

Profile: Cameron and Max Mona



Cameron Mona, who was diagnosed with CVID eight years ago, is fully embracing life by planning to attend college and continue to play music. He is pictured with his dad, Nick, older brother, Max, and younger brother, Nate.

LIKE MANY families living with an immune deficiency disease, the Mona family found abundant support through the Immune Deficiency Foundation (IDF). That's why when siblings Cameron and Max decided they wanted to raise money for their favorite nonprofit and also boost awareness about Cameron's common variable immune deficiency (CVID) diagnosis, they decided to basically "go big or go home." An avid mountain climber, Max floated the idea of trekking Mount Kilimanjaro (the highest mountain in Africa and the highest single free-standing mountain in the world), and right away the brothers knew they had found their fundraiser. In July 2019, after rigorous preparation and training, Max successfully reached both his fundraising goal and the summit, successfully paying tribute to the little brother he considers his "hero."

By Trudie Mitschang

Trudie: Tell us about your CVID diagnosis.

Cameron: After I received my diagnosis, my immunologist suggested intravenous immune globulin (IVIG) therapy. His hope was that the treatment would prevent infections and increase my energy levels. I received my IVIG infusions over two long 10-hour days every four weeks. I had to receive my medication slowly and receive extra fluids, so the treatments took a little longer than my doctor anticipated. This treatment plan prevented the infections as my doctor intended, but the energy levels were not improving as he expected.

Trudie: What is your treatment plan today?

Cameron: After my energy levels were not improving, my nurse suggested I increase the frequency of my infusions. Once I did, I felt much better. Now, I receive my IVIG infusions once every two weeks. They only last about eight hours now, so I am not out of commission for the whole day.

Trudie: How did your life improve after IVIG?

Cameron: My diagnosis and treatment have allowed me to come as close as I can to waking up and feeling "normal." After a long hiatus from playing baseball, I've been able to play varsity at my high school for the past two years, and I have been able to follow my true passion: music. IDF gave me the opportunity to learn more about CVID at different conferences I've attended. It's also helped my family and friends begin to really understand what I go through on a daily basis.

Trudie: What inspired you to host a

fundraiser for IDF?

Cameron: IDF has helped me and my family, and I would like to give back to the organization. Our hope is that the money the fundraiser generates will allow others in my situation to learn more about their own primary immunodeficiency diseases and help them empathize with those who suffer from CVID like me.

Max: When I had planned to climb Mount Kilimanjaro, I wanted to raise money for a cause I believed in. Within five minutes of discussing the idea, Cameron and I decided to donate all the funds we raised to IDF. The organization does amazing work and has definitely helped our family move forward with Cameron's CVID diagnosis.

Trudie: Why Mount Kilimanjaro?

Max: I have long enjoyed mountain climbing and hiking, and I have always been very motivated by competition. Once the idea of Mount Kilimanjaro was brought up by a friend, I knew I wanted to reach the summit, and I started making travel plans soon after.

Trudie: What was your fundraising goal, and how did you promote it?

Max: Our fundraising goal was \$2,500 originally, and Cameron and I quickly reached that goal. We later raised our target to \$5,000 and continued to work toward that. We used Facebook and social media promotions and email, and Cameron and I had also reached out via phone to connections we had.

Trudie: Did you train for the actual trek?

Max: Yes, I did. I think it was a little easier having already been an NCAA athlete, and the climb was during the

summer between my sophomore and junior years. I was already in pretty good shape, but I put an emphasis on long-distance cardio. I spent a lot of time on the treadmill and stair climber at my gym with my hiking boots on.

Trudie: Tell us about the hike. Who participated, and what was it like?

Max: I went with three friends who were experienced climbers, having already been to the Mount Everest base camp twice, and it was a beautiful and life-changing experience. The Mount Kilimanjaro hike takes you through the jungle before your summit attempt, and I really enjoyed every moment. The most difficult aspect of the climb was during summit day. After hiking for eight hours, we briefly rested and then woke up at 1:00 a.m. to hike for 14 hours to reach the summit during the optimal time frame. Morale was low, but we were all able to summit Mount Kilimanjaro, and as you can imagine, it was quite emotional at the top!

Trudie: What has this experience taught you about yourselves?

Cameron: This experience was a big part of learning to love myself despite my illness. I used to loathe myself because of my CVID and the social and physical effects it had on my everyday life. Having an opportunity to educate others about what I go through every day showed me that although I was indeed different from a lot of other people, being different is not a bad thing. I now look at my CVID as my unique strength since it continuously presents me with adversity to conquer and grow.

Trudie: What is your involvement with IDF now? Do you plan other fundraisers?

Max: Yes! Mount Kilimanjaro was my first of the seven summits (highest mountains in each continent). Although



Cameron and his brother, Max, wanted to raise funds for IDF to give back for the help the organization gave their family. They held their first fundraiser with Max (second from left) hiking to the summit of Mount Kilimanjaro with three friends: climbing guide Seraphin (left), climbing expert Ryan (second from right) and climbing guide Michael (right).

COVID-19 has delayed my schedule, I am planning to climb Mount Elbrus in 2021, and I am continuing to raise money for IDF. As I continue to climb more difficult mountains, I plan to set higher fundraising goals and donate more money to IDF.

Trudie: What are your goals for the future?

Cameron: I am graduating high school this year and am pursuing a college education. In addition, my band Port Amerigo, in which I sing and play guitar, released our debut album "Head Rush" this December. I plan to continue to release music with the band and hopefully play shows whenever the COVID-19 pandemic becomes manageable in the United States.

Max: I plan to graduate from Concordia College in the spring, and I am planning to attend either MIT or Vanderbilt for my master's degree. I'm also a musician, and my music duo Golden Age has recently signed with FrtyFve records, a music label in London. We plan to continue producing/releasing music in the near future. Long term,

I'd love to work in either sustainable finance or in the music scene in some of the bigger cities throughout the United States.

Trudie: What advice do you have for other young adults living with CVID?

Cameron: I would say to explore your passions and not let your diagnosis define you. My condition has been manageable for years now, but fully embracing my CVID took time. Finding my passion for music and realizing that sometimes the social/physical effects from

CVID are out of my control helped me do that.

Trudie: How do you keep a positive attitude toward life?

Cameron: I remain positive because I know how much progress has been made since my diagnosis. Before I was diagnosed with CVID, I remember missing school constantly, failing to gain a foothold in any social groups, and being doubted or ridiculed by teachers, peers and even some doctors. Now that I have had my diagnosis for eight years, I recognize the life I can lead is as close to normal as ever.

Max: As someone who hasn't had to deal with the effects of CVID, I always say Cameron is my hero. He's able to do so much and not let anything inhibit his ability, and I think that's what's always given me my positive outlook on life. 



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