What Is Huntington’s Disease?
Huntington’s disease (HD) is an inherited neurologic disorder that causes involuntary movements, emotional symptoms, and loss of cognitive abilities. The involuntary movements may first appear as restlessness, and later include random movements of the limbs and face. In addition, many patients also develop stiffness, difficulty with walking, reduced control of fine movements, and problems with speech and swallowing. Emotional symptoms may include depression, reduced control over feelings and impulses, or irritability. Cognitive symptoms may include problems with memory, concentration, motivation, and planning. Weight loss is an important complication.

The Genetics of Huntington’s Disease
HD is a genetic disorder and is usually, inherited within families with a history of the disease. Men and women have an equal chance of inheriting the gene from an affected parent. The children of an individual with HD each have a 50 percent chance of inheriting the gene. A person who inherits the Huntington’s disease genetic mutation will develop the symptoms of the disease if he or she lives long enough.

The discovery in 1993 of the genetic mutation that causes HD has led to extraordinary progress in understanding the disease. This discovery has also made it possible to determine whether the genetic mutation is present in individuals who are at risk for inheriting it (presymptomatic testing) or who appear to be exhibiting signs of HD (diagnostic testing). Genetic testing helps to ensure an accurate diagnosis and for some at-risk individuals may help with making informed decisions about issues such as family planning.

The New England HDSA Center of Excellence
The greater Boston community has had a long commitment to patients with Huntington’s disease and to their families. The Massachusetts General Hospital (MGH) HD Clinic was established in 1980 to provide a focus for clinical care and research. The MGH program, based in the Department of Neurology, has grown to become one of the leading HD centers in the United States, providing medical care, psychological and genetic counseling, and social services to HD families throughout the New England area. In 1997, Tewksbury Hospital opened an outpatient clinic and a dedicated inpatient unit. What is now Lowell Health Care, has a long history of serving the inpatient long-term care needs of HD families. As a Center of Excellence, a partnership amongst the HDSA, Massachusetts General Hospital, Tewksbury Hospital, Boston University Medical Center, and Lowell Health Care, our mission is to continually improve access to care and services for New England HD families.

Follow-up Care
There is increasing optimism that treatments to slow or prevent the symptoms of HD will be available in the foreseeable future. At present, however, medical therapy is primarily aimed at improving symptoms and optimizing function. Depending on an individual’s needs, ongoing care might include education, counseling and support, advice about nutrition and fitness, medications for specific symptoms, physical therapy, occupational therapy, speech therapy, psychotherapy, or management of residential care. Regular follow-up is helpful in reducing symptoms, optimizing the quality of life, and staying abreast with advances in research.

Predictive Genetic Testing
Predictive genetic testing is offered to at-risk individuals following specific clinical guidelines. Those undergoing testing must select a support person to participate in the process. Test results are delivered in person and follow-up care is available as needed. Please contact Judy Sinsheimer, LICSW at 617-726-2603 for more information.
Inpatient Hospitalization
When necessary, inpatient hospitalization for acute medical or behavioral problems is available at MGH.

Long-Term Care
Lowell Health Care has a long-term care unit dedicated to HD patients. Tewksbury Hospital accepts patients for medium-term care for management prior to long-term care.

Social Services
On-site social work consultation is available for emotional support and referral to community resources. Please contact Judy Sinsheimer, LICSW at 617-726-2603 for more information. Social work resources are also available through the regional HDSA Social Worker (888-554-8102) for assistance with community support, housing and long-term care home placement.

Clinical Research
The Center for Excellence is committed to helping find better treatments for HD. Individuals followed at the Center may have opportunities to participate in clinical trials of new treatments. Laboratories doing HD related research receive support from the federal government and from private foundations including the HDSA and the Hereditary Disease Foundation (HDF).

Major Areas of Basic HD Research
There are many research laboratories associated with the institutions that are part of the Center of Excellence. Some areas of active research include:

• Neuroanatomic and chemical changes.
• The huntingtin protein.
• Animal and cell models.
• Experimental treatments.
• Brain imaging.
• Genetic modifiers of HD.
• Alterations in gene and protein expression and function.
• Biomarker development.

Brain Donation Program
Brain tissue for research may be donated to an HDSA supported brain bank through MGH. The 24-hour contact number is 617-724-5700 page #21300. For information about planning, call Alex Bender at (617) 724-2227 or acbender@partners.org.

Appointments
To schedule an appointment with one of our Huntington’s disease specialists, please call (617) 724-9234 (MGH) or 978-851-7321 (Tewksbury). To speak to someone about the Center of Excellence or about any of the ongoing clinical studies, please call Alex Bender at (617) 724-2227.

The HDSA
The Huntington's Disease Society of America (HDSA) is a not-for-profit national health agency dedicated to finding a cure for HD through research, helping individuals and families affected by HD, and educating the public about the disease. For more information, call (888) 554-8102.

The New England Regional Office of the HDSA
The New England Regional Office serves greater New England, including Massachusetts, Maine, New Hampshire, Rhode Island, Vermont, and Connecticut and participates with the Center of Excellence through fundraising events, shared professional interaction, and educational development. The Chapter also sponsors 10 support groups in 5 states, volunteer resources, social activities for families, a twice yearly regional convention, a Hoop-a-thon and many other fundraising and education events. It maintains a toll-free helpline for information and social service requests, as well as publishing a quarterly newsletter. If you have questions or would like to join the fight against HD, please contact us at:

HDSA New England Regional Office
6 Courthouse Lane Unit 12
Chelmsford, MA 01824
Tel: (978) 454-8102
Toll Free: (888) 554-8102
http://www.hdsa-ne.org

How can you help?
For information about giving and naming opportunities at the Center, please call Dr. Hersch at (617) 726-1254 or contact the HDSA at (888) 554-8102.

Feedback
Communications related to the administration or services of the Center can be directed to Dr. Hersch (617) 726-1254 or to the social worker (888) 554-8102.

Contacts
MGH: 617-724-9234
Tewksbury: 978-640-6317
Research Info: 617-724-2227
Social Service: 617-726-2603
HDSA NE: 888-554-8102
Helpline: 888-554-8102.
Director: 617-726-1254