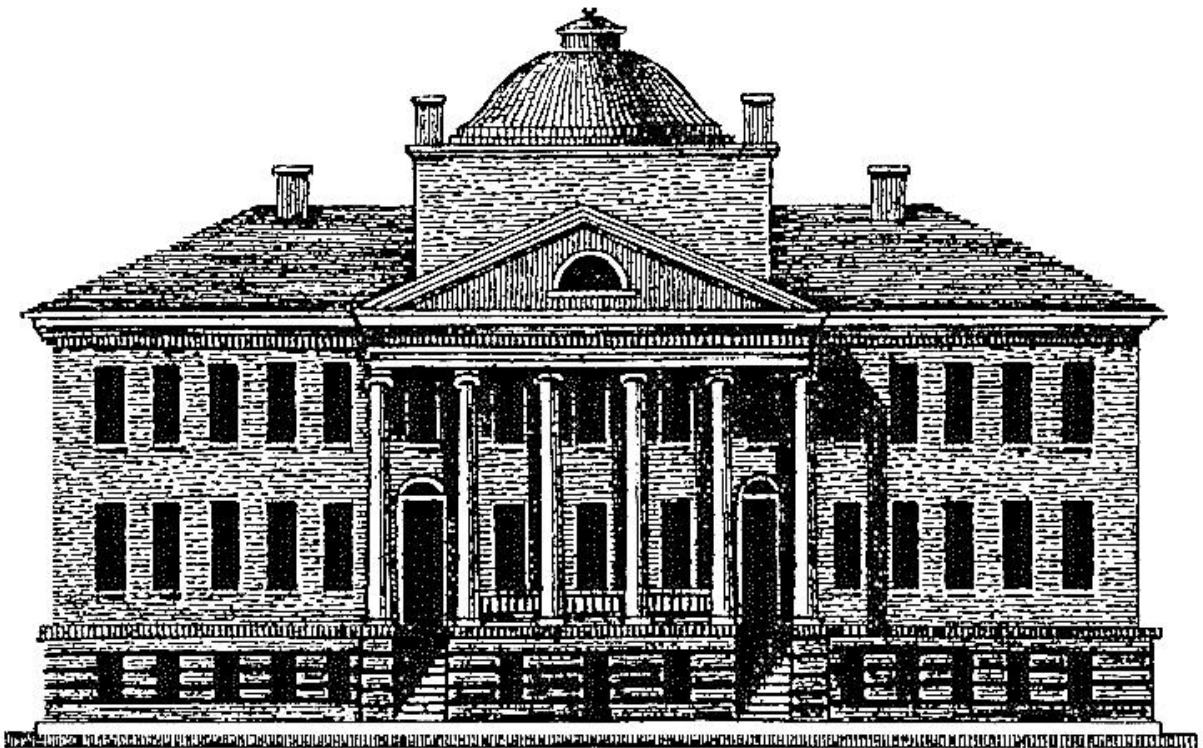




MASSACHUSETTS
GENERAL HOSPITAL



2016

PATIENT & FAMILY ADVISORY COUNCIL
ANNUAL REPORT

OUR MISSION

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

Mass General Overview

Founded in 1811, Mass General is the third oldest general hospital in the United States and the oldest and largest in New England. Mass General continues its tradition of excellence today. In 2016, Mass General was ranked the third best hospital in the country by *US News & World Report* based on the quality of care, patient safety and reputation in 16 different specialties. In 2003, Mass General 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 2013, the hospital was redesignated a Magnet hospital. Patients and families help to advance the hospital's mission, sitting on many hospitalwide committees, such as Quality Oversight and the Mass General Council on Disabilities Awareness, and they play an active role in a multitude of care improvement efforts, from selecting the hospital's information system to designing new buildings ... and more.

Mass General is a 999-bed academic medical center that offers sophisticated diagnostic and therapeutic care in virtually every specialty and subspecialty of medicine and surgery. The hospital's five multidisciplinary care centers—known worldwide for innovations in cancer, digestive disorders, heart disease, transplantation and vascular medicine—unite specialists across the hospital to offer patients comprehensive, state-of-the-art medical care. 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. The MassGeneral Hospital *for* Children, Mass General provides a full range of pediatric health care services, from primary care to leading-edge treatments of complex and rare disorders. The hospital holds concurrent Level 1 verification for adult and pediatric trauma and burn care.

In FY '15, Mass General:

- Admitted more than 50,000 inpatients
- Handled more than 1.5 million outpatient visits
- Recorded nearly 106,000 emergency room visits
- Delivered more than 3,800 babies

Mass General has long been a leader in successfully bridging innovative science with state-of-the-art clinical medicine. Mass General conducts the largest hospital-based research program in the United States, with an annual research budget of more than \$781 million. This funding drives discoveries and breakthroughs in basic and clinical research, which translate into new and better treatments that transform medical practice and patient care. In addition, Mass General is the original and largest teaching hospital of Harvard Medical School, where nearly all Mass General staff physicians have faculty appointments. Since the hospital's founding, Mass General has been committed to training and mentoring the next generation of international leaders in science and medicine, providing a wealth of

opportunities for physicians, nurses, and other health professionals. These clinicians, in turn, lend fresh and innovative perspectives on how to treat and care for patients.

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 Mass General

Mass General formed its first Patient and Family Advisory Council seventeen 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 Mass General.

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.

General Hospital PFAC

General Hospital PFAC

The Massachusetts General Hospital General Patient and Family Advisory Council, (G-PFAC) was formed in 2011 to advance the patient experience and promote patient and family involvement in all aspects of hospital operations. The G-PFAC has an enterprise-wide focus, including operations and services across the continuum of care, from inpatient to outpatient. It is dedicated to fostering a partnership between patients, families, and staff to support Mass General in meeting its strategic goals and initiatives.

The G-PFAC is comprised of a dedicated group of patient and family members who have experienced many different aspects of care and services at Mass General and who volunteer their time, with their expertise and input, to make that care even better. Additionally, other key stakeholders from the hospital staff sit on the G-PFAC. The Council is co-chaired by a patient member and staff and meets monthly throughout the year.

Year in Review

This past year the G-PFAC introduced 14 new members and elected a new patient co-chair. The G-PFAC assigned buddies to provide support, to answer questions and to help guide the new members into the role of G-PFAC members. Additionally, to further engage with the hospital as a whole, all G-PFAC members participated in the Mass General hospital volunteers orientation and training. There has been an increase in G-PFAC member participation throughout the organization and regular requests for G-PFAC members to participate in speaking engagements. Additionally, the G-PFAC has revised and updated its by-laws and established an executive committee that meets monthly to actively respond to requests for patient participation and proactively reach out to departments and administrators to request presentations and offer feedback.

2015-2016 Presentations and Feedback:

- Provided feedback on Kitty Hawk Project and reducing physician administrative burden while optimizing patient care.
- Reviewed MGH Case Management Levels of Care document to ensure patient understanding in preparation for discharge.
- Reviewed Health Information Services consent form for clarity and readability on the Mass Health Information Highway project, which allows a patient's clinician to safely and quickly send health information to where it is most needed.
- Reviewed Interventional Radiology brochure entitled "Choosing a Medicine for Your Port Placement," designed to individualize pain medication based on patient preference prior to port placement.
- Reviewed summary Safety Culture survey results and advanced ideas on Patient Safety Awareness week.
- Provided feedback on the new Diversity Mission statement.
- Provided patient perspective on Opioid education.
- Participated in simulation training and provided feedback.
- Provided feedback on telehealth programs.
- Provided input on ID badges for Department of Medicine to help patients and family identify the clinician's role on the care team.
- Provided input to the Healthcare Transformation Lab regarding its Ether Dome Challenge, and ways to engage patients in idea generation.
- Provided patient perspective on impact of capacity issues.
- Reviewed and provided feedback on informed consent policy and overlapping surgical staffing of two rooms.
- Provided feedback on primary care phone tree redesign.

- Identified opportunities for seamless transition of medical care for Mass General patients living in Florida during winter months.
- Provided feedback on enhancements to Epic Patient Gateway, an online tool to help patients navigate through their medical information.
- Learned about the Office of Patient Advocacy and its scope of operations.

General PFAC Working Committees

Patient Education—This working committee focuses on a variety of aspects of patient education throughout the Mass General experience. Through independent outreach, the patient education committee has been working in close collaboration with the Blum Patient & Family Learning Center.

Patient Experience/Care Coordination—This committee includes members who have personal experiences with and interest in provider communications, care coordination, and alternative means of accessing care. The committee has been working in partnership with MGH Telehealth, providing feedback on educational materials, terminology, and programmatic decision points. The very relevant experiences and interests of members have helped to inform conversations and made for robust collaborations.

Patient Voice and the MGH/G-PFAC Relationship—This committee within the G-PFAC focuses on the relationship between Mass General and the G-PFAC. The committee works to enhance awareness about PFACs throughout the hospital and let clinicians and administrators know that members are willing and ready to lend the patient perspective.

Patient Participation in Hospital Committees and Task Forces:

- Kitty Hawk Task Force Advisory Council
- Partners Telehealth
- Partners Patient Engagement Committee
- Mass General Quality Oversight Committee
- Patient Perspective on Perioperative Care Committee
- National Patient Safety Awareness Week
- HealthCare for All, Massachusetts Dept. of Public Health--PFAC Steering Committee

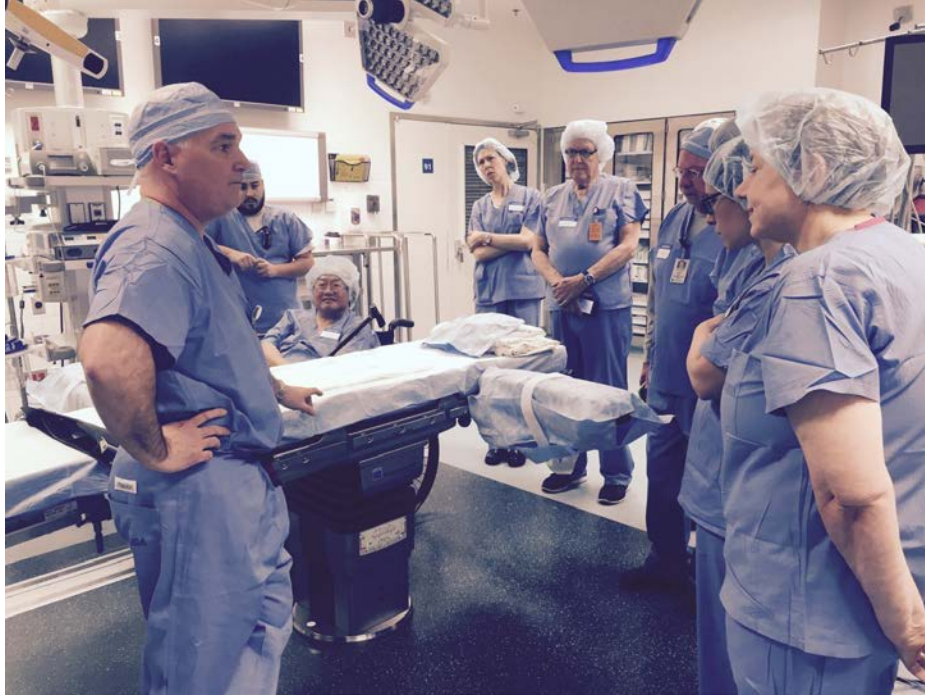
Additional Activities and Outcomes

- Designed and hosted the Annual Joint PFAC Evening on October 2nd 2015 with Dr. Peter Slavin, President of Mass General, presenting Mass General strategic plans and priorities.



