



What is an HD Center of Excellence?

Danny Bega, MD

*HDSA Center of Excellence at Northwestern University
Chicago, Illinois*

Jennifer G Goldman, MD, MS

*HDSA Center of Excellence at Rush University
Chicago, Illinois*

Sandra K Kostyk, MD, PhD

*HDSA Center of Excellence at The Ohio State University
Columbus, Ohio*



The information provided by speakers in workshops, forums, sharing/networking sessions and any other educational presentation made as part of the 2017 HDSA Convention program is for informational use only.

HDSA encourages all attendees to consult with their primary care provider, neurologist or other healthcare provider about any advice, exercise, medication, treatment, nutritional supplement or regimen that may have been mentioned as part of any presentation.

Presenter Disclosures

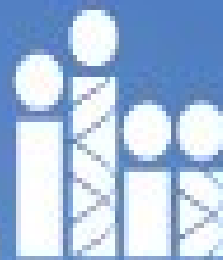
Danny Bega
Jennifer Goldman
Sandra Kostyk

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose
or list



Huntington's Disease
Society of America



Huntington's Disease
Society of America

Centers of Excellence



Huntington's Disease
Society of America

THE HD SA COE program has recently been increasing the number of centers.

- There are currently 41 active centers.

- Albany Medical College (NY)
- Beth Israel Deaconess Medical Center (MA)
- Cleveland Clinic (OH)
- Colorado Neurological Institute
- Columbia Health Sciences/NYS Psychiatric Institute
- Duke University (NC)
- Emory University (GA)
- Georgetown University (DC)
- Hennepin County Medical Center (MN)
- Indiana University
- Johns Hopkins University (MD)
- Massachusetts General Hospital
- Northwestern University (IL)
- Ochsner Health System (LA)
- Ohio State University
- Rush University Medical Center (IL)
- University of Alabama, Birmingham
- University of California, Davis Medical Center
- University of California, Los Angeles
- University of California, San Diego
- University of California, San Francisco
- University of Colorado
- University of Florida
- University of Iowa
- University of Louisville (KY)
- University of Miami (FL)
- University of Nebraska Medical Center
- University of Pennsylvania
- University of Pittsburgh Medical Center (PA)
- University of Rochester (NY)

- University of South Florida
- University of Tennessee Health Science Center – Memphis
- University of Texas Health Science Center- Houston
- University of Utah
- University of Vermont, Frederick Binter Center for Parkinson's Disease & Movement Disorders
- University of Virginia
- University of Washington (WA)
- University of Wisconsin- Madison
- Vanderbilt University Medical Center (TN)
- Virginia Commonwealth University
- Washington University School of Medicine (MO)

EXAMPLE: If you click on one of the sites links, you get the following information

HDSA Center of Excellence at University of California, San Diego

UC San Diego Health – Hillcrest Medical Offices North
Neurology, 3rd Floor, Suite 1
200 West Arbor Drive
San Diego, CA 92103

Director: Jody Corey-Bloom, MD, PhD

Phone for appts: 858-249-0568

Clinic Coordinator: Sungmee Park
Phone: 858-249-0568
Email: sup035@ucsd.edu

Social worker: Tracey Truscott, MSW, LCSW
Phone: 858-249-0563
Email: ttruscott@ucsd.edu

Website: hd.ucsd.edu

There are three levels of center funding and designation.

Level one centers tend to be larger centers with a longer history of caring for individuals with HD. These sites collaborate with and/or nurture other developing centers in nearby regions.

Level two centers follow large numbers of patients, have a well established multidisciplinary team and active research programs.

Level three centers follow smaller numbers of patients and have at least one half day a month of a multidisciplinary HD specialty clinic.

Goals of the HDSA Center of Excellence Program

- Increase access to the best possible clinical care and services for individuals affected by Huntington's disease
- Provide professional and lay education in local geographic areas
- Be involved in HD clinical research.
- Work with HDSA locally and nationally in its efforts to continually improve the lives of those affected by HD and their families.

- Huntington's Disease is a rare disorder.
- Many general practitioners have never treated anyone with HD.
- Many general neurologists have only seen a few HD affected individuals over time.

