As a patient, you and your family are the most important part of our team. We believe that knowing what to expect during your hospital stay can help lessen your anxiety and provide a sense of control. Most patients can expect during their hospital stay.

**Patient Care Pathway**

**Cardiac Surgery**

**Recovery Stage 1**
- The cardiac surgical team of doctors, physician assistants, nurses, therapists and case managers will review your case, medications and discharge needs each morning.
- Your family will be contacted by cardiac care.
- Cellular phone use okay

**Recovery Stage 2**
- The cardiac surgical team of doctors, physician assistants, nurses, therapists and case managers will review your case, medications and discharge needs each morning.
- Your family
- Cellular phone use okay

**Recovery Stage 3**
- A case manager will evaluate your discharge needs and discuss with you and your family.
- Meet with Social Worker for help with coping
- Meet with Smoking Counselor if needed
- Meet with dietitian
- Meet with Physical Therapist
- Meet with Occupational Therapist
- Meet with Smoking Counselor if needed
- Meet with Respiratory Therapist
- Meet with Social Worker for help with coping
- Meet with Dietitian
- Meet with Physical Therapist
- Meet with Occupational Therapist

**Patient Care Rounds**
- The cardiac surgical team of doctors, physician assistants, nurses, therapists and case managers will review your case, medications and discharge needs each morning.
- Your family
- Cellular phone use okay

2009 Patient and Family Advisory Councils
# Massachusetts General Hospital
## 2009 Report on Patient and Family Advisory Councils

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I. INTRODUCTION

The Massachusetts General Hospital mission — rewritten in 2008 with direct input from patients and families — 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 one important vehicle for that collaboration.

II. MASS GENERAL — 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, the North End and Revere. The hospital also holds concurrent Level 1 verification for adult and pediatric trauma and burn care.

Each year Mass General:

• Admits 47,250 inpatients
• Handles 1,297,819 million outpatient visits
• Records 82,550 emergency room visits
• Performs 33,466 operations
• Delivers 3,450 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.

Ours is a large, fast-paced and complex environment of care.

III. PFACs at Mass General

Overview
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.

“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

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. Individually, these PFACs are optimally situated to directly impact the delivery of care. Collectively, they are able 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 most common 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 those based within the MassGeneral Hospital for Children (MGH/C) (established: 1999), MGH Cancer Center (established: 2001), and MGH Heart Center (established: 2007).

In addition, patients and family — 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, as well as the MGH Council on Disability Awareness (established: 2004). The approach provides for both frontline, grass roots 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.

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**Patient and Family Advisory Council (PFAC)**

Over the past six years, the Patient and Family Advisory Council has moved from a pilot program to an important part of the fabric of the Cancer Center because of the honesty, respect and openness of its volunteer members. The Council embodies the commitment to patient and family-centered care at the Cancer Center. It is the silver lining to the dark cloud of cancer.
**PFAC Structure(s)**
Currently, each of the Mass General PFACs maintains certain commonalities in structure and operations. Each is supported by MGH staff, includes staff as members, meets monthly, and has a defined charge and agenda of priority initiatives. At the same time, the PFACs feature distinct differences that reflect their particular composition and charge. This is integral to their success. For example, the Cancer Center and Heart Center PFACs include both patient and family members, while the MassGeneral Hospital for Children advisory council, by choice, includes only family members and no patients/children under the age of sixteen. An MGH staff member chairs the two-year-old Heart Center PFAC, while the Pediatric FAC is cochaired by family members.

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 FAC**

*Mission and Purpose:*
Established in 1999, the MassGeneral Hospital for Children Family Advisory Council (FAC), is the hospital’s original PFAC/FAC. The self-articulated mission of the Council is to foster 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.

More specifically, council members have defined their purpose as working with the administration and staff of MGH/C to promote Family-Centered Care; collaborating with the MGH/C staff in improving the quality of health care provided to children and their families in both inpatient and outpatient settings; improving patient, family and staff satisfaction; ensuring an attractive environment that is responsive to the needs of children and their families; acting as an advisory resource to MGH/C leadership on issues of planning, evaluation of programs and services, policies and new facilities; acting as an advisory resource to MGH/C by giving input to teaching documents generated by the hospital regarding families; promoting a positive relationship between MGH/C and the community; serving as a vital link between the community at large; and contributing to the educational process of new professionals as positive resources and teachers in support of the mission of the MGH/C.

