Psychological Consequences of a Negative Test Result
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Presenter Disclosures

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

No relationships to disclose or list
Objectives

• Review Basics of Testing
• Discuss Why People Get Tested
• Discuss Common Responses
• Discuss Who is Affected
• Suggestions for Easier Adjustment
Basics of HD Testing

- Measures CAG repeats
  - 40+ repeats = will develop HD, 50% risk for children
  - 36-39 repeats = may develop HD
  - 27-35 = indeterminate, No HD, small risk to kids
  - <27 repeats, normal, no HD, no risk to kids
Basics of HD Testing

• Positive test results means got the HD gene
  – Will get symptoms
  – 50% risk to kids

• Negative test result
  – Did not get the gene
  – No risk to kids
Who Gets Tested?

• More women than men
• More married people than single people
• Must be 18 or older
Why Do People Get Tested?

- Family planning
- Marriage
- To Relieve Anxiety
- To Reduce Uncertainty
HDSA Testing Guidelines

• Initial telephone contact/pre-screening interview

• Three pre test, in-person sessions for genetic counseling, neurological evaluation and psychological evaluation

• Fourth session for disclosure of results

• Post test counseling
“Soon everyone is going to have an option like this. You make the decision to test, you have to live with the consequences.”

Nancy Wexler, PhD
President, HDF
“I’ve been thinking about this for years and I’m ready now. Can’t we just do it?”
Positive or Negative Results

• More preparation for positive results
• Short-term distress worse for positive results
• Long-term distress the same for positive and negative results
• Anxiety lower for both groups post-results
Common Responses to Negative Results

• Joy
• Relief
• Elation
Common Responses to Negative Results

- Survival guilt
- Why did I get lucky?
- How can I be happy when my siblings got the gene?
- I “want” to take care of everyone else
- It is my “job” to take care of everyone else
Common Responses to Negative Results

• I wasted so much time
• Regret for past decisions
  – Kids, education, career
• I need to do something important with my life now
Common Responses to Negative Results

• Are these really my results?
• What if the results are wrong?
Common Responses to Negative Results

• Initial period of elation followed by low period
• “The good news didn’t change my life as much as I thought it would”
• Same old pressures
• What now?
Who is Affected? Spouses

- Same distress as person getting tested during the process
- After testing, partners have lower anxiety than when results are positive
- Different future
- Change in roles
Who is Affected? Children

- No longer at risk
- Won’t be HD caregivers to parent
- Did they know parent was at risk or getting tested?
- When to tell them?
Who is Affected? Extended Family

- Are they at risk?
- Do they have the gene?
- Did they know about the test?
- When to tell them?
Easier Adjustment

• Testing protocol with counseling
• Clear reasons for getting tested (for example family planning decisions)
• Have a test partner
• Have discussed outcomes
• Discuss feelings after testing
Easier Adjustment

- Not depressed at beginning of test process
- “Stable sense of self”
Easier Adjustment

- Realistic sense of what will change with the results
- Realistic understanding of “normal” feelings after a negative result
- Adjustment takes time
- Change takes time
- Seek support
Thank you for listening. Now let me hear what you have to say!