



MASSACHUSETTS  
GENERAL HOSPITAL  
1811 - 2011

# PATIENT FAMILY ADVISORY COUNCIL ANNUAL REPORT 2010-2011



“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.”*

*Mass General* 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 visits
- Records 88,300 emergency room visits
- Performs 38,000 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.

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.

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 its many 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.

*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 distinct from that of a pediatric, cancer, neurology, or general medicine patient, or 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.

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) (1999), MGH Cancer Center (2001), and MGH Heart Center (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 MGH Council on Disability Awareness (established: 2004). The approach provides for both frontline, grass roots involvement, as well as broad-based, hospitalwide impact. Several ad hoc groups have also benefited from patient involvement.

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 PFAC — *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; and,
- 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) allows for 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 ongoing work.

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.

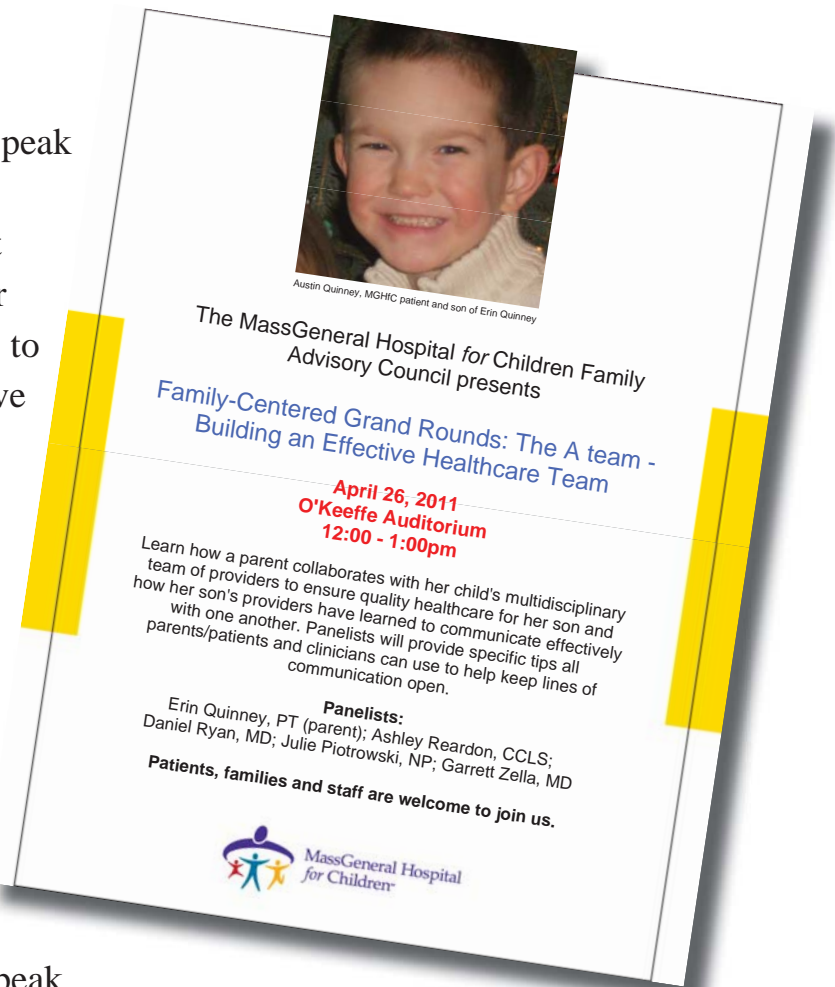
These electronic files date back to 2007. Minutes and accomplishments are also transmitted to the hospital's governing body. Council documents are also stored on a Google Groups site where members can communicate between meetings.

