Cleveland Clinic

CENTER FOR NEUROLOGICAL RESTORATION

Huntington’s Disease
Comprehensive Care Clinic
Advancing Treatment and Improving Quality of Life for Patients with Huntington’s Disease

**Huntington’s Disease**

Cleveland Clinic Neurological Institute’s Center for Neurological Restoration provides innovative treatment and restoration of neurological function to those suffering from a variety of neurological, neuropsychiatric and neurodegenerative conditions. We are focused on advancing treatment of Huntington’s disease (HD) through ongoing basic and clinical research, expertise in medical management, surgical restoration and innovation.

**Clinical Experience**

Our group is an integrated and multidisciplinary team, offering the latest medical and surgical innovations for patients with intractable movement disorders and other neurological conditions. Our team is made up of neurologists, neurosurgeons, psychiatrists, neuropsychologists, neurophysiologists, imaging specialists, specialized nurses and mid-level practitioners — who all work together to provide patient-centered care in one convenient outpatient clinic location. Our care is integrated to optimize physician communication and collaboration in patient care, research and education.

We also offer a HD Comprehensive Care Clinic, a multidisciplinary clinic providing the full spectrum of care for patients and families. In addition to our team members from neurology, psychiatry and neuropsychology, additional specialists from genetics, physical therapy, occupational therapy and speech therapy work collaboratively with patients and their families to address their physical, emotional, cognitive and behavioral needs.

### HD Patient Volumes

<table>
<thead>
<tr>
<th>Year</th>
<th>Patient Volumes</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012</td>
<td>100</td>
</tr>
<tr>
<td>2013</td>
<td>114</td>
</tr>
<tr>
<td>2014</td>
<td>125 (PROJECTED)</td>
</tr>
</tbody>
</table>
**Research Experience**

We have expanded our basic and clinical research programs to facilitate clinical trials and cutting-edge treatment modalities. We participated in research trials with the Huntington Study Group and Cure for Huntington Disease Initiative Foundation. Cleveland Clinic is among the most experienced in the world at performing deep brain stimulation (DBS) surgeries, having implanted hundreds of neuromodulation devices to improve function and quality of life in patients with disabling movement disorders. Our new intraoperative MRI suite for DBS and other neurological procedures integrates innovative technologies and significantly improves patient safety.

Our neurosurgical research focuses strongly on movement disorders, but our investigators are also developing and researching novel therapies for disabling neuropsychiatric disorders such as treatment-resistant depression, obsessive-compulsive disorder, motor impairment secondary to stroke and refractory chronic pain syndromes.

Cleveland Clinic neurosurgeons implanted more than 100 neuromodulation devices in 2013.

---

**CNR NEUROSURGICAL VOLUMES**

- **2012**: 455
- **2013**: 382
- **2014**: 501
- **PROJECTED**: 501

---

**OUR CENTER** employs three full-time stereotactic and functional neurosurgeons whose expertise allows for the use of specialized techniques in surgical modulation of the nervous system to treat neurological diseases such as movement disorders, epilepsy, chronic pain, degenerative diseases, neurological injuries and psychiatric disorders.
Huntington’s Disease Trials

CREST-E: A global, multicenter, randomized, double-blind, placebo-controlled clinical trial in individuals 18 years of age and older with HD designed to assess the potential of high-dose pharmaceutical grade creatine for neuroprotection.

ENROLL-HD: A global longitudinal, observational study of HD aimed at collecting a common set of data for all participants across all sites around the world to learn more about the disease, improve clinical care and find new treatments.

PREDICT-HD: Observational study examining the nature and pattern of neurobiological changes and neurobehavioral changes that occur in the period leading up to a diagnosis of HD. The intent of the study is to learn more about the beginning changes in thinking skills, emotional regulation, brain structure and brain function as a person begins the transition from health to HD.

Other Movement Disorders Clinical Trials

AbbVie M12-920: An open-label, two-part, multicenter study to assess the safety and efficacy of Levodopa Carbidopa Intestinal Gel for the treatment of non-motor symptoms in subjects with advanced Parkinson’s disease (PD).

DBS for OCD: An NIH-funded trial of deep brain stimulation for obsessive compulsive disorder.

DBS for TPS: An NIH-funded study of the safety and therapeutic benefits of bilateral VC/VS deep brain stimulation in 10 patients with medically refractory, severe pain associated with thalamic pain syndrome.

INTREPID: Evaluating the safety and effectiveness of an implantable DBS system in advanced PD patients with levodopa-responsive PD that is not being adequately controlled with medication.

MYOSENSE: An NIH-funded study to design, develop and clinically validate MyoSense™, a clinician-worn, high-resolution sensory enhancing device to quantitatively characterize and distinguish different types of muscle hypertonia.
A Coordinated Approach for Evaluation and Treatment

At Cleveland Clinic’s Huntington’s Disease Comprehensive Care Clinic, patients have access to medical specialists who work together to evaluate, diagnose and offer treatment options for complex neurological conditions and brain diseases.

**PPMI:** The Parkinson’s Progression Marker Initiative and collaboration with The Michael J. Fox Foundation. The goal was to identify and assess biomarkers in people who are at risk to develop PD as well as those with typical symptoms.

**COMMUNITY RESOURCES**

Cleveland Clinic supports the Northeast Ohio chapter of the Huntington’s Disease Society of America (HDSA) through collaboration and sponsorship. We have been a proud sponsor of the local HDSA Fundraiser Gala and a regular participant of the annual Open Forum, focusing on promoting awareness and education for HD patients and families.

