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

—The Mass General Mission—

2013-14 PFAC ANNUAL REPORT
MGH OVERVIEW

The third oldest general hospital in the United States and the oldest and largest hospital in New England, MGH continues its tradition of excellence today. In 2014, MGH was ranked second in the nation and first in New England by *US News & World Report* based on the quality of care, patient safety and reputation in 16 different specialties. In 2003, MGH became the first hospital in Massachusetts to receive the highest honor for nursing excellence awarded by the American Nurses Credentialing Center: Magnet designation. In 2008 and 2012, the hospital was redesignated a Magnet hospital.

Massachusetts General Hospital is a 999-bed academic medical center, located in the heart of Boston, offering sophisticated diagnostic and therapeutic care in virtually every specialty and subspecialty of medicine and surgery. In addition, the hospital provides care and services in multiple health centers located within neighboring communities, including Back Bay, downtown Boston, Chelsea, Charlestown, Danvers, Everett, North End and Revere, as well as at MGH West and the North Shore Medical Center. The hospital also holds concurrent Level 1 verification for adult and pediatric trauma and burn care.

Each year MGH:
- Admits approximately 48,000 inpatients
- Handles nearly 1.5 million outpatient visits
- Records more than 100,000 emergency room visits
- Performs more than 42,000 operations
- Delivers more than 3,600 babies

MGH also conducts the largest hospital-based research program in the United States with an annual research budget of nearly $786 million. This funding drives discoveries and breakthroughs in basic and clinical research, which translate into new and better treatments that transform medical practice and patient care. In addition, MGH is the original and largest teaching hospital of Harvard Medical School, where nearly all MGH staff physicians have faculty appointments. Since the hospital’s founding, MGH has been committed to training and mentoring the next generation of international leaders in science and medicine, providing a wealth of opportunities for physicians, nurses, and other health professionals. These clinicians, in turn, lend fresh and innovative perspectives on how to treat and care for patients.
MISSION DRIVEN
Within this large, complex environment of care, it is our mission that guides our individual and collective beliefs, decisions and actions — our work. Rewritten in recent years with direct input from patients and families, this statement of purpose provides the foundation for the hospital’s patient- and family-centered approach to care:

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

Our Patient and Family Advisory Councils (PFACs) serve as a primary vehicle for incorporating the patient and family care experience into our planning and day-to-day hospital operations.

PFACs at MGH
MGH formed its first Patient and Family Advisory Council fourteen years ago, with the launch of the MassGeneral Hospital for Children (MGHfC) Family Advisory Council in 1999. Following their lead, other high-volume specialty areas launched their own service-specific PFACs: MGH Cancer Center in 2001 and the MGH Heart Center in 2007, and the hospital formed a General PFAC in 2011. In addition, the hospital’s Ambulatory Practice of the Future operates a Care Alliance. These PFACs represent the hospital’s most widely used clinical services and represent a large proportion of the care provided at MGH.

The hospital, patients and families have found it beneficial to operate multiple, targeted PFACs, each bringing voice to a specific patient and family experience, environment of care, and/or priority area for the hospital. These PFACs are optimally situated to impact the delivery of care for their respective and unique patient populations. Collectively, they are positioned to influence hospitalwide initiatives, with the added benefit of bringing multiple, authentic and highly relevant perspectives to the table, and ultimately, to the hospital’s governing body, the Board of Trustees.

The PFACs continue to direct and shape the patient experience at Mass General by participating on key service-based and hospitalwide committees, reviewing educational and other materials for patients and families, lending their wisdom and voice to staff orientation sessions and educational offerings, bringing forward new ideas for services and service enhancements, reviewing blueprints and plans for new patient facilities, and so much more. Above all, they bring an experience and perspective to the table that no others can replicate, and for that we are all the better.
Planned Annual Joint PFAC Dinner and Presentation. This year the hospital hosted its 6th Annual PFAC Dinner, offering members an opportunity to come together to network, share ideas and experiences and learn about activities and plans of the hospital from its senior leadership. Peter Slavin, MD, president of MGH, and Jeanette Ives Erickson, RN, DNP, senior vice president for Patient Care and chief nurse, opened the evening with welcoming remarks. Presentations of past year PFAC accomplishments were provided by representatives from each PFAC. Susanne Goldstein, General PFAC member, facilitated a Patients Corner session which elicited live feedback related to the clinician-patient team. David Finn, MD, severed as the evening’s keynote speaker, and talked about the Medical Home initiative at MGH.

Administered recruitment inventory questionnaires, which were distributed to the chairs of each MGH PFAC. Best practices were collected and opportunities for joint recruitment and standardized on-boarding processes for new members were identified.

Submitted and received grant award from the Ladies Visiting Committee to fund a resource project role to work on initiatives across all PFACs. This will include brochure development for recruitment purposes; publications to promote MGH PFACs; engagement with community health centers to increase outreach for diverse membership; seeking internal and external opportunities for presentations; and developing a joint PFAC orientation program.

Reviewed educational materials and provided feedback to the Back Pain Care redesign team.

Organized a joint event with the Kenneth B. Schwartz Center for Compassionate Care. Collaborated with the Schwartz Center for Compassionate Care and chief nurse of Patient Care Services to present a joint PFAC event focused on creating a more compassionate healthcare system. This provided an opportunity for patients and family members to influence a national agenda.

Provided feedback to the Emergency Department Patient Experience Committee on communication items related to various roles and responsibilities of healthcare providers that patients may encounter in that setting.
Patient and Family members identified topics/areas of personal interest in which they desired to affect positive change. For each topic, a resource within MGH was identified. Presentations are used to inform the PFAC of activities in these critical areas and may lead to projects or opportunities for further patient and family involvement.

**PFAC Recruitment Packet.** Designed recruitment brochure, introductory letter and application, which were mailed to 7,000 patients randomly selected from a list of MGH patients recently discharged from the hospital. Review of applications, interview and selection took place August-September 2014.

Met with the MGH Disability Coordinator and provided feedback on how MGH’s Disability Program can be further enhanced going forward.

Facilitated the formal launch of a new PFAC focused on Pediatric Oncology.

**Electronic Medical Record and Patient Portal.** Met with Parnters eCare leadership and provided feedback on how the implementation of the new Partners electronic medical record and patient portal can be made even more patient- and family-centered.

Provided feedback to the MGH Marketing Department on website design and functionality.

Provided recommendations to Partners for patient membership for key committees – e.g. – Patient Journey Engagement Committee.

Consulted with Biobank on venues for further patient engagement; referred patients for participation.

Presented at the State PFAC Conference on development and strengthening of PFAC’s.

Provided consultation to several departments and services considering a new patient and family advisory council or boards.
## 2014 - Topics and Projects for General PFAC Involvement

<table>
<thead>
<tr>
<th>Topic</th>
<th>Detail/Questions</th>
<th>Next Step</th>
<th>Meeting Schedule</th>
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| Services for Patients with Disabilities | • What services are available?  
• What efforts are underway to improve services?  
• What structures exist in the hospital to address these issues? | • Invite Zary Amirhosseini, MGH Disability Program Coordinator, to speak on MGH’s Disability Council and overall efforts | April 29, 2014    |
| Interpreter Services          | • How are services provided and coordinated?  
• Special focus on services for deaf and hard of hearing patients  
• Future plans to strengthen or expand services? | • Invite Anabela Nunez – Director of Interpreter Services – to speak with the group about MGH’s program. |                  |
| Patient Engagement and Portal Development | • How are Visit Summary Reports and Discharge Summary reports being used? Can their use be improved to better engage patients?  
• How is the new patient portal for Partners eCare (Epic) being designed? | • Invite Andy Karson or others associated with development of the Patient Portal to present on current work to the PFAC.  
• Goal – influencing Portal development before it is finalized. | Dr. Gwen Crevensten June 24, 2014 |
| Virtual Visits                | • How can we maximize time for patients with their providers?  
• What alternatives are there to facilitate longer and meaningful visits – especially with chronically ill patients?  
• What is being done to facilitate visits using technology? | • Invite Sarah Sassong – Director of MGH’s growing Telemedicine Program – to present to the PFAC. | May 27, 2014      |
| MGHfC – PFAC and its Activities | • What is the PFAC for the MGH Hospital for Children working on?  
• How can we support or be involved? | • Reach out to Sandy Clancy – Pediatric PFAC Co-Chair and ask for members of that PFAC to visit with the General PFAC at a future meeting. |                  |
| November Joint PFAC Meeting   | • What feedback was generated/shared at the November Joint PFAC meeting?  
• Can we review and see if there are needs or action steps? | • Share and discuss the collected feedback at a future meeting. | March 2014        |
A Patient or Family Advisor should be ...

- Able to listen to differing opinions and share different points of view
- Positive and supportive of MGH’s mission
- Willing to speak with candor within a group
- Able to use his or her family’s experience constructively
- Able to work productively and collaboratively with families whose backgrounds, experiences and style may be different from their own
- Able to reflect on issues and problems that are different from their own
- Able to fill identified time commitments
- Able to see many points of view
- Able to observe MGH’s policies on patient confidentiality

Become a Patient Family Advisor and ...

- Share your perspectives and ideas for improving the patient health care experience.
- Work directly with other patient and family advisors and hospital staff to increase the quality of support and education.
- Create meaningful change throughout MGH.

YOU can make a difference.

How do I apply to become an Advisory Council Member?
For more information or an application, please call: 617-726-1685 or email pcscpfac@partners.org or pick up an application at the Blum Family Learning Center.

What if YOU could design a better health care experience for yourself and your loved ones?

Become a Patient and Family Advisor and do just that!

Patient- and Family-Centered Care
Massachusetts General Hospital has pursued its mission of providing high quality and compassionate care to those we serve for more than 200 years. This commitment includes striving to understand the needs of our patients and families and continuously improving the care and service we provide.

What is a Patient and Family Advisory Council?
Patient and Family Advisory Councils (PFACs) are made up of volunteers like you, who have a variety of experiences with MGH. Council members participate in monthly meetings and help shape our programs, services and even our new facilities. Over the years, these councils have made a huge difference at MGH and have helped to enhance “patient- and family-centered care.”

What is Patient- and Family-Centered Care?
Patient- and family-centered care is an approach to the planning, delivery and evaluation of health care that is built upon a mutually beneficial partnership among health care providers, patients and families.

Why should I consider becoming a PFAC Member?
As someone who has experienced using the services of MGH, you bring a valuable perspective to the people who work here. You bring expertise about what it is like to be a patient or family member of a patient at MGH. Your involvement can help us to be sure our services are designed to meet your needs.

Patient and Family Advisory Councils at MGH:
MGH has five PFACs focused on different aspects of care at the hospital, including:
- MGH General Hospitalwide PFAC
- MGH Cancer Center PFAC
- MGH Hospital for Children PFAC
- The MGH Institute for Heart, Vascular and Stroke Care PFAC
- The Care Alliance – Ambulatory Practice of the Future PFAC
- MGH Pediatric Oncology Advisory Committee (FAC)

What do Patient and Family Advisory Council’s Do?

**DVISE:** Work in an advisory role to enhance patient and family initiatives by collaborating with PFACs and focus groups

**UPPORT** staff and MGH leadership in their patient- and family-centered activities and initiatives. Review new and existing programs across MGH.

**PARTICIPATE** in committees and work groups, such as patient safety, quality improvement, facility design, service excellence, ethics and education.

**IDENTIFY** and replicate existing best practices in patient- and family-centered care across the organization.

**EPRESENT** patient and family perspectives about the health care experience at the MGH and make recommendations for improvement.

**DUCATE:** Participate in MGH staff orientation, patient and family education, access to information, and discharge/transition planning.

**EVALUATE** the role of Patient and Family Advisory Councils in improving outcomes for all patients and families.
Creating a more compassionate healthcare system

Learning from patients and families

— by Robin Lipkis Orlando, RN; Rick Evans; and Lin-Ti Chang, RN

On Tuesday, February 25, 2014, nearly 80 patients, family members, and staff from six Patient and Family Advisory Councils, the Council on Disability Awareness, and the Schwartz Center came together to dialogue about ways to create a more compassionate healthcare system. The event was hosted by Jeanette Ives Erickson, RN, senior vice president for Patient Care, and Beth Lown, MD, medical director of the Schwartz Center.

Based at MGH, the Schwartz Center is a national non-profit organization dedicated to strengthening the relationship between patients and healthcare providers and preserving the human connection in health care. It was founded by Kenneth B. Schwartz shortly before he died of lung cancer in September of 1995. In an article printed in The Boston Globe Magazine in July of that year, Schwartz wrote, “For as skilled and knowledgeable as my caregivers are, what matters most is that they have empathized with me in a way that gives me hope and makes me feel like a human being, not just an illness.”

That sentiment was echoed many times throughout the evening by patients and family members.

Powerful stories were shared about the experience of receiving compassionate care at MGH. Attendees told of clinicians who took the time to sit and listen; who responded to distress with a warm touch; who went above and beyond to create connections within and outside the hospital; who encouraged and supported families to be present during emergent situations; who knew how to make them smile; who respected patients’ wishes; who provided information in a sensitive and timely manner; who knew when to bend the rules; who recognized the unique cultural needs of patients and families; who were able to see what was needed even when you couldn’t; who individualized care to meet the needs of every patient; and who repeatedly assured patients, “We’re in this together.”

In addition to sharing personal stories, attendees offered recommendations on how to foster an environment of compassionate care. Recommendations were based on the seven commitments put forth by the Schwartz Center as part of a national ‘call to action’ on compassion in health care.