Mass General President Peter Slavin presenting at the 2015 Annual Joint PFAC

Group tour of Lunder Building operating suites, including cutting edge technology and the role of teamwork in the OR. G-PFAC members learned more about surgical scheduling and the process of the OR throughout the day, including Total Care time, Prep time, Procedure time, and Emergence time, as well as surgeon/patient conversations prior to surgery.



Dr. Peter Dunn (left) Executive Medical Director, Perioperative Services, giving a tour of an operating room at Mass General

- Hosted PFAC table in lobby to educate Mass General community on role of PFACs.
- Three members participated in panel discussion in the Department of Medicine annual retreat for Educators on April 29th.
- Five members attended the annual Healthcare for All Statewide PFAC Conference –June 2016. One member delivered a Gallery Walk on supporting multiple PFAC’s in a Hospital.
- One patient participated in Surgical Grand Rounds.
- Participated in simulation to educate patients and families as part of the Learning Laboratory Community Outreach Initiative.
- Developed a tool to obtain feedback on PFAC contributions Below are some of the comments received:

“ . . .the feedback we received was great! We are actively working to change our mission statement based on comments from the group.”

“I found the group to be highly engaged and offered valuable insights that we need to ensure we are on the right track with various initiatives.”

“Working with the [subcommittee] is an absolute delight in all ways.”

- Led a recruitment effort that resulted in the identification and placement of over 50 new members to the hospital's array of PFACs – the largest such effort ever conducted at Mass General.
- Created and implemented a uniform process for the orientation and onboarding of new PFAC members.
- Conducted outreach to key areas of the hospital to promote the creation of new PFAC's. Interest is currently being pursued at the Charlestown Health Center, The Research Institute and in GI.
- Provided input into key elements of the Partners eCare system – especially in the development of patient facing aspects such as the new patient portal.
- Provided feedback into the naming and positioning of the new patient portal as it is rolled out.
- Met with and provided feedback on enhancements to the hospital's interpreter services program.
- Met with and provided feedback to the Mass General program to address the needs of patients with disabilities.
- Met with leaders of Telehealth program and provided feedback on the incorporation of technology in communications between the patient and physician, both from an individual and employer perspective.
- Provided guidance to the hospital's strategy to reduce administrative burden on physicians – allowing them to devote more hours to direct patient care. Placed two members on the hospital task force that is guiding this work.
- Supported the participation of two patient advisors on the hospital's Quality Oversight Committee and coordinated the recruitment and turnover of a new advisor to the committee.
- Provided feedback on a Partners-level research study to assess attitudes of patients and physicians on increased transparency of patient ratings and comments.
- Recruited and placed a patient advisor on the Partners system Patient Engagement Steering Committee.
- Facilitated regular meeting of the Chairpersons of all of Mass General's PFAC's and assisted with coordination of efforts across all groups.
- Sponsored an annual joint PFAC meeting of all of Mass General's patient advisors with the hospital's CEO to discuss major hospital priorities and initiatives.

- Presented on PFACs and PFAC development at the national Institute for Healthcare Improvement meeting in Orlando, FL in December of 2014.
- Presented at the Massachusetts state PFAC Conference in Worcester in April of 2015.
- Participated in an interview about PFAC's with Kaiser Healthnews that was published widely across the US, including in USA Today.
- Provided feedback into education materials and programming for both patients and providers about post-acute levels of care to assist with better patient placement, more informed decision making and reduced length of stay.
- Formed and launched PFAC work groups addressing access to care, patient experience, behavioral health, PFAC integration into hospital operations and coordination of care.
- Informed and enhanced the hospital's program to improve the patient experience and the ratings given by patients to the hospital about care.

General PFAC Members

Executive Committee

Susanne Goldstein
Patient Co-Chair

Robin Lipkis-Orlando
Staff Co-Chair

Liza Nyeko
Staff Co-Chair

Julie DeCosta
Incoming Patient Vice-Chair

Debbie Kanady
Patient Secretary

William Kieffer
Patient Member-at Large

Members

Kay Bander
Emily Bider
Robert Chen
Hilary Deignan
Ann Galdos
Melissa Hoyt
Linda Kane (staff)
Jean Lowenberg (retired)
Sue Lunn
Stuart Murphy
Kim Nunnari (retired)
Matt Reid
Maria Rivera Brown(retired)
Lisa Scheck (staff)
Carrie Stamos
Kathy Verni
David Wooster

General PFAC Bylaws

Article 1. Overview

The Massachusetts General Hospital General Patient Family Advisory Council (G-PFAC) provides a formal communication vehicle for patients and families to take an active role in improving the patient experience at Mass General. The G-PFAC focuses on representing the patient voice in providing feedback to departments, services, programs, and practices across Mass General so as to enhance the patient and family experience.

Our vision is to achieve a level of care where patient and family involvement is expected and welcomed by all. We will achieve this through collaborative efforts between patients, families, staff, physicians, and administration of the hospital.

Article 2. Mission Statement

Guided by the Mass General Mission, Credo and Boundaries, the G-PFAC is dedicated to ensuring that our patients and families have a successful, compassionate, and supported healthcare experience.

Article 3. Goals

Section 1. Advise

Work in an advisory role to enhance patient and family centered care initiatives at Mass General.

Section 2. Support

Support Mass General staff and leadership in enhancing patient and family-centered focus. Act as a sounding board for implementation of new programs and review and enhance existing programs across Mass General.

Sections 3. Participate

Encourage and solicit patient/family member representation on committees and work groups per requests from across the organization.

Section 4. Inform

Proactively identify opportunities for patients to influence and participate in educational initiatives.

Section 5. Represent

Bring forward patient and family perspectives about the healthcare experiences at Mass General and serve as a central resource for the voice of the patient and family.

Section 6. Evaluate

Assess the role of the G-PFAC in improving experiences for patients and families.

Article 4. Structure and Membership

The G-PFAC will consist of at least 16 patient/family members ideally representing the diversity of the Mass General community. Up to 8 Mass General staff members also may serve on the G-PFAC. The G-PFAC will include a Patient/Family Co-Chair, a Staff Co-Chair, Patient/Family Vice Chair, and an Executive Committee, as provided for in Articles 7 and 8. Patients or family members should co-lead the G-PFAC. The structure of the G-PFAC may change over time.

Article 5. Nomination and Application Process

Section 1. Recruitment

Recruitment of patient and family G-PFAC members is initiated by referral, solicitations through targeted mailings, and/or conversations with potential candidates.

Section 2. Membership Criteria

Members are selected based on the following criteria:

- Experience as a patient or family member at Mass General
- Ability to represent patient care experience
- Willingness to work in an advisory role
- Good listening skills
- Ability to interact well with differing groups of people
- Respect of others' perspectives
- Ability to participate in a consistent and agreed upon schedule of meetings
- Ability to participate in subcommittees and in hospital committees, meetings, and/or workgroups, strongly preferred
- Commitment to serve for a 2 year term with potential to renew at the end of the term

Section 3. Membership Selection

Applications are sent to identified prospective members. Applicants are screened by staff, and those identified as viable candidates are then interviewed by selected G-PFAC members and staff. Those who are identified as top candidates by interviewers will be reviewed by the Executive Committee, and subsequently notified by the Co-Chairs of the G-PFAC as to their selection.

Section 4. Terms of Appointment

- G-PFAC patient/family members are appointed for a term of 2 years, beginning on January 1 of each year.

- G-PFAC patient/family members may request to be reappointed for an additional term of 2 years, with total consecutive years not to exceed 6.
- G-PFAC patient/family members who have completed the 6 year term may apply to become a member. again after a hiatus of 1 year. G-PFAC members who are selected to join again become eligible, as any G-PFAC member, for another 2 year term. A member shall not serve more than a total number of 8 years.
- Resignations will be submitted in writing or via e-mail to the Co-Chairs.
- Vacancies may be filled during the year as needed.

Article 6. Roles and Responsibilities

Section 1. Roles and Responsibilities for Patient/Family Members

- Attend each G-PFAC meeting or, whenever possible, notify a Co-Chair in advance, if unable to attend.
- Prepare and engage thoughtfully and constructively with respect to the issues and ideas discussed during each session.
- Proactively drive improvement and bring creative ideas for change.
- Respect the unique background and perspective of each member.
- Be realistic and mindful of the hospital's budgetary constraints.

Section 2. Roles and Responsibilities for Staff Members

- Attend each G-PFAC meeting or, whenever possible, notify one of the co-chairs, in advance, if unable to attend.
- Identify, invite, vet and/or orient potential G-PFAC patient and family members.
- Align with and facilitate G-PFAC subcommittees.
- Facilitate discussions and engage all members.
- Provide reports to the G-PFAC of progress on ongoing projects and any hospital initiatives of interest to the group.
- Minimize potential barriers to achieving established goals.
- Be an advocate for the G-PFAC.

Article 7. Roles and Responsibilities of Officers of the G-PFAC

Section 1. Patient/Family Member Co-Chair

- Attend and preside at each G-PFAC meeting.
- In collaboration with the Executive Committee, develop and implement strategic initiatives of the G-PFAC.
- In collaboration with the Executive Committee, set agendas for meetings.
- In collaboration with the Executive Committee, manage the patient and family member recruitment process.
- Manage communications with G-PFAC members, including distribution of agendas, minutes, any additional materials.
- Work with staff Co-Chair in communicating activities of the G-PFAC to Mass General leadership.

- Work with staff Co-Chair in serving as an advocate for PFACs across Mass General and Partners.
- Represent Mass General PFACs in the health care community, as appropriate.
- Participate in PFAC Chairs meeting.
- Participate in planning of annual PFAC meetings.

Section 2. Staff Co-Chair

- Attend and preside at each G-PFAC meeting.
- In collaboration with the Executive Committee, develop and implement strategic initiatives of the G-PFAC.
- In collaboration with the Executive Committee, set agendas for meetings.
- In collaboration with the Executive Committee, manage the patient and family member recruitment process.
- Work with Patient/Family Member Co-Chair in managing communications with G-PFAC members.
- Communicate activities of the G-PFAC to Mass General leadership, and serve as a liaison with Mass General staff.
- Serve as an advocate for PFACs across Mass General and Partners.
- Represent Mass General PFACs in the health care community, as appropriate.
- Participate in PFAC Chairs meetings.
- Participate in planning of annual PFAC meetings.
- Check in at least quarterly with former G-PFAC members serving on Committees throughout the hospital, to ensure seamless transition and positive participation in the Committees, and act as liaison between former G-PFAC members and Committee Chairs as needed.

