

Finding a Tribe

I'm Chelsi, a young adult who is at risk for HD. The disease runs heavily in my family, generating from my mom's side. My mom was a strong, hilarious, driven and beautiful soul. A sassy and classy lady that I



clearly take after. She was sick the majority of my life and I was one of her caregivers. As I began to write, I figured I would share with you my story from my recent HDSA articles, as I'm writing for youth and young adults affected by HD. Sharing from the past and connecting through stories feels like a beautifully woven connection we all have in the HD community, especially to youth who don't know where to turn. These articles, although important to be read and digested, weren't clicking, and when it came time for this article I felt stuck. Stuck in anxiety of not knowing what to say (for the first time!) The girl from my personal story articles is very real, and what I write is the true heart of Chelsi, the teen whose mom was sick. But as I re-read my story from the lens of my present 25 year-old self, I feel anxious of not knowing in all the ways. The risk of HD is not just affecting a teenage caregiver in a HD household, but now affecting a woman trying to make life decisions that have been split into two paths. One path with HD and one without.

What do you do? Earlier this year, I realized I needed a tribe that understood that see-saw feeling that weighs on your chest carrying something like HD. Not just the group I write to monthly, but a group to



unravel the mystery of an HD life.

Finding this group has been challenging, because I would rather help someone else than have someone help me. I have very important people in my life that

have been my anchors, that I can count on and share with my whole soul. I have my Crossfit family, which pushes me to keep fit, so when/if I am sick, I am in a better place physically to help myself. They also keep me accountable to be a part of the daily workout struggle and get through it together. I also focus a lot on nutrition

and have an amazing sponsor and dear friend that supports me in that aspect of feeding the body what it needs, to prepare for what could come. Not only does her food taste incredible,



but her protein ballz are a lifesaver! Through that daily practice of mind,

body, and soul with “my peoples,” fear and anxiety didn’t go away instantly, but it did help.

All of this was great, but I really wanted to connect with other people and families who were affected by HD. I immediately joined with the HDSA - TN board, and when we met for the first time, it was so refreshing when



we all spoke. You received the same look of “I get you and I understand.” Being a part of this chapter was the missing piece I needed to start unraveling this new challenge in my life. How HD fits in my career, my love life, buying a house, having kids? Wanting to get tested or not?

This is where I am right now, and I have far to go with this journey, but this will not be the end. I am my mother’s daughter and I was born to survive.

Chelsi

You can help young people facing Huntington’s disease find their tribe – those people who understand Huntington’s disease who can help them unravel the mystery of HD. Support HDSA programs that help people living with HD connect by donating online [here](#) or if you prefer to donate by check, you can send your check to HDSA – Tennessee Chapter, P.O. Box 62, Brentwood, TN 37024.