## ***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 at Grand Rounds on “Building an Effective Healthcare Team.” This featured the mother of a patient with complex medical needs and her child's healthcare team, which consists of a surgeon, surgical nurse practitioner, gastroenterologist, resident, and child life specialist. The panelists discussed the challenges of team communication when caring for a medically-complex patient.
- 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.
- Displayed posters explaining the principles of patient- and family-centered care and the Family Advisory Council, which are on view throughout MGH/C.
- Continued to distribute ID badge attachments explaining the principles of patient- and family-centered care and practical tips for practicing family-centered communication to residents and staff.
- Participated on the committee designing the flow for the changes to the Pediatric Admission, Pre-Op, and Discharge areas, and advised the team renovating the Pediatric Emergency Department about aspects that would be the most family friendly (e.g., 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.
- PFAC members actively served on the following committees:
  - MGHfC Quality & Safety Committee
  - MGHfC Quality & Safety “Speak Up” Subcommittee
  - MGHfC Quality & Safety Handoffs Subcommittee
  - Ethics Committee
  - Autism Hospital Admissions Committee
  - Patient Experience Committee
- Participated in a dinner for members of all Mass General Family Advisory Councils with the president of MGH and chief nurse to share experiences, challenges and insights.



- Organized for parents to participate in an Ambulatory Care rotation for residents to share their experiences of having their child cared for in primary care. The purpose was to allow residents insight into the experiences of families in primary care.
- Family member of the PFAC spoke at “Chief of Service Rounds” sharing his insight about his experiences of care in the hospital with his chronically ill child with a multidisciplinary group of providers.



- Family members for PFAC participated in two training sessions for residents designed to enhance their skills in having difficult conversations with parents and patients. Family members participated in simulations with healthcare providers.
- Family member presented a Power Point speech for Quality and Safety Grand Rounds along with a nationally recognized expert in patients' rights and responsibilities for their own care.
- Family member helped develop a template for a hospital admissions plan for children with Autism.
- Family member along with MGH/C Web Developer explored more efficient ways to orient new family members to PFAC by creating a on-line resource containing up-to-date informational materials.
- Family members were advised on the importance of patient confidentiality and new hospital regulations around protecting patient health information.
- Family members provided feedback to the team devising a new needle insertion program to reduce pain in children.

# 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 for cancer patients and their families
- Supporting patient- and family-centered care
- Promoting staff education, and sharing with/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 28 members (22 patients and family members, and 6 MGH Cancer Center staff members). Our membership represents diverse perspectives and experiences relative to age, gender, diagnosis and socioeconomic status. Current members represent eight different Cancer Center disease programs, as well as two different sites (MGHCC Boston and MG/North Shore Cancer Center). We currently have 8 Emeritus members, as well, who maintain their involvement in PFAC activities, if available, but are not required to attend the monthly PFAC meetings on a regular basis. The six Cancer Center staff members include the Cancer Center's executive director, an oncology social worker, an inpatient nursing director, an outpatient clinical nurse specialist, a clinical physician and an executive assistant.

Members must have treatment history with the MGH Cancer Center, either themselves or with 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 attending monthly PFAC meetings, and sub-committee efforts (when available).

Prospective members are nominated by a Cancer Center staff member or clinician. They complete an application form, and a PFAC staff member reviews the application and interviews the candidate via telephone or in person, which is preferred. A current patient/family member on the council is then matched with each candidate to conduct an additional interview. At the end of this process, the applicant is invited to join PFAC.

Upon joining, members are required to become official MGH Volunteers, a process 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. 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.

Members are asked to make a two-year minimum commitment. There are no formal term limits; current membership ranges from 5 months to almost 10 years. It is important to have this wide range of experiences, given the tremendous variation in cancer treatment and survivorship issues.

By choice, the Cancer Center PFAC has no formal “chair” but that staff and council members all work equally together to develop agendas and manage the flow of meetings. There are no elected officers for the council, either.

Beyond monthly PFAC meetings, members have also served on review and steering committees for Supportive Care Services, the Ambulatory Practice of the Future, Quality and Safety and Survivorship Day. Members serve in an educational/advisory capacity via scheduled meetings with the new oncology fellows, Cancer Center Support Staff and nursing staff. They have participated in the interview process of



oncology nursing leadership, the review of patient satisfaction data and quality data, and in programming (cancer survivorship, HOPES program workshops), 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 over the past year:

