



Getting Support and Staying Connected

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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

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

No relationships to disclose
or list



Welcome to HD SA!



The Huntington's Disease Society of America is the premier nonprofit organization dedicated to improving the lives of everyone affected by Huntington's disease.

From community services and education to advocacy and research, HD SA is the world's leader in providing help for today and hope for tomorrow for people with Huntington's disease and their families.

Defining Best Practice

- Identify and work with multidisciplinary care team
- Knowledge base of HD including:
 - Genetics, Research, Advanced Directives, State and federal insurances, Long term care, Family dynamics
- Provide Resources
 - Written materials
 - Support group information
- Provide in-services to LTC
- Promote Advocacy

Where to direct families for services?

- HDSA National Helpline
- HDSA Centers of Excellence
- HDSA Chapters



Huntington's Disease
Society of America

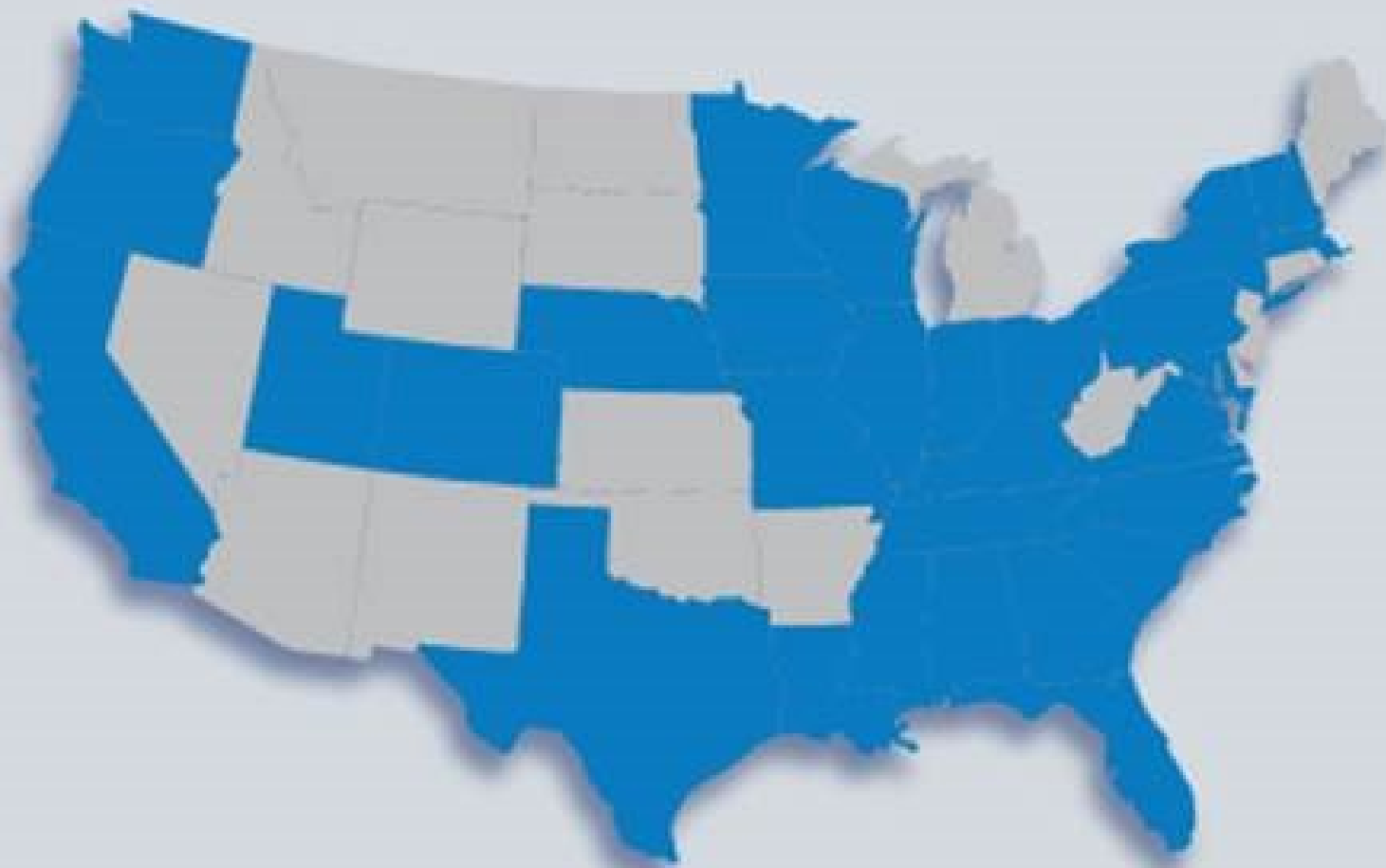
