



To Test or Not to Test Panel

Moderator: Lynn Ross, LMSW

Panelists:

Tina Hellum

Andrea Olitsky

Jeanine Smith

HDSA Annual Convention

June 22, 2013



Huntington's Disease
Society of America

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Presenter Disclosures

Lynn Ross, LMSW

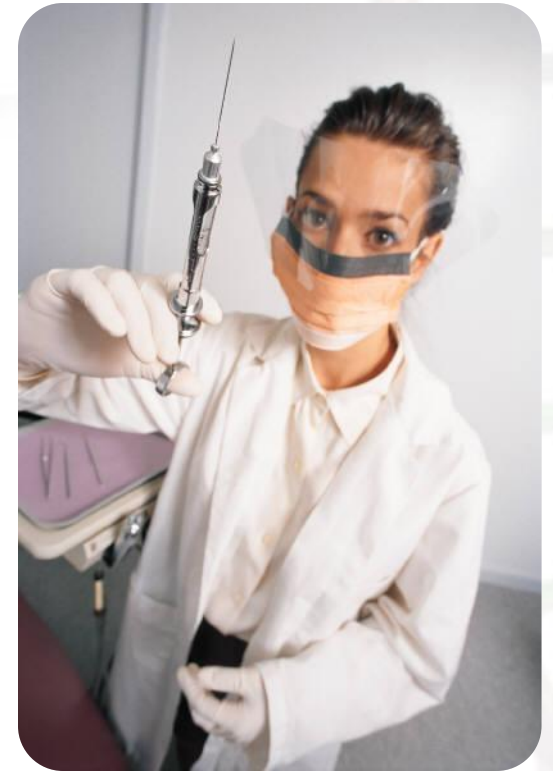
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No relationships to disclose
or list



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 fetus has the HD gene

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

Confirmatory

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

Done by amniocentesis or chorionic villus sampling (**CVS**)



Should you get tested?

- Only 4-10% at risk have been tested
- Very Individual Choice!



YES

NO

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



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Department of Neurology

Resources

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- ❖ 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.”
 - ❖ Jones, R. (1996). *Walking the Tightrope: Living at Risk for Huntington’s Disease*. Huntington’s Disease Society of America. New York. Can be ordered from HDSA.
 - ❖ Wexler, A. (1995). *Mapping Fate: A Memoir of Family, Risk, and Genetic Research*. Random House.
 - ❖ U. S. Huntington’s Disease Testing Group. (Revised 2001). *Genetic Testing for HD: Its relevance and implications*. HDSA. New York.

References



- ❑ *Genetic Testing for HD*. Family Guide Series. 2009. Huntington's Disease Society of America. New York.
- ❑ Jones, R. (1996). *Walking the Tightrope: Living at Risk for Huntington's Disease*. Huntington's Disease Society of America. New York.
- ❑ Rosen, A. (April 2011). *To Test or Not to Test? We Are HDSA!* *Support Group Newsletter*. Huntington's Disease Society of America. New York.
- ❑ U. S. Huntington's Disease Testing Group. (Revised 2001). *Genetic Testing for HD: Its relevance and implications*. HDSA. New York.



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