Toni English's Journey from Mucosal Melanoma Patient to TIL Clinical Trial Participant and Advocate

In 2015 Toni saw a doctor because of frequent nosebleeds. She was diagnosed with a rare melanoma (cancer) and given six months to live.

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In the five years since overcoming Stage 4 mucosal melanoma, Toni English has found her life's passion advocating for patients and families and championing research to answer the many questions that surround this rare melanoma.

Accounting for just 1% of melanoma diagnoses each year, mucosal melanoma develops in the mucous membranes of the body (like the lining the mouth, nose, throat, anus, or genital areas) and is generally more aggressive than cutaneous melanoma – resulting in poorer prognoses for patients. Potential causes of mucosal melanoma are not yet fully understood, representing an important area of needed research.

Receiving a Rare Melanoma Diagnosis

For Toni, her journey with mucosal melanoma began in early 2015 when she started experiencing head cold–like symptoms. She initially treated her symptoms with over-the-counter medicine. However, her symptoms did not improve and soon progressed to nosebleeds. While Toni didn't think much of it at the time, her nosebleeds were becoming a frequent interruption at work and her boss encouraged her to see a doctor.

Heeding her boss' advice, Toni visited a local doctor to see about stopping her nosebleeds. The doctor identified a small lump in her nostril, took a biopsy of it, and sent the sample to a pathologist to examine it. Just a few days later, Toni received a shocking call; the cause of her head cold-like symptoms and nosebleeds was mucosal melanoma. Not only that, but she was told her prognosis was very poor and she likely only had six months to live.

"At the time in 2015, there was nowhere I could go to find out more about this cancer," said Toni.

It is estimated that there are around 1,200 new cases of mucosal melanoma diagnosed in the United States each year, making it incredibly rare and an area of research often overlooked. “Today, there’s a lot more information and research being done, but we still have a long way to go,” she said.

Self Advocating and Seeking a Second Opinion

After digesting the news of her diagnosis with her husband Roger, they decided to seek out a second opinion. Toni reached out to her family doctor, who referred her to a local and well-regarded Ear Nose and Throat (ENT) specialist. The ENT doctor was quick to get Toni in for an exam where he confirmed her diagnosis. He also told her that he had a colleague from medical school who was very knowledgeable about mucosal melanoma and recommended that Toni see him immediately. Seeing a specialist well versed in your specific melanoma is very important, especially for patients diagnosed with a rare melanoma subtype.

Arrangements were made and Toni was scheduled for laparoscopic surgery with the specialist recommended by her ENT doctor. This surgical method was ideal for her because she did not want to lose her eye or undergo facial reconstruction. “I woke up from surgery feeling wonderful because all the pressure in my face was no longer there. I was so blessed to have the surgery go well,” recalled Toni. Following the surgery, scans showed a bit of melanoma remained near her eye. She then began what would end up being 30 sessions of high-dose targeted radiation until there was no evidence of disease.

Toni then began surveillance scans every three months to monitor for recurrence. Just one year after finishing radiation, scans revealed melanoma metastases in her lungs, kidney, and brain. Toni was immediately put on a single agent immunotherapy and underwent gamma knife radiation for her brain metastases. After eight immunotherapy infusions, there was no reduction in size of the metastases on her lungs and kidney. However, gamma knife radiation successfully treated the lesions on her brain.

Around that same time, Toni and Roger learned that they were going to be grandparents. They decided to sell their house in Georgia and move to Florida to be closer to their soon-to-be grandson. “However much time I had left, I wanted to spend it being a grandmother,” Toni recalled thinking. “My grandson ended up being my medicine throughout this journey. He was a gift that kept me motivated and positive.”

As soon as their boxes were unpacked in Florida, Toni began researching the best cancer specialists in the area, which led her to Dr. Sajeve Thomas’ office. She restarted immunotherapy, but had to discontinue the infusions after three courses due to toxicity. Toni’s prognosis was once again dire, and she and her doctors worried they were running out of options. That’s until a new clinical trial testing Tumor Infiltrating Lymphocyte (TIL) Therapy opened at her hospital.

