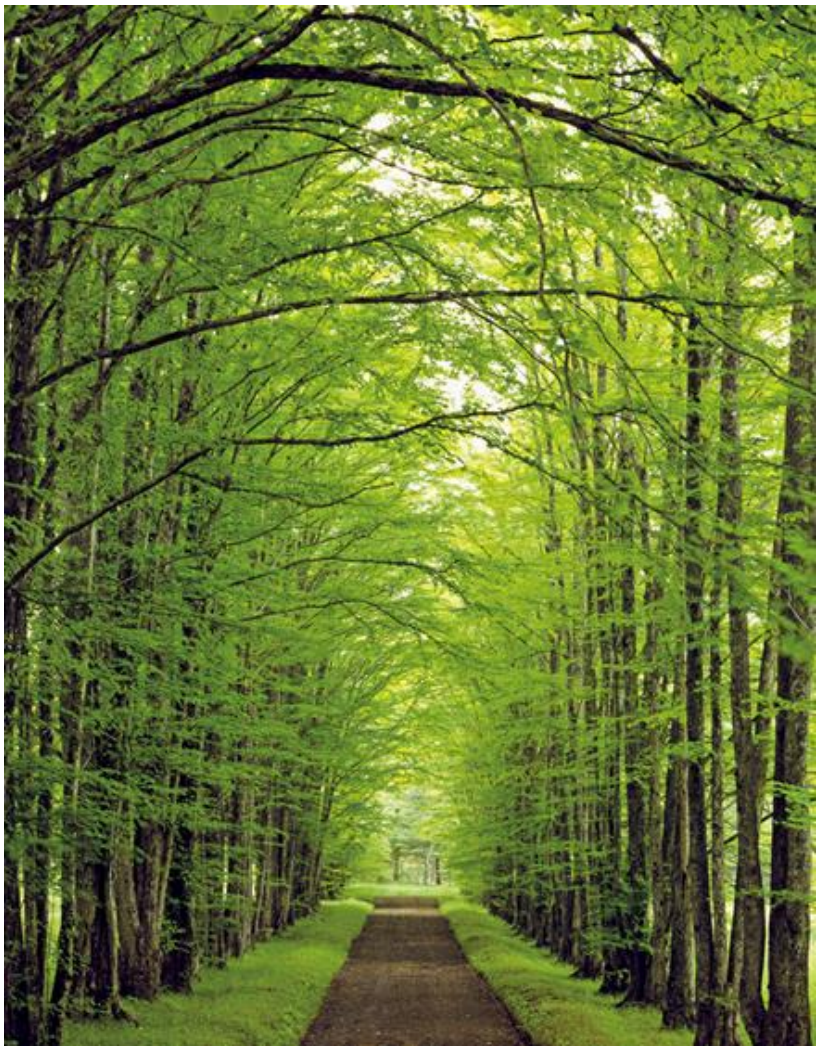
Beth Israel Deaconess Medical Center

HARVARD MEDICAL SCHOOL TEACHING HOSPITAL



The image of the arbor represents the coming together of BIDMC's work in patient and family engagement and healthcare quality and safety

2016 Patient and Family Engagement Annual Report

2016 Patient and Family Engagement Annual Report

Hospital Name: Beth Israel Deaconess Medical Center
Date of Report: September 30, 2016
Year Covered by Report: October 1, 2015-September 30, 2016, or Fiscal Year (FY) 2016
Year Patient and Family Engagement Program Established: 2010
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Staff PFAC Contact E-mail and Phone: cpmoore@bidmc.harvard.edu, 617.667.4608
Report is available by request and posted online at http://www.bidmc.org/quality-and-safety/patient-family-advisory-council.aspx .

Summary

This report provides an overview of patient and family engagement activities and contributions during fiscal year (FY) 2016, October 1, 2015 – September 30, 2016. It provides information about the Hospital-Wide Patient and Family Advisory Council (HW PFAC), as well as four other advisory councils: the Adult ICU Advisory Council, the Neonatal Family Advisory Council, the Universal Access Advisory Council, and the HCA Advisory Council. The report also outlines the many other ways in which patient and family advisors serve at Beth Israel Deaconess Medical Center, including participation in:

- standing committees;
- Advisor Rounding (a program launched in FY 2016); and
- A wide range of "ad hoc" activities.

Ad hoc activities include a wide variety of short-term activities, such as:

Participating in

- staff trainings;
- videos;
- press interviews;
- focus groups; and
- presentations.

Advising on

- research projects;
- space redesign;
- patient information materials; and
- usability testing of websites.

"E-advising" - providing e-mail feedback on a plethora of projects.

This report will also demonstrate the growth in BIDMC's patient and family engagement program, the increased diversity in types of engagement, and the evolution of the culture of patient and family engagement at BIDMC over time.

BIDMC is encouraged by the continued increase in requests for advisors to partner with staff on ad hoc projects. While the HW PFAC and other advisory councils have historically made up the foundation of the patient and family engagement program at BIDMC, an increased demand for patient and family input has broadened both the reach and scope of advisor activities. In FY 2016, participation on traditional PFACS represented less than 10% (8.2%) of activities in 2016. Advisor Rounding (described later in this report) represented 30.5% of activities, participation on standing committees represented 42%, and participation in ad hoc activities represented 20% of advisor activities.

Since 2010, 275 patient and family advisor applications have been submitted to BIDMC, and after careful screening, 151 of these applicants have gone on to participate in councils, committees, short-term projects, or e-advising projects. Reasons for applicants not participating as advisors after submitting applications include: lack of an opening on a particular council in which an advisor was interested; incomplete screening; change in an applicant's availability to serve as an advisor; or determination by the Patient and Family Engagement team (including advisors who assist with interviewing candidates) that an applicant does not possess the qualities or skills to be an effective advisor (see http://www.ipfcc.org/advance/Advisory_Councils.pdf for qualities and skills that BIDMC seeks in advisor candidates).

Between October 1, 2015 and the end of September 30, 2016, the period covered by this report, BIDMC received 20 new advisor applications. Of these new applicants:

- 3 joined the HW PFAC;
- 2 joined Universal Access Advisory Council;
- 2 joined the ICU PFAC;
- 1 joined the NICU PFAC;
- 1 joined the Inpatient Psychiatry Advisory Committee
- 6 became ad hoc advisors; and
- 5 did not become patient and family advisors.

