



Rare Disease Day



FOR IMMEDIATE RELEASE

Richmond Resident Explains Life with a Rare Disease and Promotes Awareness for Rare Disease Day® on February 28

RICHMOND, VIRGINIA —February 27, 2015— Twenty-year-old Richmond resident Tori Anderson has a rare disease and is working with Dysautonomia International to raise awareness on **Rare Disease Day®** on February 28.

Tori explains, "I started getting sick at 15-years-old with severe gastrointestinal problems that lead to vitamin deficiencies and thinning bones. By the time I was 18, I was completely dependent on intravenous feedings for nutrition and unable to care for myself, work, or go to school. I had spent more time inside the hospital than out of it. At 19-years-old I was finally diagnosed with Autoimmune Autonomic Ganglionopathy (AAG), a rare form of dysautonomia that has mainly affected my ability to eat, regulate blood pressure and body temperature, and empty my bladder. In between my plasmapheresis procedures, chemotherapy sessions, and immunosuppressant regimen to keep the disease at bay, I volunteer for a women's rights project and someday I hope to attend nursing school."

Dr. Steven Vernino, Professor of Neurology & Neurotherapeutics at UT Southwestern Medical Center in Dallas and member of Dysautonomia International's Medical Advisory Board, explains, "fewer than 100 Americans are diagnosed with AAG each year, although some cases may go undiagnosed due to a lack of awareness. Diagnosis of autonomic disorders can be challenging because there are many symptoms that may seem disconnected. Major problems in most AAG patients relate to orthostatic hypotension (a drop in blood pressure when standing which causes lightheadedness or fainting), severe constipation, and trouble emptying the bladder. Some patients lose the ability to sweat, to make saliva or even to properly focus their eyes. Undiagnosed and untreated, AAG is extremely disabling. Some patients with AAG have antibodies that block the relay centers in the autonomic nerves and prevent signals from reaching their targets. Treatments to remove or reduce these antibodies may allow the autonomic nervous system to resume normal function. AAG is just one of many rare diseases affecting the autonomic nervous system."

Lauren Stiles, President of Dysautonomia International, notes "Dysautonomia International is committed to raising awareness about rare forms of dysautonomia like AAG. Many patients remain undiagnosed or misdiagnosed for years due to a lack of awareness, which can lead to devastating health consequences. We applaud Tori for sharing her story on Rare Disease Day and encourage the public to learn more about AAG and other forms of dysautonomia on our website, www.dysautonomiainternational.org."

According to the National Institutes of Health (NIH), a disease is rare if it affects less than 200,000 people. One in 10 Americans have a rare disease—nearly 30 million people—and two-thirds of these patients are children. For the 7,000 known rare diseases, there are only approximately 450 FDA-approved treatments.

Rare Disease Day takes place every year on the last day of February (February 28 or February 29 in a leap year)—the rarest date on the calendar—to underscore the nature of rare diseases and what patients face. It was established in Europe in 2008 and is now observed in more than 80 nations.

For more information about Rare Disease Day, visit <http://rarediseaseday.us/>. To search for information about rare diseases, visit NORD's website, www.rarediseases.org. To learn more about rare diseases, visit NORD's website, www.rarediseases.org.

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About Dysautonomia International

Dysautonomia International is a 501(c)(3) non-profit that advocates on behalf of patients with disorders of the autonomic nervous system, collectively known as “dysautonomia.” The organization funds medical research, physician education, public awareness and patient empowerment programs. You can learn more about AAG and other autonomic disorders at www.dysautonomiainternational.org.