



Caring

Headlines

September 7, 2017



New pediatric wheelchairs

listening to the voice of our patients with a little help from the Pediatric Oncology Patient-Family Advisory Committee

(See story on page 5)

10-year-old patient, Jennifer Perez, is a perfect fit for these new pediatric wheelchairs, the culmination of an idea brought forward by a parent at a meeting of the Pediatric Oncology Patient-Family Advisory Committee.

Nursing & Patient Care Services
Massachusetts General Hospital

"Guided by the needs of our patients and their families..."

OUR MISSION

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

MASS GENERAL 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. Massachusetts General Hospital has been ranked among the top five hospitals in the United States by U.S. News & World Report since the rankings began. In 2017, Mass General is recognized as #4 out of nearly 5,000 hospitals considered in the ranking; Mass General is the only hospital ranked in all 16 specialties considered by U.S. News & World Report, a testament to the breadth and depth of our expertise. Mass General patients rate their experiences highly, with nearly all indicating they would be very likely to recommend Mass General to others. The hospital consistently achieves high ratings from professional organizations, including the American Nurses Credentialing Center, the Society of Thoracic Surgeons, The Joint Commission, and the Leapfrog Group. In addition, our clinicians and researchers are recognized at home and internationally for their contributions to the field.

Patients at Mass General have access to a vast network of physicians, nearly all of whom are Harvard Medical School faculty and many of whom are leaders within their fields. Our many multidisciplinary care teams—known worldwide for innovations in cancer, digestive disorders, the neurosciences, heart disease, orthopaedics, transplantation, urologic diseases and trauma care—unite specialists across the hospital to offer comprehensive, state-of-the-art medical care. In addition, MassGeneral Hospital for Children provides a full range of pediatric health care services, from primary care to leading-edge treatment of complex and rare disorders.

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.

Mass General annually:

- Admits approximately 48,000 inpatients
- Handles nearly 1.5 million outpatient visits
- Records more than 100,000 emergency room visits
- Performs more than 42,000 operations

Mass General and Brigham and Women's Hospital are the founding members of Partners HealthCare, an integrated health care delivery system that includes community hospitals, primary care and specialty physicians, specialty facilities, community health centers and other health-related entities.

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.

Jeanette Ives Erickson

Patient and Family Advisory Councils

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

Patient and family advisory councils are comprised of patients, family members, and staff who give generously of their time and ideas to help us improve care and refine systems.

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

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



Jeanette Ives Erickson, RN, senior vice president for Patient Care and chief nurse

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

The General PFAC

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

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

continued on next page

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."

The hospital's 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 PFAC

— *established 2011* —

The General Patient and Family Advisory Council (G-PFAC) continuously embraces and promotes the opening words of the Mass General Mission Statement, “Guided by the needs of our patients and their families. . . .” Over the past year, the G-PFAC has engaged in numerous partnerships and collaborations to achieve these opening words through integration of the patient and family voice across the organization.

This past year the G-PFAC introduced several new patient, family and staff members and transitioned leadership to the newly elected patient co-chair. The G-PFAC continued the practice of assigning buddies to provide support, answer questions, and help guide new members into the role of G-PFAC membership. All new G-PFAC patient and family members participated in the Mass General Volunteer Services orientation, as in past years, further enhancing engagement throughout the hospital. There has been an increase in G-PFAC member participation throughout the organization and regular requests for G-PFAC members to participate in committees and additional collaborations.

2016-17 GOALS

- Recruit new G-PFAC members during 2017 who will help foster the mission of the G-PFAC.
- Promote and facilitate G-PFAC member participation on MGH/MGPO committees and task forces, and participate in providing feedback on services, programs and initiatives.
- Enhance G-PFAC member understandings of MGH/MGPO infrastructure and operations, by inviting leaders and representatives to G-PFAC meetings.
- Align G-PFAC activities with the 4 strategic imperatives of the hospital - Clinical Care, Research, Community, Education, and include focus on infrastructure and additional areas of strategic importance.
- Expand awareness of the G-PFAC across the MGH/MGPO.

PRESENTATIONS and FEEDBACK

Through monthly meetings and targeted requests, the G-PFAC reviewed, provided feedback on, and learned about a spectrum of topics spanning Mass General settings and strategic imperatives. These topics included the following:

- Partners 2.0 opportunity statement.
- Surgical informed consent policy.
- Autism Patient Navigator resource and advocate.
- Direct scheduling prospect and future directions.
- Community Health Improvement initiatives and directions.
- Ambulatory Psychiatry access, and efforts to address capacity constraints.
- Development and Philanthropy.
- Excellence in Action, and potential future directions.
- Health Story Collaborative, and the therapeutic aspects of patient narratives.
- Emergency Department capacity initiatives as well as patient experience initiatives.
- Emergency Department informational brochure.
- Police and Security approaches to creating a safe environment.
- Outpatient Pharmacy improvements and future enhancements.
- Medication communication current state and ideas for improvement.
- Ambulatory Surgery patient and family materials.
- Neurology poster review and revision.
- Shared Decision Making initiatives.
- Welcoming environment current state and ideas for improvement.

G-PFAC MEMBER PARTICIPATION IN HOSPITAL COMMITTEES and TASK FORCES:



- Blum Patient & Family Learning Center — A working committee of several G-PFAC members focuses on a variety of aspects of patient education throughout the Mass General experience, and collaborates closely with the Maxwell & Eleanor Blum Patient and Family Learning Center.
- Kitty Hawk Task Force Advisory Council
- Quality Oversight Committee
- Patient Perspective on Perioperative Care Committee
- National Patient Safety Awareness Week
- Partners and Mass General Telehealth.
- Partners Patient Engagement Leadership Committee.
- Anesthesia Quality and Safety
- Outpatient Psychiatry Access Committee

ADDITIONAL ACTIVITIES

- 3 members presented the G-PFAC mission and goals to Development Office staff.
- Hosted a G-PFAC recruitment table in the White lobby to educate Mass General community about the G-PFAC and the role of PFACs, as well as to recruit new members.
- Facilitated ongoing meeting of Mass General's PFAC Chairs.
- Planning annual joint PFAC meeting of all MGH patient and family advisors for November 2017 – this year featuring PFAC patient/ family member panel discussions, facilitated by Dr. Annie Brewster, Health Story Collaborative Founder and Executive Director. The evening provides an opportunity for all PFAC members to network and share experiences.
- Collected feedback on G-PFAC collaborations over the past year. Below are some of the comments reflecting these collaborations:

“Ongoing collaborations have been very valuable as they allow us to get real-time feedback on items that are in process.”

“We are actively working to change our mission statement based on comments from the group.”

“The task force has been able to help us think through improving the patient materials that we have as well as the terminology that we use. We are looking forward to continuing [this] collaboration.”

“His perspective and thoughtful contributions have been absolutely invaluable.”

“Sometimes the priorities of our patients are different than those of the caregivers, and it's important to know this.”

“Great perspective. Really helpful.”

“I would like to see more G-PFAC members sit on MGH committees to provide the patient and family perspective.”

G-PFAC MEMBERS

EXECUTIVE COMMITTEE

Julie DeCosta
Patient Co-Chair

Robin Lipkis-Orlando
Staff Co-Chair

Liza Nyeko
Staff Co-Chair

Susanne Goldstein
Past Patient Co-Chair

William Kieffer
Patient Member-at Large

Kay Bander in Memoriam

“We are deeply saddened by the loss of our inspirational member, Kay Bander, this year. Her wisdom, generosity, and vision will guide us in all future endeavors, as we strive to promote and realize continuously the opening words of the Mass General Mission Statement: “Guided by the needs of our patients and their families. . .”