Along with our committed group of new advisors, our core groups of existing advisors remained highly active in 2015-16 as well. Overall this past year, 113 advisors in total participated in an average of 6.6 meetings or other activities each. Advisors contributed a total of 1,330 volunteer

hours, valued at $38,570. Over the four years of the program, advisors at BIDMC have contributed a total of 5,445 hours, valued at $153,049.

This year, advisors offered the following statements as reflections of their involvement in Patient and Family Engagement program at BIDMC:

- *Being a part of Patient and Family Engagement at BIDMC allows me to think critically about the delivery of healthcare, especially as it relates to safety and communication. When I am invited to join a committee or participate in a workshop it reinforces the importance of having our (patient and families) perspective as part of the conversation. I continue to be impressed by the depth and breadth of opportunities available to our advisors.* -- Betsy Lowe

- *Volunteering at the hospital is very rewarding for me. It is my way of giving back to the hospital.* -- Susan Johnson

- (On Advisor Rounding) *When we are admitted to the hospital, we are literally putting our lives in the hands of strangers. Encountering the friendly face of someone who has experienced the same vulnerability can go a long way to alleviating stress and inspiring the desire to change. Helping someone shift their perspective to hope from hopelessness– to seeing there is another way– inspires and enlightens everyone.* -- Matt Robert

- *When I was hospitalized in BIDMC five years ago, I saw the hard work and dedication of the hospital staff including administrators, doctors and nurses. I also felt that some improvements could be made in the hospital from a patient point of view. It is my honor to help BIDMC as a volunteer of the Patient-Family Advisor Program, so the hospital keeps improving for both workers and patients.* -- Anonymous

- *I have appreciated the sincerity of the staff and departments at BIDMC in requesting input on the services provided to patients and their families. All were genuinely interested in comments given and in considering making changes based upon those comments.* --Natalie Nathan

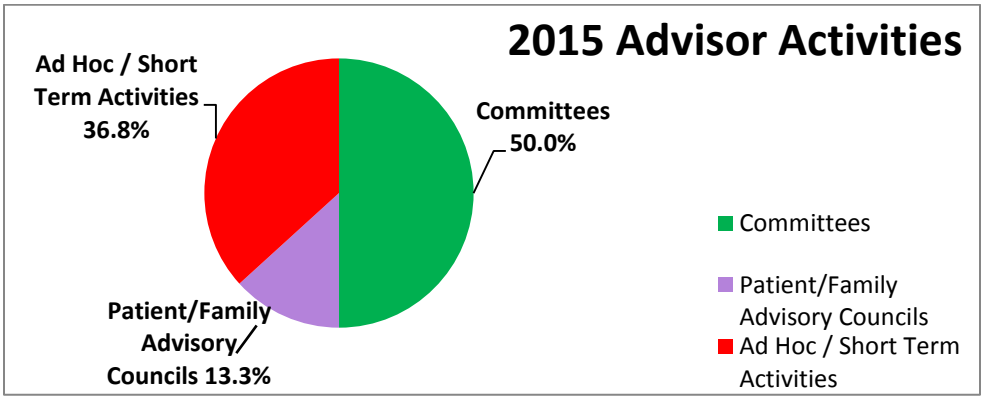
- *What impresses me is the wide range of volunteer opportunities for Patient and Family Advisors. They range from attending presentations on hospital initiatives, taking tours of departments, to giving my opinion on everything from the setup of the cafeteria to a comfort cart for grieving families to highlighting a compassionate staff member in an Ethics for Everyone poster. And those are just a few examples. Not only have I been able to feel I am making a positive impact on the hospital as an advisor, but learning new ideas and expanding my horizons have made a positive impact on me as well. What a win-win situation!* -- Joyce Black

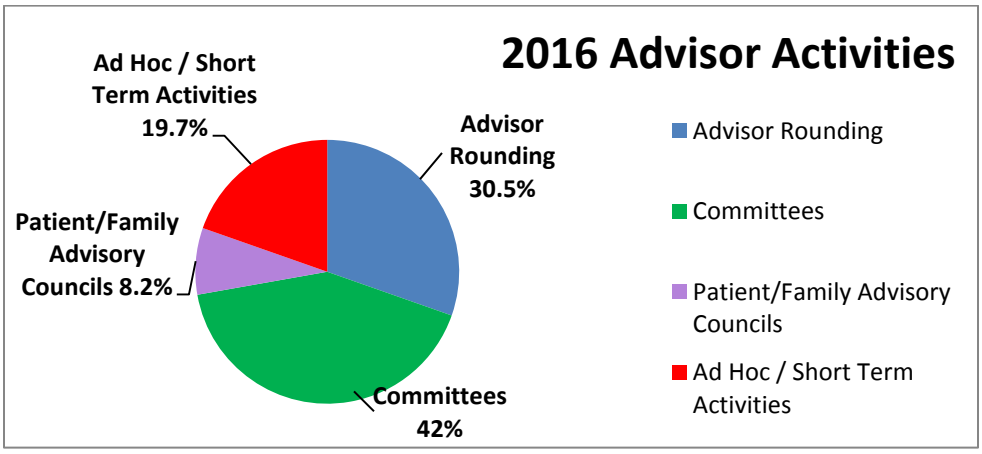
Unfortunately, two advisors, both members of our Hospital-Wide PFAC passed away this year. Both gave generously of their time, wit, and wisdom, and are greatly missed.

Patient and Family Engagement Facts and Figures

Since last year, BIDMC's patient and family engagement program has expanded and diversified. The number of active advisors has increased, the number of advisor activities has increased, and the amount of time contributed by advisors has increased. In one year, the number of active advisors increased by 20 (this number includes new advisors as well as inactive veteran advisors who became active again); the number of advisor activities increased by 103; and the number of hours contributed by advisors increased by 304. The monetary value of the time donated by BIDMC's advisors during FY 2016 was $38,570, $10,027 more than the prior year.

The following charts show the change in the distribution of types of engagement in which advisors participated over the past two years, grouped into four main categories: advisory councils, standing committees, "ad hoc" or short term projects, and Advisor Rounding. Advisor Rounding began in fiscal year 2016 so does not appear on the 2015 chart.

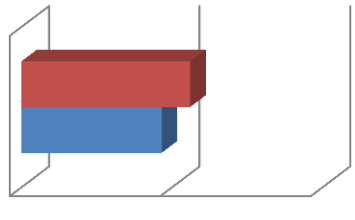




The following graphs demonstrate the increase over the past year in: active advisors; amount of time contributed by advisors, number of advisor activities (PFAC meetings, committee

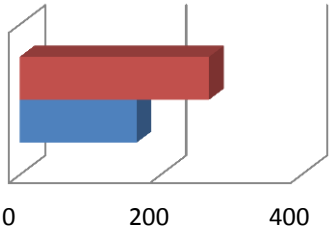
meetings, and ad hoc activities including e-advising requests); and other indicators of program growth.

