

Profile: Kelley and Connor Hodges

By Trudie Mitschang

IN JANUARY 2014, Kelley Hodges read an article in *IG Living* written by Terry Harville, MD, PhD, outlining how an antibody deficiency is diagnosed. Her interest was piqued because her formerly healthy 17-year-old son, Connor, had been diagnosed with Epstein Barr virus (EBV) and, later, common variable immunodeficiency (CVID). Because the family lived in a small town with limited access to specialty medical care, Kelley hoped Dr. Harville could offer some much-needed advice. Not only was Dr. Harville able to answer her specific questions surrounding Connor's diagnosis, he also referred her to several nearby specialists with expertise in Connor's condition. Five years later, Connor is now a college senior and an award-winning NCAA Division 1 swimmer, graduating with honors and successfully managing his own healthcare. We caught up with Kelley and Connor to hear their stories.



Connor Hodges, pictured with his mother Kelley, father Michael and sisters Mikayla and Katy, was diagnosed with CVID after contracting the Epstein Barr virus.

Trudie: Tell us about Connor's journey to diagnosis.

Kelley: In the summer of Connor's junior year in high school, he contracted EBV and was sick several times after that. Initially, we didn't know he had EBV, but after being sick for the third time, we took him to his long-time pediatrician who ordered blood work that showed he had IgG levels below 200. His pediatrician called me on his 17th birthday to tell me he needed to have an X-ray and additional blood work — that day. Since Connor had little history of being sick and had never been hospitalized, I didn't understand her concern. She scheduled an appointment with an immunologist, but the closest appointment we could get was

three months away. Connor didn't show any signs that something was wrong; he swam four hours a night, never missed school and was earning all As in school. In November, he met with an immunologist who gave him the pneumovax vaccine and, in December, he became ill with a virus. We didn't treat it because he seemed fine with the exception of having a sore throat. Then, on December 30, he had a tonic-clonic seizure at 6 a.m. We took him to his pediatrician who admitted him to the hospital for testing. On January 1, he was diagnosed with CVID.

IG Living: What led you to reach out to Dr. Harville?

Kelley: After Connor's diagnosis, I researched everything I could about CVID and its connection to EBV. I found a case study written by Dr. Harville about a young man who was 17 when he contracted EBV, which resulted in CVID. I was encouraged because the patient showed signs of recovery when he was 24. I decided to email Dr. Harville and share our story.

IG Living: How did Dr. Harville's advice help Connor?

Kelley: I am grateful every day that he decided to answer an email from a mother in Florida who needed help and advice. He pointed me toward experts in our area who conducted research and were very knowledgeable about CVID. We ended up seeing Dr. Harry Schroeder at the University of Alabama (UAB) who evaluated Connor and corrected his immune globulin (IG) therapy dosage.



IG Living: What has been the biggest hurdle, and how did you overcome it?

Kelley: Initially, the biggest hurdle was finding a doctor. Connor was 17, not really a child yet not an adult either. He could see a pediatrician for another year, or he could see a doctor who might not understand adolescence. In addition, we live in a small town with limited access to specialists. To overcome the hurdles, we spent six months driving to UAB, Emory University and the Mayo Clinic in search of care. Next, we faced financial hurdles. Our insurance company charged us \$600 a month for intravenous IG (IVIG), and Connor had a difficult time with side effects. After four months, we switched him to subcutaneous IG (SCIG), and our insurance company lowered our out-of-pocket cost to \$35 per month. SCIG is perfect for Connor; it gives him control over his treatment.

IG Living: Connor is now a young adult. How have you transitioned the management of his care?

Kelley: A year and a half after his diagnosis, Connor moved into a dorm at Florida Atlantic University (FAU) 10 hours away. His doctor at UAB recommended an immunology practice near his college, and that was the first place we visited after moving him. For the first two years of college, I attended his doctor appointments at the beginning and end of the year with him. For the appointments in between, I would talk to him before each one to discuss questions or concerns he had. After the second year, he went to all of the appointments by himself. By the end of his second year of college, we made another decision to place him in control of ordering his medicine and communi-

cating with the insurance company. When mistakes have been made with an order, I have him talk to the insurance representatives. It was important to us to make him coordinate all of his care by the time he turned 20.

IG Living: Connor's athletic and academic accomplishments are impressive. How does he juggle these accomplishments while living with CVID?

Kelley: Before Connor left for college, I had each of his doctors talk to him about drinking and drugs. I knew the temptations would be present in college, and I also knew he needed to hear it from someone other than me. He left for college understanding he needed to follow his treatment plan and that the consequences of not following the plan could end his dream of swimming in college and earning a degree in electrical engineering. It was hard because I worried about everything from dirty door knobs to him not taking a sore throat or the flu seriously. Within the first year of college, we felt confident he would follow his treatment plan and see his doctors if he wasn't feeling well. With swimming, he had to travel throughout the school year. He would plan his infusions around that schedule. His coaches knew he had CVID and were very supportive.

IG Living: What advice do you have for other parents?

Kelley: Find the best doctors who specialize in your child's diagnosis, and share your story. I have learned so much from others by sharing our story, and I have been able to help others. I have shared the list of doctors Dr.



An accomplished student-athlete and award-winning NCAA Division I swimmer, Connor learned to take charge of his medical care by age 20.

Harville gave me with multiple families in similar situations. I also read all of the literature the Immune Deficiency Foundation sends us.

IG Living: Connor, what has this journey with chronic illness taught you?

Connor: I learned to never give up. I also try to appreciate everything.

IG Living: Has having CVID impacted your personal and social life?

Connor: One of my favorite parts of college was being on the FAU swim and dive team. I don't feel like having CVID impacted my social life or my ability to be a part of the team. I am able to do everything I want to do.

IG Living: What advice do you have for other teens/young adults?

Connor: I would tell them to focus on the areas of their life over which they have control and continue with their normal activities as much as possible. I can control my sleep, the food I eat and the way I think. When I was first diagnosed, this helped me to stay focused and continue with school and swimming.

IG Living: What are your goals for the future?

Connor: I would like to continue my education and pursue a master's degree in electrical engineering. ■

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