Centers of Excellence

HDSA has expanded its Centers of Excellence program to forty-three clinics across the nation.



Blue indicates states with HDSA Centers of Excellence





Blue indicates states with HD SA Centers of Excellence

Albany Medical College (NY)
 Beth Israel Deaconess Medical Center (MA)
 Cleveland Clinic (OH)
 Colorado Neurological Institute
 Columbia Health Sciences/NYS Psychiatric
 Institute (NY)
 Dartmouth-Hitchcock Medical Center (NH)
 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)
 Stanford University (CA)
 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 Nebraska Medical Center
 University of Pennsylvania
 University of Pittsburgh Medical Center (PA)
 University of Rochester (NY)
 University of South Carolina School of
 Medicine

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)

HDSA Center Of Excellence Partners
 Cole Neuroscience Center, University of
 Tennessee
 Kaiser Permanente
 Oregon Health Sciences University
 University of Tennessee, Erlanger Health
 System
 University of Mississippi Medical Center
 University of Alabama

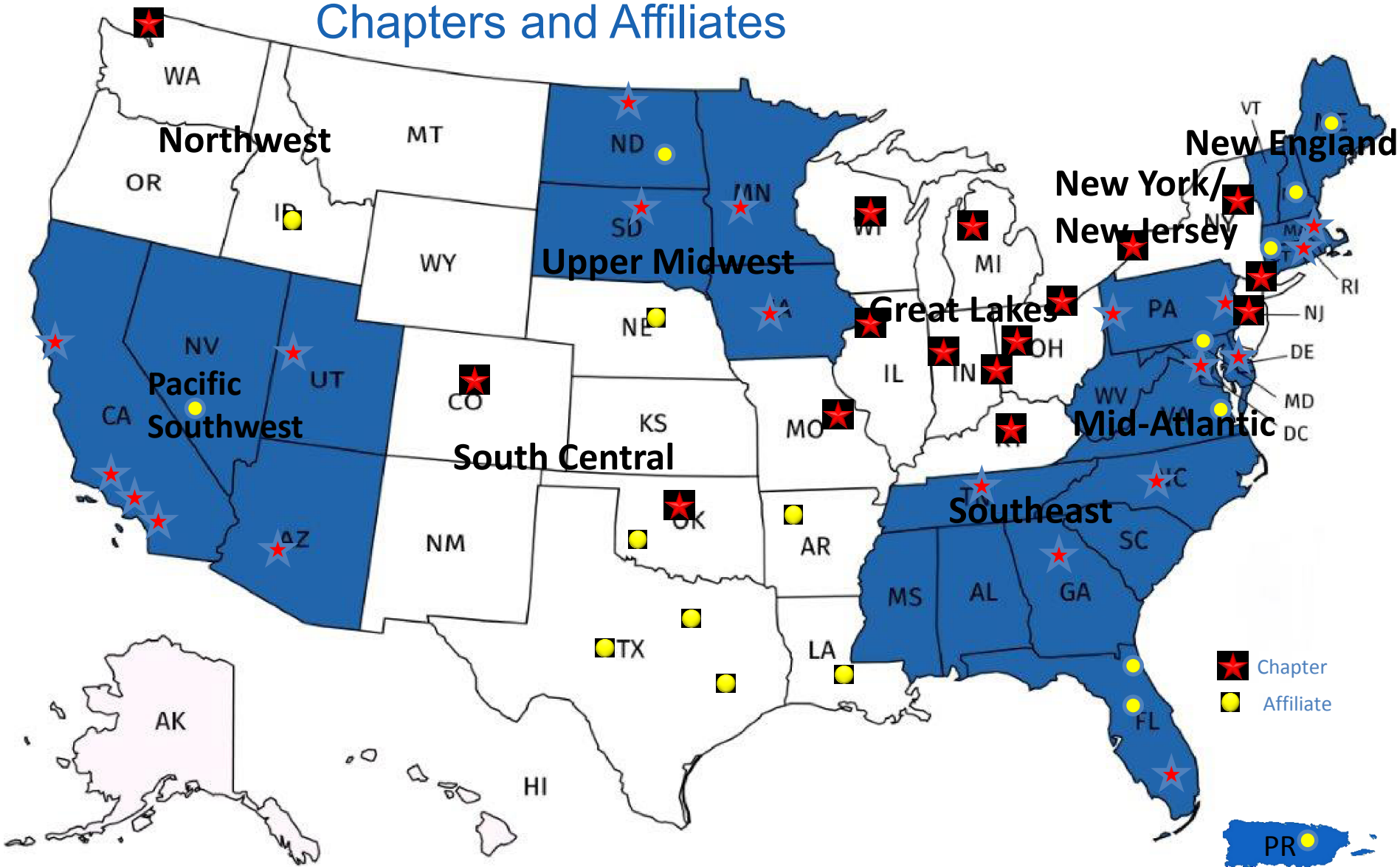
What is an HDSA Center of Excellence?