Active Advisors



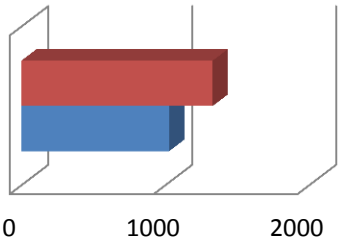
	Number of Active Advisors
FY 2016	112
FY 2015	93

Number of Advisor Activities



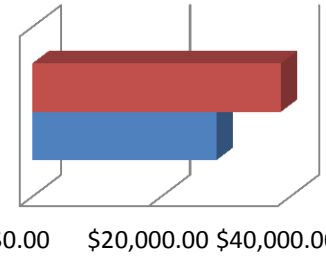
	Number of Advisor Activities
FY2016	269
FY2015	166

Number of Advisor Hours



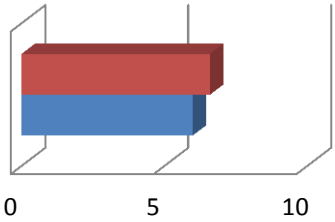
	Advisor Hours
FY2016	1330
FY2015	1026

Total Value of Advisor Time



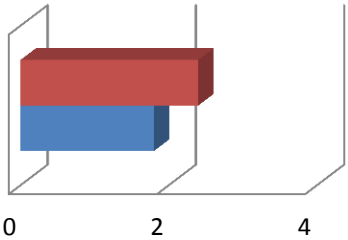
	Value of Advisor Time
FY2016	$38,570.00
FY2015	$28,543.00

Average Number of Activities in Which Each Advisor Participated



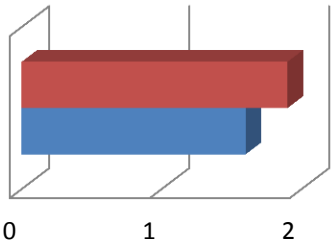
	Average Number of Activities Per Advisor
FY2016	6.6
FY2015	6

Average Number of Advisors Participating in Each Activity



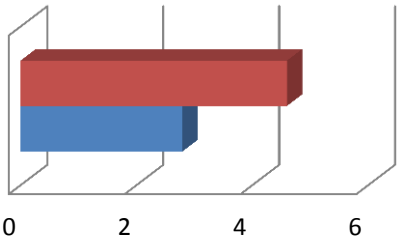
	Advisors Per Activity
FY2016	2.4
FY2015	1.8

Average Time Spent Per Activity, Per Advisor



	Hours
FY2016	1.9
FY2015	1.6

Average Number of Advisor Hours Per Activity



	Average Number of Advisor Hours per Activity (# Advisors per activity x # hours per advisr)
FY2016	4.6
FY2015	2.8

Much of the growth in number of activities and the increase in contributed time can be attributed to the new Advisor Rounding program, which accounted for 82 of the additional 103 activities in the past year. Aside from that program, other factors which have influenced growth have included an increase in requests for BIDMC advisors' from parties outside of our institution, an increase in awareness of the patient and family engagement program within the institution, and increases in advisor participation in presentations, at conferences, and in interviews for web and print publications.

The next section of the annual report includes summaries of BIDMC's five PFACs.

Hospital-Wide PFAC

HW PFAC Membership and Recruitment

The HW PFAC is presently comprised of 13 patient and family advisors (62%) and 8 BIDMC staff members (38%). Staff members include the Senior Vice President for Patient Care Services and Chief Nursing Officer; Director of the Office of Improvement and Innovation; Director of Patient Safety; a Hospitalist with an appointment as Associate Director for Inpatient Quality; 2 Ambulatory Directors, a Quality Improvement Project Manager; Senior Director of Social Work and Patient and Family Engagement. The Program Leader for Patient and Family Engagement coordinates the council and also attends meetings. The HW PFAC is co-chaired by a patient/family advisor and BIDMC's Senior Director of Social Work and Patient and Family Engagement.

This year, 4 advisors reached the end of their four-year terms, however 1 of these advisors was elected as co-chair, so his term was extended an additional two years. The other 3 outgoing advisors became emeritus members. While they will no longer attend meetings, they will continue to be active participants in various other patient and family engagement opportunities. Four new advisors joined the council. Two advisors passed away in 2016. (For more information about membership, recruitment, terms limits, and other operational details, please see the HW PFAC bylaws, attached.)

While it is an ongoing challenge to recruit PFAC members who are representative of the diverse patient population served by BIDMC, the diversity of the PFAC has increased over the past year. The patient/family advisor membership is currently made up of 4 men and 9 women. Ages of members span nearly 50 years. It is difficult to determine the degree to which our HW PFAC members represent the population in race and ethnicity since we do not currently ask applicants to identify these characteristics in the screening process. That being said, we remain committed to seeking members who reflect the diversity of the populations that we serve.

New members are recruited through print brochures placed around the medical center, a webpage with applicant information on the BIDMC public website, and through staff referrals. One new HW PFAC member this year had been an ad hoc advisor for several years prior and was invited to join the council. Two new advisors submitted print brochures and one applied via a web link to the application on the BIDMC website.

The complete screening process of a new candidate includes: completion of a paper or web-based application; a phone interview with the Program Leader for Patient and Family

Engagement; an in-person interview with the Program Leader and an advisor; a CORI (criminal background) screening; and an in-person, group orientation and training session. New members are matched to current member "mentors" who help them get acclimated to the group and are available to discuss questions or concerns.

Advisors receive free parking or reimbursement for The Ride or the MBTA. They also receive dinner. If requested, they would receive reimbursement for childcare or eldercare. Advisors do not receive stipends.

HW PFAC Agendas and Meetings

The HW PFAC meets 6 times per year for 2 hours. Agendas are largely shaped by requests by staff members, providers, researchers, as well as health care professionals from outside organizations to present at HW PFAC. Areas of focus include new hospital initiatives, research projects, marketing materials, policies, patient and family support protocols, communication strategies, and other initiatives. All requests are reviewed by the co-chairs of the PFAC and the Program Leader of Patient and Family Engagement before being added to the agenda.

