meetings.

PFAC Member Recruitment: Prospective members are nominated by Cancer Center staff with the patient’s or family member’s permission. Nominees are asked to complete an application form which is reviewed by a Cancer Center PFAC staff member prior to an interview with the candidate. Cancer Center PFAC staff selects new Cancer Center PFAC members with a goal of having a diverse membership, in terms of cultural, socioeconomic, cancer diagnosis and treatment.

Membership Requirements and Training:
Cancer Center PFAC members are required to meet Mass General volunteer standards, which include HIPPA training and annually signing the Mass General confidentiality statement. Cancer Center PFAC members play an active role in orienting new members, serving as “buddies” to new members and providing peer mentoring on the role.

New members are encouraged to attend Cancer Center new staff orientation. 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 Leadership:
By choice, the Cancer Center PFAC has no formal chair or elected officers. Currently the meetings are co-facilitated by the nursing director and the Resource Room director, who is a licensed social worker. Agenda items are prioritized by staff members based on topics discussed at Cancer Center PFAC meetings and requests from Cancer Center and MGH-wide staff that wish to consult the group.
PFAC Roles and Activities
In addition to their attendance at monthly Cancer Center PFAC meetings, members are also asked to serve on Cancer Center and Mass General steering and review committees. Committees on which Cancer Center PFAC members have served include Patient Experience, Care Redesign, Quality and Safety, and Survivorship Day.

Cancer Center PFAC members have participated in the interviewing 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. Staff who have benefitted from these dialogues include residents/fellows, support staff and nursing staff.
The MGH Cancer Center PFAC has had many accomplishments during the past year. The following represent areas that demonstrate the impact of the PFAC on the Cancer Center’s patient experience:

- **Peer Guide Program:** During 2013, the PFAC recommended the development of a comprehensive Cancer Center orientation program for patients and families. The response to this feedback was the development of the Peer Guide Program. The goal of this program is to improve the patient experience and encourage patients to participate in their own care through onsite peer orientation and support during outpatient cancer treatment. The Peer Guide is a specialized volunteer, generally a cancer survivor or family member, who is stationed in the practices and treatment areas. The volunteer provides general support and communicates with patients about Cancer Center resources such as the Resource Room, Hopes Program, Parenting at a Challenging Time, Support Groups, etc. Each Peer Guide receives extensive training and ongoing supervision by one of the Resource Room’s licensed clinical social workers. There are currently 5 Peer Guides. Regular updates on the Peer Guide program are shared with PFAC.

- **Termeer Center for Targeted Therapies:** In January 2013, Mass General opened the Termeer Center for Targeted Therapies, a 10-bed, outpatient infusion unit for Phase I Clinical Research. Given that patient stays in this infusion center are significantly longer and more complex than the average treatment, the PFAC provided suggestions on how the Cancer Center could create an optimum experience. As part of this process, PFAC provided the nursing leadership and administration with feedback related to the patient experience for the new unit. The PFAC also provided feedback on a new website related to the launch of the Termeer Center. The website matches a patient’s disease and cancer mutations to the clinical trials available at MGH and across the nation. The PFAC members’ input was essential to ensuring the proper tone and terminology for the trial-matching system. The new website is [https://targetedcancercare.massgeneral.org/](https://targetedcancercare.massgeneral.org/).
• **Cancer Center Patient Experience Council:** During FY2013, the Cancer Center launched its first Patient Experience Council. This is a multi-disciplinary committee including physicians, nursing, administration, communications, social work, PFAC, and MGH’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 Master Space Planning Process:** The Cancer Center is in the process of developing a 10-year master space plan. The PFAC was asked to participate in a 90-minute brainstorming session with NBBJ, the architects retained by MGH, to provide input on the current patient flow and the patient/family member experience. In preparation for the meeting, PFAC members were asked to complete a survey about the existing patient experience. PFAC members identified areas for architectural redesign, more efficient patient flow, and increased use of technology. The input from PFAC was integrated into the master plan report that was shared with leadership.

• **Cancer Center Communications:** During FY2013, the CC PFAC provided feedback to the Cancer Center on its first multi-media advertising campaign, *Everyday Amazing*, which included television, print, radio and web. The advertisement featured two survivors, and PFAC member input on the creative was important to the process. Another communications initiative was the refresh of the Cancer Center and Resource Room websites; PFAC members provided valuable input to improve the use of these sites. PFAC members also assisted in developing new processes to connect patients to Cancer Center programs and resources, a major theme of many of the CC PFAC meetings.

• **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 Quality and Safety Committee, which meets monthly. This committee reviews safety incidents and develops performance improvement initiatives to promote quality and safety. This year, the committee developed a standardized process for chemotherapy administration that was implemented across all of the infusion centers in the Cancer Center. PFAC members also participate in quality rounds, a team-based rounding process to educate and promote awareness about quality and safety. During FY2013, the Cancer Center was also asked to participate in the Hospital Quality and Safety Committee, which provides even greater perspective to our Council about quality and safety across the MGH.
• **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 FY13, PFAC provided feedback about patient communications related to a two-week closure of the Yawkey 8 Infusion Center Pharmacy. PFAC members provided advice related to an outpatient-inpatient handoff project, sharing information related to key barriers to effective communication during this critical transition. PFAC members also provided guidance for several important programs, including Parenting at a Challenging Time, Cancer Fertility, Cancer Sexual Health Program, Cancer Outcomes Research Program, and Patient Gateway.