Recommendations included:
- Commitment #1 to compassionate health care leadership
  Recommendations:
  - Everyone serves a leadership role in the eyes of the patient
  - Leaders rise above daily operations and remain focused, attentive, and in control

- Commitment #2 to teach compassion
  Recommendations:
  - Learn from patients and families; they are the best teachers
  - Develop a template of guidelines for compassion

- Commitment #3 to value and reward compassion
  Recommendations:
  - Find ways to recognize compassion with accolades, rewards, or money
  - Form support groups to help caregivers process events

- Commitment #4 to support caregivers

continued on next page
Recommendations:
• Provide training in interpersonal relations
• Promote teamwork
• Commitment #5 to involve, educate, and learn from patients and families
Recommendations:
• Invite PFAC members to be part of clinical teams
• Learn best ways for patients and families to learn, including patients and families with disabilities
• Commitment #6 to build compassion into the fabric of health care
Recommendations:
• Make compassion part of the first encounter, including phone contact, registration, and front-desk interactions

• Develop a system for hand-overs that reinforces continuity of care
• Commitment #7 to deepen our understanding of compassion
Recommendations:
• Conduct research to measure the impact of compassion and patient-centered care
• Provide empathy training
To learn more, go to: www.committocompassion.org.
For information about the Schwartz Center, go to: www.theschwartzcenter.org
For information about Patient and Family Advisory Councils, e-mail PCSCPAC@partners.org.
Thanks & More

We would like to thank the members of each of the MGH PFACs for their hard work and dedication this past year. We look forward to many more opportunities to nurture and support the entire MGH community through the important work we do.

To Learn About:

♦ The MGH PFACs: www.massgeneral.org/patientadvisorycouncils
♦ Becoming a patient and family advisory council volunteer, please email PCSCPFAC@partners.org or call (617) 643-3911
♦ To request patient input on an initiative or start a new departmental PFAC, call Rick Evans at 617-724-2838

Host Committee
The MGH General PFAC
Co-Chairs:
Robin Lipkis-Orlando, RN, Director of Patient Advocacy
Rick Evans, Sr. Director Service Improvement

Patient/Family Members:
Patrick Brannelly
Susanne Goldstein (Chair of the Host Committee)
Win Hodges
Sue Lunn
Kathy Varela
David Wooster

Staff Members:
Kay Bander, Volunteer
Linda Kane, LCSW, Office of Patient Advocacy
Karen Konnor, LICSW, Clinical Director, Social Service
Bessie Manley, RN Nurse Director, Phillips House 22
Liza Nyeko, MS, MGH/MGPO Center for Quality & Safety
Steve Reardon,

The General PFAC at MGH is proud to host

The Annual Joint Patient Family Advisory Council Dinner
Celebrating the work of the five PFACs at MGH

Keynote speech by David S. Finn M.D.
on The Medical Home Initiative

November 13, 2013, 6:00—9:00pm
MGH Wang ACC Lobby
About our Keynote Speaker

**David S. Finn, MD** is a primary care physician and the Medical Director of the Mass General Medical Group. In 2011, Dr. Finn was appointed the Assistant Medical Director for Primary Care Innovation and Transformation at Massachusetts General Hospital.

Dr. Finn chose primary care as a career because he wanted to care for the whole patient throughout their life. As the practice of primary care became more complex, Dr. Finn has sought to improve the delivery of primary care. Through care redesign, Dr. Finn is developing innovative systems to enhance the experience for patients and physicians, while at the same time improving quality and controlling costs.

Committed to these goals, Dr. Finn has been instrumental in leading Mass General’s efforts on care redesign, working broadly across the institution and with multiple specialties. The principle focus of this work is the implementation of the Patient Centered Medical Home.

Dr. Finn presents Mass General’s progress in care redesign to audiences both at MGH and beyond.

Dr. Finn received his bachelor’s degree from Johns Hopkins University and his MD from Tufts University School of Medicine. He completed residency in internal medicine at Massachusetts General Hospital.

The Medical Home at Mass General

Dr. Finn will be talking about The Medical Home Initiative at Mass General. The Medical Home is a patient-centered health care delivery model designed to address the needs of the “whole person.” Different from traditional fee-for-service models, The Medical Home looks to maximize health outcomes by focusing on prevention instead of treatment, easy-access healthcare communications, and exceptional patient experience. Dr. Finn will be speaking about the growing role of the primary care physician in care redesign globally, as well as how this model is enhancing the quality of care at Mass General.

Program

Registration & Buffet Dinner

Welcoming Remarks

Introduction: Rick Evans, Co-Chair The General PFAC
- Peter L. Slavin, MD, President of Mass General Hospital
- Jeanette Ives-Erickson RN, DNP, Senior VP for Patient Care Services & Chief Nurse

Dinner & PFAC Presentations

Introduction: Robin Lipkis-Orlando RN, Co-Chair The General PFAC
- The General PFAC: Kathy Varela
- The Cancer Center PFAC: Debbie Kanady
- The Institute for Heart Vascular and Stroke Care PFAC: Terri Fryer
- Mass General Hospital for Children PFAC: Lisa Cimino
- The Ambulatory Practice of the Future Care Alliance: Rebecca Petersen

The Medical Home at Mass General

Introduction: Susanne Goldstein, Patient, Chair of the Host Committee
- Speaker: David S. Finn, MD
- Q & A

Patients’ Corner

Introduction & Instruction
- Patients’ Corner Session

Live Patient feedback Session to David Finn

Closing Remarks

Win Hodges, Patient, The General PFAC and APF Care Alliance PFAC
MGH Patient and Family Advisory Councils

Ambulatory Practice of the Future Care Alliance

MGH Cancer Center
Patient and Family Advisory Council

MassGeneral Hospital for Children
Family Advisory Council

MGH Institute for Heart, Vascular and Stroke Care
Patient and Family Advisory Council

Pediatric Oncology Family Advisory Committee

The General Patient and Family Advisory Council

The Schwartz Center for Compassionate Healthcare

The Schwartz Center, based at Massachusetts General Hospital, is a national nonprofit organization dedicated to strengthening the relationship between patients and their healthcare providers and preserving the human connection in healthcare.

For more information, visit www.theschwartzcenter.org

Massachusetts General Hospital
Patient and Family Advisory Councils

&

The Schwartz Center for Compassionate Healthcare

“Creating a More Compassionate Healthcare System: Learning from Patients and Families”

Tuesday, February 25, 2014
5:30 PM – 8:00 PM
The Liberty Hotel
Ballroom
215 Charles Street · Boston · MA 02114
(Located next to the MGH Yawkey Building)
The Schwartz Center’s Guiding Commitments to a More Compassionate Healthcare System

**Commitments to a More Compassionate Healthcare System**

1. **Commitment to Compassionate Healthcare Leadership**
2. **Commitment to Teach Compassion**
3. **Commitment to Value and Reward Compassion**
4. **Commitment to Support Caregivers**
5. **Commitment to Involve, Educate and Learn from Patients and Families**
6. **Commitment to Build Compassion into the Fabric of Healthcare**
7. **Commitment to Deepen Our Understanding of Compassion**

To learn more, please visit www.committocompassion.org

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**Agenda**

5:30 PM – 5:35 PM
**Welcome & Introduction**
Jeanette Ives Erickson, RN  
*Chief Nurse & Senior Vice President for Patient Care Services*

5:35 PM – 6:05 PM
**Dinner**
*Coffee & Dessert*

6:05 PM – 6:15 PM
**Call to Action: Purpose & Goals**
Beth A. Lown, MD  
*Medical Director, The Schwartz Center*

6:15 PM – 6:21 PM
**Paired Exercise**
Sharing Experiences of Compassionate Care  
Staff Facilitator

6:21 PM – 6:30 PM
**Quartet Exercise**
Reflecting on a Definition of Compassionate Care  
Staff Facilitator

6:30 PM – 6:50 PM
**Debrief**
Beth A. Lown, MD

6:50 PM – 7:20 PM
**Call to Action Theme Exercise**
Beth A. Lown, MD

7:20 PM – 7:55 PM
**Debrief**
Beth A. Lown, MD

7:55 PM – 8:00 PM
**Closing Remarks**
Rick Evans, MA  
*Senior Director, Service Excellence*
A Call for a More Compassionate Healthcare System

“In my new role as patient, I have learned that medicine is not merely about performing tests or surgeries, or administering drugs. These functions, as important as they are, are just the beginning. For as skilled and knowledgeable as my caregivers are, what matters most is that they have empathized with me in a way that gives me hope and makes me feel like a human being, not just an illness.” – Kenneth B. Schwartz (1954-1995)

If there is one issue that unites patients and their healthcare providers, it is the yearning for a deeper human connection. Compassion is recognizing the concerns, distress and suffering of others and taking action to address them. As such, compassion is essential to high quality healthcare and should be at the heart of our healthcare system.

Compassionate care is not separate from other kinds of care, nor is it reserved for the end of life; it is fundamental to all patient-caregiver relationships and interactions. Without it, care may be technically excellent but depersonalized and cannot address the unique cultures, concerns, distress and suffering of patients and their families.

In today’s healthcare system, we believe compassionate care is at significant risk. Despite improvements in quality and safety and a focus on patient-centered care, caregivers face numerous challenges that impede their ability to form meaningful relationships with patients and families, including fragmentation and uncoordinated care, burgeoning clerical and administrative responsibilities, increased cost and market pressures, inadequate reinforcement of communication and listening skills, and technologies that both help and hinder communication and relationship-building.

To foster a more compassionate healthcare system, we are calling on all who believe in the importance of compassion and compassionate healthcare to support and endorse the following set of commitments, which we believe would go a long way toward making compassion a priority in our healthcare system.

1. **Commitment to Compassionate Healthcare Leadership**  
Healthcare leaders who embrace and model compassion foster a culture of compassion within their institutions and organizations. They play a crucial role in communicating the value and benefits of compassionate care and marshaling the resources necessary to make compassionate care possible.

2. **Commitment to Teach Compassion**  
Healthcare leaders, educators and caregivers who model, teach and reinforce the core values and skills of compassionate care foster them in students and trainees.
These skills include attentive listening, empathic concern, mindful self-awareness, effective communication, and the ability to elicit, understand and appropriately respond to the concerns, distress and suffering of patients and their families.

3. **Commitment to Value and Reward Compassion**
   Healthcare institutions that value, support and reward the cognitive, emotional and collaborative work and time required for caregivers to provide compassionate care allow such care to thrive. These institutions are committed to the development of valid and reliable measures and methods to assess and reward compassionate care.

4. **Commitment to Support Caregivers**
   Healthcare institutions that demonstrate compassion for caregivers equal to the compassion shown to patients and families help preserve caregivers’ resilience and sense of purpose. Excessive workloads, lack of control, lack of rewards, loss of a sense of community with colleagues and co-workers, perceived unfairness and lack of respect, and conflict between organizational and individual values contribute to burnout and erode engagement with one’s work.

5. **Commitment to Involve, Educate and Learn from Patients and Families**
   The needs and perspectives of patients and their families should be an organizing principle around which compassionate care is delivered. Patients and families should be involved in designing and evaluating care delivery and organizational policies at all levels. Healthcare, consumer and advocacy organizations can play a key role in educating patients and family members about the elements and importance of compassionate care, their right to ask for it when it is absent, and to take action when its absence impacts their health or wellbeing.

6. **Commitment to Build Compassion into the Fabric of Healthcare**
   Those who design care processes should consider how changes in care delivery and associated tasks affect caregivers’ capacity, ability and time to interact directly with patients and families. The continuity of patient-caregiver relationships should also be a priority within and across healthcare settings as well as in the community to lessen patients’ sense of being alone and unknown when they are most vulnerable.

7. **Commitment to Deepen Our Understanding of Compassion**
   An integrated research agenda should be developed and funded to study the neuroscientific, psychological and clinical aspects of compassionate care, its outcomes, and what compassionate care means to diverse patient populations.

We, the undersigned, support and endorse these commitments and pledge to do all that we can to ensure that our healthcare system is a humane and compassionate one for patients, families and caregivers.

©The Schwartz Center for Compassionate Healthcare
A key focus for 2013-14 has been to increase the visibility and utilization of the Institute for Heart, Vascular and Stroke Care Patient and Family Advisory Council (Institute PFAC) across the Institute and to strategize around the diversity of PFAC representatives. Goals are to:

- Represent the patient and family voice and perspective in the implementation of new Institute programs and initiatives and improvement of existing programs.
- Extend the reach of the Institute PFAC beyond monthly meetings, including Patient-Centered Outcomes Research Institute, CRICO, Quality and Safety Committee, etc.
- Participate in the review and revision of Patient Education materials and Care Redesign processes.
- Provide input and ongoing evaluation of MGH Innovation Units and related initiatives.
- Influence and participate in the education of Staff, including physicians, nurses and support staff.
- Recruit new council members who will continue to represent the diverse interests and concerns of all patients across the Institute care continuum.

Membership update: The Institute PFAC and MGH community thank Doug Henderson, administrative director for Clinical Operations, Department of Neurology for his service. Doug made a decision to relocate his family to Denver. The group welcomed Janet Caruso, administrative Manager, Department of Neurology, who transitioned to Doug’s role, representing neurology outpatient clinical operations.

The Institute PFAC achieved several noteworthy outcomes. In addition, members participated in, and provided valuable input for an array of activities beyond the standing monthly meetings including:
ENHANCING PATIENT AND FAMILY CENTERED CARE

Participated in the Kenneth B. Schwartz Center’s “Call to Action for a Compassionate Healthcare System” Dinner (February 25, 2014).

On Feb 25, 80+ patients, family members and staff from six MGH PFACs, including 14 Institute PFAC members, came together to dialogue with Beth Lown, MD, medical director of the Schwartz Center, and Jeanette Ives Erickson, RN, DNP, senior vice president for Patient Care and Chief Nurse, about ways to create a more compassionate healthcare system. Council members shared personal stories and offered recommendations on how to foster an environment of compassionate care. Recommendations were based on the seven commitments put forth by the Schwartz Center as part of a national “call to action” on compassion in health care.