- The HDSA Centers of Excellence program was created to provide **comprehensive array of services** for HD families
 - **All** services are offered under one umbrella known as an “HDSA Center of Excellence.”
- The **heart** of the program: Multi-disciplinary team
- Access to research is **central** to the program
 - Two highest levels of funding require participation in research projects

Goals of the HDSA Center of Excellence Program

- **The 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 (HD) and their families through a geographically diverse network of local and/or regional clinical centers.
 - Provide professional and lay education in the geographic areas they serve.
 - 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.

Chapters and Affiliates



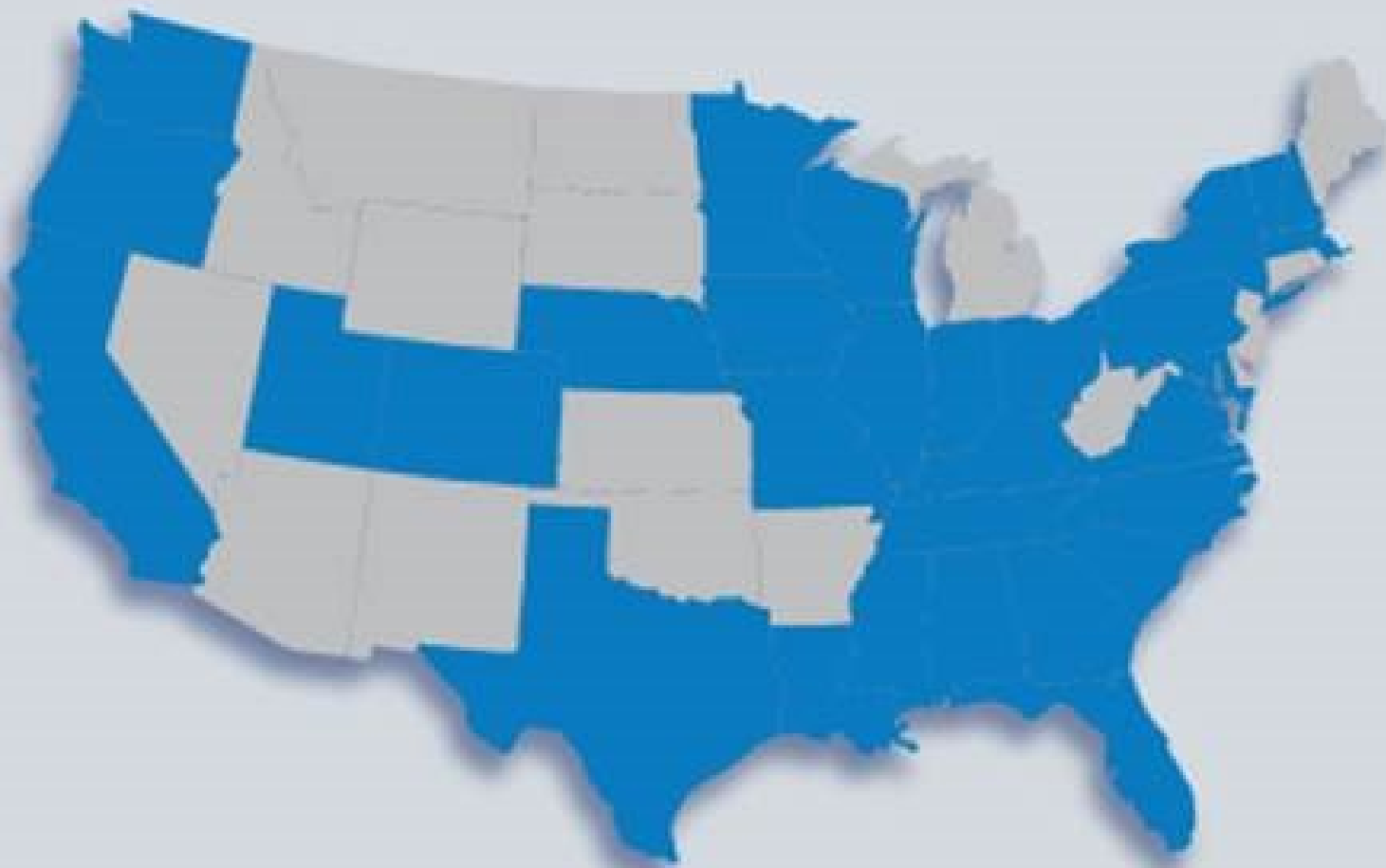
Chapters and Affiliates

- Tasked with organizing grassroots fundraising and awareness initiatives in their local communities
 - Team Hope walks
 - Hoopathons
 - Celebration of Hope dinners
- Educational events