MEMBERS

Evelyn Abayaah (*staff*)

Emily Bider (*retired*)

Robert Chen

Hilary Deignan

Ann Galdos

Melissa Hoyt

Linda Kane (*staff, retired*)

Debbie Kannady (*retired*)

Susan Keshian

Sue Lunn (*retired*)

Stuart Murphy

Kim Northrop (*staff*)

Daniel Ranti

Matt Reid

Elsir Sanousi (*staff*)

Lisa Scheck (*staff*)

Carrie Stamos

Kathy Verni

David Wooster (*retired*)

Joy Wu

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 MGH community. Up to 8 MGH 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 MGH
- 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.
- 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 OF MEMBERS

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 MGH 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 health-care 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 MGH guidelines and Health Insurance Portability and Accountability Act (HIPAA) standards and guidelines. The Volunteer Department of MGH 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 2017

CANCER CENTER PFAC

— *established 2001* —

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 6 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, 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 MGH, 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 MGH confidentiality statement. CC PFAC members play an active role in orienting new members. Members serve as “buddies” to new members and provide peer mentoring on the role. New members are also encouraged to attend Cancer Center 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 MGHwide staff that wish to consult the council.

ROLES and RESPONSIBILITIES

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.

ACTIVITIES and ACCOMPLISHMENTS

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
- Minimize delays and increase efficiency of patient care
- Increase awareness of clinical trials and targeted therapies

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:

- Innovative Approaches to Patient Centered Care for MGH Breast Imaging- Dr. Constance Lehman, MD. Presented new patient-centered and innovative approaches in Breast Imaging. Specialists in the center detect and diagnose breast cancer with state of the art analysis utilizing specialized mammographic views, magnification views, ultrasound, MRI and CT scans. The committee engaged in discussions of their own experiences with Breast imaging and feedback for continued improvements.
- Chaplaincy- Katrina Scott reviewed the various services offered to patients from the Chaplaincy program at MGH. Patients are provided with spiritual care for all traditions, religions and cultural beliefs. The committee and Katrina discussed the benefits chaplaincy involvement can offer patients and families in addition to the versatile exercises used to approach spirituality at MGH.
- Music Therapy- Lorrie Kubicek presented an entertaining and interactive update on the Expressive and Music Therapy program offered to patients and families at MGH. PFAC members learned about the benefits music therapy including stress relief, alleviating physical symptoms from treatment, relaxation and the effects on improving patient and family moods when dealing with a difficult diagnosis.
- Termeer Center for Targeted Therapies-PFAC experienced an enlightening and heartwarming presentation from Sarah Colella, RN Resource Nurse with the Termeer Center for Targeted Therapies. The Termeer Center brings research and collaboration among physicians and investigators across disease groups to patients enrolled in Phase I, II and II clinical trials. Sarah reviewed some of the cutting-edge research being done in the center to

help with the fight against Cancer. Her emotional and dedicated description of the Termeer Center's commitment to its research and patients was welcomed by the group who engaged in discussion of their own experiences with the center.

- Survivorship Program- Jeffrey Peppercorn, MD & Elyse Park, PhD presented details on the Survivorship Program offered to patients in the Cancer Center. The survivorship program focuses on promoting the health and wellbeing of patients with cancer following the completion of treatment. PFAC members were very involved in giving feedback on their own experience after completing treatment and the importance of the program for patients.
- Online Research Resource for Patients- Jeanhee Chung, MD & Holly Parker presented on the current on line research resources available for patients. The presenters were interested in the feedback from PFAC members regarding the existing process and ideas on how to improve accessibility of resources and involvement in studies for patients in the future.
- Patient Navigation at MGH Chelsea- Silvestre Antonio reviewed the patient navigation process at MGH Chelsea for Cancer Patients. Patient Navigators work closely with their patients to identify barriers and improve access for this vulnerable patient population. Each navigator aids in the timely coordination and completion of appointments while acting as an advocate for the patient's wellbeing.
- Psychiatry Onc- Joseph Greer, PhD and Carlos Fernandez-Robles, MD presented an overview of the current Psychiatric Oncology program at MGH. The program focuses on improving treatments and outcomes for patients suffering from psychological distress in the cancer treatment setting. Their team focuses on research and care of patients with depression, anxiety and other mental health issues. PFAC members engaged with questions and feedback on how to improve awareness and resources for family members of patients as well as the patients themselves.
- Caring for a Cure- Sara Stevens and Laura White introduced the PFAC Committee to the amazing things being done for patients and families by Caring for a Cure. The program was founded in 2011 by the nurses of the Adult Hematology/Oncology and Bone Marrow Transplant program. Caring for a cure provides patients and families with small and large comforts during their cancer journey. Members were touched by some of the opportunities their charity provides including lodging for family members, spa treatments and makeovers for patients, even a wedding was organized and performed for a patient being treated at MGH.

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- Severe Mental Illness and Cancer Center Patients- Kelly Irwin, MD. Discussed presented on how the Cancer Center approaches the care for patients suffering from severe mental illness in addition to a cancer diagnosis. Dr. Irwin is committed to the goal of improving the care patient through facilitating access to a social worker who can advocate for the patient's needs and make the challenges of the diagnosis and the treatment clearly communicated and organized.
 - MIT Project Launch- Beth Souza presented a new scheduling initiative being introduced to the Cancer Center to reduce patient delays in Infusion. The Cancer Center has partnered with MIT to create a specific algorithm which calculates most appropriate infusion times based on the availability. PFAC members were asked for feedback on best methods to communicate this new change to our patients and asked their thoughts/concerns with the new process.
 - Task Force Report on Enhancing Patient Connection to Cancer Resources-PFAC Task Force reported on the team's recommendations for enhancing patient connection to cancer resources: 1. Communication is most effective through relationships, 2. Systematic and collaborative approach to communicate all treatment programs and 3. Innovation. MGH Operations team will review the recommendations and make plans to find ways to implement for the upcoming year.
 - CAR-T Cellular Therapy and Lymphoma Clinical Trials Program- Dr. Jeremy Abramson discussed the unique approach of cellular therapies, particularly the CAR-T Cellular Therapy and Lymphoma Clinical Trials Programs. CAR-T cell therapy involves drawing blood from patient and separating out the T cells. Genetically engineered T cells are then produced and returned to the blood to attach to the tumor cells and help the body recognize and kill cancer cells. Dr. Abramson's research is focused on clinical trial development, laboratory investigations to optimize treatments and CAR- T cell technology and eventually to build our own CAR- T cells for clinical investigation.
 - Tour of Center For Cancer Research- PFAC members participated in a full tour of the Center for Cancer Research at the Charlestown Navy Yard. Nick Dyson, Scientific Director, presented an overview of the Center where members were introduced to some of the key researchers and specific areas of interest. PFAC members learned about the ongoing research in the Circulating Tumor Cell Lab, Molecular Therapeutics Lab, and the High Throughput Screening Lab for 1,000 Cell Lines; PFAC members received a hands-on tour of the labs with some of the research PIs including, Cyril Benes, Aaron Hata and Shyamala Maheswaran, MD.

