From Melanoma Patient to Caregiver

At first Leah Adams was ashamed of her diagnosis at age 26—shortly after her dad's diagnosis of the skin cancer—but now she's an advocate.

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By the time she was 26-years old, Leah Adams had spent countless hours tanning. Growing up in Ohio where the winters were long, she felt a pressure to stay tan far beyond the summer months, so she turned to tanning beds. Despite her habits, skin cancer — let alone melanoma — was nowhere on her radar. That all changed when her dad Gary was diagnosed with Stage 0 melanoma in 2019. When melanoma is Stage 0, also referred to as 'melanoma in situ,' it is contained completely in the epidermis, the very outer layer of the skin. Her dad underwent surgery to remove his melanoma.

From her dad's experience, Leah learned a bit about melanoma for the first time. Considering her family history, past sun exposure, and the fact that she noticed some new and changing moles appearing on her body, she scheduled her first ever full body skin exam with a dermatologist. While at her appointment, the dermatologist removed and biopsied a mole from Leah's chest. "I was sure it was nothing," Leah recalled thinking. "And if it was something, they will just remove it and I can move on."

Melanoma Diagnosis at 26 Years Old

Unfortunately for Leah: both assumptions were wrong. Two weeks after her initial biopsy she was diagnosed with melanoma that was Stage 1A bordering on 1B. This meant that she needed a wide local excision to remove the lesion and what is called a Sentinel Lymph Node Biopsy (SLNB) to determine if the melanoma had spread beyond the skin to the nearest lymph nodes. Because of melanoma's ability to spread to other parts of the body, Leah's dermatologist did not want to waste any time. Within two weeks, and just over a month after her dad's melanoma removal, Leah underwent her own surgery.

"I had no idea what to expect from my surgery or recovery," said Leah. "A lot of people just think you walk in and walk out. My experience was much more intense than that." Following her surgery, Leah was in recovery for over twelve hours before she was able to leave the hospital. The incisions on her chest and armpit were very sensitive — and her stitches stayed in for nearly three weeks. Leah, an avid runner who was eager to continue her active lifestyle, found the recovery from surgery to be both physically and mentally challenging.

Luckily, within a few weeks, Leah finally received some welcomed news: the SLNB results came back negative for melanoma — meaning that her melanoma had not spread. Leah also underwent additional diagnostic testing to determine the risk of her melanoma returning. The commercially available test, known as DecisionDx-Melanoma, is used by some doctors and patients to inform their decisions about:

- the need to perform a SLNB,
- what level and frequency of follow-up visits are needed,
- the need for additional imaging, and
- to determine if referrals to other specialists are appropriate, such as medical oncologist to discuss adjuvant therapy.

Fortunately, Leah's test results showed that her melanoma had a low risk of returning.

Coming to Terms with a Melanoma Diagnosis and Spreading Awareness

Following her experience, "I felt very embarrassed and ashamed," explained Leah. "I felt like I gave myself cancer. I was so upset with myself." Like Leah, many patients with melanoma struggle with feeling a sense of responsibility for their diagnosis because most melanomas are caused by exposure to ultraviolet rays from the sun and indoor tanning. Because of this shame, Leah kept her diagnosis secret from most people in her life. It took time for Leah to accept her diagnosis, her new scars, and her new normal without blaming herself for it.



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A post shared by Leah Alexis Adams (@theleahalexis)

In time, she decided she was ready to share her story more publicly for a couple of reasons. First and foremost, Leah wanted to share her experience in the hopes that it would help other melanoma patients and survivors feel less alone. Additionally, she hoped her story could serve as a point of warning to other people about the dangers of sun exposure — especially those who are intentionally tanning. The use of tanning beds before the age of 35 — just like Leah experienced — increases one's risk of melanoma by 75%.

Leah took to Instagram to share her story –— and was met with an outpouring of love and support. "Ever since that moment, I've become an advocate in the melanoma space. I believe I've found my purpose," said Leah.