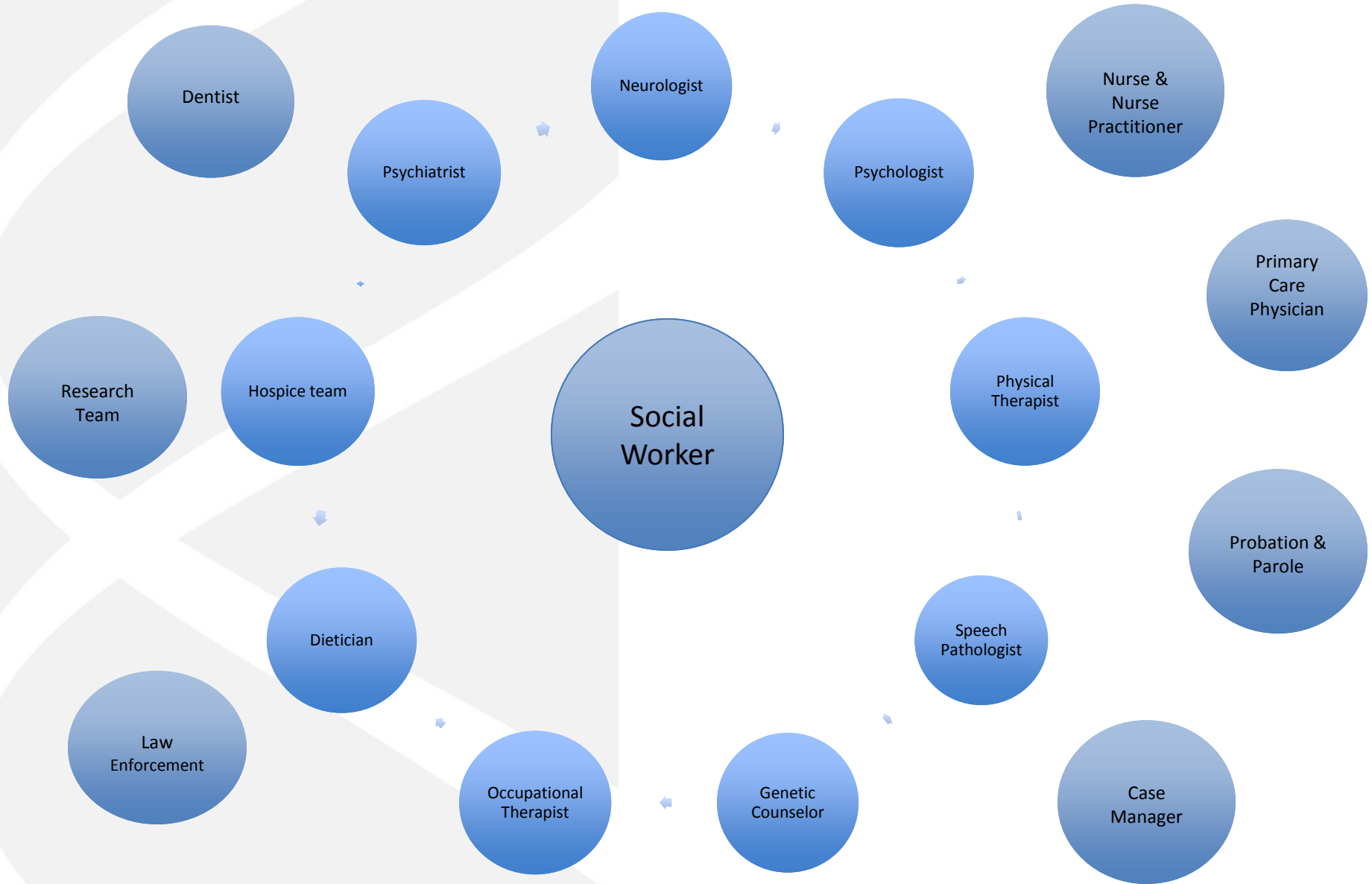
Social Workers at HD SA

HDSA Social Workers

- Three types of social workers:
 - Chapter/Affiliate/Regional Social Workers are hired through a local chapter, affiliate or region.
 - Center of Excellence Social Workers are hired through a Center of Excellence. They often work out of clinics.
 - Dual Social Workers work with both the Chapter and the Center of Excellence.



Blue indicates states with HD SA Centers of Excellence



Support Groups and Counseling

160 support groups across the country

Access list through <http://hdsa.org/about-hdsa/locate-resources/>

Online support groups through Support Groups Central

5 licensed HDSA social workers leading primarily caregiver groups

www.supportgroupscentral/hdsa.com

HD trained social workers and psychologists at American Well offering 8 free sessions to those with HD and their family

