

Huntington's Disease

Huntington's Disease (HD) is an inherited progressive brain disorder that affects control of movement, cognitive abilities, mood, and behavior. The disease can strike at any age, with peak age of onset from 35-45 years of age. Each child of an HD-affected parent has a 50% chance of developing the disease. Fortunately there are medications to manage symptoms, and environmental adjustments that can improve quality of life.

Huntington's Disease is a family illness. It is not unusual that when a family sees the end of HD in a parent, a child begins to develop symptoms. Once it begins, it is often a lifelong experience for all family members. Huntington's Disease demands creativity, hard work, and resourcefulness for its successful management.

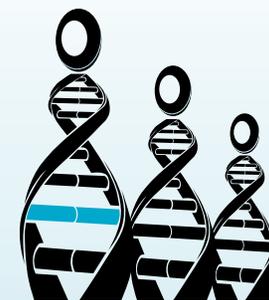


A Portal to Clinical Services:

- Crisis Intervention
- Coordinated intake into clinical programs
- Referrals to programs that provide financial, housing, pharmaceutical, and other means of support
- Caregiver support and education
- Web-based resources for home-bound families and community physicians
- All services are supported by private donations

A Voice for Advocacy:

- Partnership creation with existing programs that provide clinical services needed by HD families
- Advocacy to government programs to develop guidelines, making services and benefits more accessible
- Education and outreach to community clinicians, hospitals, and long-term care providers



The North Carolina Center for the Care of
Huntington's Disease

Providing access to care, education and community resources for patients and families affected by Huntington's Disease in North Carolina.



The North Carolina Center for the Care of
Huntington's Disease

1004 Dresser Ct. Suite 107, Raleigh, NC 27609

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EMAIL: hdinfo@nc-cchd.org



Reasons for Hope

Although there is presently no treatment to slow progression, this is a time of great hope for families with Huntington's Disease. Since the discovery of the HD gene in 1993:

- The Huntington's Study Group has recruited 80 research sites and conducted 20 clinical trials
- Scientific interest in HD is greater now than ever, stimulated by the CHDI Foundation, Inc.
- For over ten years, the NC Chapter of the Huntington's Disease Society of America (HDSA) has created opportunities for families to interact and share information about common challenges
- In 2008, tetrabenazine was approved by the FDA for the treatment of chorea in Huntington's Disease, blazing a path from clinical trials to FDA approval for future drugs to treat HD
- With the passage of the Genetic Information Non-Discrimination Act (GINA) in 2008, at-risk individuals are protected from employment and health insurance discrimination

The main concern raised by researchers now is that there will not be enough study participants to test all promising drug candidates! However, with all of these reasons for hope, NC families can join others from around the world in creating the optimal environment in our state for research participation, drug discovery and treatment advancements. Now is the time to make this significant step!

When Patients and Families Need...

- Confidential, knowledgeable assistance available by phone, internet, and in person
- Timely diagnosis by clinicians experienced in the evaluation and treatment of HD
- Accurate information about symptoms, course of disease, and treatment options
- Referrals for genetic counseling and testing
- Support for all affected family members
- Strategies for the prevention of complications
- Assistance with financial and legal needs
- Referrals and resources for psychiatric symptoms
- Information about research opportunities such as clinical trials



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Clinical Sites

WAKE FOREST UNIVERSITY HD CLINIC

Francis Walker, MD, and Christine O'Neill
4th Floor, Richard Janeway Clinical Science Tower
Winston-Salem, NC 27157
Phone: (336) 716-8611 or (336) 716-4101
Fax: (336) 716-7794

DUKE UNIVERSITY HD CLINIC

Burton Scott, MD, and Ginger Williams
932 Morreene Road, Durham, NC
Phone: (919) 668-2493
Fax: (919) 681-4935

TRIANGLE PSYCHIATRY CLINIC

Mary Edmondson, MD
1004 Dresser Court, Suite 107, Raleigh, NC 27609
Phone: (919) 876-3330
Fax: (919) 876-3325

UNC GENETIC TESTING CLINIC

Debbie Keelean-Fuller, MS, CGC
Room 1071, 1st Floor Memorial Hospital
101 Manning Drive, CB#7487, Chapel Hill, NC 27514
Phone: (919) 966-4380 or (919) 966-1595
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For more information, visit us on the web at: www.nc-cchd.org