Enrolling in a Clinical Trial

During TIL therapy, immune cells known as lymphocytes are extracted from a patient's tumor that has been surgically removed. These cells are then expanded in large quantities in the lab and subsequently reinfused back into the patient to fight the cancer. But before receiving their personalized TIL infusion, the patient's existing lymphocytes are depleted with chemotherapy. Following the TIL infusion, patients receive therapy aimed at activating the immune system. The newly introduced TILs then work to eradicate the cancer cells within the body.

Toni immediately jumped at the opportunity to join the trial, which only had four openings. Fortunately, Toni responded well to the experimental therapy. In just six months, her scans showed No Evidence of Disease (NED). Toni's success wasn't isolated. In fact, 31% of heavily pre-treated patients enrolled in the study had durable clinical benefit.

TIL therapy recently gained Food and Drug Administration (FDA) approval in February 2024, making it the first cellular therapy to treat patients with unresectable or metastatic melanoma that have failed immune or targeted therapy, representing a significant treatment advancement in the fight against melanoma.

"I hadn't even heard of clinical trials before it was offered to me as an option," said Toni. "Ever since my time as a trial participant, I have become an advocate for more awareness around clinical trials – especially for mucosal melanoma patients, because we are eligible for so few trials." After her experience, Toni partnered with Dr. Thomas to help promote trials to patients, and even referred several patients for compassionate use of TIL Therapy before its recent approval.

Becoming a Mucosal Melanoma Advocate

Outside of her clinical trial work, Toni's advocacy within the mucosal melanoma community began long before her success with TIL Therapy. While trying to find more information about mucosal melanoma after her initial diagnosis, she came across the Mucosal Melanoma Warriors Facebook group. The group was founded in 2015 by people affected by mucosal melanoma who were at a loss for more information about the disease. When Toni joined in 2016, the group was small but mighty. It has since grown into an international community, reaching across the globe.

Through her involvement with the Mucosal Melanoma Warriors group, Toni grew close to a family whose loved one died of the disease. The family went on to create the Mucosal Melanoma Warriors Foundation (MMWF), a nonprofit dedicated to providing up-to-date information and resources on mucosal melanoma, where Toni currently serves as the Director of Operations. "The entire mucosal melanoma community works hard to reach as many people as we can to provide not only information, but also support and hope," said Toni.

Part of that outreach includes participating in twice-weekly video calls with the mucosal melanoma

community – where members can share their struggles, get answers to questions, and stay up to date on research. It was through one of these meetings where Toni first heard about MRA's RARE Registry. The RARE Registry gives patients with acral, cutaneous, and mucosal melanoma the opportunity to provide information about their disease journey to help researchers better understand the risk factors, tumor biomarkers, treatment effectiveness, clinical trial awareness, and quality of life of patients throughout their journey.

"Before the registry, mucosal melanoma patients had no network or pipeline to connect with researchers," explained Toni. "I encourage all patients I meet to take part in this initiative. The more people we have involved, the more we can help inform research about our disease."

Reflecting on her own melanoma journey and the challenges she faced in accessing information and effective treatment options, Toni underscores the continued need for awareness and research. By sharing her story, she hopes to amplify the voices of all those affected by this rare melanoma subtype, not just her own.

"My journey is important because it is what brought me to where I am today," explained Toni. "But my focus remains on advocating for others who might not have the same outcome as myself."

Through her advocacy, Toni continues to emphasize the importance of educating both patients and medical professionals about this often-misdiagnosed cancer. The struggles that many patients face in getting both an accurate and timely diagnosis and effective treatment has led to Toni losing many fellow mucosal melanoma warriors. Despite the personal toll, Toni's dedication remains stronger than ever, driven by a desire to prevent further loss and improve future outcomes.

"Any cancer diagnosis is horrible, but to be diagnosed with a rare cancer you've never heard of before can be very isolating. You wonder how you are going to fight it," said Toni. "What I really want people to know is that there is hope – and no one fights alone!"

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