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- Global Health Care Efforts- Jim Cusack, MD presented on Global Health efforts in Uganda. An oncology unit was developed for both adult and pediatric cancers using philanthropy for support. Tom Randall, MD presented on Global Health initiatives in GYN Oncology in Africa and presented data on the global burden of cancer. PFAC members were impressed with these MGH efforts to improve the quality of cancer care in Africa.
 - Research to Improve Breast Cancer Quality of Life- Ian Solsky, MD presented on research in the Dept. of Surgery focused on communications with patients with breast cancer. One research grant focused on providing patients with real-time information on disease prognosis and outcomes. The other grant focused on using an app for real-time support for patients with breast cancer throughout their cancer journey. PFAC members provided a lot of feedback on the utility of data about outcomes and whether patients would be honest. The app was well-received.
 - Living with Cancer Book- David Ryan, MD & Vicki Jackson, MD presented members of PFAC with their new book, "Living with Cancer". Dr. Ryan and Dr. Jackson have partnered their knowledge and experience together to offer a "How To" comprehensive guide on coping and living with the diagnosis of Cancer. Members each received a copy and discussed some of the common issues and perspectives reviewed in the book.
 - Cancer Center Addiction Programming- Carlos Fernandez-Robles, MD and Helen Shih, MD presented on the difficult journey for patients suffering from cancer and addiction. They discussed a new monthly Tumor Board that brings together multidisciplinary providers from Psychiatry, Social Work, Palliative Care, Cancer Oncology, and Addiction Services to discuss best approaches for both cancer and addiction treatment.
 - Antibody Drug Conjugates Targeted Against Triple Negative Breast Cancer- Dr. Aditya Bardia, MD, updated the PFAC committee on the promising results of research regarding antibody drug conjugates targeted against triple negative Breast Cancer. This type of treatment contains an antibody linked to a chemotherapy and can deliver significant doses of medication to cancer cells while helping to keep normal cells healthy. Dr. Bardia's research is making significant strides in improving the treatments options available to breast cancer patients.
 - EPIC Exam Reminders in Radiology- The director of Clinical Operations in Radiology, Mary-Theresa Shore, discussed new efforts being made to improve appointment reminders and the exam experience for patients coming in for radiology testing. The radiology team is prioritizing contacting patients before their visit by

either an automated phone call or direct contact from a staff member to discuss specific screening questions, and text messages for appointment reminders and questions.

CONFERENCES: As part of its mission to educate others about the value and role of PFACs, members participated in several external forums. During FY2017, members participated in the following forums:

- Cancer Center's Annual Conference for Patients and Families- October 2016
- 2016 Survivorship Conference: Sustaining Hope and Cultivating Resilience—The Emotional Impact of Innovations in Cancer Therapies
- National Patient Safety Foundation Webcast – March 2017
- Partners Patient Experience Summit- April 2017
- Support Staff Luncheon- May 2017
- Cancer Center Oncology Dinner Discussion- June 2017

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 Quality & Safety Committee
- Cancer Center Patient Education Committee
- Cancer Center Ether Dome Challenge

LOOKING FORWARD

As FY18 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.

CANCER CENTER PFAC BYLAWS

MISSION STATEMENT and PURPOSE

MISSION STATEMENT

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

PURPOSE

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

MEMBERSHIP

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

QUALIFICATIONS

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

SELECTION

Patient and family member representatives are nominated by a Cancer Center staff member, PFAC member or clinician as part of a formal recruitment process that is comprised of the following components:

- Completion of an application form created specifically for the Cancer Center PFAC.
- PFAC staff leadership reviews membership applications, evaluates candidates based on the above qualifications, interviews each candidate via telephone or, preferably, in person and makes final membership selections.

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

TERMS

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

ALUMNI MEMBERS

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

OFFICERS/CHAIRS

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

ORIENTATION

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

ROLES

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

RESPONSIBILITIES

Members commit to:

- Adhere to all MGH policies as reviewed in the PFAC orientation, including the non-solicitation policy and HIPAA privacy policy.
- Adhere to all volunteer policies as covered in the MGH Volunteer Department orientation.
- Fully participate in monthly meetings.
- Participate in other PFAC communications, subcommittees and activities as needed.
- Be active listeners.
- Advise and collaborate with the Cancer Center.
- Be respectful.

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.

Revised January 2014

CANCER CENTER PFAC MEMBERS

MEMBER

Laura Allen
Neha Anand
Joan Archibald
Katherine Baker
Victoria Bond
Eric Buckley
Ann Buckley
Nia Chester
Bill Connors
Trudi Fondren
John Gillis
Sandra Gillis
Lee Higgins
Bernadette Macon-Bell
Philip McGranahan
Paul O'Leary
Jay Petri
Rhoda Sapers
Nikki Shepherd
Andy Vien

STAFF

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

HEART AND VASCULAR CENTERS PFAC

— *established 2007* —

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 Massachusetts General Hospital.

Our 2016-2017 quarterly meetings were devoted to 4 important topics:

- Future of Outpatient Cardiology
- Patient Experiences and Focus Measures
- Same Day Discharge after Cardiology Procedures
- Development of Inpatient Administrative Coordinator Role
- Current Opioid Crisis and MGH Response

RECENT WORK

SEPTEMBER 2016

Ami B. Bhatt, MD, FACC, Director, Outpatient Cardiology. Dr. Bhatt reviewed a brief PowerPoint presentation Future of Outpatient Cardiology, for the purpose of our meeting focusing on:

- Promoting a team approach with patient and provider always being connected
- 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?

Dr. Bhatt looked to our members to respond to the challenges with the current Outpatient Cardiology clinic set up:

- Follow up test results, staff and providers set expectations with patients as to when they can expect to receive their test results

ACTIVITIES and ACCOMPLISHMENTS

- Providers communicate to patients how they can expect to receive their test results via letter, phone, and/or Patient Gateway
- Can patients who don't require an additional visit, receive results via Patient Gateway or via a virtual call a week after their visit?
- Can patients and providers check in at set times with their provider, regarding:
 - Blood Pressures?
 - Weight?
 - Nutritional update?
- In reviewing processes in the clinic, it was discovered that EKGs were all scheduled at the same time first thing in the morning. A simple change to a staggered schedule will allow a more uniformed process for patients and staff with patients having a scheduled time to come in, and not to all arrive in the Outpatient clinic at the same time.
- How are patients informed on their wait times? Members would like:
 - Front desk staff acknowledge and apologize for wait
 - Medical Assistants keep patients informed of delays when patients waiting in exam room
- Provider apologizes when entering exam room. Creating a team for patient care. Nurse Practitioner and Cardiology group work together providing consistencies for patients and handoff to the new fellow for continuity of care. Reduce burden on the "new" fellow regarding patient history.

Members of the committee also offered the following suggestions for the Outpatient Cardiology practice:

- Offer tutorial for patients regarding accessing Patient Gateway, not all patients are computer savvy:
 - Suggested front desk staff provide assistance with setting up access and troubleshooting access concerns patients may have
 - Patients may not be aware that they can request prescription renewals, cancel appointments, review test results
 - Encourage patients to be more accountable

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- Pilot a questionnaire prior to appointment to providing a starting point for the visit with specific questions, sending either via postal mail or patient gateway
 - Concern with visit summary in Patient Gateway was mentioned, currently this report is not seen as having value
 - Challenges of documenting in Epic was discussed, providers may “delete” the message and type in a brief summary of the visit
 - Scheduled virtual visits may not be the best approach for all patients.

Dr. Bhatt shared that the Cardiology Outpatient clinic is undergoing extensive re-organization and that the EP/Arrhythmia Lab, Heart Failure, and Transplant will all be moving to Yawkey 5 over the next 18 months:

- Creating an infrastructure of collaboration of providers, RN's, NP's, medical assistants and administrative assistants.
- Dr. Bhatt will revisit our PFAC for patient/family perspective as restructuring continues.

DECEMBER 2016

Mary O. Cramer, Organization Effectiveness and Chief Experience Officer shared detailed information on this newly created position. Reviewing 2016 Year to Date HCAHPS and CG-CAHPS Focus Measures. Survey's are sent to out to patients two weeks post discharge. They must answer “always” for the response to be counted as a positive response.

- The three main areas of focus currently are:
 - Quiet at Night
 - Medication Communication
 - Staff Responsiveness

Quiet at Night: continues to have challenges; unit Nursing Directors are consistently looking at ways to improve these scores, including providing headphones for patients who would like to watch television, closing patient doors when appropriate, and reminding staff to speak in soft low tones. One challenge that continues to be a challenge is other patients who may call out or be disruptive. Members of the group asked: could nurses stations be placed “behind glass” to decrease some of the unavoidable noises of the busy nurses station.

Medication Communication: provides opportunity to educate patients and families regarding the medication, dosage and side effects of their prescribed medications. A pilot is underway on a few units “Meds to Beds”; a pharmacist delivers the patient’s discharge medications to the bedside, providing one on one education. The pilot has been well received and will be offered on all units in the near future.