*Structure and Operations:*
Membership consists of fifteen people whose children have received care at MGH/C or are patients, sixteen years or older, who have received care at MGH/C. Those meeting the criteria for membership can submit an application to the FAC Membership Committee. Applications are available for download via the FAC’s web site (http://www.massgeneral.org/children/patientsandfamilies/support/familyadvisorycouncil.aspx). In addition, the MGH/C’s medical director, associate chief’ nurse, executive director, and inpatient director of Quality and Safety serve as ex-officio members. The MGH/C also appoints four staff members to serve on the Council on a rotating basis. Other MGH/C staff attend meetings as relevant to the work of the Council, and all Pediatric staff receive meeting minutes approved by the Council to help disseminate knowledge regarding the agenda and the FAC’s on-going work. 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.
The group meets monthly and is cochaired by family members. Its operations are guided by a formal Charter/Bylaws document that includes its mission, purpose, membership committee, membership, membership terms, membership responsibilities, cochair responsibilities, and those responsibilities that fall upon the MassGeneral Hospital for Children. In addition, members of the Council are integrated into a variety of key Pediatrics committees, including Pediatric Pain Subcommittee, MGH/C Quality & Safety Committee, Transitions Committee, Ethics Committee, Pediatric Endoscopy Planning Committee, Pediatric Quality & Safety “Speak Up” Subcommittee, Pediatric Guide Book Advisory Group, Safety Initiative for Pedi Patients (SIPPs), and the Pedi Palliative Care Interdisciplinary Team (IDT).

Outside of the Council’s monthly meetings, the group continues to connect via a private, self-managed FAC Google Group web site that helps ensure accurate, timely and inclusive communications. Council members use the site to carry forward important dialogue, review draft materials, access video and other project-related communications, store meeting minutes, locate key reference materials, etc.

Priorities and Outcomes:
To help guide its work, the FAC has identified several top priority areas of focus, including:
• Enhanced communication between family and providers
• Pain management
• Systems to improve communication between specialists (when there are more than two involved in the plan of care), particularly for inpatients with complex medical conditions
• Promote a “team” care approach
• Emergency Department experience
• Parent education opportunities (provide resources around alternatives)
• Palliative and Hospice Care
• Patient and family role in medical care
Their work has proven invaluable to the MGH Pediatric Service, touching many critical areas. For example, the Council produced a teaching video that demonstrates a parent/physician dialogue that was less than optimal. The FAC has since conducted two physician meetings using the video, which sparked a rich dialogue about the provider/parent relationship and communications. The physicians gained added perspective on the level of participation that parents might want in developing their child’s plan of care. And the parents developed a better understanding of the struggle physicians have in terms of what and how much information parents may want or need; not all parents have the same needs. Plans are underway to use the same methodology with other clinical groups (i.e., nurses, child life specialists, social workers, etc.). Likewise, the video directly contributes to the educational process of new professionals, a key Council priority.

FAC members also provided their perspectives on how to improve pain management of children in the Mass General Emergency Department via a direct dialogue with the physician chief of the Pediatric Pain Service. Although the physician is a particularly strong patient- and family-centered caregiver, through a deeper and focused discussion, the parents were able to offer valuable insights into “anticipatory pain.” The dialogue focused less on pain medications and more upon managing the child’s anxiety about pain, addressing fears up front to allay them as quickly as possible, and techniques for engaging the parents as subject matter experts in the process. FAC members likewise participated in the research design of an Emergency Department-based pain study, providing input into the measurement tool/questionnaire.

“I felt that sharing my experience and discussing it with the medical community was just going to help make changes in the hospital, and benefit the children. I met with so many specialists for so many years; I felt I could provide some feedback.”
— Pascale Gouker, an FAC member who lost her 6-year-old son to a biogenetic disorder

In the earliest stages of its design, FAC members made recommendations to the administrative director of the Emergency Department (ED) regarding the design of the new Pediatric ED, which will open in 2011. These included improved seating for families, and ideas for distracting children during ED visits. And when the Ronald MacDonald Foundation agreed to support the renovation of the Pediatric Family Lounge, the FAC provided valuable recommendations regarding aspects of the design that would be most family friendly, provide both a respite for families and a much-needed distraction during a stressful hospital stay.

