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Perspectives on Being a Caregiver for a Loved One With Mucosal Melanoma

Patricia Janiak learned how to ask the tough questions when her husband was diagnosed with mucosal melanoma.

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“Being a caregiver can be the hardest job,” says Patricia Janiak. “Your loved one might be the one going through this – but we’re the ones who have to put on our brave face while always being a step ahead. We’re the ones who call the doctors, ask the tough questions, and when needed, we push the envelope.”

It all began in February 2018 when John, her husband, reluctantly took her advice to see a doctor. He hadn’t been feeling well for several months, but thought it was just run-of-the mill hemorrhoids.

The gastroenterologist was concerned, and referred John to a surgeon. The surgeon agreed – this was more than hemorrhoids and scheduled surgery thinking it was rectal cancer. A week later, he called John with news that would change everything.

The surgeon explained to John that he had a rare form of melanoma that forms in mucosal tissues of the body and that this was far more serious than rectal cancer.

Mucosal melanoma is a rare form of melanoma that affects mucosal tissue in the body including the nasal cavity, lining of sinuses and mouth, the GI tract, vagina, anus, and other areas. Mucosal melanoma accounts for about 1% of all melanoma diagnoses. Unlike cutaneous melanoma, it is not believed to be caused by exposure to the sun or other sources of ultraviolet radiation. (Click here to learn more about mucosal melanoma. Later this year, MRA will launch the RARE Registry specifically for patients facing mucosal and acral melanoma.)

“I was sitting in San Francisco at a café when I got the call from John with the news,” says Patricia. “I took the red eye and 48 hours later we were at Massachusetts General Hospital.”

At Mass Gen, they met with a team of doctors to plan next steps, and two weeks later John underwent a second surgery to get closer margins. However, they weren’t able to get all of the tumor tissue.

In June, after a few weeks to heal, he began a combination of chemotherapy agents temozolomide + cisplatin to reduce the risk of his melanoma returning. A small study based in China had found that this combination resulted in significantly lower risk of recurrence and metastasis in resected mucosal melanoma.[1] Unlike the far more common cutaneous melanoma, mucosal melanoma has fewer effective treatment options.

He continued this regiment until January 2019 when scans revealed new growths. This time, his doctors suggested the combination of immunotherapy drugs, ipilimumab + nivolumab. After his third session of the combo, he developed colitis – a common side effect, or immune related adverse event, affecting 14.5% people who take the combo.[2] He never completed the fourth infusion.

In June, John suffered a car accident. He suddenly blacked out going 15 mph. After a week in a local hospital then another in a rehab facility — they told Patricia to take John back to Boston and Mass Gen.

Doctors there determined that he was experiencing a life threatening immune related adverse event that caused his brain to swell, called encephalitis.

“To be honest, no one ever talks to you about the worst-case scenario side effects — or all that doctors don’t yet know about these drugs,” says Patricia. “We didn’t know that this was even a possibility, but here I was calling the family because we didn’t think he was going to make it.”

After 75 days — in the hospital and rehab — John did make it. “It was a very scary period, but we got through it. After finally getting the swelling under control with large doses of steroids, he also had to learn to walk all over again.”

For Patricia, this period is when her role as a caregiver may have been the most important because John wasn’t always in a position to advocate for himself or make his own wishes known. It’s also when the challenges of caregiving were the most difficult for Patricia.

“I was a caregiver to three people at that point. John, our 44-year old son with Asperger’s Disease who lives with us, and my 94-year old mother,” recalls Patricia. I learned quickly how to advocate for everyone — while also taking care of myself.”

After learning the hard way of the importance of asking tough, probing questions – Patricia was no longer afraid to push the envelope. “I realized that you don’t get all the information you need if you are afraid to ask questions. So, I started to push back by asking about the overall plan and what was coming next.”

Thankfully — life began to calm down for Patricia and her family, but in February, 2021 they received more bad news. John’s melanoma had crossed his blood/brain barrier — and he would need a craniotomy to remove the new tumor.

“It was another scary period, but he came back. He even still practices as a lawyer part time,” says Patricia. “It really is amazing what the human body can take — and still come back from.”

Today, John is doing well and keeping busy with some work and the family’s new puppy. This summer has been full of grandchildren, visits with friends, and living life to its fullest.

Throughout her journey, Patricia learned a few lessons that she would like to share with others.

First, she recommends that everyone do their research. “It isn’t about knowing things inside out or backwards, you need to do the homework so you can get a sense of what you don’t know. This will help guide your questions,” says Patricia.

The next point that Patricia makes is that melanoma affects everyone involved – not just the patient. “You love your person, and you are trying to take care of them, their illness, and everything else that life requires. Don’t forget to make time for you — or you’ll burn out,” says Patricia. “I love my family dearly, but I don’t know what I would do if I didn’t have other outlets so that I could take a break and do something for myself. Know yourself — and if you need to get out, do it.”

Patricia still works part time as a realtor and would often head to the office for a few hours in the morning, play a few holes of golf, or meditate and do self-Reiki. “There isn’t a right or a wrong way to get through this, you have to find your own way.”

And finally, she suggests taking life — and challenges — one step at a time. “This is an overwhelming experience — and that really comes with the territory. You are going to get upset at times, but if you take it one day at a time — you’ll surprise yourself.”

Patricia is also helping to advance research into mucosal melanoma as a member of MRA’s RARE Registry Oversight Committee. The direct-to-patient registry, for people facing acral or mucosal melanoma, will help to answer critical unanswered questions about these rare subtypes. The registry, now in beta testing, will launch later this year.

In reflecting on her caregiving experience, Patricia says: “When I first learned of John’s melanoma, we were told that he had maybe one year to live. That was 3.5 years ago. I know how lucky we’ve been so far. And, I know that we won’t always be that fortunate, but right now, we are. I try to focus on that — and let that be enough.”

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