Patient and Family Advisory Councils

*a valuable mechanism for tapping into the suggestions and ideas of patients and families*

Sometimes, some of the most important work in the hospital takes place behind the scenes with no fanfare or recognition, but it’s nonetheless crucial to our ability to achieve our goals and fulfill our mission. Certainly, the work of our dedicated patient and family advisory councils (PFACs) falls into that category. These councils are comprised of patients, family members, and staff who give generously of their time and ideas to help us improve care and refine systems.

On Wednesday, September 7, 2016, I had the opportunity to attend a meeting of the General Patient and Family Advisory Council (see Fielding the Issues on page 11 for more information about the G-PFAC) to get their feedback on our plans to implement Partners 2.0. As you may know, Partners 2.0 is the initiative led by Partners president and CEO, David Torchiana, MD, along with MGH president, Peter Slavin, MD, and BWH president, Elizabeth Nabel, MD, to ensure collaboration, efficiency, and coordination of services across all Partners entities. The G-PFAC was one of the first groups to provide feedback on the ‘big opportunity’ statement for this initiative. It was so helpful and instructive to hear their comments and get a sense of the MGH experience from the patient and family’s perspective. I can’t thank them enough for sharing their insights and impressions.

My visit to the G-PFAC meeting was a wonderful reminder of the good work being done by all our patient and family advisory councils. So I thought I’d use this week’s column to share some of that work with you. What follows is a partial summary of some of the projects that are benefiting from the input of our general, cardiac, cancer, pediatric oncology, and MassGeneral Hospital for Children patient and family advisory councils.

**The General PFAC**

This past year, the G-PFAC participated in the MGH volunteer’s orientation and training program to enhance their understanding of hospital culture and policies. They provided feedback on a number of activities and initiatives, including:

- The Kitty Hawk Project, an initiative geared toward reducing physician burden while optimizing patient care, such as the use of medical scribes to document patient-physician encounters.

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Jeanette Ives Erickson (continued)

My visit to the G-PFAC meeting was a wonderful reminder of the good work being done by all our patient and family advisory councils. So I thought I’d share some of that work with you. This is a partial summary of some of the projects that are benefiting from the input of PFACs throughout the hospital:

- The Levels of Care document ensuring patients understand their placement options prior to discharge
- The Health Information Services consent form, which allows clinicians to send health information where it’s needed
- The Interventional Radiology brochure, *Choosing a Medicine for Your Port Placement*
- A summary of Safety Culture Survey results to advance ideas on Patient Safety Awareness Week
- The Diversity and Inclusion Vision Statement
- Opioid education
- ID badges to make it easier to identify clinicians’ roles
- The informed consent policy regarding overlapping surgical staffing in ORs
- Enhancements to Patient Gateway
- G-PFAC Working Committees include:
  - The Patient Education Committee that focuses on patient education and works closely with the Blum Patient & Family Learning Center
  - The Patient Experience/Care Coordination Committee, comprised of members with experience and an interest in provider communication, care coordination, and alternative means of accessing care. The committee works in partnership with MGH TeleHealth, providing feedback on educational materials, terminology, and programmatic decisions
- Patient Voice and the MGH/G-PFAC Relationship Committee works to enhance awareness about PFACs throughout the hospital

**The Heart Center PFAC**
The Heart Center PFAC has been involved in discussions about transition of care; changes in leadership within the Heart Center; implementation of eCare and its impact on the Heart Center; and restructuring of the outpatient program. They provided feedback on:

- The MGH Strategic Plan and Hospital Priority Overview, submitting questions to Dr. Slavin about the plan and hospital priorities
- Our policy related to concurrent-surgery practices, weighing in on specific situations and the appropriateness of concurrent surgery
- Preparing for eCare, sharing ideas on the communication plan for patients, families, and staff, including creating a brochure regarding Patient Gateway that would address changes and questions
- Broader education around palliative care for clinicians throughout the hospital to ensure a common understanding of what palliative care is and what it isn’t. Members shared ideas on ways to initiate conversations about palliative care with patients and families
- Raising awareness about the Partners Healthcare Biobank, including ways to improve recruitment and consent