Staff Responsiveness: members reported they felt staff were attentive to their needs. However, they could understand that the response could reflect the fact that perhaps their own nurse wasn’t always the one to answer the patients call, and a PCA or OA may have. Members suggested, set expectation with patients and family that other care team members are available and that the staff work as a team. Patients are aware that their nurses are very busy and may not be aware other team members could provide assistance.

Cindy Sprogis shared some of the initiatives that are currently being undertaken to reduce noise on the inpatient units. Each unit has a designated quiet time; this is communicated to patients and families, with new posters recently being updated. Lights are turned off on units, doors are closed when possible, and minimized conversations take place at nursing stations and other areas. Encourage families to take a break to allow their loved one the opportunity to rest, offer headphones to those who would like to watch TV or listen to music. Ask family members to make phone calls only in designated areas and away from patient rooms and clinical interventions will be minimized. Recently the electrical shop installed plates at light switches to designate which lights should be turned off during quiet time. New food carts were recently purchased and unfortunately are quite loud; new wheels are being installed by building and grounds.

Quiet time’s scores are higher in Lunder, due to the new building and all rooms being private. Older buildings have more unpredictability due to two bed rooms and older “acoustics”. Units with cardiac monitors also factor into to both quiet times and quiet at night.

Some of the unit specific opportunities include:

- Placing foam crates in the landing of the pneumatic tube system
- Replacing missing quiet time posters and rooms signs
- Working with Materials Management regarding stock deliveries, quiet time schedules have been provided to Materials Management
- Loud ringers on phones are being turned down at the nurses’ station

Cindy asked members of the group if “Shhhhh” signs were offensive; overwhelming the members agreed that they are not. A few suggestions to provide reminders to patients and families, included:

- Change the light color at the entrance of the unit to designate quiet time
- Volunteers to round on units reminding patients and families of quiet time, provide earphones and books to patients
- Have volunteers provide a visual “cue” perhaps sit and read in the hall way
- Encourage staff to close patient room doors when appropriate
- Install glass window in current doors, or replace doors with a glass window
- Make a check list for the Unit Coordinators to ensure lights are turned down, announcements are made and phone ringers are turned down.

Cindy encouraged the group to reach out with additional thoughts and ideas.

MARCH 2017

Sharon McKenna, RN, Nursing Director Cardiac Catheterization and Arrhythmia Labs, and Katy Wetzel, NP, Inpatient Cardiology, reviewed the new same day discharge after Percutaneous Coronary Intervention (Angioplasty and stents). How can we prepare patients?

- New program launched January 1, 2017
- Patients discharged from the Cath Lab same day as their procedure
- These are planned elective procedures, angioplasty or stent, are referral based, non urgent, diagnostic testing
- Primary benefit of same-day discharge after percutaneous coronary intervention are related to improved patient satisfaction, decreased length of hospital stay, and better resource use of health care dollars (JAMA Cardiology May 2016 Vol. 1 No. 2 p. 216)
- Patients are excluded if (any of the following): less than 18 years of age or older than 70 years of age, not staying within 60 minutes of medical care, no responsible adult to stay overnight or at discharge, unstable symptoms prior to the procedure, presence of contrast allergy, multi-vessel or high risk disease, complications

during PCI procedure, unstable vascular access site, failure to return to baseline ambulatory status, complications during recovery care, inability to secure post procedure platelet medications from pharmacy and has no provider follow-up for the next day

- Post Procedure Observation & Evaluation, post sheath (catheter in artery) removal a repeat EKG is done and reviewed with the team, discharge instructions and medications will be reviewed with the patient and family member, prescription and discharge instructions will be provided
- Patients can expect a 5 hour stay post procedure in the Cath lab.

Members of the committee were enthusiastic to learn of this new program, did express concern regarding patients going home alone. Sharon and Katy both emphasized that the patient must have a responsible adult with them and they must be able to stay overnight. They are also called the next day at home to check on them.

- Members suggested that information for patients coming in for this elective procedure starts with the referring Cardiologist. Notify patients that they possibly will go home the same day to ensure they have a ride and someone to stay with them overnight. Send a message to the patient via Patient Gateway.
- Members suggested education for referral physicians to access when scheduling patients for these elective procedures. Start the conversation in their office regarding the possibility of going home the same day.
- Members would welcome continued discussion on this subject.

Annie Elfar, MHA: Inpatient Administrative Coordinator Program, MGH Department of Medicine provided the background summary of the program, and projections for the future:

- The Department of Medicine undertook a pilot in January 2016; the program began with 1 IAC and has grown to 7 members, with increasing demand!
- The Inpatient Administrative Coordinator (IAC) work with patients admitted to medicine, cardiology general inpatient and oncology services
- The IAC decreases the administrative burden for providers and assists patients at the bedside with scheduling discharge follow up, appointments with both internal and external providers before leaving the hospital

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- Obtain faxes of patients home medication lists from outpatient pharmacy's, obtain copies outside hospital and physician records by fax (obtaining HIPAA patient consent), obtain discs of outside radiology scans and upload into the MGH system, fax discharge summaries to primary care providers outside of MGH, call hospital departments to whether a procedure is scheduled for that day, assist with prior authorizations, assist in scheduling family meetings by coordinating timing with involved inpatient and outpatient providers, booking space, attend multidisciplinary rounds for assigned teams when feasible
 - IAC document in Epic
 - Annie asked members of the committee for their input in the creating of a more definitive name for these valuable members of the care team, suggestions included:
 - Discharge Assistant
 - Discharge Planner
 - Patient Care Coordinator
 - Appointment Manager
 - Members of the committee shared the value of this role in assisting patients with appointments before they leave the hospital. They expressed challenges arranging post hospitalization care
 - Patient and families have both responded very positively to this role.

JUNE 6, 2017

Christopher Shaw, NP, Team Leader, Inpatient Addictions Care Team (ACT) discussed the ACT Consult Team, available across the entire hospital seeing more than 3150 patients with Substance Abuse Disorders (SUD's) last year. Patients seen by ACT have lower 30-day readmission, reduced addiction severity 30 days post-discharge, and increase days abstinent at 30 days post discharge.

Substance Abuse Disorders (SUDs) Initiative Mission is: To improve the quality, clinical outcomes and value of addiction treatment for all MGH patients with SUD. To accomplish this mission, patients must have access to evidence based treatment that is readily available and standardized across the system.

Members introduced themselves and included questions/concerns they have regarding substance use. On the topic of screening for substance use,

members inquired as to what happens if a patient denies substance use. Chris explained that there are still “teachable moments.”

Chris asked members their thoughts on how providers should start the conversation with patients about how much is too much drinking. Members discussed the value of patient education materials, including something with illustrations to demonstrate differences in drink sizes, etc.

Theresa asked members if there was an opportunity to make an explicit connection for patients/families between substance use and health risks. Members endorsed this approach as well.

Other questions and answers ensued on topics including:

- How Narcan works
- How drinking is acculturated
- The need to educate grade school teachers and staff about how much drinking unsupervised youth are engaging in at home
- Stigma (e.g. don't see substance use/overdose as cause of death in obituaries)
- Length of time it takes for someone to become addicted
- Number of patients who recover (most do).

Chris also asked members for suggestions on how to handle lack of privacy in 2 bed rooms when addressing substance use issues. Members endorsed Chris' suggestion that providers request patients' visitors step-out of room for 10 minutes to increase patient privacy.

Members voiced need for increased patient/family education, particularly relating substance use to health conditions, e.g. endocarditis (infection of heart valves) and arrhythmias such as Atrial Fibrillation. Members suggested use of picture boards and/or videos on tablets that could be given to patients in the hospital or in waiting rooms.