• **Education:** A major role of the Cancer Center PFAC is to provide continual education to 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. PFAC members also participate in the monthly Cancer Center staff orientation. These forums have been highly successful and provide a venue for faculty and staff to ask difficult questions about a variety of sensitive topics, such as how patients and family members cope with a cancer diagnosis. The PFAC also participated in the annual MGH PFAC meeting, which includes all MGH PFACs. This is a wonderful forum where PFAC members have the opportunity to network and share experiences with the other MGH PFACs. PFAC is also extensively involved in the development of the annual Cancer Center Survivor’s Conference, including the selection of speakers, panelists, and special guests. The FY2013 Survivors Conference was entitled, *Let’s Talk: The Changing Landscape of Cancer Care.* This program included a lecture by Lecia Sequist, MD, of the MGH Thoracic Oncology Center, on personalized medicine, as well as a patient-provider panel moderated by local TV news anchor Liz Brunner. Special guests included experts in laughter yoga and relaxation.

• **Conferences:** PFAC members participate in several external forums, as part of the group’s mission to educate others about the value and role of PFACs. During FY2013, two PFAC members had the opportunity to present the abstract, *Reflections: Year Ten of a Patient and Family Advisory Council,* at the annual Institute for Patient and Family Centered Care Conference (IPFCC). Two abstracts have been submitted by PFAC members for the FY2014 IPFCC annual conference. One abstract is about the Peer Guide program and the other shares the role of Cancer Center PFAC members on hospital committees. PFAC members also participated in the Health Care for All PFAC Conference, which focused on the role of patient education in connection with the expansion of the Affordable Care Act.
Committee Participation: PFAC members participate in a variety of Cancer Center committees. 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 an update at the monthly meetings. PFAC members participated in the following committees during FY2013:

- Cancer Center Quality Committee
- Cancer Center Quality Rounds
- Cancer Center Patient Experience Council
- Cancer Center Patient Education Steering Committee
- Cancer Center Illuminations Art Program
- Cancer Center Network for Patients & Families
- Cancer Center Peer Guide Task Force
- Cancer Center Survivorship Conference
- Friends of the Massachusetts General Hospital Cancer Center
- Hospitalwide PFAC Committee
- Hospitalwide Quality Committee

Looking Forward:
As FY14 begins, many of the committees and activities listed above will continue. Cancer Center staff and leadership seek out the opinions and perspectives of Cancer Center PFAC members, as staff are now aware of the diversity of experience and perspectives that can make an excellent initiative or program even better. Cancer Center PFAC members also contribute to the Mass General Cancer Community by sharing information learned—from personal experience or active learning and participation—to help guide the Cancer Center in new directions that will improve the patient experience.
1. **Purpose/Goals/Mission Statement:**

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.

To act in an advisory capacity to influence Patient- and Family-Centered Care as well as staff education and support. PFAC also strives to share and learn from others in an effort to expand the voices of patients and families throughout the MGH by engaging with other PFAC councils.

2. **Membership:**

At a minimum, at least 50% of council members shall be current or former patients or family members. Currently 75% of council members meet this requirement. The council’s qualification and selection process reflect its commitment to being representative of the community served.

**Qualifications:**

- Recent treatment history for themselves or a family member. *(General Guidelines: Patients currently receiving treatment or having completed treatment in the last 5 years, inclusive of chemotherapy, clinical trials, radiation, proton therapy and surgery.)*

- These individuals should possess the ability to represent the perspective of patients and family members and understand cancer issues beyond one's own cancer experience.

- Diverse perspectives and backgrounds

- Ability to work as both a team player and an initiative taker

- Ability to make the time commitment for meetings and sub-committee efforts
Selection:

- Members are nominated by a Cancer Center staff member or clinician
- Completion of an application form, specifically created for PFAC
- PFAC staff member review of the application and interview of each candidate via telephone or in person (preferred)
- Applicant is invited to join PFAC.
- Matching with a current PFAC patient/family member in preparation for their first council meeting

Terms:
Two-year minimum commitment with the option to move to Emeritus status after that time, or continue as an active member. Emeritus members maintain their involvement in PFAC activities, as available, but are not required to attend the monthly PFAC meetings on a regular basis. No formal term limits have been set. Current membership ranges from 1.5 years to 11 years.

Officers/Chairs:
We do not have elected officers or a formal chair or cochair role. PFAC staff members facilitate the meetings as equal members of the council. PFAC patient/family members have requested that PFAC does not have a formal role of chair but that all members of the council are equally active participants to develop agendas and manage the flow of meetings.

3. Orientation:

Individual meeting with PFAC staff member and PFAC patient/family member (see "match" outlined above). A PFAC staff member presents a formal orientation to PFAC at the new members' first meeting. This orientation was last updated in August 2012. New members are also oriented to the hospital via the MGH Volunteer Department. New members are given the option of attending the Cancer Center new staff orientation if they are able to do so. Continuing education is offered via our monthly PFAC meetings.

4. Roles:

PFAC acts in an advisory capacity for issues involving patient- and family-centered care, staff education and sharing and learning from others. Beyond the monthly PFAC meetings, members are offered the opportunity to serve on Cancer Center committees and workgroups, as needed. Members are also invited to serve in an educational/advisory capacity several times a year via scheduled meetings with the new oncology fellows, Cancer Center support staff and nursing staff.
Other opportunities for additional roles are presented to members as they arise:

- Interview process for oncology nursing leadership
- Review of patient satisfaction data and quality data
- Program planning, such as cancer survivorship programs, HOPES workshops
- Review and planning of patient education materials, such as the new patient guide, chemotherapy DVD
- Operational efforts (workflow redesign/consultation, wait times, patient communication materials)

5. Responsibilities

Members commit to:
- Adhere to hospital policies around HIPPA as reviewed in their orientation to the Volunteer Department.
- Fully participate in monthly meetings
- Be good listeners
- Be an advisor and collaborator with the Cancer Center
- Be respectful

6. Logistics:

- The Council meets on a monthly basis, the second Wednesday of each month, from 5:30-7:30pm.
- Minutes of the monthly Council meetings are taken by the Executive Assistant or another designee acting on his/her behalf, and will be maintained in an online file, accessible to all PFAC staff members, for a minimum of five years.
- Minutes and materials are available for review and will be transmitted to the hospital’s governing body as required/requested.
MGH INSTITUTE
FOR
HEART VASCULAR AND STROKE CARE
PATIENT AND FAMILY ADVISORY COUNCIL
A key focus for 2012-13 has been the recruitment of new members to enhance the integration of the Institute for Heart, Vascular and Stroke Care (IHVSC) Patient and Family Advisory Council (PFAC). Four new patient and family members representing vascular and stroke care joined the group: Bob Brunelle, Mary Theresa Daniels, Pat Hollenbeck and Tom Quirk. In addition, three new staff members joined: Heidi Bas, MD, Anesthesia (replacing Nandita Scott, MD, Cardiology), Douglas Henderson, Neurology Administration, and Cindy Sprogis, Service Excellence.