The FAC recently expanded its membership in order to include more family representation on a broader range of Pediatrics committees. They have been active participants in Quality/Safety & Palliative Care Rounds. They have also sent a team of clinicians and family members to the Institute for Patient- and Family- Centered Care (IFCC) International conferences as a way to share their own practices more broadly and to learn from what other PFACs and FACs are doing nationally and internationally.
**MGH Cancer Center PFAC**

*Mission and Purpose:*
The MGH Cancer Center PFAC was established in 2001 with a stated mission to ensure that the voices of patients and families are represented in an effort to enhance their entire experience at Massachusetts General Hospital. It is an opportunity to hear feedback and recommendations from patients and families about the care they received during their healthcare experience in the Cancer Center. Staff in the Cancer Center value the opinions of patients, families and friends, and wanted a formal mechanism to incorporate patient/family viewpoints on an ongoing basis. Staff sought to establish a partnership between providers, patients and families to help ensure the best outcomes in all areas, for the patient, the family and at the systems level. Specifically, members serve in an advisory role regarding aspects of planning and providing cancer care; focus on improving the human experience; support patient- and family-centered care; promote staff education; and share with and learn from others.

*Structure and Operations:*
The Cancer Center PFAC membership consists of sixteen patients and five family members who represent a diverse perspective and experience relative to age, gender, diagnosis, socioeconomic status, and sexual orientation. Current members also represent nine different disease centers, including Head/Neck, Lung, Gastrointestinal, Genitourinary, Sarcoma, Breast, Melanoma, Leukemia/ Lymphoma and Neuro-oncology. 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.

The current PFAC also includes six Cancer Center staff, including the physician clinical director of Cancer Center, associate chief nurse, executive director for Cancer Center Administration, director of the HOPES Program (a social worker), executive assistant, and a physician.

Members commit to a two-year term with opportunities for renewal beyond that current membership. There currently are no term limits.

The PFAC is piloting an “emeritus” status for current members. This role presents an opportunity for members who might wish to reduce their participation but not completely step off the PFAC. Emeritus members maintain their involvement in PFAC activities, such as participating in the fellows and support staff meetings. However, they are not committed to attend the monthly PFAC meetings on a regular basis as expected of active PFAC members.
Council meetings are held monthly, and chaired by staff of the MGH Cancer Center. Additional meetings are scheduled based on need and task. The agendas are set jointly by staff and patients/family members, and to facilitate the participation of the patients and family members, dinner and parking reimbursement are provided.

Priorities and Outcomes:
PFAC members have identified three general areas of interest for their work, including:

- Patient-and family-centered care and support;
- Staff education; and,
- Sharing with and learning from others.

“The meeting was a great way to interact with patients and families of patients in a setting where we didn’t have any responsibility for patient care and could focus entirely on the patient’s experience rather than thinking about our related clinical responsibilities — to have an opportunity to just listen instead of trying to figure out what to do next.”

— Radiation oncology resident

As a result of PFAC efforts, there has been a formal integration of the patient and family experience into teaching, staff training, building design and patient care throughout the MGH Cancer Center and beyond. Members have participated in and provided advice on a variety of Cancer Center initiatives, including LEAN process improvement projects. For example, as part of a workflow process improvement project, PFAC members offered consultation about the patient/family experience in waiting rooms, check-in and exam rooms. They also provided immediate feedback to process improvement proposals during this project. They have provided feedback on the Patient Experience section of the Center’s revised web site. They brought an instrumental voice to the development of the overall tone and content of the Cancer Center’s Patient Guide, which includes information about the PFAC at the beginning of the guide, along with a welcome letter from its members.

PFAC members have likewise influenced the development of various patient support and education programs, such as the HOPES workshops, which are designed to share information about treatment, symptom management, etc., that help reduce the fear and anxiety of patients and family members. PFAC members also participated in the production of a Chemotherapy DVD, designed to educate new patients about chemotherapy, the Cancer Center’s infusion unit and supportive care services available to them.
The PFAC has profoundly enriched the dialogue around the human experience of living with cancer and for those who care for patients with cancer. They have played a significant role in staff education, including participating in twice-yearly discussion groups with hematology oncology fellows (since 2005), neuro-oncology fellows and radiation oncology residents, and support staff of the cancer center (since 2007); participating in the monthly orientation for all new Cancer Center staff; and, participating in offerings for MGH nursing leadership.

The impact of the Cancer Center PFAC’s work has extended well beyond the walls of Mass General. Nationally, the program has served as a model for adult-based PFACs in a variety of hospital and community settings. PFAC members — staff, patients and family members — have provided consultations with outside hospitals and organizations, including Yale-New Haven Hospital, BJC Healthcare in St. Louis, and the Cleveland Clinic. The goal was not to replicate the Cancer Center PFAC but to help them better understand how the voices of patients and families could be integrated into their own settings. For example, in 2004, Kaiser Permanente in Oakland, CA, contacted us because they were interested in developing a Patient Safety Advisory Board. They met with our PFAC to learn more about its work and role within the Cancer Center. Members have also made a total of nine oral and one poster presentation at national meetings, including all four of the Institute for Patient- and Family- Centered Care (IFCC) International conferences (2003, 2005, 2007 and 2009). PFAC members also participated in the IFCC’s 2009 conference, “Hospitals and Communities Moving Forward with Patient- and Family-Centered Care” in Boston.