At the start of each meeting, advisors share positive or negative health care experiences that they, or a family member have encountered since the last meeting. Hospital staff members who are present on the council are often able to respond immediately, or take note of the occurrence in cases where follow-up is needed. Alternatively, the Program Leader follows up after the meeting by contacting the appropriate staff person at BIDMC, with the permission of the advisor.

Following the exchange of advisor experiences and announcement, a typical meeting includes two presentations followed by discussion.

HW PFAC Topics and Impact

The HW PFAC provides patient-and family-centered input on topics largely rooted in the BIDMC's strategic priorities, which are outlined in the annual operating plan. A key strategic priority relates to the provision of extraordinary care through improvement in: quality, safety, and the patient experience. Some of the topics discussed at HW PFAC meetings over the past year include:

- Support for family members of patients who are dying in the hospital
- Advisor Rounding
- Health Care for All Conference discussion
- HW PFAC's membership in the national PFAC of the Society for Hospital Medicine

- Patient/Family Advisor opportunity in a multi-site research project about cultural competence in surgery
- Sharing BIDMC's model of Patient/Family Engagement at a conference in Tokyo, Japan
- Serious Illness/Palliative Care
- Mystery Shopping program in Ambulatory Care
- Accommodations and standards to support patients with disabilities
- Concurrent Surgery policy
- BIDMC's operating plan and strategic goals
- Open Notes and PatientSite

Presenters in 2016 unanimously expressed appreciation for the feedback they received by advisors, have adopted several suggestions of advisors, and have expressed intent to return. Five presenters were first-time presenters at a BIDMC PFAC meeting. Past presenters and their colleagues have cultivated relationships with the PFAC and its individual members (including emeritus members) by working with advisors outside of PFAC meetings to advance improvement projects. Examples of such projects include: support of families when a patient is dying in the hospital; website review; radiology staff training; and space renovation.

HW PFAC members have had a tremendous impact beyond the walls of the PFAC meeting. Four members participate in the Advisor Rounding program and one gave a presentation about the program at the 2016 International Conference on Patient- and Family-Centered Care. Several advisors were featured in posters at the Silverman Symposium and Ethics is Everyone event. Two sit on board-level committees: one on the Patient Care Assessment Committee and another who is co-chair of the Ethics Advisory Council. One is a member of the Inpatient Psychiatry Advisory Committee and also a member of the Open Notes Governance Committee. Two participated in a cataract safety taskforce of the Betsy Lehman Center. Virtually all HW PFAC Advisors participated in one or more ad hoc advisor activities this year.

HW PFAC Goals and Priorities:

The PFAC has not had a formal goal-setting process. Aside from the work on the Medical Center's strategic priorities, other HW PFAC goals discussed in the course of meetings include:

- Improving regular communication about past and ongoing work in which the PFAC has participated, by providing regular updates to the PFAC at meetings and via the internet;
- Improving communication about patient and family engagement work that is occurring outside of the council, to allow PFAC members to feel more connected with the greater scope of advisor work taking place;

- Writing and publishing papers about the contributions of advisors to quality improvement at BIDMC; and
- Enhancing opportunities for advisors to inform the PFAC agenda and collaborate on presented projects outside of meeting.

Early in the year, patient and family advisors expressed a desire to identify areas of improvement on which HW PFAC could focus and seek to make a difference. The PFAC engaged in a priority-setting exercise led by a patient advisor. By the end of the exercise, the advisors had identified a list of ten specific areas of focus that were encapsulated into three overarching "buckets":

- **Respect and Dignity** – (What can BIDMC do to make patients and their family members feel welcome and comfortable, ensuring their privacy, and treating everyone with respect, including those with disabilities, language issues, or other challenges that may make them vulnerable, scared, confused, or less able to get the care they need or express themselves?)
- **Environment** – (What can BIDMC do to ensure cleanliness, comfort, safety, and improve navigation of a complex facility; what can BIDMC do to make the environment healthy, to make the experience as good as it can be from an environmental standout?)
- **Communication** – (What can BIDMC do to provide patients and families with information they need in a way that makes them feel comfortable, relaxed, and informed, and how can BIDMC standardize the experience across clinics (phone etiquette, greetings, wait times, check-in protocols). What can BIDMC do to better partner with family members and improve transparency?)

Further discussion and voting on the ten specific areas of focus resulted in the identification of three main foci in which a majority of advisors believed more attention should be paid both at BIDMC and in the PFAC meetings. They are in order of importance:

- Partnership with patients and families, including giving them the information they need throughout the care experience;
- Communication about roles; staff and providers introducing themselves – inpatient and outpatient; and
- Care transitions, including providing better information & support in discharge process.

The priorities and preferences identified and discussed by advisors have already been utilized by several BIDMC committees in their own goal-setting processes, including the senior-level

committee in charge of developing BIDMC's strategic operating plan, the new Patient Experience Taskforce, and the Radiology Service Excellence Committee. The HW PFAC will repeat this exercise periodically in order to continue to influence the goal-setting of the hospital at large, and of other groups and departments at BIDMC who value this information.

HW PFAC Challenges:
The challenges that the HW PFAC has experienced this year are consistent with those of prior years and are reflective of its success, growth, and increased recognition by the medical center of its value. The greatest three challenges were:

1. A greater number of staff wishing to consult with our PFAC than we could accommodate during the course of PFAC meeting. Utilizing other patient and family engagement modalities, including surveys, focus groups, interviews, and small work groups has helped us to meet this challenge, but demand will continue to rise as awareness of the value of our PFAC grows.

2. Related to the above, meetings are dense as we attempt to maximize the time to generate feedback for projects on the agenda; we are challenged to allow time in meetings to reflect on the goals and interests of the PFAC members and cultivate group cohesion through collaborating on advisor-initiated projects.

3. The number of applicants, combined with our commitment to increase the diversity of our PFAC and ensure that it is as representative of our patient population as possible, has required that we defer strong candidates. Fortunately we have ample other patient engagement opportunities in which new advisors can participate.

The following section includes annual summaries of BIDMC's four other Advisory Councils, provided by the co-chairs of these councils.

NICU Family Advisory Council

The NICU Family Advisory Council (NFAC) was created in 2006. Currently, the council includes 20 family members and 8 staff members. In FY 2016, the council met three times, advising on the following initiatives:

- The NICU staff worked with the March of Dimes to initiate the March of Dimes Family Support Program. This provides families and staff in the NICU with educational and practical supports during their time in the NICU.

- The NICU continues to work on its major care initiative for patients and families this year to have skin-to-skin with their infant.