The MGH Institute for Heart, Vascular and Stroke Care PFAC has achieved several noteworthy outcomes. In addition, members participated in, and provided valuable input for an array of activities beyond the standing monthly meetings including:

**Enhancing Patient- and Family-Centered Care**

- Contributed to renaming MGH TeleHealth to MGH Connect

*Institute PFAC Input:*

MGH TeleHealth was viewed negatively as:

1. Vague and ambiguous
2. Resonates better with internal audiences
3. Not an accurate description of the services offered
4. “Tele” feels antiquated and related to telemarketing
5. Confusing to market and patients if different departments within MGH are offering their own variation on telemedicine
6. MGH Connect: an umbrella name that serves as the primary brand
7. New name should serve as a wrapper that encircles all of TeleHealth/TeleMedicine offerings at the MGH
• **Recommended best strategies and support for patients to access MGH Connect**

*Institute PFAC Input:*

“Seeing your doctor from home is a good idea. It provides opportunity for patients in remote communities to connect to experts for care.”

1. Provide detailed instructions on how to log-in to the system
2. Address minimal requirement for technical ability
3. Address privacy concerns that match level of electronic health record
4. Consider potential for a clock on the screen to guide both provider and patient with time progression during the appointment
5. Communicate wait time expectations for appointments and develop options for short or long appointments

• **Recommended revisions to welcome letter and provided input to the patient fact sheet for the Cardiology & Primary Care Shared Care Pilot**

*Institute PFAC Input:*

“It is important for providers to engage patients to be better partners. Best care is when the patient is an active participant.”

• **Recommended input for two study proposals: Patient Centered Outcome Research Initiatives (PCORI) of patient centered vascular research and on shared decision making for patient with Peripheral Artery Disease (PAD) and Asymptomatic Carotid Disease**

*Institute PFAC Input:*

1. Booklet is reliable but has too many pages
2. DVD and booklet combined provides more information but should have just one
3. Informational material should be available in several languages

• **Participation in Meeting with Magnet Appraisers (March 6, 2013)**

Four Institute PFAC members (Teri and Tom Fryer, and Susan and Phil Geary) met with the three Magnet Appraisers from the American Nurses Credentialing Center and shared their accomplishments and patient experiences at Mass General.
Enhancing Staff Education

- **Recommended an Educational Event for the Blum Patient and Family Learning Center**
  
  Pat Hollenbeck suggested Ester Gokhale “posture guru” as a seminar topic on reducing work related back problems.

- **Guest Speaker and Participation in Institute Nursing Conference (Oct. 15, 2012)**

  Sr. Jon Julie and Denise Mallen participated at the full-day Institute Nursing Conference on "Complex Issues in Heart, Vascular & Stroke Patient" at Mass General. In addition, Denise was a guest speaker and shared her patient experience on organ donation and transplantation: opportunities for HVSC patients.

  **Participant Feedback:**
  
  “Thank you to Denise, from the Institute for Heart Vascular and Stroke Care Patient and Family Advisory Council, who shared her patient experience. It was a very powerful message for Organ Donation.”

- **Panel Speaker in CRICO Conference: Challenges of Training Surgical Residents in the New Millennium (June 25-26, 2013)**

  David Wooster participated at a panel discussion and shared patient perspectives about obligations to the patient around the transparency of the residents’ role in care.

  **Staff Feedback:**
  
  “Thank you Pat, I have passed it along to colleagues who coordinate staff education and support. I highlighted that this is a very nice example of what we see consistently with our PFAC members, advocating for those who provide their care. Caring for the caregiver underscores our value for them and how important they are to our shared success in providing excellence.”

Enhancing Patient Communication, Service and Development

- **Dialogued with MGH Director of Clinical and Translational Research**

  **Institute PFAC Input:**
  
  “The notion of bringing basic scientific research closer to clinical experiences and results makes sense to me.”
“Our PFAC Team can be helpful in structuring the communication and solicitation to a variety of constituencies resulting in participation by a broad spectrum of people touched by MGH. We have on our team a group that covers an amazing variety of experiences and viewpoints that I feel reflects the vast community MGH serves.”

- **Recommended tactics to improve volunteers/patients participation in research at the MGH**

*Institute PFAC Input:*

1. Include latest research and integrate with patient stories as part of the patient and doctor conversation.
2. Reinforce that teaching goes hand in hand with research.
3. Patient Gateway could be one solution to recruit research participants by sharing patient conditions, but will need better method to ensure patient confidentiality and consent for permission.
4. Use the PCP model as linkage to research by making informational flyers available at the PCP office.
5. Put a brief summary of research results in newspaper or other media.
6. Use electronic information that provides more than one language, simple and understandable.
7. Patients do contribute to research, such as data captured in patient satisfaction.

- **Recommended strategies to improve volunteer participation, consent process, and Partners Human Research Committee Internal Review Board (IRB) in research at the MGH**

1. Approach patient at an appropriate time for consent to alleviate a patient key concern that, “If I don’t participate am I going to receive care?”
2. Reinforce that when patients do not feel they are in charge of their care, there is a power inequity.
3. Consent language needs to be clearer without influence or coercion.
4. Providing clarity and adequate time to think of concerns and questions is critical.
5. Concerns regarding advertising for seeking research study volunteers.

