



Biology of Blood and Marrow Transplantation

journal homepage: www.bbmt.org



ASTCT Notes

ASTCT Notes

A Former ASTCT Member Reflects on His Own Transplant and Patient Care

It didn't matter how much training Naoto T. Ueno had, how many patients he had seen in his lifetime and how many medical books he had read. When he was sitting there on the other side of the table—as a patient and not as a doctor—nothing seemed to prepare him for how he felt.

“I was scared,” said Ueno, MD, PhD, FACP. “I thought, ‘Am I going to die?’ and if I did, was it going to be slow or fast? When I was working I tried to stop worrying about it, but at home with my family, I was like ‘I can't think about the future. I can't visualize myself five years from now.’”

In 2008, Ueno—a world-renowned breast cancer doctor and researcher at The University of Texas MD Anderson Cancer Center—was diagnosed with stage 2 sarcoma. It started with mass in his right thigh, and soon he found himself undergoing intense treatment. Six years later, he received more troubling news: he was diagnosed with myelodysplastic syndromes and required an unrelated mismatch allogeneic transplant in July 2017.

It was especially strange for Ueno, not only because he was a breast cancer doctor who saw patients undergoing some of the same treatments he was, but because he trained as an oncologist specializing in BMT. Now, two years after his transplant, the former ASTCT member and Chair of the ex-Solid Tumor Committee, is sharing his story in hopes to transform the way oncologists think about their patient interactions during these trying times.

“It's a very different perspective: doing transplant to other people versus doing it to yourself,” Ueno said. “I think we always need to be humble. We have to be humble about what we're trying to

provide to your patient and about the impacts of that care as well.”

For him, being a former transplant doctor in treatment of his own was a blessing and a curse. As doctors gave him a prognosis, they spoke to him in terms of outcomes—something he understood. He mulled it over with friends, among his family and with himself. While comforting in some ways, in others it was excruciating measuring the risks from each treatment course.

“We have the tendency to give hope to the reality of things,” he said. “But I was coming up with calculations for myself, and I was struggling. I said ‘This is not good to hear when I applied it to myself.’”

He learned very quickly that while his doctors remained professional and supportive, their approach to explaining his diagnosis was not patient-friendly. Even he struggled with knowing exactly what to do in his case, and the anxiety of “information overload” took a toll on Ueno and his family. He took risks in his treatment, trying experimental things that had lingering side effects, and sometimes felt regret for his choices.

If he was feeling this way, what was it like for a patient with none of the knowledge he had?

“How do we empower the patient in the decision process?” he said. “I thought I was really spending a lot of time with my patients going over their care, but retrospectively, I wasn't. I wasn't really thinking about what my patient was experiencing behind the scenes, and I found out the hard way. It's not just about transplant or treatment, the process of how we tell our patients why they need a treatment is much more complex than you think.”

Looking back, he realized there were a lot of things doctors were doing that

created more stress for the patient. He started advocating for oncologists to walk through risk and rewards for different type of procedures, to take time explaining the process and not just the outcomes and to be understanding and compassionate through it all.

While Ueno is still conscious about his health, he believes he's out of the woods. He's feeling good—both physically and mentally. He said he still feels a little slower than before, but he's energetic and grateful to be alive.

“I am more aware that living a life day-to-day is a conscious effort,” he said. “Most people don't think about why you're alive, but I do. Every day I appreciate it. Whether it's positive or negative. I'm still happy.”

ASTCT NEWS AND UPDATES

Attend Upcoming Educating APP Clinical Trials in Nashville, Seattle and Boston

These two hour meetings were developed to address the challenges of getting patients enrolled in clinical trials. The presenters determined there needs to be more education available to Advanced Practice Professionals in the community oncology clinics.

The two-hour sessions will focus on:

- The viability of clinical trials
- Best time to refer a patient for consult
- How to make contact with centers conducting clinical trials

Session registration is free and the meetings will take place in Nashville October 15, Seattle November 15 and Boston November 18. Click on the city nearest you to register! Sessions will be led by Darren Johnson, PA-C, Michael Wilson, PA-C and Dr. Corey Cutler, MD, MPH, FRCPC, respectively.

For more information, visit astct.org/meetings-events/educating-apps

Stay Tuned for the Upcoming Institutional Membership

The Institutional Affiliate Membership provides members within an institution to purchase affiliate membership as a group, offering a single invoice for multiple affiliate members. Institutional

members enjoy the same benefits as individual ASTCT affiliate members, including access to the community, ability to join a SIG or Committee, subscription to BBMT, access to policy and reimbursement updates and discounted registration to the TCT Meetings. The

institutional membership enables institutions to bring more of the employees in their cell therapy programs to participate in ASTCT as affiliate members and lower financial barriers for affiliate level members.

Visit astct.org for more info.