- The NICU and NFAC held a memorial service for infants who died in its care. This tradition invites parents back from years ago.

- The NICU staff is also re-examining its ante-partum procedures for families who will most likely end up in the NICU after delivery. They are doing focus groups with past families to get feedback about how best to prepare families for their NICU.

- As expansion of the NICU is anticipated in the next year, it is anticipated that families and staff will participate in giving feedback about how new facilities can best serve families and provide care.

- Through the generosity of an NFAC families of patients continue to receive Sweet Peas care packages to help with their comfort and daily concerns in the NICU.

- The NFAC is anticipating holding our next NICU reunion in 2017, an event where alumni/ae patients and their families spend time together and reconnect with staff.

Council members have also informed the following NICU programs:

- Meet and Greet monthly socials, during which families come back for a coffee and meet with current families.

- Pre- Thanksgiving event: The NICU PFAC also hosts an evening for alumni families to come and share pie and good cheer with current NICU families. This event will take place again this year in November 2016.

ICU Patient and Family Advisory Council

The ICU PFAC was initiated in 2008. The council gained 2 new patient/family advisors this year, for a total of 4 patient advisors and 4 family advisors. Four staff members and a physician also

participate in the council. The ICU PFAC has a unique structure: every three months, the ICU PFAC and the Critical Care Experience Taskforce (made up of staff members and providers) have a combined one-hour meeting; following this meeting, the ICU PFAC meets on its own for one hour.

Highlights of this year included:

- Critical Care Grand Rounds: 2 of our advisors shared their experiences as family members of former BIDMC ICU patients with a room full of physicians, nurses, social workers, pharmacists, and respiratory therapists. This event came about as a result of the success of a similar event in 2015 in which two former ICU patients shared their experiences. The feedback for both events was overwhelmingly positive and advisors will continue to be invited to speak at Critical Care Grand Rounds in the future.

- MyICU: MyICU is a computer interface that was designed to enhance communication between providers and patients/families. It is intended to encourage patients and their loved ones to participate in care, feel more engaged with staff, and provide them with information that supports decision making. ICU PFAC advisors were instrumental this past year in providing feedback about the program, resulting in significant changes, including the ability of patients and family members to use MyICU on their smartphones or personal laptops instead of having to use hospital-provided iPad on loan. The advisors also provided many ideas to improve the design, content, and usability of the web-based program.
- Care transitions: Advisors have been influential in providing the medical center with ideas on how to improve transitions out of the ICU. A subgroup of clinicians and advisors is being formed to improve transitions by helping to set expectations for patients and families.

The ICU PFAC Project Manager continues to reach out ICU providers to recruit additional members for this advisory council.

Universal Access Advisory Council

The Universal Access Advisory Council was created in 2010. The goal of the council is to provide accessible and respectful care to those with disabilities, and to ensure that people with disabilities are getting the same excellent quality of care that other patients are getting at the medical center. The first five years, the focus was on physical improvements, such as accessible scales, door openers, low counters, and ramps. As this work progressed and with the help of

advisors, it became apparent that staff education needed to coincide with the physical plant changes. As a result, the past two years have represented a significant transition point for the Universal Access Advisory Council, with a shift away from facilities issues, and an increased focus on awareness, training and operations.

The UAAC currently includes 8 patient/family advisors bringing experience about a range of disabilities, 6 staff members, and 2 disability consultants from a private consulting firm. Patient and family members on the council have been helpful in providing guidance and feedback on a tremendous amount of accessibility-related work taking place around the medical center, and have directly participated in this work when possible. This year, the council and/or individual members:

- Established an organizational structure to continue building off the work related to the physical plant changes. Created a shared drive for the staff to easily access information and other resources to better care for patients with disabilities and presentations;
- Presented/communicated about the work at leadership, in news stories to physicians, and a broadcast on the portal;
- Implemented a tool for safe check in of limited English speakers that has also provided an opportunity for Interpreter Services to pilot a more efficient work flow for Spanish interpreters;
- Conducted a visual impairment training for staff council;
- Conducted a Deaf and Hard of Hearing training for staff council;
- Began work on a tool box content for service, resources and equipment for these areas;
- Began discussions of how to provide better care for patients with cognitive impairment;
- Reviewed shuttle accessibility as part of their plan to purchase more vehicles;
- Enhanced the Service Animal policy, began efforts to communicate with staff how to handle animal behavior issues, and created a document to help communicate with our patients and visitors our policies prior to bringing a dog;
- Added Sorenson video phone to Labor and delivery;
- Provided mini accommodation updates to Ambulatory CORE team and Ambulatory Operations Council – service animal, check in tool;
- Drafted an article in the Disabilities Matter journal highlighting the work of BIDMC advisors;
- Participated in the MITSS conference (Medically-Induced Trauma Support Services
- Provided valuable input into OpenNotes safety research;
- Assisted with the improvement of a website designed to help patients and family members find community resources to help them during an illness.

The UAAC looks forward to continuing this important work, integrating critical improvements in facility accessibility with expanded awareness and training for all staff, and identifying operational improvements to that support equitable and improved access to care universally.

Healthcare Associates Patient and Family Advisory Council

The Healthcare Associates (HCA) PFAC, the advisory council for the primary care practice located at BIDMC, was initiated in 2013. This council meets quarterly and includes 5 advisors and 1 provider – a primary care physician. It is co-chaired by one advisor and the primary care physician. In addition to participating in periodic PFAC meetings, advisors have also been embedded in staff committees: 1 advisor participated in monthly Operations Committee meetings and another participated in bi-weekly team meetings. The HCA PFAC spent a considerable amount of time this year assessing their accomplishments to date, their goals, and future directions for patient engagement in HCA. In 2016, the HCA PFAC:

1. Gave Feedback to HCA about Patient Experience
    - Call Center: language barriers; automated prompts; timely access to desired providers; multi-purpose phone calls; wait time; scheduling appointments; after hours calls
    - Prescriptions: medication information; renewals; wait-time; coordination with pharmacies and insurance companies
    - Waiting Room: Setting the tone for visit; Form of address; lines to check-in; privacy; visuals (white board, monitors, posters, etc.); HCA/BIDMC health-related reading materials
    - Patient Feedback—Discussed ways to elicit, increase relevance and use (questionnaires, Press Ganey, Shadowing, others)

2. Provided Feedback to HCA re New Practice Initiatives
    - Chronic Care Management
    - Population Management/Screening/Metrics

