# “I Am Worth It”: One Patient’s Fight to Access a Breakthrough Treatment for a Rare Melanoma

The tale of Ed’s journey with acral melanoma, from diagnosis and amputation to the cellular therapy that ultimately saved his life.

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When Ed was 56 years old, he noticed something unusual about his fingernail: it had split down the middle. At first, this change in his nail did not seem like much, something that many would initially dismiss or overlook. However, a visit to the doctor soon brought unexpected, devastating news. The split nail was the result of acral melanoma – a rare and aggressive form of melanoma that arises from melanocytes found under nails or on the palms of the hands and soles of the feet.

Acral melanoma, also known as acral lentiginous melanoma, accounts for 2-3% of all melanoma cases in the United States. Unlike the most common form of melanoma (cutaneous melanoma), which develops on sun-exposed skin, acral melanoma is not believed to be caused by sun exposure. Although it can affect people of all races and ethnicities, it disproportionately affects people of color. Acral melanoma is often associated with a worse prognosis than cutaneous melanoma, particularly when it is diagnosed at more advanced stages.

Initial Treatment for Acral Melanoma

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Ed underwent amputation of the affected finger to remove the acral melanoma – and it seemed as though the worst was behind him. However, in the time from diagnosis to amputation, Ed's acral melanoma had spread to his lymph nodes.

Once melanoma spreads, additional treatments – like immunotherapy – are sometimes needed before or after surgical removal. For Ed, immunotherapy treatment initially appeared to eliminate the cancer cells that spread, and life went back to normal. "I still feared that my cancer would return one day," Ed recalled.

Only a few years later, Ed's acral melanoma reappeared, spreading to both of his lungs. Ed's prognosis was grim – doctors tried to fight his disease with radiation and several immunotherapies, but nothing worked. "They told him to get his affairs in order," said his devoted wife and caregiver, Angie.

## Exploring Cellular Therapy for a Melanoma Recurence

As Ed's acral melanoma continued to advance, options were running out. That's when Angie began searching for other therapeutic options. Her research led her to a new treatment for patients with melanoma called tumor-infiltrating lymphocytes therapy, or TIL – a cellular therapy that harnesses the body's own immune cells to attack cancer cells. AMTAGVI (lifileucel), approved for the treatment of patients with advanced melanoma in the second line treatment setting, was the first individualized TIL therapy to earn FDA approval for any cancer. While rare melanoma subtypes like acral and mucosal melanoma are often excluded from clinical trials, it is incredibly fortunate for Ed and other patients that in this case, they were part of the study that that helped get AMTAGVI FDA approved.

Angie's discovery of this treatment offered hope, and Ed's doctors supported him trying TIL therapy, but the process of getting it approved by insurance became an unexpected hurdle that Angie negotiated with research, advocacy, and tenacity. She was determined to get Ed access to a treatment that could potentially save his life.

It became very clear that the challenges of a rare cancer diagnosis extended beyond the disease itself, leaving patients like Ed with fewer resources and the exponential burdens of research, expenses, and advocacy.

"My wife is my rock. She advocated for me when I couldn't advocate for myself," said Ed.

Angie wrote letters and arranged phone calls to her senator, the Office of the U.S. Attorney General, and eventually, the White House. Seven days later, Ed was approved to receive TIL therapy. "Knowledge is powerful: if we don't try, we won't ever know," said Angie.

## Hope for Patients with Rare Melanomas: TIL Therapy

Undergoing TIL therapy was not easy, but it saved Ed's life. An in-patient hospital stay is part of

the process (usually 12-13 days, but every patient is different, and it was longer for Ed). Ed also had follow-up physical and occupational therapy at home to help the recovery process. Day by day, Ed pushed forward, and for him and Angie, it was worth it all. Today, Ed is No Evidence of Disease (NED) and continues to be monitored.

For Angie, the journey as a caregiver was just as intense. There were many moments when she was not sure whether her husband would ever come home again. She became not only a caregiver but also a fierce advocate, navigating a rare disease in a complicated healthcare system. This determination was mirrored by the dedicated care team and a steady stream of visitors in the hospital that also never gave up on Ed.

“Persistence, and a willingness to challenge the system, made the difference,” Angie reflected.

Now one year after receiving TIL therapy, Ed and Angie reflect on their collective journey. Ed still remembers how bleak his future once seemed; but today, he has a new outlook on life.

Ed hopes that sharing his story gives others hope. For Angie, her message to patients and doctors is to know about treatments like TIL therapy before melanoma advances to late-stage disease, and to remain persistent if health insurance denies or present challenges with new therapy like TIL. Their advice to others facing a rare melanoma diagnosis is this: advocate for yourself, ask questions, and never stop fighting. “Time is everything. I am worth it and so are you,” said Ed.

**AMTAGVI (lifileucel) is the first and only FDA-approved one-time T cell therapy treatment for people with previously treated melanoma that has spread or cannot be removed by surgery. To learn more about this therapy, visit https://www.amtagvi.com/ and speak to your doctor about whether it might be right for you.**

**To learn more about current research directions in TIL therapy, including the ongoing TILVANCE-301 (NCT05727904) trial which is enrolling patients with Stage 3 or 4 unresectable or metastatic cutaneous, mucosal, or acral melanoma to test lifileucel as first-line treatment, visit MRA’s interview with Stephanie Goff, MD, senior research physician in the Center for Cancer Research at the National Cancer Institute (NCI).**

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