HEART and VASCULAR CENTERS

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

HEART CENTER and VASCULAR CENTER PFAC BYLAWS

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 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 acknowledgment 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 two-year term to council members
- At the end of a two-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:

a. MGH HVC:

MGH HVC Co-Directors, Program leadership and staff

- 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

b. MGH HVC PFAC Members:

Mass General Staff: Mass General staff will be appointed by the MGH Heart Center Co-Directors 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.

c. 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

d. 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
- 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

e. 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

f. Trustees Patient and Family

- Complete Mass General volunteer program application and on-site orientation

ATTENDANCE

Members attend quarterly meetings with dinner

Location: MGH Trustees Boardroom

Time: 5:30 PM to 7:00 PM

.

MASS GENERAL HOSPITAL *for* CHILDREN FAC

— *established 1999* —

The MGHfC FAC continues to foster partnerships between patients, parents and professionals to improve the hospital and enhance patient and family-centered care. In 2016-2017 it attained its goals of supporting parent to parent efforts by participating in a NICU peer mentor program, increased parent member participation on hospital committees, developed patient and staff education most notably in the form of a video to help reduce stress for children who are waiting in the Emergency Department and aligned with the hospital's Patient Experience efforts with parents helping to develop and facilitate staff trainings.

PRESENTATIONS and FEEDBACK

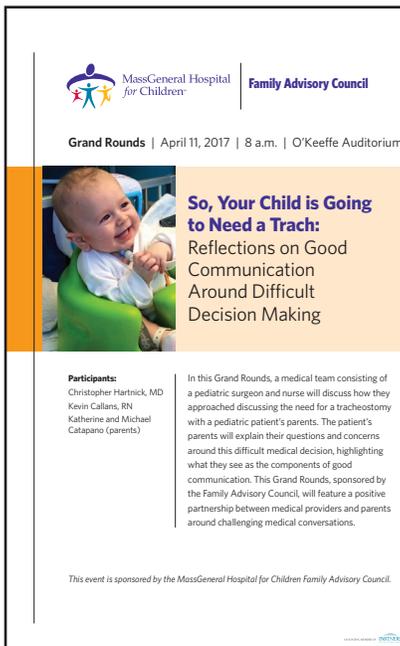
- Provided feedback to Kevin Callans, NP, who presented about the Parent to Parent program she developed for parents whose children have undergone tracheostomies.
- Two FAC members reported back to the group after presenting a poster at the Institute of Family-Centered Care's International Conference that outlined a staff training in courtesy and helpfulness in which FAC parents had participated. The staff training resulted in higher hospital C-GCAP scores in courtesy and helpfulness.
- Provided input to Karen Turner, MGH Patient Navigator, who plans for and accompanies patients who carry a diagnosis of autism during their appointments and in-patient stays.
- Eve Megargel, a parent member of FAC, gave a presentation to our group on her newly published book titled 'Learning to Kiss' about her son who is a young adult with autism treated at MGH.
- Learned about the work of Annie Brewster, MD, MGH physician and founder of the Health Stories Collaborative who discussed her work on the importance of storytelling around illness.

PATIENT and STAFF EDUCATION

- Provided the parent perspective to Dr. Jeanne MacDonald and Sandra Stokes, LICSW who spoke about their work developing a Perinatal Bereavement Program at MGH.
- Developed a Grand Rounds that was presented on April 11, 2017 titled 'So Your Child is Going to Need a Trach: Reflections on Good Communication Around Difficult Decisions' featuring an ENT Surgeon, Nurse Practitioner, and parents whose infant underwent a tracheostomy discussing their decision-making process before the procedure.
- Three parent members spoke to pediatric interns in a session titled "Introduction to Bedside Rounding" explaining that bedside rounding is an important way for them to ask questions and partner in their child's care.
- Sandra Clancy, Co-Chair of the Family Advisory Council, co-presented a workshop titled 'Harnessing the Power of the Patient Voice' at the annual conference of the Association of Pediatric Program Directors that demonstrated how video of patient presentations is a powerful tool in medical education and used video of pediatric patients speaking at FAC Grand Rounds in 2016.
- Darcy Daniels, FAC Co-Chair, was a panel speaker at the Partners Patient Experience Summit and noted the importance of her work on the FAC as a way to improve the hospital.
- Two parent members and their children who are pediatric patients at MGHfC spoke about their experiences to a dinner hosted by the MGHfC Advisory Board. The two teenage patients provided insight into what they learned when they were patients and shared advice for clinicians treating children.
- Wendy's Welcome, a video developed by a pediatric patient and her mother who is a FAC member was featured on several news outlets. Its purpose is to introduce pediatric patients to the Emergency Department and help them to relieve anxiety about what will come next. The video was featured in news stories on WCVB, CBS Boston (Malika Marshall), Boston Magazine, Patients' View Institute, Chronicle, STAT News, and Healthcare Design Magazine.



OTHER ACTIVITIES



MassGeneral Hospital for Children | Family Advisory Council

Grand Rounds | April 11, 2017 | 8 a.m. | O'Keefe Auditorium

So, Your Child is Going to Need a Trach:
Reflections on Good Communication Around Difficult Decision Making

Participants:
Christopher Hartnick, MD
Kevin Callans, RN
Katherine and Michael Catapano (parents)

In this Grand Rounds, a medical team consisting of a pediatric surgeon and nurse will discuss how they approached discussing the need for a tracheostomy with a pediatric patient's parents. The patient's parents will explain their questions and concerns around this difficult medical decision, highlighting what they see as the components of good communication. This Grand Rounds, sponsored by the Family Advisory Council, will feature a positive partnership between medical providers and parents around challenging medical conversations.

This event is sponsored by the MassGeneral Hospital for Children Family Advisory Council.

- Voted in a new parent Co-Chair.
- Added 5 new parent members.
- Updated the website to include committees on which parent members serve, staff members and activities.
- Discussed and finalized a list of priorities for the upcoming year. Analyzed progress made on priorities for the previous year. They are, in order of priority:
 - Support parent to parent networks throughout MGHfC
 - More FAC parents on hospital committees
 - Patient and staff education efforts
 - Further alignment with patient experience efforts
 - Organize a family-centered hero award
 - Focus on transition to adult care
 - Relationship with Office of Patient Advocacy
 - Outreach to MGH healthcare centers for recruitment
 - Create language for parents around patient safety
- In response to parent member's observation that pediatric patients do not fit properly in MGH's adult wheelchairs, FAC and the Pediatric Cancer Center PFAC spearheaded an effort and the hospital purchased 12 pediatric wheelchairs.
- Initiated a parent member recruitment drive. Steps taken include creation and putting up recruitment posters, providing letters to each Unit Chief at MGHfC so that they could target 5 to 10 families and educate them about the FAC, and having the FAC Co-Chair make a presentation to the monthly Unit Chief's meeting.
- FAC Co-Chairs participated in conference call with members of a new MGHfC Parent to Parent group whose mission is to provide support to families whose children have Irritable Bowel Disease and gave information about our group's formation, development and mission.
- Several members participated in the hospital's annual Santa's Workshop gift wrapping event that provides gifts for families of children whose hospital stays take place over the holidays.



Want to Get Involved? Participate in the Family Advisory Council

The Family Advisory Council is dedicated to the continuous development of a positive partnership among parents, children and staff to ensure the needs of children and families are met during their experience at MassGeneral Hospital for Children.

The council is composed of family members, hospital leaders and patient-care staff who work together to:

- Promote family-centered care
- Focus on improved quality in care
- Serve in an advisory role to hospital leadership
- Develop educational materials for families
- Serve as a link from the hospital to the community

For more information about our projects, how to get involved or to apply to become a member, please email FAC@partners.org or visit www.massgeneralforchildren.org/FAC.



