

*Shelley Bowen, Director Family Services & Advocacy  
Brett Smith, Operations and Communications Lead  
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## MEET KEVIN

### How old are you now?

I think I'm thirty-one. It's been a long year. So, I guess I am still thirty-one.

### Are you working?

Yes. I work for the Chester County Community Foundation. It's a non-profit in West Chester, Pennsylvania. Initially, my title was an Administrative Assistant, but it has since changed to Portfolio Administrator. I have been there for four years now.



The Chester County Community Foundation advises and administers the funds for about four hundred private charitable foundations. These foundations generally are set up as legacy funds in a family name. Let's say someone wants to set up a foundation in their family name; they would give us money to make investments so the funds would hopefully continue to grow in perpetuity. When the family is ready to donate funds to a charity, they can let us know the specific charity and the amount they wish to contribute. Alternatively, they can tell us they want to donate to a charity with a particular focus. If they're going to donate to a charity with a specific focus, we provide suggestions about non-profits doing good work in that area. Ultimately, the donor always makes the final choice about who receives the money.

I work with our scholarship program. I also work with the board in preparing our annual grant program. I run the events for an estate planning organization we manage. Right now, with COVID-19, all the events are virtual. I still order supplies for the office. I enjoy my job. It's good to have something to do.

### Was there ever a time when you thought you wouldn't be able to attend college?

Yes. I saw the struggles the guys a little bit older than me were going through as they were in college. I didn't think it would be a realistic option to go to college. When I graduated from high school, I didn't plan to attend college. Right after graduation, I

had surgery on my foot. I spent that first semester staying at home recovering from the surgery. All of my friends had gone off to college, and I was bored out of my mind.

The college I attended, Immaculata University, is minutes away from my house. We decided to go to an open house they were hosting, and I just signed up on the spot to attend. The nice part about going to college is you have the option to make a schedule that works for you. For example, I once signed up for a full day of classes, and after one day, I realized that wasn't going to do. I was able to adjust my schedule without any issues. There is more flexibility with college than I had with high school. It took me six and a half years to get my bachelor's degree, but that's okay. It doesn't matter how long it took to get it. I have my degree. I'm okay with that. If you find something you want to study, I think it is perfectly manageable.

### **What was your major in college?**

I majored in communications. My focus was on public relations, but in the search for a job, I realized I didn't have the gift of the spin for PR in the business world. I have always had an interest in working for non-profits. So, I started looking for a job in that sector. I volunteered with local organizations and found that work to be very satisfying. It's much easier to do a marketing campaign for something that I believe in vs. selling a product that is just dumb.

### **Did you have concerns about working in a full-time career?**

In terms of finding work, I couldn't work a full-time job. I am lucky to have found a part-time job that I enjoy. I do think about working full-time, but I have to be realistic about what I can do. If things were okay all the time, which they are not, I might be able to go to work in the morning, come home, crash, and sleep all weekend, maybe, but doubtful.

Figure out what it is that you want to do for work.

It doesn't matter how many hours you work. You want to find a job you enjoy, doing something you enjoy for the hours you can work. I interviewed for a job selling ink toners. I didn't get the job. In retrospect, I think I would have been miserable if I had.

I'm lucky that I found a job with flexibility that allows me to work part-time. I have a pretty ideal schedule for my energy level. I work 20 hours a week, and I'm off on Friday.

**That's an interesting observation. Putting things into perspective in terms of not looking at the timeline but focus on the goal.**

That's right. If you want to go to college and have the grades and means to go, you should try. It doesn't matter how long it takes. What matters is you are making progress in reaching the goal. Even if you want to do a job that doesn't require a degree, maybe you need a certificate. Go for it. Don't give up. Just because your path or timeline isn't the same as most people, you can get there if you are willing to work for it.

**How is your energy right now?**

I'm taking a new medicine right now, and I believe I have more energy, but with the quarantine, I really can't get out to see if my energy has improved. I want to get an exercise bike because I felt the bike helped me when I was in Todd Cade's study. I bought one back in college, but it was so bad that I seldom used it. I sold it. I want to get a new one, but I want to get a nice one, but inventory depleted. I can tell that my energy and stamina are deficient with being shut-in. I walked a short distance last week, the same walk that I have done for four years with no problem, and it wore me out. It didn't take long for my legs to start getting heavy.

