



2009-10 Patient and Family Advisory Councils

“GUIDED BY THE NEEDS OF OUR PATIENTS AND THEIR FAMILIES, we aim to deliver the very best healthcare in a safe, compassionate environment; to advance that care through innovative research and education; and, to improve the health and well-being of the diverse communities we serve.”

— *The Massachusetts General Hospital Mission* —

“The Hospital’s Patient and Family Advisory Councils provide an invaluable service to the Mass General Community. Because their contributions, energy, insights and unique perspectives directly inform our work, they ensure that we keep true to our mission...and remain truly guided by the needs of our patients and their families.”

— Jeanette Ives Erickson, RN, MS, FAAN
senior vice president for Patient Care and chief nurse

MASSACHUSETTS GENERAL HOSPITAL 2010 REPORT ON PATIENT AND FAMILY ADVISORY COUNCILS

TABLE OF CONTENTS

I. Mass General—A Snapshot	2
II. The Mass General Mission	2
III. Patient and Family Advisory Councils (PFACs) at Mass General	3
IV. Mass General PFACs Background	3
• MassGeneral Hospital <i>for</i> Children FAC	4
• MGH Cancer Center PFAC	9
• MGH Heart Center PFAC	12
V. Additional Councils/Committees/Mechanisms	16
• Multicultural Advisory Committee	16
• Mass General Council on Disabilities Awareness	17
• Additional Areas	19
VI. Summary	20
VII. Policies & Procedures	
Hospital	22
MassGeneral Hospital <i>for</i> Children FAC	24
MGH Cancer Center PFAC	28
MGH Heart Center PFAC.....	30

MASSACHUSETTS GENERAL HOSPITAL — A SNAPSHOT

Massachusetts General Hospital is a 907-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, 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 Mass General:

- Admits 47,650 inpatients
- Handles 1,386,000 million outpatient, health center and emergency visits
(88,300 emergency room visits)
- Performs 38,000 operations
- Delivers 3,560 babies
- Translates medical information between English and 60-plus different languages

Mass General also conducts the largest hospital-based research program in the United States with an annual research budget of nearly \$550 million. This funding drives discoveries and breakthroughs in basic and clinical research, which translate into new and better treatments that transform medical practice and patient care. In addition, Mass General is the original and largest teaching hospital of Harvard Medical School, where nearly all Mass General staff physicians have faculty appointments. Since the hospital's founding, Mass General has been committed to training and mentoring the next generation of international leaders in science and medicine, providing a wealth of opportunities for physicians, nurses, and other health professionals. These clinicians, in turn, lend fresh and innovative perspectives on how to treat and care for patients.

THE MASS GENERAL MISSION

Within this large, complex environment of care, it is our mission that guides our beliefs, decisions and actions — our work. This statement of purpose was rewritten in recent years with direct input from patients and families, and 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.”

All activities of the hospital are driven by the needs of those who entrust Mass General with their care. Hearing their voices, examining the delivery of care through their eyes, and tapping into their personal experiences ensures that the hospital serves our many and varied patients and families to the best of its ability. And as Mass General incorporates the patient and family care experience into its planning and day-to-day hospital operations through a variety of mechanisms, Patient and Family Advisory Councils (PFACs) serve as a primary vehicle for that collaboration.

PFACs AT MASS GENERAL

Mass General's patient and family advisory councils are grounded in the belief that often the most informed voices on the care team are those of the patient and family. Ultimately, they alone can confirm whether a plan of care was explained thoroughly; the clinical information provided was fully understood; their questions and fears were appropriately addressed; care was tailored to their specific needs; they felt safe; systems worked efficiently and effectively; and, each was treated as a person — a whole person — and not simply as a chart or a medical record.

In contrast to being cared for at a hospital with a distinct specialty (i.e., cancer, pediatrics, diabetes) in which patients are more likely to present with common diagnoses, challenges and courses of treatment, patients and families of Mass General are likely to enter with differing sets of needs and to follow varying pathways. The experience of a cardiology patient will be quite distinct from that of a pediatric, cancer, neurology, or general medicine patient, or that of a new mother.

In light of the broad spectrum of patient and family experiences within the same institution, Mass General, along with participating patients and family members, have found it beneficial to operate multiple PFACs, each bringing voice to a specific patient and family experience, environment of care, and/or priority area for the hospital. To this end, the minutes of all PFAC meetings and their accomplishments are provided directly to the hospital's governing body, its Board of Trustees. Individually, these PFACs are optimally situated to impact the delivery of care directly. Collectively, they positioned to influence hospitalwide initiatives, with the added benefit of bringing multiple, authentic and highly relevant perspectives to the table. The PFACs we have developed cover the hospital's most widely used clinical services and represent a large proportion of the care provided at Mass General.

MASS GENERAL PFAC BACKGROUND

The first Patient and Family Advisory Council was formed at Mass General in 1999. Today, clinically-based PFACs at the hospital include the MassGeneral Hospital *for* Children (MGH/C) (established: 1999), MGH Cancer Center (established: 2001), and MGH Heart Center (established: 2007).

In addition, patients and/or their family members — often existing PFAC members — serve on key service-based and hospitalwide committees, including the Pediatrics Ethics Committee, which provides regular case review and ad hoc discussion/consultation; the perinatal Advisory Committee; as well as the Mass General Council on Disability Awareness (established: 2004). The approach provides for both frontline, grassroots involvement, as well as broad-based, hospitalwide impact. Several of *ad hoc* groups have also benefited from patient involvement. For example, our new Ambulatory Practice of the Future, slated to open in 2010, has had a patient involved in all aspects of its planning throughout the last several years.

As stated within the hospital's mission, Mass General is committed to improving the health and wellbeing of the diverse communities it serves. In an effort to better inform this critical work, Mass General also operates a Multicultural Advisory Council (MAC) (established: 2003), comprised of staff, patients and families, and representatives from the community at large.

While the Mass General Patient and Family Advisory Councils are, in essence, self-determining in terms of setting priorities and driving agendas, they all have specific structures and guidelines that are designed to facilitate governance and support members.

MASSGENERAL HOSPITAL *for* CHILDREN — established 1999

Purpose and Areas of Focus

The MassGeneral Hospital *for* Children’s Family Advisory Council (PFAC) 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. The council’s goals are to align with the broader Mass General/MGH/C goal of enhancing patient-physician communication by fostering family-centered communication and promoting the principles of patient- and family-centered care:

Dignity and Respect:

Honoring patient and family perspectives, choices, knowledge, values, beliefs and cultural backgrounds.