4. Provided Feedback regarding Patient Communications and Publications
    - HCA Welcome Packet
    - Breast Cancer Awareness Posters
    - Diabetes Handbook
    - Various fliers and pamphlets

5. Contributed to and Participated in BIDMC Initiatives

- Silverman Symposium Poster
- Medical Staff Training Video

6. Contributed to and Attended HCA Initiatives outside BIDMC
    - Academic Innovations Collaborative
    - HMS Center for Primary Care

The HCA PFAC also collaborated on the creation of a list of recommendations to improve patient engagement in the Health Care Associates practice, falling into five broad categories:

- Communication between patients & HCA
- Chronic care management: engaging patients in treatment of chronic illness
- Advance care planning
- Use of (and increased awareness of) quality metrics to affect quality care
- Working with Patient/Family Advisors to help HCA achieve patient engagement

With the support of senior leaders in HCA, members of the HCA PFAC are actively seeking opportunities to make progress on these recommendations through increased partnership between advisors, staff members and providers in settings in which decision-making takes place. Accomplishing this goal will necessitate recruitment of more advisors and increasing awareness of staff and providers in HCA about the benefits of patient and family engagement.

Committees

Advisors have continued to serve in several standing committees at BIDMC, including (number of advisors in parentheses):

- Ethics Advisory Council (board level – 3 advisors)
- Ethics Advisory Council Subcommittee (1 advisor)
- HCA (Health Care Associates) Operations Committee (1 advisor)
- HCA (Health Care Associates) Team Meetings (1 advisor)
- Inpatient Psychiatry Advisory Committee (4 advisors)
- Medication Safety Committee (1 advisor)
- OpenNotes Steering Committee (2 advisors)
- Patient Care Assessment Committee (board level – 2 advisors)
- PatientSite Governance Committee (1 advisor)
- Perioperative Medical Home Steering Committee (1 advisor)
- Service Excellence Steering Committee (2 advisors)

Advisors have also served on committees of community-based organizations, including:

- Betsy Lehman Center project committees

- Health Care for All PFAC subcommittees
- PatientCareLink Steering Committee
- Society of Hospital Medicine Patient Experience Advisory Committee

Advisor Rounding

In fall of 2015, the Patient and Family Engagement program launched a pilot program involving patient and family advisors visiting with patients and/or family members on three inpatient units. The program was modeled on a similar program called "Voices" at Dartmouth-Hitchcock Medical Center. The aim of advisor rounding is to engage with patients and families to learn about their experiences in real time, effectively respond to their concerns, and enhance communication. The project was partly inspired by a discussion among advisors in a Hospital-Wide PFAC meeting about the vulnerability of patients and the need for patients and families to have a safe means by which to express their concerns.

Ten veteran patient and family advisors were carefully selected and underwent six hours of training, by the Program Leader of Patient and Family Engagement and the Senior Director of Patient and Family Engagement. Rounding started in November. For the first four months of the project, the Program Leader of Patient and Family Engagement accompanied advisors to the floor to help foster relationships with the floor staff and also to be available if an advisor had a concern. Starting in late March, advisors rounded independently. Since late November, advisors have documented nearly 300 visits.

An advisor rounds on each floor once per week for 60 – 90 minutes. Visits last an average of 10-15 minutes. Advisors enter rooms and initiate conversations about the patient's or family member's experience on the unit. Conversations are unscripted but advisors are trained to listen for or explore themes that align with patient satisfaction measures: ability to communicate with the doctor or nurse, responsiveness, hospital environment, and care transitions.

Observations and comments are recorded on a web-based form that are completed after visits on an advisor's smartphone, home computer, or on iPads purchased specifically for this project. Patient identifying information is not recorded except in cases in which a patient or family member requests follow-up for a concern and gives permission to the advisor to identify him or her to the appropriate staff member who will provide follow-up.

Quantitative and qualitative data from the forms is synthesized into reports that are shared with Nurse Directors of each unit. The reports summarize the positive and negative comments across each theme area, and also list staff members and providers who were mentioned as having provided compassionate or extraordinary care. Staff and provider compliments are shared with supervisors.
Advisor rounding has become an innovative, low-cost way to improve the patient and family experience by:

- offering patients and families a new, personalized means by which to share concerns

- capturing, and allowing us to better respond to patient feedback in real time
- increasing employee awareness of the impacts of their actions on the patient experience
- identifying areas for improvement
- capturing a fresh perspective on the patient experience that can be used in training and education
- advancing the culture of patient and family-centered care at BIDMC
- yielding positive, measurable outcomes in patient satisfaction and responsiveness
- and strengthening partnerships between patients, families, and staff

Advisor Rounding has generated a great deal of attention from other medical centers interested in exploring and possibly replicating this model. Members of the Advisor Rounding team have provided consultations by phone and have presented in various forums including the Health Care for All Annual PFAC Conference, the International Patient and Family Centered Care conference, and the World Congress for Patient and Family Engagement. In addition to helping spread awareness about this innovative and effective program, the Patient and Family Engagement team looks forward to training additional advisors and expanding Advisor Rounding to other floors.

Other Advisor Contributions

The following list summarizes ad hoc advisor contributions at BIDMC in FY2016.

- Teaching and training
    - Family members of former ICU patients presented at Critical Care Grand Rounds
    - Meetings with representatives of Chugai Academy for Advanced Oncology (Tokyo) who are interested in patient/family engagement
    - Reviewed, provided feedback on front line staff training script
    - Radiology Service Excellence Goals – testimonials and assistance with a staff training video
    - Shadowing ambulatory staff trainings
- Developing and reviewing materials (print, web)
    - Wellist website development and user testing
    - Reviewed 2 versions of Heart Healthy brochure
    - BIDMC Website redesign feedback
    - MyIcu- version 2 development and user testing
- Taskforces and Workgroups
    - Patient Experience Task Force
    - Code of Conduct workgroup
    - Medication Shortage Task Force

