Patient and Family Engagement
Spring 2015 Newsletter

Patient and Family Advisor
Appreciation Celebration
Wednesday, May 13, 5:30 – 7 PM
Beth Israel Deaconess Medical Center
For more information or to RSVP, please contact Caroline Moore at cpmoore@BIDMC.Harvard.org or 617-667-4608

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Photo by Mal Malme, Advisor
Scholarship Allows a BIDMC Advisor to Attend IHI Conference: An Interview with Ashleigh Robert, Patient and Family Advisor
By Erica Dente, Patient and Family Advisor

Ashleigh Robert is a member of the ICU Patient and Family Advisory Council at BIDMC. In 2014, she was the recipient of the James Conway Patient and Family Advisor Scholarship, which enabled her to attend Institute for Healthcare Improvement’s (IHI) 26th Annual National Forum on Quality Improvement in Health Care. This conference, attended by nearly 6,000 individuals, took place in Orlando, FL in December 2014. Ashleigh attended the conference with her mother.

Tell us a little about your interest in attending the Institute for Healthcare Improvement (IHI) conference and what were the steps you had to take to receive the scholarship?

I was interested in attending the IHI conference because of what they stand for in healthcare. I love that they are their own organization and are not affiliated with any healthcare organization. Their mission is simple, to make people healthy. It’s the question that is more complex: “What would that take?” It takes so much more than medicine, and it is beautiful how they acknowledge that.

I received an email from BIDMC’s Patient and Family Engagement program in the summer about an opportunity to apply for a scholarship to attend their annual conference. The application involved answering a few questions, basically about my experience at Beth Israel Deaconess, and what does healthcare mean to me. The answers flowed onto the paper easily. I spoke about my illness and how Beth Israel not only healed me medically but they healed my soul.

I sent in the application in and waited. Never in a million years did I think that I would be picked for this amazing opportunity. It was enough for me just writing
the words. For months, I forgot all about my submission. When I received an email in October stating I was awarded the scholarship and could not believe it!

**Can you tell us about the highlights of your experience at the Conference?**

Every day was a new adventure, allowing me to gain new knowledge. There were so many highlights from the trip, from sitting in the front row with the all of speakers, to having my mom be able to share this experience with me. There are two moments that really stood out to me. The first one was attending the gala on the last night. I was just sitting there and then all of a sudden from across the room I saw my ICU doctor - the same doctor who asked me to be part of the PFAC. I raced across the room to where he was. (It is important to know that he no longer works at Beth Israel Deaconess, or lives in the Boston area, and I had not seen him in over a year). Dr. Howell was talking to other people, so I apologized for interrupting and explained to the others how I knew him, and the important role he played in my even being at this conference. Two people at his table jumped up, and one said, “Ashleigh! I feel like I know you! We hear your voice all of the time!” The two people with Dr. Howell were Ken Sands and Pat Folcarelli from BIDMC. Their greeting validated for me that what I do as a member of the PFAC matters, and what I say is heard.

The second highlight of the conference was meeting all of the other advisors from around the country. They made me feel so welcomed and so loved. They told me that I was now part of their family. It was so amazing to feel such a bond with people that I had just met. From then on they were my people; we had all gone through something traumatic and were trying to do something to make it easier for other people who have to go through the same experience. That is something I will remember forever, that we are family.

**Are there three takeaways from the conference that will change and/or influence how you partner as a Patient and Family Advisor?**
The first takeaway was that it is not all about medicine. There was a clear message that to keep someone healthy, it takes more than just medicine; it takes patience, it takes kindness and it takes knowing the whole person, beyond seeing them as a patient.

The second take away that I got was that people can learn a lot from you no matter where you fall under the healthcare umbrella. I knew being a member of a PFAC was great and rewarding, but it was amazing to hear people talking about patient and family advisory councils, and expressing their excitement and pride about having them at their hospital.

Finally, the third takeaway that I left with is from a quote that Robin Roberts said: “make your mess your message.” That quote has stayed with me. She had mentioned that everyone has something, whether it is good or bad, that makes you who you are, it defines you, and you need to make that your message to people. For a long time I was scared to talk about my experience, to hear what people thought, to see their reactions. After attending this conference I see that none of that matters, and if I can help someone, just one person with my message, then that is enough for me.

**BIDMC Physician Reflects on the Value of Working with Patient and Family Advisors: Interview with Jennifer Stevens, MD, MS**

**Please tell us a little bit about your position and role at BIDMC.**

I am a pulmonary and critical care fellow in the last year of my clinical training and I will be coming on staff here at the BIDMC as a medical critical care physician in July. I also conduct research on health care delivery and how to reduce unnecessary variation in patient care that doesn’t help the patient. One of my biggest interests is studying how we provide specialty care in the hospital and in the intensive care unit through a process known as “consultation”.