MassGeneral Hospital
for Children

- Created a binder for new members that contains photographs of all members of the group and brief biographical statements, copy of the bylaws, yearly list of accomplishments, and the committees on which parents serve.
- Collaborated with the Director of Volunteer Services to enable parent members to undergo volunteer orientation on-line. Now members receive HIPPA training, safety instruction, and orientation on-line.
- The Co-Chairs interviewed candidates for the position of Nursing Director on Ellison 17 and 18 and provided their feedback to the group directing the hiring process.
- Committee formed with the goal of improving the parent experience in the PICU when a child has a long stay in the Unit and has reviewed existing patient education material in the PICU and is developing more comprehensive material that will be prominently displayed.
- Collaborated with MGHfC's Ambulatory Patient Experience Committee which developing a 'Secret Shopper' form enabling parents to complete an on-line survey immediately after an appointment with a provider at MGHfC. FAC parents will pilot the form when it is complete.
- Planned with the Ambulatory Patient Experience Committee that is preparing training material for staff around improved courtesy and helpfulness and will engage FAC parents in the trainings.
- FAC will participate in MGHfC Day at the Massachusetts Statehouse on November 14, 2017. This is an opportunity for members of the Massachusetts delegation to learn more about the hospital.
- FAC member who is a PICU nurse initiated a program in the Unit in which the medical team rounds on adolescent patients, allowing adolescent patients to discuss their care with the entire team.

PARENT PARTICIPATION IN HOSPITAL COMMITTEES and TASK FORCES

- MGH Quality Oversight Committee
- MGH Gun Violence Prevention Committee
- MGHfC Ambulatory Patient Experience Committee
- MGHfC In-Patient Experience Committee
- MGHfC Ethics Committee
- MGHfC Advisory Board
- MGHfC Pediatric Wheelchair Committee
- MGHfC PICU Parent Life Committee

MASS GENERAL HOSPITAL FOR CHILDREN FAC MEMBERS



PARENT MEMBERS

Seta Atamian
Debby Cartisser
Lisa Cimino
Darcy Daniels (*Co-Chair*)
Michael Doiron
Charlene Harper
Roxanne Hoke-Chandler
Cindy Matuszewski
Matthew McGuinness
Janice Morris
Eve Megargel
Erin Quinney
Randi Stempler

STAFF MEMBERS

Sharon Badgett-Lichten
Debra Burke
Monic Chardin
Sandra Clancy (*Co-Chair*)
Anne Fonseca
Kate Gerne
Peter Greenspan
Esther Israel
Karen Manning
Jessica Mascola
Sandra Dodge McGee
Eleanor McLaughlin
Anne Pizzano
Alexandra Sobran
Kim Whalen

MASS GENERAL HOSPITAL FOR CHILDREN FAC CHARTER/BYLAWS

1. MISSION STATEMENT:

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

2. PURPOSE:

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

3. MEMBERSHIP COMMITTEE:

- 3.1. Members of the Membership Committee will be appointed by the MGHfC Associate Chief, Department of Pediatrics;
- 3.2. The Membership Committee will consist of three current FAC members and two MGHfC Council members;
- 3.3. Members of the Membership Committee will track membership terms and actively recruit new members.

4. MEMBERSHIP:

- 4.1. Membership is by application to the Membership Committee;
- 4.2. Membership consists of fifteen people whose children have received care at MGHfC or are patients sixteen years or older who have received care at MGHfC;
- 4.3. Family members will serve as the Council Co-Chairs;
- 4.4. The MGHfC 's Medical Director, Associate Chief Nurse of Pediatrics, Executive Director, and Inpatient Director of Quality and Safety will be ex-officio members;
- 4.5. The MGHfC Inpatient Director of Quality and Safety will be allowed to vote in times where a tie-breaking vote is required.
- 4.6. The MGHfC will have four rotating staff members of the Council;
- 4.7. Other MGHfC staff will attend meetings as needed and receive meeting minutes approved by the Council to have knowledge regarding the agenda and on-going work.

5. MEMBERSHIP TERMS:

5.1. Each year in September, the Council will seek to appoint three family members to serve a three-year term to the Council;

(Beginning with the Council in 2007, the 9 appointed family members will be appointed to one, two, and three year terms, the same with the 3 MGHfC staff);

5.2. Members can re-apply for appointment for up to six years. After this time, members can still be active on committees but must wait three years before reapplication to be a member of the Council;

5.3. Membership will elect in March a Council Co-Chair for a two-year term with co-chair election to follow six months later.

5.4. Any Council member that misses four consecutive meetings will be considered an inactive member unless the absence has been approved by the Membership Committee;

5.5. If a Council member cannot fulfill his/her commitment to the Council, they can resign in writing and a new member will be chosen to serve the balance of his/her term.

6. MEMBERSHIP RESPONSIBILITIES:

6.1. Participate in the formation and evaluation of FAC yearly goals and objectives and be an active participant in Council activities;

6.2. Prepare for and attend meetings;

6.3. Be an advocate for all patients and families by identifying and representing their needs and concerns;

6.4. Maintain patient confidentiality according to HIPPA guidelines at all times;

6.5. Consider serving on other MGHfC committees when requested;

6.6. Support the MGHfC publicly;

6.7. Notify the Co-Chairs if unable to attend meetings;

6.8. Agree to attend the Volunteer Program Initiation and Training as well as participate in the Volunteer Program;

6.9. MGHfC staff members will act as the hospital liaisons to the Council.

7. CO-CHAIR RESPONSIBILITIES:

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

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

7.3. Set meeting agendas and schedules;

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

7.5. Appoint subcommittee chairs, who will be responsible for:

- updates of the subcommittee work to the Council at regular intervals;
- goals and objectives for the subcommittee;
- annual reports of the subcommittee.

8. MASS GENERAL 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.

PEDIATRIC ONCOLOGY FAC

— *established 2003* —

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 have 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 and enhancing the patient experience.

OBJECTIVES

- 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 clinic's operations and programs
 - Enhance the Advisory Committee member's role as a change agent within the practice
- Collaborate with other PFAC's and integrate into the already established 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
- 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 specific 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 and promote members' participation.

This year the Committee honored 4 members of the Committee who departed after several years of service. Another Committee member took a hiatus from the FAC to care for her ill child. Subsequently, the Family Advisory Committee also welcomed 5 new enthusiastic parents to the membership of the Committee. Clinical staff participation remained constant.

ACTIVITIES and ISSUES

- Family Advisory Committee members initiated a meeting with MGH Nursing Leadership to discuss concerns related to port-a-cath access in the Emergency Department for pediatric oncology patients. Members of the Emergency Department leadership and staff along with multiple stakeholders within MGHfC convened in ongoing problem solving to address this issue. New ED nursing staff participate in training within the Pediatric Oncology clinic where they learn approaches and techniques for port access with young patients. Standards of practice and care have been revised and tools for communication between the Pediatric Oncology clinic and ED have been put into place. Continued planning within nursing administration about improving the competencies of the ED nurses in this arena.
- Completion of a Patient/Family Education Center within the clinic's waiting area. This area includes dedicated space for our Adolescent and Young Adult patient population. Resource materials, technology and a quiet space are offered for researching and learning about childhood cancer, coping with treatment and optimizing support and care for children during their therapy. The Family Advisory Committee provided guidance throughout the development of this center.
- The Family Advisory Committee met with David Ekrem, Web site developer to discuss enhancements to the Pediatric Oncology web site. Goals and timeliness were established for the Pediatric Oncology team to implement changes to enhance the site and better reflect the achievements of the team and programs available within the clinic's practice. Clinical staff continued to consult with the FAC as changes continue to be made.

