‘She is My Inspiration’: Glioblastoma Patient Watches His Daughter Grow Up

While battling glioblastoma, Eric Smith feared he wouldn’t get to see his daughter grow up. He’s had the chance thanks to a clinical trial.

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Three-year-old Emily Smith loves to play doctor. She takes great care of her patient — her father, Eric Smith — by pretending to listen to his heart with her toy stethoscope, just like they do on her favorite TV show, Doc McStuffins.

But Emily leaves the care of the “boo-boo” on her father’s head to the experts: Smith’s care team at Dana-Farber, who enrolled him in a clinical trial that has not only controlled his glioblastoma, an aggressive brain cancer, but enabled him to watch his daughter grow up.

A headache signals something more serious

By the time Smith was referred by a family friend to Dana-Farber in mid-2017, he already had part of his “boo-boo” — scars from two brain surgeries.

In July 2014, months after Smith’s wedding and soon after his 33rd birthday, a terrible headache sent him to the emergency room in Springfield. An MRI revealed two abnormalities in his brain. One was dismissed as perhaps a bruise from Smith’s football days. The other, identified as a benign (non-cancerous) acoustic neuroma, was surgically removed.

It took a while to regain his balance and for the numbness on his left side of his face to wear off, but Smith bounced back from the operation. “We just started living our life again,” he says.

In early 2017, he had a follow-up MRI. He was outside shoveling snow when the doctor called with the results. His wife, Joanna, pregnant at the time, answered the phone inside.

“I looked up and saw Joanna bawling through the window,” he recalls. The other spot on his brain — the one dismissed earlier — had grown significantly. He needed a second operation as soon as possible.

The day he and Joanna returned to the Springfield hospital to review the surgery results “was literally the best and worst day of my life up to that point,” he says. First, they stopped in the

OB/GYN wing of the hospital for the ultrasound that revealed they were having a girl. Then, on the oncology wing, they were informed that the surgeon wasn't able to remove all of the tumor, which was diagnosed as a grade 3 anaplastic astrocytoma, a rare type of brain cancer.

'I felt so comfortable'

Smith followed a standard regimen of oral chemotherapy and radiation, but he wanted a second opinion. He followed his friend's advice and scheduled a consult in July 2017 at Dana-Farber's Center for Neuro-Oncology with neuro-oncologist Lakshmi Nayak, MD, who is also director of the Center for Central Nervous System (CNS) Lymphoma.

"The second I met her, I felt so comfortable," Smith says. "She is a brain-cancer specialist. This is what she does."

A new MRI showed the tumor was in an accessible location, and Nayak recommended surgery at Brigham and Women's Hospital.

Three days after surgery, Smith got an urgent call: Joanna had gone into premature labor in Springfield. His medical team cleared him to go to Joanna's bedside. Smith's father drove him there, and Smith arrived just in time for Emily's birth

"There I was, next to Joanna in a wheelchair, with a shaved head and giant scar on the side of it, holding my newborn daughter," he says. "It was unreal."

Nurturing his health and his child

When he returned to Dana-Farber, he proudly showed pictures of Emily to everyone. Nayak, however, had a different picture to share with him. While the tumor had been completely and successfully removed, his cancer had progressed to an aggressive grade 4 glioblastoma.

There are several treatment options for patients with adult brain tumors, and some are new approaches through clinical trials to aid in the development of more effective therapies. Nayak suggested Smith enroll in a clinical trial of an experimental medication called an IDO1 inhibitor. "Blocking IDO1 can lead to an increased activation of immune cells, which can then eliminate the cancer," Nayak explains.

Smith started the oral regimen of four pills twice a day, which he remains on to this day. His brain healed nicely from the surgery. He has felt strong enough to return to work as a sales consultant in the restaurant industry, and he can help out Joanna a lot more as they have adjusted to their life as parents.

"Emily has been the inspiration for me through all of this," Smith says. "When we used the term 'cancer' for the first time, I wasn't sure if I would even get to meet my daughter. Just getting to watch her grow up — and to focus on her instead of the cancer — has been one of the happiest things for me over these past four years."

He has compiled his reflections on this and other bright spots of his medical journey into a book titled Beauty in Grey Skies, which he hopes to publish soon.

Joanna still holds her breath when her husband goes in for an MRI every other month, but every scan has been clean.

Nayak first met Emily when she was around six months old, and they've since become close pals.

"Emily talks about Dr. Nayak all the time," Smith says. "She insists that I put her on Facetime with Dr. Nayak during my appointments so she can say 'Hi.' She constantly says she wants to be a doctor when she grows up, just like Dr. Nayak.'"

First, though, Emily will soon have a new patient to care for at home: Her younger brother, Eric Smith Jr., is due to join the family in May.

"Eric has had a remarkable response to an investigational drug," Nayak says. "He is a constant reminder that every individual is unique and responds differently to medications. He continually motivates me to develop personalized medicine for my patients."

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