



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

HDSA Northeast Ohio Chapter
presents

Huntington's Disease – It's a Family Affair: Finding Help and Hope

2014 Open Forum for Patients, Families, and Healthcare Providers

Saturday, April 12, 2014

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



Huntington's Disease – It's a Family Affair: Finding Help

2014 Open Forum for Patients, Families, and Healthcare Providers

Keynote Speakers

Jang-Ho Cha, MD, PhD

Neuroscience Lead, Discovery Medicine



Jang-Ho Cha obtained his M.D. and Ph.D. from the University of Michigan and did his residency in Neurology at Massachusetts General Hospital in Boston, MA, where he became a faculty member. He specialized

in both clinical and research aspects of Huntington's disease. His first research grant was a fellowship from the HDSA. Later, he was one of the HDSA Coalition for the Cure investigators. Dr. Cha is now at Merck as the Neuroscience Lead in Discovery Medicine, where he looks for new targets for neurological and psychiatric diseases. Dr. Cha is a member of the HDSA National Board where he currently serves as Vice Chair as well as the Chair of the Scientific Advisory Board.

Jim Pollard, MA

CDHI Foundation, Inc.



In 1986, Jimmy Pollard, a special education teacher by training, began his career of working with folks and family touched by HD. He became interested in how HD's cognitive changes

challenge both people living with it and their caregivers; and how care settings can accommodate their unique needs. Over the years he learned that listening to families and collaborating with colleagues was essential to better understanding and, most importantly, improved care.

He has written *A Caregiver's Handbook for Advanced Stage Huntington's Disease* and *Hurry Up & Wait! A Cognitive Care Companion for Huntington's Disease*, which have been translated into eight languages by national HD associations around the world, and spoken at national HD meetings in Australia, England, Italy, Portugal, Ireland, Switzerland, Poland, Scotland and Canada.

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.

CHDI Foundation

CHDI Foundation is a privately funded, not-for-profit biomedical research organization devoted to a single disease – Huntington's disease. Its mission is to develop drugs that will slow the progression of Huntington's disease and provide meaningful clinical benefit to patients as quickly as possible. To achieve this CHDI manages a diverse portfolio of research projects through a novel virtual model that encourages scientific collaboration to more directly connect academic research, drug discovery and clinical development. This helps bridge the translational gap that often exists between academic and industrial research pursuits, and which adds costly delays to therapeutic development. CHDI's activities extend from exploratory biology to the identification and validation of therapeutic targets, and from drug discovery and development to clinical studies and trials.

For more information, visit CDHIFoundation.org.

Accreditation

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.

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

James Crawford, JD

HDSA Northeast Ohio Advocacy Chair
Cleveland, OH

Eric Hutchins, LNHA

Wyant Woods
Akron, OH

Constance Eyman, LNHA, LSW

HDSA Northeast Ohio Chapter Social Worker
Cleveland, OH

Allison Layton, LISW

Cleveland Clinic and HDSA Northeast Ohio Chapter
Social Worker
Cleveland, OH

Joseph Giuliano

CHDI Foundation, Inc.
Princeton, NJ

Aaron Nicka, OTR/L

Cleveland Clinic
Cleveland, OH

Joseph Hanna, MD

MetroHealth Medical Center
Cleveland, OH

Mayur Pandya, DO

Comprehensive Huntington's Disease Clinic
Cleveland Clinic
Cleveland, OH

Michelle Harrison-Cudnik, PT, MSCS

Cleveland Clinic
Cleveland, OH

Mackenzie Platten

President, HDSA Northeast Ohio Chapter
Cleveland, OH

p and Hope

Open Forum Schedule

April 12, 2014

8:30-9:00	Registration and Breakfast
9:00-9:15	Welcome and Introductions <i>Mackenzie Platten and David Waltermire</i>
9:15-9:45	Morning Keynote Presentation: HDSA and Research <i>Jang-Ho Cha</i>
9:45-10:15	Enroll HD – Joseph Giuliano
10:15-10:30	Advocacy Update – James Crawford
10:30-10:45	Break/Exhibits
10:45-11:30	Breakout Session I
11:30-12:30	Lunch/Exhibits
12:30-1:30	Afternoon Keynote Presentation: Hurry Up and Wait – Thinking About Thinking with HD – Jim Pollard
1:30-2:00	Respite Care – Eric Hutchins
2:00-2:45	Breakout Session II
2:45	Adjourn

Breakout Sessions

- Physical and Occupational Therapy in HD**
Aaron Nicka and Michelle Harrison-Cudnik
- Q&A: The Clinicians Answer Your Medical Questions**
Jang-Ho Cha, Joseph Hanna and Mayur Pandya
- Linking HD Patients and Families with Community Resources**
Allison Layton and Constance Eyman



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

April 12, 2014

Please register by Monday, April 7, 2014

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

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.ccfcmf.org/hdsa14

Please print:

First Name: _____ Last Name: _____ Degree: _____

Address: _____

City/State/Zip: _____

Phone: _____

Email: _____

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

Registration Type: ☐ Individual: \$10

☐ Family: \$20

Additional Names:

1. First Name _____ Last Name _____

2. First Name _____ Last Name _____

3. First Name _____ Last Name _____

☐ 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.ccfcmf.org/hdsa14

For questions, call Monet Smith at 216.444.9380.

