Sézary Syndrome: Elizabeth's Story

Liz Bowen seized the opportunity to try a new type of transplant to cure her burning pain.

Elizabeth Bowen
Hampton, New Hampshire
Transplant: 2019
Diagnosis: Sézary Syndrome

Many thanks to Dana-Farber Brigham Cancer Center, the American Society for Transplantation and Cellular Therapy, and Incyte for helping to share Liz’s story.

In 2012 -- shortly after she quit smoking and took up running -- Liz Bowen developed an itch on her arm that wouldn't go away. Over the next two years the itch spread body-wide, coming and going in waves. Five years into this medical conundrum, Liz’s skin was so
itchy, red and irritated that it felt, as she describes it, as if “I had a third-degree sunburn.” She’d been seen by a myriad of
dermatologists and still had no clear diagnosis.

In July of 2017, Liz was referred to the department head of the Cutaneous (Skin) Cancer Treatment clinic at Dana-Farber Cancer Institute in Boston. Finally, doctors determined that -- though she didn’t fit the typical profile -- Liz most likely had Sézary syndrome, an aggressive form of a blood cancer called cutaneous T-cell lymphoma. As sobering as this diagnosis was, it seemed to offer a clear treatment path via proven medications.

Unfortunately, Liz developed resistance to the first drug, and moved through several alternative treatments and trials without a permanent solution. As Liz remembers, “After each option failed, the cancer came back, ten times worse. And the pain was terrible.” By late 2018, even though Liz was responding well to a new FDA approved treatment, her history of medication resistance led her medical team to suggest she consider a stem cell transplant.

Simultaneously, Liz and her husband were preparing for the wedding of their oldest daughter. Liz told her doctors, “As long as we can do it after Oct 4th, (the wedding date) no problem!” Unfortunately, time was of the essence. With their family’s usual aplomb and good spirits, the wedding was moved up to June.

Immediately after the celebration, Liz began a unique protocol as the first patient in the new Ambulatory (Outpatient) Transplant Program at Dana-Farber, the first of its kind in New England. The program is designed to reduce hospital stays for patients who undergo reduced-intensity conditioning, which allowed Liz to go on living at home through the entire transplant process. “I was so incredibly fortunate,” she says, “that I was not hospitalized.”

Outpatient care did, of course, require some exceptionally long days “in clinic,” made more bearable by the outstanding nursing care Liz received. As she says, “I was sitting there ‘by myself’ for 10 hours, but I was never alone.” Liz’s gratitude for the nurses she met along the way abounds. “Being the first outpatient transplant patient was great because the nurses and I were teaching each other along the way…To this day, when I go in and see the nurses I was close to we’ll be like ‘Hey let’s sneak in a hug’!”

Liz is finally far enough from transplant to look back. “It will be three years this July,” she says, “and I’m still coming to terms with it. Some days I’m like, what just happened? I have no idea what the chemo or trials I was on will do to my body, but that doesn’t matter. What matters is that I’m here. And I have a family who loves me unconditionally and whom I love unconditionally. I have a husband who’s amazing and we get time together.”
Liz emphasizes the many unanticipated, as she calls them, “blessings” of transplant: more time with her adult daughters as well as a deeper relationship with her husband, her parents and her own sisters (one of whom, Mary, was her donor). Recently, Liz and her husband moved to a quiet New Hampshire community near the ocean where she was able to cut back on work. Most days, they walk together on the beach.

“I know it sounds crazy,” Liz says, "It’s just such a gift, not just the transplant but the entire journey.”

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