- HD starts insidiously
- Symptoms include changes in:
 - Behavior
 - Motor function
 - Cognitive function
- Symptoms progresses continuously
- **Patient and family needs change over time.**

Huntington's Disease:

No two patient's symptoms present exactly the same.

No two families are the same.

No two communities are the same.

The heart of the COE program: A Multi-disciplinary team with experience in HD. (in alphabetical order)

- Genetic counselor
- Neurologist
- Nurse/Nurse Practitioner
- Nutritionist/dietician
- Occupational therapist
- Physical therapist
- Psychiatrist/neuropsychiatrist
- Psychologist/neuropsychologist
- Social Worker
- Speech therapist



Advantages of a specific designated multidisciplinary team

Familiarity with HD builds subspecialty expertise and stimulates HD specific research and interventions and preventative strategies.

Familiarity with individual clients and family members helps with understanding socio-dynamics..... facilitates cooperation and likelihood of compliance.

Proximity and direct interactions between team members increases exchange about HD patient specific needs and treatment strategies.

Knowledgeable primary subspecialty team can be a resource for training and referrals to off site providers.

HDSA Centers of Excellence

- No two HDSA COE's are the same
- Each medical center, each department, each state is different
 - What works in Columbus, Ohio may not work in Omaha, Nebraska or in Chicago, Illinois

Teamwork!

Social worker



Genetic counselor



Therapist

Psychiatrist

Neuropsychiatrist



Nurse

Therapist

The occasional roadblocks and caveats.

- Possible conflicts in billing issues if initial assessment is done in a center but patient lives far away and will need on going local therapy.
- Not all patients have coverage for all services.
- If all or even some patients see all providers, they may be in clinic all day! (patient/family burnout)
- Not all providers can always be present on the same day

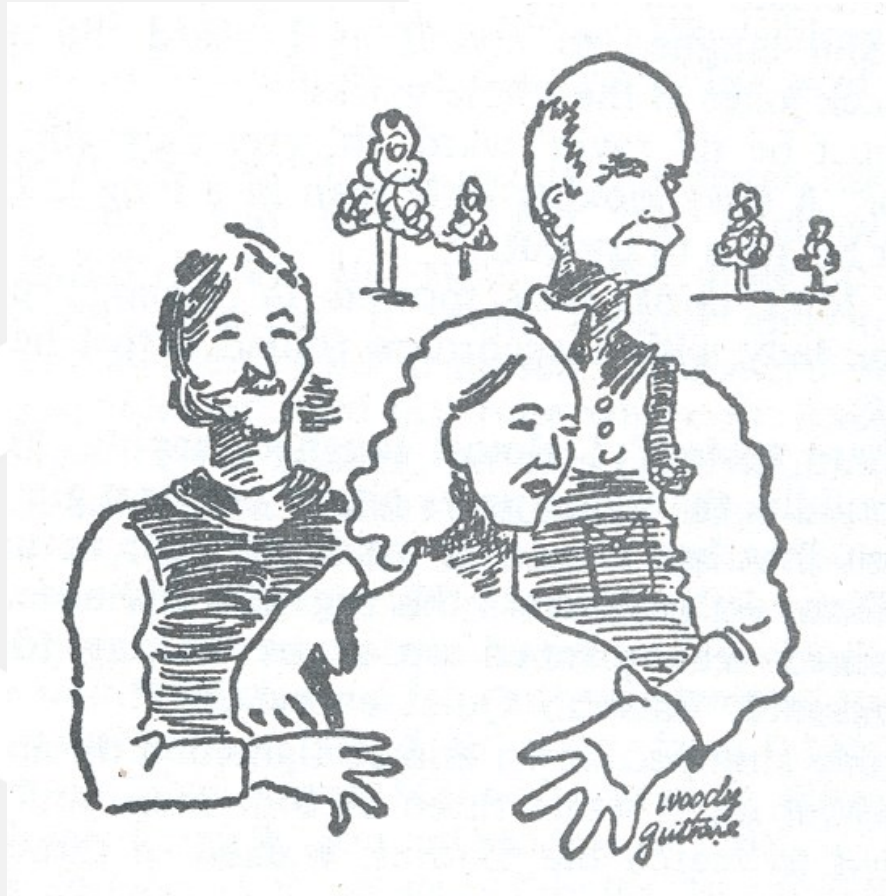
Access to research is central to the program

- The majority of patients want frequent updates on research.
- Participation in research offers hope.
- ENROLL-HD. A well characterized patient population --- Helps identify new biomarkers, helps track variations in disease progression, helps to get a jump on future clinical trials.
- HSG- participation in the Huntington Study Group research projects.
- Many centers also participate in industry or NIH sponsored research trials.
- Many centers initiate their own local clinical observational or treatment trials.