Section 3. Vice Chair

- Support the G-PFAC Co-Chairs in ongoing activities, as described above.
- Serve as Co-Chair of G-PFAC meetings, as necessary.
- Support documentation and measurement of the successes of the G-PFAC.

Section 4. Secretary

- Record minutes of each G-PFAC meeting.
- Record minutes of each Executive Committee meeting.
- Provide minutes to Co-Chairs, and/or designated Executive Committee member(s) in a timely manner, for their review, prior to distribution to members of the G-PFAC.

Section 5. Immediate Past Patient/Family Member Co-Chair

- Upon completion of the term as Co-Chair, the patient/family member would serve as Immediate Past Co-Chair for a term of 1 year.

- This position would be exempt from the maximum 6 consecutive year term limit, and 8 total year limit.

Article 8. Executive Committee of the G-PFAC

Section 1. Membership

The Executive G-PFAC Committee will consist of the Patient/Family Member Co-Chair, the Staff Co-Chair, Vice-Chair, Secretary, and staff members, and may include a selected G-PFAC member at large. The total membership shall not exceed 7.

Section 2. Duties and Responsibilities

- Act as the nominating committee of the G-PFAC membership, bringing forth nominations for Patient/Family Member Co-Chair, Vice-Chair, and Secretary annually in the Fall.
- Participate in the G-PFAC membership selection process, as provided in Article 5, Section 3.
- Participate in the setting of agendas for each G-PFAC meeting, and other such duties as may be determined.
- Act on behalf of the G-PFAC between meetings, as necessary.

Article 9. Terms of Officers

The terms of G-PFAC Officers will be as follows:

- The term of the G-PFAC patient/family member serving as Co-Chair is not to exceed 2 years.
- The term of the Vice Chair shall be 2 years, directly preceding the assumption of the role as Patient/Family Co-Chair.
- The term of the Secretary shall be 2 years, subject to renewal for 2 subsequent 2 year terms.
- The term of the Immediate Past Co-Chair shall be 1 year, directly following the term as Co-Chair.
- Vacancies will be filled as necessary, as provided for in Article 5, Section 3.

Article 10. Activities of the G-PFAC

The G-PFAC will engage in the following activities:

- Represent the patient voice across Mass General, as requested, and seek opportunities to do so.
- Provide targeted feedback to departments, services, programs and practices across Mass General.
- Participate in a variety of hospital committees and workgroups, as a whole, and individually as members.
- Provide regular updates to the Mass General leadership and annual progress reports to the Department of Public Health (DPH).
- Promote awareness and recognition of the functions and importance of PFACs across the hospital, system, and healthcare community.

Article 11. Orientation and Training

Section 1. Mass General Orientation and Training

All selected G-PFAC patient and family applicants will receive orientation and training as to the mission and goals of Mass General, Training will include hospital regulatory and privacy issues, and through this training, G-PFAC members will commit to adhering to Mass General guidelines and Health Insurance Portability and Accountability Act (HIPAA) standards and guidelines. The Volunteer Department of Mass General will provide the Mass General orientation and training.

Section 2. G-PFAC Orientation

All selected G-PFAC patient and family applicants will receive orientation specific to the G-PFAC, including review of the bylaws.

Article 12. Confidentiality

G-PFAC members must not discuss any personal or confidential information revealed during G-PFAC meetings outside of the G-PFAC meetings. G-PFAC members must adhere to all applicable HIPAA standards and guidelines. If a member violates these guidelines, the Co-Chairs will remind them of the guidelines. Repeated violations may result in repeating HIPAA training or reevaluation of membership status.

Article 13. PFAC Meetings

Meetings will be held monthly. Each meeting will be 1 to 2 hours in length.

Section 1. Agenda

Meeting agenda will be set by the Executive Committee and will be distributed to the membership prior to each meeting, along with any pertinent materials for discussion during the meeting.

Section 2. Meeting Minutes

The Secretary will take minutes of each G-PFAC meeting and Executive Committee meeting. Council minutes will be retained for a minimum of 5 years.

Section 3. Attendance

It is expected that the members of the G-PFAC will make every attempt to attend each meeting held. Teleconference call in is acceptable when physical presence cannot be achieved.

Participation by every member is expected. Confirmation of attendance is requested for each meeting. If a member is not able to attend 3 consecutive meetings, the Co-chairs will contact the member to discuss their commitment to the G-PFAC.

Article 14. Termination

The G-PFAC Executive Committee reserves the right to dismiss any member who the committee deems not to be compliant with the responsibilities as set forth by the bylaws.

Article 15. Bylaws

The bylaws of the G-PFAC shall be reviewed at least every 3 years. These bylaws will be reviewed by the Executive Committee of the G-PFAC, and accepted via a voting process in which at least 75% of the members of the G-PFAC participate. The bylaws may be amended as necessary by the members of the G-PFAC, as stated herein.

Updated: August 2016

MGH Heart Center and Vascular Center PFAC

MGH Heart Center and Vascular Center PFAC

In order to highlight the unique strengths of the Corrigan Minehan Heart Center and Fireman Vascular Center individually, in February 2015, a change in the organizational framework of the core components of the Institute for Heart, Vascular and Stroke Care placed a greater emphasis on what each Center offers to patients. Accordingly, the Institute Patient and Family Advisory Council (PFAC) was renamed the Heart and Vascular Centers (HVC) PFAC.

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 Mass General.

Year in Review

2015-2016 Changes in Meeting Schedule

- At the end of last summer, we met with our PFAC members to discuss changes at Mass General. Topics discussed were transition from IHVSC to Heart and Vascular Centers; changes in key leadership positions within the Heart Center in particular, and the Mass General-wide commitment required from all over the next year as we prepare to safely and effectively implement eCare.
- We proposed moving to a quarterly meeting schedule for the next 18 months at which time we will reevaluate. This change would ensure that our meetings would continue to be well planned, coordinated with center strategies, and are meaningful and productive.
- We discussed potential ways to engage patients in the process of EPIC Transition and planned to schedule this topic for a future meeting. We also discussed potential opportunities for PFAC members to participate and provide representation to various initiatives.
- We scheduled the quarterly meetings to minimize cancellations for weather, holidays etc
- We plan to re-evaluate meeting frequency at the end of 2016.

2015-2016 quarterly meetings were devoted to 5 important topics:

- Mass General Strategic Plans and Hospital Priority Overview (Annual Joint PFAC Meeting)
- Concurrent Surgery Practice
- Patient Preparation for E-Care (EPIC) rollout
- Palliative Care at Mass General
- Partners Healthcare Biobank

Activities and Outcomes

October 19, 2015

The Annual Joint Mass General PFAC meeting was held on October 19th. This year Dr. Peter Slavin, Mass General President and CEO, shared the Mass General Strategic Plan and Hospital Priorities Overview with all our Mass General PFAC members. Our members participated by reviewing a summary of the Mass General Strategic Plan before the meeting and submitting questions to Dr. Slavin about the plan and other important hospital priorities. The program was a great success and members' feedback was obtained at our next meeting.

December 1, 2015

1. Feedback regarding the hospital-wide Annual PFAC meeting was very positive. Members appreciated Peter Slavin's honesty and frankness, his compassion for the opiate addiction crisis in MA and also the critical lack of psychiatric beds in MA. He mentioned that there are resources to care for diseases of the body like heart disease and diabetes but not enough to care for patients with diseases of the mind. Most of the group felt that their questions were answered.
2. Kevin Whitney, Associate Chief Nurse, gave an excellent presentation regarding the Boston Globe Spotlight article and the practice of concurrent surgery. Kevin directed members to the Mass General website that highlights this issue, including policies and other practices. The website is: www.massgeneral.org Our members asked numerous questions and were very understanding regarding the need and appropriateness of concurrent surgery in the specific situations outlined in the Mass General policy.
3. Cindy Sprogis from Service Excellence also gave an informative presentation on the communication plan for staff, patients and families for eCare go live. Suggestions from members:

Patients should receive more detailed information regarding the new Patient Gateway functionality, including who to contact if there are questions about information in your medical record.

- Of note, Cindy spoke with one of the eCare Communication Committee leads on Wednesday regarding the Patient Gateway questions that you all raised. She confirmed that there is a brochure being developed that will address the Patient Gateway changes and questions

- Configure office furniture and computer to improve eye contact and enhance communication

March 1, 2016

Mihir M. Kamdar, MD, Associate Director Mass General Division of Palliative Care, spoke to our members regarding Palliative Care and the expansion of the program at Mass General. Palliative care specializes in trying to help patients get the most out of their remaining lives. The Palliative Care Task Force met for the last year and used the IOM report as a framework and set out to develop our own set of recommendations to ensure Mass General is delivering the very best care to patients who are seriously ill or in the final phase of their lives. Dr. Kamdar requested feedback on the updated program from our members.

First, Dr. Kamdar described the vision for this expanded palliative care effort at the Mass General is multi-faceted. It involves:

- Establishing an education program to help patients and families understand palliative care and engage in dialogue about end-of-life issues, and to provide primary palliative care education to clinicians to give them the tools and confidence to initiate and participate in discussions with patients;
- Expanding and enhancing primary and subspecialty clinical delivery of palliative care, including creating an inpatient palliative care unit and extending palliative care subspecialty teams to increase services in outpatient settings, home-based palliative care and pediatric palliative care;
- Ensuring that processes such as electronic health records can support integration of primary palliative care and ensure appropriate referrals to subspecialty palliative care staff;
- Studying and evaluating the impact of the efforts and sharing findings and best practices.

PFAC Feedback:

Suggest broader education for all clinicians and at the institutional level to ensure there is a common understanding of what Palliative Care is and is not

1. Increase comfort for clinicians in initiating palliative care discussions with patients and families
 - a. Include role playing for providers, nurses, health professions during palliative care education & training
 - b. Pair clinicians most comfortable in initiating a palliative care discussion with those not as comfortable...coaching/mentoring approach
 - c. Celebrate/recognize clinicians who do this well to encourage continued positive performance as well as to encourage coaching others
 - d. Offer emotional/psychosocial education for clinicians to assist with palliative care discussions
2. Be supportive to patients; however, be direct
 - a. Sometimes when not as direct, patients and families may not have as clear of an understanding of what palliative care is and/or the situation
3. Suggest rebranding Palliative Care since many associate this with end of life care
 - a. Palliative care is a "Medical Term" – consider calling it "Supportive Care"

During this meeting, Cindy Sprogis, Senior Project Manager, Practice Improvement, Service Excellence, provided a brief overview of the current process as Mass General moves towards Epic. Staff continue to attend Epic classes and are looking forward to using Epic for patient documentation. Cindy also updated the group that Patient Gateway will be updated as the Partners wide patient portal for patients. IHealth will be transitioning to Patient Gateway on April 2nd, 2016 which offers:

- Online connection to physician and other health care providers at Mass General
- Check lab results, reports and letters from your provider
- Review latest updates and visit summaries
- Send non-urgent messages to your doctor's office
- Access your medical information 7 days a week 24 hours a day
- Review prescriptions and make requests
- View conditions, allergies and immunizations
- Search patient education and wellness materials

June 7, 2016

Dr. Susan A. Slaughaupt, Ph.D., Scientific Director, Mass General Research Institute, gave us an overview of the Partners Biobank and requested feedback from members on improving the recruitment process.