Information Sharing:

Communicating and sharing complete, unbiased, accurate and timely information with patients and families so they can effectively participate in care and decision-making.

Participation:

Encouraging and supporting patient and family participation in care and decision-making at the level they choose.

Collaboration:

Partnering with patients and families in the delivery of care; policy and program development and evaluation; healthcare facility design; and, professional education.

The PFAC exists to:

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

Council Operations

The membership of the MassGeneral Hospital *for* Children’s Family Advisory Council (PFAC) consists of fifteen individuals whose children have received care at MGH/C or are patients sixteen years or older who have received care at MGH/C. The current membership includes nine such parents and/or patients. The PFAC recently voted to expand patient/family membership from nine to fifteen, in order to increase the PFAC presence on MGH/C committees, and is actively recruiting additional members. In addition, there are four hospital staff members and four ex-officio hospital staff members. The MGH/C’s medical director, associate chief nurse, executive director, and inpatient director of Quality and Safety serve as ex-officio members. Other MGH/C staff will attend meetings as needed and receive meeting minutes approved by the Council to have knowledge regarding the agenda and on-going work.

“The PFAC provides a wonderful opportunity for family members of patients to share their incredible knowledge and hard-earned expertise about how the hospital can better care for children. A real partnership between staff and families has developed, which is profoundly transformative and mutually beneficial. Parents know that their voices are heard and respected and staff truly recognize the wisdom that families have to share.”

— Sandra Clancy, program manager, Coordinated Care Clinic and the Palliative Care Service, MGHfC and PFAC member

The membership process begins with an application to the PFAC Membership Committee. Each September, the Council seeks to appoint three family members to serve a three-year term to the Council. Upon joining the PFAC, members are required to become active members of the Mass General Volunteer Department, which involves HIPAA training and the annual signing of a hospital confidentiality statement. Ongoing education and training occurs during Council meetings as dictated by need and specific project work. Members may re-apply for appointment for up to six years. After this time, members may still be active on committees but must wait three years before they can reapply for Council membership. 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.

The PFAC members elect two family members to serve as Council cochairs for a two-year term. The election cycle is sequenced so that an experienced cochair is partnered with a newly-elected cochair. The Council cochairs establish the goals and objectives of the Council annually with the Membership. They complete an annual progress report to be submitted to the chief of Pediatrics, chief of Pediatric Surgery MGH, vice-president of Pediatrics, senior vice-president for Patient Care and chief nurse, and Storybook Ball Committee cochairs. The Cochairs set meeting agendas and schedules; represent the goals and objectives of the PFAC with any correspondence approved by the membership with hospital administration and staff; and appoint subcommittee chairs, who are responsible for updates of the subcommittee work to the Council at regular intervals; developing goals and objectives for the subcommittee; and, providing annual reports of the subcommittee.

General Council members are encouraged to participate in ways that match their time constraints and interests. Their main roles include:

- Consultative/advisory (hear presentations at monthly meetings and give feedback)
- Preparation/review/revision/critique of written materials
- Education (give input on design of training programs and/or participate in delivering training programs or other educational sessions)
- Participation on MGH/C Committees and in reward and recognition efforts
- Development and implementation of projects related to the council's goals of promoting the principles of patient- and family-centered care and/or fostering family-centered communication.

The PFAC meets monthly; the Council cochairs prepare the agenda, and an MGH/C staff member attends each meeting and takes minutes. Minutes are sent to members electronically and are approved at the following meeting. Electronic files containing minutes are maintained on hospital servers, which are backed up nightly. These electronic files date back to 2007. Minutes and accomplishments are also transmitted to the hospital's governing body.



Council documents are also stored on a Google Groups site where members can communicate between meetings.

Activities & Accomplishments

The MGH/C Family Advisory Council has established a visible presence within the MGH/C and the larger hospital community and continues to positively influence patient care by providing a parent's perspective on how to deliver meaningful patient- and family-centered care, with a special emphasis on family-centered communication. The following represents a sampling of the results of the Council's collaboration with hospital leaders and staff:

- Planned and presented a Grand Rounds on "Difficult Communication" in which a mother

and her son's physician described how they navigated a breakdown in communication during a critical clinical juncture, and how they emerged with a stronger partnership. In addition to being greatly moved by the story, the physicians and other clinicians attending the session noted the great need for this type of discussion but the few venues where it actually takes place. One of the outcomes of this session was the development of a proposal for a pilot program to enhance resident communication skills. This proposal was recently funded by the MGH/C Quality and Safety group and will be implemented in fiscal year 2011.

- Helped MGH/C chief residents plan family participation in Chief of Service Rounds, resulting in the inclusion of families in three sessions to date.
- Hosted a “Meet and Greet” event for new MGH/C residents and an “Ice Cream Social” for all MGH/C residents during which parents explained principles of patient- and family-centered care and informed the residents about the PFAC and its activities.
- Created posters explaining the principles of patient- and family-centered care and the Family Advisory Council, which are on display throughout MGH/C.
- Created ID badge attachments explaining the principles of patient- and family-centered care and practical tips for practicing family-centered communication, and distributed them to MGH/C residents and staff.
- Participated on the committee designing the new Pediatric Endoscopy area, and advised the team renovating the Pediatric Family Lounge about aspects that would be the most family friendly (i.e., the height of counters in the registration area, layout of the waiting and play areas and selection of colors and materials to promote a relaxing environment).



- Participated in Quality/Safety “Speak Up!” rounds, an award-winning initiative developed by The Joint Commission with the Centers for Medicare and Medicaid Services to engage patients in taking an active role in preventing healthcare errors. They also helped design and implement a forum for families to participate in the Quality & Safety “Speak Up!” program.
- Provided input on the design of and reviewed the results of a survey on patient- and family-centered care given to MGH/C staff members, which resulted in a pilot to include discussion of daily goals with families during hospital rounds.
- Met with the Mass General Council on Disabilities Awareness to provide input on various improvements needed to make the hospital more welcoming to people with disabilities. Helped plan the hospital’s successful “Appointment Buddy” program that provides volunteer assistance to families of children with special needs.
- PFAC members actively served on the following committees:
 - MGH/C Quality & Safety Committee
 - MGH/C Quality & Safety “Speak Up” Subcommittee
 - MGH/C Quality & Safety Hand-offs Subcommittee
 - Ethics Committee
 - Pediatric Endoscopy Planning Committee
- Participated in a dinner for members of all Mass General Family Advisory Councils to share experiences, challenges and insights.
- Participated in user testing of the MGH/C website to assure the navigation and language were most accessible to families.
- Participated in reward and recognition programs by judging application for MGH/C Patient- and Family-Centered Care Awards.
- Presented with a Partners in Excellence Award, recognizing the Council’s contribution to the Quality and Safety “Speak-Up” initiative

MGH CANCER CENTER PFAC — *established 2001*

Purpose and Areas of Focus

The mission of the MGH 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. The PFAC provides a valuable opportunity to hear feedback and recommendations from patients and families about the care they received during their healthcare experience in the Cancer Center. As such, members serve in an advisory role regarding aspects of the planning and delivery of care. Their areas of focus include:

- improving the human experience,
- supporting patient- and family-centered care,
- promoting staff education, and sharing with and learning from others, in an effort to expand the voices of patients and families beyond the Cancer Center.