*Photo courtesy of Jen Stevens*
How are you using advisors in your current work?

Our advisors are my research collaborators. When ICU physicians call in specialists to help with a particular part of a patient’s care — sometimes for a procedure, sometimes for advice — usually it is important and valuable to the care of the patient. But if communication is poor, unnecessary tests and procedures may be ordered. If transitions of care are muddied, involving more doctors in the mix can sometimes make things worse. Advisors have been critical to my work in refining my research questions, helping improve my research design, and helping get the word out about what we’re doing.

Can you share an example of when a patient advisor or advisors influenced your work or your perspective about patient care?

Patient advisors not only influenced my research but they fundamentally changed how I practice. I attended my first meeting of the ICU PFAC early in my clinical training in critical care. As a physician, I had always valued patient rest and sometimes tried not to disturb them when I entered their room late at night. But one advisor showed me how entirely wrong that was. She described the fundamental feeling of dread and fear that she would have when people entered her ICU room without announcing themselves, comparing it to the terrifying feeling of thinking someone is creeping about in your bedroom. That sounded awful. I’ve never not announced my presence again. Just that brief story was practice-changing for me.

Do you have a message for fellow clinicians or for advisors about the impact of patient and family engagement on clinical care, research, and education?

It is essential that patients and families sit at the table of discussions of all three topics – clinical care, research and education. Many assumptions (like mine about how I should behave in someone’s ICU room in the middle of the night) are 180 degrees off – even when those assumptions are well intentioned. Ours is a service profession, but we need to be listening to those we serve. Every time I do, my research and my clinical practice are improved.
Celebrating Patient Safety Awareness Week at Beth Israel Deaconess Medical Center

On March 10 and 11, in celebration of National Patient Safety Awareness Week, advisors and staff members talked with visitors at tables in the lobbies of West Clinical Center and the Shapiro building, and handed out information. The purpose of the event was three-fold:

1. Raise awareness about patient safety.
2. Raise awareness about patient and family engagement.
3. Raise awareness about the Patient Relations Department.

Patients, family members, and other visitors who approached the table were asked to write down an anonymous response to the question “What could we do to improve your care experience at BIDMC?” , and were entered into a free raffle. Here are just some of the responses:

- Please install more automatic door openers.
- As the care here excels, it is a difficult question. My difficulty answering the question translates to the hospital’s excellence!
- Put Spanish channels on the TV.
- More signs indicating where the buildings are.
- I remember being afraid to say anything to a nurse who was prepping me for surgery and was rude. I was afraid that if I spoke up, that I will be seen as a “problem patient”.
- All of my experiences here have been excellent! Three surgeries and lots of tests.
- Please be friendlier.
- I use the hospital interpreters and this is a good hospital. No complaints!

The Patient Safety Awareness event team included advisors Betsy Lowe, Erica Dente, Howard Hillman, and Susan Johnson, along with staff members from Interpreter Services, Patient Relations, Patient and Family Engagement, Chaplaincy, and the Department of Healthcare Quality.
2015 Silverman Symposium

Patient and Family Advisors were well-represented at the recent Silverman Symposium Poster Session, on April 9 at Beth Israel Deaconess Medical Center, which featured the work of over 180 Improvement Project Teams from across the BIDMC system. Three posters highlighted the contributions of advisors: “Patient Engagement: A Seat at the Table” (Author: Leonor Fernandez); “Partnering with Patients for Safety: The OpenNotes Patient Reporting Tool” (Author: Sigall Bell); and “Experience is the Best Teacher: Patient and Family Advisors at the Forefront of Provider Education” (Authors: Caroline Moore and Barbara Sarnoff Lee). You can read more about the event and see the posters here.

“Above and Beyond”: Greg Bryant, Environmental Services

As a special new feature in the newsletter, we will be recognizing a BIDMC staff member who has gone “above and beyond” for our patients. For this issue, one of our advisors nominated Greg Bryant, a member of the Environmental Services team. Greg is known for his consistently upbeat and gracious nature, his willingness to help in whatever way that he can, and his ability to put a smile on anyone’s face no matter what they may be going through. Asked to describe his job, Greg captures the “human first” spirit of BIDMC:

“I have been working here for ten years as a housekeeper. I really love my job. I love to clean, and I love to make the patients feel happy. That is important because I am doing this job for the patients. They are like my family. Sometimes if I see a patient is sad, I try to cheer them up, encourage them to have strength and believe in themselves. This job is a blessing every day.”

Congratulations to Greg on being our first “Above and Beyond” honoree! If you would like to recognize a Beth Israel Deaconess Medical Center staff member who went “above and beyond”, please email: cpmoore@bidmc.harvard.edu.
Spring Images by Patient and Family Advisors

Photo by Claudette Casey, Advisor

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Special thanks to Advisor Erica Dente for her editorial assistance with this newsletter.