

## Internet Resources for HD

<b>Huntington's Disease Society of America (HDSA)</b>	<a href="http://www.HDSA.org">www.HDSA.org</a>	Provides information and links to all issues related to HD from family support resources to research.
<b>HDSA Northern California Chapter</b>	<a href="http://www.hdsa.org/nocal">www.hdsa.org/nocal</a>	Local Chapter website for HDSA provides information and links regarding local events & resources.
<b>HDSA Center of Excellence @ UC Davis</b>	<a href="http://www.ucdmc.ucdavis.edu/huntingtons/">www.ucdmc.ucdavis.edu/huntingtons/</a>	Information and links to all issues related to HD from HD 101, Cognition, Behavioral Health, Caregiver Resource, Support Groups, Physical Therapy, Genetics, etc.
<b>Huntington Study Group</b>	<a href="http://www.huntington-study-group.org">www.huntington-study-group.org</a>	Information about research and HD basics.
<b>Huntington's Outreach Project for Education (HOPES) @ Stanford</b>	<a href="http://web.stanford.edu/group/hopes/cgi-bin/hopes_test/">http://web.stanford.edu/group/hopes/cgi-bin/hopes_test/</a>	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.
<b>Help 4 HD International</b>	<a href="https://help4hd.org/">https://help4hd.org/</a>	Help4HD is focused on helping HD families by bridging communications and partnering with institutions, industry, and professionals from every discipline. Help4HD's philosophy is always, "Family First".
<b>Huntington's Together</b>	<a href="https://www.huntingtonsdisease.com/">https://www.huntingtonsdisease.com/</a>	This website developed by Genentech in collaboration with professionals and HD community has videos, resources, practical tips covering topics of Understanding HD, Living with HD, Caring for HD and Treating HD.



### Genetics

<b>Council for Responsible Genetics</b>	<a href="http://www.councilforresponsiblegenetics.org/">http://www.councilforresponsiblegenetics.org/</a>	A non-profit, non-governmental organization that fosters public debate about the social, ethical and environmental implications of genetic technologies.
<b>HD Free with PGD</b>	<a href="http://www.hdfreewithpgd.com/">www.hdfreewithpgd.com/</a>	Information regarding pre-implantation genetic diagnosis (PGD) and in-veto fertilization (IVF)
<b>National Human Genome Research Institute</b>	<a href="http://www.genome.gov">www.genome.gov</a>	Genetic discrimination and GINA; policy and legislation; issues in genetics; database of Federal and State laws related to genetics.



## Mental Health Resources

**Mental Health America**

[www.nmha.org](http://www.nmha.org)

Website dedicated to promoting mental wellness through advocacy, education, research and services.

**National Alliance on Mental Illness**

[www.nami.org](http://www.nami.org)

Easy-to-understand information about mental illnesses, mental health care, diagnosis, treatment and recovery.

**National Suicide Prevention Lifeline**

[www.suicidepreventionlifeline.org](http://www.suicidepreventionlifeline.org)

Information on getting help, suicide warning signs, and resources.



## Research

**HD TrialFinder**

[www.hdtrialfinder.org](http://www.hdtrialfinder.org)

HDTrialFinder.org will allow you to set up a profile with your general information which will do a database search for any research studies or opportunities you may be eligible for.

**HDSA Center of Excellence @ UC Davis**

[www.ucdmc.ucdavis.edu/huntingtons/](http://www.ucdmc.ucdavis.edu/huntingtons/)

Information about current HD research opportunities at UC Davis HDSA Center of Excellence.

**HDBuzz**

<http://en.hdbuzz.net/>

Information regarding Huntington research. Site written by scientists in easy to understand terms specifically for the HD community.

**Huntington Study Group**

[www.huntington-study-group.org](http://www.huntington-study-group.org)

Information about research, clinical trials and HD basics.



## Caregiver

**AARP – resources for Caregivers and Family**

<https://www.aarp.org/caregiving/>

Provides information, support and guidance for family and professional caregivers. Website offers topics in regards to safety, home assessments, smart home technology and coping.

