

## What Marfan Syndrome means to me

Many tall people are affected by Marfan Syndrome which is a genetic disorder of the connective tissue. Marfan syndrome is an autosomal dominant disorder. It encompasses a change to the gene that makes fibrillin which results in abnormal connective tissue. (1)

Like those affected by Marfan Syndrome, I too am affected by a similar condition called Venous Malformation. While there are differences in these conditions surprisingly there are many similarities. For example, there is no cure, there is treatment available, many live a normal life and hard exercise is not encourage. Also, males and females are similarly affected, both are considered rare diseases and both Marfan Syndrome and Venous Malformation are caused by developmental errors/molecular mishaps.

To me, Marfan Syndrome means others have challenges just like me. I was born with painful, abnormal veins causing patches on my left leg resembling spots on a giraffe. At 2, I was diagnosed with Venous Malformation (VM), a rare vascular anomaly disorder. As I grew, the area on my leg spread like creeping ivy on a trellis. It was difficult for me often feeling like a boy on a deserted island.

In spite of my situation, my determined mindset helped me get to a point where VM did not define or beat me. A conscious decision to do whatever it took led me to a full and engaging life. Dealing with VM obstacles just became another hurdle to overcome not a defining disorder. Like a typical boy, I competed hard in sports and ultimately played select basketball and volleyball. Unlike a typical boy, I also danced and performed. All required a great deal of physical exertion. Sometimes, my leg would swell and be painful like the sound of a beating drum, but I wouldn't let myself fall behind. These experiences embodied a mental and physical strength in me. While others may have used it as an excuse, I used it as a motivator.

Living with VM for 18 years has strengthened and taught me numerous life skills that I may not have otherwise learned. Initially my VM diagnoses seemed dreadful, but it shaped my life and embodied characteristics that have contributed to my successes. Now, my focus with VM is helping others, especially teens, survive and thrive on their journey with VM. By forming a successful non-profit called Venous Malformation–Parker's Project, countless teens, parents and others have been touched through support of my organization. Please copy

**<https://www.venousmalformations-parkersproject.com/>** into browser to view website.

Throughout the course of my life I've pushed myself to excel and overcome obstacles. Because of this determination, I am prepared for the many academic challenges and opportunities before as I soon begin my college life. Knowing that there are other teens just like me struggling with their own conditions, whether it be Marfan Syndrome, Venous Malformation or the other 100s of disorders, makes that deserted island a little more populated.

(1)Kielty CM, Baldock C, Lee D, Rock MJ, Ashworth JL, Shuttleworth CA (February 2002). "Fibrillin: from microfibril assembly to biomechanical function". *Philosophical Transactions of the Royal Society of London. Series B, Biological Sciences.* 357 (1418): 207–17.

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