- Welcomed 9 new members. These members were nominated by a Cancer Center staff member or clinician, completed the application process, interviewed with PFAC staff member and patient/family member, and completed the MGH Volunteer Department orientation. Their first PFAC meeting was February 9, 2011. Each new member shared his or her personal experience with cancer and goals for working with the PFAC.
- Welcomed two new staff members. With a change in nursing leadership in the Cancer Center, two nurses, an inpatient oncology nursing director and an outpatient oncology clinical nurse specialist were appointed to become staff members of PFAC.
- Participated in a discussion with the coordinator for The Network for Patients and Families, a peer-matching program at the Mass General Cancer Center, which provided the opportunity to explore a broader connection between PFAC and the Network.
- Participated in care redesign initiatives. These initiatives are designed to deliver more integrated patient- and family-centered care. PFAC members were active reviewers of the colon cancer care redesign pathway and are part of the multidisciplinary team for the thoracic care redesign initiative. Two PFAC members also serve on the Lung Cancer Care Redesign Initiative as Task force members.
- Participated a joint meeting with the Heart Center and MGHfC councils that included an interactive discussion with MGH President Peter Slavin and Vice President for Patient Care Services and Chief Nurse, Jeanette Ives Erickson.
- Participated in the medical oncology inpatient nursing retreat for staff on Phillips 21, an inpatient oncology floor. PFAC shared their experiences and the importance of their relationships with nurses, from both a patient and a family perspective.

- Provided patient and family feedback to the experience of care at the MassGeneral/North Shore Cancer Center:
  - Bringing MGH Supportive Care services to the North Shore Cancer Center.
  - Standardizing care and systems across both institutions to provide seamless transitions.
  - Welcomed two cancer patients from the North Shore onto the council, to tie in their experiences and inform leadership of possible gaps and areas for improvement between sites.
- Provided substantive consultation to inpatient nursing regarding patient and family experiences related to inpatient cancer care, including the following inpatient initiatives:
  - Bringing supportive care services to inpatients who cannot make it to the Resource Room
  - Providing feedback on the Division of Hematology/Oncology's switch to an "Inpatient Rounder Model" in response to changing ACGME rules.
- Providing feedback about the new Oncology Inpatient Nurse Practitioner Unit, a 28-bed medical oncology unit managed by nurse practitioners rather than house staff.
- Accommodating family members in inpatient rooms, and supporting their needs and comfort along with that of the patient.
- Touring the new space and providing suggestions to the Lunder Building architects and nursing staff regarding the design of the two newest cancer inpatient units.
- Provide feedback on two communication devices for inpatient units. These devices were piloted by nurses but needed the voice of the patient and family to help with decision around which device to move forward with.
- 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.



MASSACHUSETTS  
GENERAL HOSPITAL  
CANCER CENTER

## A Guide to the Cancer Center for Patients and Families



George Lillie, RN, Infusion Unit nurse, with patient

- 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 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 has become integrated into the care of new chemotherapy patients within several disease centers. This daily workshop has received high marks from both patients and staff.
- Participated in the Cancer Center's Annual Survivors Day conference.
- Provided ongoing 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."

# 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 the MGH. 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 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.

### ***Council Operations***

To date, the advisory council is comprised of 16 members (8 patients, 2 family members and 6 MGH representatives) who represent a diverse perspective and experience relative to age, gender, nature of cardiovascular illness, and socioeconomic status. Recruitment of patient and family council members is initiated by referrals from all disciplines, including MGH 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 MGH 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 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. (Any resignation is submitted in writing or via e-mail to the MGH Heart Center PFAC. Vacancies may be filled during the year as needed.)