[Partners HealthCare Biobank](#) is a large research program designed to help researchers understand how people's health is affected by their genes, lifestyle, and environment. This large research data and sample repository provides access to high-quality, consented blood samples to help foster research, advance our understanding of the causes of common diseases, and advance the practice of medicine.

1. For the Partners research community, the Biobank provides:
 - a. Banked samples (plasma, serum, and DNA) collected from consented patients
 - b. Blood samples that were discarded after clinical testing in the Crimson Cores maintained in the Brigham and Women's Hospital and Massachusetts General Hospital Pathology Departments
 - c. Sample handling and preparation services
2. Recruitment and consent samples
 - a. Current practice is patients receive via email an invitation to participate prior to scheduled clinic appointments. Patients are asked to participate at the time of registration.
 - b. Enhancing Biobank Visibility, adding informational Kiosks in the Wang and Yawkey lobbies, providing materials in office lobbies, and in patient exam rooms.
3. Dr. Slaughaupt asked for suggestions to enhance awareness of the Partners Biobank Members suggested:
 - Sound bite "What is the Biobank", information prominently displayed in patient exam rooms

- Signage with Physician specific (practice) photo's this would make the information more relatable.
- Promote/advertise the Biobank in the museum
- Solicit volunteers and new staff. New staff are told about the Biobank during orientation, so that is all set. We also do "DNA Days" to promote the Biobank to employees.
- Increase inpatient recruitment- they are working on this now!
- Put info on trays the morning of recruitment and possibly other times as patients can enroll online.

September 6, 2016

"The Future of Outpatient Cardiology at Mass General: Building it Together"

Ami B. Bhatt, MD, FACC

Director, Cardiology Outpatient Services

Director, Adult Congenital Heart Disease Program

Clinical Affiliate, Healthcare Transformation Lab

Key Points:

- Patient and Provider Centric Care are the same thing: We are a team!
- Infrastructure can drive experience: What do we need to make health care easier?
- Staying connected: Can and should Outpatient Cardiology be a continuum of care?

MGH Heart Center and Vascular Center PFAC Members

Patient and Family

Michael C. Bider III
Charlie Conn
Teri Fryer
Tom Fryer
Susan Geary
Phil Geary
Pat Hollenbeck
Denise Mallen
Tom Quirk
Matt Smith
Sara Strobe
Sr. Jon Julie Sullivan
David Wooster

Staff

Theresa Gallivan
Marie Elena Gioiella
Judy Silva
Cindy Sprogis
Kevin Whitney

MGH Heart Center and Vascular Center PFAC By-Laws

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 Mass General.

Goals

Advise:

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

Support:

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

Participate:

- Provide input to improve the physical environment of care
- Provide representation on committees within the MGH HVC 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 HVC, itself
- New programs, efforts and/or mechanisms for consideration that would enable the MGH HVC patients to be able to give back to the Mass General community through either support, community or recognitions

Represent:

- Patient and family perspectives about the overall experience of care at the Mass General
- The MGH HVC in its commitment to listening to the voices of patients and families

Educate:

- Collaborate with Mass General staff to create, review, and revise MGH HVC educational materials and processes
- Influence and participate in the education of Mass General 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 Mass General 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 Mass General
- Ability to represent overall patient care experience
- Willingness to work in an advisory role
- Ability to participate in a consistent and agreed upon schedule of meetings and potential subcommittee efforts
- Commitment to serve for a 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 HVC PFAC and a thank you letter is sent to the referring Mass General clinician or staff member.

Term of Appointment

- Members of the MGH HVC PFAC select and grant one-year term to council members
- At the end of a one-year term, council members may request to be reappointed
- Resignation will be submitted in writing or via email to the MGH HVC PFAC
- Vacancies may be filled during the year as needed

Roles and Responsibilities

Membership consists of 16 to 20 members: patients, family members and Mass General staff. The three membership roles are described below.

Roles

MGH HVC

- MGH HVC Co-Directors, Program leadership and staff

MGH HVC PFAC Members

Mass General staff

- Mass General staff will be appointed by the MGH Heart Center CoDirectors and Associate Chief Nurse

Patient and Family

- Includes patients and families representing diversity in age, gender, ethnicity and nature of heart, vascular and stroke conditions

Responsibilities

MGH HVC

- Referral of potential PFAC member candidates
- Provide new PFAC members with an overview of the MGH HVC's mission, programs and strategic initiatives
- Partner with the MGH HVC PFAC to improve the patient and family experience of care at the Mass General
- Provide financial support for monthly meetings and approved Council Member activities beyond the monthly meetings

MGH HVC PFAC Members

All Members

- Maintain patient confidentiality according to Health Insurance Portability and Accountability Act (HIPAA) guidelines
- Advocate for all patients and families by identifying and representing their needs and concerns
- Establish goals and objectives of the MGH HVC PFAC at the beginning of each year
- Plan, facilitate and guide the work of the MGH HVC 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

Mass General staff

- Communicate HVSC PFAC activities to the leadership of the executive committees of the MGH HVC
- Communicate with MGH HVC 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 HVC 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 HVC & Blum Patient and Family Learning Center, Mass General 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 HVC 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 Mass General 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: Mass General Yawkey Center for Outpatient Care in Yawkey 2-220
- Time: 5:30 PM to 7:00 PM

Reappointment

MGH HVC PFAC Staff will remind Council Members for reappointment of members at the end of their term.

MGH Cancer Center PFAC

MGH Cancer Center PFAC

Mission

The mission of the Mass General 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 Massachusetts General Hospital Cancer Center.

Objectives

As an advisory council to Cancer Center administration and staff, the CC PFAC's primary objectives are to promote and support patient and family-centered care, to provide education on the patient and family experience, and to expand the voice of patients and families throughout the Massachusetts General Hospital by participating in hospital wide 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, program development, the Cancer Center's ongoing evaluation of the quality of care and other important initiatives.

Council Operations

The CC PFAC meets on the second Wednesday of each month from 5:30 -7:30 PM. Meeting minutes and materials are stored electronically for at least five years. Council minutes and a summary of the council's accomplishments are provided to the hospital's governing body.

Membership

The CC PFAC currently consists of 26 active members, 15 alumni members, and 7 staff members. Members represent diverse perspectives and diversity in age, gender, diagnosis, treatment history, race/culture, and socioeconomic status. Current members represent at least ten different Cancer Center disease programs, as well as two different sites (Boston/Main Campus and Mass General/North Shore Cancer Center in Danvers).

Staff members of the CC PFAC include the Cancer Center Executive Director, Cancer Center Associate Chief Nurse, Cancer Center Nursing Director, an Oncology Social Worker, two project/program managers, and a medical oncologist.

Qualifications for Membership

To serve on the CC PFAC, patients and family members must have a recent history of receiving cancer care at the Mass General Hospital 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 attending monthly CC PFAC meetings as well as serving on committees throughout the Cancer Center and Mass General, 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.

Membership Requirements and Training

CC PFAC members are required to meet Mass General volunteer standards which include the completion of HIPAA training and annual signing of the Mass General 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 new staff orientation as well. 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 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.

CC 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 Mass General-wide staff that 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 Mass General 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 members have 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. Residents and fellows, support staff and nursing staff have all participated in these sessions.

Year in Review

The PFAC has had many accomplishments over the past year. Each year, PFAC members are surveyed to identify their goals and priorities as advisors to the Cancer Center. This year, the committee prioritized the following objectives:

- Enhance communication to patients and families about Cancer Center programming and resources
- Ensure a culture of quality and safety
- Minimize delays and increase efficiency of patient care

The accomplishments below represent areas that demonstrate the impact of the PFAC on the Cancer Center's patient experience, in accordance with the goals mentioned above:

- **Video Therapy Program**
Meg Carleton presented the innovations being done with art therapy programs for Cancer Center patients, particularly helping patients create videos both for themselves and loved ones. These videos can be used as end of life sentiments to help support families of patients or to narrate the cancer journey of patients.
- **Cancer Immunotherapy**
The advancements of cancer immunotherapy and its successes with melanoma patients were presented by Dr. Keith Flaherty and Krista Rubin. They elaborated on the effectiveness of manipulating patient T cells to recognize altered immune cells as cancerous. This particular method has had a dramatic impact on late stage Melanoma prognosis and is now being implemented in early staged patients.
- **Mass General West Tour**
PFAC members participated in a full tour of the MGH West Cancer Center, specifically

highlighting the infusion spaces, nursing station, and family/community area which will act as a future hub location for supportive services. Sharon Johnson, Administrative Manager of MGH West, presented the locations' shared care approach, which focuses on bringing physicians from Boston to host clinics in Waltham. This approach also allows patients to receive their infusion treatments at MGH West by utilizing the de-linking process.

- **Cancer Center State of the Union**

Dr. David Ryan presented a State of the Union for the Cancer Center which focused on the following three mission pillars, 1. Providing outstanding care to the increasing number of patients we see each year, 2. Research milestones including a strong focus on immunotherapy and its impact on cancer care, and 3. Continuing to educate the next generation of leading oncologists in care and research.

- **The Schwartz Center for Compassionate Healthcare**

Pamela Mann updated the PFAC group with a thorough overview of the Schwartz Center, its Mass General origins, and the work the center does today with promoting compassionate care. The Center specifically focuses on the emotional, psychosocial and spiritual aspects of the patient experience as well as our innate need for human connections and relationships.

- **Cancer Center Survivorship Program at Mass General West (Waltham)**

Dr. Jeffrey Peppercorn, of the Breast Oncology program, has collaborated on survivorship care efforts with Dr. Allison McDonough, who has begun a primary care practice at MG West, in Waltham, focused specifically on cancer patient care. PFAC Members were able to learn about Dr. McDonough's practice and offer recommendations on methods to communicate her practice availability to cancer patients on main campus who may be nearing end of treatment.

