Cancer Health™

Elizabeth McGowan & Outpedaling “The Big C”

After being declared melanoma-free for five years, McGowan began a 4,250-mile adventure from Oregon to the Atlantic Ocean in Virginia.

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By Cody R. Barnett, MRA Director of Communications

Elizabeth McGowan grew up with melanoma. Even at the time of her birth in 1961, she says, her father was already well into his quarter-century journey with the disease. His diagnosis – and the multiple subsequent surgeries it would prompt – was a specter that constantly hung over her family. Cancer would become even more real for Elizabeth when she received her own melanoma diagnosis at age 24.

Ron McGowan, her father, was first diagnosed with melanoma in his early twenties, a few years after he enlisted in the U.S. Navy to fight in the Korean War. Doctors turned to the only treatment strategy available – surgery. This was the mid-1950s, long before our current treatment staples of checkpoint immunotherapies and BRAF/MEK targeted therapies had been developed. Despite the lack of systemic treatment options, doctors already knew then how serious the small melanoma on his neck would become if left unchecked. Heeding their advice, Ron underwent a radical neck dissection. It required removing lymph nodes and wide swaths of tissue and muscle on his right side, from his neck down to well below his armpit.

Elizabeth remembers her father, with his signature dark humor, describing his series of operations as “taking [him] one piece at a time.”

In 1976, when she was 15, she learned her father’s melanoma had spread to his brain. This time, she sensed, he wouldn’t rebound as he had before. He died that October, at just 44-years old.

“Losing a parent like that is so hard and sad,” says Elizabeth. “His will was so strong, but he just wasn’t able to fend it off anymore. And later on, I learned that doctors were astounded how long he persisted.”

Still, watching her father struggle ingrained this message into her brain: A melanoma diagnosis was a death sentence; sooner or later it would get you.

“When I was in college, at least one doctor recommended that my sisters and I have our skin checked regularly, but nobody insisted on it,” Elizabeth says. “I didn’t think about myself as being at high risk, but I would do self-checks because I knew what to look for. My ears always perked up if I read something about melanoma or heard it mentioned on the news.”

One of those self-checks in 1985 revealed a dark blue-black mole on the back of her neck. Right away, Elizabeth knew what it was. She froze in front of the mirror, remembering her father’s agony.

She was living in Burlington, Vermont, then and lined up an appointment with a doctor associated with the cancer clinic at Dartmouth College, where her father had been treated. That doctor confirmed it was a melanoma and removed it using a standard wide excision. Elizabeth, hoping this would be the end of it, never told her family because they had been through enough.

The sneakiness of melanoma became apparent a year later when she found a small bump near the melanoma scar. She returned to the same clinic where a doctor removed what turned out to be a swollen lymph node. Tests revealed that it was also malignant.

“This is the insidious part of melanoma,” says Elizabeth. “When you can see it, you can do something about it. But once it crosses that line and moves inside your body – when you can’t tell how far it has gone – that’s nerve wracking. And that’s when I knew this was serious.”

This time she knew she had to tell her family. “Explaining all of this to my mother face-to-face was harder than hearing my diagnosis,” says Elizabeth.

What happened next closely mimicked what her father experienced and that coincidence wasn’t lost on Elizabeth. Doctors knew they had to act because of her family history. First, they injected her neck with dye so a scan could show which way in her body that malignant lymph node was draining. Doctors then performed a radical neck dissection on Elizabeth’s left side, a precursor to a complete lymph node dissection that is sometimes used today. Fortunately, each of the 20-some lymph nodes removed came back negative for melanoma.

By then, researchers had started studying the effects of an early immunotherapy called interferon on a variety of cancers, including melanoma. Early results – with very small sample sizes – started to appear in medical journals in the early 1980s indicating that it could help prevent relapse. While interferon would not be approved in melanoma until 1995, it was available via clinical trials decades earlier.

In late 1986, Elizabeth enlisted in such a trial in Vermont. It required daily infusions at a clinic for the first month and then every-other-day, at-home injections for the next eleven months. Even today, interferon is considered a very difficult regimen to endure.

“I felt like I had the flu for an entire year,” says Elizabeth. “On top of that, I really had an aversion to needles. But I felt like the commitment to this clinical trial was worth it, for me and other cancer patients who might benefit from the data collected. It was a small way I could contribute to a larger cause.”