Dialogued with My Health Check √ Team, Institute for Heart, Vascular & Stroke Care (April 1, 2014). Led by a team from the MGH Cardiovascular Disease Prevention Center, Health Check is a 10-point risk factor assessment tool that evaluates health behaviors and health factors that can increase risk for atherosclerotic cardiovascular and cerebrovascular disease. This patient risk assessment is deployed on an iPad platform with content adapted from the American Heart Association, and includes additional questions regarding secondary prevention. Patients complete the risk assessment during a regular office visit to an Institute outpatient clinic. The goal is to assess every patient seen at the Institute and provide a set of recommendations to reduce individual risk for atherosclerotic cardiovascular and cerebrovascular disease.

Health Check is currently active in the following MGH clinics: Corrigan Minehan Women’s Heart Health Program, Neurology Stroke Care, Interventional Cardiology and Vascular Medicine. The Institute PFAC members were publicly thanked for providing “feedback that has been invaluable in the refinement of our tool and process.”

Dialogued with MGH director of Nutrition Services and Nutrition Services Team (June 3, 2014). The Nutrition Services Team provided a glimpse into the future of patient food service at MGH that has a focus on better service and food quality. They also conducted a tasting of new food items for feedback.

Institute PFAC Input and Recommendations:

- Provide name and description of the new food choices, as most patients may not be familiar with choices such as plant protein items.
- Create an opportunity to provide gluten free options in the future.
- Develop menu choices for patients with longer inpatient stays of more than 21-days.
Recommended in revision and process of a new Patient Experience Survey for procedural areas (June 3, 2014).

Institute PFAC Input and Recommendations:

- 5x7 index card survey works well
- Include a field to enter a date (Header) for paper survey
- Include a check box: patient or family (Header) completing the survey
- Highlight in BOLD “Your visit today” (Header)
- Edit “How long you would need to wait?” to “Did you have to wait?”
- Change exam room to treatment room
- Recommended patients to complete survey on day of his/her procedure
- Provide survey in multiple languages
- Provide option for mailing in the survey

ENHANCING STAFF EDUCATION

Provided a guest speaker and participated in the Institute’s Annual Nursing Conference “Complex Issues in Heart, Vascular and Stroke Patients” (October 18, 2013). Institute PFAC Member (P. Hollenbeck), shared his patient experience on stroke and rehabilitation.

Staff feedback, including recommendations for changes in clinical practice:

- “Having Pat Hollenbeck speak was a highlight; loved hearing Pat’s perspective of care; it was great listening to a patient’s point of view and experience.”
- “Enhance patient teaching regarding Atrial fibrillation and Coumadin or other oral and new anticoagulants.
- “Care providers should avoid turning their back to patients when on computer.”
- “I will not speak so loudly to patients. Remember that patients can hear you even when you think they can’t.”
ENHANCING PATIENT COMMUNICATION, SERVICE AND DEVELOPMENT

Furnished a panel speaker at the CRICO Conference: “Challenges of Training Surgical Residents in the New Millennium” (June 25-26, 2013). Institute PFAC member (D. Wooster) shared patient perspectives at a panel discussion about obligations to the patient around the transparency of the residents’ role in care.


Institute PFAC Input and Recommendations:
- Develop a process for closing the loop to narrow the gap on “helpfulness” for patients including:
  - Improve patient access to appointments, especially when rescheduling an appointment post-cancellation.
  - Streamline billing process for patient requesting clarification and resolution of billing issues.
  - Identify a person accountable to close the loop for a call-back when a message recorded for a clinician.
  - Improve staff and patient communication to enhance awareness of expectations regarding wait time.

Recommended enhancements to a newly integrated Institute Outpatient Access Program (October 1, 2013).

Institute PFAC Input and Recommendations:
- Enhance visibility and accessibility of referral phone number to new patients and non-MGH patients.
- Simplify internet search to increase visibility of the MGH Institute HVS Programs.
- Develop internet linkage of the MGH referral line for PCP to Specialty Care.

Recommended revisions to the MGH Patient Information Guide (March 4, 2014)

Institute PFAC Input and Recommendations:
- Most patients would prefer written materials but information should also be accessible on line such as pdf that could be downloaded.
• Narrow the content by looking at what is vital instead of unique services
• Arrange information alphabetically
• Front page include a statement about how to access to an interpreter with 4 most common interpreters available at MGH
• Say what you mean; define categories so they are understandable, i.e., What is FAU (Financial Access Unit), Accommodations (refers to hospital room in brochure as opposed to hotels or lodging)
• Quick Start manual; similar to Smart phones quick and easy access to information
• Organize information with tabs and section by clinical or visitor
• Reduce redundancy of information in other brochures
• Use bullet points, rather than narrative
• Use more graphics; it is more pleasing
• Use bold font to highlight key information
• Maps and interactive guides are essential
• List departmental phone numbers, start with area code and consider a contact person for numbers listed
• Information and photos are current and accurate
• For television service add bring/use headphones for two-patient rooms
• Information available in other languages
• Keep following information: parking, area accommodations and restaurants, public transportation, rides and hospital shuttle schedule
• Include services for patients and families for long-stay patients, such as transplant
• Explain reasons for what to bring
• Omit the following information: MGH philosophy, patient rights, telephone service, advanced directives, driving directions

Dialogued with Director of Patient Care Services Quality & Safety (July 1, 2014)

Institute PFAC Input and Recommendations:

• Share data of interest to patients and strategize around best ways to communicate partnership efforts to enhance patient safety risk awareness, such as:
o Provide daily reminders to patients and family members of fall risks

o Use personalized messaging to encourage patients to use call lights for assistance

o Conduct daily rounds to discuss and update physician order on readiness for discontinuation of urinary catheters or central lines

o Provide patient education on active listening and self-advocacy for urinary catheter removal

o Use daily rounds to reinforce safety measures for patients who over estimate their ability to negotiate assistance in toileting, getting out of bed. For example, patients under the influence of pain medications, undergoing post-procedure interventions or connected to monitoring cables and/or IV tubes may not realize how weak they are.

o Track and report on the hand hygiene practices of visitors

STRENGTHENING AND ENHANCING AWARENESS OF MGH INSTITUTE PFAC

Participated in MGH Clinical Research Program (October 7, 2013). Two Institute PFAC members (T. Quirk & H. Bas, MD) participated in a full-day retreat sponsored by the MGH Clinical Research Program to promote patient engagement in the research process for Patient Centered Outcome Research Initiatives (PCORI).


“Our 2013 highlights demonstrate that our PFAC is continually and actively engaged in making informed decisions about healthcare for all. Through their collective vision over the years, the healthcare professionals at MGH together with patients and families have developed and enhanced PFACs to help us all redesign the way healthcare is delivered. Patients and family are critical to every step in this redesign process – an enduring redesign that recognizes the significant potential of hospitals partnering with patients and families.”

Participated in a full-day course on “Update in Heart, Vascular and Stroke Care in Women 2014” sponsored by the Institute HVS (May 3, 2014). Three Institute PFAC members (T. Fryer, S. Geary and Susan’s daughter Noelle) learned about the differences between men and women with cardiovascular disease, vascular disease and stroke.

Featured in the hospital’s newsletter the MGH Hotline article “Shaping the Delivery of Care” (October 11, 2013). “D. Wooster, a recipient of two heart transplants at the MGH, says being a member of the Institute for Heart, Vascular and Stroke Care council has enriched his life. The first thing we worked on back in 2007 was the MGH mission statement. When the final statement was shown to us and there was a phrase from our group, I realized what we did in that room—what we were going to do—would have an impact on the whole institution.”

Participated in the 18th Annual Kenneth B. Schwartz Center’s Compassionate Healthcare Dinner (November 21, 2013). Four Institute PFAC members (L. Chang, D. Mallen, Sr. J. J. Sullivan and K. Whitney) joined the MGH leaders to support the Schwartz Center’s mission of promoting compassionate care giving, and enjoyed networking and raising funds for its programs.

Participated in other activities.

- T. Fryer represented the Community Advisory Panel for the Partners HealthCare Biobank in July 2014
- D. Wooster joined the Quality Oversight Committee in January 2013
- D. Wooster joined the Patient Portal Committee in July 2014

Utilized electronic communication to broaden Institute PFAC member recruitment efforts.

MGH HVS INSTITUTE: May 30, 2014 Institute Updates

Patient & Family Advisory Council (PFAC) Recruitment
The Institute Patient & Family Advisory Council (PFAC) provides a formal mechanism to ensure that the voices of patients and families are represented in the multidisciplinary effort to enhance the care experience at the Institute. The council meets once a month and comprises patient and family members with heart, vascular and stroke conditions, as well as staff from Mass General leadership representing nursing, cardiology, neurology, social service and service excellence.

The Institute PFAC is asking for your help in identifying patients and/or family members who might be interested in serving on this council. Our goal is to have a broad and diverse cross section of your patient population representing different age, gender, race, culture/heritage, language, socio-economic background and sexual orientation. Council members should be able to:

- Represent the perspective of patients and family members
- Be both a team player and an initiative-taker
- Understand cardio/vascular/stroke disease issues beyond their own experience
- Commit approximately two hours per month for council meetings and potential subcommittee efforts
- Serve a one-year term. At the end of this term, members may request to be reappointed

If any of your patients or their family members would like to participate in the Institute PFAC, please email recommendations to Lin-Ti Chang at lchang2@partners.org.
MGH Institute for Heart, Vascular and Stroke Care
Patient and Family Advisory Council
2013-14 Members

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

MGH Staff
Heidi Bas
Janet Caruso
Lin-Ti Chang
Theresa Gallivan
Marie Elena Gioiella
Judy Silva
Cindy Sprogris
Kevin Whitney
OVERVIEW
In 2012, MGH launched the Institute for Heart, Vascular and Stroke Care (IHVSC), a new model of advanced, multi-specialty integrated care designed to be patient- and condition-focused. This model serves to streamline the patient experience by connecting each patient with the right specialist for his/her condition through one, single point of contact. Each specialist works with a multispecialty team of collaborating medical professionals to address a patient's conditions.

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

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

MISSION STATEMENT
To ensure that the voices of patients and families are represented in a multidisciplinary effort to enhance the experience of care at the MGH.

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

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

Participate:
- Provide input to improve the physical environment of care
- Provide representation on committees within the MGH IHVSC to represent the voice of the patient and families
Identify:
- Opportunities to promote wellness and prevention of heart, vascular and stroke conditions
- Patient- and family-centered care strategies
- New services, programs and/or communication, for consideration, that may benefit patients with heart, vascular and stroke conditions and/or the MGH IHVSC, itself
- New programs, efforts and/or mechanisms for consideration that would enable the MGH IHVSC patients to be able to give back to the MGH community through either support, community or recognitions

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

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

MEMBERSHIP
Nomination and Application Process
Recruitment of patient and family council members is initiated by referral from all disciplines including MGH physicians, nurses, other healthcare professionals and staff. Invitation letters and application forms are then sent to potential participants.

Applicants are selected based on the following criteria:
- Current experience as a patient or family member at the MGH
- Ability to represent overall patient care experience
- Willingness to work in an advisory role
- Ability to participate in a consistent and agreed upon schedule of meetings and potential subcommittee efforts
- Commitment to serve for a one-year term with potential to renew or step down at the end of the term

Once selected, the applicant receives an acknowledgement letter from staff of the MGH IHVSC PFAC and a thank you letter is sent to the referring MGH clinician or staff member.

Term of Appointment
- Members of the MGH IHVSC PFAC select and grant one-year term to council members.
- At the end of a one-year term, council members may request to be re-appointed.
- Resignation will be submitted in writing or via email to the MGH IHVSC PFAC. Vacancies may be filled during the year as needed.
ROLES AND RESPONSIBILITIES
Membership consists of 16 to 20 members: patients, family members and MGH staff. The three membership roles are described below.

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<th>ROLES</th>
<th>RESPONSIBILITIES</th>
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<tr>
<td><strong>1. MGH IHVSC</strong></td>
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<tr>
<td>- MGH IHVSC Co-Directors, Program leadership and staff</td>
<td>- Referral of potential PFAC member candidates.</td>
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<td>- Provide new PFAC members with an overview of the MGH IHVSC’s mission, programs and strategic initiatives.</td>
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<td>- Partner with the MGH IHVSC PFAC to improve the patient and family experience of care at the MGH.</td>
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<td>- Provide financial support for monthly meetings and approved Council Member activities beyond the monthly meetings.</td>
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<p>| <strong>2. MGH IHVSC PFAC Members</strong> | <strong>2. MGH IHVSC PFAC Members</strong> |
| <strong>MGH Staff</strong> | <strong>All Members</strong> |
| - MGH staff will be appointed by the MGH Heart Center Co-Directors and Associate Chief Nurse | - Maintain patient confidentiality according to Health Insurance Portability and Accountability Act (HIPAA) guidelines. |
| | - Advocate for all patients and families by identifying and representing their needs and concerns. |
| <strong>Patient and Family</strong> | - Establish goals and objectives of the MGH IHVSC PFAC at the beginning of each year. |
| - Includes patients and families representing diversity in age, gender, ethnicity and nature of heart, vascular and stroke conditions | - Plan, facilitate and guide the work of the MGH IHVSC PFAC. |
| | - Prepare for and attend meetings. |
| | - Provide notification by email or phone in advance, if attendance is not possible at a given meeting. |
| | - Participate in meeting discussions and activities. Any pertinent information, ideas, and suggestions should be communicated at meetings or by email or phone. |
| | - Be willing to consider additional opportunities for involvement beyond the monthly meetings. |</p>
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<th>ROLES</th>
<th>RESPONSIBILITIES</th>
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| MGH Staff | **Communicate HVSC PFAC activities to the leadership of the executive committees of the MGH IHVSC.**  
**Communicate with MGH IHVSC staff re council recruitment.**  
**Review new council member application(s) and participate in selection of new council member(s).**  
**Provide new members with an MGH IHVSC PFAC name tag and a binder which includes: Meeting Schedule, Staff and Member Contact List, Status Report, PHS Confidentiality Agreement, Caring Headlines Permission Form, Website page of MGH IHVSC & Blum Patient and Family Learning Center, MGH Ground Floor Map & Directions to the Yawkey Center for Outpatient Care.**  
**Send a reminder email to council members one-week prior to the monthly meeting including agenda and attached minutes from the previous meeting.**  
**Provide copy of agenda, minutes and any handouts as required at each meeting Provide council members a copy of their signed Partners Healthcare System Confidentiality Agreement and Caring Headlines Permission Form.**  
**Provide meeting space.**  
**Provide complimentary parking and light dinner at each meeting.**  
**Provide a PowerPoint slide presentation on the ongoing Council’s activities and accomplishments as determined by the MGH IHVSC Executive Committee.** |
- Provide an annual progress report on Council’s accomplishments during the preceding year to PCS for submission to Department of Public Health.