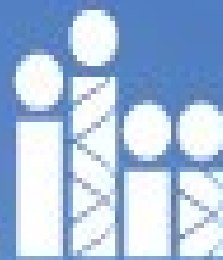
Things to do before a visit:

- Bring a list of current medications
- Keep a record of major medical problems, new medications and allergies, surgeries
- If there is a specific problem that needs to be addressed or answered, consider conveying this to the clinic team in advance so that they can be prepared to maximize help during or before the visit

Teamwork



Drawing by Woody Guthrie from “Bound for Glory” 1943



Huntington's Disease
Society of America

Centers of Excellence



Huntington's Disease
Society of America

Panel Discussion (Northwestern/Rush/Ohio State)

Questions

Audience Participation



Northwestern HD Clinic
Galter Pavilion
675 N Saint Clair, St 20-100
Chicago, IL 60611

Main Number: **(312) 695-7950**

Danny Bega, MD, MSCI

Shirley Ryan Abilitylab®



Trainee Research Projects

- **HD Caregiver Burden Survey**
 - Kenny Tan, clinical research fellow
 - What aspects of HD and the care giving responsibilities lead to the greatest difficulty and have the most impact on quality of life?
- **Impact of Family History on Clinical Features of HD**
 - Gabriel Kringlen, graduate student in genetic counseling, master's thesis
 - A positive family history of HD appears to be associated with an earlier onset of depression and overall disease manifestations independent of repeat length.

Annual Symposium: November 11th, 2017



Hope Through Education: Huntington's Disease Patient and Family Symposium



Hope Through Education: Huntington's Disease Patient and Family Symposium

*Sponsored by the Northwestern Medicine Parkinson's Disease
and Movement Disorders Center*

Huntington's Disease Support Group

***Unique group for people
who are “at-risk” and
pre-symptomatic***

Meets every other month

Contact: ezivin@hdsa.org



Rush University Medical Center HDSA Center of Excellence Chicago, IL

Clinic contacts:
312-563-2900
312-563-2030

movement_disorder@rush.edu

1725 W. Harrison Street, Suite
755, Chicago, IL 60612

www.rush.edu/huntingtons-disease



Huntington's Disease

Rush University Medical Center

The Rush Parkinson's Disease and Movement Disorders Program provides diagnosis and comprehensive treatment, research and clinical trial opportunities, and educational and support programs for patients and families living with Huntington's disease and those at risk for the disease.

The Huntington's disease program at Rush provides care for Huntington's at all stages of the disease through a holistic, comprehensive team approach.

Our program has been designated by the Huntington's Disease Society of America as a Center of Excellence since 2005. It was the first program in Illinois to receive this distinction.



Our goal is to serve patients and families affected by Huntington's at all stages of the disease. We provide the following services:

- New consultations and second opinions
- Follow-up care for patients who are symptomatic, who are at risk for developing the disease, or who have tested positive for Huntington's (or, gene positive) but are not yet symptomatic
- Predictive testing
- Genetic counseling
- Research and clinical trial opportunities
- Education and support

Our multidisciplinary team approach includes

- Movement disorder neurologists
- Psychiatrists
- Neuropsychologists
- Social workers
- Nursing
- Speech therapists
- Occupational therapists
- Physical therapists
- Nutritional counseling
- Palliative care services

HD research at RUSH COE

- ENROLL-HD study
 - HD, HD at risk, HD families, healthy controls
 - Annual visits
- Gait, balance, and cognition in HD
 - HD patients and healthy controls
 - Rush Master of Science graduate student and Rush Medical Student Dean's Fellowship awardee
- Biomarker studies in HD
 - DNA repository
 - Brain donation program

Education and support groups at RUSH COE

Please join us for a bimonthly support group for those impacted by HD as well as family and friends who are caring for a loved one or those who are at-risk for developing HD.

