A Brother's Reflection on Down Syndrome Related Alzheimer's Disease

Written by Amit Das, sibling to a 38-year-old man with Down syndrome

My brother, Rohan, was born 38 years ago in the city of Bangalore in India. He was born with Down syndrome. When he was three years old, my parents made the difficult decision to move to the United States to ensure he would have the opportunity to thrive. I was born six years later in Boston, and my life has been shaped by Rohan from the moment I entered this world.

Rohan has always been my role model. Kind, hardworking, and beloved by everyone he meets – Rohan brings joy to everyone around him. He has already accomplished so much at 38 years old. He lives independently. He has a great job. He manages his own social calendar. Rohan is the shining star of our family.

As long as I can remember, I have known that there was something "different" about Rohan. That understanding became curiosity and drove me to learn as much as I could about medical science. Genetics was my favorite subject in high school. As I continued to learn, I began to understand something profound about the way my brother is – there is no such thing as a "cure" for Down syndrome.

And why should there be a cure? Rohan is perfect the way he is. Does he need to take medicine to make sure his thyroid is in check? Absolutely. But does he need some kind of therapy to fundamentally change who he is? Absolutely not.

I recall a conversation I had as a teenager with another sibling of a person with Down syndrome. They had made it their life's goal to improve medical care for people with Down syndrome. They asked me at the time whether, if I had the power to do so, I would "remove" the Down syndrome from my brother. The answer was instantly clear to me. No, I would not. Having Down syndrome is a part of what makes Rohan his amazing self. It is most certainly not all that makes him who he is, but without it, he would not be the brother I know and love.

My passion for medical science continued to grow as I went off to college and began my own career, but my daily connection to Down syndrome began to fade.

My brother has his life, and I have my own. I wanted to help many people live lives free of the pain and uncertainty of treatable medical conditions. Nevertheless, somewhere in the back of my mind was the knowledge that the risk of dementia due to Alzheimer's disease was high in people with Down syndrome. I never spent much time thinking about that because it was always too far away to truly worry about. My perspective was that today's joy shouldn't be replaced by tomorrow's worry; and I'll cross that bridge when I get to it.

That all changed when I began working at LuMind IDSC*. All of a sudden, it became my job to be up to date on all the latest research on Down syndrome-associated Alzheimer's disease (DS-AD). Every day, I wake up and read the latest publication on the prevalence and risk of DS-AD. I browse for the newest journal article describing the age of onset of dementia in DS-AD. I scour all the scientific presentations on Alzheimer's therapies being tested in the neurotypical population, thinking of which could be used to treat Down syndrome-associated Alzheimer's disease.

Papers, papers, and more papers!

And I must confess – usually, when I read all of this information, I read it with an objective eye, because they're not about my brother. The person with Down syndrome they refer to is somebody else.

My brother is healthy. My brother does not have signs of dementia. And he never will, because he just can't. Not my brother. Not the person I love.

But there are moments when reality hits. Moments when, deep down, I have a flash of understanding that these papers are talking about my brother. In those moments, I am gripped by fear and a sense of powerlessness that feels insurmountable. I can't think straight. I have to look away.

But I cannot look away. It is my job as Rohan's younger brother to not look away. If our situations were flipped, I would expect my older brother would do everything he could for me. For all that I hope he would never wish for me to be any different than how I am, I would pray that he would do everything in his power to ensure that my sense of self is never taken away from me by a disease like Alzheimer's disease. And so, I'm trying and so are countless others.

Nevertheless, I can only speak for myself. Within my family, I am only one of four decision makers alongside my brother and my parents. Within the Down syndrome community, we are only one family amongst thousands. But I believe that today, while our fear of Down syndrome-associated Alzheimer's disease is as real as ever, we should not feel powerless.

**LuMind IDSC merged into NDSS October 2025.*

Thanks to the tireless work of self-advocates, parents, siblings, friends, researchers, and doctors, the hope for treatment and prevention of DS-AD has never been brighter.

One by one, barriers are being brought down and people with Down syndrome are finally being included in the latest advancements of medical care for Alzheimer's disease. In just the past few years, our understanding of Down syndrome-associated Alzheimer's disease has become sharper than ever before. There are clinical trials underway to treat and prevent the progression of DS-AD. The latest-approved drugs for Alzheimer's in the general population are finally being tested in people with Down syndrome to ensure their safety and efficacy for our community. New therapeutics that actually address the root causes of DS-AD related to the 21st chromosome are closer than ever to becoming a reality in the clinic.

My brother turned 38 this year. Right now, he is healthy and living his absolute best life, and for that I am so grateful. I truly believe he will never develop dementia due to Alzheimer's disease. Not because I'm avoiding thinking about the risk he faces, but because I believe in the promise of the research being done, day-by-day, across the globe, that will someday prevent DS-AD entirely.

I know getting to that future will not be without discomfort, and it will require Rohan, my parents, and me to be brave in the face of our fear. Thinking about DS-AD can be scary, and participating in clinical research is not easy. But I believe that bravery now will be worthwhile if it creates a permanently different future for my brother and all adults with Down syndrome.