**Family Caregiver Alliance**

[www.caregiver.org](http://www.caregiver.org)

Information on various caregiver topics including, Grief and Loss, Taking Care of Yourself, Community Care Options, Long Term Care, Advance Care Planning, Caregiver Tips, Legal Issues, etc.



## Advance Care Planning

<b>Caring Connections</b>	<a href="http://www.caringinfo.org">www.caringinfo.org</a>	Information about planning for the future, caring for someone, talking with loved ones and grieving a loss.
<b>Center for Health Care Decisions</b>	<a href="http://chcd.org/">http://chcd.org/</a>	Information and publications about end of life issues.
<b>Coalition for Compassionate Care of California</b>	<a href="http://coalitionccc.org/">http://coalitionccc.org/</a>	Information and resources regarding Advance Care Planning and Public Policy relating to end of life.
<b>Harvard Brain Tissue Resource Center</b>	<a href="http://www.brainbank.mclean.org">www.brainbank.mclean.org</a>	Information about how to be a brain donor and how the brain tissue is used and distributed.



## Financial & Insurance

<b>California Department of Health Care Services</b>	<a href="http://www.dhcs.ca.gov">www.dhcs.ca.gov</a>	Information & application forms for Medi-Cal, Genetically Handicapped Persons Program (GHPP) and California Children's Services (CCS)
<b>California Employment Development Department (EDD)</b>	<a href="http://www.edd.ca.gov">www.edd.ca.gov</a>	Information and applications for State Disability and Paid Family Leave
<b>California Registry</b>	<a href="http://www.calregistry.com/resources/medicare.htm">http://www.calregistry.com/resources/medicare.htm</a>	Offers fact sheets and information about How Medicare Works
<b>Health Insurance Counseling and Advocacy Program (HICAP)</b>	<a href="http://www.cahealthadvocates.org">www.cahealthadvocates.org</a>	Information about Medicare, Long Term Care Insurance and other insurance issues affecting disabled and elderly.
<b>Social Security Administration</b>	<a href="http://www.ssa.gov">www.ssa.gov</a>	Information and application forms for Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), and Medicare.
<b>U.S. Department of Labor, Wage and Hour Division</b>	<a href="http://www.dol.gov/whd/fmla/">http://www.dol.gov/whd/fmla/</a>	Information regarding the Family Medical Leave Act of 1993.



## Podcasts, Recorded Webinars, YouTube Videos, etc

You may find some past recorded webinars, education conferences, etc. on a variety of topics to offer good information. The following resources are for information and education only and do NOT replace the need to consult your medical provider regarding specific needs or treatment options for you or your family.

<b>Huntington's Disease Society of America</b>	<a href="http://www.hdsa.org">www.hdsa.org</a>	Go to <a href="https://hdsa.org/hdsa-me/">https://hdsa.org/hdsa-me/</a> <a href="http://hdsa.org/about-hdsa/annual-convention/">http://hdsa.org/about-hdsa/annual-convention/</a> (scroll to bottom to see past convention recorded sessions)
<b>Help4HD</b>	<a href="http://www.help4hd.org">www.help4hd.org</a>	Help4HD Live is an internet radio show and Help4HD TV is a video show both our topic specific and explore a variety of topics related to HD.
<b>Stanford HOPES</b>	<a href="https://hopes.stanford.edu/other-resources/hopes-podcast/">https://hopes.stanford.edu/other-resources/hopes-podcast/</a>	Podcasts with real HD stories and discussion with families and professionals.
<b>YouTube</b>	<a href="http://www.youtube.com">www.youtube.com</a>	Do a search on Huntington's Disease or the symptoms topic (depression, anxiety, cognition, chorea, etc)
<b>HD Insights Podcast by Huntington's Study Group (HSG)</b>	<a href="https://huntingtonstudygroup.org/hd-insights-podcast/">https://huntingtonstudygroup.org/hd-insights-podcast/</a>	<b>HD Insights</b> is designed to promote, disseminate, and facilitate research and science education in HD by producing informative content that will be valuable to the global community of HD.