*Institute PFAC Input:*

“The Institute PFAC team has a variety of experiences and viewpoints that reflect the vast community MGH serves. The team can structure the communication and solicitation to a variety of constituencies resulting in
participation by a broad spectrum of people touched by MGH. The team could
develop the benefit statements to the research participant and make a
difference to ensure communication is not overwhelmed by ‘legalese’ and
‘technical jargon.’”

- **Recommended MGH Paul S. Russell, MD, Museum of Medical History**
  and Innovation as a conduit for inspiring young students to develop tools
  for improving patient care.

  “Institute PFAC members bring the patient perspective of living with
  supportive medical devices.”

- **Dialogue with MGH Service Excellence Program director to identify**
  strategies for best practices for the new Institute HVSC Service
  Excellence Committee—the goal is to improve quality, safety and
  service in care.

  *Institute PFAC Input:*

  “This is very important since ‘Front Desk’ staff leave a deep impression in
  patient experience.”

  “This is so encouraging…looking into ways to integrate patient into the
decision body. We will be ready for PFAC to sit at the table. An opportunity
involving PFAC to share in training sessions.”

**Strengthening and Enhancing Awareness of MGH Institute HVSC PFAC**

- **Participation in Institute for Heart, Vascular and Stroke Care Kick Off**
  “Power of 3” (September 12, 2012)

  Six Institute PFAC members (Susan and Phil Geary, Teri and Tom Fryer, Tom
  Quirk, and David Wooster) participated and engaged the Institute staff in a
  full-day event including:

  1. Exhibit demonstrations and examples of research efforts and
     technological innovations being carried out by Institute staff
  2. Learning about collaborative approaches to treating atrial fibrillation
  3. Sneak Preview of Institute Translational Research Projects

- **Participation in Schwartz Center Annual Dinner (November 8, 2012)**

  Four Institute PFAC members (Pat Hollenbeck, Teri and Tom Fryer, and Tom
  Quirk) joined the MGH Leaders at the Schwartz Center Annual Dinner Event.
• **Award Recipient in MGH Celebrating 50 Years of Transplantation (April 8, 2013)**
On April 8th, MGH celebrated 50 years of transplantation. At the reception, MGH acknowledged and presented David Wooster, Institute PFAC member, the Sandy Cushman Award. This award was given to transplant patients for their exceptional efforts to improve the lives of other transplant patients at Mass General.

• **Participation in Health Care For All (HCFA) PFAC Conference (May 17, 2013)**
Four Institute PFAC members (Teri Fryer, Tom Quirk, Heidi Bas and Judy Silva) attended the first inaugural Healthcare for All (HCFA) PFAC Conference.

*Participant Summary:*

PFAC teams are important because they change the way we experience care at hospital and outpatient care centers. PFAC members represent the consumer voice in healthcare; they operate as the link between the patient and the hospital. The goal is to ensure that the patient experience is more effective, more comfortable and less confusing.

PFAC teams fulfill an important role in the hospital: members can provide direct feedback to hospital management about the experience of clinical care, service, and safety, as well as identify problems and needs for improvement.
OVERVIEW
In 2012, MGH launched the Institute for Heart, Vascular and Stroke Care (IHVSC), a new model of advanced, multi-specialty integrated care designed to be patient- and condition-focused. This model serves to streamline the patient experience by connecting each patient with the right specialist for his/her condition through one, single point of contact. Each specialist works with a multispecialty team of collaborating medical professionals to address a patient's conditions.

In February, the Heart Center Patient & Family Advisory Council (PFAC) membership established in 2007, transitioned and expanded to include representatives in Vascular and Stroke Care.

The mission for the Institute is to set the standard for excellence in multidisciplinary, comprehensive, and innovative heart, vascular and stroke care, drawing upon an unparalleled depth and breadth of clinical experience, to achieve the best outcome for every patient. The Institute will also lead in the discovery of new therapies and create an environment in which information is constantly shared and conversations lead to innovation. As such, the mission statement and goals of the MGH IHVSC PFAC are as follows:

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 MGH.

GOALS
Advisory:
- Work in an advisory role to enhance cardiovascular care at the MGH IHVSC

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

Participate:
- Provide input to improve the physical environment of care
• Provide representation on committees within the MGH IHVSC 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 IHVSC, itself
• New programs, efforts and/or mechanisms for consideration that would enable the MGH IHVSC patients to be able to give back to the MGH community through either support, community or recognitions

**Represent:**

• Patient and family perspectives about the overall experience of care at the MGH
• The MGH IHVSC in its commitment to listening to the voices of patients and families

**Educate:**

• Collaborate with MGH staff to create, review, and revise MGH IHVSC educational materials and processes
• Influence and participate in the education of MGH 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 MGH 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 MGH
• 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 IHVSC PFAC and a thank you letter is sent to the referring MGH clinician or staff member.

**Term of Appointment**

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

**ROLES AND RESPONSIBILITIES**

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

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<th>ROLES</th>
<th>RESPONSIBILITIES</th>
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<td><strong>1. MGH IHVSC</strong></td>
<td><strong>1. MGH IHVSC</strong></td>
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<td>- MGH IHVSC Co-Directors, Program leadership and staff</td>
<td>- Referral of potential PFAC member candidates.</td>
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<td>- Provide new PFAC members with an overview of the MGH IHVSC’s mission, programs and strategic initiatives.</td>
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<td>- Partner with the MGH IHVSC PFAC to improve the patient and family experience of care at the MGH.</td>
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<td>- Provide financial support for monthly meetings and approved Council Member activities beyond the monthly meetings.</td>
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<p>| <strong>2. MGH IHVSC PFAC Members</strong> | <strong>2. MGH IHVSC PFAC Members</strong> |
| MGH Staff | All Members |
| - MGH staff will be appointed by the MGH Heart Center Co-Directors and Associate Chief Nurse | - Maintain patient confidentiality according to Health Insurance Portability and Accountability Act (HIPAA) guidelines. |
| | - Advocate for all patients and |</p>
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<th><strong>Patient and Family</strong></th>
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<td>• Includes patients and families representing diversity in age, gender, ethnicity and nature of heart, vascular and stroke conditions</td>
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<th><strong>MGH Staff</strong></th>
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<td>• Communicate HVSC PFAC activities to the leadership of the executive committees of the MGH IHVSC.</td>
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<td>• Communicate with MGH IHVSC staff re: council recruitment.</td>
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<tr>
<td>• Review new council member application(s) and participate in selection of new council member(s).</td>
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<tr>
<td>• Provide new members with an MGH IHVSC 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 IHVSC &amp; Blum Patient and Family Learning</td>
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Center, MGH 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 IHVSC 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 MGH 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: MGH Yawkey Center for Outpatient Care in Yawkey 2-220
- Time: 5:30 PM to 7:00 PM

