

Approved January 29, 2020



HUNTINGTON'S DISEASE (HD) FAMILY COMMUNICATION RESEARCH STUDY



Do you or a loved one have **Huntington's Disease?**

We are conducting an **anonymous, confidential online survey** of people who have Huntington's disease (HD) in their family. This study was designed by researchers at Johns Hopkins University to improve our understanding of how individuals and families communicate about HD risk and the results of genetic (DNA) testing for HD, and how this information influences the choices and lives of people who are at risk for HD and their families. Our findings will be used to help inform counseling and communication about such results to patients, family members, and the larger community.

You may qualify for the survey if you:

- Have a family history of HD including yourself and/or other members of your family
- Are or have been in a romantic relationship with an individual with HD and/or a family history of HD
- Have a child or children who is/are at risk for HD or has HD

And:

Are age 14 years or older

We would like to learn from your experience in order to help other families.

- Participation is completely voluntary
- Participation involves completing a one-time, online survey

For more information, please contact:

- Principal Investigator Dr. Debra Mathews, *Johns Hopkins Berman Institute of Bioethics*; (410) 614-5581; dmathews@jhu.edu or
- Dr. Jason Brandt, Johns Hopkins School of Medicine; (410) 955-2619; jbrandt@jhmi.edu
- You can also visit our Facebook page: www.facebook.com/HopkinsHD25

To participate in the survey, please use the following link:

https://jhmi.co1.qualtrics.com/jfe/form/SV_erZX5eMhwFwntw9?survey=hdsa

This research study was approved by the Johns Hopkins Medicine IRB, protocol # IRB00203489