

We Are HDSA!



Huntington's Disease
Society of America

Support Group Newsletter • www.hdsa.org • (800) 345-HDSA • Issue 3, April 2012

HDSA Information

Short Survey

HDSA's Long Term Care Workgroup invites the Huntington's disease community to take a short survey to gather information about insurance, employment and long-term care.

The results will be used to provide information about the kind of health insurance people with HD currently have, how many in the HD community have long-term care insurance, and will be used to help identify the barriers families encounter in placing loved ones in residential facilities.

The HDSA Long-Term Care Workgroup will release a Report to the Field in late 2012 that will contain short and long term recommendations in the areas of care, education and public policy.

To take the survey, please use the following link:
www.hdsa.org/lcworkgroup

Thank you for taking the time to assist the HDSA Long-Term Care Workgroup. Your help is greatly appreciated.

Talking to Employers

Workplace Accommodations for Huntington's Disease (HD)

By the Job Accommodation Network

People with HD often find themselves having issues at work due to their medical condition. Before these issues become too serious, employees may want to request reasonable accommodations under the Americans with Disabilities Act (ADA). The ADA is a federal law that requires covered employers to accommodate qualified individuals with disabilities. Reasonable accommodation is defined as any modification or adjustment to a job or the work environment that makes it possible for an individual with a disability to perform the essential functions of a job or enjoy employee benefits or privileges. Reasonable accommodations include, for example, modifying facilities, job restructuring, modifying schedules, work from home, or use of leave.

Timing of an accommodation request is important. You should request an accommodation before performance or conduct suffers because employers do not have to rescind disciplinary actions (including termination) that occur before an accommodation request is made.

To request an accommodation, you need to notify your employer that a change or adjustment at work is needed due to a medical reason. There is no need to use ADA language; "plain English" is enough. Although not required, you might want to make your request in writing so you have documentation. You should also know that when you make an accommodation request, your employer is entitled to medical documentation that shows you have a disability and need the requested accommodation because of the disability.

As mentioned above, there are various types of accommodations that are considered reasonable under the ADA, but there are some things employers do not have to do. Employers never have to remove essential functions (primary duties), lower production or qualification standards, or provide an accommodation that poses an undue hardship (meaning excessively costly, disruptive, or alters the nature/operation of a business).

Once you ask for an accommodation, your employer should determine if the accommodation can be provided. If your employer denies your initial request, find out why so you can provide alternative ideas. And keep in mind, under the ADA, the employer ultimately decides what accommodation to implement; the employer does not have to provide your preferred accommodation, as long as the accommodation provided is effective.

Once your accommodation is in place, you are responsible for letting your employer know if it does not work so other options can be explored. Also, if you later realize that you need another accommodation, repeat the above process. The duty to accommodate is ongoing, so you are not limited to a single accommodation.

If you have questions or concerns about asking for reasonable accommodations, JAN can help guide you before you approach your employer. You can contact **JAN at (800)526-7234 (Voice), (877)781-9403 (TTY), or visit the JAN Website at AskJAN.org.**

For accommodation ideas, see Job Accommodations for People with Huntington's Disease at AskJAN.org/media/eaps/employmenthdEAP.doc.

Also see: Ideas for Writing an Accommodation Request Letter at AskJAN.org/media/accommrequestltr.html

HDSA Educational Grants Program:

HDSA is pleased to announce the renewal of the grant program designed to help support HDSA field-based educational events, including guest speakers for support groups in 2012. To apply for an educational grant, please contact Deb Lovecky at Dlovecky@hdsa.org or Jane Kogan at Jkogan@hdsa.org.

Upcoming Education Days:

April 21:

Wisconsin Chapter

May 5:

Northern California Chapter

May 20:

New Jersey Chapter

HDSA Disability Portal:

To find out more about applying for Social Security Disability, please visit the disability section of the HDSA National Website at www.hdsa.org/disability. Have feedback? Contact Jane Kogan at jkogan@hdsa.org.

By Karen Tarapata

It is true. Over time, HD changes everything. Living with HD – whether as the person with the disease, a family member, caregiver or friend – causes the gradual transformation of many things the average person can take for granted – health, independence, family stability and companionship. These changes are profound and they can trigger intense emotions, including grief.

There is a phrase called “disenfranchised grief,” which is bereavement that is not acknowledged by society. Many of the gradual losses that occur in HD fall in this category, including:

- The inability to talk freely about your fears for the future. You may worry that others think you are predicting trouble that may never come or that sharing will result in discrimination.
- The loss of healthy relationships with our families, friends, & even casual acquaintances and coworkers as HD lessens an individual’s emotional and social abilities, or the stresses of caregiving reduce time and patience with others.
- Social awkwardness when others don’t know how to respond to HD or when they avoid the topic altogether.
- Sadness at seeing a spouse, partner, parent, or friend change as a result of the disease. The individual is alive but the relationship is very different.
- The loss of hopes and dreams such as growing old together, playing with grandchildren, traveling, etc.