REAPPOINTMENT
MGH IHVSC PFAC Staff will remind Council Members for reappointment of members at the end of their term.
MGH Institute Heart, Vascular and Stroke Care
Patient and Family Advisory Council
Members

Patient/Family

Michael C. Bider III
Bob Brunelle
Mary Therese Daniels
Teri Fryer
Tom Fryer
Susan Geary
Phil Geary
Pat Hollenbeck
Denise Mallen
Tom Quirk
Christine Rice
Sr. Jon Julie Sullivan
David Wooster

MGH Staff

Heidi Bas
Lin-Ti Chang
Theresa Gallivan
Marie Elena Gioiella
Douglas Henderson
Judy Silva
Cindy Sprogis
Kevin Whitney
Kim Wilbur
We are pleased to announce that the MGH Heart Center Patient and Family Advisory Council (PFAC) is in the process of transitioning to become the Institute for Heart, Vascular and Stroke Care PFAC.

The current council meets once a month and is comprised of ten cardiac patient/family members and representation from MGH leadership in nursing, cardiology, and administration. The monthly meeting has provided a formal mechanism to insure that the voices of patients and families are represented in the multidisciplinary effort to enhance the care experience at the MGH Heart Center.

Major categories of improvement that patients and families have identified include: (1) improving communication; (2) patient and family centered care; (3) improving continuity of patient care; (4) staff and patient education; and (5) enhancing awareness of MGH Heart Center and PFAC.

As we become the “Institute PFAC”, we are asking for your help in identifying patients and/or family members who might be interested in serving on this Council, particularly those who would represent the Vascular and Neurology (Stroke) patient population. Our goal is to have a broad and diverse council representation.

Individuals should have the following characteristics:
- Able to represent the perspective of patients and family members
- Capable of being both a team player and an initiative-taker
- Able to understand cardio/vascular/stroke disease issues beyond their own experience
- Able to commit the time (approximately 2 hours per month) for Council meetings and potential sub-committee efforts

The Council will partner with faculty, administration, staff and the community to improve the care and services that patients and family members receive in the Institute for Heart, Vascular and Stroke Care.

The Council will focus on the following issues:
- Patient and family care (including process improvement, program development, etc.)
- Training of health care providers in patient/family-centered care
- Potential institutional improvements (including design of facilities, process of care improvement, etc.)
- Information and marketing

If you would like to recommend any of your patients or their family members to participate in the Institute for Heart, Vascular and Stroke Care Patient and Family Advisory Council, please submit name/s (via email) to Lia-Ti Chang at ichang2@partners.org. We will then contact your office for further information and make contact with the patient and/or family member.

Thank you in advance for joining us in our efforts toward creating a more effective partnership between patients, families and their healthcare providers. We believe this collaboration will play a major role in ensuring the best outcomes for patients and ultimately for the Institute for Heart, Vascular and Stroke Care.
MASSGENERAL HOSPITAL for CHILDREN
PATIENT AND FAMILY ADVISORY COUNCIL
## MGHfC Family Advisory Council
### 2012-13 Activities & Accomplishments