- Retain Council minutes for a minimum of 5 years
- Transmit minutes and annual accomplishments to the hospital’s Board of Trustees

Patient and Family
- Complete MGH volunteer program application and on-site orientation (which will occur at PFAC meeting for subsequent new members).

**ATTENDANCE**
Members attend monthly meetings on the first Tuesday of each month
- Location: MGH Yawkey Center for Outpatient Care in Yawkey 2-220
- Time: 5:30 PM to 7:00 PM

**REAPPOINTMENT**
MGH IHVSC PFAC Staff will remind Council Members for reappointment of members at the end of their term.
Mission
Established in 2001, the mission of the MGH Cancer Center Patient and Family Advisory Council is to ensure that the voices of patients and families are represented in an effort to enhance their entire experience at the MGH Cancer Center.

Objectives
As an advisory council to MGH Cancer Center staff and administration, the Cancer Center PFAC’s (CC PFAC) primary objectives are to promote and support patient- and family-centered care, to provide staff education on the patient and family experience, and to expand the voice of patients and families throughout the MGH by participating in hospitalwide committees and engaging with other patient and family advisory councils.

The Cancer Center PFAC has an ongoing commitment to meet these objectives by advising Cancer Center leadership on important initiatives such as space planning, communications to patients and families, web site design, program development, the Cancer Center’s ongoing evaluation of the quality of care and other initiatives.

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

Membership
The CC PFAC currently consists of 25 active members, 14 alumni members, and 8 staff members. Members represent diverse perspectives based upon age, gender, diagnosis and socioeconomic status. Current members represent approximately ten different Cancer Center disease programs, as well as three different sites (Boston/Main Campus, Mass General/Danvers, and Mass General/Emerson).

Staff members of the CC PFAC include the Blum Cancer Resource Room director, Cancer Center executive director, Cancer Center associate chief nurse, Cancer Center nursing director, Cancer Center project managers, and Cancer Center oncologist.
Qualifications for Membership
To serve on PFAC, patients and family members must have a recent history of receiving cancer care at the MGH Cancer Center. They must be able to use their own individual cancer experience in an objective way so that they can ask questions and offer a perspective that could be applicable to many patients and families living with cancer. They must possess good listening skills and be able to work collaboratively with others. CC PFAC members are asked to commit to attend monthly CC PFAC meetings as well as serve on committees throughout both the Cancer Center and the hospital, as well as CC PFAC subcommittees. Members are asked to make a two- to four-year commitment. Alumni members have the option to remain involved by attending select CC PFAC activities, if available, but do not attend the monthly council meetings.

PFAC Member Recruitment
Prospective members are nominated by Cancer Center physicians, staff or current CC PFAC members with the patient or family member’s permission. Nominees are asked to complete an application, which is reviewed by a CC PFAC staff member prior to an interview with select candidates. CC PFAC staff selects new CC PFAC members with a goal of having a diverse membership representing the cultural and socioeconomic diversity of Cancer Center patients and a variety of cancer diagnoses and treatments.

Membership Requirements and Training
CC PFAC members are required to meet MGH volunteer standards, which include the completion of HIPAA training and annual signing of the MGH confidentiality statement. CC PFAC members play an active role in orienting new members. Members serve as “buddies” to new members and provide peer mentoring on the role. New members are also encouraged to attend Cancer Center staff orientation. Ongoing education is provided throughout the year by invited staff who present on a variety of topics, such as cancer survivorship programming, quality of care, supportive care resources and changes in clinical care.

PFAC Leadership
By choice, the CC PFAC has no formal chair or elected officers. Currently the meetings are facilitated by Cancer Center leadership. Agenda items are prioritized by staff members based on topics discussed at CC PFAC meetings and requests from Cancer Center and MGHwide staff who wish to consult the council.

Roles and Activities
In addition to their attendance at monthly CC PFAC meetings, members are also asked to serve on Cancer Center and MGH steering and review committees. Committees on which CC PFAC members have served include the Patient Experience Council, Care Redesign Projects, Quality and Safety Committee, Patient Education and Communications Subcommittee, and Survivorship Day.

CC PFAC has participated in the interview process for oncology nursing leaders, the review of patient satisfaction and quality data, and the design of programming and patient education efforts. They have also been involved in Cancer Center initiatives to
improve clinical operations such as feedback on new nursing communication devices, the design of new clinical units, and projects to improve wait times and workflow.

Members also serve in an educational capacity by providing Cancer Center staff with a forum to discuss patient/family member perspectives and to address strategies on how to address different interactions across the continuum of care. Staff who have benefitted from these sessions include residents and fellows, support staff, and nursing staff.
Activities & Accomplishments

The PFAC has realized many accomplishments over the past year. The following represent areas that best demonstrate the impact of the PFAC on the Cancer Center’s patient experience:

**Advice and Feedback.** A major role of the CC PFAC is to serve in an advisory role to leadership and staff in an effort to continually improve the patient experience. Throughout the past year, CC PFAC members provided guidance for many programs and initiatives including: Palliative Care Services, the Cancer Center Access Nursing Program, the Lazarex-MGH Cancer Care Equity Program, Nutrition Services, infusion scheduling, the Pre-Admission Testing Area, Inpatient Oncology Service, Inpatient Innovations Unit and Cancer Center Genetic Counseling.

**Peer Guide Program.** During 2014, the CC PFAC implemented a comprehensive Cancer Center orientation program for patients and families. The response to this feedback was the development of the Peer Guide Program. The goal of this program is to improve the patient experience and encourage patients to participate in their own care through on-site peer orientation and support during outpatient cancer treatment. The Peer Guide is a specialized volunteer, generally a cancer survivor or family member/caretaker, who is stationed in the practices and treatment areas. The volunteer provides general support, communicating with patients about Cancer Center resources: the Katharine A. Gallagher Integrative Therapies Program, Parenting at a Challenging Time, Support Groups, etc. Each Peer Guide receives extensive training and ongoing supervision by one of the licensed clinical social workers. There are currently five Peer Guides. Regular updates on the Peer Guide program are shared with the CC PFAC.

**Cancer Center Patient Experience Council.** During the previous fiscal year, the Cancer Center launched its first Patient Experience Council. This is a multi-disciplinary committee including physicians, nursing, administration, communications, social work, CC PFAC representation, and MGH’s Service Excellence Department. The goal of the committee is to provide a process for continuous improvement of the patient experience. The council uses Press Ganey survey results as a way to understand the current state of patient satisfaction. Three subcommittees have been formed, including Patient Education, Service Expectations, and Survey Review. The council has published patient satisfaction targets and is launching a leadership/staff training program, service recovery program, and is facilitating enhanced patient education methods, including exploring new technologies.
Cancer Center Master Space Planning Process. In 2012, the Cancer Center led a master space planning initiative, and CC PFAC members provided input during a session with NBBJ, the architectural firm. This year, CC PFAC members continued to provide feedback to Cancer Center leadership and architectural firms pertaining to key Cancer Center space initiatives. In August 2013, Steffian Bradley Architects presented the draft of the space plans for MGH West to the CC PFAC and conducted a feedback session. CC PFAC's feedback was considered, and much of it was incorporated into the final designs. In July 2014, CC PFAC advised on the upcoming space transitions and associated communications planned for late 2014 and 2015, including the moves of Bone Marrow Transplant and Leukemia services. CC PFAC members held a brainstorming session regarding the transition of the Cancer Center Resource Room space, and the opportunity to bring its services and resources directly to patients.

Breast Cancer Care Redesign. In April of 2014, the CC PFAC provided feedback to Barbara Smith, MD, and the Breast Cancer Care Redesign Team on several components of the initiative. The Care Redesign project focuses on ensuring patients who have completed active treatment for breast cancer receive follow up care in a consistent and clinically appropriate manner, while aiming to increase efficiencies, timely access to care for new cancer patients and reduce costs where possible. As part of this project, a special visit conducted by nurse practitioners was designed for all patients finishing active treatment in order to help transition them to their new follow-up care schedule and educate them about Cancer Center resources. Additionally, the Care Redesign team sought advice about the potential to incorporate Virtual Visits into the Breast Oncology Practice. PFAC members advised on these two issues, as well as how patients may respond to a somewhat less frequent approach to follow-up appointments. This feedback was incorporated into the project deliverables moving forward. The name of the new visit type was even changed from “Graduation Visit” to “Bridge Visit,” due to members’ feedback.

Parking Policy. CC PFAC members met with the MGH Parking Office and Cancer Center administrators in late 2013 to better understand the existing MGH parking policy as they applied to cancer patients receiving treatment requiring frequent on-site visits. Council members advised that the parking options and structure were not always made clear enough to patients in the Infusion Center. They recommended that administrators and the Parking Office partner to ensure that as many patients as possible could benefit from special rates offered to certain Cancer Center patients. Cancer Center leadership formed a small operations team to address this issue and improve communications surrounding the parking options for patients and families. The MGH discounted parking rate is now routinely communicated to patients; this has been a major patient satisfier.

Quality and Safety. CC PFAC members continue to play an active role in the quality and safety efforts of the Cancer Center. A CC PFAC member serves on the Quality and Safety Committee that meets monthly. This committee reviews safety incidents and develops performance improvement initiatives to promote quality and safety. CC PFAC members also participate in quality rounds, a team-based rounding process to educate and promote awareness about quality and safety. The Cancer Center was also asked to
participate in the MGH Quality & Safety Committee, which provides even greater perspective to the Council about quality and safety across the MGH. During this year, special projects in oral chemotherapy compliance and reducing readmissions were a major focus.

**Education.** A major role of the CC PFAC is to provide continual education to patients and families, staff and faculty about the human experience of living with cancer. CC PFAC members participated throughout the year in several “Meet the Patient” forums that were attended by fellows, residents, support staff, and nurses as a way to educate faculty and staff about patient and family member needs and viewpoints. CC PFAC members also participate in the monthly staff Cancer Center orientation. These forums have been highly successful and provide a venue for faculty and staff to ask difficult questions about how patients and family members cope with a cancer diagnosis. CC PFAC members also participated in the annual Joint MGH PFAC meeting, which includes all MGH PFACs. This is a wonderful forum where the CC PFAC has the opportunity to network and share experiences with the other MGH PFACs. The CC PFAC is also extensively involved in organizing the annual Cancer Center Survivor’s Conference, including selection of speakers and panelists, and special guests.

**Revised CC PFAC By-Laws.** The CC PFAC convened a subcommittee to review and update the council’s by-laws. Subcommittee participation included CC PFAC staff members and several patient and family members. Key changes to the by-laws included the specification that members can nominate new members during recruitment cycles, additional clarification around the PFAC orientation process, the addition of membership term limits, and more structure regarding the transition to alumni status. The new by-laws, revised January 2014, are attached to the end of this report.

**Conferences.** As part of its mission to educate others about the value and role of PFACs, members participated in several external forums. This year, three CC PFAC members had the opportunity to attend the Sixth International Conference on Patient and Family Centered Care in Vancouver, Canada. Members gave two presentations, entitled “Strengthening and Sustaining the Cancer Center PFAC with Participation on Hospital-wide Committees and Initiatives” and “Through our Own Voices: A Peer Guide Program at the MGH Cancer Center”.

Members also attended the following forums:
- The Kenneth B. Schwartz Center’s Call to Action for Compassionate Care, February 2014
- Institute for Patient and Family Centered Care: the Intensive Training for PFAC Members, March 2014
- Health Care for All Conference, May 2014
- Massachusetts Statewide PFAC Conference, May 2014

**Committee and Subcommittee Participation.** CC PFAC members also participated in a variety of Cancer Center committees and subcommittees, which helps to ensure that
the patient and family member perspectives are well integrated into the fabric of the MGH Cancer Center. CC PFAC representatives on these committees provide periodic updates during the monthly council meetings. CC PFAC members participated in the following committees during 2013-14:

- Cancer Center Quality Committee
- Cancer Center Quality Rounds
- Cancer Center Patient Experience Council
- Cancer Center Patient Education and Communications Subcommittee
- Cancer Center Illuminations Art Program
- Cancer Center Network for Patients & Families
- Cancer Center Peer Guide Task Force
- Cancer Center Survivorship Conference
- Friends of the MGH Cancer Center
- MGH Patient and Family Advisory Council
- MGH Quality Committee
- The Professional Friends of the MGH Cancer Center
- Cancer Center PFAC By-laws Subcommittee

Looking Forward

As FY15 begins, many of the committees and activities listed above will continue. Cancer Center staff and leadership seek out the opinions and perspectives of CC PFAC members as staff are increasingly aware of the CC PFAC members’ diversity of experience and perspectives that can make an excellent initiative or program even better. CC PFAC members also contribute to the Mass General Cancer Community information learned, from personal experience or active learning and participation, to guide the Cancer Center in new directions and continually improve the patient experience.
1) **Mission Statement and Purpose**

**Mission Statement**
The Massachusetts General Hospital Cancer Center Patient and Family Advisory Council ensures that the voices of cancer patients and their families are represented in all aspects of cancer care at the Massachusetts General Hospital.

