



HDSA Northeast Ohio Chapter
P.O. Box 14668
Cleveland, OH 44114

HDSA Northeast Ohio Chapter
presents

Huntington's Disease: Comfort, Compassion and Coordination of Care

2013 Open Forum for Patients, Families, and Healthcare Providers

Saturday, May 11, 2013

Embassy Suites Cleveland - Rockside
5800 Rockside Woods Boulevard
Independence, OH 44131



Huntington's Disease: Comfort, Compassion and Coordination

2013 Open Forum for Patients, Families, and Healthcare Providers

HDSA Mission Statement

The Huntington's Disease Society of America (HDSA) funds both basic and clinical HD research, provides services and referrals to HD families and educates the public and healthcare professionals about this fatal genetic disorder. HDSA provides the vital link between care and cure of HD and is committed to making this the last generation with Huntington's Disease.

Accreditation

Approval is pending for AAPA Category I CME credit by the Physician Assistant Review Panel. Physician Assistants should claim only those hours actually spent participating in the CME activity. This program was planned in accordance with AAPA's CME standards for Live Programs and for Commercial Support of Live Programs.

Physical Therapy – Credit is being applied for with the Ohio Physical Therapy Association – Approval is pending.

Occupational Therapy – Credit is being applied for with the OT section of the Ohio OT PTAT Board – Approval is pending.

Social Workers/Independent Social Workers – Credit is being applied for with the State of Ohio Counselor, Social Worker and Marriage and Family Therapist Board – Approval is pending.

The Ohio Board of Nursing will accept at face value the number of contact hours awarded for a continuing education activity that has been approved by a nationally recognized accreditation system of continuing education approval. Therefore physician *AMA PRA Category 1 Credits™* will be accepted for nursing credits. Nurses from other states should contact their State Board of Nursing.

Keynote Speakers

Martha Nance, MD

Struthers Parkinsons Center
Golden Valley, MN



Martha Nance is a board certified neurologist and clinical geneticist with special interest in movement disorders such as Parkinson's disease, Huntington's disease, hereditary

ataxias and spastic paraplegias, and other neurogenetic disorders. She has served as the medical director of the Struthers Parkinson's Center since 2000.

In addition to the care of patients and families with neurologic diseases, Dr. Nance is also involved in clinical research to develop better treatments for Parkinson's disease and Huntington's disease, and is interested in education for both patients and medical professionals. She is a Clinical Professor of Neurology at the University of Minnesota. Her other current regional and national professional activities include serving as the Medical Advisor to the Minnesota Chapter of the Huntington's Disease Society of America since 1992.

Joanne Wojcieszek, MD

Associate Professor of Neurology
Indiana University School of Medicine
Indianapolis, Indiana



Joanne Wojcieszek is Clinical Associate Professor of Neurology, Director of the Movement Disorders Clinic and is a senior member of the neurology staff at the Huntington Clinic. She is

part of the nation's leading centers for the study of Huntington's Disease and similar movement disorders which is recognized as a Center of Excellence by the Huntington's Disease Society of America. She has lectured and written extensively on various movement disorders, including a paper on Woody Guthrie and HD.

Forum Co-Directors

David Waltermire

HDSA Northeast Ohio Chapter Past President
Cleveland, OH

Mayur Pandya, DO

Comprehensive Huntington's Disease Clinic
Cleveland Clinic Center for Neurological Restoration
Cleveland, OH

Forum Speakers

Charles Bae, MD

Cleveland Clinic
Cleveland, OH

Julie Burnett, BS, LSW

Wyant Woods
Akron, OH

Tiffany Cousino, LISW

HDSA Northeast Ohio Chapter Social Worker

James Crawford, JD

HDSA Northeast Ohio Advocacy Chair
Cleveland, OH

Carol Crowe, MD

MetroHealth Medical Center
Cleveland OH

Emily Fitzpatrick, MS, CCC-SLP

Cleveland Clinic
Cleveland, OH

Joseph Hanna, MD

MetroHealth Medical Center
Cleveland, OH

Michelle Harrison-Cudnik, PT, MSCS

Cleveland Clinic
Cleveland, OH

Richard Lynch, BSN, RN

Wyant Woods
Akron, OH

Mayur Pandya, DO

Comprehensive Huntington's Disease Clinic
Cleveland Clinic
Cleveland, OH

Laura Shoemaker, DO

Hospice of the Western Reserve
Cleveland, OH

Amy Shealy, MS, MMP

MetroHealth Medical Center
Cleveland, OH

Open Forum Schedule

May 11, 2013

8:30-9:00	Registration and Breakfast	
9:00-9:15	Welcome and Video from Louise Vetter	
9:15-9:45	Morning Keynote Presentation Silence is Golden: Turning Off the HD Gene	Martha Nance
9:45-10:15	Sleep Issues in HD	Charles Bae
10:15-10:30	Advocacy Update	James Crawford
10:30-11:00	Break/Exhibits	
11:00-11:45	Breakout Session I	
11:45-1:00	Lunch / Exhibits	
1:00-1:30	Afternoon Keynote Presentation Management of HD Symptoms	Joanne Wojcieszek
1:30-2:00	Palliative Care in HD	Laura Shoemaker
2:00-2:15	Break/Exhibits	
2:15-3:00	Breakout Session II	
3:00-3:15	Closing Remarks	