- **Survivorship Program in the Bone Marrow Transplant Program**

Dr. El-Jawahri presented the survivorship Program in BMT to PFAC members. The program, which went live July 2016, addresses the quality of life concerns of this patient population and their caregivers. The program specifically focuses on addressing issues of depression & anxiety, prevalence of pain, long-term complications and chronic graft versus host issues in the patients. Some of the components of Survivorship Care include the prevention of recurrence and new cancers, surveillance for mets, recurrence or secondary cancers, interventions for impacts of cancer and its treatments and the coordination between specialists and primary care physicians.

- **Mass General Substance Use Disorder Initiative**

The Mass General Substance Use Disorder Initiative was put in place to review survey findings from our local health centers that reported substance abuse as a paramount quality of life issue. Based on a chronic disease model, Mass General is updating their treatment system in order to increase quality of care which will ultimately decrease cost of care. The focus is currently on treatment and access, a change in philosophy (expect relapse), developing community supports and linkages, and enhanced education and prevention efforts in the community.

- **Lifestyle Medicine Clinic**

Dr. O'Donnell presented on the Cancer Center's newfound Lifestyle Medicine Clinic, where patients are encouraged to seek therapeutic activities beyond traditional treatment and care. In

this phase of care patients are educated on how best to thrive after they overcome their disease, with emphasis on diet and regular exercise.

- **Parking Office**

PFAC members were given the opportunity to provide the Mass General Parking Office with feedback on service and ideas for future opportunities to collaborate with the Cancer Center patient population. This topic also served as a catalyst to a larger conversation around accessibility to main campus compared to the opportunities at Cancer Center satellite locations.

- **Patient Education**

Steve Herskovitz and Devon Punch introduced the Px survey and shared copies of the newly created booklet “Important Things to Know about Oral Cancer Medication.” The booklet was created specifically from the feedback received by PFAC. The committee also discussed best practices for improving communication of patient education information.

- **Call Center**

Dr. Phil Saylor, who chairs the newly formed Call Center Advisory Board for the Cancer Center, presented on the current state of the Call Center, the challenges the Call Center has faced over the past year, and the opportunities for success moving forward. PFAC members engaged in a lively discussion around their experience with patient access over their years of care and how this has vastly improved in the Cancer Center over time.

- **ASCO Updates**

Dr. Inga Lennes updated committee members on the innovative studies and events happening in Cancer Research during the ASCO (American Society of Clinical Oncology) convention held in Chicago, IL. She noted that Vice President Joe Biden spoke at this years’ event. Some of the academic highlights were in the areas of survivorship, financial toxicity, end of life care, palliative care, and especially immunotherapy and the combination with chemotherapy. Some big announcements at the convention included Dr. Paul Goss of Mass General for his study showing 10 years of hormone therapy reduces breast cancer recurrence. Another Mass General provider, Areej El Jawahri also presented research regarding early palliative care and its benefits for family caregivers of patients with cancer.

- **Financial Costs of Cancer Care**

Terry McDonnell and Joseph Ianelli presented on the financial burdens patients diagnosed with cancer face during their Cancer Center care. Terry and Joseph are the cofounders and co managers of a Financial Care Coordination Team, which prioritizes minimizing financial exposure for patients from the moment they are diagnosed. Coordination focuses on working with patients to identify the potential insurance coverage issues and costs for their care and preventing interruption of care due to financial burdens. They also showed the partnership they work on developing between the providers and finance in order to support patients during treatment.

- **Cognitive Rehabilitation Therapy in Cancer Patients**

Joyce Shapiro Gordon from the Speech Language Pathology department presented on the benefits of cognitive rehabilitation for patients suffering from Chemo brain, the definition of

cognitive rehabilitation, the role of speech language pathologists and their treatment approach for helping patients with chemo brain.

- **Oncology Social Work**

Lourdes Barros, LICSW, spoke with the PFAC members regarding what Oncology Social Work has to offer our patient populations. Social Workers focus on a particular disease and prioritize learning about that specific disease as well as the treatments available for it in order to best serve the patients they are working with. Committee Members engaged in a discussion regarding their positive experiences with social workers during their care at Mass General.

- **PFAC Task Force on Enhancing Patient Connection to Cancer Center Supportive Care Resources**

The PFAC recognized an opportunity to improve the communication surrounding the Cancer Center's numerous supportive care services, and thus was empowered to create a Task Force with the guidance of Paula Gauthier, from Oncology Social Work, and Steve Herskovitz, from Cancer Center Marketing, together with a PFAC member as the task force's chairs. The Task Force has outlined objectives and plans to meet monthly to fulfill the workgroup's goals and present a final plan to Cancer Center administration by January of 2017.

- **Conferences**

As part of its mission to educate others about the value and role of PFACs, members participated in several external forums. During FY2015, members participated in the following forums:

- Institute for Patient & Family Centered Care Conference (July 2016)
- MGH Cancer Center Annual Conference for Patients & Families (October 2015)
- Mass General Annual PFAC Meeting (October 2015)
- Review Committee Meeting for ACS Institutional Review Grant (February 2016)
- Mass General Workshop on Research Methods in Supportive Oncology (February 2016)
- 4th Annual Patient and Family Advisory Council (PFAC) Conference: "Strengthening Patient and Family Engagement in Massachusetts Hospitals" (June 2016)
- ACS Roundtable

- **Committee and Subcommittee Participation**

PFAC members also participate in a variety of Cancer Center committees and subcommittees. This ensures that the patient and family member perspective is well integrated into the fabric of the Cancer Center. PFAC representatives on these committees provide periodic updates during the monthly council meetings. PFAC members participated in the following committees during FY2016:

- PFAC Task Force on Enhancing Patient Connection to Cancer Center Supportive Care Resources
- Cancer Center Patient Experience Council
- Cancer Center Quality & Safety Committee
- Cancer Center Patient Education Committee

Looking Forward

As FY17 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 PFAC's 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 to continually improve the patient experience.

MGH Cancer Center Members

Patient and Family

Laura Allen
Katherine Baker
Eric Buckley
Ann Buckley
Judy Cadorette
Lisa Dooling
Tracy Doyle
Linnea Duff
Brenda Estella
Trudi Fondren
Whitney Grace
Theodore Groves
Lee Higgins
Sarah Kalil
Maxine Nogard
Paul O'Leary
Jay Petri
Steven Prokesch
Rhoda Sapers
Nikki Shepherd
Bill Starratt
Maxine Wish

Staff

Jill Allen
Mara Bloom
Debra Burke
Paula Gauthier
Lisa Goggin
Judith McInerney
Erika Rosato

MGH Cancer Center PFAC By-Laws

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 Mass General.

2) Membership

Membership of the council is comprised of current and former patients of the MGH Cancer Center, their family members, and Mass General 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 Mass General 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 Mass General 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 Mass General 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 Mass General 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.

Mass General Pediatric Oncology PFAC

Year in Review

The Pediatric Oncology Family Advisory Committee (FAC) has continued to remain integral to the Pediatric Oncology clinical service, providing input around clinical practice and program planning. This has been a long standing, active group since 2003 with a changing membership to reflect the needs of the parents and practice. Parents of children receiving cancer treatment and parents of those children who had completed treatment join with members of the multidisciplinary team of clinical professionals to collaborate with the common goal of providing excellence in pediatric oncology care. The Committee's prior work in formalizing their mission statement and bylaws, inspired the Committee to work with even greater passion to involve themselves in meaningful initiatives to enhance patient care.

Objectives

1. Build a consistent and committed membership
 - Initiate a vigorous recruitment process, including promoting diversity amongst members
 - Develop an orientation program in collaboration with Mass General's Volunteer Services program for all members joining the Committee
 - Increase awareness of the value of the Advisory Committee's role within the clinics 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 Mass General
 - Co-chairperson (Mass General 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 meetings five times annually, with additional meetings scheduled when the group or a subgroup is working on a particular 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 attend in person meetings of the Advisory

Committee. Opportunities to call into meetings or Facetime, have been made available to members, so to offer flexibility to engage members' participation.

Specific activities and issues throughout the 2015-16 year included:

- Creation of a parent mentoring program (Mass General Hospital Pediatric Oncology POPS – Parents Offering Parents Support). A training module was developed by the Clinical Social Worker and implemented to prepare parent volunteers for participation. Program to be launched in September 2016 with 6 parents available as trained mentors.
- Collaboration with the clinical staff in the Emergency Department to address concerns related to port-a-cath access for pediatric oncology patients. Health care staff invited to participate in training within the Pediatric Oncology clinic, where they learned approach and technique for port access with young patients. Continued discussion amongst nursing administration about improving the competencies of the ED nurses in this arena.
- Development of a Patient/Family Education Center within the clinic's waiting area. This area to include dedicated space for our Adolescent and Young Adult patient population (based on the survey completed last year with these patients). Resource materials, technology and a quiet space will be offered for researching and learning about childhood cancer, coping with treatment and optimizing support and care for children during their therapy.
- Identification by FAC families about need to enhance disability access within the clinic space. A handicapped access door (automatic open) replaced an existing door to provide better access for patients coming into the clinical area in wheelchairs or strollers. Many positive accolades from other families after this improvement.
- Tracking of Patient Experience Data and input offered by the Committee around clinical improvements
- Review of eCare implementation and impact on patient/families perceptions of care.
- Consideration of technology resources to provide information to patients/families about clinical issues. Discussed value of VidScripts and engaging families and staff to identify clinical needs.
- FAC Co-Chairperson, Elyse Levin-Russman, LICSW, OSW-C presented at the Health Care for all Conference in Norwood, Massachusetts on Developing and Sustaining a Family Advisory Committee in Pediatrics over many years.
- In an effort to involve the chief of Pediatric Oncology more directly with the Committee, Howard Weinstein, MD, attended the fall Board Meeting in September 2015 to provide practice updates and continue an ongoing dialogue with the FAC.
- Family Advisory Committee members provided guidance about the development of psychosocial care programs for patients and families throughout the year. Programs including parent education/support, creating connections between families and honoring patients for their participation in arts programming were planned with FAC input.

- All members of the Family Advisory Committee and POPS program completed Mass General Volunteer Services training.

Pediatric Oncology FAC Members

Parents

Joseph Barnes
Nancy Barnes
Mary Cincotta
Michael Doiron Frankland
Patricia Flaherty
Kim Kayajan
Michelle McKiernan
Dawn Regan (Co-Chair)
Janice Theriaque
Tarrah Zedower

Staff

Mary Huang, MD
Heidi Jupp, RN
Elyse Levin-Russman, LICSW, OSW-C (Co-Chair)
Ellen Silvius, RN, BSN

Pediatric Oncology FAC By-Laws

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-Chair 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.

MassGeneral Hospital *for* Children FAC

MassGeneral Hospital *for* Children FAC

Mission Statement

The MassGeneral Hospital *for* Children's Family Advisory Council 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.