**Purpose**
To act in an advisory capacity to MGH Cancer Center staff, services and programs regarding topics that affect the quality of the patient experience at MGH.

2) **Membership**
Membership of the council is comprised of current and former patients of the MGH Cancer Center, their family members, and MGH staff and physicians as selected by Cancer Center leadership. The council will be comprised of 25-35 members and at least 50% of council membership shall be current or former MGH Cancer Center patients or their family members. The council's qualification and selection process reflects its commitment to PFAC membership being representative of the community served.

**Qualifications**
- Cancer treatment history for themselves or a family member. General guidelines: patients currently receiving treatment or having completed treatment, inclusive of chemotherapy, clinical trials, radiation, proton therapy and surgery.
- Ability to represent the perspective of patients and family members and understand cancer issues beyond one's own cancer experience.
- Represent diverse perspectives and backgrounds.
- Ability to work as a team player and to take initiative.
- Ability to make the time commitment for meetings and subcommittee efforts.

**Selection**
Patient and family member representatives are nominated by a Cancer Center staff member, PFAC member or clinician as part of a formal recruitment process that is comprised of the following components:
- Completion of an application form created specifically for the Cancer Center PFAC.
- PFAC staff leadership reviews membership applications, evaluates candidates based on the above qualifications, interviews each candidate via telephone or, preferably, in person and makes final membership selections.

The recruitment process takes place every two years and can be initiated in the interim as needed.

**Terms**
A term of Active Membership will consist of two years. After two years, members in good standing may renew for one additional two year term. At the conclusion of a member’s term of Active Membership, subcommittee membership may cease with the goal of rotating membership. If a council member takes a leave of absence due to illness, the duration of the leave is not encompassed in the term of Active Membership.

**Alumni Members**
Council members who have completed their term of Active Membership may become Alumni members. PFAC alumni will receive an annual report each year and invitations to select events. Alumni members may be called upon to serve on ad hoc task forces and participate in subcommittee efforts as needed.

**Officers/Chairs**
PFAC staff members act as the meeting facilitators and develop meeting agendas. PFAC does not have an elected council chair and each member plays an equal role in meeting facilitation, developing agendas and managing the flow of council meetings.

**3) Orientation**
PFAC members will be oriented to the role through a formal orientation process by current PFAC members and staff. All PFAC members will adhere to all Massachusetts General Hospital policies and procedures. PFAC members are MGH volunteers and will also be trained by the volunteer office.

**4) Roles**
PFAC members advise on a range of Cancer Center initiatives that impact patient care. In addition to the monthly PFAC meetings, PFAC members may serve on MGH or Cancer Center committees or PFAC subcommittees formed to accomplish PFAC goals. Key areas of focus for PFAC members include: operational improvement, patient education and communication, review of patient satisfaction and quality efforts, and program planning. Members are also invited to serve in an educational and advisory capacity annually via scheduled meetings with the oncology fellows, Cancer Center support staff and nursing staff. Participation in subcommittees is encouraged but not mandatory.

**5) Responsibilities**
Members commit to:
- Adhere to all MGH policies as reviewed in the PFAC orientation, including the non-solicitation policy and HIPAA privacy policy.
- Adhere to all volunteer policies as covered in the MGH Volunteer Department orientation.
- Fully participate in monthly meetings.
- Participate in other PFAC communications, subcommittees and activities as needed.
- Be active listeners.
- Advise and collaborate with the Cancer Center.
- Be respectful.
6) Logistics
- The council meets on a monthly basis.
- Minutes of the council meetings are taken by a PFAC staff member and will be maintained internally in an online file. They will be distributed to members monthly and available to members upon request.
- An annual report will be compiled for each fiscal year and will be available to council members for review.
- The annual report and meeting minutes will be transmitted to the hospital’s governing body.
The Pediatric Oncology Family Advisory Committee (FAC) has been a long standing, active group since 2003. Parents of children receiving cancer treatment and parents of those children who had completed treatment were joined by a multidisciplinary team of clinical professionals to collaborate with the common goal of providing excellence in pediatric oncology care.

In January 2014, the Pediatric Oncology Family Advisory Committee began the work of integrating with the other Advisory Committees within MGH. The Pediatric Oncology FAC formalized its mission statement and created bylaws. It developed new goals and plans for the upcoming year. It clarified the requirements of membership, and reviewed its current membership, setting in motion plans to expand its current group. This process proved inspiring to the Committee. Defining their mission provided the FAC focus and definition, and reaffirmed the value of the work of the Committee.

The FAC’s objectives are:

1. **Build a consistent and committed membership**
   - Initiate a vigorous recruitment process, including promoting diversity amongst members
   - Develop an orientation program for all members joining the Committee
   - Increase awareness of the value of the Advisory Committee’s role within the clinic’s operations and programs
   - Enhance the Advisory Committee member’s role as a change agent within the practice

2. **Collaborate with other PFAC’s and integrate into the already establish infrastructure of Advisory Groups at MGH**
   - Co-chairperson (MGH staff member) will attend Chairpersons Council
   - Advisory Committee members will have opportunities to participate in professional conferences within the region for education and collaboration
3. **Document initiatives and successes to organizational leadership**

- Provide periodic reports to practice leadership
- Compile a yearly report detailing annual activities
- Identify opportunities for collecting additional data for evaluation and action

The Pediatric Oncology FAC holds quarterly meetings with additional meetings scheduled when the group or a subgroup is working on a particular project. As an example, last year the group participated in the development of a new Family Guide in Pediatric Oncology. As the project was time sensitive, a couple of additional meetings were scheduled, as well as conference calls, to discuss the project. There is a clear understanding of the competing demands of families when a child has cancer—family, other children, work and of course, treatment, all impact the ability of any member to actively engage in the Advisory Committee. The majority of the meetings held this past year focused on the development of the Committee, including new bylaws and a mission statement.

**Additional activities and issues addressed included:**

- Enhanced membership and identifying mechanisms for recruitment
- Discussed the role of adolescents/young adults within the Advisory Committee as well as their unique needs as patients cared for in the practice. Recognized the importance of soliciting information directly from the patients. As a result, a questionnaire was developed for the co-chairperson/clinical staff member to implement in early fall. (see Appendix A)
- In an effort to involve the chief of Pediatric Oncology more directly with the Committee, Howard Weinstein, MD, will attend the fall Board Meeting in September 2014 to provide practice updates and begin an ongoing dialogue with the FAC.
- The Pediatric Oncology Ambulatory nurse manager reported on current Patient Experience Data and solicited feedback from the group.
- The Family Advisory Committee co-chair attended the Health Care For All conference in May 2014.
- Family Advisory Committee members provided guidance about the development of educational programs for families.
- FAC members served as a resource for the practice’s informational table for Childhood Cancer Awareness Month in September 2014.
Pediatric Oncology Family Advisory Committee

Overview: In 2003, the Massachusetts General Hospital for Children’s Cancer Center launched its’ initial Advisory Committee. Parents of children both currently receiving cancer treatment, as well as parents of children who had completed treatment joined with a multidisciplinary team of pediatric oncology providers to develop a framework for collaboration to inform clinic operations and program development. The committee quickly became an important voice in meeting the center’s expressed goal of providing family centered care. Since its’ inception, the Family Advisory Committee has seen changes in membership, as parents typically move off the Committee after several years of service. This has afforded the Committee the opportunity to move forward with new input while building upon past accomplishments.

Mission Statement: Massachusetts General Hospital for Children’s Cancer Center Family Advisory Committee (FAC) is committed to fostering a partnership between families and caregivers to promote excellence in the care of children with cancer.

Purpose:
- Parents, patients and health care providers work together to improve the quality of care for children and their families during and after cancer treatment.
- Promote Family Centered Care as a central principle within the Pediatric Oncology practice.
- Optimize the patient and family experience.
- Provide guidance and input on family education and the development of resources to support patients and families.
- Act as an advisory resource on issues of planning and evaluation of programs, services and clinic operations.
- Contribute to ensuring that the physical environment of the clinical areas are responsive to the needs of children and their families.
Membership:

The goal of membership is to have more than 50% of all committee members be parents of patients either currently in treatment for cancer, or those who have completed treatment. The remainder of the membership will include clinicians of the Pediatric Oncology health care team. The Clinical Social Worker will serve as the Co-Chairperson of the Committee. A Pediatric Oncologist and representative of the Nursing staff will maintain membership in the Advisory Committee. Other MGH Pediatric Oncology staff may attend a FAC meeting as needed.

Adolescents and young adults cared for within the Pediatric Oncology practice will be invited to participate in the FAC as needed. Specifically patients will be included as ad hoc committee members, serving as subject experts and advisors on projects and new program development.

Membership Qualifications:

- There will be an open enrollment process for participation in the Family Advisory Committee. Parents who are interested in joining should speak with the Clinical Social Worker who can provide information about the Committee. Additionally, parents can be recommended by staff for participation. In those cases, the Clinical Social Worker will contact the identified family member to discuss membership in the FAC. Information about the Committee will remain available in the Pediatric Oncology waiting area.
- Parents should have a child currently in treatment or be followed in the Pediatric Oncology practice for ongoing follow up care.
- Individuals participating should possess the ability to represent the perspective of the patients and family members and be able to consider issues beyond one’s own cancer experience.
- Ability to work collaboratively amongst a team of parents and clinical staff members.
- Ability to make a time commitment for meetings and special projects, as they arise.
- Represent diverse perspectives and backgrounds so as to reflect the clinic’s population.
Membership Terms/Responsibilities:

- Members will be expected to make a two-year commitment with the option to renew after that time.
- No specific term limits have been set.
- Meetings will be held quarterly, with a schedule provided at the beginning of each year.
- Additional meetings, either in person or via conference calls, may be added to address special projects or input from the Committee that needs to be obtained before the next scheduled meeting.
- Members are expected to participate in the quarterly meetings, and make a reasonable attempt to participate in meetings outside the quarterly schedule.
- Participate in MGH Pediatric Oncology community programs such as Fall for the Arts and Winterfest to provide a presence for the Committee and serve as a point of contact for other parents.
- Members will maintain patient confidentiality according HIPPA guidelines at all times.

Co-Chairpersons Responsibilities:

- A Parent with the Pediatric Oncology Clinical Social Worker will serve as Committee Co-Chairs.
- Parents will make a one year commitment to this role, with the option to continue for an additional year.
- Co-Chairpersons will define and distribute the meeting agenda.
- Follow up with committee members in between meetings to address action items.
- Be available as the point of contact for family members who would like to discuss Committee participation.
- Develop an annual report with input from the Committee.
- The role of recorder will be delegated by the Co-Chairpersons at each meeting on a rotating basis amongst other committee members.
MassGeneral Hospital for Children’s Cancer Center’s Responsibilities:

- Work collaboratively with the FAC to promote the best possible family centered practice.
- Insure respectful collaboration in policy making, program planning and evaluation.
- Offer orientation to new members of the FAC to include training around safety and privacy.
- Review and respond to recommendations of the FAC in a timely manner.
- Provide free parking for FAC meetings.
- Provide suitable meeting space and refreshments with each meeting.
- Retain FAC minutes for a minimum of 5 years.
- Provide minutes and annual reports to the Hospitals Board of Trustees, as requested.

Amendments to the By-laws:

- Committee members should request the item added to the agenda.
- Revisions are sent out prior to the meeting, with discussion at the FAC meeting.
- The Committee will vote on the amendments and approve through a majority vote.
Pediatric Oncology Family Advisory Committee
Membership

Co-Chairs

Elyse Levin-Russman, LICSW, OSW-C  Joseph Barnes
Clinical Social Worker  FAC Parent

Staff Members:

Mary Huang, MD
Pediatric Oncologist

Heidi Jupp, RN, CPON
Pediatric Oncology Nurse

Ellen Silvius, RN, BSN
Ambulatory Nurse Manager

Parent Members:

Nancy Barnes
Mary Cincotta
Kim Kayajian
Agatha McEachern
Michelle McKiernan
Dawn Regan
Garry Waldeck
MGH Pediatric Hematology-Oncology
Teen/Young Adult Survey

We need your help! As we are trying to make the experience of coming to the clinic and hospital better for you and other teens/young adults, we hope you will share some of your thoughts. We are particularly interested in learning how we can best provide you with information about your cancer and its treatment when you first learned about it. When you complete the survey, which will only take 5-10 minutes, your will be able to select a $10.00 gift card of your choice as our thanks for helping with this.

If you are under 18 years old, we need your parent’s permission for you to complete this survey. Please have either of your parents sign here before continuing.

I have been informed of the purpose of this survey and agree to have my son/daughter participate in its completion. The information my child shared will not be publicized, nor will their name be attached to any summary findings.

Son/daughter’s name; ____________________________________________
Your name/relationship __________________________________________ Date: __________________

A couple of questions to start:

Your age when you were diagnosed ______  How long ago were you diagnosed? __________

Are you male or female? (please circle)

1.  Thinking about when you were first diagnosed, would it have been helpful to receive information about your diagnosis and treatment specifically written for you?
   Yes ______  No ______  I don’t know ______

2.  If you said yes, how would you have like to receive this information?
   In writing (book or binder) ______
   On a website ______
   Via email ______
   Other (please explain) ______

____________________________________________________________________________
3. Thinking back to when you were first diagnosed, would it have been helpful to talk with someone your age with a similar diagnosis who had already received treatment?

Yes ______ No ______ I’m not sure ______

4. Thinking back to when you were first diagnosed, what do you wish someone had told you about your diagnosis/treatment?

______________________________________________________________________

5. Considering what you have gone through, is there something that you would tell someone your age that you wish you knew then?

