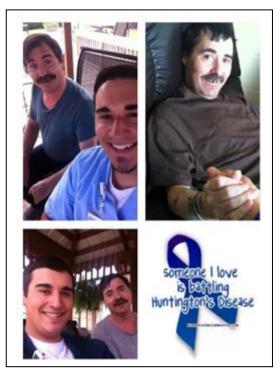
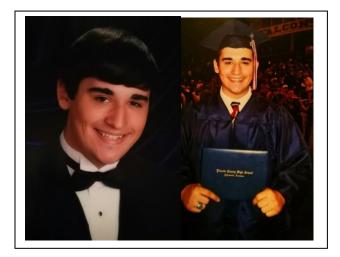
Greg Riner's Journey with Juvenile HD

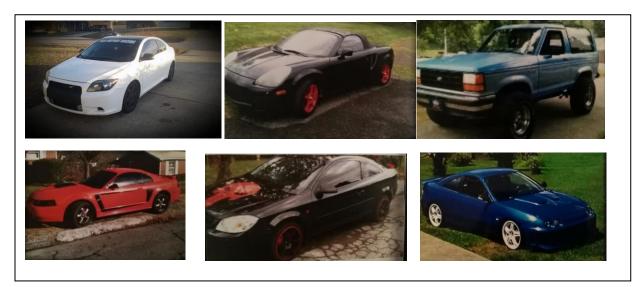
Hi, my name is Greg Riner, I am 22 years old and was diagnosed with Juvenile Huntington's Disease at the age of 18. My father, Tony Riner, was diagnosed with HD in 2005, when I was 10 years old. He and his sister both inherited HD from their mother. Their mother, my grandmother, passed away in 1990 which was 5 years before I was born. She was one of 6 children, 5 of which had inherited HD from their mother. I have lost many family members to HD and now face this battle myself. As you can see, HD/JHD is a generational disease. With multiple family members affected by HD the impact on the family is intense. Financial struggles, relationship struggles, medical, emotional, psychological struggles and legal or court related issues are just a few of the problems faced by families affected by this devastating disease.





When most 18 year olds are graduating and planning their future and making plans for college and life after high school, I was given the devastating news of a diagnosis of JHD. I struggled with depression initially and still do from time to time, but I have come to grips with my diagnosis and have become actively involved with HDSA, I attend board meetings for the TN chapter and have attended and spoken at many of the HD Hope Walks in Nashville and Mt. Juliet. In 2016, my mother and I hosted our first car show called "Cruisin' for a Cure for Huntington's Disease" in my home town of Fayetteville, TN to help raise awareness and money for HDSA. April 28, 2018 will be our 3rd year for the car show located at Lincoln County High School from 9 am -2 pm. We have raised over \$14,000 for HDSA since my diagnosis in 2013 and hope to raise much, much more in the coming years. Cars are my passion. I loved to trade cars and I truly miss having the ability to drive. I sold my car this year and it has been difficult being 22 and unable to drive. I have to rely on others to get me to where I need and want to go. Below are just a few of the cars I have had in the past.





I first became aware of HD and HDSA after my father's diagnosis of HD, my mother started researching HD and became aware of the fact that because my father has HD that put me and my younger brother at risk for having HD. We each had a 50% chance of inheriting the disease. In February of 2013, when I turned 18, I decided to be tested. In March, I went to see my primary physician and requested to be tested. In April of 2013, I received my results. I was devastated. I never expected to be told that I had HD especially JHD. I was sent to Vanderbilt to meet with a geneticist and have been seeing a neurologist through the HD Clinic at Vanderbilt ever since. We are very fortunate to have a great team of Doctors, nurses, social workers and support group leaders associated with Vanderbilt. Looking back, I realize there were signs of JHD prior to my diagnosis. In grade school, I was diagnosed with ADHD; in Junior High, I was diagnosed with a learning disability in Reading and Math and by High School, I was diagnosed with an Auditory Processing Disorder. I now realize this was part of the cognitive decline caused

by the disease. I also had a lot of emotional and behavioral issues through my teen years more so than typical teenage issues. I told my brother after being tested that I do not recommend being tested because the depression becomes so much worse if you have the disease. My brother who is currently 21 is at risk and chooses not to be tested. Each person has to make their own decision of whether or not to test. If I had it to do over – I would not. But keep in mind being at risk and not knowing is difficult also.



After my diagnosis of JHD, my mother and I began searching for information and support for this journey. We turned to HDSA and have been very blessed by the connections and relationships we have formed along the way. I was able to attend my first HDSA convention in 2014 in Kentucky, with a scholarship from Lundbeck pharmaceuticals and have attended conventions in Texas and Illinois with assistance from NYA scholarships and was fortunate enough to be able to attend the first ever North America HD Youth Camp in 2015. I am thankful for the friendships that I have made.

Prior to being diagnosed with JHD, I worked as a certified nurse tech helping to take care of others including my father who has been in the nursing home since 2007. I enjoyed being a caregiver and miss not being able to work. I have significant issues with memory and cognition, balance, swallowing, mood and involuntary muscle movements. I am currently on disability and still live independently with assistance from my family and I have a personal assistant who comes in 3 days a week for 3 hours each day to help



me with cooking, cleaning, and laundry at my apartment so that I can continue to live independently. I am thankful for the assistance and recommend others check to see if their insurance will cover those services through the ECF (Employment and Community First) or Choices program.

Life is a journey, some more difficult than others. We must make the most of the journey we are on. I will continue to help raise funds and awareness that help to bring this horrible disease to an end. I hope you will do your part to help. Please give to HDSA – Help for today and hope for tomorrow!

You can give to HDSA by clicking <u>here</u> or by mailing a check to HDSA-Tennessee Chapter, P.O. Box 62, Brentwood, TN 37027.