

The NC-CCHD Community Outreach Project

NC-CCHD is conducting a brief survey to help us understand the needs of the North Carolina HD community better and plan services around the state. We appreciate your willingness to participate in this project. You may leave any or all of the following questions blank:

1. General Information:

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Home Phone: _____ Work Phone: _____ Mobile Phone _____

Email: _____

2. How do you prefer to be contacted?

- Mobile Work phone
- Email US Mail
- Home phone Text message

4. What is your age?

- 19 or younger 41-50
- 20-30 51-60
- 31-40 61 or older

3. What is your educational background?

- less than high school
- HS or GED
- some college or technical school
- 4-year college
- post-graduate training

5. What is your sex?

- Male
- Female

Relationship to Huntington's Disease:

1. How does Huntington's Disease affect your life?

- I have Huntington's Disease with symptoms
- I have tested positive for the gene, but have no symptoms
- I am at risk for Huntington's Disease, but have not been tested
- I have tested negative for the HD gene
- I am a care partner (family or friend) to a person affected by or at risk for Huntington's Disease
- Other (please specify) _____

3. How did you find out about NC-CCHD?

- mailing
- newspaper
- website
- family member
- support group
- friend
- HDSA
- HD clinic-WFU, Duke, UNC
- neurologist
- psychiatrist
- primary care MD
- genetic counselor
- other healthcare provider
- other: _____

2. My current needs include (check all that apply):

- Caregiver support
- Living at-risk
- Planning my future with HD
- Managing behavior in HD
- Financial issues
- Disability planning
- Medications
- Long-term care
- Advance directives
- Housing problems
- Transportation and driving problems
- Helping my children at risk
- Finding health care professionals to help me
- Locating medical equipment
- Understanding Huntington's Disease better
- Specific symptoms:
- Other: _____

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**Your privacy is of utmost concern to us. We will not distribute any information about you without your permission. We distribute information by email or through the internet in a secure manner. To learn more about our privacy policy, please see our www.nc-cchd.org for more information.*

Family Communications:

1. What best describes your family's way of communicating about Huntington's Disease?

- Open communication between all generations
- Communication in affected generation only
- Communication in at-risk generation only
- Some communication, no pattern
- Communication only among unaffected family members
- No communication

2. How would you feel about participating in a study that attempts to determine the actual number of people in North Carolina affected by Huntington's Disease (including HD patients, caregivers, and at-risk individuals)?

- Enthusiastic, would definitely participate
- Open, I want to know more
- Would depend upon what was involved
- Some family members would resist
- I would be hesitant
- I definitely would not participate

3. Would you feel comfortable approaching your family about participating in a confidential study that does not identify family members by name that attempts to determine the actual number of people in North Carolina affected by Huntington's Disease (including HD patients, caregivers, and at-risk individuals)?

- Yes
- No
- Don't know

Internet Use and Social Networking:

1. Do you have access to the Internet?

- Yes
- No

2. Do you have a cell phone or other handheld device that you use to access the Internet?

- Yes
- No

3. In general, how often do you access the Internet from any location?

- Several times a day
- About once a day
- 3-5 days a week
- 1-2 days a week
- Once every few weeks

4. How likely are you to use the Internet to access information about HD?

- Very likely
- Somewhat likely
- Not at all likely
- Don't know

5. Do you participate in social networking sites on the Internet?

- Yes
- No

6. If yes, have you used any of the following sites to learn more about HD or to contact other people affected by HD?

- Face Book
- Twitter
- YouTube
- HD- related blogs
- Other (please name) _____

7. If yes, how would you describe your attitude about confidentiality related to these types of social networking sites?

- I assume my information will remain confidential so I share private information via these sites
- I assume that there could be breaches in confidentiality so I am careful not to reveal information I would not want to be shared
- I assume that there could be breaches in confidentiality so I only gather information from these sites; I do not contribute any information
- I assume that there could be breaches in confidentiality, so I never even visit these sites.
- other: _____

Additional Comments:

Is there anything else that you would have wanted us to ask on this survey that we did not? Other comments?

Please return this survey to sdawson@nc-cchd.org,
mail to 1004 Dresser Court, Suite 107, Raleigh, NC 27609, or fax to (919) 876-3325.
For more information, please visit our website at www.nc-cchd.org.
Thank you for helping us to better understand your needs.