Council Operations

The PFAC currently consists of 24 members (14 patients, 4 family members and 6 MGH Cancer Center staff members), who represent diverse perspectives and experiences relative to age, gender, diagnosis and socio-economic status. Current members represent eight different Cancer Center disease programs, as well as two different sites (MGHCC Boston and MGH/North Shore Cancer Center). The current PFAC also has 7 Emeritus members who maintain their involvement in PFAC activities, such as participating in the fellow and support staff meetings. However, they are not required to attend the monthly PFAC meetings on a regular basis as is expected of active PFAC members. The six Cancer Center staff members include the physician research director of the Cancer Center, associate chief nurse, executive director for Cancer Center, director of the MGH HOPES Program (social worker), a clinical physician and an executive assistant.

Members must have a treatment history with the MGH Cancer Center for themselves or a family member. They must demonstrate the ability to represent the perspective of patients and family members beyond their own individual experience, have diverse perspectives and backgrounds, be able to work as both a team player and an initiative taker, and commit to participating in the monthly PFAC meetings and sub-committee efforts.

Prospective members are nominated by a cancer center staff/clinician member. They then complete an application form, and a PFAC staff member reviews the application and interviews candidate via telephone or in person (preferred). A current PFAC patient/family member is matched with each candidate to conduct an additional interview. Once this process is completed, the applicant is invited to join PFAC. Upon joining the PFAC, members are required to become active members of the Mass General Volunteer Department, which involves HIPAA training and the annual signing of a hospital confidentiality statement. New members are also given the option of attending the Cancer Center new staff orientation, if they are able to do so. Ongoing education and training occurs during Council meetings as dictated by need and specific project work, addressing such topics as cancer survivorship,

quality of care and treatment updates, to name only a few. They are asked to make a two-year minimum commitment when possible. There are no formal term limits; current membership ranges from 1.5 years to 9 years. It is important to have a range of experiences given the tremendous variation in cancer treatment and survivorship issues.

By choice of the Council membership, there is no formal role of chair; PFAC staff members facilitate the meetings. PFAC patient/family members have requested that PFAC does not have a formal role of chair but that together, they develop agendas, manage flow of meetings etc. There are no elected officers.

PFAC members act in an advisory capacity around issues involving patient- and family-centered care, staff education and sharing and learning from others. Beyond the monthly PFAC meetings, members also serve on the Cancer Center's Steering Committee for Supportive Care Services and in the hospital's Ambulatory Practice of the Future Committee. They serve in an educational/advisory capacity via scheduled meetings with the new oncology fellows, Cancer Center Support Staff and nursing staffs. They have participated in the interview process of oncology nursing leadership, the review of patient satisfaction data and quality data, and in programming (i.e., cancer survivorship, HOPES program), patient education (patient guide, chemotherapy DVD) and operational efforts (workflow redesign/consultation, wait times, patient communication materials).

The MGH Cancer Center Patient and Family Advisory Council meets on the second Wednesday of each month from 5:30-7:30 PM. Documentation of meeting minutes are stored electronically for a minimum of five years. Council minutes and accomplishments are provided to the hospital's governing body.

Activities & Accomplishments

The MGH Cancer Center Patient & Family Advisory Council (PFAC) has had many accomplishments throughout the past year:

- Presented "Learning from Patients and Families: The Development of a Patient- and Family-Centered Curricula for Support Staff" at the Institute for Family-Centered Care (IFCC) 2009 Conference in Philadelphia, PA.
- Participated in 2009 Mass General Nurse Recognition Week celebration of Nursing Excellence — On May 7, 2009, Angela Adinolfi, joined by Heart Center PFAC and MassGeneral Hospital for Children PFAC representatives, participated in a dialogue with Jeanette Ives Erickson, senior vice president for Patient Care and chief nurse. The discussion focused on the patient and family experience of care at Mass General and the role that nurses play in that experience.
- Mass General Development Office Consultation — Provided guidance as to the patient/family experience around potential third-party events.
- Participated in work flow/patient scheduling re-design projects for the chemotherapy infusion unit.
- Provided patient and family experience to chair of Cancer Center Quality Committee.
- Provided consultation to inpatient nursing (neurology) regarding surveying patients about satisfaction.

- Participated in two training sessions with oncology fellows and radiation oncology residents. Each session provided the physicians an opportunity to learn directly from patients and families about the human experience of living with cancer. The format encouraged an open and honest dialogue about the relationships between patients and their oncologists.
- Participated in “Meet the Patients” sessions with support staff. These followed the format of the sessions with fellows outlined above and offered an opportunity for support staff to meet and hear directly from patients and caregivers about their experiences and discuss concerns.
- Participated in several discussion sessions with nurses, both on the inpatient units as well as in the outpatient infusion unit, regarding the importance of relationships between providers and patients, human experience.
- Advocated for the development of a pilot program to enhance the pre-treatment chemotherapy teaching for patients and families. This led to the development of a pilot chemotherapy orientation program for patients and families, which they will be scheduled to attend. The offering, provided through the MGH HOPES Program, will be held five days a week and led by oncology nurses and pharmacists.
- Participated in the Cancer Center’s Annual Survivors Day conference.
- Provided consultation to the development of a new cancer survivorship clinic and program.
- Provided patient/family feedback for Cancer Center publications, including a “Signature” brochure and a “Guide for Patients and Families.”
- Several members of PFAC, including Maggie Carvan, Lynne Graziano Morin, Win Hodges and Renee Johnson, were honored with a Cancer Center “One Hundred Award.”
- Two members of the council provided consultation to the newly formed PFAC at Cooley Dickinson Hospital.

