

Profile: Robert Karp



Robert Karp, who has X-linked chronic granulomatous disease, was screened and diagnosed shortly after birth since his brother also has a primary immunodeficiency.

ROBERT KARP is passionate about pursuing physical challenges, from paddle boarding, racquetball and tennis to scuba diving and skydiving. Diagnosed with X-linked chronic granulomatous disease (CGD) in 1971 shortly after birth in South Africa, the full-time academic advisor has been living with X-linked CGD for more than five decades. Despite numerous severe health challenges early in life, Robert is adamant his diagnosis need not be a factor that limits his pursuit of joy and adventure, and says he is happiest when living life to the fullest.

Trudie: How did receiving a diagnosis so early in life impact your childhood?

Robert: Doctors diagnosed me with X-linked CGD in infancy, before I actually developed any infections. They knew I was at risk because my older brother Philip also had a primary

By Trudie Mitschang

immunodeficiency. Growing up, we tried to stay as healthy as possible with the medications available at the time, but eventually the development of the antibiotic Bactrim provided us with a higher level of much-needed protection and improved our quality of life. I was just a toddler at the time, but I'm told it helped prevent me from contracting major infections.

Trudie: Things became more challenging as you got older. Tell us about that.

Robert: When I was 6 years old, our family moved from Johannesburg, South Africa, to Knoxville, Tenn. That's when things got more difficult because as patients with CGD get older, they are much more likely to develop infections. We also started attending school, which exposed us to a lot of potential infections. As time went on, our pediatrician recommended we visit the National Institutes of Health (NIH) in Washington, D.C., to seek treatment. My mother was very instrumental in getting us there to ensure we got the medical care we needed.

Trudie: What happened during the D.C. trip that impacted your life?

Robert: I distinctly recall we were visiting the Smithsonian National Air and Space Museum as a side trip, and I bumped against a railing and felt something pea-sized on my back. We later discovered I had developed a major infection in my spine and lower brain. I was admitted to the hospital for four to five months and placed on intravenous antibiotics. I'm told that incident could have been fatal. Because of that, my

mother moved our family to Rockville, Md., to have closer access to NIH on an ongoing basis.

Trudie: How has being connected to NIH helped you manage chronic illness?

Robert: Over the years, my brother and I participated in various studies with interferon, which we ended up being prescribed throughout our teens. We were very fortunate to be involved with NIH. It's not an exaggeration to say the organization saved our lives countless times.

Trudie: What was it like living with CGD as a young man?

Robert: In spite of the exceptional care we received, my brother and I still developed many infections over the years. There were times when our doctors had to perform major surgeries to remove and biopsy areas of infection to determine the most effective antibiotic. As a result, we both missed a lot of school and found it difficult to explain our health challenges to friends. As kids, our friends naturally wondered if what we had was contagious. I responded by keeping to myself, but my close friends knew I had CGD.

Trudie: You lead a very active lifestyle today. How has your health improved as an adult?

Robert: I think the quality of antibiotics has improved, and as I've gotten older, my need for hospitalization has diminished. In fact, my last major infection (which required surgery, a month in the hospital and intravenous antibiotics for six months) was more than a decade ago in 2009. The only thing I notice, due to having had so many medical interventions during my



Robert has two sons, Trevor and Leo, and since the pandemic has become active counseling teens with CGD.



Today, Robert has an adventurous life, participating in sporting activities such as scuba and sky diving.

life, is my body seems 10 years older than my actual age. I have the normal aches and pains that come with aging, but for me it feels a little more severe.

Trudie: What is your basic treatment plan now?

Robert: I still take Bactrim and an antifungal as prophylactic treatment to keep infections in check.

Trudie: Have you had any side effects from long-term antibiotic use?

Robert: I have issues with irritable bowel syndrome and heartburn, but both conditions are manageable. To combat symptoms, I regularly use probiotics and heartburn medications, and I try to drink lots of water.

Trudie: What are your thoughts on curative treatments? Would you consider a bone marrow transplant?

Robert: When I was young, the survival rate of a bone marrow transplant was about 50/50, so it was too dangerous for my parents to consider. Today, thanks to the medical advances over the years, the survival odds are much better. I think it is wise for younger patients to consider all

the curative options available. But there is no “right” answer. It’s a very personal decision. If a family chooses to live with CGD, I am absolutely supportive of it, as I have lived a wonderfully normal life despite the challenges.

Trudie: You’ve lived with CGD for more than 50 years. Do you ever get discouraged?

Robert: I am a big believer in positive thinking. Yes, I have feelings of sadness and fear like anyone else when I first come down with something, but I get over that quickly, and I start focusing on what I need to do to get better and back to my life.

Trudie: Tell us about your work with young people.

Robert: I am an academic advisor at Towson University in Maryland, where I have worked since 2005. I’m also the father of two sons, Leo, 12, and Trevor, 15. Because of my life experiences, I consciously make an effort to counsel families with young children who have CGD, and I urge parents to allow their children to be more active. I hear

stories all the time from families who treat their children like they’re in a bubble, but they don’t have to do that. My brother and I are living proof of that. I also recently participated in the Immune Deficiency Foundation’s (IDF) Career Night for teens, which was very rewarding. I’ve been involved with IDF on the periphery for years, but I only started to get really involved over the past year because I had more time due to the pandemic.

Trudie: What advice do you have for young people dealing with a diagnosis like CGD?

Robert: I’d say it’s important they live within the parameters of their treatments and prophylactics. If they do that and are careful, they can have a very normal life. 



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