Survivor Guilt
Chelsea Chambers, MS, CGC
Certified Genetic Counseling
HDSA Center of Excellence at the University of Virginia
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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 others did not
  - Can occur when an individual is gene negative for HD
Resources Available:

- Huntington Disease Society of America (HDSA): [www.hdsa.org](http://www.hdsa.org)
- Huntington's Disease Lighthouse Families: [www.hdlf.org](http://www.hdlf.org)
- Huntington's Disease Youth Organization: [en.hdyo.org](http://en.hdyo.org)
- Huntington's Disease Advocacy Center: [www.hdac.org](http://www.hdac.org)
Personal Experience

• NYA board members:
  – Melissa Ryant
  – Maryann Emerick