



Survivor Guilt

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Huntington's Disease
Society of America

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Presenter Disclosures

Chelsea Chambers, MS, CGC

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose
or list



Overview:

- Briefly review HD Pre-symptomatic testing recommendations
- Discuss Survivor Guilt
- Resources
- Personal Experience:
 - Melissa
 - Maryann

HD Pre-symptomatic Genetic Testing

- International Huntington Association (IHA) and the World Federation of Neurology (WFN) proposed guidelines for presymptomatic testing in 1994
- Guidelines evaluated and updated by European Huntington Disease Network (EHDN) “Genetic Testing and Counseling” Working Group and were published in 2013

Process of HD testing

- Typically a multiple appointment process including:
 - Extensive discussion about implications of testing with a genetic counselor
 - Neurological exam
 - Sometimes evaluation by a psychologist or psychiatrist may be recommended

Decision to Proceed with Genetic testing

- Very personal decision and opinions may vary greatly even within the same family
 - Many studies report that fewer than 10-20% of individuals at-risk choose to have testing
- Reasons for testing are mainly psychological for individuals
 - Family planning
 - Feeling of “needing to know”
 - Planning for the future
 - Etc.

Survivor Guilt

- A deep feeling of remorse that occurs when a person perceives themselves to have done wrong by surviving a traumatic event when other's did not
 - Can occur when an individual is gene negative for HD

Resources Available:

- Huntington Disease Society of America (HDSA): www.hdsa.org
- Huntington's Disease Lighthouse Families: www.hdlf.org
- Huntington's Disease Youth Organization: **en.hdyo.org**
- Huntington's Disease Advocacy Center: www.hdac.org

Personal Experience

- NYA board members:
 - Melissa Ryant
 - Maryann Emerick