**We hear that term "heavy" quite a bit in these interviews. Is that what you experience when you get tired?**

That's how my legs feel. I know when I walk too far, my legs get heavy. Eventually, it will get to the point that I can't go on, but I tend to stop before it reaches that point. I guess everyone has to cross the line at some point; you know that time that you can look back and say, not again. For me, that was about ten years ago. I was at a friend's birthday party, and everyone decided we would just walk to town. The town was like six or seven blocks away. Luckily, my friends were able to hang back with me. There have since been times when the activity or exertion required was greater than my capacity, and I'd stop and not go on. It's not worth it.

**You have had quite a few cardiac arrests; leading up to those events, were you doing something to overexert yourself, or do you recall?**

Yeah, I have had eight. Mostly I was doing something very dull or nothing at all. The first one was hiding an Easter egg under the sofa. Another time it happened when I turned the water on in the shower. There were a couple of times when I was doing something more remarkable. One time I was going down a waterslide at a hotel. Another time, I was carrying a cinderblock in ninety plus degree heat. There is a bit of warning, but it comes on so fast that you can't stop it.

### **What prompted you to lift a cinderblock in ninety plus degree heat?**

It was in a situation where I really couldn't see myself at least trying. It was this girl working at a farmer's market for our internship and me. The tent kept breaking and falling on us. We tried numerous times to fix it, but finally, it was clear that it wasn't possible to remedy it. We decided just to break down. It was in the middle of this parking lot, and these cinderblocks held down the tent. The guy who was running the farmers market told us we had to put the blocks back. There was no way I would just make anyone carry all four cinderblocks while I watched. I had to try. I did make it to where it needed to be, but I didn't make it back.

### **As we do these interviews, we learn just how important it is to plan your energy as you plan your day.**

I didn't know that I would have to move those blocks before the event. The event was near my relative's house, and I thought about the location when I signed up for the event. It was my last day of college. I was thinking about that. It didn't occur to me to think about the heat. I also knew how hard it was to get people to sign up to do these things. I didn't want to let them down. I didn't want to mess things up for other people. I drank Gatorade while I was there. This was the second time I had done this type of event. The first one went fine, but at that point, the tent was fine. The first location was on grass; we just drove spikes in the ground.

### **What are your hobbies?**

I enjoy playing video games, reading and when things are open, I enjoy going out to eat. Any real hobbies have fallen by the wayside with work.

### **What are you reading?**

Right now, I am reading *Something Wicked This Way Comes*. It's an excellent Halloween book.

### **Do you play PC or console?**

I do both. I enjoy long role playing games. I just beat *The Legend of Zelda: Breath of the Wild*. I enjoyed it. Right now, I am playing *Destiny 2*. The expansion is coming. I'm trying to get ready for that. That is something you can play over and over. *World of Warcraft* is too much of a time sink investment. I rarely ever play *Fortnite*, but I recently logged in and played with a younger BTHS boy. My username is on the list we keep for BTHS guys if anyone wants to play.

### **How long have you been a part of the BSF community?**

Since the very beginning. Our family attended the first family gathering in Baltimore, which is when BSF got started. Since then, our family has attended all but two conferences. One year I had to choose between the conference or finishing college and the other I wasn't having a great year with my health.

Whenever anyone asks me to do something, I'm willing to do it. I have participated in the research during the conference. I have participated in three research studies outside of the conference. I go to the Barth clinic in Baltimore.

### **What is unique, or what do you see as the benefit of being seen through the Barth syndrome clinic in Baltimore?**

To me, it is good to get Dr. Vernon's perspective. I'm at the point where I don't need two specialists. I don't need two cardiologists. I was seen by a neurologist the last time I was there, but she told me I didn't need to see a neurologist. But there is great benefit from seeing a doctor who has a good understanding of Barth syndrome and professional experience in caring for people with the condition.

### **What was it like to transition from pediatrics to adult medicine?**

It was challenging and annoying because it was probably more complicated than it had to be. When transferring out of pediatrics, we couldn't find doctors that were the right fit in caring for someone with Barth syndrome. It was too complicated. When I reached a certain age, I couldn't be seen by the doctors who had followed me all my life at duPont. I felt like I was booted out with no safety net. It took a long time to find the cardiologist who is following me now. The transition was pretty rocky, rockier than it had to be. I hope that the process is smoother for others now because that was rough.

### **Would you like to travel?**

I would like to see Ireland and Japan. My last name is Italian, but I am like ninety percent Irish. My great aunt tells us that we have some family over there who would like to see us. Japan is probably out of my price range but I just think it would be cool to visit.