Breakout Sessions

- Speech & Physical Therapy in HD: Safety, Prevention and Management –**
Emily Fitzpatrick, Michelle Harrison-Cudnik
- Q&A: The Clinicians Answer Your Medical Questions –**
Joseph Hanna, Mayur Pandya
- Genetics Testing in HD: A Complex Question –** Amy Shealy, Carol Crowe
- Linking HD Patients and Families with Community Resources –**
Tiffany Cousino, Julie Burnett, Richard Lynch



Directions to Embassy Suites Cleveland - Independence

from Cleveland Hopkins International Airport:

Take I-480 East to I-77 South; take I-77 South to Exit 155/Rockside Road. Turn left. Go to 4th traffic light and turn left onto Rockside Woods Blvd. Hotel will be on left 1/4 mile from Rockside Road.

from Major Highways:

Traveling on the Ohio Turnpike (I-80), take Exit 11. Head north on Ohio Route 21 to Rockside Road (approx. 8 miles). Proceed west on Rockside Road to the I-77 Interchange. Go to 4th traffic light and turn left onto Rockside Woods Blvd. Hotel will be on left 1/4 mile from Rockside Road.

from the Northwest (Toledo Area):

Travel east on I-90 to the I-77 Interchange. Head south on I-77 to the Rockside Road Exit and turn left. Go to 4th traffic light and turn left onto Rockside Woods Blvd. Hotel will be left 1/4 mile from Rockside Road.

from the Northeast (Erie, PA/NY Thruway):

Travel west on I-90 to the I-271 Interchange. Proceed south on I-271 to I-480 West to the I-77 south Interchange. Head south on I-77 to the Rockside Road Exit and turn left onto Rockside Road. Go to 4th traffic light and turn left onto Rockside Woods Blvd. Hotel will be left 1/4 mile from Rockside Road.

from the Southwest (Columbus Area):

Travel north on I-71 to the I-480 Interchange. Then head east on I-480 to I-77 South. Take I-77 South to Exit 155/Rockside Road. Turn left. Go to 4th traffic light and turn left onto Rockside Woods Blvd. Hotel will be on left 1/4 mile from Rockside Road.

from the South (Akron/Canton Area):

Take I-77 North to Rockside Road-Independence exit. Turn right onto Rockside Road and go to 3rd traffic light. Turn left onto Rockside Woods Blvd. Hotel will be on left 1/4 mile from Rockside Road.

from the South/Southeast (Youngstown/ Pittsburgh Area):

Travel west on the Ohio Turnpike (I-80) to Exit 13 (I-480). Head west on I-480 to the I-77 South Interchange. Head south on I-77 to the Rockside Road Exit and turn left. Go to 4th traffic light and turn left onto Rockside Woods Blvd. Hotel will be on left 1/4 mile from Rockside Road.

*Alternate Route

Travel west on the Ohio Turnpike to Exit 11 (Ohio Route 21). Head north on Route 21 to Rockside Road (approx. 8 miles). Proceed west on Rockside Road to the I-77 Interchange. Proceed west on Rockside Road to the I-77 Interchange. Go to 4th traffic light and turn left onto Rockside Woods Blvd. Hotel will be on left 1/4 mile from Rockside Road.

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Registration

May 11, 2013

Please register by Monday, May 6, 2013

Patients and Family Members

Advance Registration Fee: \$10 per person/\$20 per family
At-the-Door Registration Fee: \$15 per person/\$25 per family

Healthcare Providers

Physicians: \$50
RNs, PAs, PTs, OTs, Social Workers: \$30

Mail or fax this form to:

The Cleveland Clinic Educational Foundation
P.O. Box 931653
Cleveland, OH 44193-1082
Fax No: 216.448.0783

Register online at www.ccfcmc.org/hdsa13

Please print:

First Name: _____ Last Name: _____ Degree: _____

Address: _____

City/State/Zip: _____

Phone: _____

Email: _____

Choose two breakout sessions: Session I: #1 ☐ #2 ☐ #3 ☐ #4 ☐
Session II: #1 ☐ #2 ☐ #3 ☐ #4 ☐

Registration Type:

☐ Individual: \$10

☐ Family: \$20

Additional Names:

1. First Name _____ Last Name _____

2. First Name _____ Last Name _____

3. First Name _____ Last Name _____

☐ Physicians: \$50

☐ RNs, PAs, PT, OT, Social Workers: \$30

☐ Check enclosed – made payable to **Cleveland Clinic Educational Foundation**. Total amount of check \$ _____

Payment by credit card must register online at www.ccfcmc.org/hdsa13

For questions, call Monet Smith at 216.444.9380.