The fourth Tuesday of even months
7:00 p.m. to 8:30 p.m.

Free of charge

Tower Resource Center (Tower, 4th
Floor, Suite 04527)

1620 W. Harrison Street, Chicago

For more information, please call:
Sarah Mitchell at 1-312-942-6445

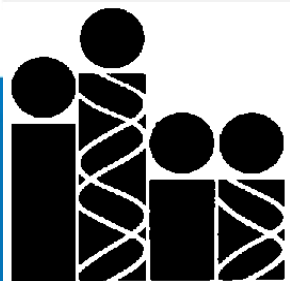
- Open to all whether you are at-risk, gene positive, currently have HD or are a family or friend of someone with HD
- Co-sponsored by Rush HDSA Center of Excellence, Rush Health and Aging, and Huntington's Disease Society of America Illinois Chapter



Wexner Medical Center

HDSA Center of Excellence at The Ohio State University Medical Center

- Allison Daley, CGC
- Erica Wright, LSW
- Anne Kloos, PT, PhD
- Megan Case, SP
- Theresa Berner, OT
- Kate Ambrogi, RN
- Jessica Truelove, CNP
- Ariane Park, MD, MPH
- Punit Agrawal, DO
- Deborah Keglemeyer PT, PhD
- Kate Brownlowe, MD
- Sandra Kostyk, MD, PhD



Huntington's Disease
Society of America



MEND Lab at The Ohio State University

Mobility and Exercise in Neurological Disorders Laboratory

Additional Videos

Our HD Exercise Program video created by the researchers in the MEND Laboratory at The Ohio State University with support from OSU Huntington's Disease Center of Excellence and the OSUMC Service Board, please click the link below

[HD Exercise Program Video](#)

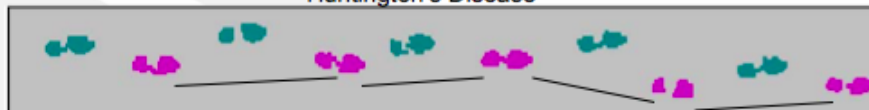
Dr. Deb Kegelmeyer's presentation on Quantitative biomechanical assessment of trunk control in Huntington's disease reveals more impairment in static than dynamic tasks.

[View Full Presentation](#)

Normal



Huntington's Disease



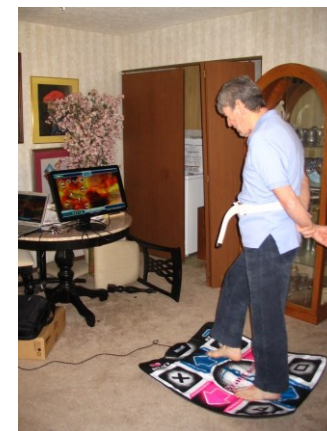
[GaitRITE](#) computerized walkway for analysis of Gait disorders



Article

Video game play (Dance Dance Revolution) as a potential exercise therapy in Huntington's disease: a controlled clinical trial

Anne D Kloos¹, Nora E Fritz¹, Sandra K Kostyk^{2,3}, Gregory S Young⁴ and Deb A Kegelmeyer¹



**CLINICAL
REHABILITATION**

Clinical Rehabilitation
0(0) 1-11
© The Author(s) 2013
Reprints and permissions:
sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/0269215513487235
cre.sagepub.com
SAGE

The Central Ohio HDSA Chapter

MONTHLY SUPPORT GROUP

2nd Thursday
of every month

1621 Francisco Rd.
Columbus, Ohio 43220

Barb Heiman
Social Worker and
Group Facilitator
614-390-8009

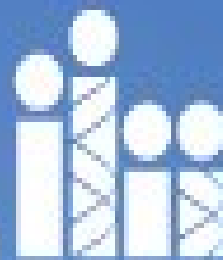
All are welcome!

Our monthly support group meeting is held at 7:00 PM on the second Thursday of each month at the Atonement Lutheran Church, 1621 Francisco Road, Columbus, Ohio 43220, which is in the northwest corner of Columbus. All are welcome!



Questions

Audience Participation



Huntington's Disease
Society of America

Centers of Excellence



Huntington's Disease
Society of America