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My dad used to say “As long as you’re breathing, you can still make changes”

even as ALS stole his life in just 14 months.

I was there for his missteps, the nights he cried out asking us to move him, the words he couldn’t utter because they cost him his breath. On August 24, 2024, my dad, Frank Albrecht, died in my arms but he wanted to live. And in his eyes—that are also my eyes—I saw what was coming for me.

As he lost his life, I lost my future—the children I may never see married. The patients I may never treat. The decades I may never have. Because I learned I had inherited the most common cause of familial ALS and frontotemporal dementia, or FTD from him: a string of nonsense in my genetic code we call the C9 repeat expansion.

I have a fifty percent chance of developing ALS or FTD by 55, like my aunt. Ninety-five percent by 65, like my nana and my dad. I’ve probably lived over half my life already.

Before 2011, ALS and FTD were thought to be two separate diseases. But Rosa Rademakers and Bryan Traynor discovered the genetic thread linking them. And connecting three generations of my family tree.

There is no cure for me yet. There’s no test to predict which disease I’ll get, when I’ll get it; or how to stop it once it starts.

But in the fight for my life, the discovery by these scientists gave me something powerful: a target. And I realized I had something useful in this fight—an MD-PhD. I am uniquely positioned —one foot in science, one foot in medicine—to fight for the lives of my patients and loved ones facing these devastating diseases.

“Help me End the Legacy of ALS and FTD?”

“Will you help me cure myself?”

I started asking scientists, CEOs, and other leaders.

In 1 year the tide is turning.

I’ve built 11 collaborative projects across eight countries—including CureC9, a program to target my mutation once and for all. My mind, turned against the C9 gibberish in my DNA (points to dress); my hands, working urgently for a cure while they can. I give my mind but also my body--my cells, my blood, my spinal fluid. *I give and give and give so that if I fail, the next generation gets to live.*

My dad and I share a genetic fate, but I’m changing my future.

Rosa Rademakers and Bryan Traynor discovered our genetic mutation. They mapped the battlefield; and now we can wage the war.

They are why someday I’ll be able to tell my patients: You have the C9 repeat expansion, and this is how we’ll fight it.

My dad used to say “As long as you’re breathing, you can still make changes”

Well I don’t know how long I’ve got, but papi, *I’m still breathing, and I’m making changes.*

