Pediatric Patient Returns to Dana-Farber After 40 Years

Cameron Smith has spent decades traveling the country by motorcycle, but nothing quite matches the trip he took to Dana-Farber this summer – his first visit in 40 years to the place where Institute founder Sidney Farber, MD, saved his life in 1961.

Smith, then a 14-month-old toddler from Connecticut, had a form of cancer that few children survived. But he beat the odds, continuing to receive follow-up care from Farber and other doctors until he was 18 and moved to the West Coast. He put cancer behind him and planned to never return to Boston until a summer 2018 trip to Fenway Park for a Boston Red Sox baseball game.

Encouraged by his girlfriend Beth Orliss, and the tug of his heartstrings, he decided the time was right. “This was where I grew up,” Smith, 58, said as he looked at the Jimmy Fund Building that until the early 1970s housed Dana-Farber’s pediatric clinical facilities. “I wanted to come back and say ‘Hey, look, I made it.’”

Although he can’t remember the surgery or chemotherapy he received, he can easily recall the follow-up care that made the three-hour drive to Boston with his dad worth it. “It was hard for my parents to come here, so starting when I was 5, my father would drop me off in front of the Jimmy Fund Building and I’d go up the steps and in to the clinic,” recalls Smith. “I’d walk past the carousel and the electric train, which I loved, and get my chart off the wall. Then, I’d take my own weight and height, give it to the receptionist, and wait until my name was called for bloodwork. At the end of the day, I got a gold star and tickets to the Red Sox game for me and my dad.”

“We grew close with everybody there — they were like family. ”

Smith says colored lines along the floor helped pediatric patients navigate their way around Dana-Farber and through underground tunnels that connected it with Boston Children’s Hospital. The lines were long gone during Smith and Orliss’ recent visit, as were the carousel and the Disney paintings on the walls that once provided him comfort. Still, he enjoyed touring the current Jimmy Fund Clinic, now a part of the Dana-Farber/Boston Children’s Cancer and Blood Disorders Center, and the expanded campus.

“We grew close with everybody there – they were like family,” says Smith. “Mom knitted hats for the young patients, and my dad and I brought in toys for the clinic kids at Christmastime. What I remember most about Dr. Farber was his kindness, and that he always had pockets full of candy.”

Looking at his medical records for the first time, including personal letters from Dr. Farber’s team to his parents, Smith felt a sense of pride, which he shared with visitors who saw him observing Farber’s portrait. “I was his patient, and they didn’t think I’d make it,” he said, a smile crossing his face. “But I did!”

This summer, Cameron Smith visited Dana-Farber for the first time since finishing treatment more than 40 years ago.
Survivor Reaches New Heights with Help from His Care Team

rounded temporarily by cancer, Matt Pierce found a way to rise high above his disease – 15,000 feet above it, in fact.

A diagnosis of Ewing sarcoma and subsequent surgery and treatment at Dana-Farber/Brigham and Women’s Cancer Center (DF/BWCC) forced Pierce to abandon his dream of becoming a U.S. Marine, but the 22-year-old college student was a military man for a day thanks to the help of his caregivers. Pierce’s doctors arranged for him to make a tandem skydive with active and retired members of the U.S. Army’s Parachute Team, also known as the Golden Knights.

“It was a culmination of everything I’ve been through,” says Pierce, who is now in remission and entering his senior year. “I’m lucky to have had the amazing people who took care of me, saved my life, and followed through on a promise.”

That pledge dated to when Pierce was diagnosed in September 2015, forcing him to leave school, undergo 14 rounds of chemotherapy, 28 radiation treatments, and surgery to remove a grapefruit-sized tumor at the base of his skull.

“My dad is retired Navy, and I planned to follow him into service once I graduated,” says Pierce. “At first, I thought it could still happen, but I learned you needed to be many years out from cancer to be considered for the military. Then, once I had part of my skull removed, and a plate put in my head, that sealed the deal.”