    - Bereavement Support workgroup
- Focus Groups:
    - OurNotes focus group
    - Center for Violence Prevention and Recovery Focus Group
- Improvement efforts beyond BIDMC
    - Betsy Lehman Patient Safety committees
    - Cataract Safety Task Force
    - Patient Care Link Advisory Council
    - BWH/BIDMC PFAC on cultural competence training for surgical providers
    - MITSS (Medically Induced Trauma Support Service) Conference
    - Communication, Apology, and Resolution Forum
    - Society for Hospital Medicine National PFAC
    - Health Care for All PFAC subcommittees and conference planning
- Presentations:
    - BID Milton PFAC meeting
    - Massachusetts Association for HealthCare Quality Webinar
    - IPFCC Conference – presentation on advisor rounding
    - IPFCC Conference – presentation on OpenNotes
    - OpenNotes Annual Kickoff Meeting presentations
    - Presentation at a conference in Tokyo, Japan about patient and family engagement at BIDMC
    - "Ethics is Everyone" event posters
    - Silverman Symposium posters:
        - *Development of a Patient-and-Family-Centered Guide for Patients with Serious Illness;*
        - *Voices of Experience: Patient and Family Advisors Rounding on Patients in the Hospital; and*
        - *Clinicians and Patient Family Advisors Come Together to Improve Care in the ICU*

- Print and Web Publications:
    - Summer 2016 Disability Issues, Vol 36, Issue 3 featuring Mal Malme Clowning Around with a Hospital Clown
    - July 22, 2016 Patient Safety Blog article featuring Mal Malme: A Patient Family Advisory Council's reduction of waiting room anxiety: I think about who's coming after me
    - July 5, 2016 Boston Globe / Stat story featuring Matt Robert: Some Hospitals Resist new Fresh Air rules for Psychiatric Patients

    - May 2, 2016 STAT news article, featuring Randy Gonchar, Pat Folcarelli, and Lauge Sokol-Hessner: Hospital takes on taboo subject: mistakes made after patients die.
    - March 14, 2016, article featuring Paul Daigneault: Hospitals working to make intensive care less terrifying
    - December 15, 2015 Boston Globe / Stat news article featuring Randy Gonchar - Should Patients be able to Record their Surgeries?
    - A member of the ICU PFAC created a blog: paulandjackiesjourney.com
    - Advisors were photographed for marketing materials of the new CardioVascular Institute
- Research
    - CRICO safety survey
    - Multi-site study on cultural competence among surgeons
    - Perioperative care of geriatric patients and their families
    - Improving inpatient consultations
- Other feedback
    - Radiology service excellence testimonials and tips for quality improvement
    - Feedback about hospital TV channels
    - Tour of radiology areas, feedback about improving the space and experience
    - Feedback about how to improve support when a family member is actively dying or has died in the hospital – information sheet and comfort cart
    - Universal Access workgroup needs (vision, hearing, cognitive disabilities)
    - Ullian cafeteria renovation feedback
    - Feedback about the Conversations on Cancer event

Taking Stock and Looking Ahead

In 2016, we saw an increase across all measures of patient and family engagement, introduced advisors to many novel roles both inside and outside of the medical center, and broke new ground with the launch of the advisor rounding program. Going forward, we will continue to foster awareness and partnerships between patient and family advisors and leaders across the organization; strive to recruit a more diverse team of patient, family, and staff advisors; and explore new methods for improving the patient experience through innovative approaches to patient and family engagement.

Appendix: Hospital-Wide Patient and Family Advisory Council Bylaws

Beth Israel Deaconess Medical Center

Hospital-Wide Patient and Family Advisory Council Bylaws

Article I. Name

The name of the organization is Patient and Family Advisory Council of Beth Israel Deaconess Medical Center (BIDMC). It is sometimes also referred to as the PFAC. It is also called the Council.

Article II. Mission

The mission of the BIDMC Patient/Family Advisory Council is to ensure that patients and their families come first and are consistently treated with respect, compassion, and the highest quality of care in all aspects of the BIDMC experience. It will accomplish this by actively collaborating with BIDMC leadership to ensure that the diverse voices of patients/families are included in all aspects of care, generating advice that leads to tangible changes in the organization.

Article III. Membership

Section 3.01 Roles and Responsibilities

(a) Patient and Family Advisors

- Attend each council meeting
- Engage thoughtfully with the issues presented for council review
- Provide constructive feedback from a patient and family perspective
- Respectfully listen to diverse opinions
- Agree to work within meeting infrastructure determined by Council
- Adhere to Confidentiality Agreement
- Inform Project Leader of changes or conflicts that would affect their ability to attend council meetings

(b) Staff Advisors

- Attend each council meeting
- Engage thoughtfully with the issues presented for council review
- Provide constructive feedback from a staff perspective
- Respectfully listen to diverse opinions

- Agree to work within meeting infrastructure determined by Council
- Adhere to Confidentiality Agreement
- Advocate for and report on progress towards incorporating Council feedback within the organization
- Inform Project Leader of changes or conflicts that would affect their ability to attend council meetings

(c) Co-chairs
- Attend each council meeting
- Work in collaboration with Project Leader
- Define process for future agenda setting and plan agendas
- Adhere to Confidentiality Agreement
- Facilitate meetings
- Present follow-up from previous meetings and provide updates on work in progress

(d) PFAC Project Leader
- Attend each council meeting
- Prepare and follow-up with staff who come to the Council seeking feedback
- Send reminders and communicate meeting logistics to members
- Recruit and orient new members and sustain current Council membership
- Report organizational outcomes as a result of PFAC feedback annually
- Define a clear process for following up on Advisory Council recommendations
- Adhere to Confidentiality Agreement
- Ensure that minutes are taken at each meeting
- Distribute minutes within 2 weeks of the date the meeting is held

(e) Board Liaison – selected by the Council co-chairs and the Patient Care Committee of the Board.
- Attend each Council meeting
- Report to the Patient Care Committee when appropriate

(f) Alumni/ae – If they request, Council members who have served their term may become Alumni/ae Members. In this role, they may be involved in subcommittee projects and working groups, but will not have Council voting privileges.

(g) Alternate – chosen from a short list of screened applicants to serve as either a staff or patient/family advisor in the event that a sitting member of the PFAC must step down

for any reason. They must meet with the Project Leader for orientation prior to joining the PFAC.

Article IV.

Eligibility

Patients, family members and staff from Beth Israel Deaconess Medical Center (BIDMC) are eligible to be members of the Council. New patient and family members will have been seen at the medical center within the past two years. Members should be committed to building a partnership of advisors and staff working to understand the needs of the constituents they represent and to implement programs and policies to address health care challenges within the medical center.

Section 4.01 Council Makeup

The Council will be made up of a broad base of fifteen to twenty patients and/or family members and up to seven staff members from the institution. The Council base shall consist of at least half patient and family representatives. If the number of patient/family Council members falls below 15, recruitment efforts will be immediately triggered.

Section 4.02 Participation

Members are expected to participate in bi-monthly meetings consisting of 2 hours.