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- Continued implementation of the Mass General Pediatric Oncology POPS – Parents offering Parents Support program. The Committee has offered guidance in marketing the program and how best to engage families’ participation. Promotional materials were created with the input of the FAC (see photo attached), which are now added to new family information provided at the time of a child’s cancer diagnosis.
 - Development of the Pediatric Wheelchair initiative. One Committee member who brought the concern forward participated in all the planning meetings and reported back to the FAC for their input and guidance. In July 2017, 11 customized Pediatric Wheelchairs were made available in the outpatient pediatric practices as a pilot project to enhance the comfort and safety of pediatric patients.
 - Collaboration with Cancer Center Administration to extend the hours of the Healing Garden to offer a place of respite and comfort both later in the day and on the weekends for pediatric patients and their families who are in the hospital. Reviewed policies which limit patients and families from having access to the Healing Garden when other programs are utilizing the space. Development of more inclusive policies to support patient and families.
 - Dr. Howard Weinstein, Chief of the Pediatric Hematology-Oncology unit joined the April 2017 meeting of this Committee providing updates around pediatric cancer research, growth and operations of the clinic practice. Dr. Weinstein’s participation in the Committee validated the importance of the Committee within the practice and provided an opportunity for face to face communication around issues of parents’ concerns.
 - Tracking of Patient Experience Data and input offered by the Committee around clinical improvements

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- Continued review of eCare implementation and impact on patient/family's perceptions of care.
 - 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.

PEDIATRIC ONCOLOGY FAC MEMBERS

PARENT MEMBERS

Mary Cincotta
Michael Doiron
Patricia Flaherty (on leave)
Susan Jacobson
Kim Kayajan
Mary Koperski
Michelle McKiernan
Peter Palamidis
Sabrina Pettinicchio
Dawn Regan (Co-Chair)
Jerry Schindler
Janice Theriaque
Tarrah Zedower

STAFF MEMBERS

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 is 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.

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- 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 can 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 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 5 times a year, 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 attend the meetings, and make a reasonable attempt to participate in meetings outside the usual schedule.
- Participate in MGH Pediatric Oncology community programs 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.

APF CARE ALLIANCE

— *established 2010* —

BACKGROUND

The Ambulatory Practice of the Future (APF) delivers primary care services to Mass General employees and their adult dependents. The APF has proven to be an innovator and leader among practices, differentiating itself by delivering patient-centered care in a team-based setting.

The Care Alliance (CA) is the APF's Patient and Family Advisory Council. It is a partnership of patients, family members, and providers, which promotes the voice of the patient, innovation, and the optimization of the care experience for all. It was founded several months before the APF practice opened in August 2010, to guide it from the start.

The APF staff members value partnership and transparency with patients and each other. The APF feels so strongly about transparency that it has service-marked TransCAREncySM for use by the MGH community. This term means promoting transparency in all the ways that the APF cares for its patients. Patients are asking for more from their relationships with their care teams and for better access to the information created about their care (this ranges from providing them with their visit notes and other medical information, to easier-to-understand billing statements, to greater collaboration between ambulatory and inpatient care teams and care plans).

The practice partners with patients by offering electronic communication, unrestricted access to test results and visit notes, and continuous care, as well as health coaching to help patients better manage and achieve their health, life-balance, and wellness goals. The CA proactively partners with staff to ensure that the care experience is rewarding for patients, patients' families, and staff, as well as to promote values that define the APF and support those values while the practice expands.

During the developmental phases of the practice, the APF relied on substantial patient- and family-member input for planning the practice and for creating the structure necessary for APF and the CA to support each other. As the practice grew initially, it called on the CA to help monitor implementation of the patient-centered model while generating and supporting opportunities to promote innovation. As demands and

pressures on staff increased, patients on the CA worked more pro-actively, surveying patients about their care experience and circling back to them with survey results and the APF's reaction to their suggestions.

The need to communicate information to patients remains important as a way to help them become more engaged in their own health care. The CA assesses means of communicating with patients and has made progress toward utilizing new venues, including social media, to deliver information to APF patients and the Mass General community. We believe that keeping patients better informed about relevant clinical information, as well as practice- and hospital-based news, is vital, especially in anticipation of continued organizational change. Doing so will further APF's goals to offer care that is based on transparency and partnerships.

Communication is a two-way street. Hospital-wide surveys, like CG-CAHPS, are one way that patients provide feedback about their care experience. Delivered at the practice level, these scores reflect patient satisfaction about various functions and services, for example: wait times, physician knowledge of patient history, willingness to refer to others, receiving coordinated care, having access to care team, having enough time during an appointment to cover all their issues, feeling respected by clinicians and team members, ease of understanding physicians' explanations of conditions and treatments, etc. The practice takes the results of these surveys very seriously and works hard to improve care.

Since the practice opened, the CA has been an integral part of the APF. The CA is excited by the continued opportunities to work with an open, supportive, and caring staff to promote the innovative patient-centered model of care with APF patients and the larger Mass General community. We also believe our efforts play an important role in helping to manage the changes and challenges that are part of current health care.

REFLECTIONS ON SEVEN 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 remained mindful of the ever-changing nature of health care and the very real limits on everyone's time. The CA streamlined its meeting structure and simplified its role to focus on brief, important communications to the APF patient population. The importance of using multiple communication vehicles became evident, and social media was added as a way to provide an easily accessible communication link between staff and patients, to keep patients better informed about relevant clinical news, information, and changes at APF, as well as broader Mass General changes impacting APF (e.g., EPIC and MyChart).
- **Year 6:** The CA reinvented its role in advocating for the excellence of the practice throughout Mass General and health care at large; built relationships and community between staff, patients and PFAC; and created innovative communication practices to better enhance APF's patients' experience and become an effective Voice of the Patient.
- **Year 7:** The CA continued to evaluate its goals and role in communicating with patients, and is striving to implement a comprehensive menu of communication tools. We have also invited new CA members whose strengths in data, patient information, media, and more help us to find solutions to being a relevant voice to our patients.

2017 GOALS

As the year comes to a close, the practice is again opening its doors to new employee patients and their adult dependents. In a hospital system where many, if not most, primary care practices are closed to new patients, it's exciting that the APF has hired new clinicians and expanded access. This new capacity, which brings new staff, patients, and energy signals growth and opportunity for the practice, but is also a change from the tight-knit, intimate nature of the original team.

The healthcare environment continues to be challenging for primary care. The uniqueness of the APF does not prevent/protect it from the impact of time and income pressures --- pressures that may be compounded given that the majority of our patients are dealing with them during their work hours, as employees. And while the APF is a practice committed, from inception, to team-based care and an extraordinary experience for patients, these commitments need constant attention and energy. As such, the practice and CA try to be protective of our commitment and temper the impact of pressures like reduced budgets, increasing patient panels, laborious medical record-keeping, and limited time resources

The CA continued to focus on engaging patients, supporting staff, building community, and contributing to practice outcomes. We know that clinicians and staff who feel valued, who have adequate time to see patients and do required follow-up tasks, and who work at the top of their license are essential to creating an extraordinary customer experience. We also know that patients who understand their position at the center of the care team are most engaged in their health and perhaps most receptive to CA initiatives. In-depth patient feedback (via surveys) to improve the care experience and stimulate innovation in the practice is important to our work, but it's dependent on ease of administration as well as a responsive audience, neither of which is easy to obtain.

In addition to its broad purpose of engaging patients, supporting staff, and contributing to practice outcomes, the CA's identified the following specific 2017 priorities, developed in response to staff, leadership, and Care Alliance member input:

1. Build a strong, effective team to represent the voice of the patient and make an impact on patients and practice
2. Introduce a patient newsletter
3. Assist in creation/administration of supplemental surveys to gather information on patients' care experiences
1. Create Vidscrips (short, single-topic videos about health conditions and treatments)

YEAR IN REVIEW

1. Built and grew a strong, effective Care Alliance

- We added several new members: the past two years have seen significant turnover in the CA membership. Two founding members retired after many years of service, one member finished her term, and one was unable to fulfill her term.
- We engaged clinicians and staff in identifying potential candidates whose skills dovetail with needs of the CA (survey creation, data analysis, patient information, etc.)
- Three new members have joined the CA. A mix of formal and informal team-building opportunities have brought the new members up to speed and helped them to contribute substantively.
- We will encourage staff to recommend patients who are family members of employees to sit on the CA, to even out the balance of employee and non-employee members.