“Our role is advisory. We are patients, survivors and caregivers who want to help the next patient coming through the door. All opinions have value because they come from our own experience at the Cancer Center. It is enormously gratifying to feel that I can make the cancer journey for someone just a little better because of this collaboration with the Cancer Center staff who do it every day!”

— PFAC Patient Member

MGH HEART CENTER PFAC — *established 2007*

Purpose and Areas of Focus

The MGH Heart Center PFAC exists to ensure that the voices of patients and families are represented in a multidisciplinary effort to enhance the experience of care at Mass General. To this end, the Council focuses on several key goals:

Advise

Work in an advisory role to enhance cardiovascular care at the MGH Heart Center.

Support

Act as a sounding board for implementation of new MGH Heart Center programs, and improvement of existing programs.

Participate

Provide input to improve the physical environment of care; provide representation on committees within the MGH Heart Center to represent the voice of the patient and families.

Identify

Opportunities to promote wellness and prevention of heart disease; patient- and family-centered care strategies; new services, programs and/or communication, for consideration, that may benefit the heart center patients and/or the MGH Heart Center, itself; and new programs, efforts and/or mechanisms for consideration that would enable the MGH Heart Center patients to be able to give back to the Mass General community through either support, community involvement or recognitions.

Represent

Patient and family perspectives about the overall experience of care at the Mass General; the MGH Heart Center in its commitment to listening to the voices of patients and families.

Educate

Collaborate with Mass General staff to create, review, and revise MGH Heart Center educational materials and processes; influence and participate in the education of Mass General staff, including registered nurses, nurse practitioners, physicians and support staff.



Council Operations

The MGH Heart Center PFAC consists of 13 members (eight patients, two family members and three Mass General representatives) who represent a diverse perspective and experience relative to age, gender, nature of cardiovascular illness, and socio-economic status. Recruitment of patient and family council members is initiated by referrals from all disciplines, including Mass General physicians, nurses, other healthcare professionals, and staff. Invitation letters and application forms are then sent to potential participants.

Upon joining the PFAC, members are required to become active members of the Mass General Volunteer Department, which involves HIPAA training and the annual signing of a hospital confidentiality statement. Ongoing education and training occurs during Council meetings as dictated by need and specific project work.

Applicants are selected based on the following criteria:

- Current experience as a patient or family member at Mass General
- Ability to represent overall patient care experience
- Willingness to work in an advisory role
- Ability to participate in a consistent and agreed-upon schedule of meetings and potential subcommittee efforts
- Commitment to serve for a two-year term with potential to renew or step down at the end of the term. (Any resignation is submitted in writing or via email to the MGH Heart Center PFAC. Vacancies may be filled during the year as needed.)

Members of the MGH Heart Center PFAC select and grant two-year terms to council members. At the end of a two-year term, council members may request to be re-appointed. Each May, members elect a patient or family member to serve as Chair for a two-year term. This individual represents the Heart Center PFAC in MGH Heart Center activities and other forums as needed, with support, input and participation of council members. He/she communicates Heart Center PFAC activities to the leadership of the MGH Heart Center executive committees, and serves as liaison to Heart Center Programs, Administration, Operations, Marketing and Development. A staff cochair supports the duties of the Chair in his/her absence.

Members meet on the first Tuesday of each month, from 5:30 to 7:00pm. Electronic files containing minutes are maintained on hospital servers, which are backed up nightly. These electronic files date back to the Council's inception in 2007. Minutes and accomplishments are also transmitted to the hospital's governing body.

Activities & Accomplishments

The MGH Heart Center Patient and Family Advisory Council (PFAC) realized many accomplishments in the prior year:

Enhancing Patient- and Family-Centered Areas

- Participated in the Institute for Family-Centered Care (IFCC) 2009 Conference
- Participated in 2009 Nurse Recognition Week celebrating Nursing Excellence — On May 7, 2009, Council member David Wooster, joined by Cancer Center PFAC and MassGeneral Hospital for Children PFAC representatives participated in a dialogue with Jeanette Ives Erickson, RN, MS, FAAN, senior vice-president for Patient Care and chief nurse. The discussion focused on the patient and family experience of care at Mass General, and the role that nurses play in that experience.
- Consulted to Mass General Development Office — Provided input on the testimonial and informational materials for fundraising and major gifts; improved patient Q & A sheet regarding the HIPAA "Use of Information Patient Authorization Form" and provided input on the implementation of the HIPAA collection process.

Enhancing Staff Education

- Participated in the Patient Care Services “Continuity of Care” conference sponsored by the service’s Doc Com Committee — Council members shared highlights of themes of the conference, which can be applied to all disciplines and support staff, including the importance of continuity of care, treat patients and family members with dignity, camaraderie and caring and, provide care for my support system as well as for me.
- Participated in the Patient Care Services “Defining Link Between Patient Education and Health Literacy with Quality and Safety” conference sponsored by the Patient Care Services Collaborative Governance Patient Education Committee — Council members shared highlights of themes, which can be applied to all disciplines including patient education as a communication between the physician and nurse; inadequate time as a main barrier to effective patient teaching/learning; the importance of providing patients with a list of questions to begin conversations with their healthcare providers; and, working with insurance companies on the reimbursement for patient education.
- Council members shared reflections of barriers and strategies to empower patient/family in a health encounter:

Barriers in Understanding Healthcare Information

1. Patients not feeling they have license to ask questions
2. Poor access to information (rounds, written materials, websites)
3. No formal access 24/7 to information and support following discharge or MD visit
4. Inadequate patient education tools

Strategies to Empower Patient/Family in a Health Encounter

1. Send message that it’s okay to ask questions and that we care
2. Make information more accessible to patients
3. Provide 24/7 systems for information and support
4. Collaborate with patients and families in design of educational programs

Enhancing Patient Education

- Supported implementation of “Cardiac Surgery Patient Care Pathway”
- Revised Patient Education Brochure titled “Understanding and Preparing for a Catheterization Procedure”
- Consulted to the Mass General Maxwell & Eleanor Blum Patient and Family Learning Center regarding video selections for Heart Failure Education
- Input to Heart Failure Patient Education piloted materials (pending final review and approval)

Enhancing MGH Heart Center Service and Patient Satisfaction

- Provided input to Timothy Ferris, MD, medical director, Massachusetts General Physicians Organization, on an improving continuity of care initiative
- Offered input to enhance communication, service and marketing, including the Heart Center website development; Heart Center Patient Portal development; Patient Care Services Clinical Support Services; Mass General Service Improvement; Knight Center for Interventional Cardiovascular Therapy (Process Improvement Team); and, Heart Center radio ad campaign.