The Cancer Center PFAC is also impacting care for the future. The group met on several occasions with the architects responsible for designing the infusion unit of the hospital’s new Yawkey Center for Outpatient Care as the project was being planned. Based upon their ability to convey the patient/family experience of treatment, the architects made numerous revisions to their designs. The PFAC has also met with the architects who are designing the Cancer Center patient care units for Mass General’s Building for the Third Century, slated to open in 2011. They likewise have met with the Cancer Center radiation leadership to provide input into the planning for the new radiation site at Newton Wellesley Hospital.

The Cancer Center PFAC has received several hospital honors, including “The One Hundred” (2008) and the Partners in Excellence Award (2001).

HEART CENTER PFAC

Mission and Purpose:
The Heart Center Patient and Family Advisory Council was formed in February of 2007 and quickly became a very active and productive group. The Council works in partnership with all members of the MGH community, focusing on services to improve patient and family experiences of care; educating health care providers from the patient perspective; and driving institutional improvements, including the design of facilities and process improvements. Their work centers around representing patient and family perspectives about the overall experience of care at Mass General; working in an advisory role to enhance cardiovascular care at the MGH Heart Center; acting as a sounding board for implementation of new Heart Center programs, and improvement of existing programs; and identifying patient- and family-centered care strategies.

Structure and Operations:
The Heart Center PFAC is currently chaired by an MGH staff person and consists of fifteen people, including 8 patients and 3 family members, designed to represent a broad spectrum of patients and family members (ranging from 25 to 65 years of age) from the many cardiovascular sub-specialties within the Heart Center, including heart transplant/heart failure, coronary artery disease, arrhythmia,
s/p ICD, valvular heart disease, and multiple risk factors. In addition, the PFAC includes 4 Mass General staff members: a cardiologist, council facilitator and staff specialist, associate chief nurse and Heart Center administrator. Members meet the hospital’s HIPAA compliance by signing a Mass General confidentiality agreement. Each member commits to a one-year term with the possibility of renewal for a second year. They attend monthly meetings and are encouraged to consider additional opportunities for involvement.

Priorities and Outcomes:
Early on, PFAC members participated in a formal process for establishing clear priorities for their work and identified the following:

1. Access to specialty care
2. Ambulatory care
3. Cardiac rehab services
4. Communication
5. Heart Center support groups
6. Clinical error management
7. Patient food
8. Prevention/community programs
9. Environment of care
10. Billing (managing once discharged)

Overall, the Council has been directly involved in reviewing and enhancing MGH Heart Center patient education materials; reasoning internal and external community awareness of the MGH Part Center PFAC; and demonstrating the MGH Heart Center’s commitment to hearing the voices of patients and families.
Specifically, the Heart Center PFAC has realized several significant outcomes, a revised Patient Care Pathway for Cardiac Surgery being, perhaps, the most significant. The pathway document was originally developed by the clinical staff as a way to help surgical patients and family members better understand what they could expect as they recovered in the weeks immediately following surgery. According to Heart Center PFAC member Susan Geary, “PFAC members thought this was a valuable concept, but one that could benefit from a stronger patient and family perspective. It needed to reflect the patient and family’s ‘lived’ experience. “After all, who knows better what it’s really like to be on the receiving end of that care?” The group assumed the task of redrafting the pathway, transforming it into something to which patients and families could better relate. The ultimate product was reviewed and approved for use by the Cardiac Nursing Practice Committee and the Cardiac Surgical Team, and then immediately distributed for use with patients and families. They are currently collaborating with staff from the Cardiac Catheterization Lab and the Heart Failure Service to develop similar tools for those areas.

“Patient and Family Advisory Council members are creating a culture of collaboration between hospitals and communities with very concrete implications for the quality of care that we all receive.”
— Theresa Fryer, MGH Heart Center council member since 2007

Additionally, PFAC members provided invaluable feedback into a draft update of the MGH mission, suggesting changes to the language that would better reflect the hospital’s commitment to patients and families. They provided recommendations to broaden the Patient Experience Survey Questionnaire (CAHPS® Hospital Survey) to focus on role groups beyond nursing and physicians. They also offered perspectives on Magnet Hospital Recognition during the MGH 2007 Re-designation Process, participating in interviews during the on site survey process.