After a year carefully scheduled around interferon, Elizabeth had developed an appreciation for what she hoped to accomplish career-wise. She was ready to move on to the next chapter, reporting for a daily newspaper in Wisconsin.

In 1989, a year and a half after her move to Wisconsin, everything seemed to be moving in the right direction. Elizabeth felt healthy enough to work full time, play rigorous sports, and maintain a garden. But she couldn’t ignore her melanoma history, so she traveled to Madison for regular checkups.

After a routine X-ray and follow-up scan, she received the worst possible news. Little metastases, or mets, appeared in both lungs. A biopsy that required a hospital stay confirmed that the cancer had recurred.

“I just remember feeling terrified,” says Elizabeth. “I’m sitting at this appointment, all by myself, and realized how isolated I’d be if I had to go through this all over again.”

Her doctor presented four treatment options that were all under study, but none seemed promising. Elizabeth, in Wisconsin, and her mother, in Massachusetts, began doing their own research, calling and mailing cancer centers across the country.

“Neither of us were scientists, but we knew we needed to learn as much as we could,” says Elizabeth. “This was pre-Google, but everyone we encountered was so helpful. When they heard my family story, it seemed nobody wanted to let down a woman in her 20s trying to beat back melanoma.”

As part of her own research, Elizabeth also reached out to the New Hampshire clinic that had initially diagnosed her. Doctors there offered an experimental cocktail of four chemotherapy drugs. It was called the Dartmouth Regimen. While these drugs are not routinely used in the treatment of melanoma today, prior to the development of checkpoint immunotherapy and BRAF/MEK targeted therapy, it was as promising as any other available alternative.

Over the summer of 1989, Elizabeth was admitted to the hospital in order to receive each of the three separate rounds of the difficult course of treatment. As is true with most medications, side effects were a very real risk. The risk is amplified as additional medications are put into the mix.

“To say it was harsh is an understatement,” says Elizabeth. “I lost so much weight that I couldn’t keep rings on my fingers. The idea of food became repulsive. But I kept working at my daily newspaper job.”

After the third of the recommended three rounds, scans revealed that her tumors had stabilized. Her doctors seemed thrilled, but Elizabeth wasn’t impressed. “When you have this inside of you, you just want it gone,” she recalls.

She asked if she could receive a fourth round. Doctors agreed. Once again, however, scans showed no change in the location or size of the lung tumors.

Frustrated, she figured she should begin planning for adventures others might put off until retirement. “I wasn’t frantic, but I was fully alive,” says Elizabeth. “A crisis sometimes brings clarity that nothing else can.”

While checkups continued to show stable disease, she also started saving money and devising a plan to hike the entire Appalachian Trail, a 2,167-mile trek between Springer Mountain in Georgia and Mount Katahdin in Maine.

By April 1991, the month she turned 30, she had given up the lease on her apartment, distributed her worldly goods, sent her cat to her mother’s house in Massachusetts and headed to Springer Mountain to start hiking north.

“I loved the experience of carrying everything I needed on my back,” says Elizabeth. “I met so many interesting people – many of whom were also facing their own big transitions. It’s a physical workout, but all of that walking, being immersed in the natural world and having time to think allowed for a mental cleansing, too.”

Upon reaching Mount Katahdin, she spent a few weeks visiting her mother in Massachusetts. Once there, she had her first scan in more than six months back at the clinic in New Hampshire. Miraculously, it showed no evidence of disease—in her lungs or anywhere else.

“I was beyond elated,” Elizabeth said. “No medical authority could explain exactly how or why that happened. Maybe the chemotherapy had acted belatedly or perhaps breathing all of that fresh air made the difference. I was just so grateful that my decision to take a long hike hadn’t been a setback to my health.”

Elizabeth eventually moved back to Wisconsin for another reporting job. Though she had fallen out of sync with her routine medical appointments, she felt fine until 1994 when most everything she ate made her sick to her stomach. That set off internal alarm bells.

In a positive twist of fate, an oncologist who played a role in making the Dartmouth Regimen available—Paul LeMarbre, MD—had transferred from New Hampshire to a small hospital in Wisconsin just 45 minutes away from where Elizabeth was living. She immediately scheduled an appointment.

As her oncologist walked into the room while examining her blood test results, she knew he suspected this wasn’t just a stomach bug.