Participating in Activities to Raise Awareness of MGH Heart Center and PFAC

- Mass General Magnet Hospital re-designation
- Recipient of 2008 Partners in Excellence Award for Exemplary: Performance in Quality Treatment and Service
- Consultation to PCS Office of Quality and Safety
- Mass General PFACs (Cancer Center, MassGeneral Hospital *for* Children) in 1st Annual Networking Dinner
- 2008 Patient Care Services Annual Report cover story “Taking Center Stage Advancing Patient- and Family-Centered Care”
- Featured in PCS Newsletter – *Caring Headlines*, “Patient Empowerment Through Health Literacy: A Quality and Safety Issue”
- Nominated Cardiac Surgery nurse practitioner Stephanie Ennis for a 2009 *Nursing Spectrum* Excellence Award (Regional Finalist)
- MGH Heart Center PFAC at Annual Cardiac Nursing Visiting Scholar Program presentation
- Conducted PFAC Heart Center patient care site visits
- “Mass General Go Red for Women: Heart-healthy Cooking” demonstration

“It’s extremely rewarding for all of us to see the ideas we discuss in Council meetings come to life within the hospital. We can see that our own perspectives as patients and family members are having a very real impact on the delivery of care.”

—Susan Geary, MGH Heart Center Patient

ADDITIONAL COUNCILS/COMMITTEES/MECHANISMS

In addition to its three clinically-focused PFACs, Mass General has formally incorporated patient, family and community membership into two significant committees that focus on the key mission-driven area of diversity. The focus here, as expressed in the hospital mission, is “...to improve the health and well-being of the diverse communities we serve.”

MULTICULTURAL ADVISORY COMMITTEE (MAC)

Mission and Purpose:

In 2003, the hospital established a Committee on Racial and Ethnic Disparities in Health and Health Care to identify and address disparities wherever they may exist within Mass General. Minorities are represented at Mass General at the same rate they are represented in the statewide population, but at a lower rate than the in the City of Boston. The majority of minorities cared for by Mass General receive their care at the hospital’s health centers in Charlestown, Chelsea and Revere, and Hispanics are seen at significant rates in these health centers, particularly in Chelsea.

The Committee early on recommended creating a multicultural advisory committee to advise Mass General on minority patients’ experience of care at the hospital; to advise Mass General on minority communities’ perceptions of the hospital, as a provider and as a community member; and, to review new and existing programs or initiatives aimed at addressing minority patient or community issues at Mass General.

Structure and Operations:

The make-up of the Multicultural Advisory Committee (MAC) is designed to be far-reaching, comprehensive, representative of the community-at-large, and empowered to take action. The MAC consists of 15-18 community members, including patients, family members, religious leaders, community leaders, business leaders, and reflects the racial and ethnic demographics of Boston and the Mass General health center communities. In addition, the membership includes the hospital’s president, senior vice-president for Patient Care Services and chief nurse officer, the cochairs of the Mass General Disparities Committee, and select members of the Mass General community.

Members are invited to serve for a three-year period. Upon joining the committee, members receive an orientation to the hospital, its staff and patient make-up and to the various initiatives in place related to issues of concern to patients and communities of color (i.e., healthcare disparities, community outreach, staff recruitment and retention, efforts to create pipelines for minority students to work at Mass General). In its second year of operation, the MAC formed an ad-hoc nominating committee that created membership criteria, including racial and ethnic representation, as well as “sector” representation.

The MAC meets quarterly and on an as needed basis. HIPAA training is not required as members provide overarching input and are not involved in direct patient care.

Priorities and Outcomes:

Through early telephone surveys that over sampled Mass General minority patients, the Multicultural Advisory Committee prioritized issues of immediate concern, including:

- How “welcomed” front line staff at Mass General make people feel;
- The importance of language in patients’ experiences of care; and,
- The impact of insurance status on patients’ experience of care.

As a result of the MAC's recommendation, the hospital launched a new program called, "The Service Matters Series." The eight-hour program trains frontline staff about providing a welcoming experience for patients and families.

As the work of the MAC progresses and Mass General initiatives are discussed and moved forward, committee members continue to provide an invaluable perspective, raising critical issues, and looking to root causes of and solutions related to problems, challenges and opportunities. For example, assessing Mass General's readiness to serve the population of people from those communities who do not see anyone at Mass General who looks like them; identifying the real barriers to improving the health status of minority patient populations; assessing the hospital's ability to serve the community in the community, rather than expecting people to come to the hospital; or, exploring partnering with pre-existing community coalitions and community-based organizations that are working on similar issues but with limited resources.

One representative example of a MAC contribution involves the hospital's Focus Group Findings in Boston Neighborhoods. These were presented to the group to solicit input and ideas for moving forward. The recommendations for action, included developing a health literacy campaign to deliver disease-specific information, health insurance and health reform information, assistance on navigating the health care system, and prescription medication information; partnering with community agencies/organizations/churches to address violence and subsequent trauma, mental health, along with other health concerns identified through the focus groups; and, fostering pipeline initiatives that result in neighborhood residents entering health careers. Results were then presented to the hospital's Diversity Committee.

MASS GENERAL COUNCIL ON DISABILITIES AWARENESS

Mission and Purpose:

Dealing with unfamiliar health concerns while navigating a complex, medical environment can be a daunting prospect for anyone. But for individuals with disabilities — physical limitations, hearing deficits, sight impairments, cognitive disorders — accessing hospital-based care can present even greater challenges. The Council on Disabilities Awareness (CDA) was formed in 2003 to help the hospital address the many and diverse needs of Mass General staff, patients and families, and visitors with disabilities. Its mission is clear: to advise, challenge, and engage the Mass General community in moving beyond the mandates of compliance to create a welcoming and accessible environment for all.

Structure and Operations:

Cochaired by hospital and Partners HealthCare leadership, the CDA membership includes several patient participants and staff from throughout Mass General, including representatives of Patient Care Services, Human Resources, Food and Nutrition, facilities, support services and senior management. Through its commitment to improving care for people with disabilities, the CDA has developed key collaborations with local organizations such as the Boston Center for Independent Living (BCIL) and the Massachusetts Commission for the Blind, to identify and sponsor hospital initiatives that address disabilities-related matters at the hospital.

