Stage 4 Mucosal Melanoma to No Evidence of Disease: Dane Thorp's Journey

A clinical trial involving mRNA therapy along with immunotherapy shrank the tumors. Next, Dane battled to come off opiates.

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"I can't hide the fact that I had melanoma," said Stage 4 mucosal melanoma survivor Dane Thorp. "And when I share my story with others, I always emphasize the importance of being your own advocate."

Dane was only 34 years old and just a few months away from welcoming his first child with his wife Jenny when he was diagnosed with mucosal melanoma, a rare subtype that develops in the mucous membranes of the body.

Mucosal melanoma is a very rare diagnosis, accounting for only about 1% of all melanoma cases — which accounts for around 1,200 cases in the United States each year.

A Seemingly Harmless Bump Develops

Dane's melanoma journey began in December 2018 when he first noticed a tiny, colorless bump on his lower lip. He assumed it was a harmless cyst and ignored it for a few weeks, expecting it to go away on its own.

When the bump did not go away and began to itch, Dane decided it was time to schedule an appointment with his primary care doctor. Dane was then referred to a head and neck doctor for further examination. The head and neck doctor did not think the lump was a serious concern, so a procedure to remove the bump was scheduled for a few months later with an oral and maxillofacial specialist.

By the time June came around for Dane's procedure, the lump had started to hurt. The oral and maxillofacial surgeon removed the lump from Dane's lip with local anesthesia and believed it to be

a clogged saliva duct. However, to be certain, his doctor sent the lump to pathology for further examination.

Three days later, Dane received an unexpected phone call: the bump in his lip that he first noticed more than six months prior was mucosal melanoma.

Being Diagnosed with a Rare Melanoma Subtype

Following this news, and to ensure all traces of melanoma were removed, Dane needed to undergo a more invasive excision under general anesthesia. Unfortunately, this surgery did not achieve clear margins and another excision was needed. Dane's second melanoma excision ended up removing about 60% of his lower lip, but margins were still positive for melanoma. "It was at that point we decided to stop chasing surgery and instead look into a therapeutic route," explained Dane.

To try and target the area more aggressively, Dane underwent brachytherapy, a form of radiation used to destroy cancer cells and shrink tumors. Dane then began a regimen of single-agent immunotherapy, pembrolizumab.

Around February 2020, and six months into immunotherapy treatment, Dane felt a lump along his jaw. He expressed concern to his local oncologist, who did not have the same concern.

Disappointed with his oncologist's lack of urgency about the new lump, Dane scheduled an appointment with his head and neck doctor, Dr. David Mullin, to get a second opinion. "In health care, you have to be your own advocate and educate yourself on your condition and what you'll potentially go through," said Dane. When he was finally seen a few months later in May, a biopsy of the lump in his jaw confirmed his worries: his melanoma was spreading.

This news prompted Dane's oncologist to switch him from single-agent pembrolizumab to combination immunotherapy ipilimumab-nivolumab (commonly referred to as ipi-nivo). But by his third dose of ipi-nivo, Dane was experiencing severe side effects that left him bed ridden.

During this same time Dane underwent a full body MRI to determine whether his melanoma spread to any other areas. Unfortunately, the MRI revealed a small metastasis in an area of the skull base known as the Meckel's or trigeminal cave. Surgical removal of the metastasis was not a safe or viable option.

To explore other potential therapeutic options, Dane received a referral to Dr. Omid Hamid at The Angeles Clinic & Research Institute, A Cedars Sinai Affiliate, Los Angeles, based on his expertise in brain metastasis.

The Discovery of a Brain Metastasis

It was clear by the discovery of Dane's brain metastasis, and the fact he was experiencing severe immune related adverse events (irAEs), that his current treatment plan was not working nor was it sustainable. Dane was also unhappy with the care he was getting from his local oncologist, especially as he was trying to get his side effects under control.

Refusing to settle and in need of trying to get his side effects under control, Dane advocated for a new oncologist for his day-to-day care. He was promptly introduced to a new oncologist at Kaiser San Marcos, Dr. Sujatha Murali, who agreed that a second opinion would be valuable, so she referred Dane to Dr. Gregory Daniels at the University of California San Diego (UCSD).

While an unusual circumstance, Dane found himself with concurrent referrals to two melanoma specialists at two leading cancer centers Dr. Daniels at UCSD and Dr. Hamid at the Angles Clinic. Taking advantage of this opportunity, Dane met with both doctors to discuss his case. Drs. Daniels and Hamid connected with one another and set out on a mission to look for clinical trials that might be a valuable treatment option for Dane's melanoma.

By October 2020, the once-small lump in Dane's jaw had grown to about the size of a grapefruit. He received local radiation to the site and completed thirty rounds, but to no avail. He also discontinued ipi-nivo and returned to single agent pembrolizumab to try and assuage some of his side effects. By the end of the year, the Meckel's cave metastasis was progressing and migrating towards his brain stem.

