

At the time, in 1987, pre-natal testing for CAH was not a thing, so it was not known I'd be born with it. I'm told that ten days after my birth I was extremely sick and my parents took me to the pediatrician. He immediately recognized my symptoms as CAH. That pediatrician knew of one man who could do anything about it so they rushed me to Westchester Medical Center where at that time I met the man who would end of saving my life and becoming a staple in it as well even to this day, Dr. Richard Noto, Chief of Pediatric Endocrinology. My parents told me that upon being admitted to the ER I had to be cardioverted and thus began my arduous journey through the early years of CAH. Just like other patients' stories that, I have read I spent time in and out of the hospital in my early years to get everything balanced. Eventually, everything settled down and the appointments with Dr. Noto transitioned from every 2 months to every 4 months to now almost 30 years later every 6 months. The regimen for treatment remains the same Solu-Cortef and Florinef twice a day to keep everything in balance but other than that I'm just like every other person my age. I went away to college, Cornell University in Ithaca, and today I am an EMT in NYS. I also commute to NYC daily for work. Only thing that sets me apart from the others around me is that I wear my Medic-Alert bracelet like I'm married to it and I also carry my Solu-Cortef everywhere I go; be it in my car, my backpack during my commute and always in my carry-on when traveling.

To the parents out there here are my few pieces of advice:

1) Explain to your kids that this disorder is not devastating and will not and should not impact the way they do activities. That is the one thing I wish I had known sooner. I had always been under the assumption that if I got hurt in sports I would need to be hospitalized, which was not the truth. I learned recently that should I require a dose of Solu-Cortef, I have up to 4 hours to get it before any negative effects start occurring.

2.) Tell your children their story; don't hide it from them. As they get older and begin to understand stuff more, tell them about the times they were hospitalized, about any procedures they had, and what it was like for you. I hear it from my mom all the time that the hardest thing for her was watching the nurses, phlebotomists, and even the doctors try to draw blood from me when I was very young. The more they know about their history with this disorder, the smarter they will be in terms of taking care of themselves.

3.) Get your kids to wear a medical ID tag from an early age. I regret not starting to wear one daily until I began working in NYC over 4 years ago. Being an EMT I blame both the providers and us as patients for not being educated more closely on Medical ID Tags. These tags can be the difference between life and death in this world that today is so unpredictable.

Thank you for listening.

THIS IS CAH

Mikey Tomechko