When Negative is not always Positive

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• HDSA encourages all attendees to consult with their primary care provider, neurologist or other healthcare provider about any advice, exercise, medication, treatment, nutritional supplement or regimen that may have been mentioned as part of any presentation.
Presenter Disclosures

Anne Leserman

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

No relationships to disclose or list
Survivor Guilt- it’s a real thing

Seen in war veterans (often associated with PTSD), Holocaust survivors, relatives spared from hereditary illness

Due to:
- Life threatening situation
- Traumatic or catastrophic event
- Illness
What to watch out for

• Spending a lot of time alone
• Comparing yourself with others
• Setting extreme expectations/Am I doing enough?
• Feeling unworthy/ashamed
• Worry that I did something wrong?
• Sleep disturbance
• Emotional numbness
• Extremes of anger and aggression
How to Cope

- Acknowledge your feelings
- Reach out for support - talk to others that have tested negative that have similar feelings.
- Let yourself mourn
- Take action
How to find meaning

- Bloom where you’re planted
- Treasure the best of each day
- Practice small acts of kindness
- Be around people
- Exercise
- Talk to a mental health professional
- Become an advocate
WHY ME?!

WHY NOT?
HDSA Guidelines - Predictive Testing Process

1. Telephone Contact

2. Visit 1
   - Genetic Counseling
   - Sign Informed Consent Document
   - Mental Health Assessment
   - Neurological Exam
   - Draw Blood

3. Visit 2
   - Disclosure of Results in Person
   - Arrange Post-result Follow-up

4. Follow-Up
   - Prearranged phone call or in-person visit
Who Tests?

About 10% of at-risk individuals choose to test.

REASONS TO TEST:
• Family planning
• Planning for the future
• I have to know
References