Since 2008, the Council has been engaged in an ambitious agenda. The CDA more than doubled its already sizable membership and identified three areas of focus: patient services and equipment, physical environment, and staff education and awareness. In an effort to

further and more systematically integrate the patient and family perspective into its work and new organizational structure, CDA leadership invited patients and family members to become active members of the larger Council. To date, several individuals have agreed to participate and represent a range of perspectives, including a middle-aged female who uses

ACCESS ABILITY

a wheelchair; a young adult who uses a wheelchair and has multiple physical challenges; a widowed spouse of a former Mass General patient who had multiple disabilities; a young man who is blind; and, a community advocate whose adult son presents with severe cognitive deficits.

In June of 2009, Mass General and Brigham and Women's Hospital leadership and members of the hospitals' respective Disabilities Councils collaborated with BCIL leaders — including several Mass General patients — to launch a comprehensive initiative reaffirming the hospitals' and Partners HealthCare's commitment to focusing on the special needs of people with disabilities at each hospital. The result is an historic plan that stands to serve as a model across the Commonwealth and beyond for equitable health care, services and access for people with disabilities.

In 2010, the Administration recognized the need to create a new role of Disabilities program manager within the Office of Patient Advocacy to help educate, recommend and champion initiatives that would move the institution closer to the Council's mission.

Priorities and Outcomes:

From the outset, patients have played an integral role in the group's work. Most notably, early on, several Council members toured the hospital with individuals with disabilities to identify potential areas for improvement. Their findings were then presented to the hospital's senior management for immediate action. For example, Capital Budget funds were approved to set up a centrally-located Access Center featuring assistive technology equipment for patient and staff use, including a Braille printer; Kensington Turbo Mouse and trackball; Infogrip Roller plus Joystick; Dragon Naturally Speaking dictation software; JAWS screen reader software; Telesensory low-vision aid; a TTY phone; and more. The hospital also hired a full-time American Sign Language/English interpreter to be available to Mass General patients and visitors, and introduced CART (Communication Access Real-time Translation) Services, in which professional captioners type the speaker's spoken words into text that displayed on a computer monitor or other display device for the individual who is deaf or hard of hearing to read on a computer screen.

With input and feedback from patients and members of the community-at-large, the Council also launched a new Accessibility web page (www.massgeneral/access) that can be reached from virtually every Mass General webpage. It is believed to be a first-of-its-kind healthcare resource. The site provides important information about transportation, parking adaptive devices and other important resources for people with disabilities who are planning their hospital visit. There is also a prominently displayed mechanism for patients and families to directly e-mail the hospital's Disabilities program manager.

Throughout the past year, CDA leadership and the Disability Program manager have conducted individual meetings with parents of adult children with severe cognitive impairments on four separate occasions. These parents voiced their concerns regarding the unique needs of their adult children. As a result, the director of the Office of Patient Advocacy and Disability Program manager met with the administrative leadership of MassGeneral Hospital *for* Children to review options and potential solutions for parents when their children are no longer under pediatric medicine but warrant alternatives before transitioning to adult medicine.

Many of the changes the council has initiated throughout the past six years have greatly benefited patients and visitors. The participation of employees from across the hospital, as well as the critical input from our council members, have helped the CDA increase awareness of disability-related issues and have enhanced the environment throughout the hospital.

ADDITIONAL AREAS

Mass General also has several additional mechanisms in place for tapping into the patient and family experience of care:

- The Office of Patient Advocacy (OPA) is responsible for managing the hospital's patient commendation and complaint process. Patient Advocates serve as liaisons between patients/families and the hospital. They coordinate, research, and resolve patient/family grievances concerning the quality of care and services by providing a formal mechanism for investigating patient complaints. In addition, the department coordinates the implementation of The Joint Commission standards and state/federal laws pertaining to patients' rights, advance directives, the Americans with Disabilities Act, and ethical issues.
- Several members of the hospital's Patient and Family Advisory Councils served as active participants in The Joint Commission and American Nurses Credentialing Center's Magnet Hospital review processes. Both reviews were quite comprehensive, with multiple surveyors spending up to a week visiting the hospital — including patient care units, service areas and laboratories — and interviewing patients, family, visitors, and staff they encountered. Patient and family participation offers increased transparency throughout the process by interjecting an authentic and truly “lived” experience.
- The hospital utilizes several survey mechanisms to collect post-hospitalization feedback from patients and families. For example, the Consumer Assessment of Healthcare Providers and Systems (CAHPS) program is a public-private initiative to develop standardized surveys of patients' experiences with ambulatory and facility-level care. This is a comprehensive and evolving family of surveys that ask patients to evaluate the interpersonal aspects of health care (Inpatient - H-CAHPS, Outpatient/Specialty Care - CG-CAHPS, Emergency Care - a modified CAHPS style survey, Pediatrics - a modified CAHPS style survey). CAHPS surveys probe those aspects of care for which patients are the best or only source of information, as well as those that patients themselves have identified as being important. CAHPS surveys are similar to patient satisfaction surveys but go beyond rating providers and health plans by asking patients to report on their experiences with health care services. In addition, the MGH Cancer Center uses an Outpatient Survey tool administered by Press Ganey.

- Mass General also supports a free service for patients and family members called CarePages. This web-based tool allows patients and families to create a free, private web page to help them stay in touch with friends and family before, during and after hospitalization. The hospital also uses Mass General CarePages to provide important quality and safety information to patients, family and visitors, in addition to offering a mechanism for them to provide feedback to the hospital and their caregivers.

SUMMARY

The hospital has long been committed to cultivating a patient- and family-centered environment of care — the cornerstone of our mission. And this cultural value comes to life every day through the actions of our broad and diverse staff. But it is the perspective — the voices and the vision — of our patients and families that provides our moral and operational compass. To this end, the Mass General Patient and Family Advisory Councils contribute greatly to the Mass General community.

With the launch of the hospital's first Patient and Family Advisory Council in 1999, Mass General began to tap into a vital mechanism for integrating the critical patient and family perspective into our day-to-day operations, various initiatives, and plans for the future. This patient/family and staff partnership continues to evolve and expand and shape the delivery of care, today and for the years to come.



FOLDER: ADMINISTRATIVE POLICY & PROCEDURE
DOCUMENT: PATIENT AND FAMILY ADVISORY COUNCILS

1.0 POLICY

- 1.1 Patient and Family Advisory Councils (PFACs) at Massachusetts General Hospital function for the purpose of obtaining patient and family member perspectives; sharing hospital information about hospital functions; and promoting positive relationships among all members to improve the quality and safety of patient care.

