



**HUNTINGTON'S DISEASE
YOUTH ORGANIZATION**

Understanding Gene Negative

February 24, 2025

HDYO has more information about
HD available for young people,
parents and professionals on our
site:

www.hdyo.org

It's common for those outside the Huntington's disease (HD) community to offer congratulations or encourage celebration when someone tests negative for the HD gene. While testing negative for HD can bring a profound sense of relief, it also comes with its own set of emotional and psychological complexities. Those who test negative are often faced with a unique journey of navigating emotions, identity, and relationships. This article explores the multifaceted experiences of individuals who test negative, including survivor's guilt, identity struggles, and the challenges of maintaining a connection with the HD community.

The Emotional Complexities of Being Gene-Negative

Testing negative can evoke conflicting emotions—relief and gratitude on one hand, and guilt, confusion, or even a sense of loss on the other. Many people who test negative for the HD gene grapple with survivor's guilt. Others, particularly if their lives have been deeply shaped by the anticipation of an HD diagnosis, may experience a loss of identity. Some also experience imposter syndrome, feeling disconnected from the HD community and unsure if they still belong or can contribute meaningfully to advocacy efforts. These emotional complexities often manifest in ways that may not be immediately understood by friends and family, further complicating the coping process.

Additionally, some individuals who tested negative may struggle with the impact of past life decisions made under the assumption that they would develop HD. Choices about education, career, relationships, or even starting a family may have been shaped by the expectation of an uncertain future. Upon testing negative, they are faced with an unexpected new reality—one filled with possibilities but also a daunting sense of "now what?" This shift can bring relief but also a sense of panic, uncertainty, and the need to redefine long-held plans and aspirations.

Understanding and Recognizing Survivor's Guilt

Survivor's guilt is the emotional burden of feeling undeserving of their results when others continue to face challenges. Recognizing survivor's guilt is a crucial step in the healing process. Acknowledging that feelings are valid and a natural part of the journey can help individuals begin to make sense of their experiences. Here are some reasons and examples of survivor's guilt.

- **Guilt Over Loved Ones' HD Diagnosis:** Testing negative for HD can evoke a profound sense of guilt, especially when individuals witness family members experiencing symptoms or testing positive for the disease. This guilt often stems from being spared while others continue to face the challenges of HD, creating a heavy emotional burden marked by feelings of helplessness or unearned privilege. The question, "Why me? Why didn't I get HD?" can linger in their minds, sparking an internal conflict that resurfaces unexpectedly and deepens the emotional complexity of their experience.

- **Identity Loss:** Many gene negative individuals find themselves questioning their sense of self after testing negative, especially if their identity was heavily tied to being at risk for HD or even anticipating HD symptoms. Receiving a negative result may leave them feeling untethered, as though they've lost a key part of their life's narrative.
- **Imposter Syndrome:** Testing gene negative can lead to feelings of disconnection from the HD community. Individuals may struggle with the perception that they don't belong or that their experiences are less valid because they don't have the disease.
- **Coping with Discomfort and Withdrawal:** Testing gene negative can lead to feelings of discomfort or unease, particularly when interacting with family members or others who are directly affected. This emotional tension can result in individuals unintentionally creating distance or withdrawing from their loved ones. They may struggle to navigate these relationships, feeling uncertain about how to offer support or reconcile their health with the challenges faced by others. This withdrawal can make it harder to maintain a sense of connection and belonging within their family or community.
- **The Burden of Positivity:** Learning of a gene negative result can come with an emotional burden of trying to remain positive and support others while carrying guilt for not having the disease. Well-meaning comments from others, such as "Why are you sad? You're going to be fine," can exacerbate these feelings, as they may minimize the complexity of survivor's guilt. This lack of understanding can leave individuals feeling isolated, as their struggles are not fully recognized. The tension between outwardly celebrating their negative result and internally grappling with guilt can make it harder for them to feel a sense of peace.

Combating Survivor's Guilt

- **Join a Support Group:** Support groups provide a safe space to share experiences with others who understand your emotions. These groups, available both in-person and online, can help normalize your feelings and reduce isolation.
- **Strengthen Connections with Loved Ones:** Rather than withdrawing, focus on supporting and spending quality time with loved ones affected by HD. Open and honest communication can deepen relationships and create a shared sense of understanding.
- **Practice Self-Compassion:** Acknowledgement of feelings without judgment and reminding oneself that a negative result doesn't lessen their value or the validity of their emotions. Techniques such as mindfulness, journaling, meditation, or therapy can help them process guilt and develop self-acceptance. Some may find comfort in spiritual-based practices as well.
- **Community Involvement and Advocacy:** Transform feelings of guilt into purposeful action by engaging with the HD community through awareness and support initiatives. Share personal stories, promote education, or mentor those newly navigating HD challenges to make a lasting impact. Volunteering, attending events, or participating in advocacy efforts fosters a sense of belonging while leveraging your unique perspective as a gene-negative individual to provide valuable insights and

encouragement to others.

Recognizing the Need for Support as a Gene Negative Individual

There is a common misconception that those who test negative for HD do not need emotional or practical support. While they may not face the physical challenges of HD, being part of an HD-impacted family or community can still take an emotional toll. These emotions are significant and can be extremely overwhelming.

These emotional complexities are real and deserve the same attention and care as those experienced by individuals directly affected by the disease. Offering emotional support through counseling, peer groups, or family discussions can help them find their place in the community. Acknowledging their struggles and validating their emotions fosters a supportive environment where everyone, regardless of their genetic status, feels heard, understood, and valued.

Conclusion

While testing negative for HD may seem like a cause for celebration, it is important to recognize and address the emotional complexities that come with this result. Survivor's guilt, identity struggles, and the challenge of maintaining connections within the HD community are real experiences for gene negative individuals. Providing support, fostering open communication, and encouraging involvement in the HD community can help these individuals navigate their feelings and find purpose. By acknowledging their emotional journeys, we ensure that gene negative individuals feel understood and supported as they contribute meaningfully to the fight against HD.



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