

Hey y'all! Both of my younger siblings have a very rare, progressive, degenerative, genetic disorder called **Ataxia-Telangiectasia** ("A-T").

My brother, Jody, was diagnosed with A-T in 2005 when he was 4 years old and my sister, Leslie, was diagnosed at age 7 the following year.

A-T affects the physical body as the disease basically means that the cerebellum of the brain is disintegrating. Symptoms of A-T are similar to those seen in cerebral palsy, muscular dystrophy, and lung disorders. *Both of my siblings used to walk independently, but now both rely on wheelchairs.* While A-T affects physical aspects of the body, it does not typically affect mental capacity. A-T slows down brain processes and cause the person to need more time to think which can cause dull facial expressions that make others think the child is "slow," "dumb," or not paying attention. *Jody just started his second semester of collegiate classes!* **There is currently no cure or treatment for A-T** and life expectancy ranges from late teens - mid-twenties.

February 28, 2021- Rare Disease Day is the last day of February (the month known for having a "rare" number of days) each year and is recognized around the world. Rare Disease Day is intended to bring awareness and advocacy to the 1 in 10 Americans and 400 million people globally who are affected by a rare disease.

Jeans for Genes is a fundraising campaign to support those with rare, genetic disorders.

Wear jeans to show your support of this genetic disease (**Jeans for Genes**). Donate a minimum of \$3 to receive a Jeans for Genes sticker to wear on your jeans!... BUT since jeans are a part of our everyday dress code here at VDS, **your donation will permit you to wear pajamas to work on Friday, February 26.**

Please consider donating to the Ataxia-Telangiectasia Children's Project to help researches find a CURE for Leslie, Jody, and the other children living with A-T!!

Ways to donate:

- ONLINE at atcp.org
- BY CHECK payable to **A-T Children's Project**
- CASH in the bucket in the Resource Room



Jody (19), Jeremiah, Allison, Leslie (22)