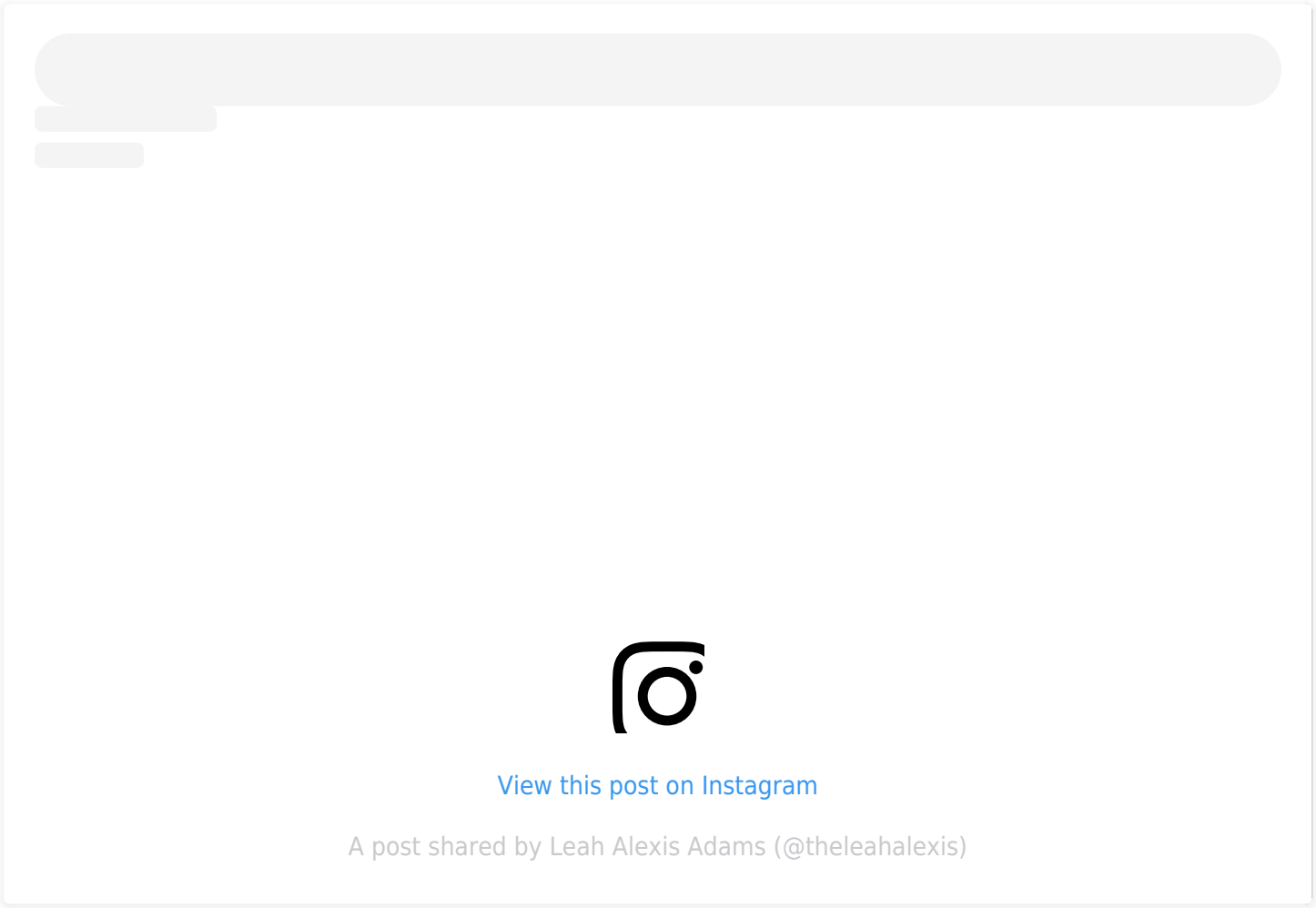
Leah is now working with and supporting several melanoma organizations, promotes sunscreen and sun protective clothing brands, and continues to raise awareness of melanoma and the importance of sun safety every day. Leah also went on to enjoy her first beach vacation post-melanoma: discovering that you can still enjoy life while being sun safe.

The Shock of a Melanoma Recurrence

Exactly one year after her melanoma diagnosis, while continuing with her quarterly dermatologist visits, Leah had her first scare. A spitz nevus — a rare type of mole that looks concerning but is actually benign — was found on her leg. Given her history of melanoma, Leah had the mole removed. While this surgery was far less invasive than her wide local excision and SLNB, it still brought her back to that moment emotionally.

