Living With Intention With Mucosal Melanoma: Eileen Walther's Story

Surgery for this rare cancer required the removal of Walther's left eye. "This is my journey," she said, "and I have to travel it."

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By Cody R. Barnett, MRA Director of Communications

In 2018, it had been just over a year since Eileen Walther had been diagnosed with follicular lymphoma, a typically slow-growing form of non-Hodgkin lymphoma that affects white blood cells. After undergoing a chemotherapy regimen known as R-CHOP, she'd been declared cancer free and was ready to get back to living her life. But what started as a recurring sinus infection finally landed her in the emergency department with an altogether new cancer diagnosis: mucosal melanoma.

Eileen's Mucosal Melanoma Diagnosis

Eileen, 64 years old at the time, had a life-long history of sinus infections. So, when she started to exhibit signs of one in spring of 2018, she thought little of it and made an appointment to see her doctor. After examining her, he prescribed an antibiotic and asked her to come back in 10 days to see how she was doing.

"I never made it to that appointment, because two days later my left eye was so swollen it looked like I'd been hit by a baseball bat," remembers Eileen. "So my daughter took me to Brigham and Women's Hospital where I received my care."

Once there, the doctors initially agreed with her primary care provider's diagnosis. Just to be safe, they took a quick CT scan. A mass was detected. "Oh, you are about to become the most popular person in the ER," the ER doctor told her.

The ER doctor was correct: a slew of doctors, representing many different specialties, flocked to see her. Ultimately, they determined that the mass was a necrotic polyp. A surgery to remove it and a biopsy would later confirm it as an altogether new cancer for Eileen: melanoma.

Despite this being her second cancer diagnosis in as many years, Eileen took it in stride.

“I felt like I had a dress rehearsal in cancer, with something that wasn’t nearly as devastating as mucosal melanoma,” said Eileen. “I had already worked through the angst and other feelings that come with the diagnosis and had even developed many of the tools I’d need later on to advocate for myself and get through this. If anyone can be ready, I was.”

Dr. Caron Jacobson, Eileen’s medical oncologist who had always steered her in the right direction for her lymphoma care, explained that melanoma was not her area of expertise. So, she referred Eileen to melanoma specialist Dr. Beth Buchbinder.

Dr. Buchbinder, an MRA funded investigator at Dana-Farber/Brigham and Women’s, specializes in treating patients with all forms of melanoma and is also well versed in the latest in melanoma research, including available clinical trials. “I trusted Dr. Jacobson with all my heart, if this is who she suggested — that was enough for me,” said Eileen.

A few days later, Eileen remembers meeting Dr. Buchbinder for the first time. Dr. Buchbinder explained that Eileen had a very serious and rare form of melanoma called mucosal melanoma. Mucosal melanoma represents about 2% of melanoma diagnoses each year, and develops in the mucous membranes of the body, such as those lining the mouth, nose, throat, anus, or genital areas. It is often diagnosed at a later stage than cutaneous melanoma, which can make it more difficult to treat. It also is often more aggressive and has a poorer prognosis than cutaneous melanoma.

Dr. Buchbinder carefully explained to Eileen that the standard treatment protocol for mucosal melanoma is surgery, followed by radiation and then immunotherapy. Dr. Buchbinder would coordinate Eileen’s care by working closely with a radiologist; an ear nose and throat (ENT) specialist, and due to the location of Eileen’s tumor, a neurologist. She then overviewed — and wrote down — each of Eileen’s various immunotherapy options, explaining the relative costs and benefits of each approach. Eileen still has the notes from that appointment.

“No decisions were made that day, but I remember one thing very clearly: I was never given an expiration date. It was always: ‘This is serious, but this is what we are going to do — here’s our game plan,’” remembers Eileen. She has always appreciated — and shared — Dr. Buchbinder’s determination.

Preparing for Surgery & Eileen’s Unicorn Challenge

At her first visit with Dr. Donald Anino, her surgical oncologist, the severity of her mucosal melanoma and its treatment became clearer. She would need a second — far larger — surgery that would require the removal of her left eye, part of her forehead, and may ultimately take away her senses of taste and smell.

The prospect of losing her senses of taste and smell bothered Eileen more than losing an eye. “I had another eye, a backup, but I didn’t have a backup for taste and smell. But, if that’s what it was going to take to save my life, so be it.”

Dr. Anino, still new to Eileen's enduring positivity despite circumstance, thought she was being cavalier. "I told him, I'd already had cancer. No one gets a get out of jail card — you always have to pay the price — and for me, that was cancer," says Eileen.

After that appointment, Eileen looked on Facebook to see if there was a support group focused specifically on mucosal melanoma. "I learned with my lymphoma that online support groups could be an important lifeline," says Eileen. She found a fantastic and active community in the private Mucosal Melanoma Warriors group. "I found so many great tips, strategies, and hope from others in the community."

Eileen also loved that the mascot of her new online support group was a unicorn, symbolizing the rarity of the cancer. "I loved that the group took ownership of mucosal melanoma in this way — it spoke to me."

