A Mother and Daughter Share their Story in Honor of Adrenal Disease Awareness Month
Silvana and Caitlin Vanderberg

Mom’s Story, Silvana Vanderberg
In honor of Adrenal Disease Awareness month, I would like to share the story of the turning point in my beautiful 23-year-old daughter’s life that shaped a 10-month journey to her diagnosis with Addison’s disease (Adrenal Insufficiency). I tell this story from my perspective as a mother; in no way can I pretend to know what it is like to have Addison’s disease, but I share this story in hopes that it will lead to more adequate and timely responses to adrenal crises.

Caitlin is and always has been an independent spirit and old soul. While in her second year of college, she joined a group of friends on a spring break trip to the Houston rodeo. After a fun and eventful week, Caitlin returned to her college quite exhausted from the plane ride back. The next day, a number of bouts of persistent nausea and vomiting brought her to the college’s health center. After noticing that her blood pressure was extremely low and that she was dehydrated, the college’s doctor felt that she needed to be sent to the ER.

This is where the nightmare began. By the time I got to the hospital in Northampton, MA from Long Island, NY, Caitlin was practically comatose. Visits from a parade of specialists (including infectious disease, gastroenterology, and toxicology) yielded no answers. In between violent vomiting and dry heaving spells, Caitlin lay semi-comatose for five whole days. She could not hold down any food or drink and was too weak to
leave her hospital bed. Despite being in this very vulnerable state, my daughter was doubted by skeptical nurses who assumed that she had been drinking and using drugs during her spring break. The nurses that “took care” of her were judgmental, chalking it up to just another typical wild college night. Caitlin spoke incoherently and had dry heaved to the point that the blood vessels in her eyes popped and she looked literally like a monster.

After the fifth day of being in the hospital with no apparent concrete diagnosis, I was in constant communication with her pediatrician who had taken care of her since birth. He willingly spoke to the doctors at the hospital, reassuring them that this was not a young woman who engaged in risky behavior or drinking and drugging. He too was perplexed and requested that they bring in an endocrinologist but they said that they were first waiting for the toxicology reports. It was at this point that he told me to just get her out of that hospital and bring her back to the hospital on Long Island where he had arranged for her to be seen by an endocrinologist who had seen Caitlin when she was younger due to his suspicions of Celiac disease. Even after this whole ordeal, she was released with no answers.

For the next 5 months, Caitlin practically slept the days away. I kept justifying it by thinking that she was still recuperating from the week that she lost. She went back to school for her fall semester, which, in hindsight, was the biggest mistake. But due to the personality changes this disease can bring, she was not making good decisions. After an unproductive and exhausting semester, Caitlin was finally diagnosed.

In total, Caitlin has had four Adrenal crises. Looking back, one of the most frightening moments was the realization of how close Caitlin came to dying. Here I was, fully confident that she was in a safe place and that these doctors knew what they were doing. These experiences have exposed a larger, more subversive issue in emergency rooms: many hospital personnel are not appropriately equipped to properly handle and treat an adrenal crisis. Despite arriving at the emergency room with all the proper paperwork, letters from Caitlin’s doctors, and medic alert bracelets, it always takes far too long for Caitlin to receive the life-saving dose of IV Solu-Cortef that she needs in a crisis. It is perplexing and alarming that this keeps on happening over and over again. This happens not just in small regional hospitals, but in large city hospitals as well. I am not sure if there is data on how many Addisonians have died due to lack of understanding and diagnosing of this invisible illness when it is not caught and addressed in a timely manner. Every time Caitlin has visited the ER, the nurses take too long to take her blood and wait for the results. Time is of the essence when it comes to adrenal crises. We urge nurses and doctors to understand that for an Addisonian, it is crucial to receive hydrocortisone intravenously right away. Even if something came back on the bloodwork, giving the life-saving dose of hydrocortisone can do no harm; it might even save a life.
Daughter’s Story, Caitlin Vanderberg

Being diagnosed with Addison’s disease can be a long, traumatic, and complicated process. Oftentimes, the diagnosis is both relieving and puzzling. For me, Addison’s disease was the answer to so many unexplained questions and symptoms that had developed over many years. Why was I so incredibly exhausted all the time? As a once very active 20-year-old, it was perplexing for my family to understand why I could barely stay awake through the day. Why had my personality changed so much? I had gone from a sensitive, caring person to someone who was indifferent and apathetic. What could explain the numerous hospital visits that never resulted in an answer? The nausea, vomiting, and extreme dizziness led to three emergency room visits, but I never left with a diagnosis. Looking back now, I realize these episodes were acute adrenal crises. When a doctor finally put together that my web of symptoms pointed very strongly to adrenal insufficiency, I turned to the internet and was dumbfounded that I had so many symptoms of this rare disease but I wasn’t able to piece it together myself.

That leads me to one of the biggest realizations I have had about Addison’s disease. When you are in it, it’s so hard to realize that something is wrong. During the time period before diagnosis, it is so hard to objectively observe your symptoms. It is far easier to play them off as unrelated and attribute them to your lifestyle, job, or school schedule. I have realized that the same thing happens when I am feeling “off” and need to adjust my hydrocortisone or fludrocortisone. It often takes too long for me to realize that my cortisol is low, and hindsight is always 20/20. My biggest tips are to write down what your symptoms are when you feel “off” or “low” and keep them handy so you can easily run through them if you’re having a day when you find yourself barely getting by. Because of how difficult it is for me to objectively assess my symptoms when I am not feeling well, I have found it is crucial to have a support network in place with people you trust.

My support network consists of two doctors, my parents, and two close friends. It can be incredibly beneficial (and potentially life-saving) to have someone in your network let you know when they notice unusual symptoms or actions. I also cannot emphasize enough how important of a resource it is to find a support group or connect with other Addisonians. Not only is it incredibly validating to connect over shared experiences, but sharing information about medication and the ins and outs of daily living with Addison’s is incredibly valuable. Though being diagnosed with Addison’s may be upsetting and traumatic, the journey doesn’t have to be. There is certainly a lot of hope and success stories to be shared among Addisonians, and thanks to NADF, many of us are able to meet and connect.