Year in Review

- **Family Advisory Council (FAC) members reviewed the Massachusetts General Hospital Strategic Plan** and formulated questions for hospital President Dr. Peter Slavin who answered them at the Annual Mass General Patient and Family Advisory Council (PFAC) event in October, 2015. A FAC parent member introduced Dr. Slavin before his remarks.
- **FAC members participated in a pilot Secret Shopper program** developed by Mass General Service Excellence Department. After out-patient appointments, FAC members can fill out a survey about their experiences and send it to the Service Excellence Department. FAC members have sent in 5 post-appointment surveys. Mass General Service Excellence is exploring the possibility of offering this program to all patients.
- One FAC member, a nurse who works in the Pediatric Intensive Care Unit (PICU), initiated and **developed a program in which the PICU medical team rounds on adolescent patients when no parent or guardian is present.** She surveyed PICU staff, worked with leadership to design the program, and helped to implement it. Her inspiration was attendance at the Institute for Patient and Family Centered Care (IPFCC) training workshop.
- **FAC hosted its annual Family Centered Grand Rounds in April 2016.** It was titled "Kids Talk: Our Patients Reflect on Their Experiences at MassGeneral Hospital for Children." The panel consisted of 4 pediatric patients, ages 12 to 18, each of whom shared advice with providers about how best to care for children.
- One parent member of FAC **worked closely with the team designing renovations to the new Pediatric Operating Room.**
- A parent member of FAC, along with her daughter and husband, worked with the Pediatric Surgery team and **created a video that introduces patients to the pre-operative experience.**

- Throughout the year, **FAC parents reviewed 12 sets of patient education materials developed by the MGHfC Patient Education editor.**
- Two (2) parent members of FAC **staffed a table in the Mass General lobby dedicated to educating the Mass General public about the work of PFACS in the hospital.**
- FAC members **set priorities for the coming year**, October 2016 to October 2017. They are, in order of preference:
 - Help various units in the hospital create and develop more parent to parent networks.
 - Have more FAC members sit on hospital committees
 - Find more opportunities for patients and families to participate in patient and staff education
 - Further align FAC efforts with those of the Patient Experience Committees at MGHfC.
 - Organize a family-centered hero award.
 - Focus on transitions to adult care.
 - Develop a relationship with the Office of Patient Advocacy.
 - Initiate outreach to the MGHfC Community Healthcare Centers for Recruitment.
 - Create language for parents around patient safety.
 - Make the hospital more EPIC friendly.
- **FAC parents served on the following hospital committees:** Mass General Quality Oversight Committee, In-Patient Experience Committee, Out-patient Experience Committee, Ethics Committee, MGHfC Advisory Board.
- **FAC parents expressed their interest in helping to foster parent-to-parent and patient-to-patient initiatives throughout the hospital.** To that end, 2 FAC members met with the Pediatric GI Inflammatory Bowel Disease Improvement Group, Pediatric Cancer Center, and Pediatric Transplant representatives to help improve and strengthen their programs and share ideas.
- FAC **hosted Erik Shank, MD** who apprised the group of the MGHfC's newly developed Enhanced Recovery for Surgical Patients protocol.
- Four (4) FAC parents **participated in MGHfC's Intern Orientation.** They shared their experiences of bedside rounding with 20 new interns, explaining why it is important for parents to partner in their children's care.
- **Head of Quality and Safety Esther Israel, MD provided data to FAC** that parent participation in staff trainings on helpfulness and courteousness resulted in improved hospital CGCAHP scores.
- 3 members of FAC, including a parent member, **collaborated with members of the MGHfC Quality and Safety Division to develop a poster that was presented at the Institute of Patient and Family Centered Care's International Conference** in July 2016. The poster described FAC

parent participation in staff trainings that were designed to improve hospital CGCHAP scores in helpfulness and courteousness. 2 members of FAC and 1 member of the Quality and Safety group travelled to the conference and presented the poster in New York City.

- **Liz Ryan, LICSW from MGHfC Pediatric Radiation Oncology Program, presented the book she created to guide pediatric patients through the process of receiving proton beam therapy.**
- FAC parents report at each monthly meeting how many hours they've worked on projects that contribute to hospital improvement. **For the months of April, May, June, July, FAC members contributed 92 hours to work on hospital improvement.**
- For the past 2 years, an FAC parent, along with her daughter who is a pediatric patient at MGHfC, **worked with hospital staff to create a video based on the daughter's experiences of care in the Pediatric Emergency Department.** The end result is an animated cartoon entitled "Wendy's Story." It is a guide to the Pediatric Emergency Department that pediatric patients can view before or during their stay. The cartoon is currently being finished by Payette Corporation who stepped in to complete the project.
- Payette Corporation staff attended a FAC meeting to **preview the cartoon, allowing FAC members input before the final cut.** The cartoon will be available in the ED, on hospital-owned iPads and on the MGHfC website.
- One (1) FAC parent **staffed a table at the annual Intern Meet and Greet** and provided information about the FAC's work to new residents on their first day at MGHfC.
- FAC **requested that the MGHfC Pain Team examine ChildKind guidelines.** ChildKind is a consortium of children's hospitals who have agreed to guidelines and protocols to ensure adequate treatment of pain in pediatric patients.
- FAC members **began preparation for Grand Rounds 2017 which will address the issue of medical error.** FAC Co-Chair and Head of Pediatric Quality and Safety presented to MGHfC's Ambulatory Operations Lead Team about the goals of this Grand Rounds.
- **Videos from FAC Grand Rounds were uploaded to YouTube, MGHfC Facebook page and the MGHfC website.**
- 5 FAC parents and several staff members **participated in the MGHfC Holiday Toy Store** in which they wrapped presents for children who were in the hospital during the winter holidays.
- FAC Co-Chair **presented webinar to Healthcare for All titled "Optimal Roles of Staff vs. Patient and Family Volunteers on PFACs: Creating Partnerships for Change"** in May 2016.

MassGeneral Hospital *for Children*

FAC Members

Parents

Seta Atamian
Debby Cartisser
Lisa Cimino (FAC Co-Chair)
Tina Cosentino
Darcy Daniels
Beth Garneau
Randi Goldman
Jan Lanosa
Eve Megargel
Janice Morris
Erin Quinney
Meagan Taylor

Staff

Mary Alexander, MD
Sharon Badgett-Lichten
Anne Bouchard Pizzano
Debra Burke
Monic Chardin
Sandra Clancy (FAC Co-Chair)
Sandra Dodge McGee
Peter Greenspan, MD
Esther Israel, MD
Rose McClory, RN
Eleanor McLaughlin, RN
Peggy Settle, RN, PhD
Alexandra Sobran, LICSW

Charter/By-laws

1. Mission Statement:

The MassGeneral Hospital *for* Children's Family Advisory Council (FAC) is dedicated to fostering the partnership of parents, children, and professionals working together to ensure a climate of responsiveness to the needs of children and their families in all areas of care delivery within Massachusetts General Hospital.

2. Purpose:

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

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.



Patients Share Lessons Learned from Their Hospital Experience at Grand Rounds

At a teaching institution like MassGeneral Hospital for Children (MGHfC), there are many educational opportunities. For providers, patients and families can be invaluable teachers in improving patient care. On April 12, four patients shared their stories and perspectives on the care they received at MGHfC during the annual MGHfC Family Advisory Council Grand Rounds. Providers and other members of the MGHfC community had the opportunity to learn about each patient's positive experiences and areas for improvement while at the hospital. Patients included Matthew Cartisser, 13, of Medfield, Mass.; Wendy Wooden, 12, of Sharon, Mass.; Jean Catulle, 18, of Hyde Park, Mass.; and Brianna Cimino, 19, of Bedford, Mass.

Matthew shared several tips that focused on keeping children as well as their parents informed every step of the way. "Talk to my parents, but tell me what's going on. Hearing it from my mom or dad isn't the same as talking to the doctors myself," said Matthew, who was diagnosed with a desmoid tumor in his jaw at 12 months. At 14 months, he started chemotherapy and had surgery to remove the tumor. After surgery, Matthew developed lockjaw. After several rounds of treatment, including surgery to graft tissue from his back to line his jaw, Matthew was deemed cancer-free at age 10.

Giving children control over small aspects of care and understanding fear triggers are also important, said Cartisser. "When I was in the hospital, the smell of hand sanitizer scared me," he said. "When I heard plastic rustling, I knew something painful was about to happen. I don't like white coats, so my mom asked the doctors not to wear white coats when they visited me. They didn't and that helped a lot."

For Wendy Wooden, 12, telling patients and families what to expect can be helpful in easing fears during a trip to the emergency room, which Wendy has been familiar with since childhood. Wendy and her mother, Darcy Daniels, are working with Boston-based architecture firm Payette to create a cartoon that walks children and families through the emergency room experience.

"I want children to feel welcome and not so scared of the emergency room. The cartoon goes through steps of the emergency room and what to expect while you're there," said Wendy, who was diagnosed with hemolytic uremic syndrome (HUS) at age 3, caused by an E. coli infection. Complications from HUS damaged Wendy's kidneys and pancreas, leaving her diabetic. At age 5, Wendy received a kidney transplant from a deceased donor and had part of her intestines removed as a result of damage from HUS.

Brianna Cimino, 19, also had a deceased donor kidney transplant at age 13 after a diagnosis of nephrotic syndrome at age 2 damaged her kidneys. In addition to sharing her story on video, her mother, Lisa, also spoke on her behalf. "For Brianna, having doctors and nurses there to share the important details was crucial to her," said Lisa.

Being involved in decision-making was also an important part of care, said Jean Catulle, 18, who suffered a spinal fracture in 2014 while playing with friends. “It’s helpful when doctors and nurses explain the procedures in detail and they made sure I had a voice in my care, even when I didn’t have one while I had a trach tube in,” said Catulle, who is currently at Spaulding Rehabilitation Network in Charlestown, Mass. “Having hope is also what got me through this.”



Grand Rounds Talk

Good morning:

I'm Matthew Cartisser and I'm 13. I was born here and have been treated here ever since. I've had 18 trips to the operating room for everything from ear tubes to big surgeries. I've learned a huge amount from all that I've been through. I've developed skills and have understandings about myself that are the silver linings to all this. So, I'm here to tell you some of the things I know that will help you help other kids.