With this inspiration, Eileen decided to set out on what she called her Unicorn Challenge. "I came up with a laundry list of every taste and smell that I was going to miss — to put it in my memory banks," says Eileen. "From puppy's breath to the smell of a newborn's head, people really came out of the woodwork to help me. The kindness of strangers, it really is amazing."

Eileen still sees some of the kind strangers who helped her cement some of the harder to find tastes and smells during her challenge. In fact, she's become the proud winkie — a grandmother of sorts — to the now almost six year old whose mother allowed her to smell her newborn's head over coffee. "It's funny how friendships start," says Eileen.

With the Unicorn Challenge now completed, the surgery was fast approaching. Even her doctors weren't entirely sure what to expect or how extensive the melanoma would be until the surgery was underway.

"It was a scary prospect, but this is my journey, and I have to travel it," Eileen recalls thinking.

Thankfully, Eileen did not lose her sense of taste or smell but did sacrifice her left eye to achieve clear margins around the tumor. Her surgeon also needed to replace a large section of her forehead. "The most painful part of the entire thing was the donor site from the skin graft used to close the site. They gave me Tylenol – and that was enough."

Radiation, Immunotherapy, & Celebrating Despite Melanoma

About a month after the surgery, Eileen began her radiation therapy. In mucosal melanoma, radiation is often used after surgery to increase the likelihood that all stray cancer cells were eliminated. She would undergo daily treatments for 22-days.

"The radiation sessions weren't that bad. They played music and each session was about a song and a half," remembers Eileen. "My friends, they really carried me through this. When facing melanoma, a support group is so important."

Parallel to her radiation sessions, Eileen also started immunotherapy infusions of Opdivo (nivolumab). She started to develop side effects from the immunotherapy, which prompted additional scans. Unfortunately, these identified new metastases on her liver.

“We thought I had gotten through the worst of it, but out of the whole journey, telling my daughter that the melanoma was back was the most difficult,” says Eileen. “We had our pity party and cried and then we put on our ‘big girl panties’ and soldiered on.”

At this point, Eileen and her care team decided that combination immunotherapy, with Opdivo + Yervoy (ipilimumab), would be the next step. In clinical studies, the combo had shown higher rates of efficacy at the cost of higher rates of adverse events.

Throughout this time, Eileen still found time to laugh and smile. The same friends who came with her to her daily radiation sessions would come out in a big way to celebrate Eileen’s 65th birthday. She woke up to find a giant inflatable unicorn in her yard with 65 bras hanging from the trees.

“With so much of this, you can laugh, or you can cry. Both are important, but my default is always laughter,” says Eileen. “I believe we all get to pick how we live our lives, and I’ve always made the conscious choice to embrace joy and gratitude. It’s made all the difference.”

Overcoming Side Effects, Being Declared NED & Living with Intention

Eileen completed two sessions of the combination immunotherapy before colitis made it impossible to continue. Colitis is a common gastrointestinal side effect that can cause abdominal pain, severe diarrhea, rectal bleeding, and weight loss. It is faced by some patients receiving checkpoint immunotherapy. Her team sprang into action, but prednisone and infliximab — common drugs used to help curb colitis — weren’t helping.

Dr. Buchbinder referred her to a gastrointestinal doctor who specialized in treating patients with cancer. This doctor suggested an older medication called budesonide that had been recently reformulated. It became Eileen’s miracle drug.

With the colitis in check, Eileen restarted treatment with Opdivo monotherapy in February 2019. By late spring, her scans were clear. Six months later, in November, her scans continued to be clear, and she was officially declared no evidence of disease (NED). She would continue her monthly infusions until March 2021.

Today, Eileen continues to be cancer free and receives regular surveillance scans just to be safe. She also is heavily involved with the Livestrong program at her local YMCA. “While focused on improving physical strength for cancer survivors — exercise and health eating and what not — it’s also a support group. We have more parties than anything. It’s great,” says Eileen.

She also has become a mucosal melanoma advocate and looks for opportunities to raise awareness of this rare melanoma subtype where she can. One way she does this is as a patient

advisor on MRA's direct-to-patient RARE Registry, which aims to accelerate research focused on mucosal and acral melanoma. "As people impacted by a rare cancer, we have to come together in order to be counted and to get the attention we deserve. That's what RARE is doing," says Eileen.

Eileen encourages anyone facing melanoma — or any cancer — to talk about what they are going through with their friends and family. "I've learned that people do want to help, while secrets will only ever do anything but help," said Eileen. "That doesn't make it easy. Learning to ask for help was one of my hardest lessons to learn."

Throughout her entire life — particularly through her journey with mucosal melanoma – Eileen has always tried to be grateful for life, even when it gets messy. Every night before she goes to sleep she thanks her left eye for taking one for the team and her right eye for doing the work of two. "So much about this is perspective," says Eileen. "We may all be on our own journey, but that doesn't mean we have to do it by ourselves."

Help advance mucosal melanoma research:

By joining MRA's RARE Registry, you'll be joining a supportive and growing community of patients, advocates, and loved ones who are committed to advancing research into rare melanoma subtypes.

Learn More About MRA's RARE Registry

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