How to educate others about your rare disease

My husband has 2 rare diseases. Ataxia who? ataxi what? mitochondri huh? Where do I get information? Google? Been there done that and as I’m sure you can relate it was very overwhelming and scary and worse than that I wasn’t sure it was even reputable. Honestly, it scared me to death. It was so technical. I needed a PhD to understand it and I didn’t have that kind of time. I needed the information now, not in 10 years from now when I got my doctorate and to boot family, friends, acquaintances and complete strangers were all looking to me to explain it. They just didn’t get it. Heck, I didn’t even get it. You know that glazed over look when you start to explain what ‘quote-unquote’ is wrong with you. You better be prepared for the cliff notes version. Anything longer than 2 sentences and now they’re experiencing a brain freeze. This is what got me thinking about finding a better way. I wanted to be heard. I wanted them to understand. My experience as a corporate trainer told me I had about 30 to 60 seconds to get my point across. In that amount of time, I could give them a kiss. A ‘Keep it simple stupid’ kiss. Step 1: Ditch the medical terms. Step 2: create a mental picture using descriptive words. Let me show you what I mean, we’re going to play a visualization game. Can everyone look down or close your eyes picture a zebra. Do you have a mental image in your mind? How would you describe the zebra? What colors do you see? How many legs does it have? Picture a red delicious apple. What shape is it? Or what about a can of Coca-Cola? How about a stop sign? Or a traffic light? Think about the words you would use to describe these pictures. Zebra has 4 legs and is white and black. The apple is oblong. Coke can is red with white lettering. Stop sign is a red hexagon. Stoplight has three colored circles, one red, one yellow, one green. Ok, you can look up or open your eyes now. Does this make sense? Be as descriptive as possible so people can see what you’re describing and not get lost in the words! It really does help people understand. It takes some thought but the beauty of it is, its re-useable. Once you’ve determined the words to use you can create a descriptive elevator speech that you use every time someone asks about your condition. You are the expert. Like it or not you are both the person with the disease and the spokesperson for that disease. You have to educate everyone you come in contact with including your doctors. I don’t know about you but that makes me feel pretty smart. Oh, and another responsibility I take on is correcting the misinformation someone has about the disease. Like when someone thinks you’re going to get better. Like you get better from a cold. Or that you can fix it with medication. Or how about when they think your better or not progressing because ‘you look good’. I often hear that one. John looks great! He must be doing better. Ever hear that? I often wonder ‘how are you supposed to look?’ It goes back to that mental picture in your head. People think you have to look a certain way when you have a rare disease. They can’t wrap their head around the fact that it might not be visually obvious. And that can be the hardest part and the main reason why it’s important to explain your condition as visually as possible. I would challenge you to think differently. Change your perspective. Be your own advocate. Develop a comfort level with sharing what you are experiencing with others. You can be empowering and change the stereotypes. As we say in Boston. do your job. And your job is to spread awareness about your rare disease.

Biography

Curious, knowledgeable wife of someone with 2 rare diseases, Ataxia, and Mitochondrial disease. Since 2005 her mission has been to share reputable Ataxia information in short, simple, digestible servings. In 2014 she launched a video series on YouTube, Twitter and Facebook called ‘Did You Know Ataxia facts’ that reach 17 countries with 300 videos to date. She was the first to author 4 PSA’s about Ataxia for the National Ataxia Foundation. Professional experience includes senior Learning and Development Specialist, Corporate Trainer, and currently senior Learning Technology Specialist. She is a member of the New England Ataxia Chapter encompassing 4 support groups, has 11 years’ experience coordinating Ataxia fundraising events and 5 years participation in the Boston abilities expo. Most recently she joined awareness efforts with the Ataxia Unit at Massachusetts General Hospital in Boston for Ataxia education.

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