1. Talk to my parents but tell me directly what's going on. Even when I was really little, I wanted to know what was happening. It was helpful when the doctors & nurses had a conversation with my parents but then turned to me and talked to me about it too. Hearing it from my mom afterwards isn't the same as being able to talk to doctors or nurses myself. When you come in a room for a procedure, tell me what is going to happen, don't just start doing things to me. It's very scary.
2. Please don't ask my mom or dad to help hold me down for a painful procedure. It's confusing and makes it much scarier.
3. Please call me by my name if you can.
4. Take me on a tour of the hospital. I'm afraid of many things in the hospital, but fear of the unknown is one of the biggest. Show me the pre and post op rooms. Show me a picture of the OR. Take me to the pedi-floor and show me the playroom. Tell me I can go into the OR with a parent and my favorite stuffed animal.
5. Ask me about my preferences I will be glad to tell you what I like or don't like. It will help me to feel more comfortable and feel like I have a voice in this whole process.
6. Give me a little control. The hospital is a place of absolutely no control. If you give me some choices, even about very little things, it helps. Having that little bit of control helped me be less anxious.
7. Look for my fear triggers. Smells to me are still huge fear triggers. Hand sanitizer gives me flashbacks. I can be afraid of sounds. When I had my graft surgery a team would come in to check the blood flow to my free flap by poking it with a syringe. When I was sedated, I could hear the ripping of the plastic wrapping of the syringe. I was scared to death of that sound. . My mom mentioned that I had "white coat phobia" at check-in once and 3 doctors came in the exam room without their white coats on, just to make me more comfortable.
8. Listen to my parents. If I'm really little, I may not have much of a voice but my parents know me best and they can tell you. I had my second big surgery when I was 4. My parents knew it took a lot more drugs than the average adult just to keep me sedated and that I burned through them really quickly. My mom knew when I was a baby & was hallucinating from withdrawal. I couldn't talk but she saw me following things in the air with my finger that weren't there. Because a nurse listened, I got better care.
9. Tell me if you don't know something. The best of the best were the care givers who weren't afraid to tell us they didn't know. I knew I had a rare disease. I also knew having lock jaw was rare. We went to 7 different hospitals to get opinions. Not everyone had an answer for us and that was okay. Just tell me if you don't know.
10. Be open to learning from me. When I was in a drug induced coma, the doctors and nurses assured my parents I couldn't hear and couldn't respond when I was really out from the medicine. My parents kept insisting that it wasn't

true, that I could hear and I did know what was going on in the room and I could participate. They found out that I could respond and communicate to them by moving my finger when completely out on versed and fentanyl.

11. Teach me to communicate with you. When I was 4 I was trached for the first time. We didn't know in advance this would happen so my parents told me my voice had been turned off for a little while. We made up our own sign language so I could have a voice. Teach me to have a voice with you. Give me your words so I can communicate in your language.

12. Talk about the effects of long term medical treatment with me and my family. Help me to understand that there will be mental and emotional side effects from all this treatment. Help my parents to know what learning disabilities I may have from prolonged sedation and chemotherapy and show them what to look for. Teach us to look for issues I might face like anxiety or depression.

13. Connect me with other kids. The cancer center had some parties where I was with other kids who understood what my life was like. A social worker connected us with another family whose son was being treated for the same tumor at the same time as me. It was nice to know there were other kids out there who understood. Being with kids who "get it" is important.

I really want to thank all the people at this hospital who have helped me over the years. I have met some amazing people who have really inspired me. The stand outs were the ones who I formed connections with because they cared so much about me, not the kid with the desmoid tumor and trismus, but Matthew Cartisser, the 4 year old who loved airplanes, or the 9 year old who wanted to be in the army or the 13 year old who wants to be a facial reconstructive surgeon. I credit the amazing people at Mass General for saving my life and there are no words to express the gratitude I feel.



News Article

Wednesday, April 13, 2016

Patients Share Lessons Learned from Their Hospital Experience at Grand Rounds

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Matthew shared several tips that focused on keeping children as well as their parents informed every step of the way. "Talk to my parents, but tell me what's going on. Hearing it from my mom or dad isn't the same as talking to the doctors myself," said Matthew, who was diagnosed with a desmoid tumor in his jaw at 12 months. At 14 months, he started [chemotherapy](#) and had [surgery](#) to remove the tumor. After surgery, Matthew developed lockjaw. After several rounds of treatment, including surgery to graft tissue from his back to line his jaw, Matthew was deemed cancer-free at age 10.

Giving children control over small aspects of care and understanding fear triggers are also important, said Cartisser. "When I was in the hospital, the smell of hand sanitizer scared

me," he said. "When I heard plastic rustling, I knew something painful was about to happen. I don't like white coats, so my mom asked the doctors not to wear white coats when they visited me. They didn't and that helped a lot."

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"I want children to feel welcome and not so scared of the emergency room. The cartoon goes through steps of the emergency room and what to expect while you're there," said Wendy, who was diagnosed with hemolytic uremic syndrome (HUS) at age 3, caused by an E. coli infection. Complications from HUS damaged Wendy's kidneys and pancreas, leaving her diabetic. At age 5, Wendy received a [kidney transplant](#) from a deceased donor and had part of her intestines removed as a result of damage from HUS.

Brianna Cimino, 19, also had a deceased donor [kidney transplant](#) at age 13 after a diagnosis of [nephrotic syndrome](#) at age 2 damaged her kidneys. In addition to sharing her story on video, her mother, Lisa, also spoke on her behalf. "For Brianna, having doctors and nurses there to share the important details was crucial to her," said Lisa.

Being involved in decision-making was also an important part of care, said Jean Catulle, 18, who suffered a [spinal fracture](#) in 2014 while playing with friends. "It's helpful when doctors and nurses explain the procedures in detail and they made sure I had a voice in my care, even when I didn't have one while I had a trach tube in," said Catulle, who is currently at Spaulding Rehabilitation Network in Charlestown, Mass. "Having hope is also what got me through this."

The Ambulatory Practice of the Future Care Alliance

Background

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

2016 marks the 6th year of operation for the APF. The APF has proven to be an innovator and leader in delivering patient centered primary care services for Mass General employees and their spouses/partners. APF differentiates its practice by delivering on a daily basis a patient-centered model of care including staff's commitment to a team-based practice.

Staff value partnership and transparency with patients and with each other. APF partners with patients by offering electronic communication, unrestricted access to test results and visit notes, along with continuous care and coaching to help patients better manage and achieve their health, life balance, and wellness goals. The Care Alliance (CA) proactively partners with staff to promote making the care experience equally rewarding for patients, their families, and staff, and to ensure that the values that define APF remain strong while the practice expands.

The initial needs of APF called for substantial patient and family member input into planning and implementing this patient-centered practice, along with creating the necessary structure for APF and the CA to support each other. Next, the initial growth in the practice called for a CA that could help monitor implementation of this patient-centered model while generating and supporting opportunities to promote innovation. As demands and pressures on staff increased, patients on the CA needed to work more pro-actively. We surveyed patients about their care experience and communicated back to patients both the survey results and how staff addressed their suggestions. The need to communicate information to patients remains increasingly important as a means to help patients become more engaged in their own health care. In looking forward, the CA is in the process of streamlining its meeting structure and better utilizing multiple media, including social media to better communicate with APF patients and the Mass General community. We believe that keeping patients better informed about relevant clinical news, information and changes is important, especially in anticipation of continuous organizational change. Doing so will further APF's goals to offer care that is based on transparency and partnerships.

During 2016, the Care Alliance took on the role of advocate for the continuation of Open Notes by identifying the benefits and impact on patients to support APF leaders.

2016 also marks the 6th Anniversary of APF's Care Alliance (CA). The CA is actually older than the APF, founded several months before APF opened, to guide it from the start. The first patients were seen at APF in August 2010.

The Care Alliance is happy to be such an integral part of The Ambulatory Practice of the Future. We enjoy the opportunity to promote this patient-centered model of care with such open, supportive and caring staff. We are excited about the new opportunities to promote this innovative model of care with

APF patients and the larger Mass General community via social media. We believe our efforts play an important role in helping to manage the changes and challenges that are part of current health care.

Reflections on 6 years of the Care Alliance

Pre-APF

Patients were members of the APF Development Team and served as strong advocates in the design of APF and its model of care years before APF opened its doors.

Years 0-2

The Care Alliance was founded in April 2010, several months before the APF opened. The name Care Alliance (as opposed to Patient and Family Advisory Council) was selected to reflect a partnership of providers with patients and families. The Care Alliance (CA) membership was established to be roughly equivalent in numbers of providers and patients/family members and to be chaired by patients. Patient members wrote the by-laws for the CA.

It was understood from the outset that there would be a ramp-up period for the practice to add patients and convert concepts into operations. The CA provided valuable feedback to this process, with ample opportunity for patient and family members to add value to the transformation. The chairs of the Care Alliance attended staff meetings and managed CA meetings and their agendas. Attendance at staff meetings allowed the chairs to offer immediate input as operational concepts such as patient and staff scheduling were discussed.

Years 2-3

As the practice grew, development turned into fine-tuning. The budgetary and operational support for a practice exploring a new way of delivering care evolved to become the same as that for all primary care practices. With budget cuts and hiring restrictions, the pressure on providers and staff increased. The CA monitored available practice outcomes with staff. Staff also asked the CA to explore ways to assess and understand patient engagement and the patient experience at APF.

Years 3-4

In response to continued budget cuts, patient and family members of the Care Alliance took responsibility for projects like developing and executing APF patient feedback surveys, and promoting the use of the uniquely transparent patient portal, iHealthSpace. A former chair worked with practice leadership to explore opportunities for innovators and the APF to jointly test innovative technologies and procedures. As patient panels continued to grow, so also did pressure on a staff trying to maintain the values that differentiate APF from other primary care practices. As a result, staff has had far fewer resources to invest in CA projects.

Year 5

The CA remains mindful of the ever-changing nature of health care and the very real limits on everyone's time. The CA is now in the process of streamlining its meeting structure and simplifying its

role to focus on brief, important communications to the APF patient population. This involves rethinking both messages and media in light of the fact that current patient communication vehicles will be changing. The team is exploring ways to develop patient communications based on the principle that the key to reaching an audience is to use multiple media. We believe it is important to increase our use of social media to provide an easily accessible communication link between staff and patients in order to keep patients better informed about relevant clinical news, information and changes at APF, and any broader Mass General changes impacting APF (e.g., EPIC and MyChart). Doing so will further APF's goals to offer care that is based on transparency and partnerships.

Year 6

The Care Alliance is reinventing its role in advocating for the excellence of the practice throughout Mass General and health care at large; building relationships and community between staff, patients and PFAC; and creating innovative communication practices to better describe APF's patient experience and become an effective Voice of the Patient.

2015 Goals

We continue to focus on Patient Engagement, Staff Support, and contribution to Practice Outcomes. The Care Alliance believes it is essential to explore and better understand with patients what is an extraordinary customer experience, the best practices to meet those needs, the unique nature of the APF and how best to support patients to become a partner in their own healthcare. We also believe it is vital to obtain in-depth patient feedback to improve the care experience and stimulate innovation in the practice. APF's patients are primarily Mass General employees and we are mindful of the impact of reduced budgets, increasing patient panels, and limited time resources on our patients, APF, the Care Alliance, and the entire Mass General community.

