“A Letter to the Boy in the Bubble”

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You may have heard the story of David Vetter. Some may know him as the “boy in the bubble.”

David Vetter was an American child born in 1971 to Carol Ann Vetter and David Joseph Vetter Jr, the second of the couple’s children to be born with severe combined immunodeficiency, or SCID. At the time, treatment for SCID was limited and involved sterile isolation until an appropriate match for bone marrow transplant was found.

For David, “life in the bubble” was no ordinary life. Rather, he spent the majority of his infant and toddler years living at the Texas Children’s Hospital in Houston, Texas. It was only after the development of a special transfer chamber that he was allowed to spend time at home with his family. While at home, he continued to live in a sterile bubble space, powered by loud motors that made communication with his family difficult. His diapers, food, water, and toys required extensive sterilization before they could enter his chamber, and loved ones could only interact with him through sterile gloves. As David grew up, his parents did everything they could to help him maintain as “normal” of a life as possible, introducing toys into the chamber and encouraging him to receive an education. When David was around 6 years old, he even received a special suit from NASA that would allow him to venture into the outside world, while still connected to his sterile bubble.

Later in life, David received a bone marrow transplant from his sister, Katherine. However, despite the efforts, he unfortunately died from Burkitt lymphoma at the age of 12, as Katherine’s bone marrow contained undetectable levels of dormant Ebstein-Barr virus that catalyzed the development of his disease.

When I was younger, David Vetter's story had a profound impact on me. It did not make sense to me that, while he remained confined in a bubble, I could walk to school, learn alongside my classmates, and do after-school activities without worrying about accidentally contracting a life-threatening disease. I could spend hours reading a book in the grass until my kneecaps turned green, or spend every single recess getting scratched up on the pavement while playing four-square with my friends. If I wanted to, I could even *ask* to be seated in between two messy strangers in a crowded flight.

I could never understand what it felt like to be the "boy in the bubble," but last year, on my inpatient neurology rotation, I finally got a glimpse.

This is a letter to a patient I took care of a few months into starting my clinical rotations who, years after learning David Vetter's story, only further taught me the value of life, the importance of family, and how limited our time is here on Earth.

Dear Patient X,

I hope you're doing well right now.

Walking into your patient room on Day 1, I knew your life was filled with love. While you were in the hospital bed, confused and scared because you had started to develop a tremor in your hand, your father was at your bedside, asking the doctor all the questions you had but couldn't put into words. Every day and every night, he stayed by your side. He took as many days off of work as possible but, when he couldn’t take more, he brought in his work laptop and took meetings from your hospital room. He made sure you ate every meal and ordered food that you liked, and on the days you didn’t have the energy to read the menu, he knew exactly what you would’ve liked and ordered it for you. When the provider team walked in while you were asleep, he expressed all of his worries and fears but, if you woke up in the middle of it, he put on an instant smile and toughened himself out so you wouldn’t see his pain.

The love I saw inside that hospital room was unlike any other. Specifically, it was the love of a father who knew that his son was diagnosed with an illness that could take his life at any moment. It was the love of a father who was beginning to understand that this very moment may be the one he had been dreading his whole life.

Fear.

Dread.

Disbelief.

Your father told me a lot about you during your hospital stay. He said that you have a loving little sister and mom who miss you very much. He said you would be graduating from college soon with a degree in computer science. He told me that you like Pokémon very much, which became evident after I spotted the Pikachu backpack you had in the corner of your room. He also said you like milk tea, which, as someone from the Bay Area, I very much related to.

A week into your hospital stay, it broke my heart to hear that your symptoms were getting worse. The hand tremors turned into left-sided hyperreflexia, and you were now having trouble closing your eye. A brain MRI revealed new white-matter changes in locations that matched your symptoms. The problem, however, was that we did not yet know the reason for the changes and we needed to keep you in the hospital longer.

I knew you wanted to be discharged. You would be graduating soon and wanted to spend time with your friends. You wanted to go to your classes and spend time doing things that someone your age does, not live in the hospital. I wish we didn’t need to break the unfortunate news that you would have to remain in the hospital for longer. I wish I could tell you that we had a definitive explanation for your symptoms and that you could get treated for it at home. I wish I could tell you that we had a cure for SCID. Unfortunately, I was not the bearer of such news.

As I watched the tears roll down your face, I wished there was more that I could do.

For the next few days, you underwent more testing. Through more blood tests, more panels, lumbar punctures, lymph node biopsies, and a CT scan, you stayed strong. The answers would come in soon.

On my last day on the team, and what would be my last day taking care of you, the team decided to get you a treat: milk tea. You had been through so much during this hospital stay and we thought you could use some cheering up.

Now, let me just say that the smile on your face when you saw us medical students come into your room with your favorite milk tea brightened my entire day. Despite everything, there was still joy inside of you. It had been a few days since we’d seen it.

Later that same day, however, came the news we all hoped wasn’t true. The next-generation sequencing results returned to us with an explanation for your symptoms and MRI findings; JC virus had been detected in your cerebrospinal fluid.

“I knew it,” your father said. “I was hoping for anything but that.”

He was talking about progressive multifocal leukoencephalopathy, or PML, a white matter disease caused by JC virus. While many individuals carry a latent form of JC virus, it can become reactivated and cause havoc in those who are immunocompromised. Your father had been doing some research of his own and was wondering about PML for a few days before your results came in. He expressed his fears and deepest hopes that this was not what had happened to you. It was not the news we were hoping to deliver.

You sat and listened as the doctors explained the prognosis. You didn’t say much, and it was understandable. I couldn’t even begin to imagine all the thoughts that must have been going through your head. I could see the tears behind your eyes but, this time, you didn’t let them fall.

After this day, it was time for me to switch services and see different patients. Yet, to this day, you and your father still remain on my mind. Although I learned a lot of medicine while taking care of you, the lesson I learned most was one of love and resilience. They synergize, especially when times are tough. Love fosters resilience, resilience fosters hope, and hope fosters more resilience. I have hope that you will get the care that you need, and I know that the love your family has for you will give you the resilience you need to endure it.

It’s been a lifetime of hearing

“No honey, he can’t play outside; the neighbor’s kid has a cold.”

Saying,

“Mommy, please! I just want to be normal.”

Understanding,

“I know you hate these pills, son, but they’re keeping you alive.”

All you wanted was to be like the other kids. Hopefully, one day, you will.

Take care, Patient X. You have lots of people rooting for you.

Sincerely,
Just another milk tea-loving medical student

References

1. “The Story of David Vetter.” Immune Deficiency Foundation, 2016.
2. “Progressive Multifocal Leukoencephalopathy.” National Institute of Neurological Disorders and Stroke, U.S. Department of Health and Human Services, 2023.