



Profile: Keegan and Laura Concannon

By Trudie Mitschang

AT 13, KEEGAN Concannon is more than a teenager actively beating the odds while living with chronic illness. Although diagnosed with common variable immune deficiency (CVID) as a toddler, this incredibly resilient young man has not only fought alongside his parents to obtain VGo robotic technology in his Hudson, Mass., school district, he's also defied his physical setbacks and become a part of a local football team. We chatted with Keegan and his mom, Laura, to learn more about this family's hurdles and their commitment to keeping CVID from defining Keegan or limiting his accomplishments. Perhaps Keegan says it best regarding his recent achievement: "I am not the fastest. I am not the best. I try my hardest. I bring a positive attitude. I educate my coaches, friends and other teams. I am a *football player.*"



Keegan Concannon has suffered from the effects of common variable immune deficiency since he was just 4 days old. Thankfully, with his mother Laura's advocacy, Keegan is living life to its fullest.

Trudie: Tell us about Keegan's journey to diagnosis with CVID?

Laura: Keegan's journey began when he was 4 days old, the same day we brought him home from the hospital. Keegan was home for a few hours and developed his first infection and fever from his circumcision. We were simply floored. We had no idea as new parents a baby could become so ill.

Trudie: When did you realize it was not just an isolated incident?

Laura: We spent day after day in our pediatrician's office with ear infections, pneumonia and fevers. Keegan started on antibiotics from that first day we brought him home. It was a very long process for diagnosis; our doctor would send us to Children's Hospital Boston, they'd get his fever down and send us home. We were first told Keegan was having immunodeficiency issues when he was 3 months old, which led to years of guessing games. Finally, when Keegan was 2-and-a-half years old, we received a formal diagnosis of CVID.

Trudie: What other issues has Keegan battled as a result of CVID?

Laura: Keegan misses massive amounts of school, on average 60 to 100-plus days in any given year. As a family, CVID has been very difficult

due to constant illness and canceling plans on a regular basis. We also had to educate our school system, friends, family and ourselves. When Keegan was first diagnosed, we did not know where to turn or how to help our son. We had to learn how to navigate our new world and did not realize how dangerous it was until one of Keegan's diagnosing doctors told us we were lucky he was able to survive all of the illnesses he'd endured. As a mom, it broke my heart that I could not fix this for my son.

Trudie: Tell us about the VGo proposal.

Laura: When Keegan was in kindergarten, I fought to have him included as much as possible in the classroom setting and asked that he be allowed to access his classroom via Skype. Keegan loves school and has always excelled in the classroom. In first grade, Keegan began Skyping with limited access into the classroom because our school district was so unwilling to think outside the box to educate a chronically ill child. Around the same time, I began seeing stories on the news about children accessing their classrooms using a VGo robot. The robot basically replicates a person in a distant location so they can see, hear, talk and move around as if they were there. I started requesting this technology in our school district and received countless excuses as to why they could not allow the robot in the classroom setting. It was difficult because the way the school district reacted was to retaliate against Keegan. Meetings we attended became very argumentative due to their lack of education regarding a child with CVID.



Trudie: How did you take your fight to the next level?

Laura: Keegan asked us to ramp it up after he joined our local football league. He became very determined to have access into his classroom as he was finally included in a sport. We fought for several years, eventually taking Keegan's story to our local Senator Jamie Eldridge and Representative Kate Hogan. Keegan wanted his voice heard and asked for help from one of his most prominent advocates, Gary Blumenthal, former CEO of Association of Developmental Disabilities Providers (ADDP). Gary started attending meetings and voicing his concerns. This led to Keegan and his best friend Ethan Bushey presenting the VGo in front of other families who had children with medical disabilities. Then, two years ago, we were watching CNN and learned of this incredible foundation called Grahamstastic Connection, which helps provide medically ill children access to their classrooms with donated VGo robots free of charge. I contacted them immediately to see if Keegan would qualify. I was confident our school district would not want to fight a free piece of technology. Boy, was I wrong. Keegan was immediately approved for a VGo robot, but our former superintendent created new reasons as to why they could not accept this piece of incredible technology that would allow Keegan to attend school.

Trudie: What was the eventual outcome?

Laura: Thankfully, we got a new superintendent, Dr. Marco Rodrigues! The VGo was approved in September of the 2017-2018 academic year. Dr. Rodrigues made this decision at a very critical time for Keegan as he became very ill and ended up in Children's Boston throughout October and November of

that year. Dr. Rodrigues has not only welcomed the VGo into the school, but the principal and Keegan's academic team have embraced it as well. We will forever be thankful to Dr. Rodrigues for thinking outside the box and understanding Keegan wants merely to participate in his education just like any other kid.

Trudie: Tell us about Team IMPACT.

Keegan: Team IMPACT is a national nonprofit that connects children facing serious and chronic illnesses to local college athletic teams. They connected my mom and me to Worcester Polytechnic Institute (WPI) so I could participate in the football program there. It's very special to me because it helps me feel like I am part of a team. I have not always felt this way until I discovered football. It makes me feel like I am a part of something that is bigger than myself.

Laura: As a parent, I will forever be thankful to Team IMPACT and WPI. This group of coaches and players has welcomed Keegan onto the field and its team. Keegan has always had an incredible drive, which has not been easy due to infusions, side effects and illnesses, but you will see him on the sidelines with his uniform on waiting for one more play even on the sick days. Keegan will not allow himself to miss football.

Trudie: What has living with chronic illness taught you?

Keegan: Living with a chronic illness has taught me to get the most out of every day and to appreciate every good thing that has come my way. I also feel grateful to all my doctors, teachers, caregivers and, especially, my parents for helping me to try to live an ordinary life.

Trudie: What are your goals for the future?

Keegan: One day, I want to become a biomedical engineer to figure out what it is I have and to try to help develop a



Keegan, with the help of his best friend Ethan Bushey, Representative Kate Hogan and Senator Jamie Eldridge, successfully advocated for VGo robotic technology to allow him to participate in school when he is sick by replicating himself in the classroom from a distant location.

more effective treatment for other kids and even myself. If you're young enough like I am, finding out all about CVID can make a huge difference in your life.

Trudie: What are you thankful for?

Laura: We would like to thank everyone who has supported Keegan: The Hudson Massachusetts community; his physicians Dr. Kenneth Whittemore and Dr. Rima Rachid; HPS under the new administration; Team IMPACT and WPI; Grahamstastic Connection for making it possible for Keegan to have the VGo in the classroom; and Keegan's nurses, our families and friends. Most importantly, I would like to thank Keegan, who has taught us life may be filled with bumps, curves and hills, but you have handled all of the obstacles with compassion, empathy, tolerance, understanding and love. ■

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