

The Note

By Elizabeth Titus

The radiologist left a hastily scrawled note beside my husband's hospital bed, saying he disagreed with the oncologist. "Call me tomorrow. I still think I can get the tumors to shrink."

He must have come into the room after midnight. I was asleep on a cot after a dinner of potato chips and chocolate bars from the Yale New Haven hospital vending machines. I woke at 3 a.m., read the note, then crumpled it up and put it into my backpack. I wouldn't be showing it to Gregory, who had lost the ability to speak, his brain ravaged by melanoma. And I wouldn't be calling the doctor.

Five years later, I ponder the doctor's note. When we met with him to discuss whole brain radiation, he patiently explained the images of Gregory's brain and his plan of attack. He loved his work, we could tell, and he gave us a slight sense of optimism.

Our oncologist at Yale, on the other hand, was never optimistic. He had done research on melanoma at NIH and knew the statistics and how they applied to Gregory, who had late stage 3 melanoma. He was one of many doctors we consulted after the diagnosis in late 2005. The surgery to remove the tumor on Gregory's nose took place at New York University. Then, all we could do was wait. Interferon was the only FDA-approved option, with just a ten percent success rate, and few doctors recommended it. We met with doctors at M.D. Anderson, the University of Pennsylvania, and Memorial Sloan-Kettering (MSK). Ultimately, Gregory chose a vaccine trial at MSK. Slightly over a year from his diagnosis, his speech slurred, he rushed from his office in midtown Manhattan to MSK and learned he had fourteen large brain lesions.

There is always hope, people told us. Whole brain radiation is relatively painless, and with precise imaging tools tumors can be pinpointed and attacked. The success rate, at ten percent, was not encouraging. But we thought we could be in that ten percent. And why not? Up until Gregory's diagnosis, we had beaten many odds. He was a partner in a successful architecture firm and had recently been named a Fellow of the American Institute of Architects (FAIA), while I had transitioned from English teacher to communications director at American Express after getting an MBA at Wharton when few women did. We survived the horrors of infertility treatments and miscarriages and emerged from the flames to adopt a daughter in China in 1994.

We decided to do the treatment at Yale, since our home in Connecticut was under an hour away. It was a good decision. But Gregory felt there was no one in charge of his care, which was partially true, based on his decision to leave NYU for the trial. When a patient is in a trial

at MSK, it is about finding a cure for a disease, not for each patient. I had few complaints, but I wasn't the patient. Looking back, I'm not sure the trial was the best choice. A perfectionist by nature, Gregory wanted results about his particular case. He never really understood that this was an experiment, not a treatment.

Everyone at Yale wanted to help, and I have nothing but admiration for people who can endure the emotional roller coaster ride that melanoma forces upon them as they struggle to help patients with a terminal cancer.

I think of the radiologist and the note he left that night five years ago. He was so involved with his patient that he refused to give up. Was it the right thing to tell us that Gregory could have more time? Should doctors on the same team tell patients they disagree with each other? And my response, or lack thereof. Should I have called the doctor? And did he try to call us? I'll never know. The next day, Gregory's sister and I took him to the house he had designed for his final days. We took on more than we could handle; worse, Lili got involved with her father's care, keeping a notebook on drugs to administer through his IV. She had no idea that he was dying. I cowardly left the job of telling her to our psychiatrist, who came to our home. Gregory and I met Dr. Jane Rosenthal in 1994 when she was a professor at Columbia focusing on infertility and we were desperate for a child; when Gregory was dying she was also at NYU's Langone Medical Center as Director, Consultative Liaison Psychiatry Service. She told me that we should not be giving Gregory so much morphine and that we needed to let him die.

I believe that the radiologist acted out of passion for his work and that he truly believed there was hope for Gregory. Perhaps he crossed a line, but I understand. I am certain that I made the right decision. Gregory's time had come to die, and my only regret is that I may have unwittingly extended his suffering.

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