UI Health Care Huntington's Disease Society of America (HDSA) Center of Excellence

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What should we expect?

A **Predictive Testing Appointment** is for people with a family history of Huntington disease (HD) and want to talk about their risk. You can also talk about genetic testing to learn about your risk for the disease.

This does **not** mean you must have genetic testing that day. Some people come to the visit to help learn more. Then, they decide if testing is right for them.

Who will we meet?

You may meet with a:

- Neurologist
- Genetic counselor
- Psychiatrist
- Social worker

What will happen?

UI Health Care is a HDSA Center of Excellence. Your care team's goal is to provide the best care.

We may talk about:

- Genetic and inheritance of HD
- Family communication
- Treatment and therapy
- Clinical trials

Your care team may do:

- **Cognitive assessment.** A doctor will do a short test of memory. Then they will test other cognitive functions, such as strengths and weaknesses in the thinking.
- **Functional and behavioral assessment.** A doctor will ask about mood and level of day-to-day functioning.
- **Health and psychiatric history.** A doctor will ask about your past health history. They will ask about history of mental health, such as depression and anxiety.
- **Motor assessment.** A doctor will look for signs of movement disorder. They might look at chorea, posturing, rigidity, coordination, and balance.

Timeline of Predictive Testing

First contact phone call.

First visit with an exam by the neurologist and a meeting with the genetic counselor

Follow-up visit to meet with the psychiatric provider and then do sample collection for genetic testing with the genetic counselor.

Follow-up visit to learn genetic testing results. This is about 3 to 4 weeks after the first visit. You talk with the genetic counselor and psychiatric provider.

1 month follow-up visit is offered to everyone after you learn about test results.

Frequently Asked Questions

How do I know if predictive testing is right for me?

Making an informed choice is very important. Things to think about are:

- My relationship with my spouse or significant other.
- My relationship with other family and siblings.
- My relationship and the need to tell my children.
- Who should I tell, and where should I get support?
- How will this impact my education, work, career, and life plans?
- How will this impact my insurance eligibility and financial planning?
- How do I cope with stress? Would professional support help?
- Is this the right time in my life to be tested?

How do I get ready for my visit?

We will collect family history. It may help to gather information about your affected relatives. It is helpful to know:

- How old were they when they first had signs?
- What signs have they had?
- How old they were when they were diagnosed?
- Who and how (clinical or genetic) were they diagnosed?
- Their HD genetic testing results, or the repeat number of the abnormal gene.

You must bring a support person to the visits. This should be a person who is not also at risk to develop HD. An ideal support person would be a spouse or close friend. If you are not able to, please talk with us.

What is genetic counseling?

These visits are for people who:

- Have a family history of HD who want to learn about their risk
- Have positive genetic testing for HD
- Want to determine the genetic cause of their HD signs

The goal is to help you

- Better understand the genetics and inheritance of HD in your family
- Decide if genetic testing is right for you and your family

It does not mean you must have genetic testing.

During a genetic counseling session:

- Family history is taken.
- Health history is reviewed.
- The genetic counselor talks about how genetic conditions are passed down through families.
- The genetic counselor talks about genetic testing options. They share the advantages and limitations of each test.

What is the cost of testing?

It costs $250 if you are paying out of pocket. Many insurances cover this testing.

To learn more, go to:

- **Huntington's Disease Society of America**: hdsa.org
- **Huntington's Disease Youth Organization**: en.hdyo.org

This Handout was modified from the "Huntington's Disease Center" Form from Johns Hopkins University.