Learning of Pierce’s derailed dreams, his DF/BWCC plastic surgeon Edward J. “E.J.” Caterson, MD, PhD, mentioned his friendship with a retired member of the Golden Knights. He could arrange for Pierce to skydive with them, but it might take time to plan. It took almost one year, but eventually Pierce learned he’d be jumping with the group on June 6 – the anniversary of the D-Day invasion at Normandy that turned the tide of World War II in 1944.

“Matt faced cancer and his treatments with optimism, and determination, knowing that great things were ahead for him,” says Priscilla Merriam, MD, Pierce’s primary oncologist at DF/BWCC. “Getting the chance to jump out of a plane with some of those who were most supportive of him during his journey was an exciting opportunity and honor. It’s emblematic of how Matt has embraced all of his opportunities, including pursuing his dreams in school, since finishing treatment.”

The day of the event, held at the Fort Bragg, North Carolina, base of the Golden Knights, was memorable. Pierce, his girlfriend Emily Johnston, and Pierce’s neurosurgeon Ian Dunn, MD, each made tandem jumps, in which a skydiving instructor is connected by harness to a student to ensure safety. Caterson watched from below.

“The Golden Knights were great; they held a whole ceremony for me. It was an honor and a privilege to jump with them,” says Pierce, who now hopes for a career in federal law enforcement. “It is something I’ll never forget.”

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Tips for Living with Metastatic Breast Cancer

Treatment for metastatic breast cancer focuses on extending and ensuring the best possible quality of life. Dana-Farber patients, Hanna Homenko and Krista Lawrence, and Liz Farrell, LICSW, a social worker specializing in consulting women with metastatic breast cancer talk about living with this diagnosis.

Process your diagnosis before explaining it to others

When Homenko was diagnosed, “there was a lot of fear and unknown,” she says, “but you learn how to navigate and treat [the cancer].” She encourages patients to educate themselves about the disease, which can be empowering, and prepare them for telling others. Although this can be difficult, Homenko sees it as “an opportunity to provide information and advocate for funding,” she says.

Don’t use the internet for all of the answers

Information that patients find online will not always be relevant to their case. “It can create unnecessary fear and worry,” says Farrell. For accurate information, talk to your care team and ask them for educational materials.

Be honest with your family

Telling loved ones can sometimes be the hardest step in acknowledging an incurable illness, especially children. Farrell recommends consulting a social worker to determine the best approach and time to communicate this to adolescents. Have honest responses ready for the questions your family may have. This can help reduce anxiety. It is also important to ensure the emotional pressure of comforting loved ones does not fall on the patient. “Kids and caregivers should have their own emotional support,” say Farrell. This can come from social workers, therapists, or friends.

Don’t be afraid to accept or ask for help

Many patients find it hard to ask for help. But loved ones can make the day-to-day a little easier, whether it’s offering a ride to an appointment, watching the kids during treatment, or preparing a meal.

Letting others know specifically how they can help – and what areas you have under control – is another way to guide well-wishes to something that helps you manage your routine.

Look into resources

Farrell recommends joining a support group for women with metastatic breast cancer, either at your cancer center or online. Lawrence found that regularly attending the support group offered at Dana-Farber gave “an opportunity to see women who are living life with metastatic breast cancer at all stages,” she says.

Farrell also emphasized that anxiety and depression can be common, and that resources for emotional and psychological support for patients and families are paramount. A patient’s care team should include a social worker or therapist to help address larger emotional issues that are associated with a metastatic breast cancer diagnosis.

To learn more about Dana-Farber’s Metastatic Breast Cancer Program, visit dana-farber.org/breastcancer. For more information on support groups, call 617-632-5606.

