To Test or Not to Test Panel

Moderator: Lynn Ross, LMSW

Panelists:
Tina Hellum
Andrea Olitsky
Jeanine Smith

HDSA Annual Convention
June 22, 2013
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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

Lynn Ross, LMSW

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

No relationships to disclose or list

Huntington’s Disease Society of America
What is Genetic Testing?

- A biochemical way of determining the presence of a particular gene in an individual
- Blood test
Testing Process

• Involves several sessions with various professionals, both before and after testing, depending on the needs of the individual and staff composition at the facility.
Testing Process

• Includes genetic counseling, discussion of the results, (always given in person) and follow up
Genetic Counseling

• Purpose is to ensure that the person about to undergo testing understands the implications of this knowledge and is prepared to receive the results.

• Sessions are usually spread out over a month or more and may require repeat visits to a testing center.
What does the test cost?

- Varies from center to center
- Ranges from $315 to $1,500
Categories of Testing

**Presymptomatic**
is for people at risk for HD but showing no symptoms

**Prenatal** testing is used to determine whether a person showing possible HD symptoms actually has the HD gene

**Confirmatory** testing determines whether a person showing possible HD symptoms actually has the HD gene

**Prenatal genetic diagnosis utilizing in vitro fertilization (IVF with PGD)**

Done by amniocentesis or chorionic villus sampling (CVS)
Should you get tested?

- Only 4-10% at risk have been tested
- Very Individual Choice!
Things to Consider Before Predictive Testing

The effects it will have:

• YOU!
• Relationships
• Life Stage
• Decisions regarding future
• Discrimination issues
Emory HD Center of Excellence

- Randi Jones, PhD, Clinical Director
- Stewart Factor, DO, Medical Director
- Thomas Wichmann, MD
- Michael Silver, MD
- Lynn Ross, LMSW
- Ami Rosen, MS, CGC
- Cathy Wood-Siverio, MS
- Elaine Sperin, LPN
- Cherita Turner, Scheduling Secretary
Resources

❖ To find a Center of Excellence, call 800-345-4372 or visit www.hdsa.org, Click on “Living with Huntington’s Disease”, “HD Care”, “Centers of Excellence,” then click on the blue highlighted states.

❖ To find other HD Testing Centers, call 800-345-4372 or visit www.hdsa.org, Click on “Living with Huntington’s Disease”, “HD Care”, “Genetic Testing Centers,” then click on the blue highlighted states.

❖ To find a chapter or affiliate, call 800-345-4372 or visit www.hdsa.org, click on “About HDSA,” then click on “Find Your Local HDSA Chapter, Affiliate, or Regional Office.”


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