Barth Syndrome Foundation®

Family Focus

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MEET ANDREW

How old are you now?
I'm thirty-one.

What's been going on with you since 2010?
I graduated from Florida State University in the summer of 2010. I began law school at the University of Florida in the fall of 2011 and graduated in the summer of 2014. After graduation I went to St. Louis to participate in one of Dr. Cade's study.

Following graduation, I went to the conference in July of 2014. I took the bar exam and passed in the fall of that year. Toward the end of the summer and around the time I took the bar exam I began to notice that I was fatiguing quicker and winded. After I took the bar exam, and prior to returning to school to do my masters in tax law I went to my regularly scheduled cardiologist appointment. At the appointment I found out that I was in AFIB. I was also told that my heart function had declined. My doctors attempted to treat the AFIB and heart function, but my function continued to decline and I was ultimately listed for transplant in September 2014. I was transplanted 14 days after being put on the list.

My memories surrounding transplant are pretty incomplete which is unusual for me because my memory is usually excellent. I suspect it is because it was a traumatic experience and not one that I want to relive.

After my transplant, I took a year off to recover, at which point I was able to return to school and complete my masters. I then took a job at a law firm in Tampa working on tax, estate planning, and corporate work predominantly in the private wealth space.

Have you noticed a difference in your fatigue since having the transplant?

The fatigue is different. I think that's the best way to describe it. It's not gone but it's not the same. When I was in heart failure, I couldn't catch my breath if I walked up a flight of stairs. Now, when I walk up a flight of stairs, I don't get winded. The fatigue is more localized in my legs. I will say the few years after I had the transplant, particularly when I returned to school, I felt the best I have felt in my entire life. I was able to exercise, my diet was great, I had energy. Now I am working full time and have other responsibilities which makes it more difficult to devote as much time to my health.

Is there a way that you could take more time to take care of yourself?
It can be hard to find a balance to do work and those other things. I both need to work and enjoy working. There's always a question about whether I should push through fatigue or not push through. It can impact how I structure my day. For example, if I exercise earlier in the day, I could exhaust myself and not have energy to do my job later. If I plan to exercise after work, I could be too tired from work.

What is that like with the localized fatigue in your legs?
I don't know. I don't really have a good description. There are just random days when I'm tired. I can't really describe it. It's like your body has a hard time holding itself up.

I have heard others use the term heavy when describing fatigue would you agree with that?
Yeah, I think that heavy is a good description of what it's like when I'm tired. I feel weighted. I feel the gravity more. I feel pushed down like your skin is stretched across your bones. I don't know how to describe it. It's a very unique feeling. Sometimes everything just feels burdensome.

What do you do to restore your energy when you get to that burdensome fatigue level or do you just push yourself?
I to tend to structure my day in such a way that I work when I have more energy. When I am tired, I take my lunch break, or if I am feeling good, I may not take a break. If I have energy in the evening I will work at night. Fortunately, I do have some flexibility with my job which allows me to do that.

What are your hobbies or what do you do for fun?
Prior to COVID I was doing a good amount of traveling. Currently, I like playing video games. I play online with my brothers. It's been a good way for us to stay in touch with each other during COVID. I've probably played more games in the last three

months than I have played in the past two years. My girlfriend and I just bought a house and that takes up a pretty good chunk of my time. I also volunteer on the patient advisory panel at our local hospital.

What would be your dating advice for someone who has Barth syndrome?
(Laughs)… My advice to someone who is reluctant to ask someone out would be just give it a try. Sure, being rejected sucks but everyone gets rejected at some point. You just move on because that person is not right for you. My advice to someone with Barth syndrome would be if you are interested in pursuing a relationship, pursue a relationship. Don't let Barth syndrome be the cause of holding you back.

On the other hand, don't get into a relationship just because people think it's what you should do.   You are dealing with a finite amount of energy. You just have to figure out a what's important to you and focus your energy on that goal.

I've seen all those photos of your family vacations. So where would you want to go for our dream vacation that you haven't been before?
I'd like to go somewhere in South America. Maybe Australia someday.

You have people in Australia!
I know we saw Florence when we were in France, that was a lot of fun.

What has been your experience in sharing your diagnosis of Barth syndrome when dating?
My thought was as long as I am honest with this person and they are aware, that's their decision to make, not necessarily mine. I guess dating is a little harder for someone with Barth syndrome. Internet dating probably makes it a little easier than it used to be.

When I first started dating, I had some trepidation in bringing up my diagnosis. Surprisingly most people really didn't care. Typically, if someone goes out on a few dates with you, they like you, so, it really wouldn't matter. I really don't talk about my health unless necessary. I don't' want Barth Syndrome to define me. I just don't talk about it that much. I have it. It's there but it's not who I am. I'm sure there was some level of reluctance to ask someone out when I was younger or to get in a relationship because I didn't want to burden them with my condition. At some point, I guess after the transplant that all changed. Maybe coming face-to-face with my own mortality put things into perspective.