“Cancer patients are adept at reading faces. Often, they know what news doctors will deliver before they even begin speaking,” says Elizabeth. “You learn to prepare for the worst but secretly hope for the best.”

Her suspicions were quickly confirmed. Melanoma had overtaken half of her liver. She was 33 years old. It was little wonder Elizabeth felt her lifespan would be even shorter than her father's.

Wisconsin surgeons developed an ambitious plan to remove the compromised portion of her liver. The fact that the scans showed other potential masses of melanoma lurking nearby made the rarely performed surgery even riskier. Without another option, she consented.

"After the surgery, when the doctor came in, I did my best to avoid eye contact," recalls Elizabeth. "Then, he smiled and told me that they had got it all. I had a breathing tube in and was hooked up to all sorts of monitors, so I couldn't speak. But I remember a tear trickling down my cheek."

Healing was long and arduous, but she persisted.

Except for a precautionary surgery to remove her spleen a few years later and occasional biopsies at the dermatologist's office, Elizabeth was strong and itching for a new adventure.

In early 2000, she began hatching a plan to celebrate being declared melanoma-free for five years. She wanted to launch a cross-country bicycle ride, but wanted the journey to be more than a selfish pursuit.

Elizabeth contacted the foundation at Waukesha Memorial Hospital – the regional cancer center where she had been treated – about turning the ride into a fundraiser. They were on board. Now, the journey became a mission with a name, "Heals on Wheels."

In August 2000, she drove to Astoria, Oregon with her bike to begin her 4,250-mile adventure to the Atlantic Ocean in Virginia on the granddaddy of all continental routes, the TransAmerica Trail.

Elizabeth carried all her own gear and camped each night wherever she could find enough green space for her small tent. She engaged people she met at diners, churches, stores, and hospitals because cancer outreach was such a crucial linchpin of "Heals on Wheels."

"I wanted them to know that there is life after cancer and that such physical feats aren't beyond a former patient's reach," says Elizabeth. "People need to hear this and I needed to convince myself of it, too. It was a joyful message."

She shared her melanoma story and handed out informational brochures and cents-off coupons for sunscreen.

"It was about starting a conversation," she says. "I've never met anyone who doesn't have a cancer story. I could always make a link because everyone knows someone who's had cancer."

As she shared, so too did the people she met. "I never expected so much kindness. It was refreshing and restorative to know that people were rooting for you," she says. She sent all of the money she collected to the Wisconsin foundation.

What she didn’t expect during her trek was to be so stirred by memories of her father. Although he had died 24 years prior, she fondly recalled memories of long-ago family camping trips as she pedaled through Yellowstone National Park and other familiar landmarks on her 10-state ride.

“Grief is so peculiar. You don’t always realize you are experiencing it, especially so many years later,” says Elizabeth. “I felt such a deep connection to him and realized that this ride was for him too.”

As a child, she’d struggled to make sense of why her father could be laughing one minute and raging with anger the next. Time on the bicycle helped her better understand what had shaped him into the person she remembered.

“I was able to unravel and make more sense of the complex man my father was,” says Elizabeth. “He had gone to war so young and then had the extra burden of melanoma that dogged him all of his adult life. Deep down, he must have known he’d never see his daughters grow up.”

Elizabeth reached the Atlantic Ocean in November 2000. But she soon realized that the physical part of her trip was only the beginning. It was just as much an emotional journey.

She had kept a journal along the route and the hospital foundation had posted her regular entries and photos to its “Heals on Wheels” website. Friends and family challenged her to turn those musings into a book. Even her Wisconsin oncologist LeMarbre chimed in: “These words will matter, Elizabeth. Cancer patients always need hope.”

She evidently needed time to create what she had in mind.

“Journals serve a purpose, but as a reporter I knew people would expect more substance in a book,” says Elizabeth. “If I was going to do this, I knew it couldn’t be about a charming little ride and talking to strangers. It had to be a deeper dive about cancer, discovery and hope.”

Now, 20 years later that book, Outpedaling ‘The Big C’: My Healing Cycle Across America, is available anywhere books are sold and here: https://www.renewalnews.org/book/.

“My book is for survivors first and foremost, but it’s also for any adult struggling to make sense of a relationship with a parent,” says Elizabeth. “It’s about fear, growth, resilience and recovery, and the journey you sometimes need to make to find out how the pieces fit together.”

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