Are you or were you an individual at-risk for Huntington’s disease and faced with a decision about undergoing genetic testing? If yes, we invite you to please take a moment to read our introduction letter and consider taking our anonymous survey. Please note that persons must be 16 and older to participate. Thank you.

Introduction:

We are reaching out to individuals who are considering or have already undergone predictive testing for Huntington’s disease to complete a brief survey. This information will help us to understand your opinion about anonymous predictive testing. In anonymous testing, the person is assigned a pseudonym such as “John Doe” or a numeric-letter code in order to protect their identity. We would like to know the following:

- For those who have not undergone predictive testing, how would the option of anonymous testing influence your decision to test?
- For those who have already undergone predictive testing, were you offered the option of anonymous testing? If so, how important was that option to you?

This survey includes questions about your age and background, your family history, your decision to undergo testing or not, and your experiences if you have tested. You may complete the survey on paper or by using the following link to an on-line version: https://www.surveymonkey.com/s/HDSA2014UCD1. The survey will take 10-15 minutes to complete.

We thank you for your participation and time.

Sincerely,
Alexandra Duffy, DO
Vicki Wheelock, MD
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