

My name is Robbie Harvey and I am a 25 year old with Cystic Fibrosis.

In the summer of 2018, I met my newborn niece, Blair, for the first time. As I held her in my arms I appreciated the bright aura she exuded, her face sporting an ear-to-ear toothless smile. She was beautiful. But a moment later, another characteristic of hers caught my attention; she was small. I had held only a few babies in my life, but enough to know that babies tend to have a chunkiness about them that was missing in baby Blair.

Minutes later, Blair still in my arms, my cousin received a call from their doctor. Blair had cystic fibrosis. As my cousin, her husband, and I consoled each other, a new reality set in for each of us. For Blair's parents, it was the onset of a life not yet prepared for. A mutual understanding that while there may be an increase in tough times ahead, the love, care, and support would never diminish. For myself, watching my cousin gave me a pensieve-like view of what my parents had experienced 20 some years prior. The hurt I felt for my cousin and my niece was accompanied by the realization that this would be the last time my new niece and I could be this close to one another.

That is why I hike. Every summit we reach and every dollar we raise gets families with CF closer to a cure. It gets them closer to less time spent in the hospital and more time doing what they love. And selfishly, it gets me closer to being able to properly meet my niece.

Growing up with CF brings challenges that a majority of kids are not burdened with. It requires a personal responsibility that too often contradicts being a child. Having those experiences from my own childhood, I was heartbroken that CF would be something Blair and I shared.

But I did take comfort in knowing this: Blair will grow up to be a tough person. She will be resilient. She will be empathetic, gritty, humble, and responsible. She will have an appreciation for life in all of its forms. I think those are characteristics that all people with CF have in common. It's the recompense for living with a chronic disease that far too often shortens lives.

Hiking is a metaphor for life with CF. You start at the trail head, meandering along a relatively flat path, chatting with your hiking group, and using the first mile or so to make sure your boots and backpack are comfortable. People with CF do their maintenance work. Taking medications, keeping their weight up, and doing their daily treatments and any exercise they can.

Next comes the ascent. The perpetual climb that causes your legs to ache, lungs to tire, and mind to consider how many switch backs are in your immediate future. It is damn tough. For CF, this often starts in your teens and young adult years. The courses of antibiotics, extra daily treatments, and IV's or hospital visits. You work hard to try and limit your treatments there, while understanding that an increasingly negative prognosis could be looming down the trail. This is the difficult part. Your body is in fight mode.

Finally, you reach the top of the mountain. Your hard work becomes worth it, not only for the outstanding view, but for the personal victory you've accomplished. The relief is paired with excitement. For me, this is Trikafta.

My lung function and weight steadily decreased as my body, a concoction of medications, and a team of doctors tried to rid me of a mycobacterium infection. My early 20's had to be put on hold for a few years while I figured out what I could actually manage with my new lifestyle. But then came Trikafta. A drug that for me, like many others, restored my life. Within months my lung function, weight, and ability to participate in activities I enjoy reverted back to before the mycobacterium infection and eventually eclipsed it. I could play sports, go on vacation, and plan for a realistic future life. This is currently my summit. The peak on my CF hike of life.

While the terrain can be unyielding, the environment inconsistent, and the distance exhausting, families with CF have experienced the life altering power of research and modern medicine. In the last few decades, life with CF has been upgraded. And as exceptional as that is, we aren't done. That is why we hike. Every step on the trail propels the research required to find a cure for CF. A future that allows families to spend more time enjoying life. A future that allows me to spend time with my niece.

With the help of the Cystic Fibrosis Foundation, events like the Xtreme Hike, and incredible people like you, I look forward to updating the summit on my CF hike of life. When CF stands for cure found.