2.0 BACKGROUND

- 2.1 The Massachusetts General Hospital (MGH) has a long tradition of engaging patients and family members in their overall care delivery, decision-making, information sharing, and policy and procedure development.

In 2004, the hospital administration embraced the 6 pillars articulated by the Institute of Medicine emphasizing that we believed in patient care that is safe, equitable, efficient, effective, timely, and patient and family-centered. These aims for improvement are used in support of the hospital mission.

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

MGH has established numerous mechanisms to formally engage patients and family members in the advancement of this mission. These include the establishment of the Office of Patient Advocacy, The Maxwell & Eleanor Blum Patient and Family Learning Center, the utilization of data from patient surveys and feedback, the inclusion of patients and families in focus groups and hospital committees, and the establishment of Patient and Family Advisory Committees.

3.0 GOALS

- 3.1 The four concepts of patient and family centered care, as stated by the Institute for Patient-Centered Care, define the MGH goals for patient and family member involvement in healthcare participation.

1.1.1 DIGNITY AND RESPECT

Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.

1.1.2 INFORMATION SHARING

Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.

1.1.3 PARTICIPATION

Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

1.1.4 COLLABORATION

Patients, families, health care practitioners, and hospital leaders collaborate in policy and program development, implementation, and evaluation; in health care facility design; and in the delivery of care.

4.0 MEMBERSHIP

- 4.1.1 Includes both patients and family members (exclusion: children under 16 will not be patient members of MGH/C's advisory committee)
- 4.1.2 Includes staff as members
- 4.1.3 Co-chairs are patients/family members
- 4.1.4 Patients or family members represent a minimum of 50% of members

5.0 RESPONSIBILITIES OF MEMBERSHIP

- 5.1.1 Understand role definition
- 5.1.2 Participate in orientation
- 5.1.3 Attend education for HIPAA
- 5.1.4 Sign MGH Confidentiality Statement
- 5.1.5 Participate on hospital committees, including patient safety issues, as necessary
- 5.1.6 Maintain minutes of Council meetings for a minimum of five years.
- 5.1.7 Transmit minutes and accomplishments to the hospital's Board of Trustees

REFERENCES

Rules and Regulations Governing Patient and Family Advisory Councils, 105 CMR

Institute for Family-Centered Care, <http://www.familycenteredcare.org/>

Institute of Medicine, <http://iom.edu>

Approved: Patient Care Services Executive Committee, September 2010

Approved: Senior Management, September 2010



Family Advisory Council Charter/By-laws

1. Mission Statement:

The MassGeneral Hospital *for Children*'s Family Advisory Council (FAC) is dedicated to fostering the partnership of 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 patient- and 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 MGH/C will have four rotating staff members of the Council;
- 4.7. Other MGH/C 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 MGH/C 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 Pediatrics, chief of Pediatric Surgery MGH, Vice-President of Pediatrics, MGH, Vice-President, Chief Nurse, MGH, Storybook Ball Committee Chairs;

- 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 MGHfC;
- 8.2. Work together with the FAC in policy-making, planning and evaluating of programs and services;
- 8.3. Review and respond to recommendations of the FAC in a timely manner;
- 8.4. Offer new member orientation to the MGHfC structure, decision-making process, committee structure, and HIPPA regulations;
- 8.5. Provide meeting space and refreshments;
- 8.6. Provide free parking for FAC meetings and work in hospital;
- 8.7. Provide financial support for approved FAC activities based on submitted proposals.
- 8.8. Provide staff support person to:
 - take meeting minutes;
 - notify members of upcoming meetings with agendas;
 - distribute meeting minutes to the Council and others on the distribution list;
 - keep the FAC distribution list up to date;
 - 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.



Patient and Family Advisory Council Charter / By-laws

1. **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

2. **Purpose:**

- To act in an advisory capacity to influence Patient and Family-Centered Care as well as staff education and support.
- PFAC members strive to share and learn from others in an effort to expand the voices of patients and families beyond the walls of the Cancer Center.

3. **Membership:**

A minimum of 50 percent of the Council membership will be comprised of patients and family members.

Qualifications:

Members must have:

- a treatment history at the MGH Cancer Center for themselves or a family member
- ability to represent the perspective of patients and family members beyond their own individual experience
- diverse perspectives and backgrounds
- ability to work both as a team player and an initiative taker, and
- ability to make the time commitment for meetings and sub-committee efforts.

Selection: Prospective members are nominated by a cancer center staff/clinician member. They then complete an application form, and a PFAC staff member reviews the application and interviews candidate via telephone or in person (preferred). A current PFAC patient/family member is matched with each candidate to conduct an additional interview. Once this process is completed, the applicant is invited to join PFAC.

Orientation/training: Upon joining the PFAC, members are required to become active members of the MGH Volunteer Department, which involves HIPAA training and the annual signing of a hospital confidentiality statement. New members are also given the option of attending the Cancer

Center new staff orientation, if they are able to do so. Ongoing education and training occurs during Council meetings as dictated by need and specific project work, addressing such topics as cancer survivorship, quality of care and treatment updates, to name only a few.

Terms: Members are asked to commit to a 2 year minimum term; there are no formal term limits. Extended terms allow for a range of experiences to be represented relative to various cancer treatments and survivorship issues.

Officers: By choice of the Council membership, there is no formal role of chair; PFAC staff members facilitate all meetings. PFAC patient/family members have requested that the PFAC not have a formal role of chair but that together, the members develop agendas, manage flow of meetings, and attend to other operational issues. There are no elected officers.

4. Membership Responsibilities:

- PFAC members act in an advisory capacity around issues involving patient and family-centered care, staff education and sharing and learning from others.
- Beyond the monthly PFAC meetings, members also in an educational/advisory capacity via an array of scheduled meetings (i.e., oncology fellows, Cancer Center Support Staff, nursing staff).
- Members will participate in various operational activities of the MGH Cancer Center (i.e., interview process of oncology nursing leadership, the review of patient satisfaction data and quality data, and in programming, patient education, and related operational efforts as dictated by need and/or interest.
- Members will respect patient privacy and confidentiality (see orientation, section 3).

5. Meeting schedule and reporting:

The MGH Cancer Center Patient and Family Advisory Council meets monthly from 5:30-7:30 PM. Documentation of meeting minutes are stored electronically for a minimum of five years. Council minutes and accomplishments are provided to the hospital's governing body.