______________________________________________________________________

6. Where do you go now to get questions answered about your health care? (you can choose more than one answer)

Online ______
Talk to my Doctor ______
Talk to my Nurse ______
Friends ______
Facebook ______
Other ______ (please explain) ______________________________

7. A focus group is a discussion group with other teens/young adults along with Pediatric Oncology staff to help design ways to better help other patients your age. Would you be interested in participating in a focus group?

Yes ______
I’ll think about it ______
No thanks ______

If you answered yes or I’ll think about it, please give us your name and best way to reach you.

Name: ________________________________

Cell Phone and/or email contact: ________________________________

THANK YOU FOR COMPLETING THIS SURVEY!
MassGeneral Hospital for Children FAC

2013-14 PFAC ANNUAL REPORT
FAC members participated in the Kenneth B. Schwartz Center’s “Call to Action for a Compassionate Healthcare System” Dinner (February 25, 2014) at which they shared their experiences of compassionate care and learned about the latest research on strategies for health care systems to promote compassionate care.

Created educational videos. Two FAC parents created three-minute videos that have been placed on the MGHfC website. One provides advice on managing a team of many subspecialists while the other offers guidance on the benefits and challenges of internet research.

Attended Pediatric fellows retreat. FAC parents met with twenty Pediatric fellows at their annual fellows retreat. The Fellows shared challenging clinical encounters they had experienced, and parents provided insights into how to approach similar situations in the future.

Familiarized the FAC with Health Care For All. Invited Deborah Wachenheim, Health Quality Manager for Health Care For All, to attend an FAC meeting. She gave a presentation about her organization’s involvement in the legislation requiring hospitals to created PFACs, as well as their other priorities and work.

Presented at HCFA Conference. FAC Co-Chairs Lisa Cimino (parent) and Sandy Clancy (staff) gave a talk at the Health Care For All Conference at Holy Cross College in Worcester outlining how MGHfC’s practice of an annual Grand Rounds led by a parent has increased awareness of the FAC throughout the hospital.

Developed FAC slideshow. The FAC put together a photography slide show with captions that represent the events in which FAC participates. This was then posted to the FAC webpage on the MGHfC website: http://www.massgeneral.org/children/news/multimedia.aspx?id=762

Organized a Grand Rounds session. FAC organized a well-attended Grand Rounds in which three senior physicians discussed the topic of how their own illnesses and hospitalizations impacted their practice of medicine.
Provided feedback to MGH Marketing. FAC provided feedback to MGH Director of Marketing about a new radio campaign. FAC’s feedback was integrated into the final product.

Sponsored an ice cream social. FAC sponsored and hosted an annual Ice Cream Social for all staff and patients on the pediatric in-patient units as a way to increase awareness of FAC and its work.

Presented at Pediatric residents’ orientation. Two FAC parents met with incoming Pediatric residents at the Intern Orientation event in order to apprise them of FAC’s work throughout the hospital.

Participated in resident education longitudinal curriculum. FAC parents were invited to participate in the resident education longitudinal curriculum in May 2015, meeting with junior residents and sharing their experiences of care at the hospital.

Provide outpatient input. FAC parents were invited to meet with MGH/fC nurses who work in the ambulatory setting in order to share experiences of care specific to the outpatient setting.

Developed a children’s handbook. One FAC parent and her daughter, an MGH/fC patient, wrote a draft of a children’s handbook to be given to pediatric patients upon their arrival to the MGH/fC Emergency Department. The FAC is developing a hospital-wide committee and interdisciplinary team tasked with creating the final version of the handbook.

Attending IPFCC seminar. The Department of Pediatrics will fund a team to attend the Institute for Patient and Family Centered Care’s training seminar in Cambridge, MA in Nov. 2014. The team will include two FAC parents, a PICU nurse, a resident, a resident educator, and the FAC’s staff co-chair.

Participated in MGH’s Annual Joint PFAC Meeting. FAC parents and staff attended MGH’s annual joint PFAC dinner held in November 2013, at which parent co-chair Lisa Cimino provided a synopsis of the FAC’s work during the past year.

Conducted goal-setting session. In September 2013, the FAC had a goal-setting session and defined goals for the year, including:

- To increased patient engagement
- To create more opportunities for patients and parents to share their experiences in the hospital
- To create a parent support network
- To develop more PICU educational material, and
- To develop a better relationship with the Office of Patient Advocacy.
Furthered peer support group participation. Several FAC members viewed a webinar “Developing Patient- and Family-Centered Peer Support Programs,” sponsored by the Institute for Patient and Family Centered Care, as a way to work toward the goal of integrating an FAC parent into a Neonatal ICU support group. The FAC co-chair and a social worker formed a working committee along with the Neonatal ICU social worker, nurse director and nurse in order to determine the feasibility of adding a parent to a NICU support group.

Informed playroom renovations. An FAC parent joined an MGHfC hospitalwide committee charged with overseeing the renovations of the playroom on the inpatient units. She attended monthly meetings and reported back to the FAC.

Provided feedback regarding the Patient Bill of Rights. FAC parents provided feedback to the director of the Office of Patient Advocacy about revising the Patient Bill of Rights that is posted throughout the hospital and provided in each new patient welcome packet.

Informed research design. Elsie Tavares, MD, chief of the Department of General Pediatrics at MGHfC, visited FAC and gave a presentation on her groundbreaking work on obesity in children, soliciting feedback from FAC on research design.

Helped create a patient/family education. FAC worked with the Pediatric ICU (PICU) nurse director to create a patient education document orienting new patients and their families to the unit. The document is now provided to all new PICU patients and families.

Helped increase visibility and awareness of MGH PFACS. FAC parent co-chair Lisa Cimino was profiled in an article about the hospital’s Patient and Family Advisory Councils in the hospital’s newsletter, MGH Hotline.

Participated in important MGH committees. FAC parent members continued their service on hospitalwide committees, including Ethics, Quality and Safety, Autism Collaborative Project, MGHfC Advisory Board, and the NICU Peer Support Initiative.
Massachusetts General Hospital for Children
Family Advisory Council Membership
Summer 2014

Parent Members

Seta Atamian
Debby Cartisser
Lisa Cimino (FAC Co-Chair)
Darcy Daniels
Sarah Grallert
Jan Lanosa
James Massman
Mark Matusueski
Eve Megargel
Janice Morris
Erin Quinney
Meagan Taylor

MassGeneral Hospital for Children Staff Members

Sharon Badgett-Lichten, Senior Project Manager, Office of Service Excellence, MGH
Debbie Burke, Associate Chief Nurse
Monic Chardin, Practice Manager, Pediatric Group Practice
Sandra Clancy, Program Manager and Patient Advocate of Coordinated Care Clinic and Palliative Care Service (FAC Co-Chair)
Sandra Dodge McGee, Executive Director
Peter Greenspan, Medical Director
Esther Israel, Director of Quality and Safety
Rose McClory, Nurse on Ellison 18
Eleanor McLaughlin, Nurse in PICU
Jenna Reardon, Nurse in PICU
Peggy Settle, Nurse Director of NICU
Alexandra Sobran, Clinical Director of Social Work
1. **Mission Statement:**
   The MassGeneral Hospital for Children's Family Advisory Council (FAC) is dedicated to fostering the partnership of parents, children, and professionals working together to ensure a climate of responsiveness to the needs of children and their families in all areas of care delivery within Massachusetts General Hospital.

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

3. **Membership Committee:**
   3.1. Members of the Membership Committee will be appointed by the MGHfC Associate Chief, Department of Pediatrics;
   3.2. The Membership Committee will consist of three current FAC members and two MGHfC Council members;
   3.3. Members of the Membership Committee will track membership terms and actively recruit new members.
4. **Membership:**
   4.1. Membership is by application to the Membership Committee;
   4.2. Membership consists of fifteen people whose children have received care at MGHfC or are patients sixteen years or older who have received care at MGHfC;
   4.3. Family members will serve as the Council Co-Chairs;
   4.4. The MGHfC ‘s Medical Director, Associate Chief Nurse of Pediatrics, Executive Director, and Inpatient Director of Quality and Safety will be ex-officio members;
   4.5. The MGHfC Inpatient Director of Quality and Safety will be allowed to vote in times where a tie-breaking vote is required.
   4.6. The MGHfC will have four rotating staff members of the Council;
   4.7. Other MGHfC staff will attend meetings as needed and receive meeting minutes approved by the Council to have knowledge regarding the agenda and on-going work.

5. **Membership Terms:**
   5.1. Each year in September, the Council will seek to appoint three family members to serve a three-year term to the Council;
      *(Beginning with the Council in 2007, the 9 appointed family members will be appointed to one, two, and three year terms, the same with the 3 MGHfC staff)*;
   
   5.2. Members can re-apply for appointment for up to six years. After this time, members can still be active on committees but must wait three years before reapplication to be a member of the Council;
   5.3. Membership will elect in March a Council Co-Chair for a two-year term with co-chair election to follow six months later.
   5.4. Any Council member that misses four consecutive meetings will be considered an inactive member unless the absence has been approved by the Membership Committee;
   5.5. If a Council member cannot fulfill his/her commitment to the Council, they can resign in writing and a new member will be chosen to serve the balance of his/her term.

6. **Membership Responsibilities:**
   6.1. Participate in the formation and evaluation of FAC yearly goals and objectives and be an active participant in Council activities;
   6.2. Prepare for and attend meetings;
   6.3. Be an advocate for all patients and families by identifying and representing their needs and concerns;
   6.4. Maintain patient confidentiality according to HIPPA guidelines at all times;
   6.5. Consider serving on other MGHfC committees when requested;
   6.6. Support the MGHfC publicly;
   6.7. Notify the Co-Chairs if unable to attend meetings;
   6.8. Agree to attend the Volunteer Program Initiation and Training as well as participate in the Volunteer Program;
   6.9. MGHfC staff members will act as the hospital liaisons to the Council.
7. **Co-Chair Responsibilities:**

7.1. Establish goals and objectives of the Council with the Membership in September;

7.2. Complete an annual progress report to be submitted in January to the Chief of Service, Department of Pediatrics, Chief of Pediatric Surgery, Vice-President of Pediatrics, MGH, Vice-President, Chief Nurse, MGH, Storybook Ball Committee Chair;

7.3. Set meeting agendas and schedules;

7.4. Represent the goals and objectives of the FAC with any correspondence approved by the Membership with hospital administration and staff;

7.5. Appoint subcommittee chairs, who will be responsible for:
   - updates of the subcommittee work to the Council at regular intervals;
   - goals and objectives for the subcommittee;
   - annual reports of the subcommittee.

8. **MassGeneral Hospital for Children Responsibilities:**

8.1. Work collaboratively with the FAC to promote the best possible family-centered practice at the MGH/C;

8.2. Work together with the FAC in policy-making, planning and evaluating of programs and services;

8.3. Review and respond to recommendations of the FAC in a timely manner;

8.4. Offer new member orientation to the MGH/C structure, decision-making process, committee structure, and HIPPA regulations;

8.5. Provide meeting space and refreshments;

8.6. Provide free parking for FAC meetings and work in hospital;

8.7. Provide financial support for approved FAC activities based on submitted proposals.

8.8. Provide staff support person to:
   - take meeting minutes;
   - notify members of upcoming meetings with agendas;
   - distribute meeting minutes to the Council and others on the distribution list;
   - keep the FAC distribution list up to date;

9. **Quorum:**

9.1. A quorum represents 7 members, one of whom must be a staff member, needed for any official meeting.

10. **Amendments:**

10.1. The process to amend the FAC By-Laws is as follows:
   - Council member submits suggested revision in writing.
- Revisions are sent out to members and discussed at a Council meeting.
10.2. The Council will vote on the amendments and approve through majority vote.
Family Advisory Council

The MassGeneral Hospital for Children (MGHfC) Family Advisory Council (FAC) is dedicated to fostering partnerships 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 MGHfC.

Family-Centered Care Core Concepts

- **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 parent 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; health care facility design; and professional education.

Our Goals

- Collaborate with MGHfC staff to promote family-centered care, as well as improve the quality of care provided to children and their families in both inpatient and outpatient settings.

- Enhance 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 MGHfC leadership on issues of planning, evaluation of programs and services, policies and research.

- Contribute to the development of teaching materials produced by the hospital for families and staff.
Who We Are
A partnership of family members, hospital leadership and staff dedicated to working together to improve the care and experience of patients and their families who receive care at MGHfC.

- Diverse group of 15 family members whose children have received care at MGHfC
- Co-chaired by family members
- MGHfC leadership including:
  - Medical Director
  - Associate Chief Nurse
  - Executive Director
  - Director of Quality & Safety
  - Representation from nursing, social services, child life and other health care disciplines

Some of Our Accomplishments
- Developed a Grand Rounds for all MGHfC clinical staff on the topic of communication between physicians and patients.
- Worked closely with chief residents to include family members in Chief of Service Rounds.
- Created ID badge attachments for MGHfC staff explaining the principles of family-centered care and practical communication tips.
- Provided input to Mass General Council on Disabilities Awareness on ways to make the hospital more welcoming to families of children with disabilities.
- Participated in a staff recognition program by judging applications for MGHfC Family-Centered Care Awards.
- Provided feedback for redesign of family lounge on the pediatric inpatient ward and pediatric emergency department.

Council Membership on MGHfC Committees
- Quality and Safety Committee
- Quality and Safety “Speak Up!” Subcommittee
- Ethics Committee
- Endoscopy Space Planning Committee

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

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

Family Advisory Council
MassGeneral Hospital for Children
175 Cambridge Street, 5th Floor
Boston, MA 02114

For more information on membership, please visit our website: massgeneral.org/children
or email our membership liaison at: fac@partners.org.
The MassGeneral Hospital for Children Family Advisory Council presents:

Reflective Practice: The Physician as a Patient

April 22, 2014
O’Keefe Auditorium
8:00 – 9:00 a.m.

In this Grand Rounds, three physicians will reflect on how their experiences as patients have changed their practice of medicine.