With the help of Drs. Daniels and Hamid, they identified a TIL clinical trial at UCSD for which Dane was eligible in January 2021. TIL therapies involve extracting immune cells called lymphocytes from a patient's tumor, growing them in a laboratory, and then reinfusing them back into the patient's body — harnessing their own immune system to target and destroy melanoma cells. This provided immediate hope, but unfortunately Dane's immune cells failed to grow in the lab, and he was forced to disenroll from the trial.

Enrolling in a Clinical Trial

Around that same time, Dane was informed that he would need to decide on one melanoma specialist to move forward with. Happy with both Dr. Daniels and Dr. Hamid, Dane decided to move forward with Dr. Daniels due to a matter of logistics: UCSD was closer to where he lived.

With the TIL trial behind him, Dane began an Interleukin-2 (IL-2) combo with nivolumab in March. Scans during treatment revealed his metastasis reached the brain stem and was 1.4cm in size. The tumor in his mouth was too large to measure. "This was all bad news," recalled Dane. "My life expectancy at this point was weeks to months."

Despite moving forward with Dr. Daniels as his specialist, Dr. Hamid still had Dane's case on his

mind. He heard about another clinical trial (NCT03946800) testing investigational mRNA therapy, MEDI1191, in combination with immunotherapy, durvalumab. He reached out to Dr. Daniels with this information. “We had high hopes, but no expectations,” said Dane.

Dane enrolled in the clinical trial in May, which consisted of injections directly into his mouth tumor every 3 weeks. By the start of the trial, the tumor had eaten away at surrounding teeth and bone. However, after each immune injection, the tumor showed a significant response by shrinking. “I knew the treatment was working immediately, but I didn’t understand how well it was working until my first scan,” explained Dane.

At his first brain scan on week six of the clinical trial, Dane’s brain metastasis shrunk from 1.4cm to 0.4 cm. Three weeks later, it shrunk again to 0.1cm. By the 12-week mark in August 2021, his brain metastasis was undetectable. It finally seemed like things were heading in the right direction, but a very complicated and invasive surgery to remove what was left of his mouth tumor loomed.

A Complicated Surgery to Remove All Traces of Melanoma

After a tumor board review, Dane’s surgery was approved by both UCSD and Kaiser, and ultimately scheduled with Dr. Mullin at Kaiser San Diego.

“This surgery was a bigger deal than I ever expected, but it was a life-or-death choice, and I had a young daughter to live for,” said Dane.

On September 30th, 2021, Dane underwent a mandibulectomy and fibula free flap reconstruction. This entailed the removal of all cancerous tissue, which had invaded more than half of his lower jaw. Then, a large portion of leg tissue and a portion of his fibula were extracted and used to reconstruct his jaw. He also required a skin graft taken from his thigh to cover the site where the tissue and fibula piece were removed. The complex surgery took 14 hours in total, and a long road of recovery followed.

Due to the location of his surgery, Dane needed a feeding tube to eat and a tracheotomy to assist with breathing. His recovery was not easy or close to over, but on day five Dr. Mullin delivered the news that the surgery achieved clear margins and Dane was officially cancer free. However, just a few days after the news of being cancer free, he had a scary setback and underwent emergency surgery for a complication with his tracheotomy site. He remained in the hospital for nearly four weeks after his initial surgery before he was finally able to go home and reunite with his family at the end of October 2021.

Fighting Another Battle and Adjusting to a New Normal

Despite recovering from his surgery and the good news of being ‘No Evidence of Disease’, Dane had an unexpected battle ahead. That is because earlier on in his melanoma journey, he developed severe mucositis – a common side effect of radiotherapy that can cause painful

inflammation. Back then, to treat his mucositis, his doctors prescribed him opiates. And as it worsened over time, his dosage was increased.

“My doctors were doing their best to keep me comfortable through all of my treatments and side effects,” explained Dane. “I wasn’t expected to survive my melanoma, so there was never a concern about me having to come off of the opiates.”

It took nearly a year after his mandibulectomy surgery for Dane to feel like himself again, in part due to the opiate dependency he developed throughout treatment. His palliative doctor suggested a dosage de-escalation schedule to taper off the opiates every 6 weeks, but Dane wanted to start living life sooner rather than later. He decided to move the process along a bit faster, and towards the end stopped the opiates abruptly.

“I was sick of being beholden to either cancer or drugs,” Dane recalled, “I wanted my life back.” He experienced withdrawals for the following four months. He had no interest or enjoyment in life at that time, despite having just beat cancer. “I survived melanoma to have the next ten months of my life be a horrible battle. It was the hardest thing I went through, and a very lonely journey” he said.

But with pure willpower and persistence, and the loving support of his family, Dane survived an unimaginable journey. And in January 2023, Dane and Jenny welcomed their second daughter. “My biggest fear was always that I was going to leave my daughter without a dad,” he shared. “But now we don’t have to worry about that, and I get to be a dad to my two girls.”

Today, Dane’s scans continue to show No Evidence of Disease (NED).

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