



Janelle Applequist

Janelle, a Ph.D. Candidate of The Pennsylvania State University's College of Communications shares how she uses her personal experience to inform her research and instruction. By describing her personal history with the field of health care, she talks about the ways in which academia can privilege individual voices and stories, but from an even larger scale, how sharing your story can be an applicable skill for any field, experience, or personal relationship.

Watch [Janelle's Presentation](#) on sharing YOUR story to make a difference.

Find Your Moment and Share It With The World!

May, 2014 - Janelle Applequist, a PhD candidate of Pennsylvania State University and fellow Chiari warrior, has recently shared how the retelling of personal journeys can assist and further public and private passions. With the help of TEDxPSU, Janelle was able to share her experiences with a live audience as well as online followers who are interested in community oriented "Ideas Worth Spreading" (ted.com). [Author's note: I was also able to contact Janelle for additional information and quotes relating to her Chiari journey.]

Janelle starts off her presentation by asking her audience, "Have you ever had a moment in your life when you knew that everything was about to change... that nothing would ever be the same after that moment?" Since we are human beings, these moments are inevitable; everyone has some kind of struggle which defines who they are in the world. For Janelle, this battle started when she tumbled off of a trampoline in her gymnastics class when she was thirteen years old.

"Before I had my accident, I was a straight-A student, captain of my cheerleading squad, and student council president. Upon my return to school [after having decompression surgery], I was bullied because I still had to wear my neck brace for stability. To this day, that bullying impacts me; by living through that experience, I know how important it is to treat others kindly because you never know what they are going through in life," explained Janelle.

Currently, 314 million people reside in the United States of America; of the entire population, 1.5 million individuals experience some type of brain injury. Out of the 1.5 million who endure head traumas, 230,000 are hospitalized but survive, 85,000 experience onsets of a long-term disability, and 50,000 pass away. Janelle was one of the 230,000 who are hospitalized; however as with most head injuries, her situation became worse before it improved.

Janelle then describes the general diagnosis of a Chiari malformation. She explains how the disruption of spinal fluid causes many issues with the nervous system. For example, problems with eating, speaking, and balance restricted her from living a normal life as a child.

"Along with struggling from the physical attributes of Chiari, I believe the journey also psychologically and emotionally impacts an individual. As a teenage girl, I certainly felt the pressure to conform to society's standards of beauty, and once I knew something wasn't 'quite right' on the inside of me, it made the pressure to be normal on the outside all the more important," said Janelle.

The morning her parents drove her to the hospital, she was overwhelmed with emotions and to this day, she is still affected by the memory. Her two older brothers chose to miss school, against their parents' wishes, to be with their little sister—lending love and support all along the way. When she woke up after surgery, Janelle felt pain, but also remembered seeing her brothers waiting patiently across her room. She will never forget the compassion she felt for her family as they stood beside her.

Although she had her loved ones with her, Janelle experienced excruciating pain and keeps fighting to feel as healthy as any Chiarian can to this day. She reminds everyone that the moment change happens, it doesn't mean your life is over.

"What I went through has taught me empathy, grace, and humility. I learned that I could be proud of being different. If I could speak to someone younger who has a Chiari malformation, I would tell them to acknowledge how challenging and scary the battle is, but at the same time explain how he or she could change the world. Chiari makes everyone unique and we can use that difference to help others," said Janelle.

Today, Janelle shares her story with everyone to make the world a better place; she studies health communication at Penn State University and is also pursuing a PhD in mass communications. She analyses patients and how they are represented in the media because she knows how important it is for patients to understand that they have a voice. Janelle's goal is to instill a sense of hope within those who are suffering.

"Chiari has shaped who I have become professionally, but I cannot deny that it is an extremely difficult condition to have at times. I can still feel a constant pressure in the back of my head, and often times, I have headaches that are unbearable. Yet, at the same time, I absolutely love researching, teaching and being there for my students. I know that my health is the most important factor because if I am not healthy, then I can't be there for those that I love," explained Janelle.

Throughout her academic career, she didn't feel pressured to be published or to receive high acknowledgements because those kinds of recognitions didn't appeal to her. For Janelle, academia is about the education and instruction—it's about what she takes to teach students, such as her Chiari journey.

Janelle states that sharing stories are of the utmost importance. Each day she shares something about her

life with her students and she believes that if all forms of higher education did this, the world would be a better place.

“Storytelling is important because I think it connects us to one another, whether it be on a professional or personal level. As members of a fast-paced society, we can lose track of how little we are connecting with someone. Some of the best conversations can happen in just a matter of minutes. I want everyone to know that Chiari isn’t the end of our lives, it can be just the beginning,” said Janelle.

I feel that this is definitely something important for the Chiari community to engage in— it helps spread awareness because every case is never the same. It can also be a form of therapy to help us remember how far we have come since our diagnosis. There are [many] Chiarians who live in the United States and we all should make our story count!

Ed. Note: *The opinions expressed above are solely those of the author. They do not represent the opinions of the editor, publisher, or this publication. Ms. Eubanks is not a medical doctor and does not give medical advice. Anyone with a medical concern is strongly encouraged to seek professional medical care.*



Jennifer Eubanks

Chiari Community Columnist

Ms. Eubanks is a professional writing and researching scholar from Purdue University Northwest. After being diagnosed with a Chiari I Malformation in 2011, she quickly decided that being conquered was not an option—she was committed to fight and pursue a budding love of healthcare/medical writing. Spreading awareness and hope to others battling Chiari is her largest motivator alongside educating others who have not heard about the condition. Reporting for Ideas in Motion Media and tutoring at the Writing Center (Purdue University North Central) has been immensely beneficial to her success as well as all the remarkable individuals who helped her become the composer and analyst she is today.

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