

# Profile: Carl Schlacht

By Trudie Mitschang

**AS A RETIRED** professional motorcycle racer turned insurance agent and entrepreneur, Carl Schlacht is a prime example of someone who refuses to let chronic illness hold him back. The 35-year-old Cleveland, Ohio, resident was diagnosed with X-linked agammaglobulinemia (XLA) as an infant, but he has gone on to defy the odds by pursuing his dream to compete in extreme sports.



*Carl Schlacht, diagnosed with XLA when he was just 1 year old, is following his dreams.*

**Trudie:** Tell us about your diagnosis.

**Carl:** My journey began at 1 year of age. I was at my babysitter's house when I reached up onto the coffee table and spilled hot tea on myself. I ended up in the hospital with a third-degree burn. While I was in the hospital, I acquired a severe infection and my physician ran some tests and diagnosed me right away with XLA, a rare primary immunodeficiency. We learned XLA is a condition that affects the immune system and occurs almost exclusively in males. People with XLA have very few B cells, which are specialized white blood cells that help protect the body against infection.

**Trudie:** How did your family educate themselves about this rare disease?

**Carl:** Since I was diagnosed so young, we relied on my physician and immunologist. These days, it is so much different with all of the great online resources.

**Trudie:** What was life like for you growing up?

**Carl:** As a young active kid I loved playing outside with my friends. The last thing I wanted to do was sit in the hospital for hours after school or on a weekend getting infusions, but I had no choice. Otherwise, I lived a normal life, going to school and catching a cold here and there. At an early age, I decided I wasn't going to let anything get in the way of realizing my dreams.

**Trudie:** How did you get interested in racing motorcycles?

**Carl:** My dad was into cars, and my parents encouraged my interest in racing. When I was 3 years old, they bought me a four-wheeler. I started riding in the backyard and, slowly, the track got bigger and more challenging. A couple years later, I got my first dirt bike and started racing around the country as an

amateur. Every day after school when other kids were playing video games or watching TV, I would come home and practice riding to be ready for the next race. It kept me out of trouble, and I loved it. When I was on that bike, nothing else mattered. I wasn't a kid with a serious immune disorder who had to have infusions. I was free and happy. Nothing could stop me. I felt like I was a healthy, normal child most of the time.

**Trudie:** Were you or your parents ever concerned about you pursuing a high-risk career given your diagnosis?

**Carl:** When I was a kid, my parents would make sure I had the right protective gear and got the right coaching to make sure I was safe and could excel in the sport. I did have injuries growing up and some surgeries, but I always stayed on top of my infusions and



never had any problems with infections after an invasive surgery. My mom said she wasn't really scared until I was at the pro level because of how intense, competitive and fast we were going.

**Trudie:** Tell us how you went pro.

**Carl:** Through my school years, I became very competitive and my parents were able to take me to some of the big national races around the country. Through that experience, I was able to make a name for myself, which led to me getting qualified to move up to the pro level after high school graduation. Motocross is a very physical sport, and I practiced on the bike and worked out physically in the gym with a trainer.

**Trudie:** Did managing your infusions ever get in the way of racing?

**Carl:** Initially when I was racing, I would receive intravenous immune globulin (IVIG) infusions once a month. I would be tired and not feel good before and after my infusions. So, for about two weeks out of the month, I felt good. This had a major impact on my racing career. It wasn't until I switched to subcutaneous IG (SCIG) when I saw a big positive shift in how I felt. SCIG really made a huge difference, and that was right at the beginning of my pro career.

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

**Carl:** I infuse Hizentra, which is an SCIG product. I made the switch from IVIG more than 10 years ago, and I infuse at home on my schedule once a week. Frequent dosing keeps my levels much more consistent, which keeps me healthy and able to manage my busy lifestyle. I really enjoy the convenience of self-administration because it works with my hectic schedule.

**Trudie:** Why did you retire from racing?

**Carl:** I was injured in 2013 and was going to come back in the 2015 season, but I decided to retire and just do it for fun while I still can. I have friends who are paralyzed and even worse — some passed away from injury. I had a career in insurance lined up for several years with a friend's company, so I was just waiting for the right time in my life. I am also a filmmaker, and I have won several awards for some of them at film festivals. I continue to make films, and I am getting back into racing in 2020 — just not on bikes. I'm transitioning to rally car racing. I am very excited about this!

**Trudie:** What are your goals now?

**Carl:** My goals for the future are to have a family, make movies and win rally car races around the world, along with sharing my story and helping others follow their dreams.

**Trudie:** Have you performed any patient advocacy work with the Immune Deficiency Foundation (IDF) or other organizations?



*Refusing to let immune deficiency hold him back, Carl excelled at professional motocross for years. Today, he is an insurance agent, filmmaker and, never getting enough of extreme sports, is rally car racing.*

enjoy giving people hope to know they can follow their dreams and not let anything hold them back. I was 3 years old when I first dreamed of racing bikes. Today, every time I ride, I still feel the same way I did when I was a kid riding my first dirt bike. Everything else drops away, and nothing can stop me. With determination

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**Carl:** I attend many IDF programs, as well as do patient advocacy for CSL Behring.

**Trudie:** As you look back on your life so far, what are you most proud of?

**Carl:** I am so proud I have been able to accomplish my goals and continue to reach new goals that allow me to share my story with others. I

and support from my family and my doctors, I've been able to achieve my goals. Whatever your dreams may be, you don't have to let an immune deficiency keep you from realizing them. ■

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