2. Introduced The LINK patient newsletter

- The LINK was first produced in the spring (see attached) after thorough discussion about its purpose and value.
- The initial goal was to inform patients about practice happenings, highlight staff members, educate about good health practices, etc. The first edition was provided in printed form only and made available in the lounge at the APF.

THE LINK
Your APF Care Alliance

A partnership of patients, family members, and providers that promotes innovation and the optimization of the care experience for all.

The LINK is a new quarterly newsletter, written by patient members of the Care Alliance, to be the voice of patients and staff, and to improve communications between us all. You, the patient, are the most important link in your health care, and we want you to be an informed and active participant! Here you will find out what's happening in your medical home—get to know your care team, learn health and wellness tips, and understand the impact of changes at the MGH and Partners.

Meet Ben Crocker, Medical Director

Ben Crocker, MD, has been the Medical Director of the APF for three years. Did you know that he climbs big mountains (Kilimanjaro), has run marathons for fun and fund raising (Boston), loves genealogy and a capella singing, and one of his favorite foods is home-made arugula, beet, and goat cheese pizza?

Ben has clinical training and expertise in team-based care, point-of-care technologies and health coaching in primary care. He has also been instrumental in introducing innovative medical technologies at the APF and Mass General. And, Ben co-founded the APF's Innovation Learning Program, which seeks to improve patient care with technology.

He went into medicine (MD from University of Massachusetts) and completed his residency in internal medicine at Boston Medical Center (as chief resident), including an additional year of instruction and research in India.

Ben is passionate about how teams leverage technology to enhance the patient experience and operations of clinical care. The most important thing about delivering care to MGH employees is to help them see their challenges not as "problems," but as opportunities for improving health and wellness.

Ambulatory Practice of the Future Care Alliance
A patient-provider partnership that promotes the voice of the patient, innovation and optimization of the care experience for all.

How Was Your Care Experience Today?

Patients on the APF Care Alliance developed this survey to keep your care experience an excellent one. Your honest and critical feedback will be reviewed anonymously by APF's Care Alliance. Please return this form to the front desk. Thank you!

1. I received the health care in the way I wanted and needed.
 Strongly Agree 5 4 3 2 1 Strongly Disagree

2. What was the best aspect of your care experience?

3. What might we do differently to make the care and service we provide you the best possible?

Want a voice in keeping your health care a great experience? Consider joining APF's Care Alliance. Ask the greeter for a Care Alliance Information sheet.

- Logistical barriers to providing the newsletter to each of our 4200 patients caused us to change the focus of the newsletter to a strictly clinical one, so that we could take advantage of mailing it through the patient portal (where a clinical message is required). This still does not allow us to reach more than one-quarter of our patients (they must be active users of the portal), but was deemed the most reliable venue. We are hopeful that the access will increase.
- The second edition (see attached), produced in the summer, was emailed through the patient portal. We received positive feedback and plan to track penetration in the future.
- The newsletter is posted on the APF website, and content was chunked for use on social media
- We will aim to produce the newsletter on a quarterly/seasonal basis.

3. Surveyed patients about their care experience at the APF

- As a way to be a viable voice of the patient, we looked for innovative approaches to access feedback about their care experience.
- We worked with the staff to write a brief survey that would be administered via electronic tablet in the office, by staff, during/after a patient appointment.
- The survey was designed to provide more pointed and immediate feedback than other required surveys.
- It was difficult to insert this survey into the workflow. Resources were limited, as were results.
- We will continue to explore viable innovative approaches to gathering patient feedback.

4. Contributed to vidscrips library

- We have posted several vidscrips to inform patients about the CA and as an introduction to the practice, becoming a patient, and the patient portal. "Scripts" for these introductory segments have been updated, and will be filmed in the near future.
- A series of clinical topics has been identified. Clinicians will write scripts and involve CA members as appropriate.

-
- Topics include: stress management, EAP, cold/flu, asthma, allergies, tick-borne illness, sun

5. Participated in focus group

- The Foundation for Informed Medical Decisions ran a focus group with the CA to evaluate our (as patients) receptivity regarding various modes of outreach from health care providers.

AMBULATORY PRACTICE OF THE FUTURE CARE ALLIANCE MEMBERS

The CA leadership remains patient-driven. In 2017, CA leadership continued to be shared by two patient members, Paul O'Leary and Julie Martin. Due to staff restraints, the monthly meetings were reduced to bi-monthly meetings with CA meeting on their own on the "off" months to ensure continuity and project momentum. Patient members facilitate meetings on a rotating basis and communicate between meetings to brainstorm and work on action plans. The CA continues to use Rapid Action Teams, when necessary, to deliver urgent, pragmatic, problem/opportunity focus that produce action-oriented results. CA 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.

PATIENTS

Paul O'Leary (*Co-Chair*)

Julie Martin (*Co-Chair*)

Nancy Davis

Ann Erwin

Robert Evans

Jarrett Maggio

STAFF

Lakeya Bryant

Mary Jane Byrnes

Tina Byrnes

Ben Crocker, MD

Theresa Egan

Maryann Feliciano

Annie Helgason, MD

Dan Henderson, MD

Aaron Hoffman, MD

Jessica Hu, MD

Cassandra Laine

Stephen Lynch

Jane Maffie-Lee, NP

Mary Ann Marshall

Lori Newman

Quentin Nichols

Betzaida Pacheco

Sarah Sherwood

Glenda Shuel

Ramilly Teixeira

Donna Winderl-Malyak

AMBULATORY PRACTICE OF THE FUTURE: CARE ALLIANCE BY-LAWS

ARTICLE I. NAME

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

ARTICLE II. MISSION

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

ARTICLE III. GOALS

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

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

ARTICLE IV. MEMBERS

Section 1. Roles and Responsibilities.

Advise: Work in a pro-active advisory

partnership role to enhance the patient and staff experience of primary care at the APF.

SUPPORT: Act as a sounding board for implementation of new and innovative APF initiatives and improvement of existing programs.

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

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

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

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

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

Section 2. Membership Eligibility

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

Section 3. Membership Categories

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

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

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

Active Members are expected to participate in all monthly regular meetings and such special meetings as may be called from time to time. One active patient or family member serving on the Care Alliance should attend each staff meeting. It is hoped, but not expected, that some patient or family Active Members will consider opportunities for involvement in special projects initiated by the APF or the APF Care Alliance. All Active Members must be in compliance with the requirements for Care Alliance participation and active volunteer status. 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 re-nominated 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 is specifically requested.

Section 2. Nomination Procedure

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

Section 3. Election Procedure

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

Section 4. Term

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

Section 5. Vacancies

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

Section 6. Termination

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

ARTICLE VI. MEMBERSHIP PROCEDURES

Section 1. Membership Application

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

Section 2. Application Process

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

Section 3. Leave of Absence

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

Section 4. Resignation

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

Section 5. Termination

Care Alliance members who are not fulfilling the role of an Active Member as outlined in Article IV, Section 2, having been given appropriate notice and an opportunity to fulfill the requirements, may be terminated from the Care Alliance, by a vote of two-thirds of the Active and Staff voting members via electronic vote. The APF and the Care Alliance reserve

the right to terminate any volunteer who does not uphold the APF's professional behavior standards.

ARTICLE VII. MEETINGS.

Section 1. Regular Meetings

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

Section 2. Special Meetings

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

Section 3. Quorum

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

Section 4. Voting

Only Active and Staff Members may vote on official Care Alliance business when voting is required. All issues to be voted on shall be decided by a simple majority vote of those Care Alliance members present at the meeting. In addition, election or termination of Co-Chairs and approval of revisions to bylaws require a vote of Active and Staff voting Members. Such votes may be counted by being present at meetings, submission of an absentee ballot, or submission of an

electronic ballot. In the event of a tie vote, all voting members will be asked to recast their votes. Three consecutive tie votes results in the motion being tabled indefinitely.

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

ARTICLE VIII. CONFIDENTIALITY

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

ARTICLE IX. AMENDMENT PROCEDURE

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

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