<table>
<thead>
<tr>
<th>Topic</th>
<th>Accomplishment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Membership</strong></td>
<td>Recruited two new parent members, bringing our parent membership to 13</td>
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<tr>
<td><strong>Patient Bill of Rights</strong></td>
<td>FAC provided feedback to Ellison 17 and 18 Nursing Director about revising Pediatric Patient Bill of Rights that is given to all patients upon admission to the wards after a presentation by Robin Lipkis-Orlando, Director of Patient Advocacy, informing FAC about purpose and goals of Patient Bill of Rights</td>
</tr>
<tr>
<td><strong>HealthStream Video</strong></td>
<td>Parent Co-Chair of FAC was featured in an instructional video viewed by all MGH staff discussing the importance of good communication and professionalism when interacting with patients</td>
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<tr>
<td><strong>Pediatric Grand Rounds</strong></td>
<td>Organized a Pediatric Grand Rounds in which a parent member of FAC and her daughter’s physician discussed their partnership in caring for the patient through a crucial time in her treatment, outlining the principles of good doctor/patient communication</td>
</tr>
<tr>
<td><strong>NICU patient education documents</strong></td>
<td>The Nursing Director of the NICU and a parent member of FAC met to plan the development of patient education documents orienting new parents to the NICU. Committee formed to carry out</td>
</tr>
<tr>
<td><strong>FAC – Pediatric Fellows Luncheon</strong></td>
<td>Six members of the FAC met for two hours with Pediatric Fellows during the Fellows’ annual retreat. They engaged in frank discussions that enabled each side to gain insight into the experience of the other side. The main take away was that parents want to be more informed in the clinical setting and need information to better partner with physicians and medical staff</td>
</tr>
<tr>
<td><strong>Pediatric Emergency Department</strong></td>
<td>Director of Pediatric ED shared proposed renovation to the ED with FAC members so that FAC could provide feedback before final changes will be made</td>
</tr>
<tr>
<td><strong>Health Care Reform</strong></td>
<td>MGHfC Medical Director Peter Greenspan and Administrative Director Sandra McGee presented PowerPoint on Health Care Reform and how specifically it will affect MGHfC Pediatrics</td>
</tr>
<tr>
<td><strong>Review of Patient Education Material</strong></td>
<td>FAC members continue to review patient education documents before they are distributed throughout the hospital. Examples include “Instructions Following Sedation/Anesthesia”</td>
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<tr>
<td>Continuous Care Initiative Study</td>
<td>Dr. Ryan Thompson presented Pediatric findings from the CCIS which measures patients’ perceptions of the coordination of their healthcare. Upon recommendation of FAC, Dr. Thompson was asked to share findings at Pediatric Unit Chiefs meeting</td>
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<tr>
<td>MGHfC Website</td>
<td>Updated the MGHfC website to highlight the role of FAC in the hospital. Met with Web Master David Ekrem to brainstorm ways to make it easier for interested parties to find information on FAC. Took head shots of each FAC member so they can be placed on the FAC webpage along with short bios of each member</td>
</tr>
<tr>
<td>Orientation for new Pediatric Interns</td>
<td>Two FAC members participated in the orientation event for new Pediatric interns, providing them with written material about FAC and answering questions about family-centered care</td>
</tr>
<tr>
<td>HCAHPS presentation</td>
<td>Upon the request of FAC, Sharon Badgett-Lichten from MGH Service Improvement presented about the MGHfC’s surveys and scores</td>
</tr>
<tr>
<td>FAC Members on Hospital Committees</td>
<td>Parent member of FAC continued to serve on and be recruited to many MGHfC hospital-wide committees. Members continued service on the Ethics Committee and Quality and Safety Committee and were recruited to the Transitions Committee, Conflict of Interest Committee, and MGHfC Advisory Board</td>
</tr>
<tr>
<td>Team Building</td>
<td>Members of FAC (parents and all staff) reserved one hour after a monthly meeting for social engagement with the goal of getting to know each other better</td>
</tr>
<tr>
<td>Pediatric Care Coordination</td>
<td>FAC members worked with Jan Horsky, PhD, from Partners IS, sharing the type of information and functions they would like to see available to them regarding accessing their child’s medical record electronically</td>
</tr>
<tr>
<td>MGH Diversity Committee</td>
<td>The Chair of the MGH Diversity Committee, Dr. Arauz Boundreau, informed FAC members of the hospital’s efforts to increase diversity on staff and better serve MGH’s diverse patient community, soliciting insight from FAC members on future committee efforts</td>
</tr>
<tr>
<td>Innovations Units</td>
<td>Brenda Miller, Nurse Director of Ellison 17 and 18 and Rick Evans, Director of Service, presented to FAC about the Innovations Unit initiative, outlining the changes implemented, goals developed and progress toward those goals</td>
</tr>
<tr>
<td>Medication Reconciliation</td>
<td>FAC parent served on a Pediatric Medication Reconciliation Work Group whose mission was to design and implement a medication reconciliation process for all patients on wards during morning rounds. Program was a success</td>
</tr>
<tr>
<td>Selection of New Co-Chair</td>
<td>FAC conducted a selection process for a new Co-Chair who assumed her position in November. The former Co-Chair stepped</td>
</tr>
<tr>
<td>Family Faculty</td>
<td>FAC parent member continued to be part of the Ambulatory Care Rotation (ACR), sharing her experiences caring for two small children with pediatric residents</td>
</tr>
<tr>
<td>NICU and PICU tea time</td>
<td>The FAC organized and carried out a tea time event for patients and staff in the NICU and the PICU. The purpose was to promote knowledge of FAC throughout the hospital and provide a time of respite and relaxation</td>
</tr>
<tr>
<td>Harvard Medical School Review</td>
<td>A section on the MGHfC Family Advisory Council was included in the MGHfC review for the Harvard Medical School</td>
</tr>
<tr>
<td>Grand Rounds Videos</td>
<td>Upon suggestion of Dave Ekrem, MGHfC webmaster, FAC members looked through four videos of past FAC Grand Rounds presentations to choose sections that will be included on the MGHfC website</td>
</tr>
<tr>
<td>Conference/Course Participation</td>
<td>Two parent members of FAC attended conferences. One attended a patient-centered care conference sponsored by Health Care for All. The other attended the Harvard Medical School Clinical Bioethics course.</td>
</tr>
</tbody>
</table>
Parents and fellows gathered for the unique opportunity to ask pressing questions they normally would not be comfortable asking in a formal setting at the Mass General Hospital for Children Family Advisory Council Luncheon on April 17th.

Fellows and Family Ask Important Questions

SM#0319


Open and forthright comments were the norm at this day as Mass General Hospital for Children (MGH) parents and fellows gathered for a unique opportunity to ask pressing questions they normally would not be comfortable asking in a formal setting. The MGH Family Advisory Council hosted the Family Advisory Council Luncheon on April 17th, an event to create a safe and empowering space for open and direct dialogue.

Fellows who attend the luncheon were training in Pediatric Critical Care, Pediatric Endocrinology, Pediatric Neurosurgery, and Pediatric Plastic Surgery.

Allin MHSC PAC co-chair Randy Chang, PhD, led off the discussion, questions and conversation engaged, beginning with Jannah Mabey, a fellow who asked parents their opinion of training needs.

PAC member Erin Quaterman, PT, argued that while it was important for parents to have a parent-to-parent support group, the PAC must also prioritize training needs. She emphasized the need for parents to know the training needs and how to communicate with other medical professionals about their child.

"It’s a delicate balance," O’Hara said. "There needs to be interaction with dialogue and questions.""Another fellow asked whether family members were able to participate in the training needs survey or whether parents prefer to be informed of their child’s needs through medical correspondence. All agreed that each situation should be handled completely and be dependent on the parent and the group’s preferences.

