

On-Line Resources for HD

<i>General Information About Huntington's Disease</i>		
Huntington's Disease Society of America (HDSA)	www.HDSA.org	This website provides information and links to all issues related to HD from understanding HD, living with HD, genetics, family care and research.
Huntington's Disease Society of America–Northern California Chapter	www.hdsa.org/ncach	This is the Local Chapter website for HDSA and provides information and links regarding support groups, clinical trials, events and living with HD resources.
HD Lighthouse	www.hdlighthouse.org	Provides information about HD, treatment and care, diagnosis, reseach and HD community.
Huntington's Disease Advocacy Center	www.hdac.org	Offers a information on a variety of topics: living with HD, caregiving, genetic testing, etc. They also have online support.
Huntington Study Group	www.huntington-study-group.org	Information about research and HD basics.
Huntington's Outreach Project for Education at Stanford (HOPES)	http://hopes.stanford.edu/	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. Information on variety of topics including: the causes and symptoms of Huntington's disease; existing drug and supplement options for those diagnosed with Huntington's disease; recent advances in Huntington's disease research; lifestyle choices for managing Huntington's disease.
Lundbeck, Inc	www.choreamatters.com	Website designed by Lundbeck, Inc. Has information about HD symptoms, understanding chorea and how to talk to your MD about HD symptoms.

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<i>Genetics</i>		
Council for Responsible Genetics	www.councilforresponsiblegenetics.org	A non-profit, non-governmental organization that fosters public debate about the social, ethical and environmental implications of genetic technologies.
HD Free with PGD	www.hdfreewithpgd.com/	Information regarding pre-implantation genetic diagnosis (PGD) and in-veto fertilization (IVF)
National Human Genome Research Institute	www.genome.gov	Genetic discrimination and GINA; policy and legislation; issues in genetics; database of Federal and State laws related to genetics.
National Institute of Health – Office of Legislative Policy and Analysis	www.olpa.od.nih.gov	Bill tracking; public laws; legislative hearings
<i>Managing Behavior</i>		
International Foundation for the Education and Research of Depression	www.ifred.org	Information about the causes of depression, support for those dealing with depression, and to combat the stigma associated with depression.
Mental Health America	www.nmha.org	Website dedicated to promoting mental wellness through advocacy, education, research and services.
National Alliance on Mental Illness	www.nami.org	Easy-to-understand information about mental illnesses, mental health care, diagnosis, treatment and recovery.
National Suicide Prevention Lifeline	www.suicidepreventionlifeline.org	Information on getting help, suicide warning signs, and resources.

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<i>Nutrition and Swallowing</i>		
Huntington's Disease Society of American (HDSA)	www.HDSA.org	Information about Nutrition and Swallowing for HD patients.
<i>HD Research</i>		
European Huntington's Disease Network	www.euro-hd.net	Information about research and clinical trials for HD.
HD Trials	www.hdtrials.org	HDTrials.org web site will provide quick notification to Huntington families of opportunities for participation in clinical trials and studies through a confidential email list.
CHDI Foundation	www.highqfoundation.org	CHDI is a private, non profit research organization that works with an international network of scientists to discover drugs that slow the progression or delay the onset of HD.
UC Davis Stem Cell Therapy Lab--Jan Nolte	www.jannolta.com	Information regarding the advances in Stem Cell Therapy.
HDBuzz	hdbuzz.net	Information regarding huntington research. Site written by scientists in easy to understand terms specifically for the HD community.
California Institute for Regenerative Medicine (CIRM)	www.cirm.ca.gov	Information regarding the latest stem cell research and findings.
Huntington Study Group	www.huntington-study-group.org	Information about research, clinical trials and HD basics.

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Kids and HD		
Hospice Net	www.hospicenet.org	Information for families dealing with a life threatening family illness. Topics include coping, advance care planning, family medical leave, caregiving, etc.
Huntington Disease Association, UK	www.hda.org.uk/download/fact-sheets/HD-Talking-To-Children.pdf	Recommended answers to some questions children might ask.
Huntington's Disease Youth Organization (HDYO)	www.HDYO.org	The site gives support, provides education and offers motivation to get involved for children and young adults.
Talking to Kids About Huntington's Disease	www.talkingtokidsabouthd.com	Information about the book, author and opportunity to purchase book.
Caregiver Resources		
Caregivers Media Group: Today's Caregiver	www.caregiver.com	Provides information, support and guidance for family and professional caregivers. Website offers topic specific newsletters, online discussion lists, back issue articles of <i>Today's Caregiver</i> magazine, chat rooms, etc.
We Move	http://www.mdvu.org/downloads/HD_CGG_4.pdf	Caregiver's Guide to HD. Has useful information about how to talk with MDs, where to seek support, long term care, etc.
Family Caregiver Alliance	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.

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<i>Advance Care Planning</i>		
Aging with Dignity, 5 wishes	www.agingwithdignity.org	Information regarding how to express, discuss and document your wishes as you age.
National Academy of Elder Law Attorney's, Inc	www.naela.org	Information on Elder Law Attorney's and Estate Planning.
California Hospital Association	www.calhospital.org/public/advance-health-care-directive	Blank California Advance Health Care Directive and instructions to complete.
Caring Connections	www.caringinfo.org	Information about planning for the future, caring for someone, talking with loved ones and grieving a loss.
Center for Health Care Decisions	www.sacdecisions.org	Information and publications about end of life issues.
Coalition for Compassionate Care of California	http://coalitionccc.org/	Information and resources regarding Advance Care Planning and Public Policy relating to end of life.
Harvard Brain Tissue Resource Center	www.brainbank.mclean.org	Information about how to be a brain donor and how the brain tissue is used and distributed.
UC Davis Donated Body Program	www.ucdmc.ucdavis.edu/cellbio/donatedbodyprogram/	Information about how to donate your body to medical science.
UCSF Willed Body Program	http://anatomy.ucsf.edu/WBP/index/html	Information about how to donate your body to medical science.
Golden State Donor Services	www.gsds.org	Information about how to become an organ donor.
California Transplant Donor Network	www.ctdn.org	Information about how to become an organ donor.
Donate Life California	www.donatelifecalifornia.org	Website for California organ donor registry

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Benefits: Financial and Insurance		
California Department of Health Care Services	www.dhcs.ca.gov	Information and application forms for Medi-Cal, Genetically Handicapped Persons Program (GHPP) and California Children's Services (CCS)
California Employment Development Department (EDD)	www.edd.ca.gov	Information and applications for State Disability and Paid Family Leave
California Registry	http://www.calregistry.com/resources/medicare.htm	Offers fact sheets and information about How Medicare Works
Caring Voice Coalition	http://caringvoice.org	Programs include: financial assistance programs, insurance education and counseling and patient support program for persons affected with serious, chronic disorders.
Health Insurance Counseling and Advocacy Program (HICAP)	www.cahealthadvocates.org	Information about Medicare, Long Term Care Insurance and other insurance issues affecting disabled and elderly.
Long Term Care Insurance National Insurance	www.longtermcareinsurance.org	Website providing information and long term care insurance resources.
Social Security Administration	www.ssa.gov	Information and application forms for Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), and Medicare.
U.S. Department of labor, Employee Benefits Security Administration	www.dol.gov/ebsa	Information regarding Consolidated Omnibus Budget reconciliation Act (COBRA).
U.S. Department of Labor, Wage and Hour Division	www.dol.gov/whd/	Information regarding the Family Medical Leave Act of 1993.