Section 4.03 Membership Term

A term of active membership consists of two years. Following the initial creation of the Council, up to two thirds of the members may elect to serve one additional year. Each year thereafter approximately one third will rotate and new members will be added.

Amendment: After two years, members in good standing will be invited to renew their membership for an additional year. Members may serve for two additional years, for a maximum of four years. All active members must be in compliance with the responsibilities listed in Section 3.01.

Section 4.04 Vacancies/Leaves of Absence

Council members may resign or request a Leave of Absence from the council at any time during their term. A member may request a leave of absence when unusual or unavoidable circumstances require that the member be absent from meetings and activities from 3 to 6 months. The member will submit his/her request in writing to the Co-Chairs, stating the reason for the request and the length of time requested. The Co-Chairs will determine if the request will be accepted.

If a member cannot return at the end of the requested leave, he/she will resign from the Council. At any resignation, the Council may choose to add a replacement at that time or to leave the position open until the next rotation of members.

Section 4.05 Recruitment & Selection

Council members and BIDMC staff and resources will be utilized to recruit and recommend future members. Potential members will fill out an Advisor Application Form. The PFAC Project Leader will review the application, conduct a brief phone interview, and then interview the candidate with another member of the PFAC interview subcommittee. After successful completion of the interview the candidate will be invited to a Council meeting. The PFAC Project Leader and Council Co-Chairs will determine the candidate's eligibility for membership. The PFAC Project Leader will notify the potential member of the decision.

Article V. Officers

Section 4.01 Co-Chairs and Duties

There shall be two chairpersons, known as Co-Chairs. One BIDMC staff Co-Chair will be chosen by the institution. The second patient/family member Co-Chair will be elected by the Council. The Co-Chairs will be responsible for setting Council meeting agendas, chairing and conducting meetings, providing leadership for the Council members and representing the Council within the Institution.

Section 4.02: Nomination Procedure

To be eligible as a nominee, Advisors will have had at least one year of experience on the council by the start of the next Co-Chair term (See Section 4.04: Term). Council members may communicate nominations for the office of Advisor Co-Chair to the Program Leader by email, phone, or in person. A Council member may not nominate him or herself.

Section 4.03: Election Procedure

The Advisor Co-Chair will be elected by an online, emailed, or mailed ballot. Members will have a minimum of two weeks to return their ballots. Once the established deadline has been reached, the Program Leader will tally the votes. The nominee with the highest number of votes will be elected as co-chair. In the case of a tie, the standing Advisor Co-Chair will determine how to break the tie.

Section 4.04: Term

The standard term of office will begin and end at an annual meeting held in September, unless otherwise specified. The standard term will be two years, even if this means the Co-Chair will exceed member term limits by one or two years.

Section 4.05 Vacancies

A Co-Chair may resign from office at any time. The Council may choose to either elect a replacement who will serve the remainder of the resigned officer's term, or leave the position open until the start of the next annual meeting, whereupon a newly elected Co-Chair will begin a standard two-year term of office.

Article VI: Meetings

Section 5.01 Regular Meetings

Regular meetings of the Patient and Family Advisory Council will be held on the fourth Wednesday of each month from 6:00 PM to 8:00 PM, with dinner served at 5:30, unless otherwise ordered, presuming the presence of a quorum.

Section 5.02 Special Meetings

Special meetings may be called by the Council Co-Chairs as they deem necessary. Council members will be given at least 48 hours' notice of the meeting schedule and agenda.

Section 5.03 Quorum

An official meeting will require the presence of a minimum of one-half of the members to be called to order.

Section 5.04 Attendance Requirements

Advisors will be dismissed from Patient and Family Advisory Council membership when they have missed three scheduled meetings during any calendar year. Advisors may call-in to one meeting per year and still be considered present. When absences are expected, Advisors must notify the PFAC Project Leader prior to the scheduled meeting. Up to two exceptions may be made by the Project Leader or Co-Chairs for emergencies, inclement weather, unexpected personal or family illness, etc. Additional absences will be monitored.

Section 5.05 Voting

Votes may be conducted to address the business and structure of the Council, including review of mission and bylaws. Amendments to Council Bylaws, including the mission statement will require the affirmative vote of two-thirds of the members present and voting.

Votes may also be conducted when appropriate, if the organization requests a definitive recommendation from the Council. The majority will rule in such cases.

Section 5.06 Agenda

Meeting agendas will be set by the Co-Chairs and PFAC Project Leader and distributed to the membership a week prior to each meeting. Anyone, PFAC member or otherwise, may request time on the Council agenda by submitting an Agenda Request to the PFAC Project Leader.

The Co-Chairs and Project Leader will evaluate and prioritize each request by discussing with prospective presenters their item's appropriateness and/or clarifying the subject matter. Co-Chairs and the Project Leader may also suggest alternative means of involving the PFAC, including email, focus groups and subcommittees.

All recipients of PFAC assistance must submit to the Council or Project Leader a follow-up report summarizing the help requested, the recommendations made by the PFAC, and the current status of the initiative.

Section 5.07 Minutes

The PFAC Project Leader will distribute the minutes in a timely manner to all PFAC members and the BIDMC Board. The Project Leader will keep the minutes and all other pertinent council records.

Section 5.08 Inclement Weather

Council meetings will be cancelled in weather emergencies. If a member resides in a different county that declares a weather emergency, that member must notify the PFAC Project Leader to have their absence excused. Should a meeting be cancelled due to inclement weather, all Patient and Family Advisory Council members will be notified in a timely manner by the PFAC Project Leader or Council Co-Chairs.

Article VII. Committees

From time to time, the Chairs may deem it necessary to create a special committee or task force in order to further the work of the Council. The initiation of such a committee may be requested by any Council member.

Article VIII. Volunteer Requirements

Patient and Family Advisors are considered BIDMC volunteers and must adhere to volunteer requirements specific to our advisors. Prior to membership, incoming council members will

participate in an orientation to BIDMC, including HIPAA (Health Insurance Portability and Accountability Act of 1996) training, and a CORI background check.

Article IX. Confidentiality

Council members must not discuss any BIDMC business, personal or confidential information revealed during a council meeting outside their role as a patient or family advisor. What happens in a meeting should stay in the meeting.

Council members must adhere to all applicable HIPPA standards and guidelines. Confidential information includes, but is not limited to a patient's name, contact information, date of birth, diagnosis, treatment and current medical status, as well as information about the patient and his/her family's social history and overall experience here at BIDMC.

If an advisor violates these guidelines, membership status may be revoked.

Article X. Amendment Procedure

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