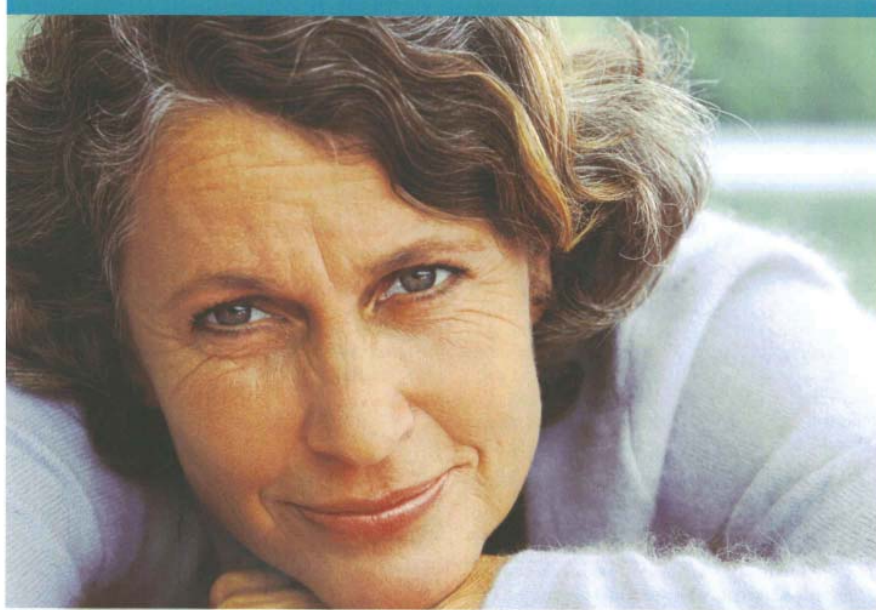
Members of the MGH Heart Center PFAC select and grant two-year terms to council members. At the end of a two-year term, council members may request to be re-appointed. Each May, members elect a patient or family member to serve as Chair for a two-year term. This individual represents the Heart Center 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.

The MGH PFAC meets the first Tuesday of each month from 5:30-7:30 PM. Documentation of meeting minutes are kept in Founders 345 for a minimum of five years. Three meetings were cancelled due to inclement weather and low participant availability.



MASSACHUSETTS  
GENERAL HOSPITAL

Heart Center | Vascular Center



Understanding and Preparing for a  
**CATHETERIZATION PROCEDURE**



A FOUNDING MEMBER OF **PARTNERS**  
HEALTHCARE

## ***Activities & Accomplishments***

The MGH Heart Center Patient & Family Advisory Council (PFAC) has achieved many accomplishments from July 2010 to 2011:

### *Enhancing Patient and Family-Centered Areas*

- Contributed to establishment of the MGH 2011 Quality Goals
- Recommended dedicated outpatient Social Worker for the MGH Heart Center
  - Reexamined process in the intensive care unit regarding patient referral and access to Social Service
  - Took the opportunity to build a case for disease-focused social workers in the MGH Heart Center outpatient area
  - Linked quality perspectives with development of discharge education for *65plus* plan of action
- Recommended MGH Chaplaincy Service involvement for all codes
  - Benchmarked Chaplaincy Service with other comparable urban teaching hospitals
  - Explored Chaplaincy role in the Code Team to support family and staff
- Replicated the “Ellison Caregiver Resource Binder” and made available in the Blum Patient and Family Learning Center
- Replicated “Get to Know Me” poster for all cardiac care units; instituted a protocol for providing this to families (e.g., at a predetermined time).
- Developed a “Patient/Family Survival Guide” including various resources (collaborated with MGH Service Improvement)
- Enhanced current information technology to trigger referral to Chaplaincy (i.e., Provider Order Entry)
- Revised MGH Chaplaincy Channel 16 to incorporate and expand patient/family resources

### *Enhancing Patient Education*

- Recommended revisions to cardiac catheterization patient education brochure “Understanding and Preparing for a Catheterization Procedure”
- Recommended revisions to the DVD “Pre-Cardiovascular Procedure” for patients
- Recommended signs, posters, screen savers and educational materials to Partners Tobacco Cessation Team to warn patients, families and visitors about the dangers of second hand smoke

### *Enhancing Patient Communication, Service and Development*

- Dialogued with MGH Heart Center Outpatient Access Program Nurse Manager to Reduce System Gaps
  - Provide access to outpatient clinicians for questions
  - Shorten notification of lab results
  - Streamline scheduling process
  - Reduce wait time in procedure labs

- Recommended revisions to the “Patient Authorization Form” for the MGH Development Office
- Consulted on the development of iHealthspace, a web-based patient/provider communication tool that will be used by the MGH Heart Center
- Developed a proposal for areas of focus:
  - MGH Heart Center Outpatient Services
    - Access to designated clinician and continuity of care for both new and long-term Heart Center patients
    - Patient education and support for living with newly diagnosed and advanced level heart conditions
    - Education regarding programs, material and information provided upon diagnosis and throughout process of care
  - Staff education re patient experience and perspective
  - Patient/Family Give-Back: Volunteer and Support Groups, Development