Patient and Family Advisory Council Charter / By-laws

OVERVIEW

While the Massachusetts General Hospital (MGH) prepared to celebrate the launch of the MGH Heart Center in 2007, planning was initiated to form the MGH Heart Center Patient & Family Advisory Council (PFAC). The first meeting was held on February 6, 2007.

The MGH Heart Center's mission is to set the standard for excellence in multidisciplinary, comprehensive, and innovative cardiovascular care, drawing upon an unparalleled depth and breadth of clinical experience, to achieve the best outcome for every patient. The MGH Heart Center will also lead in the discovery of new therapies and in the education of healthcare professionals throughout the nation. As such, the mission statement and goals of the MGH Heart Center 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

Advise:

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

Support:

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

Participate:

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

Identify:

- Opportunities to promote wellness and prevention of heart disease
- Patient- and family-centered care strategies
- New services, programs and/or communication, for consideration, that may benefit the heart center patients and/or the MGH Heart Center, itself
- New programs, efforts and/or mechanisms for consideration that would enable the MGH Heart Center 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 Heart Center in its commitment to listening to the voices of patients and families

Educate:

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

MEMBERSHIPNomination 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 two-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 Heart Center PFAC and a thank you letter is sent to the referring MGH clinician or staff member.

Term of Appointment

- Members of the MGH Heart Center PFAC select and grant two-year terms to council members.
- At the end of a two-year term, council members may request to be re-appointed.
- Each May members will elect a council Chair for a two-year term.
- The council Co-Chair shall carry out the duties of the Chair in his/her absence.
- Resignation will be submitted in writing or via email to the MGH Heart Center PFAC. Vacancies may be filled during the year as needed.

ROLES AND RESPONSIBILITIES

Membership consists of 14 to 16 members: patients, family members and MGH staff. The three membership roles are described below.

ROLES	RESPONSIBILITIES
<p>1. MGH Heart Center</p> <ul style="list-style-type: none"> ▪ MGH Heart Center Co-Directors, Program leadership and staff 	<p>1. MGH Heart Center</p> <ul style="list-style-type: none"> ▪ Referral of potential PFAC member candidates. ▪ Provide new PFAC members with an overview of the MGH Heart Center’s mission, programs and strategic initiatives. ▪ Partner with the MGH Heart Center PFAC to improve the patient and family experience of care at the MGH. ▪ Provide financial support for monthly meetings and approved Council Member activities beyond the monthly meetings.
<p>2. MGH Heart Center PFAC Members</p> <p><u>MGH Staff</u></p> <ul style="list-style-type: none"> ▪ MGH staff will be appointed by the MGH Heart Center Co-Directors and Associate Chief Nurse <p><u>Patient and Family</u></p> <ul style="list-style-type: none"> ▪ Includes patients and families representing diversity in age, gender, ethnicity and nature of cardiovascular illness 	<p>2. MGH Heart Center PFAC Members</p> <p><u>All Members</u></p> <ul style="list-style-type: none"> ▪ Maintain patient confidentiality according to Health Insurance Portability and Accountability Act (HIPAA) guidelines. ▪ Advocate for all patients and families by identifying and representing their needs and concerns. ▪ Establish goals and objectives of the MGH Heart Center PFAC at the beginning of each year. ▪ Plan, facilitate and guide the work of the MGH Heart Center PFAC. ▪ Prepare for and attend meetings. ▪ Provide notification by email or phone in advance, if attendance is not possible at a given meeting. ▪ Participate in meeting discussions and activities. Any pertinent information, ideas, and suggestions should be communicated at meetings or by email or phone. ▪ Be willing to consider additional opportunities for involvement beyond the monthly meetings.

ROLES	RESPONSIBILITIES
	<p data-bbox="751 367 898 394"><u>MGH Staff</u></p> <ul style="list-style-type: none"> <li data-bbox="751 401 1256 470">▪ Communicate with MGH Heart Center staff re council recruitment. <li data-bbox="751 476 1276 588">▪ Review new council member application(s) and participate in selection of new council member(s). <li data-bbox="751 594 1281 850">▪ Provide new members with an MGH Heart Center PFAC name tag and a binder which includes: Meeting Schedule, Staff and Member Contact List, Status Report, PHS Confidentiality Agreement and Caring Headlines Permission Form, Website page of MGH Heart Center & Blum Patient and Family Learning Center, MGH Ground Floor Map & Directions to the Yawkey Center for Outpatient Care. <li data-bbox="751 1087 1256 1270">▪ Send a reminder email to council members one-week prior to the monthly meeting including agenda and attached minutes from the previous meeting. <li data-bbox="751 1276 1281 1535">▪ 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. <li data-bbox="751 1541 1105 1570">▪ Provide meeting space. <li data-bbox="751 1577 1273 1646">▪ Provide complimentary parking and light dinner at each meeting. <li data-bbox="751 1652 1256 1877">▪ Provide a PowerPoint slide presentation on the ongoing Council’s activities and accomplishments as determined by the MGH Heart Center Executive Committee. <li data-bbox="751 1883 1243 1953">▪ Provide an annual progress report on Council’s accomplishments

	<ul style="list-style-type: none"> ▪ Retain Council minutes for a minimum of 5 years ▪ Transmit minutes and annual accomplishments to the hospital's Board of Trustees <p><u>Patient and Family</u></p> <ul style="list-style-type: none"> ▪ Complete MGH volunteer program application and on-site orientation (which will occur at PFAC meeting for subsequent new members). ▪ Participate in the nomination and election process of the council Chair.
<p>3. Chair</p> <ul style="list-style-type: none"> ▪ Patient or family member will serve as the council Chair ▪ Election process determined by council 	<p>3. Chair</p> <ul style="list-style-type: none"> ▪ Represent the Heart Center PFAC in MGH Heart Center activities and other forums as needed, with support, input and participation of council members. ▪ Communicate Heart Center PFAC activities to the leadership of the executive committees of the MGH Heart Center. ▪ Serve as liaison to Heart Center Programs, Administration, Operations, Marketing and Development.
<p>4. Co-Chair</p> <ul style="list-style-type: none"> ▪ MGH staff will serve as the Co-Chair 	<p>4. Co-Chair</p> <ul style="list-style-type: none"> ▪ Support the duties of the Chair in his/her absence.

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 Heart Center PFAC Staff will remind Council Members that council Chair may be reappointed at the end of their term.