www.hdsa.amwell.com

HDSA Website

Resources and Tools

www.HDSA.org

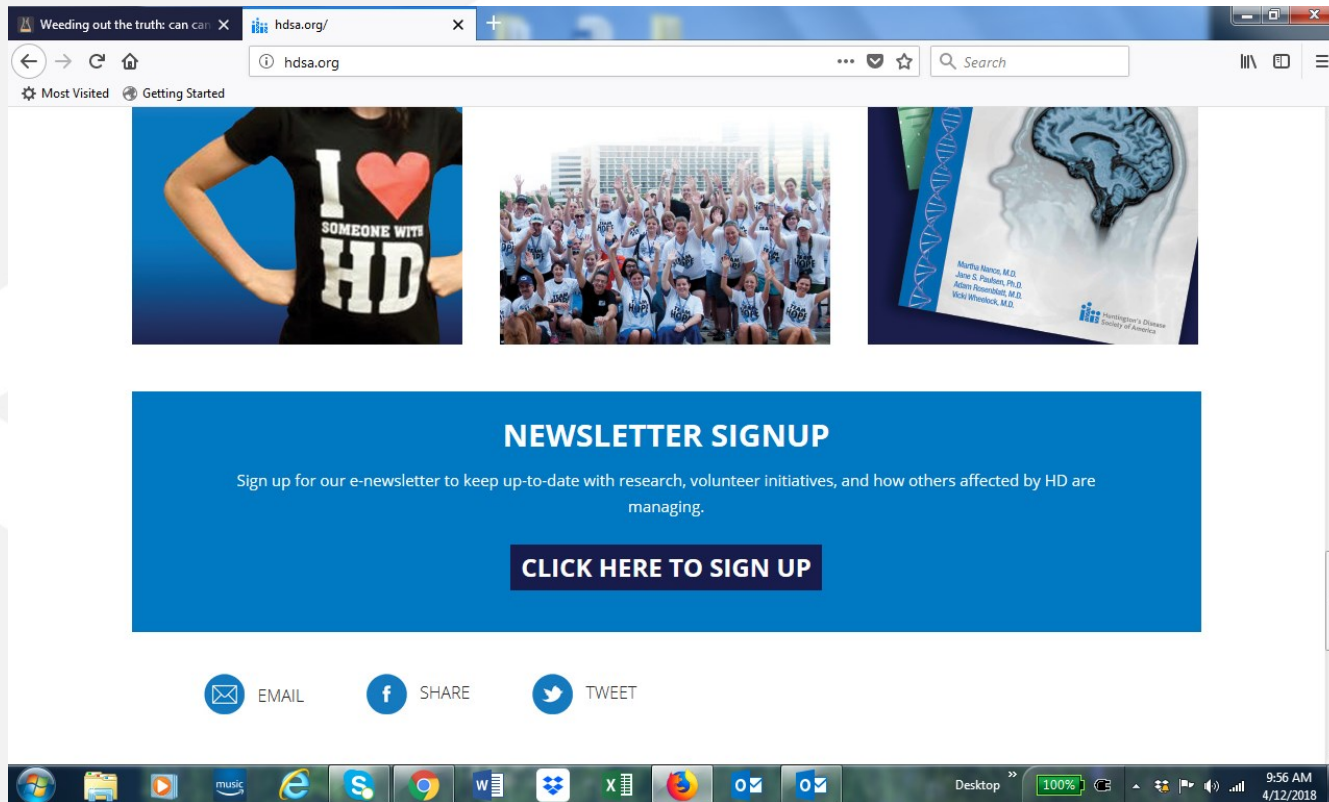
- On line publications may be downloaded and ordered
- Educational Guides
 - Caregiver Guide for Mid to Late Stage HD
 - Family Caregiver Guide
 - Law Enforcement Toolkit
 - Physician Guide
 - Understanding Behavior in HD
- Learn more about HD
 - Caregiver's Corner webinars- care management
 - Research webinars
- For healthcare professionals

Publications

- Educational Guides
 - Caregiver Guide for Mid to Late Stage HD
 - Family Caregiver Guide
 - Law Enforcement Toolkit
 - Physician Guide
 - Understanding Behavior in HD
- Pamphlets

Family Guide, Talking to Kids, Law Enforcement toolkit, Caregivers' guide to Communicating with Healthcare providers, Physical and Occupational Therapy, Speech-Language and Swallowing Difficulties, Genetic Testing

Sign up for Newsletter



Email Lists Include:

- Advocacy
- Educational Events
- Fundraising Events
- General Interest
- Research
- Team Hope

Enroll in a Clinical Trial



HDSA Programs and Services

Advocacy

- Speak up politically to improve access to care and benefits for individuals impacted by Huntington's disease at the national level. Advocacy is also educating legislators in the U.S. Congress about HD. Social workers working with HD families make great advocates. (Please review your institution's policy on using your work/edu address)
- **Introduce families to advocacy and help them have the opportunity to effect change for their families.**
- Go to www.hdsa.org/advocacy to learn more and download the tools you need to participate
- Contact Jennifer Simpson at jsimpson@hdsa.org or by phone at 800-345-4372 ext 226



National Youth Alliance



Educational Events

- Many Chapters and Centers of Excellences offer educational events to provide information on HD to people in the area.
 - This can happen as a joint venture.
- HDSA has grants available to support local educational events.
- Educational events are an excellent opportunity for regional social workers (Center of Excellence and Chapter) to build relationships with other HD-knowledgeable clinics.
- For more information on education events, please contact Deb Lovecky at dlovecky@hdsa.org.

Main Contact Information

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