Bullous Pemphigoid Diary: A Prescription for Hope

Naomi Bishop

I've always been blessed with good health and a sharp mind. I was an exercise junkie and prided myself in working through injuries, illnesses, and a host of internal signals that I was overdoing it. I was a mom, an intensive care doctor, and a fitness fanatic. I did not tolerate moderation from myself or those around me. I took for granted that the gifts from Mother Nature and my ancestors would usher me painlessly into old age.

Just before the COVID-19 pandemic transformed the world as we knew it, I pivoted away from clinical medicine. After 20 years of my identity being defined by two letters attached to my name—MD—I walked away without a firm plan for the future. I needed to return to my creative roots. I packed up my apartment and moved across town, where I would live incognito and make a fresh start. I was planning to be an independent consultant to families with relatives in the ICU. I thought it would all happen overnight, and I'd live happily ever after in my new luxury (translation: extravagant) apartment with large corner windows and granite countertops in an elevator building with a 24-hour doorman, a pool, and a gym. I imagined my son and I would have French toast and mimosas every 4th Sunday at our favorite café and take in a movie on nights when he found himself without a better option. I'd use my oven for cooking, rather than storage, and have cocktail parties and opera subscriptions.

Halloween has always been my favorite holiday. It's the one week each year that I allow myself to finish off the stash of candy I hoard for an unexpected deluge of costumed little people that I know will never come. But this year was different. I'd barely managed to complete my usual 10-mile walk-run in the park the day before, and I was winded and light-headed from walking one block to buy my favorite candies: Tootsie Roll Pops and Milk Duds. I blamed it on being awakened several times during the night by an unrelenting itch in a spot on my back just out of reach. It was unlike any itch I'd experienced before; a burning sensation as much as an itch, and the hydrocortisone that had always worked on my eczema did nothing to soothe it. Then I remembered the disturbing experience I'd had in the shower the day before. As the hot water hit my back, I spasmed like a caught fish reeled onto the deck before it realizes that fighting for the solace of the sea is futile. And there were three new bumps on my neck.

After two weeks of sleepless nights, and no relief after changing my detergent, soaps, body lotion, and makeup, I reluctantly called a dermatologist. I didn't have an internist. I'd relied on my colleagues to sign the annual medical forms required by my employee health department. I had not been on the other side of an exam table since I'd seen a neurologist in a panic after experiencing my first ocular migraine more than 10 years earlier. I thought I knew as much about my body as any doctor who would be seeing me for the first time. After all, I was an experienced pediatric intensive care doctor. I'd overlooked the fact that while I knew quite a bit about childhood ailments, 65-year-old adults were not just big children.

I was fortunate to find a compassionate physician with an available opening the next day. He listened patiently to my story, examined the rash (which had blossomed overnight to cover my whole body), and told me he was certain I had scabies (although my rash was in all the wrong places). I was to apply an ointment from head-to-toe and leave it on for 12 hours, wash everything that could go into a washing machine, and seal in air-tight plastic bags anything that couldn't. I was also to contact my landlord for a bedbug inspection. I asked for a biopsy of one of the bumps, and he obliged me. Armed with a prescription for a stronger anti-itch cream, I left the office, exhausted and skeptical. How does an obsessive germaphobe who always keeps a bottle of Purell within arm's length contract scabies?

Two weeks later, I returned for my follow-up appointment. I'd lost nearly 10 pounds, had not slept more than three hours a night, and my rash had morphed into hives. One small blister adorned my right upper thigh. The initial biopsy came back as nonspecific inflammation. Though somewhat perplexed, my doctor advised me to reapply the scabies ointment. He prescribed a stronger anti-itch lotion, and performed a second biopsy.

Four days later, my phone rang at 10:00 p.m. The call was from a cell phone number I didn't recognize. It was my dermatologist, who had saved my call for last so he wouldn't be rushed. "Dr. Bishop, I received your biopsy results, and you don't have scabies. You have bullous pemphigoid."

In one brief phone call, this gentle and compassionate stranger rocked the world as I knew it. I was no longer the strong, youthful, indefatigable, superwoman who would never fall prey to her limitations.

During my 20 years of practice at a major medical center, three years of residency at a top-ranked children's hospital, and four years of medical school, I couldn't recall ever hearing of bullous pemphigoid (BP). I had been the student who read and memorized the captions beneath the illustrations in the textbook. How had I missed the one that described the condition that would later afflict me?

In one brief phone call, this gentle and compassionate stranger rocked the world as I knew it. I was no longer the strong, youthful, indefatigable, superwoman who would never fall prey to her limitations. I imagined myself in freefall— somersaulting towards a scary and dark unknown netherworld— catapulting from confident and respected physician to quivering, chronically-ill patient, facing an unknown future. I felt alone and isolated, left to find my way without a compass.

Dr. A. explained what he knew about this rare disease, the pity in his voice only partially shielded behind "med speak." I grasped only an occasional word here and there; the rest sounded garbled, as though he was speaking under water. I was focused on my life sentence.

As a physician, I always researched illnesses that I knew little about. I owed it to my patients to be as knowledgeable as I could be so that my decisions about their care were based on evidence. Now that I was the patient, I was even more determined to read every reference I could find.

In the days that followed, I sat hunched over my laptop, scouring PubMed. I was searching for answers to my questions: *Why me? Will this be forever? Will my 96-year-old mother outlive me?*

I then remembered how my ex-husband had found out he had diabetes just before our 15-year wedding anniversary. I'd watched him navigate his diagnosis, normalizing it as much as he could. He was determined not to let the condition define him. He'd hesitated at first, but later joined a support group.

I closed the PubMed site and opened a new Google search bar. As if they were on autopilot, my fingers tapped the keys with a new sense of urgency: B-U-L-L-O-U-S P-E-M-P-H-I-G-O-I-D S-U-P-P-O-R-T G-R-O-U-P-S N-Y-C. One entry appeared: pemphigus.org. I spent the next several hours reading every article, and marveling at how normal the people with this condition looked and acted. They had jobs, families, and hobbies. They had lives. Many were in remission and, most importantly, they had futures. A ray of hope returned to my world.

It's been five months since my diagnosis. With the help of the IPPF, a brilliant medical team, and my family, I am healing. My BP is under control. The itching returns periodically, but it's tolerable. The simple act of getting out of bed, once a chore, is again routine. I am enjoying my favorite foods, freed from the medications that nauseated me. I've even been able to enjoy dinner with my son at our favorite eatery. My memories of those tough early days are fading. The after-effects of the steroids are slowly going away. Spring is coming, and I hope to return to my beloved running trail in Central Park. I'll be satisfied with two miles and comforted knowing that the body I no longer recognize may one day feel familiar.

My journey with this disease has taught me so much: how it feels to be the one with a chronic condition instead of the sympathetic outsider looking in; how challenging and unsympathetic our medical system can be, even to "medically-privileged" patients; how willing my new BP friends are to share their practical tips and tricks; and how helpful support groups can be. It will be a while before I no longer see myself as a patient. But with the help of the IPPF, the love of my family, and support from my fellow BP warriors, I know I can soldier on.

With the help of the IPPF, a brilliant medical team, and my family, I am healing.

Naomi Bishop is a semi-retired physician-writer living in New York City. She was diagnosed with bullous pemphigoid in November, 2021. She currently shares an empty nest on the Upper West Side of Manhattan with five sun-loving plants. When she's not working, she reads voraciously, and enjoys podcasts and conversations with her two adult children. The four things she could never live without are The Atlantic, The New Yorker, New England Journal of Medicine, and her iPhone.