



# Profile: SamMichael Long

By Trudie Mitschang

**TO SEE** SamMichael Long today, you would never guess this active and ambitious college student spent much of his childhood in and out of hospitals. Diagnosed with common variable immune deficiency (CVID) at a young age, SamMichael has resisted the temptation to let his illness define him. Drawing on his relentless optimism to excel in life, in spite of chronic illness, SamMichael serves as a mentor and volunteer for the Immune Deficiency Foundation (IDF) Teen and Young Adult Council. When he is not focused on giving back and helping other teens navigate the often-difficult road of primary immunodeficiency (PI), this Minnesota native is busy pursuing a computer science degree at Saint Mary's University of Minnesota.



*SamMichael Long has thrived since being diagnosed with CVID in 2005 and is now pursuing a computer science degree and working with the Immune Deficiency Foundation Teen Council.*

**Trudie:** When were you diagnosed with CVID?

**SamMichael:** I was in and out of the hospital for the first seven years of my life. I was diagnosed with CVID in 2005, and during the first year, I was treated with Xolair (omalizumab). After that, I was switched to intravenous immune globulin (IVIG) therapy for six years, and then was switched again to subcutaneous IG (SCIG) therapy. I was treated with SCIG for four years, but I discontinued IG therapy almost four years ago.

**Trudie:** What is your current treatment plan?

**SamMichael:** I am taking an antibiotic supplement called azithromycin in place of IG therapy, and I have never

felt better. I go in once a year for labs to check my immunoglobulin levels, and I am currently doing great.

**Trudie:** How has living with chronic illness impacted your life?

**SamMichael:** Living with a PI has helped me develop into the person I am today. One of the best pieces of advice I have ever received was when I first learned about IDF from a wonderful lady named Kathy Antilla. She told me: "You cannot let your disease control you; you have to control it." I live by that motto every day. I don't let my PI stop me from doing anything I want to do. Just because my body doesn't work the same as everyone else's doesn't mean I can't do what they are doing. Granted, I have to be more careful about certain things, but my PI has never held me back. I played sports all through high school, I go hiking, camping and swimming, and I live a pretty normal life. I cannot thank IDF for all it has done for me and my family over the years.

**Trudie:** What is your role on the IDF Teen Council, and how did you become involved?

**SamMichael:** My role with the IDF Teen Council is to be a mentor and an advocate. I have been blessed to travel around the country and speak to further educate people on PIs and what IDF does. I started becoming really involved after I attended my first IDF Teen Escape event in 2011, which helped me figure out that working with IDF is something I wanted to pursue. First, I started volunteering at local



*"Music has literally become my whole life," said SamMichael, who uses it to help him maintain a positive attitude.*

family conferences. When I turned 16, I was put in touch with Dan Antilla, the head of the Teen Council, and that's when things really took off. That same year, I was sent to California to attend a Teen Escape, but as a leader. That was a surreal moment for me because it was like everything had come full circle. Since then, I have attended numerous Teen Escapes and Family Conference Days, as well as spoken on Capitol Hill for IDF Advocacy Day in April 2016.

**Trudie:** What does the Teen Council do?

**SamMichael:** We work in conjunction with IDF staff to advocate for youth living with PI to let them know they are not alone, and to help educate them on their specific disease. All of the members of the Teen Council come from different walks of life, and each of us has our own unique story. We serve as mentors for those who want to be educated, but mostly we serve as a family. We welcome each kid we meet and interact with into our little family. Because the PI community is so small, knowing there are people out there just like you means the world. We are just

like a family, and we are always here for each other.

**Trudie:** What are some of the unique challenges teens face living with PI?

**SamMichael:** The challenges vary depending on the exact diagnosis, as well as its severity. Speaking on my own behalf, I know it was hard for me growing up to keep a high energy level. I would go in for tri-weekly

infusions, and by the end of that third week, my energy level would be depleted. Once I received treatment, my energy level would return. When I switched to SCIG, my energy level was more consistent because I was receiving treatments twice a week.

**Trudie:** How do you maintain a positive attitude?

**SamMichael:** Family and friends really keep me going. They are a constant motivator for me to keep striving for my goals. I also use music to maintain a positive attitude. Music is an escape for me; I find it to be the best tool to use. I just strap on my headphones and listen. I met one of my closest friends, Keegan, at an IDF event, and ever since that day, he has been like my brother. We always motivate each other and call each other when something is up.

**Trudie:** What role does music play in your life?

**SamMichael:** I have been playing music since I was little. I started piano when I was in second grade, and I am mostly self-taught. In middle school, I picked up percussion and have been

doing that ever since. When I started college, I really wanted to learn something new, so I taught myself how to play the ukulele. By the end of the semester, I was playing at gigs around campus and for variety shows! Then, just this past summer, I decided to teach myself guitar, and started playing around campus and at church mass. Music has really embodied my whole life. One of my favorite quotes of all time goes like this, "Music speaks what cannot be expressed, soothes the mind and gives it rest; heals the heart and makes it whole, flows from heaven to the soul." Music has really helped me to express myself over the years, and really helped me to find a center in times of trouble and hardship. It is something that I use as a tool to connect with people, and help them cope in situations. I also use it as a tool to praise Jesus and spread his message. Music has literally become my whole life.

**Trudie:** What lessons have you learned that you can pass on?

**SamMichael:** Be who you want to be, and don't let anyone tell you no. Even with your PI, you can do anything that you set your mind to. There are no limits; the world is your playground. Do not let your disease control you; you have to control it. Once you do that, nothing can stand in your way. If I have learned anything over the years, it is to always ask questions about things you don't understand, and treat every day like a fresh start. Live in the present. There is no point in living in the past because it already happened, you can't change it and the future is unknown. But you have full control over the present, so seize it and make it your own. ■

**TRUDIE MITSCHANG** is a contributing writer for *IG Living* magazine.