- Recommended revisions to the MGH Heart Center Patient Warning and Termination Letters
- Recommended revisions to in-patient communication device prototype for patients and families

*Strengthening and Enhancing Awareness of MGH Heart Center PFAC*

- Ensure compliance with new Department of Public Health PFAC regulations
- Appointed a Patient Chair for PFAC
- Formalized MGH Heart Center PFAC Charter/By-Laws
- Hosted 2nd Annual MGH PFAC Networking Dinner
- Published “Patient & Family Advisory Councils Partnering for an Even Better Future,” in December 2, 2010 PCS *Caring Headlines* newsletter
- Participated in American Heart Association “Go Red for Women” Luncheon Event
- Participated in “MGH Go Red for Women” presentation “Heart Disease in Women”
- Participated in 5th Annual Cardiac Nursing Visiting Scholar Program
- Participation in MGH Center for Quality & Safety Forum “Listening to the Voice of Patients and Families” in honor of National Patient Safety Awareness Week



# MGH PFAC Networking Dinner Hosted by the MGH Heart Center PFAC

*Forty-four participants representing the MGH Heart Center, MGH Cancer Center and the MassGeneral Hospital for Children PFACs joined the networking event.*



On November 2, 2010 MGH Heart Center PFAC hosted the 2nd Annual MGH PFAC Networking Dinner with guests MGH president, Peter Slavin, MD and senior vice president for Patient Care and chief nurse, Jeanette Ives Erickson, RN, DNP, FAAN, for a Q & A Forum.

Lists of questions were collected from all council representatives, categorized into four key areas of focus and presented to MGH leaders to begin a dialogue.

For example:

*Question to MGH leaders:* Would you share your perspectives as to the role that Patient Family Advisory Committees play now and in the future at MGH?

*PFAC reflections:* Dr. Slavin expressed his vision for the future that five years from now he “hopes to see more PFACs to make sure that patient and family perspectives are at the forefront of care at MGH.”

*Question to MGH leaders:* Would you comment on challenges and opportunities faced with new Health Care Legislation and Reform, and any role the Patient Family Advisory structure might play in responding to those?

*“The interaction between the administrators element in enabling the partnership between*

*PFAC reflections:* Question concerned palliative care, particularly associated with cancer patients, and how that relates to concerns that the new healthcare legislation might interfere with offering this type of care. Dr. Slavin explained that recent studies support the idea that palliative care positively assists patients and their families in coping with the problems that accompany challenging diseases. In many cases it increases the longevity and quality of life. Dr. Slavin suggested that the palliative care practices employed in the MGH Cancer Center can be applied to other areas of the hospital where patients and families are confronted by similar challenges.

*Question to MGH leaders:* How has the patient population that MGH serves changed, and what changes do you anticipate in the future?

*PFAC reflections:* Dr. Ives Erickson reflected upon the ability of MGH to modify, adjust and adapt to the continuously changing needs and expectations of the local, national and international patients served. She stressed that it is the hospital's priority, across

all disciplines, to give voice, respect and representation to all patients and their cultural communities. Moreover, the hospital has formed a disability committee of patients and clinical staff and is starting a multicultural advisory committee. The goal will be to align efforts with existing PFACs.

*Question to MGH leaders:* How will MGH outpatient services keep pace with growing demands and what is being done to help ensure continuity and integration of care?

*PFAC reflections:* Dr. Ives Erickson recognized the contributions made by PFACs in partnering with staff across the care continuum to develop improved information and educational resources. She spoke specifically about the important priority of hearing and learning from the experiences of PFAC members as the institution works to redesign care delivery across the health care delivery system. She signaled the importance of the value of PFACs as a steadfast reminder of where the focus and efforts must be directed at MGH. Dr. Slavin stated "PFACs help make sure MGH doesn't lose focus."

*and the PFAC members represents an important MGH and its PFACs" —PFAC member*

## 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.”

# Mass General Council On Disabilities Awareness — *established 2003*

## ***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.

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 a wheelchair; and a young woman who is blind.