"I’ve offered the opportunity to every group, but the parents prefer to be informed of their child’s needs through medical correspondence," O’Hara said. "Parents feel the need to be informed of their child’s needs through medical correspondence, and the feedback when parents are informed is positive.""The PAC, who plans to host this event again next year, represents a group of dedicated parent volunteers who provide family-centered care. They work to provide care that is child-centered, holistic, and family-focused. The PAC also serves as a support group for families and provides a venue for open and direct dialogue. The PAC’s goal is to ensure that the needs of children and families are met and that the care provided is empowering and safe.
As a way to spread the word about the work of the MassGeneral Hospital for Children Family Advisory Council, hosted a special ‘Tea Time’ event on the Neonatal and Pediatric Intensive Care Units.

Tea Time with the PAC
OLPH00013

Relocation and repairs from Hall, Linda Plavner, RN, pediatric pharmacists Martha Scheckler, PCU operations associates Joanne Ross, RN, and Harvey Chenard, RN.

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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 (MGHfC) to promote Family-Centered Care;
   2.2. Collaborate with the MGHfC staff in improving the quality of health care provided to children and their families in both inpatient and outpatient settings;
   2.3. 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 MGHfC leadership on issues of planning, evaluation of programs and services, policies and new facilities;
   2.6. Act as an advisory resource to MGHfC giving input to teaching documents generated by the hospital regarding families;
   2.7. Promote a positive relationship between MGHfC 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 MGHfC.

3. **Membership Committee:**
   3.1. Members of the Membership Committee will be appointed by the MGHfC Associate Chief, Department of Pediatrics;
   3.2. The Membership Committee will consist of three current FAC members and two MGHfC 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 MGHfC or are patients sixteen years or older who have received care at MGHfC;

4.3. Family members will serve as the Council Co-Chairs;

4.4. The MGHfC’s Medical Director, Associate Chief Nurse of Pediatrics, Executive Director, and Inpatient Director of Quality and Safety will be ex-officio members;

4.5. The MGHfC Inpatient Director of Quality and Safety will be allowed to vote in times where a tie-breaking vote is required;

4.6. The MGHfC will have four rotating staff members of the Council;

4.7. Other MGHfC staff will attend meetings as needed 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 family member to serve as Council Co-Chair for a two-year term. Six months later, membership will elect a second family member to serve as Council Co-Chair for a two-year term.

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 monthly FAC 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 MGH/C committees when requested;
6.6. Support the MGH/C 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. MGH/C 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 for monthly meetings;
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 MGH/C;
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 MGH/C 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;
- retain Council minutes for a minimum of 5 years
- transmit minutes and annual accomplishments to the hospital's Board of Trustees

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.
AMBULATORY PRACTICE OF THE FUTURE

CARE ALLIANCE

2012-13 ACTIVITIES & ACCOMPLISHMENTS

In addition to the Mass General’s General PFAC and three service-specific Patient and Family Advisory Councils, the hospital’s Ambulatory Practice of the Future operates its own Care Alliance. This provides another structure that facilitates an ongoing partnership with patients and families.

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

The Ambulatory Practice of the Future (APF) is an innovative primary care practice charged with caring for employees of MGH and their spouses/partners. APF is a team-based practice partnering 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 practice, which opened in 2010, is now operating with nearly one and a half of its anticipated three health care teams. An important goal of this practice is to make the experience of care equally rewarding for patients, their families, and staff. The Care Alliance (CA), which is made up of patients and staff providers, is committed to partnering to ensure the values that define APF remain strong as the practice expands. With a solid CA structure now in place, the CA was able to make major strides in furthering its goals in 2013.

Leadership, Membership, and Meetings

Leadership responsibilities are held by patient members. Win Hodges, a founding Care Alliance member, stepped down as chair at the end of 2012, but remains an active member/chair emeritus. Mr. Hodges remains involved with other PFACs at MGH and provides an important link to this broader network. Current co-chairs are Steve Lynch and Rebecca Petersen. Two new patient members were added to reflect the viewpoints of the second APF Care Team (Paul O’Leary and Priscilla White). The physician and nurse practitioner from the second care team now regularly attend CA meetings. The group is currently looking to add more patient members to increase the breadth of the personal and professional experiences and perspectives represented on the CA.

Patient members facilitate meetings on a rotating basis and have added a monthly virtual meeting to brainstorm and work on action plans prior to its formal meeting.
A patient CA member continues to attend APF staff meetings to provide the patient perspective, and staff concerns are regularly summarized for other CA patient members to offer additional input. Staff concerns remain a monthly agenda item to provide a vehicle for more patient input and collaborative problem solving.

2013 Priorities:

**Patient Engagement:** The CA believes it is essential to inform patients about the unique nature of APF and how best to become a partner in their own healthcare. They also believe it is vital to obtain in-depth patient feedback to improve the care experience and stimulate innovation in the practice.

**Staff Concerns:** The CA strives to increase communication between staff and CA patient members by establishing mechanisms to keep informed of current staff issues. This allows CA members to provide patient feedback, partner with staff in problem solving, and contextualize patient feedback from patient surveys.

**Establishing Guidelines for Engagement:** Guidelines are being established to effectively solicit patient feedback, and build effective communication processes with APF staff, Mass General and external organizations.

