

# Huntington's Disease:

## Care, Information, Education and Support:

### **Huntington's Disease Society of America:**

<http://www.hdsa.org>

### **Caring Voice Coalition:**

\*\* Assistance with medicine co-pays and disability applications.

<http://www.caringvoice.org/supported-diseases/huntingtons/>

### **HD Lighthouse Families:**

<http://www.hdff.org/welcome>

### **Help 4 HD:**

Support, information, and education re HD management, research and resources.

<https://help4hd.org>

### **Help 4 HD Radio:**

<https://help4hd.org/help-4-hd-radio>

### **Chorea Matters:**

\*\* Lunbeck website regarding chorea and how to treat it. If you sign up, you get a free recipe cookbook geared toward HD nutrition.

<http://www.choreamatters.com/Default.aspx>

### **HD Youth Organization (If you are young and at risk or have HD, this is a great website!):**

<http://en.hdyo.org/you>

### **HDSA Webinars:**

<http://hdsa.org/living-with-hd/caregivers-corner-webinars>

### **The International Huntington Association:**

<http://www.huntington-assoc.com>

### **HD and Sexuality:**

[https://www.huntingtonsvic.org.au/virtual-library/resources-list/doc\\_view/103-information-sheet-13-sex-sexuality-and-huntington-s-disease](https://www.huntingtonsvic.org.au/virtual-library/resources-list/doc_view/103-information-sheet-13-sex-sexuality-and-huntington-s-disease)

### **HD Identification Bracelets:**

<https://interland3.donorperfect.net/weblink/weblink.aspx?name=E5596&id=150>

## Medical Care and Genetic Counseling- Northern California:

### **UCSF Memory and Aging Center Huntington's Disease and Ataxia Clinic**

<http://memory.ucsf.edu/patientcare/neurogenetics>

### **Stanford Huntington's Disease and Ataxia Clinic**

<https://stanfordhealthcare.org/medical-clinics/movement-disorders-center/huntingtons-disease-ataxia-clinic.html>

### **UC Davies Huntington's Disease Clinic**

<https://www.ucdmc.ucdavis.edu/huntingtons>

## Written Materials:

### **Educational Publications about HD:**

<http://hdsa.org/shop/publications>

### **In Person Support Groups:**

### **California & National:**

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

### **CA Support Groups for people with HD and their care partners:**

[2018 HD Support Group.pdf](#)

## Online Counseling and Support:

### **Free Online Counseling Sessions for People with HD and their family caregivers (NEW!):**

<https://www.americanwell.com/press-release/huntingtons-disease-society-of-america-launches-first-of-its-kind-free-telehealth-counseling-for-hd-families/>

### **HDSA Online Support Groups (NEW!)**

[https://www.supportgroupscentral.com/groups\\_detail\\_as.cfm?cid=27&CFID=46719556&CFTOKEN=84a6459652a1a375-E5DDFA2E-BAAA-C092-301F321A24B01A8B](https://www.supportgroupscentral.com/groups_detail_as.cfm?cid=27&CFID=46719556&CFTOKEN=84a6459652a1a375-E5DDFA2E-BAAA-C092-301F321A24B01A8B)

## HD Care:

### **HD Physician's Reference Guide**

[http://hdsa.org/wp-content/uploads/2015/03/PhysiciansGuide\\_3rd-Edition.pdf](http://hdsa.org/wp-content/uploads/2015/03/PhysiciansGuide_3rd-Edition.pdf)

**Understanding Behavior in HD**

<http://hdsa.org/wp-content/uploads/2015/03/Understanding-Behavior.pdf>

**A Caregiver's Handbook to Late Stage HD:**

<https://www.huntingtonsnsw.org.au/sites/default/files/Care%20Giver%20Handbook.pdf>

**Health Insurance:**

**Genetically Handicapped Persons Program (GHPP)**

<http://www.dhcs.ca.gov/services/ghpp/Pages/default.aspx>

**Safety:**

**Driving and HD:**

[http://web.stanford.edu/group/hopes/cgi-bin/hopes\\_test/driving-and-huntingtons-disease/](http://web.stanford.edu/group/hopes/cgi-bin/hopes_test/driving-and-huntingtons-disease/)

**Law Enforcement Training Guide:**

<http://hdsa.org/wp-content/uploads/2015/05/HDSA-LET-Guide1.pdf>

**Research Information:**

**Trial Finder: Information on research trials currently recruiting.**

<http://www.hdtrialfinder.org>

**HD Buzz:**

International HD science articles authored by scientists for a lay audience. Has an RSS feed.

All recent articles (with subject tags linking to other related articles):

<http://en.hdbuzz.net>

**CHDI:**

A US non-profit biomedical foundation that aims to "rapidly discover and develop drugs that delay or slow the progression of [Huntington's disease](#)"

<http://chdifoundation.org>

**HOPES:**

HOPES is a student-run project at Stanford University dedicated to making scientific information about Huntington's disease (HD) more readily accessible to patients and the public. Our goal is to survey the rapidly growing scientific and clinical literature on Huntington's disease, and to present this information in a coherent, reliable web resource.

<http://www.stanford.edu/group/hopes/cgi-bin/wordpress>

**HD NEWS:**

<https://huntingtonsdiseasenews.com/>

**Documentaries:**

"Her Mother's Daughter"

<http://hdsa.org/hmdfilm/>

"The Lion's Mouth Opens"

<http://www.lucywalkerfilm.com/THE-LION-S-MOUTH-OPENS>

"Huntington's Dance" by Chris Furbee

<http://www.huntingtonsdance.org>

We Have A Face

<http://www.wehaveaface.org>

Twitch

<http://twitchdocumentary.com>

**Past Events:**

**HD Symposium Nov. 19, 2016/ UCSF:**

[2016 HD Research Symposium Agenda.pdf](#)

**HD Events around the US:**

<http://hdsa.org/events>

**HD Symposium 2013/ UCSF:**

Live talks addressing HD research updates and practical tips for care:

<http://memory.ucsf.edu/blog/10th-annual-huntington-disease-research-symposium-611>