Then, just a couple of months after her spitz nevus scare, in January 2021, Leah's dad had a

terrible accident. She learned that her dad suffered a seizure while driving. While hospitalized, scans found lesions in his lungs and brain — indicating that his melanoma returned and was now Stage 4. “We were shocked,” said Leah. “How was his melanoma back so soon, and so much worse?”



Most people with early stage melanomas will be treated successfully when their melanoma is found and detected early, but unfortunately, a slim minority of patients will relapse.

Leah was unable to visit her dad while he was in the Intensive care Unit (ICU) due to COVID-19 restrictions. Her mom kept her updated as he recovered from his seizure and began to make treatment decisions. When he was stable enough to begin treatment, Leah’s dad underwent Gamma Knife radiation therapy on his brain and started combination checkpoint immunotherapy Opdivo (nivolumab) + Yervoy (ipilimumab) for the rest of his metastatic disease.

Caregiving as a Melanoma Survivor

The sudden turn in her dad’s health propelled Leah into the role of caregiver. “My dad had a lot taken away from him in a really short amount of time. It was hard to see him go through that. As an only child, I took on a caregiver role not only to help him, but also to support my mom in all she was going through,” recalled Leah. Because of the aggressive nature of her dad’s melanoma and the related seizure, he spent a significant amount of time in the hospital, at appointments, taking

medications, and managing treatment side effects. Leah was able to support her dad in all of these things. In fact, throughout this process their relationship grew even stronger. “Strangely enough, melanoma brought us closer together,” said Leah.

Riding the rollercoaster of shifting into a caregiver role just over a year after her own melanoma diagnosis really reinforced Leah’s desire to be a voice in the melanoma community. For Leah, it was important to show the full spectrum of the melanoma experience. From early to advanced melanoma, and from surgery to the various therapeutic approaches — the juxtaposition between her experience and that of her dad’s displayed perfectly that melanoma is no simple disease.

Leah’s passion for spreading awareness and sharing her story has proven impactful. She has encountered a lack of awareness and education around melanoma and the dangers of UV exposure. “We have a long way to go in educating the public about this cancer, how to prevent it, and the signs to look for,” said Leah.

The Role of Clinical Trials in a Melanoma Journey

While searching for other ways to get involved with melanoma awareness and advocacy, Leah learned about a Cleveland Clinic study run by dermatologist Dr. Josh Arbesman. The study builds from Dr. Arbesman’s work with colleague Dr. Pauline Funchain in establishing The Gross Family Melanoma Registry to explore the genetic risk factors of melanoma and other cancers. Leah and her dad both joined the registry and underwent required testing and blood draws. They will continue to be monitored and sampled over the next five years in the hopes of identifying familial and genetic connections in the occurrence of melanoma. Leah’s dad also entered a research study on his own that is looking to better understand necrosis as it pertains to cancer care.

“If nobody takes part in these studies or clinical trials, how are we expected to learn anything or find better detection and treatment methods?” asked Leah. “We have got to do something about the many misconceptions that surround clinical research!” It is true that there is a stigma and many negative misconceptions surrounding clinical trials. Today, only 1 out of 20 cancer patients enroll in a clinical trial.

Learn more about melanoma clinical trials.

Moving Forward with Prevention and Detection at the Forefront

February 2023 will mark two years of immunotherapy for Leah’s dad. Since last summer, he has not needed any additional Gamma Knife radiation sessions, and scans show that his melanoma, while not shrinking, is at least stable. They are taking things day-by-day, but continuing to be positive.

View this post on Instagram

A post shared by Leah Alexis Adams (@theleahalexis)

Leah continues to regularly see her dermatologist for full body exams. Between her own diagnosis and her dad's current battle, she is staying vigilant. "I'm so fortunate and grateful that my melanoma was caught early, but that doesn't mean it can't return some day," she said, just like her dad's did.

For Leah, her priority right now is moving forward, being there for her dad while living her life sun safe, and spreading awareness about melanoma. "Many of us have made poor decisions in the past when it comes to protecting our skin, but we can't stay in the past because of it," said Leah. "You have to live your life in the present and for the future. Don't let melanoma live life for you."

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