

Good Morning my name is Hannah Whitson and I would like to Thank you for having me her today to discuss October being Dysautonomia Awareness month.

### You may be wondering what Dysautonomia is?

Dysautonomia is an umbrella term that is used to describe several different neurological conditions caused by a malfunction in the autonomic nervous system. The autonomic nervous system controls all things that we don't have to think about like breathing, Heart Rate, regulation of Blood Pressure, Body Temperature control, Digestion and Kidney Function, and many more. This is not a rare disease over 70 million people worldwide have a form of Dysautonomia. It takes an average of 4 years and 2months for patients to be diagnosed. There is no cure, but there are medicines and treatment plans that can help some patients to reduce some of their symptoms, many symptoms can be disabling for patients.

### What does dysautonomia mean to me?

Before being diagnosed with a form of Dysautonomia called Postural Orthostatic Tachycardia Syndrome or POTS for short, I was an active child. I enjoyed being outside with friends, cheering and swimming competitively. I have now been on this crazy journey for almost <sup>4</sup>~~3~~ years, and since I was first sick I have learned many things about my illness. This is not an illness that just affects the patients like me, but it also affects our families

who we depend on to help on those days we physically cannot get out of bed, because we feel like we will pass out, don't have the energy (as some say we have used all of our spoons) or we are in so much pain like when my ankles swell and I cannot walk on them. To many people I look like a healthy 13 year old girl, but they don't realize when I stand up like I am today my blood is pooling to my feet causing my legs to turn a purplish color, my blood pressure without my medicine that I take every 2 hours to help constrict my blood vessels will drop at least 20 points, my heart rate goes anywhere from in the 80s while sitting to over 120 beats per minute standing. This continue to make it difficult to attend school like a normal child, I am currently enrolled in the homebound program through our

~~local school system.~~ I am currently enrolled in daphne high school, I have ~~through a local school system.~~ also been a student. enrolled through the

Like many others battling this invisible illness we must travel outside of Baldwin County for treatment. Most patients with this illness have more than one illness, that has either led to having dysautonomia or dysautonomia is just an underlying illness for something else. For myself I have been diagnosed with POTS, Ehlers-Danlos (connective tissue disorder), Blood clots that I developed earlier this year in my right arm that I than developed Complex Regional Pain Syndrome ~~that has now spread to my chest area.~~, and most recently gastroparesis.

homebound program. the last three years.

Many patients have a complex medical history, which is why it is so important to bring awareness to Dysautonomia. The more awareness and chatter we can create, the more hope that our local medical community will research more to be aware and listen to their patients. One story I would like to share is when I ~~recently~~ went back to my local cardiologists and she told me that by having me as a patient and all the doctors I have seen that have sent her information on my case, she has been able to recognize and diagnosis other pediatric POTS patients.

I hope that by the County Commission making this proclamation today for dysautonomia awareness month. Others will learn more about this illness. I hope they will be compassionate to kids like me facing this illness and share the knowledge they have learned with teachers, doctors, and others in our community. I hope that other kids with dysautonomia and their families will not feel alone and we can be a team to struggle forward together.

Thank You to the Baldwin County Commission for taking the time today to recognize and learn about dysautonomia. I appreciate you allowing me to share my story with you this morning.