Participants:
Verne Caviness, MD
Ronald Kleinman, MD
Gleeson Rebello, MD

Patients, families and staff are welcome to join us.

The Pediatric Family Advisory Council is a group of patients and parents who meet monthly with hospital leadership and staff to promote family-centered care. To learn more email FAC@partners.org

For more than a decade, the MGH Patient and Family Advisory Councils have provided communication vehicles for patients and families to share their experiences.
BRIDGING GAPS: MGHfC council members Cimino, left, and Sandy Clancy

“It can feel so overwhelming at times and you feel so alone. It’s a comfort to know someone has been through it and has a voice,” says Lisa Cimino, member of the MassGeneral Hospital for Children (MGHfC) Family Advisory Council.

For more than a decade, the MGH Patient and Family Advisory Councils (PFACs) have provided communication vehicles for patients and families to share their experiences. The councils – made up of caregivers, administrative staff, former patients and family members – meet monthly with the goal of shaping and enhancing delivery of care.

There are four PFACs at the hospital: MGHfC; MGH Cancer Center; Institute for Heart, Vascular and Stroke Care; and the General Council. In addition, the hospital’s Ambulatory Practice of the Future operates a Care Alliance, which facilitates an ongoing partnership among patients and staff to promote innovation and the optimization of care. Each PFAC addresses a distinct patient population, providing a different perspective to influence initiatives throughout the hospital. Most members are referred by clinicians but some seek out the council on their own.

The first PFAC was formed in 1999 with the launch of the MGHfC council. “I felt if there was a way I could help the hospital make this the best experience possible for families, I wanted to be a part of that,” says Cimino. When her daughter underwent a kidney transplant, it was an emotional experience – numerous checkups, appointments and tests marked by a procedure with unpredictable outcomes. “The council is a place where I can share what I went through and my concerns that are then carried on and applied to improve care in the future,” says Cimino.
The MGHfC council is comprised of a child life specialist, a social worker, a nurse, a resident, attending doctors and 13 family members, including Sarah Grallert who serves as a voice for outpatients. Grallert’s experience was different than that of other parents on the council because her children were only seen in an outpatient setting. “So what’s my place? What’s my role? What I’ve found is that there’s a lot of room to bridge distances between the provider and family in the outpatient room.”

One of Grallert’s most gratifying experiences has been working with staff as part of the Ambulatory Care rotation. “We talk to the pediatric residents about what goes on in a parent’s mind, what worries us and how scary it can be.”

Lynne Morin, a childhood cancer survivor, also knows how scary the hospital can be. She was only 15 years old when she received treatment at the MGH for bone cancer. Twenty-five years later, Morin is a member of the Cancer Center PFAC. “I wanted to give back to the MGH but I also wanted to give back in a way that would make things better for the patients and families that followed.”

Morin has been a member of the council since its inception in 2001. The center’s PFAC has influenced some major milestones over the years: construction of the Cancer Center’s facilities in the Yawkey Building, the rooftop Healing Garden and MGH West.

“I’m getting so much out of it, I don’t want to leave,” says Margaret Carvan, another Cancer Center PFAC member. “The teams are valuable because everybody’s journey and perspective is different.”

David Wooster, a recipient of two heart transplants at the MGH, says being a member of the Institute for Heart, Vascular and Stroke Care council has enriched his life. “The first thing we worked on back in 2007 was the MGH mission statement. When the final statement was shown to us and there was a phrase from our group, I realized what we did in that room – what we were going to do – would have an impact on the whole institution.”

Formerly known as the Heart Center PFAC, the council expanded in 2012 to include representatives in vascular and stroke. Their work over the years has included everything from reviewing education materials, to room design, to evaluating software.

In addition to the three patient-centered councils, the Ambulatory Practice of the Future – a primary care practice model piloted internally – created a Care Alliance, which addresses the staff experience as well. Rebecca Petersen, one of two patient co-chairs, says, “The staff here is already patient-sensitive, which frees our group to work on other ways to make the practice better.” She and other alliance members have played a major role in developing and providing input about written information for new patients and staff processes as well as reviewing survey results.
Established two years ago, the General Council has a broader focus and serves as an educational resource for all PFACs, explains member Kay Bander. “It is a problem-solving resource and an information absorbing resource.”

The chair of each PFAC also can sit on the General Council. “This provides an opportunity for PFACs to share information and discuss strategies for recruitment, orientation and learning initiatives” says Bander. "Influencing an academic health center as large as the MGH is not a simple task.”

For more information about PFACs or to view the recently released 2012-2013 Annual Report, visit [www.massgeneral.org/patientadvisorycouncils](http://www.massgeneral.org/patientadvisorycouncils).
“Welcome to the Hospital”
(Draft written by an FAC parent and her 10 year old daughter)

Hi! My name is Wendy. I have spent a lot of time in the hospital because of my illness. I know you must be in the hospital if you are reading this book. Or maybe you’re going to the hospital soon. Don’t worry! I’ll tell you all about it so that you can be prepared. A hospital isn’t so bad after all!

Maybe you arrived by car with your parents, or maybe you arrived by ambulance, which is a vehicle equipped to take people to the hospital where they can be cared for. The special thing about an ambulance is that it can put on its lights and sirens and get you to the hospital faster. Cars have to pull over when they see an ambulance coming.

You might arrive at the Emergency Department. This is a place in the hospital where doctors and nurses can look at you immediately and figure out what the problem is. They will ask you a lot of questions about what hurts and where. They just want to be very sure that they know how to make you feel better.

This is a page where you and your parents can write down what the problem is. [What hurts? When did it start? Draw a picture of how you feel. What questions do you have for the doctor?]

A lot of times, doctors will order tests so that they can see what’s inside of you, like an X-ray to look at your bones or your lungs. You can ask to see the pictures when they are done. They are really cool! Often doctors will want you to get labs. These are tests to make sure everything is ok with your blood. The nurse needs to prick your arm to get the blood, and it might hurt a little, but not for long. She might leave an IV in your arm. This is a little plastic straw that the doctors use to put medicine into your body so you don’t have to take it by mouth. Everyone who stays in the hospital has an IV in their arm.

You’ll also have to wear special clothes that the nurses give you. These are called Johnnies, and they are shirts that have snaps along the sleeves and ties in the back. Sometimes you can wear two, one for the front and one for the back. You can still wear your own underwear and socks from home. Bring your slippers!

If the doctors decide to keep you for a few days, it’s called getting admitted. That means you will get a bed in a room. Your mom or dad will stay there too. The doctors do this so they can figure out what is wrong with you, and when they do, they call it a diagnosis. A diagnosis is the first step to leaving the hospital. Once the doctors figure out the diagnosis, then they can figure out how to treat it. You are on the road to recovery!
You will see the doctors and nurses and every day. They are normal people but with important jobs. Make sure you tell them how you feel, both in your body, and with your emotions. If you’re a little bit scared, you should tell them that! If you have any questions about what is happening, they will be happy to explain that to you too. Doctors and nurses are there to help you.

There are other people in the hospital whom you will see everyday too. The Child Life Specialists are there to make sure you are having a good time. They can get you games and crafts to make the days go by quickly. There might be an Art Therapist or Music Therapist who will come to your room to make artwork or play on instruments. Sometimes there are volunteers who come in with their therapy dogs so you can pet them. Everyone wants to make sure you are as happy as you can be while you are getting better.

Sometimes you might have to get an operation, which is called a surgery. The surgeon is a special doctor who will perform the operation. Don’t worry, you will be asleep when he or she does it. There is another doctor called an anesthesiologist who makes sure that you are comfortable and sleepy before the surgery. Your parents will be with you before you fall asleep and again after you wake up. You even get to bring a stuffed animal in to the operating room with you if you want to!

You are in the hospital to get better. That’s your job while you are there! It has a special name, called recovery. The doctors will monitor your progress and come up with a good time to discharge you. A discharge means that you are going home because you’re well enough for your parents to take care of you again. You still might be sore or unhappy for a while, but hopefully you will be back to your old self in no time.

When you get discharged, your parents will be given a whole list of things to do, like buy medications, and make follow up appointments with your doctors. Don’t worry, these are details that have to get attended to so that you can be comfortable at home. If you have any questions, be sure to ask them before you leave the hospital, or you can call the doctors when you get home.

Hospitals might seem scary, but they are really just a place for you, your parents and the doctors to work together to make you feel better. Go team! Then, once you feel better, you get to go home again.

Thanks for letting me show you around a hospital! I hope that you don’t have to stay long, but if you do, try to make the best of it. I hope you feel better soon!

[Back page with helpful hints for parents about the hospital admission process and helpful resources.]
MGH Ambulatory Practice of the Future Care Alliance

2013-14 PFAC ANNUAL REPORT
The MGH Ambulatory Practice of the Future
Care Alliance
2013-14 Activities and Accomplishments

The Care Alliance is a partnership of patients, family members and providers that promotes innovation and the optimization of the care experience for all.

Ambulatory Practice of the Future
The Ambulatory Practice of the Future (APF) is an innovative primary care practice charged with caring for employees of MGH and their spouses/partners. APF is a team-based practice partnering with patients by offering electronic communication, unrestricted access to test results and visit notes, along with continuous care and coaching. The approach is designed to help patients better manage and achieve their health, life balance, and wellness goals. The practice, which opened in 2010, is now operating with nearly one-and-a-half of its ultimate goal of three healthcare teams. An important aim of this practice is to make the experience of care equally rewarding for patients, their families and staff alike. The Care Alliance, which is made up of patients and staff providers, is committed to partnering to ensure the values that define APF remain strong while the practice expands.

Care Alliance Leadership and Membership

**Patient Members**
Steve Lynch (Co-Chair)
Rebecca Petersen (Co-chair)
Win Hodges (Chair Emeritus)
Stephanie Geohagen
Paul O’Leary
Judith Webb
Priscilla White

**Staff Members**
Ben Crocker, MD, Medical Director
Elizabeth Donahue, NP
Annie Helgason, MD
Laura Keogh, MD
Mary Ann Marshall, RN
Jane Maffie-Lee, NP, Clinical Program Dir.
Care Alliance leadership is shared by two patient members, Steve Lynch and Rebecca Petersen. Founding member Win Hodges is our chair emeritus, who provides valuable input from his extensive PFAC experience. Patient members facilitate monthly meetings on a rotating basis and additionally meet as needed in a virtual meeting to brainstorm and work on action plans. A Patient Care Alliance member attends APF staff meetings to provide the patient perspective, and staff concerns are regularly summarized for other Care Alliance patient members to offer additional input. Staff concerns are a monthly agenda item to provide a vehicle for more patient input and collaborative problem solving. Given the proactive activities of our Care Alliance, we believe it is important to retain experienced PFAC members, while growing our Care Alliance. Two new patient members joined our Care Alliance in December of 2013: Stephanie Geohagen and Judith Webb. We plan to add additional patient members in 2015.

APF providers and staff members work in partnership with patient members to achieve the goals of the APF and its Care Alliance. This has proven to be a close, pro-active and productive partnership. David Judge, MD, the creative force behind APF, has left the practice to join a firm developing team-based care practices for healthcare organizations. Ben Crocker, MD is now medical director and continues to provide creative leadership for the APF and its Care Alliance, maintaining focus on the values and goals upon which the APF was founded. In May of 2014, we were pleased to welcome and orient APF’s new physician, Annie Helgason, MD, to the Care Alliance.

2014 Goals

The Care Alliance believes it is essential to inform patients about the unique nature of APF and how best to become a partners in their own healthcare. The group also believes it is vital to obtain in-depth patient feedback to improve the care experience and stimulate innovation in the practice. Therefore, the group’s goals continue to focus on Patient Engagement, Staff Support, and Review of Practice Outcomes. In the past year, the Alliance has targeted its emphasis on Patient Engagement by looking at the patient experience at APF and identifying aspects of that experience that contribute to strong patient engagement. The Alliance initiated a patient experience survey as a way to explore the patient experience and provide meaningful feedback to support APF’s mission to provide patient-centered care for MGH employees and their partners or spouses.
The MGH Ambulatory Practice of the Future
Care Alliance
2014 Accomplishments

**Patient Experience Survey.** During the Fall of 2013, the Care Alliance implemented a Patient Experience Survey to better understand what patients value most about their APF experience and to solicit input on what changes they would recommend. It also asked patients to rate and provide comments about the quality of their care, the information provided, their confidence in managing their health issues, and their use of iHealthSpace, the practice’s patient portal.

Providers solicited feedback from more than 200 patients, with patient members on the Care Alliance analyzing results and providing detailed feedback to both APF staff and patients. Patient comments repeatedly emphasized how much they value APF’s patient-centered care (see results slides).

Patient Care Alliance members prepared a patient survey brochure to summarize how APF addressed all patient suggestions. To encourage APF patients to use iHealthSpace, the Alliance developed a single page user guide to insert with its brochure. They also developed summaries of full survey results for patients, shared via lobby slides and on the APF website. The survey results have had numerous applications:

**Applications of Patient Experience Survey**

- Discussion of patient suggestions by patient and staff Care Alliance members has led to joint problem solving
- Feedback to patients has validated the patient voice
- Feedback to staff has validated APF’s model of care
- Inclusion in APF’s Medical Home application
- Promotion of iHealthSpace usage
- Additional patient input into EPIC eCare design
- Our survey process and results have been the basis for several presentations
Patient Feedback. Care Alliance patient members continue to provide regular feedback to APF staff and leadership about the patient experience at APF. Care Alliance patient members make sure the patient voice is represented through attendance at weekly staff meetings. Additionally, we used our experience with APF’s patient-centered patient portal to provide extensive recommendations on EPIC eCare and MyChart design. Care Alliance members have also provided input on several MGH patient education brochures and offered extensive feedback on a phone app for a Smart-CATCH pilot program for diabetes patients.

Care Alliance Presentations. In this past year, patient members on the Care Alliance actively sought out opportunities to promote the unique work of APF and its patient-centered model of care.

