

Quinn Aaronson

Mr. Greco

English III

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Marfan Managed : An Invisible Illness

Christy Nath and her partner Rahil Nath enjoy spending time engulfed in the world of technology. Having their own separate Nintendo switches and a shared PS5, they game together, enjoying games like Splatoon 2 and Mario Kart 8 Deluxe. Rahil, who codes for a living working in the tech industry, loves learning about the mechanics of the games he plays. Christy uses gaming as somewhat of an escape. When they first met, they were both working in the same tech support team and became close friends. Eventually they became romantic. Christy is a kind-hearted, open and optimistic person who loves making connections with others. She has many people who look up to her and ask her for advice about things that range from relationships to coding, although Rahil mostly helps with those. From anyone's point of view, Christy's life seems ideal; however, Christy suffers from an invisible illness.

Her connective tissue leading to her heart is missing a critical gene, the fibrillin gene, which “provides instructions for making a large protein called fibrillin-1” (FBN1 Gene: Medlineplus Genetics). Through the Fibrillin Gene, fibers are made to support nerves and important organs. However, since Christy is missing the Fibrillin gene, she suffers from Marfan Syndrome. Christy uses her social media platforms like Twitch, Twitter, Instagram, Tiktok and Facebook to help spread awareness about Marfan Syndrome since, like me prior to meeting

Christy, most people have no idea what Marfan Syndrome is. She hopes to spread awareness through her platforms: “the more people that do know about it, we can potentially save lives” (C. Nath). She was 22 when she first learned about Marfan Syndrome and over the years she began to make connections with others that also have Marfan Syndrome. There is a whole community within the Marfan Foundation working together to spread awareness. Fundraisers like walks, T-shirt and sticker selling happen quite often. A study published by the Canadian Mental Health Association states that “[s]ocial connection can lower anxiety and depression, help us regulate our emotions, lead to higher self-esteem and empathy, and actually improve our immune systems” (“The Importance of Human Connection”). Christy finds great mental health benefits through promoting and continuing to contribute to the Marfan Foundation in her spare time.

When Christy first heard the words “Marfan Syndrome” she was being wheeled into emergency open heart surgery, “the doctors just told me I was having an aortic dissection” (Christy). An aortic dissection is a very serious condition where “a tear occurs in the inner layer of the body's main artery[...]Blood rushes through the tear, causing the inner and middle layers of the aorta to split” (Mayo Clinic). The aorta is the connective tissue leading to the heart, which is what causes this to be so dangerous and life threatening. Before being rushed into surgery, she had attempted to use an ambulance as a way of transport to the hospital, the EMT’s assured her that she was just having heartburn, however she knew something was wrong, as she had had heartburn before and this felt much worse. When she woke up from her surgery, the doctors had lost her tissue samples so she did not get a confirmation of diagnosis until much later.

Growing up the only noticeable symptoms that Christy had was how people could see her heart beating outside of her chest and a high palate within her mouth. Her more noticeable features appeared more when she started getting into her teenage/adult years such as long skinny

fingers and damaged eyesight. She began working for a tech support company and in 2008 she ended up working on the same team as her now husband, Rahil. “We were pretty drawn to each other and became really close friends for a good while until things started to become romantic” (Rahil). When meeting Christy, Rahil had no idea that Christy had any sort of medical condition. However it didn’t take long before Christy began teaching Rahil about the world of connective tissue disorders. “She’s basically an open book about her health or just in general” (Rahil). When asking Rahil about what he had noticed about how Marfan Syndrome affected his spouse’s life he was conflicted on how to answer. Although he had been through 13 years of doctors appointments and ER visits as well as multiple week long hospital stays he still couldn’t wrap his head around how much it has affected her overall. “Christy is the strongest woman I have ever known. It’s a big part of why I fell in love with her but at the same time, it makes it really difficult to notice how much Marfan Syndrome affects her life” (Rahil). This just goes to show that even with a life threatening illness, Christy is just as strong as the rest of us.

In the past, the doctors turned her away, convincing her that it was nothing more than heartburn. Luckily, Christy’s past boyfriend wouldn’t let them send her home until they ran more tests because they were both sure that something was wrong. When running more tests, they discovered an enzyme in Christy’s blood that indicated she had a blood clot. After running more tests they determined that surgery was necessary. “[T]here's been people that I've heard stories about that go to the hospital and then they do go home and then they end up not making it and so I mean that's what we you know potentially would like to avoid as well as people trying to avoid emergency open heart surgeries like mine, cause when its emergent [...] your bodies already received that damage so you know you it's a little bit more harder to heal from as well as you'll potentially have more side effects down the line” (Christy). Due to Christy’s late discovery of her

Marfan Syndrome, damage had already been done. She had to receive around three follow up surgeries on her right coronary artery in order to reconnect it to the graft of her aorta.

Currently Christy is working on getting her disability benefits sorted out, which includes disability insurance. Her future looks really bright, but Marfan Syndrome still holds her back in some ways. Lifting objects over 15-20 pounds, roller coasters, as well as contact sports, like football, are out of the question as they put strain on her connective tissue. Furthermore, she is highly discouraged from having her own biological children due to her open heart surgery.

“[T]here's people that have had their own children after having open heart surgery, but it's very difficult to find doctors that will support that decision [...] there's also a 50% chance that I would pass it down to a child so I've just known that I probably won't have kids if I do ever decide at some point to have kids I will probably just adopt” (Christy). Although they don't have their own biological children, Christy and Rahil serve as parent figures for a lot of people. People in her twitch community call her “Mama Nath” and lean on her for guidance. She is one of the most selfless people I know, and has so much love and support for everyone around her.

Rahil and Christy continue to live life to the fullest every single day, and even if some days are full of naps and video games, they keep themselves accountable by staying positive. Rahil spends some of his time writing songs and Christy is always happy to listen. “Not even the end of the world could affect you, if you are with the person you love. We can't choose who we love but all we can do is just try to be there for them and keep making the best of whatever Marfan Syndrome throws their way” (Rahil). Even though they have been through so much, I don't think I've seen a happier couple. When asking Christy about how Marfan Syndrome affected her, she responded, “I feel like it's given me you know that strength and kind of a

stability just knowing you know that I'm stronger than I probably give myself credit for"

(Christy).

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