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## MEET PETER

**First of all, congratulations on being on the BSF board. Your mother would be very proud.**

Thank you, I am sure she would be. I was surprised when I was appointed to the BSF board.

**Tell me about your interests.**

I love watching YouTube and Netflix. I also enjoy doing programming, mostly for the Minecraft community. It's a game where people play together. I don't play the game myself, but I do maintain a server for the game with a website. I enjoy playing games on my phone as well. I very much enjoy computer programming. YouTube has a variety of interesting videos available where you can learn about a variety of topics or watch entertaining videos.

**Do you enjoy cooking?**

Not particularly. I like to experiment a little, I rarely do so.

**Are you a picky eater?**

Yes, I am a fairly picky eater. There are few things that I do like, mostly potatoes, soft meats, usually fried stuff. I like the texture and the tastes of those foods. The meals offered during the conferences are always great.

**Did you go to university/college?**

I did, I left school after completing my first year which took me seven years to complete. I did get a certificate for that. The next step would be three years for a healthy person. At the same rate that it took me to complete the first year it would take me another fourteen years to complete. That wasn't going to happen.



### **How do you get around?**

I have a mobility scooter for medium distances. I walk short distances under 1km. For longer distances I use public transportation.

### **When using public transportation, do you stand?**

I have but I am rather unstable. It is much easier for me if I can find a seat.

### **Are you living on your own?**

Initially, around 2006, I lived in student housing when I attended university. I later moved out on my own. I now live in a studio apartment. I have lived by myself for about eight years now. My apartment is up one flight of stairs but there is also an elevator where I live which comes in handy. When I have a lot of stuff with me I use the elevator.

### **Do you enjoy living alone?**

Having more friends would be nice but I like being alone most of the day.

### **How do you meet people?**

Mostly, I meet people online. My ability to meet people in person is quite limited. I would like to date someone. I do find it quite taxing. I do miss the personal contact. I am continuously looking for a good balance for how often I see people and how much time I spend by myself. I am quite shy and prefer to initiate conversation like that.

### **How do you know when you have reached your limit?**

Usually it starts with me having trouble focusing. My thoughts run everywhere. I can't really maintain my attention during a conversation. That is generally a sign that I need to stop and continue at a later time. My legs will hurt when I exert myself too much. I also get very tired. I would say Aldo's description of fatigue is very accurate. My legs also get heavier and more difficult to move when I am fatigued. I also find that sitting in the same position for too long causes me to become stiff. It becomes really difficult to physically lift my legs. I find it helpful to move around at least every half hour.

### **Is there a window of time for you to have some type of warning when this stiffness or heaviness is about to happen?**

I can usually tell this is about to happen one to two minutes before it gets too heavy to lift my legs at all. I try to take a seat if there is a seat nearby. Otherwise, I will

just stand still or try to lean on something. It can take at least two to ten minutes to recover enough to make it another two or three hundred meters.

**Has this changed over time?**

It has definitely gotten worse over time. As a child I could walk five kilometers. Now, I can only walk about half a kilometer.

**Is there anything that seems to make it worse?**

Snow and ice make it more difficult to balance myself. In that case, it takes more effort to walk. Extreme cold and rainy or extreme heat also makes it worse. The conference in Florida is good weather for me.

**If you were planning to go somewhere with a friend what kinds of accommodations would you seek?**

I would look at the proximity to public transportation. I would consider how much walking was required. Going to a theme park or taking a city tour would be very difficult for me.

**How is your medical being managed?**

I see the family doctor on a monthly basis, twice a year for the cardiologist and once a year with the neurologist. They are all in three different places. I frequently request medical records. AMC does have an electronic health record option which is helpful.

**Tell me something more about yourself that we didn't discuss during our time together.**

I'm always happy to help in any way I can. I may not know the facts right away, but I am happy to find out. I am always happy to have new challenges. Healthcare is an issue of concern worldwide and an issue that is really important to me. The level of inequality gets bigger every year. Something needs to change.