Our 2016 goals have been in the following areas:

1. Become a **partner and positive resource for APF staff and patients to manage change**. Over the last year major change has been introduced throughout Partners and Mass General with the implementation of the new software system, EPIC, and electronic record keeping process and sharing. The nature of change is that in the process of implementing new systems and approaches, there can be significant impact on the on-going operations as change is implemented. Our goal was to collaborate with APF staff to identify current strengths of the practice, target potential challenges to current best practices, and to develop the what and how to best communicate with APF patients to prepare and help them to manage change and take action for positive results.
2. Develop a **proactive communication process that is patient-centered** and -driven to better understand the patient experience and needs, while building a strong collaborative community of APF patients, staff, and Care Alliance.
3. Establish a **role for patient participation in innovation and research**.

Year in Review

1. A partner and resource to staff and patients in managing change:

- *A Collaborative CA / APF staff process for managing change:*
A **discussion and action planning session** that detailed the EPIC changes, the potential impact on operations and care, and plans for the simplification and seamless usage of the system.
- *A strategy and outreach to patients to proactively encourage them to enroll in EPIC Patient Portal:*
A CA rapid action team was formed which developed a **patient communication letter** sent to all APF patients to inform, educate, and create buy-in to the new system. The letter was provided to the **Partner's Patient Gateway Support Team** to support their **patient communication**.
- *Advocate for APF leadership:*
Open Notes was seen as critical to the continuous practice of transparent and open communication between APF provider, team, and patient to increase the level of trust and true partnership in patient care. The Care Alliance served as an advocate for APF leadership to negotiate APF's becoming a demonstration project for the use of Open Notes and adapt its use in the EPIC system in the near future. The CA developed a document detailing the mutual benefits, outcomes, and significant patient experience of having patient access to Open Notes for use by APF leadership.

2. A Proactive Communication Process That Is Patient-Centered

- *Patient Voice Survey:*
A new and enhanced survey, the Patient Voice Survey, was designed and implemented to provide an immediate rating and description of the patient's experience of their care visit. The survey was piloted after the EPIC implementation to better understand the impact of change on our patient's experience. The plan is to use this survey as a periodic outreach for patient feedback. The survey completion utilizes a tablet to gain real-time feedback from patients.
- *Patient Newsletter:*
A newsletter to APF patients designed, developed, and managed by the Care Alliance to provide a behind-the-scenes understanding of the practice and team delivery of care, gain patient feedback, and build stronger relationships between APF staff, Patients, and the Care Alliance. The newsletter will be piloted by January 2017.

3. A Role For Patient Participation In Innovation and Research

- *Innovation and Technology:*
A collaborative relationship and project development has been established between the Director of APF ILP and the Care Alliance focused on the website, social media, and promoting innovative practices such as Coaching.

Research:

Care Alliance hosted a collaborative meeting with the Hope Project to provide input to Partners Research Project. The relationship and involvement is now in development.

The Ambulatory Practice of the Future Care Alliance Members

Patients

Paul O’Leary (Co-Chair)
Julie Martin (Co-Chair)
Rebecca Petersen
Stephanie Geohagen
Robert Evans

Staff

Ben Crocker, MD
Annie Helgason, MD
Mary Ann Marshall, RN
Jane Maffie-Lee, NP
Steven Lynch
Sarah Sherwood
Maryann Feliciano
Aaron Hoffman
Lori Newman

The CA leadership remains patient-driven. In 2016, CA leadership has been shared by two patient members, Paul O’Leary and Julie Martin. Patient members facilitate monthly meetings on a rotating basis and communicate between meetings to brainstorm and work on action plans. The CA has developed a new approach to delivering urgent, pragmatic, problem/opportunity focus that produce action oriented results. We call them Rapid Action Teams. Care Alliance patient members have an open invitation to attend weekly APF staff meetings to understand current staff concerns and provide additional patient perspectives. APF Leadership is active, supportive and easily accessible to CA members. The CA will be recruiting new patient members over the next 6 months. Staff members now attend CA meetings when interested and involved.

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 an 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. Nonemployee 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 CoChair, 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.

Additional Information

Open Notes

Making the case for instituting Open Notes and for including the APF in any pilot program APF leadership was invited to participate in discussions about the benefits and concerns of implementing Open Notes at Mass General. The Care Alliance shared their thoughts about why Open Notes have been so important to the care they receive at the APF and why they believe access should continue.

Paul O'Leary

Extraordinary health care is the combination of the wisdom, experience, communication, skills and caring of the provider and team with the responsibility, accountability, motivation, caring and trust of the patient. Open notes is a key tool to help the provider, care team and patient to achieve that outcome. The APF patient has had access to Open Notes and not being able to use it is a huge loss in their care. As a patient, Open Notes gives me the knowledge that my provider and care team are my consistent advocates for my health and well-being, helps me to understand what was discussed and own my responsibilities and the actions I need to take, supports me to confidently ask question if I have a concern(s) and can become a key resource in a thoughtful, shared decision making process between provider, team and patient. Revisiting the note summary before my next visit provides me with the opportunity to better understand the illness / problem, what is most important, what was provided and hold myself accountable for my actions to become an active participant in the management of my health. My access and the transparency of the notes has maximized my trust in my provider, team and the care that I am receiving.

Pam Rahn

I hope Open Notes becomes standard of practice across health care systems as I feel it will become a vehicle of patient engagement and empowerment and creates partnerships for better healthcare.

Julie Martin

Having access to my physician's notes increases my feeling that my care team and I are really a team! I can make sure they heard me correctly, and the notes can remind me of things I forgot during our appointment. It's also helpful to read the notes before an upcoming appointment, so I can speak to what's changed regarding my previous health issues. The notes keep me accountable and striving for my best health. Plus, it's fascinating to see my current health status accounted for in one place, and I'm amazed at how many topics my care team must cover in order to be compliant!

Rebecca Petersen

I like knowing that my full chart information is available whenever and wherever I need it. The message this open access conveys is that my health care team sees me as a full partner in my healthcare. Knowing this makes me feel more comfortable in contacting my healthcare team when health questions or concerns arise.

Stehanie Geohagen

Keeping the level of communication open and transparent between patient and provider is one of the major reasons why having access to Open Notes is important. I was able to point out a discrepancy within the notes, that may not have been noticed if I (the patient) didn't have access to notes. It absolutely increases the feeling of teamwork geared towards the maintenance of our health.

Win Hodges

Open Notes should be designed in a way that can meet the needs of practices on a continuum from conservative to pioneering. It should allow providers the ability to control delivery of bad news and patients the ability to grant access to their notes to a family member, a partner, or a friend. For pioneering practices Open Notes can provide transparency and support partnering with patients to be empowered members of their care team who share in decision-making regarding their health goals and care. Open Notes can include summaries of goal setting and discussions with coaches as well as providers. Open Notes supports the transition from episodic care to continuous care. Notes would be available as a reference 24/7 and as a resource when preparing for the next visit. And finally, a Visit Summary is not truly a visit summary without notes on what was discussed at the visit.

EPIC communication to patients

Dear <First Name> <Last Name>:

Partners Patient Gateway is the patient portal used by the Partners new Epic system. It replaces both iHealthSpace and Patient Gateway. Those of you who are Mass General employees know that the hospital started using Epic in December. It is being rolled out across Mass General in waves through April 2016.

The projected Epic launch date at the APF is April 2, 2016.

How this impacts you and what you should do:

- If you already have a Patient Gateway account: You don't need to do anything. Your iHealthSpace providers, appointments, test results, and allergies will be added to your existing account in April.
- If you do not have a Patient Gateway account: Please visit www.patientgateway.org to create a new account. We highly recommend you do this now, before the APF transitions to Epic! This will give you the most access to your patient information during the transition.
- Need help creating an account? Follow these step-by-step enrollment instructions, read helpful FAQs, or contact Patient Gateway Support.

Transition Timeline

- March 31: iHealthSpace prescription requests and message sending will be turned off starting at 5:00 am.
- April 2: iHealthSpace will be frozen. You will use Partners Patient Gateway to view your medical information and connect with your provider's office from now on. Your information from prior to April 2 will still be available to view on iHealthSpace for a limited time.
- After April 2: Many of the iHealthSpace functions you are used to, including your medication list and health problem list, will be added to Partners Patient Gateway in coming months.
- Early July: Your past medical information will no longer be available in iHealthSpace.
- Future: We will send you alerts and reminders as we receive information.

Your APF care team and the Care Alliance are truly excited about moving to Partners Patient Gateway, but we know there may be some bumps in the road. We will be working hard to ensure that the quality of care we deliver remains at the level you have come to expect at the APF.

Sincerely,

The APF Care Alliance

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

Care Alliance Farewell

by Win Hodges, Care Alliance Chair Emeritus

My retirement from the Care Alliance winds up almost 20 of the most fulfilling years of my life as an advocate for patients and for partnership in healthcare. A few of the highlights include matching with newly diagnosed lung cancer patients and having the honor of playing a part in their journey. Serving on the Cancer Center PFAC in the early years was especially rewarding being able to improve the patient experience and to have real input into the design of Yawkey's Cancer Center outpatient floors and its Healing Garden as well as playing a part in designing the patient rooms in the Lunder building. Role-playing and coaching Kate Treadway's HMS students in giving cancer diagnoses and bad news was another highlight.

I had the exceptional opportunity to serve for eight years as a facilitator for Schwartz Rounds in five area hospitals. These Rounds offered opportunities for clinicians to share emotionally challenging experiences and to be more supportive of each other and more compassionate with their patients.

The most rewarding experience for me has been participating in the development and first five years of operation of the APF. During my professional career in publishing and financial services I participated with high hopes in many improvement initiatives, such as Quality, only to find the "talk" not being "walked" and having to watch these initiatives fade away. The APF is not only an exciting pilot, it has also offered me an opportunity to play a part in helping develop and realize its potential. From its inception in 2004, I participated in every phase of the process including the design and layout of this office. Most exciting to me was playing an important role in defining APF culture, working with Jeanhee Chung on the development of iHealthSpace, and creating the Care Alliance. This is one time I have seen the talk being walked and the hopes being realized. It has been challenging and I appreciate everything you have done to keep it real.

In the interest of full disclosure, the work that I have been given credit for over the years has really been the result of a joint effort supported by my bride and executive editor, Margie. Anybody who has taken care of me knows first-hand how much she does. So it is really "we" that are retiring. I have been slowing down but one of the real reasons for retiring is to spend time on the interests that I am passionate about and have been promising myself that I would enjoy someday. They include military history (I was a Navy brat in World War II), traditional watercraft and their design, ancient Egypt, Celtic music and culture (the pipes stir something deep inside me), Buddhism and scanning photographs from pre-digital days, which is a wonderful way to savor special times and memories. Thirteen years after my professional retirement it is nice to realize that "someday" has arrived. I have tremendously enjoyed working and learning with you and the relationships we have developed over the years.

Now, when it comes to being an APF patient, my Experience, my Sense of Security, my Care, your Communication and your Compassion all get 10s across the board!

MASSACHUSETTS GENERAL HOSPITAL

55 Fruit Street
Boston, MA 02115
(617) 726-2000



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