Cleveland Clinic Center for Neurological Restoration is committed to discovering novel and effective treatments for HD. As our physicians and scientists gain more knowledge about the changes in circuitry that contribute to the development of movement disorders, behavioral disturbances and cognitive decline, we will utilize our experience, resources and commitment to improve the quality of life of those with HD and develop interventions that will alter the progression of this devastating disease.
Team of Specialists

The Huntington’s Disease Comprehensive Care Clinic is led by Mayur Pandya, DO, staff psychiatrist in the Center for Neurological Restoration in the Department of Psychiatry and Psychology at Cleveland Clinic. Dr. Pandya is an Executive Board Member of Northeast Ohio’s Chapter of HDSA and the site principal investigator of ENROLL-HD. Dr. Pandya works alongside Anwar Ahmed, MD, staff neurologist in the Center for Neurological Restoration at Cleveland Clinic. Dr. Ahmed directs the Movement Disorders Fellowship Program, is a member of the Huntington Study Group and the site principal investigator of CREST-E and a co-investigator of ENROLL-HD. Stephen M. Rao, PhD, ABPP-CN, staff neuropsychologist in Cleveland Clinic’s Lou Ruvo Center for Brain Health is the Director of the Schey Center for Cognitive Neuroimaging at Cleveland Clinic and the site principal investigator of PREDICT-HD.

CENTER FOR NEUROLOGICAL RESTORATION

Staff Listing

Andre Machado, MD, PhD  
Neurosurgeon  
Director, Center for Neurological Restoration

Mayur Pandya, DO  
Psychiatrist  
Director, Huntington's Disease Comprehensive Care Clinic

Anwar Ahmed, MD  
Neurologist

Jay Alberts, PhD  
Biomedical Engineer

Kristin Appleby, MD  
Neurologist

Hubert Fernandez, MD  
Neurologist

Darlene Floden, PhD, ABPP-CN  
Neuropsychologist

John Gale, PhD  
Researcher

Michal Gostkowski, DO  
Neurologist

Ilia Itin, MD  
Neurologist

Cynthia S. Kubu, PhD, ABPP-CN  
Neuropsychologist

Richard Lederman, MD, PhD  
Neurologist

Darlene A. Lobel, MD, FAANS  
Neurosurgeon

Donald A. Malone Jr., MD  
Psychiatrist

Sean Nagel, MD  
Neurosurgeon

Ela B. Plow, PhD, PT  
Biomedical Engineer

Stephen Rao, PhD  
Neuropsychologist

Joseph Rudolph, MD  
Neurologist

Stewart Tepper, MD  
Neurologist
Convenient Locations

Our center includes locations in Cleveland, Ohio; Weston, Florida and Las Vegas, Nevada. Our experts at each site collaborate closely together to maximize resources and advance research and treatment. Cleveland Clinic’s Lou Ruvo Center for Brain Health in Las Vegas is dedicated solely to the pursuit of more effective treatments for brain diseases and to providing leading-edge care for patients affected by these diseases and their families.

Cleveland Clinic main campus
Mellen Center/U3
1950 E. 89th St.
Cleveland, OH 44195
866.588.2264

Chardon Road Medical Office Building
34500 Chardon Road
Willoughby Hills, OH 44094
866.588.2264

Lakewood Hospital
14601 Detroit Ave.
Lakewood, OH 44107
866.588.2264

Medina Hospital
1000 East Washington St.
Medina, OH 44256
866.588.2264

Richard E. Jacobs Health Center
33100 Cleveland Clinic Blvd.
Avon, OH 44011
866.588.2264

Willoughby Hills Family Health Center
2570 SOM Center Road
Willoughby Hills, OH 44094
866.588.2264

Cleveland Clinic Florida
2950 Cleveland Clinic Blvd.
Weston, FL 33331
877.463.2010

Cleveland Clinic Lou Ruvo Center for Brain Health
888 W. Bonneville Ave.
Las Vegas, NV 89106
702.483.6000

24/7 Referrals
To refer a patient to Cleveland Clinic’s Center for Neurological Restoration, please call 216.444.8001 or 800.223.2273, ext. 48001. Visit us on the Web at clevelandclinic.org/neurorestoration.
The Neurological Institute is a leader in the diagnosis and treatment of common and complex neurological disorders of adult and pediatric patients. Its more than 300 specialists combine expertise and compassion to achieve measurably superior results. By promoting innovative research and integrated care models, the Neurological Institute accelerates the adoption of new treatments and technologies into patient care. The Neurological Institute is one of 27 institutes at Cleveland Clinic, a nonprofit academic medical center ranked among the nation's top hospitals (U.S. News & World Report), where more than 3,000 physicians and researchers in 120 specialties collaborate to give every patient the best outcome and experience.

Consult QD | Neurosciences

The neurosciences field is changing rapidly, and so are all of our practices. Join clinicians and researchers from Cleveland Clinic's Neurological Institute in this open forum for discussion of the latest advances in patient care, research and technology — specifically for healthcare professionals.

Visit consultqd.clevelandclinic.org/neurosciences today!

Referring Physician Hotline | 855.REFER.123

Your 24/7 connection for referrals. Or download our new free “Physician Referral” app at the App Store or Google Play.