In June of 2009, Mass General and Brigham and Women's Hospital leadership and members of the hospitals' respective Disabilities Councils collaborated with Boston Center for Independent Living (BCIL) leaders—including several Mass General patients—to launch a comprehensive initiative reaffirming the hospitals' and Partners HealthCare System'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 Disability 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. This position was approved, recruited and filled with a highly qualified advocate for the Mass General staff, patients and families, and visitors with disabilities.

### ***Structure and Operations***

Cochaired by hospital 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 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 several areas of focus. The following subgroups were revived or created to address community needs: Human Resources Improvement and Accommodation Initiatives; Education and Training; Transportation; and Facilities and Resources.

Keeping true to its mission, the CDA as a whole and through the workings of the subgroups, has altered the focus toward creating a paradigm shift of awareness. This culture change has been set in motion

in collaboration with and support of the role of Disability program manager within the Office of Patient Advocacy.

### ***Priorities and Outcomes:***

From the outset, patients and members of the disabilities community have played an integral role in the group's work. Findings and recommendations have been presented to the hospital's senior management for immediate action.

The CDA is currently supporting a measure being worked on by the Hospital's Disability program manager to expand on web access. The WGBH's National Center for Accessible Media (NCAM) was contacted to:

- design and build from scratch an accessible, internally-facing Intranet site for all staff at MGH;
- make accessible all additional content, such as PDFs and multimedia, prior to being posted to the site, with the understanding that this may add to the time line;
- provide related training—around the creation and posting of accessible content—to MGH staff who are tasked with administration and maintenance of the site;

- create a complementary Guidelines Document that would provide written instruction about the creation and posting of accessible content.

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 Mass General 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.

### ***Human Resources Improvement & Accommodation Initiatives:***

Focus on the MGH workforce to recruit, hire and retain employee's with disabilities. Change the culture and create increased awareness through communication while promoting self-disclosure and appropriate accommodation.

### *Education & Training:*

Focus on cultural change through employee and staff education for all clinical and nonclinical staff. The endeavor began in January of 2011 with 25 large auditorium sessions scheduled through 2012, which were created in collaboration with and presented by the Institute for Community Inclusion. There is an offering through the hospital's HealthStream educational application targeting clinical staff, and specific offerings for nonclinical staff and physicians are being developed.

### *Transportation:*

Focus on public transit modes, pedestrian access getting to and from the Hospital and then navigation throughout the campus after arrival. This involves reviewing policy and process pertaining to outside services such as the Partners Shuttle, accommodating the Ride and educating the staff through increased communication. Some of the targeted groups are Ambassador, Information Desks, Parking Services and Police & Security.

### *Facilities & Resources:*

Focus on public spaces by proactively working in conjunction with the Planning Office to exceed and achieve consistency through set standards hospitalwide.

In addition to the committee work the CDA has enjoyed several guest speakers who have addressed topics such as Autism, ALS, Traumatic Brain Injury and Accessibility. Valuable and thought-provoking information was acquired as a result. This knowledge has helped to frame understanding and acceptance of life-altering consequence based on illness due to stroke and other issues resulting in cognitive decline.

Many of the changes the council has initiated throughout the past seven 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, as well as ethical issues.

The Massachusetts General Hospital is launching a new Patient Family Advisory Council designed to further the hospital's commitment to incorporating the voices of its patients and families into institutional decision making.

The new MGH PFAC will complement existing councils by exploring and helping to share and replicate best practices in patient- and family-centered care across the organization. The Council is creating a pool of patient/family advisors to serve on new and existing committees and serve as an advisory resource for staff, physicians, administrators and the community. The ultimate goal is to allow patients and families to have the

most successful, compassionate and supported healthcare experience. The staff will be working with MGH staff and PFAC's to support patient/family centered activities and initiatives.

Recruitment for council members has been underway and a kick-off meeting and orientation of members is planned for the fall of 2011. The planning committee, which included MGH staff and a patient advisor, has completed PFAC bylaws.

- Several members of the hospital's Patient and Family Advisory Councils have 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 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.

## 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. 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.





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