Art Spotlight: Basquet Ball

Los Carpinteros have created some of the most important works to emerge from Latin America in the past decade. Spanish for “the Carpenters,” their moniker underscores the importance of craft in their practice, aligning their studio in solidarity with communal artisan guilds and skilled workers. The artists (Alexandre Arrechea, Marco Castillo, and Dagoberto Rodriguez) merge architecture, design, and sculpture in unexpected and often humorous ways. They draw their inspiration from the physical world, particularly that of common urban structures. Their carefully crafted work sets up contradictions between object and function. The artists live and work in Madrid, Spain and Havana, Cuba.

Basquet Ball is a watercolor on paper. It shows a basketball court with a backboard that arches like the trajectory of a bouncing ball. This piece is an early concept drawing for a large-scale sculpture that has since been constructed on the grounds of the Indianapolis Museum of Art. It explores the notion of a “game changer,” prompting the observer to imagine what this new sport – one in which the old rules don’t apply – would be like.
Genetic Testing and Counseling

For people diagnosed with, or have significant family history of cancer, genetic testing can shed light on the cause or an individual’s chances of developing it or other cancers. This information can be critical in determining treatment and how to lower the risk.

Jill Stopfer, MD, LGC, associate director of Genetic Counseling at Dana-Farber, answers questions about the benefits of genetic testing.

What is the role of genetic testing and counseling in cancer care?

Genetic testing can be helpful for people with a cancer diagnosis. Testing the tumor may offer insight into its biology and help guide treatment decisions.

“Germline” testing of DNA may reveal inherited genetic alterations that increase susceptibility to cancer. If someone is found to have an inherited cancer-risk mutation, this can provide important information for blood-relatives who may also carry it. Screening and cancer-risk reduction measures can be offered to family members who inherited the familial cancer syndrome.

How can knowing you carry a gene alteration for increased cancer risk be helpful?

Individuals who know they carry a gene alteration that could lead to cancer can be offered close surveillance to detect it earlier — possibly preventing a tumor from developing. Dana-Farber offers comprehensive follow-up care to manage this, including specialized physicians and nurses.

What happens during a meeting with a genetic counselor?

Genetic counselors take a detailed family history to evaluate the likelihood of an inherited predisposition to cancer. Features of a family history that suggest a hereditary susceptibility include cancer that: is diagnosed at young ages, spans generations, and occurs at multiple sites.

The genetic counselor may discuss the option of testing and will explain the relevant gene(s) and associated syndrome in terms of cancer risks and medical management challenges. Possible results, as well as the cost and logistics of testing, insurance coverage, or other payment options, will also be reviewed.

What are some important things to know about genetic testing?

One is that genetic testing of people who have cancer can identify genetic risks for other cancers, and to find other family members who haven’t been diagnosed, but who may be at risk.

Another is the misconception that genetic testing is expensive. Extensive testing, however, is available for hundreds – not thousands of dollars. Most good candidates have insurance coverage and will pay very little.

There is also concern about the potential for genetic testing results to be used to discriminate against individuals in insurance or employment. But federal legislation passed in 2008 prohibits using genetic information to underwrite in health insurance. The federal law also prohibits the use of genetic information in employment decisions.

Written by Sarah Silvia – through the eyes of her sons: Dustin, Dominic, and Drew

She told me one day that she was sick with something called cancer

But I knew she was so STRONG and this disease would not take her

She had to start a medicine that would make her feel crumby

But she was so POWERFUL that she got up each morning to fill my tummy

She began to look different to me with her head that had no hair

But she had such a great SMILE on her face that nobody seemed to care

She sometimes had to stay at the hospital so the doctors could help her feel better

But she was so BRAVE that she came back home to me so I could read her my letter

She knew there would be days her body would be frail and weak

But she was so TOUGH she always stood on the sidelines to cheer me on with a shriek

She had a hard time getting around and doing things she used to do

But she was so SELFLESS she made sure I had what I needed to get through

But I knew she was so MIGHTY I would see her kick this disease and have her by my side

Jill Stopfer, a genetic counselor at Dana-Farber