Libby Kistler: “I’m Still Here”

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Statistically, Libby Kistler shouldn’t be here. She was diagnosed with Stage IIIB melanoma in 2005, before treatment for late-stage melanoma was transformed by immuno- and targeted therapies in 2011.

Her journey with melanoma started in the late 1990s when she noticed a dark spot above her left knee. Her primary care doctor said it was nothing to worry about, so she kept an eye on it and left it at that. Fast forward to 2005, and the mark had started to bleed. Libby knew that this wasn’t right, and made an appointment with a plastic surgeon.

The second the plastic surgeon saw it, without decorum or tact, he shouted: “oh my god, I think that’s a big damn melanoma.” She felt like a truck hit her. This was day 1 of her ‘new’ normal.

At first, she played it close to the vest and didn’t tell her friends, colleagues, or her children. “I didn’t want to make a big deal or make them worry” said Libby. “It still could be nothing after all.”

But it was something. The plastic surgeon confirmed the biopsy results days later—it was melanoma. He referred her to a surgeon for a sentinel node biopsy to determine if the melanoma had metastasized to the lymph nodes located near her tumor.

After a few agonizing days the results were in. Libby’s knees buckled when she heard the news. Not only did she have melanoma, it was Stage IIIB and she was told that her prognosis was bleak.

Soon after, a surgeon removed further lymph nodes that might contain cancerous cells in what is termed a ‘complete lymph node dissection’ and Libby started regular follow up appointments. Once again, things didn’t feel quite right to Libby. “He just didn’t seem to be doing anything more than watching and waiting—and I’m just not the watch and wait kind of person.”

Even though it is a common approach to watch and wait for Stage IIIB melanoma, Libby did what any empowered patient would do and looked for FDA-approved treatments. She quickly realized that the available option wasn’t great. Interferon increased the time to relapse in a small fraction of patients — but also had significant side effects. It wasn’t a good fit for her.

Next, she looked for clinical trials that might be a good fit and found six melanoma vaccine trials that looked promising. Libby was smart to consider clinical trials. While only 1 out of 20 cancer

patients enroll in a clinical trial, they can offer access to treatment approaches that may prove more beneficial than anything currently approved by the FDA. Learn more about clinical trials or find trials that are a good match for you using our interactive Clinical Trial Navigator.

She chose a trial being offered at New York University Medical Center with Anna Pavlick, DO. Upon meeting Pavlick and her team, Libby felt like it was meant to be. She would receive injections of an experimental vaccine once a month for six months.

“Dr. Pavlick was the first doctor to ever give me any hope. And—I know this sounds silly—but I knew with the first injection that this was going to work,” said Libby. “That feeling never left.”

Over ten years later, Libby is still here with no recurrence. “I can’t pinpoint exactly when it happened, but I’ve learned to not live in 3 month increments anymore,” said Libby.

Unfortunately, the trial Libby enrolled in was judged a failure. In fact, all six of the clinical trials that Libby researched were deemed statistical failures. For early phase clinical trials this can mean, that the drug caused too many severe side effects or that the fraction of patients who appeared to benefit wasn’t any greater than what you’d expect to see in patients who received the standard of care. But even in failed trials, a very small fraction of patients may benefit. It seems that Libby might be one of these lucky few.

“I knew that I was going to be a miracle. [The trials] may have failed statistically, but that doesn’t mean they failed for me personally,” said Libby. “I’m still here. Even if I’m not supposed to be statistically.”

Today, patients with Stage IIIB melanoma, like Libby, have more treatment options than ever. While some patients are successfully treated with surgery alone, those with a high-risk of recurrence can take ipilimumab or nivolumab as adjuvant therapy. Adjuvant therapy works to reduce the risk of melanoma returning after surgery.

Libby gives back by volunteering for a variety of melanoma-related causes, including advocacy work against tanning beds. She is also an active participant on MRA’s Melanoma > Exchange online community. When she meets people who are just starting their journey with melanoma, she suggests that they “get themselves to a melanoma specialist as soon as possible.”

“Giving back has become my life’s work because I know I can help turn this around—I’m here for a reason,” said Libby.

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