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The Cancer Center PFAC

Cancer Center PFAC members participated in several educational forums, had representation on numerous Cancer Center committees and subcommittees, and provided feedback on:

- The Video Therapy Program that helps patients create videos that can be used as end-of-life celebrations or documentation of their journeys
- Communicating the advances of cancer immunotherapy, its success with melanoma patients and its dramatic impact on late-stage melanoma prognosis
- Ways to publicize the Cancer Center Survivorship Program at MGH West to cancer patients on the main campus who may be nearing the end of treatment
- Ways to publicize the Bone Marrow Transplant Survivorship Program
- The MGH Substance Use Disorder Initiative
- Ways to collaborate with the MGH Parking Office to better serve the cancer patient population and improve accessibility to the main campus and satellite locations
- The creation of the booklet Important Things to Know about Oral Cancer Medication and ideas related to sharing best practices for improving patient education
- Improving the Call Center
- The creation of a task force to enhance patients’ connection to Cancer Center supportive care resources

The MassGeneral Hospital for Children FAC

Members of the MassGeneral Hospital for Children Family Advisory Council (FAC):

- Submitted questions to MGH president, Peter Slavin, MD, about the hospital’s strategic plan and heard them answered at the annual PFAC gathering later in the year
- Participated in a pilot ‘secret shopper’ program wherein members completed surveys about their out-patient experiences and returned them to the Service Excellence Department
- Initiated and developed a program in which the PICU medical team rounds on adolescent patients when no parent or guardian is present
- Hosted its annual Family-Centered Grand Rounds entitled, “Kids Talk: Patients Reflect on Their Experiences at MassGeneral Hospital for Children,” with a panel of pediatric patients, age 12–18, who shared advice about how to care for children
- Had input into the re-design of the new Pediatric Operating Room
- Worked with the Pediatric Surgery team to create a video that introduces patients to the pre-operative experience
- Reviewed patient-education materials
- Staffed a table in the MGH Main Corridor to help educate the public about the work of PFACs in the hospital

Pediatric Oncology FAC

Members of the Pediatric Oncology Family Advisory Council completed the MGH volunteer orientation and training program and:

- Helped create the parent mentoring program, Parents Offering Parents Support, to prepare parent volunteers to participate
- Collaborated with the Emergency Department to address concerns about port-a-cath access for pediatric oncology patients and improve competency among ED nurses in this area
- Participated in developing a Patient-Family Education Center in the clinic waiting area to include a dedicated space for adolescent and young adult patients. Resources, technology, and a quiet space will be offered for researching childhood cancers and coping with treatment
- Identified a need to enhance access for patients with disabilities. An existing door was replaced with an automatic door to provide better access for wheelchairs and strollers
- Reviewed plans for eCare implementation and its impact on patients and families
- Discussed technological resources to provide information to patients and families about clinical issues
- Provided guidance around the development of psycho-social programs for patients and families including parent education and support, establishing connections among families, and recognizing patients for participating in arts programs

The Ambulatory Practice of the Future Care Alliance

Recent accomplishments of the Ambulatory Practice of the Future Care Alliance (CA) include:

- Creating a collaborative process for managing change, including discussions and planning sessions around the implementation of eCare and its impact on care and operations, and exploring ideas to simplify utilization
- Reaching out to patients to proactively encourage them to enroll in the eCare Patient Portal
- Advocating for the APF to become a demonstration project for the use of Open Notes and adapt its use in the eCare system. The group developed a document detailing the mutual benefits and outcomes of patients having access to Open Notes
- Creating a new Patient Voice Survey to allow immediate evaluation of the patient’s experience of care
- Establishing a patient newsletter to provide information about the practice, solicit patient feedback, and build stronger relationships between staff, patients, and the Care Alliance
- Hosting a meeting with the Hope Project to provide input to the Partners Research Project

We are indebted to all who participate on our patient and family advisory councils; you’re helping to make us a better hospital, improve care, and enhance the patient experience. Our strategic direction is informed by the feedback you provide. Thank-you for speaking up on behalf of all patients and families.