**Additional areas of focus deemed important include:** Increasing the diversity of the Care Alliance, technology, education and oversight of APF outcomes

2013 Accomplishments:

- A Care Alliance web page was developed on the APF website to introduce the CA and its role to APF patients.
- The Patient Experiences Survey was internally designed and implemented; the CA reviews the feedback.
- A Care Alliance email was established for APF patients to offer more in-depth feedback.
- Patient members of the Care Alliance played major roles in developing and providing input on:
  - Written information for new patients
  - The letter to patients regarding chronic pain medication management
  - Staff processes in a mock patient visit
  - Potential use of clinical practice technologies and telehealth platforms
- The CA also assisted in practice oversight by reviewing:
  - Patient Experience Survey results (CAHPS)
  - Clinical and financial outcomes in the APF Annual Report
• Progress on an ACO/Medical Home Application
• APF website activity and performance
• Three members attended the Health for All PFAC Conference in May

Additional Accomplishments:
Although the Care Alliance is primarily a group endeavor, APF leadership remains open to the unique opportunities that individual CA members offer to further the goals of APF. One member uses his extensive knowledge of PFACs at Mass General to build links with other Mass General PFACs and with national patient-centered organizations. He submitted a presentation abstract to the 2014 Institute for Patient-and Family-Centered Care Conference (“From Plan to New Model: The Ambulatory Practice of the Future”). Another member represented APF at the 2013 National Health Care Policy Conference in Washington, DC in February. A third member is facilitating the development and testing of innovative clinical practice solutions by helping to implement APF’s Innovative Learning Program (ILP). By partnering with APF’s leadership, industry, and academic leaders, he has initiated a more standardized pathway to formal learning, consulting, and research partnerships. His activities have provided additional opportunities for CA patient input on potential new technologies for improved patient care. His IT skills have been valuable in the continued development of the APF website and traffic monitoring.
The Ambulatory Practice of the Future
Care Alliance Members

Ben Crocker, APF physician
Terri Egan, APF Clinical Partner (MA)
Karen Esty, APF Clinical Partner (MA)
Elizabeth Donahue, APF NP
Ishani Ganguli, APF Resident Physician
Win Hodges, Patient (Chair Emeritus)
David Judge, APF Physician and Medical Director
Laura Kehoe, APF Physician
Steve Lynch, Patient (Co-Chair)
Jane Maffie-Lee, APF NP and Clinical Program Director
Mary Ann Marshall, APF RN
Paul O’Leary, Patient
Rebecca Petersen, Patient (Co-Chair)
Paula Sheppard, APF Administrative Assistant
Ryan Sherman, APF Health and Wellness Coach
Matthew Tobey, APF Resident Physician
Jasmine Webb, APF Clinical Partner (MA)
Priscilla White, Patient
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 advisory 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. Non-employee members must go through the Volunteer Orientation and Training, which includes a CORI background check, as well as HIPPA, safety and security training.

Emeritus Members: Care Alliance members who have served three terms as Active Members may become Emeritus Members. Individuals will be polled for their preference for continued membership annually. Emeritus Members will continue to receive materials distributed to the Care Alliance
and are expected to attend Care Alliance meetings. Emeritus Members may continue to represent the Care Alliance on committees and projects. Emeritus Members must be in compliance with the requirements for Care Alliance participation and active volunteer status.

**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 Co-Chair, and one patient or family member, jointly or separately. Upon completing the application review and interviews, the interviewers will present the nominees at a Care Alliance meeting and a vote will decide whether an offer of membership should be extended to the applicant. A new Active Member’s term of membership will commence at the next Care Alliance orientation meeting following his or her acceptance to the Care Alliance.

Section 3. Leave of Absence
An Active or Emeritus Member may request a leave of absence from the Care Alliance at any time during their term when unusual or unavoidable circumstances require that the member be absent from meetings and from working on APF committees and/or projects. The member must submit a request, in writing, to the Co-Chairs, stating the reason for the request and the length of the leave. The Co-Chairs will determine if the request will be accepted. Members on an approved leave are required to contact the Care Alliance Co-Chair prior to the expiration date of granted leave, ensure volunteer status is current, and attend the first monthly meeting after the leave ends, or request a one month extension. A position will be held for a member on leave of absence for three months or less. If a member cannot return at the end of the
three-month period, plus the one month extension if granted, he or she will be asked to resign and wait for an open seat to become available when next again able to fulfill the service requirements.

Section 4. Resignation
An Active or Emeritus Member may resign from the Care Alliance by filing a letter of resignation with the Co-Chairs and the APF Director, effective on the date specified in the notice of resignation. Patient or family members who miss three meetings in a row without explanation will be considered to have resigned.

Section 5. Termination
Care Alliance members who are not fulfilling the role of an Active Member as outlined in Article IV, Section 2, having been given appropriate notice and an opportunity to fulfill the requirements, may be terminated from the Care Alliance, by a vote of two-thirds of the Active and Staff voting members via electronic vote. The APF and the Care Alliance reserve the right to terminate any volunteer who does not uphold the APF’s professional behavior standards.

Article VII. Meetings

Section 1. Regular Meetings
Regular meetings of the Care Alliance will be held on the third Thursday of each month at the APF practice, unless otherwise planned, presuming the presence of a quorum. Care Alliance meetings are open to all interested staff members. Agendas will be distributed prior to each meeting and minutes will be maintained on file for a minimum of five years as part of the APF Care Alliance operations protocol.

Section 2. Special Meetings
Special meetings may be called by the Co-Chairs as they deem necessary. Care Alliance members will be given at least five business days’ notice of the special meeting schedule and agenda.

Section 3. Quorum
An official meeting will require the presence of a minimum of a Co-Chair, two patients and a minimum of four Staff Members to be called to order.

Section 4. Voting
Only Active and Staff Members may vote on official Care Alliance business when voting is required. All issues to be voted on shall be decided by a simple majority vote of those Care Alliance members present at the meeting. In addition, election or termination of Co-Chairs and approval of revisions to bylaws require a vote of Active and Staff voting Members. Such votes may be counted by being present at meetings, submission of an absentee ballot, or submission of an electronic ballot. In the event of a tie vote, all voting members
will be asked to recast their votes. Three consecutive tie votes results in the motion being tabled indefinitely.

A request for consensus of Active, Staff and Emeritus Members may be conducted to approve items such as annual goals, ending a meeting early, or scheduling a retreat. Consensus on these issues shall be decided by a two-thirds majority of those Care Alliance members present at the meeting.

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

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