Other important contributions include their work in revising both the heart failure and cardiac catheterization patient education brochures; providing recommendations for a cardiac patient education video; revising the Heart Center web site to improve navigation, provide information in Spanish and include information about the PFAC; and, offering input into the development of a Heart Center Patient Portal.

Heart Center PFAC members have offered consultation throughout the hospital, such as participating in the Patient Care Services Documentation and Communication Conference “Perspectives on the Impact of Nurse Continuity of Care,” a PCS Patient Education Conference “Defining the Link Between Patient Education and Health Literacy with Quality and Safety,” and, presenting and dialoguing with staff at the 4th Annual Cardiac Visiting Scholar Program.
In addition, members also have provided consultation and guidance to groups throughout the country as they seek to develop similar models within their own facilities, including Vanderbilt University Hospital, Concord Hospital of New Hampshire, Barnes Jewish Hospital, and HealthAlliance Hospital, a member of UMass Memorial Health Care. PFAC members also participated in The Institute for Patient- and Family-Centered Care 2009 Conference: “Hospitals and communities moving forward with patient- and family-centered care.”

IV. ADDITIONAL COUNCILS/COMMITTEES/MECHANISMS
In addition to its three clinically-focused PFACs, Mass General has formally incorporated patient, family and community member participation into two 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
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 MGH 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 MGH Disparities Committee, and select members of Mass General community.

Members are invited to serve for an indefinite period. (Term limits are currently under review by a subcommittee.) 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 minority concern (i.e., healthcare disparities, community outreach, staff recruitment and retention, efforts to create minority pipelines). 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 MGH 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 front line 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 MGH’s readiness to serve the population of people from those communities who do not see anyone at MGH 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 MGH Council on Disabilities Awareness (CDA) was formed in 2003 to help the hospital address the many and diverse needs of MGH staff, patients and families, and visitors with disabilities. Its mission is clear: To support the Massachusetts General Hospital in moving beyond the mandates of compliance to assure a welcoming and comfortable environment for all individuals with disabilities. To review, recommend and raise awareness regarding ways to improve access and the overall experience for patients, family members, staff, volunteers and visitors of the hospital.
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.

In 2008, the Council launched an ambitious new agenda for the near and not-so-distant future. The CDA more than doubled its already sizable membership and reorganized into three distinct subcommittees focused on patient services and equipment, the 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 is in the process of inviting patients and families to become active members of the larger Council and of its three new subcommittees. To date, four individuals have agreed to participate and represent a range of perspectives, including a middle-aged female who uses 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; and, a community advocate, a retired geriatric nurse who brings the viewpoint of older adults.

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.

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 words into text that can be 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 web page. 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 coordinator.

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 with disabilities, have helped the CDA increase awareness of disabilities concerns and has enhanced the environment throughout the hospital.

**ADDITIONAL AVENUES**

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. 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.

- 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 MGH 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.

**V. FUTURE PLANS**

Moving forward, the hospital will continue to cultivate the participation of patients and family members, incorporating their vision and voice into the work and various initiatives of Mass General. The Patient and Family Advisory Councils will serve as the premiere vehicle for doing so, and we anticipate a continued pattern of growth and influence. Throughout, the hospital will continue to support their individual and collective missions.
An inaugural “summit” meeting of all Council members this year demonstrated an opportunity to exchange best practices (e.g., standardization of HIPAA training), chart future plans, and take the work of the PFACs even further. Members broke out into focused discussion groups to compare, contrast and brainstorm around the topics of council structure, growth, communication, and integration. The PFACs will continue to come together periodically to share information and to learn from each other.

While the PFACs have done an admirable job of reflecting the diversity of clinical condition, age, gender, and sexual orientation of their respective patient populations, the recruitment of culturally diverse patients and family members who more fully represent the patient population has proven challenging. Dedicated work will be done within each clinical PFAC to recruit more minority members.

An annual report of the hospital PFACs will be delivered to the hospital’s Board of Trustees by the senior vice president for Patient Care and chief nurse, along with a designated patient/family member. This report and Council minutes will also be available for download via the hospital’s web site.

VI. SUMMARY
Mass General 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.

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.

Thank you for this opportunity to share a brief overview of our Patient and Family Advisory Councils and for future opportunities to report on their important work.

“The input from participating patients and families helps insure that our policies and initiatives keep the patient perspective on the top of the priority list. My interactions with them have definitely helped shape administrative responses to quality and safety issues as well as policy questions.”

— Medical Director,
Mass General Physicians Organization