- One of our patient members, Win Hodges, was invited to share his PFAC experience at an Institute of Medicine (IOM) Roundtable on Value and Science-Driven Health Care. He also took the lead in submitting an abstract to present the progress of APF at the Institute for Patient and Family Centered Care Conference in Vancouver, which was accepted, but due to unforeseen circumstances, was not able to be presented.

- Rebecca Petersen, PhD, presented a poster at the 2014 Annual American Psychological Association Convention in Washington, DC, which was co-authored with Ben Crocker, MD, and David Judge, MD. The presentation, “Patient-Centered Care: Full Inclusion and Full Infusion,” highlighted the strong patient-driven model of APF, as evidenced in both the patient-driven survey process and the patient-driven care explicitly valued by survey respondents.

- Steve Lynch participated in numerous Health Care for All (HCFA) work group meetings in 2013 and 2014, and Stephanie Geohagen attended the 2014 HCFA conference. Additionally, the Care Alliance presented at the Second Annual HCFA Patient- and Family-Centered Care Symposium hosted by Brigham and Women’s Hospital, and Win Hodges and Rebecca Petersen participated on the Patient Panel at the MGH Patient Centered Outcomes Research Institute (PCORI) Retreat.
Ambulatory Practice of the Future
Care Alliance By-Laws

Article I. Name.

The name of the patient – provider advisory council of the Ambulatory Practice of the Future (APF) is the APF Care Alliance, sometimes also referred to as the Care Alliance. The APF Care Alliance is a self-governing entity of the Ambulatory Practice of the Future and Massachusetts General Hospital currently operating at 101 Merrimac Street, Suite 1000, Boston, Massachusetts 02114.

Article II. Mission.

The mission of the APF Care Alliance, a partnership of patients, family members and providers, is to promote innovation and the optimization of the care experience for all.

Article III. Goals.

The APF Care Alliance is dedicated to assuring the delivery of the highest standards of comprehensive and compassionate health care by the Ambulatory Practice of the Future, a primary care practice of Massachusetts General Hospital. This is accomplished by working in active partnership with health care providers to:

- strengthen communication and collaboration among patients, family members and providers
- promote patient and family advocacy and involvement
- propose and participate in programs, services, and policies.

Article IV. Members.

Section 1. Roles and Responsibilities.

Advise: Work in a pro-active advisory partnership role to enhance the patient and staff experience of primary care at the APF.
Support: Act as a sounding board for implementation of new and innovative APF initiatives and improvement of existing programs.

Participate: Attend and participate in Care Alliance meetings with good listening skills and respect for the positions and opinions of others.

Identify: Seek opportunities to be innovative and be proactive in driving improvement of the service and practice of healthcare delivery at the APF.

Represent: Bring patient, family and staff perspectives on the APF experience to enhance the healthcare experience of all stakeholders.

Educate: Share lessons learned in the APF practice with other primary care practices within Partners Healthcare Services and with the broader medical community.

Evaluate: Review the annual accomplishments of the Care Alliance against goals set at the beginning of the year.

Section 2. Membership Eligibility.

Patients, family members and staff from APF are eligible to be members of the Care Alliance. Members should be committed to working in partnership with all APF staff to represent the needs of patients and families and to provide input in the development of programs and policies that address health care challenges within the APF practice.

Section 3. Membership Categories.

The Care Alliance will consist of Active, Emeritus and Staff Members as follows:

Active Members. The Care Alliance will be made up of a broad base of up to 12 APF patient or family Active Members (at least two-thirds patients) and serve on a volunteer basis. Each of the APF’s three care teams, when operational, will be represented by up to four patient or family Active Members.

Active Members serve for a two-year term, renewable every other year, for a maximum of three terms. Individuals will be polled for their preference for continued membership when their terms are up.

Active Members are expected to participate in all monthly regular meetings and such special meetings as may be called from time to time. One active patient or family member serving on the Care Alliance should attend each staff meeting. It is hoped, but not expected, that some patient or family Active Members will consider opportunities for involvement in special projects initiated by the APF or the APF Care Alliance. All Active Members must be in compliance with the requirements for Care Alliance participation and active volunteer status. Non-employee members must go through the Volunteer Orientation and Training,
which includes a CORI background check, as well as HIPPA, safety and security training.

**Emeritus Members.** Care Alliance members who have served three terms as Active Members may become Emeritus Members. Individuals will be polled for their preference for continued membership annually. Emeritus Members will continue to receive materials distributed to the Care Alliance and are expected to attend Care Alliance meetings. Emeritus Members may continue to represent the Care Alliance on committees and projects. Emeritus Members must be in compliance with the requirements for Care Alliance participation and active volunteer status. The Founding Emeritus Member Winthrop M. Hodges is eligible to serve as Chair Emeritus for such period as he chooses to serve. Upon his resignation, an eligible successor may be nominated by a majority of the Care Alliance to serve for two years. Only one Chair Emeritus may serve concurrently. Chair Emeritus Members may be renominated in the event no other eligible Member chooses to serve in that capacity. In the event the serving Chair Emeritus resigns before the end of their two-year term, the Care Alliance may at its discretion but is not required to nominate any Eligible Member to serve the remainder of the incumbent Member’s term.

**Staff Members.** With the exception of the APF Director and Associate Director, Staff Members may attend Care Alliance meetings on a rotating basis.

### Section 4. Other Membership Categories.

From time to time, the Council may develop other membership categories to fit with the needs of the APF and the mission of the Care Alliance.

### Article V. Co-Chairs.

#### Section 1. Duties.

The Care Alliance has two Co-Chairs whose roles are to work in partnership with APF leadership to guide Care Alliance goals and objectives; ensure the Care Alliance is following its mission and bylaws; set the meeting agenda; lead or appoint a patient Care Alliance member to facilitate monthly meetings; provide leadership for Care Alliance members; and serve on certain APF committees where one or both of the co-chairs are specifically requested.

#### Section 2. Nomination Procedure.

Candidates for the Co-Chair position will be nominated by Care Alliance members and must have at least two years of experience as an Active Member.
Section 3. Election Procedure.

A new Co-Chair will be elected every two years, requiring the affirmative vote of two-thirds cast by Active and Staff voting members. The new Co-Chair will be announced during the December Care Alliance meeting.

Section 4. Term.

The standard term for Co-Chair will be two years. The terms of the Co-Chairs will be staggered. The term of office will begin the January 1st after the Co-Chair is elected, unless otherwise specified.

Section 5. Vacancies.

A Co-Chair may resign from office at any time by submitting written notification to the Director of the APF and the other Co-Chair. The Care Alliance may choose to elect a replacement to complete the term of that Co-Chair or to leave the position vacant until the next scheduled election.

Section 6. Termination.

A Co-Chair who is not fulfilling the role as outlined in Article V, Section 1, or is not fulfilling the role of an Active Member outlined in Article IV, section 2, and having been given appropriate notice and an opportunity to fulfill the requirements, may be removed as co-chair by a vote of two thirds of the Active and Staff voting members via electronic vote. The APF and the Care Alliance reserve the right to terminate any volunteer who does not uphold APF professional behavior standards.

Article VI. Membership Procedures.

Section 1. Membership Application.

Patient and family members will be recruited every two years to fill vacant positions. Patients or family members of the practice are welcome to approach staff members to indicate their interest in serving on the Care Alliance. Any APF patient or family member may apply to be an Active Member of the Care Alliance. Membership is granted after completion of a membership application process set forth in Section 2 below. All new members will attend their first Care Alliance meeting on the same date and will be oriented to the Care Alliance together. Every two years patient or family members will be offered the option to continue as an Active Member for another two years, become an Emeritus Member or resign from the Care Alliance.
Section 2. Application Process.

An Active Member applicant may submit a membership application to the Care Alliance for review at any time. Nominations may be made by staff members or patient or family members and nominees will be interviewed by a minimum of one staff member, one Co-Chair, and one patient or family member, jointly or separately. Upon completing the application review and interviews, the interviewers will present the nominees at a Care Alliance meeting and a vote will decide whether an offer of membership should be extended to the applicant. A new Active Member’s term of membership will commence at the next Care Alliance orientation meeting following his or her acceptance to the Care Alliance.

Section 3. Leave of Absence.

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

Section 4. Resignation.

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

Section 5. Termination.

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

Section 1. Regular Meetings.

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

Section 2. Special Meetings.

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

Section 3. Quorum.

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

Section 4. Voting.

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

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

Article VIII. Confidentiality.

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

These bylaws may be amended at any regular meeting of the Care Alliance by the affirmative vote of two-thirds of the members present and voting, provided that the amendment has been submitted in writing at the previous regular meeting.
Best Aspects of your APF Care Experience

Most frequent comments indicate you especially value:

- Interpersonal Qualities of Your Provider/Team
- (kindness, warmth, listening & communication)
- Quality of Care
- Length and Thoroughness of Appointment
- Quick Access to Care

Top Comments about your Care, the Information Given, and your Confidence:

- You thought the care you received was patient-centered, excellent and thorough with quick and efficient access, service, and care

- You thought the information you received was high quality and patient-centered

- You felt confident because you felt listened to, had confidence in the quality of your team and in the quality of your care.

Care Alliance Patient Experience Survey Review

98% of APF patients who responded to our Fall 2013 survey were very satisfied with their APF care experience. 2% offered suggestions. We want to share with you how we addressed your concerns.
We received several suggestions that you would like more APF Locations, services and insurance Coverage:

We would like to see APF locations, services, and insurance plans grow over time. As a leader in innovative primary care at MGH, APF is charged with designing and providing team-based care for MGH employees and their partners/spouses covered under MGH insurance. Part of our growth strategy is to use our coaching and virtual visit capability to make it possible for APF to come to you at any location. Your continued adoption of this capability will help APF evaluate adding additional services in the future as well. Contact us anytime for further information or for assistance with how to make better use of virtual tools here at the practice.

Send your comments about this survey review to APF’s Care Alliance at Apfcarealliance@partners.org

98% of APF patients who responded to our Fall 2013 survey were very satisfied with their APF care experience. 2% offered suggestions. We want to share with you how we addressed your concerns.
Patient Convenience:

- **Minimal waiting:** If you are waiting 15 minutes or longer for your appointment, please let our Greeter know.

- **Don’t stay thirsty, my friends:** If you are looking for a drink of water, use our water dispenser (hot and cold) in the café area and brew yourself a cup of coffee or tea, or grab a cold beverage from the small refrigerator.

- **Got gown?** If you have ever struggled with the ties on a gown, try tying them first, then pull it on over your head like a sweater!

- **Making appointments:** If you need urgent care, call us at 671-724-1100. For non-urgent concerns, use iHealthSpace messaging to tell us about your concerns. Delays in scheduling new and routine appointments may occur due to increased patient panels and staff scheduling. Using our patient portal for non-urgent concerns is the most efficient way to help us schedule the kind of appointment you need.

Team-based Care:

Some of you weren’t sure how our Team-based Care works. Team-based care at APF means you will be seen at different times by Nurse Practitioners and Physicians. You may also be seen by a Nurse, a Clinical Partner (Medical Assistant), or a Health Coach. Our Health Coach is a vital member of our team and works closely with APF staff to best identify when patients are most likely to benefit from health coaching. This team approach means we can provide quicker access to care, longer visits, better back up and continuity of care. We will introduce ourselves and clarify our role when you come in. If you feel you are not being seen by the appropriate level of provider, let us know.

We continually explore and re-assess how to optimize each team member’s expertise (including your own expertise as a patient).

Practice Coverage and Hours:

If you have had concerns about who responds to your urgent after hours calls, we want you to know that after-hours phone coverage is now provided by our own APF clinicians. Call 617-724-1100 to be connected with the APF physician on-call.

Some of you requested extended hours. Staff also would like to expand the hours in the future when increased staffing would make this feasible.

Parking:

We heard your concerns about parking. Solutions are limited; here are your best options:

- **Walk from MGH (10 minutes) or North Station (5 minutes)**

- **Reduced Parking Rates** in MGH lots (Yawkey Center, Fruit St. and Parkman St. Garages) if you present your MGH card. Note that parking garage at 101 Merrimac is not part of MGH parking.

On-Call Complimentary Shuttle from MGH to APF, (617-726-2250), Mon-Fri, 7AM to 8PM (approx).

- **From MGH:** Concierge Desk at White (front) or Gray (back) entrances can call shuttle for you. Pick up shuttle from back door (Gray) on Blossom St.

- **From MGH Parking Lots:** Parking Lot concierge (Yawkey, Fruit, or Parkman garages) can call your shuttle, which will pick you up at the garage.

- **From APF:** Concierge in lobby can call shuttle for you or you can use the direct phone on the left side of concierge desk. Shuttle picks up at 101 Merrimac St.

Shuttle wait time will vary, depending on location of the shuttle when you call. Walking may be quicker, but if this is not possible, the shuttle service is available at no charge for MGH patients, visitors, and employees.
IOM Invited Presentation

Building the Patient and Family Advisory Leadership Network for Better Care

*Patient and Family Advisory Councils: Personal Experience*

Win Hodges
11/11/2013

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2014 IPFCC Abstract Summary

**From Plan to New Model Practice: The Ambulatory Practice of the Future**

Focus will be on the rewards and challenges of implementing a partnering culture, flat management structure, technology support, high-risk patient management, patient coaching, a Care Alliance (PFAC), and developing an innovation program.

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**Patient Centered Care: Full Inclusion and Full Infusion**

Rebecca Petersen, Ph.D., J. Benjamin Crocker, MD, & David C. Judge, MD

Patient-Provider Care Alliance of the MGH Ambulatory Practice of the Future

*Poster presented at the 2014 APA Annual Convention, August 7, 2014, Washington, D.C.*
For more information about MGH PFACs, please visit:
http://www.massgeneral.org/patientadvisorycouncils/