Modern society has no patience or time for grief. There are no sympathy cards for the loss of health, independence or companionship. The world’s focus seems always to be on “staying upbeat” and “moving on.” How unrealistic. Grief is a natural human reaction to loss, and even the most positive person will experience moments of grief, especially when faced with the alternations to life caused by HD.

Always putting a brave face on things can feed a tendency to bury feelings of grief, as if that is the best thing to do; as if you don’t deserve to mourn for what has been lost. Your former life, hopes, plans and dreams had value and you have a right to grieve for the your losses. Feeling sadness and anger of grief is not the same as giving in or giving up. Grief acknowledges and honors what has changed. Hope provides the path forward.

Our HD community can provide you with support and guidance on ways to manage your feelings of grief. There are forums and chat rooms on the internet where you can talk with others living with Huntington’s disease. You may want to participate in an HD Support Group. It may be helpful to talk with a counselor, a pastor, or an HD social worker. If you don’t know of someone to talk to, ask your doctor or social worker for suggestions. The important thing is to know that you are not alone in your feelings.

If you are not ready to talk about your feelings, that is perfectly alright. Writing can be a private way to explore your feelings. You could write a letter to yourself about the losses you have experienced and how they make you feel. You could create a collage of what you thought your life would be and then bury it. You could write the angriest letter to God and then burn it. It’s up to you. No other person can tell you how to grieve.

(Continued on page 3)

Caregiver's Corner:**April 24**

Diagnosing JHD

Dr. Martha Nance

Going Green!

Want We Are HDSA! delivered right to your inbox? Then sign up for the e-mail edition version of We Are HDSA!. For more information or to sign up, please contact Seth J. Meyer at smeyer@hdsa.org. To read past issues of We Are HDSA!, visit the HDSA website at www.hdsa.org.

Myths about HD

HDSA is researching myths and misinformation about HD. If you have recently heard any myths or misinformation about HD, please fill out the survey at www.hdsa.org/myths. The information gathered will be used for future initiatives.

Acknowledging that you feel grief and that it is worthy of time and space may help prevent these feelings from become overwhelming. If your grief feels out of control, talk to your doctor right away. There may be treatments that can help.

Staying healthy can also help you manage your feelings. Movement and exercise are natural anti-depressants. You will be better able to handle hard times and emotions if you take care of yourself. Make sure you eat well. Schedule those necessary medical appointments and keep them. Find ways to stay physically active, with an exercise class, a walk or by working in your garden. Getting out and moving around will relieve stress and actually make you less tired. As anyone who deals with HD knows, stress and fatigue can make strong emotions even more intense. This is as true for the caregiver as it is for a person with the disease.

The HD community knows a lot about both grief and hope. Your local HDSA chapter or Center of Excellence can help you find understanding and support within our community, whether in person or online. The support groups they sponsor can be a place for you to freely share your feelings with people who genuinely understand where you are coming from. Visit the HDSA national website at www.hdsa.org to find out more about local supports available to you.

Research Opportunities at the HDSA Annual Convention!

HDSA is pleased to announce multiple research opportunities for our HD family members who are planning to attend the HDSA 27th Annual Convention in Las Vegas in June.

On Sunday, June 10, researchers from across the country will be on hand at the Red Rock Resort to conduct small scale clinical trials and observational studies. If you are interested in participating in one or more of the studies, and can extend your stay through part of Sunday, June 10, be sure to check the HDSA web site for an announcement the week of March 26.

A list of the studies that will be conducted on June 10 will be posted on the HDSA web site along with a hyperlink to the principal investigator's contact information. HD family members who are attending the HDSA Annual Convention are encouraged to contact investigators to find out whether they fit the study criteria and can pre-register to participate.

NOTE: You must contact the investigator directly to pre-register and be qualified for the study.

HD family members can also register for individual trials at the HDSA Convention. A list of trials conducting studies on June 10 will be included in the Convention packet attendees will receive when they arrive at the HDSA 27th Annual Convention. Registration will be available at each investigator's table in the HDSA Exhibit Hall.

Due to the immense popularity of these research opportunities, the HDSA 27th Annual Convention will officially close on Saturday evening following our traditional candle lighting ceremony. A Research Initiatives Continental Breakfast will be offered on Sunday morning from 8:00 – 9:30 a.m. with clinical studies commencing at 10:00 a.m.

For more information please be sure to check the HDSA web site.



How can I find out more about Reach2HD?

www.Huntington-Study-Group.org

1-800-489-7671

Site Locations

La Jolla, CA
Englewood, CO
Farmington, CT
Charlestown, MA
Baltimore, MD (2 Sites)
Golden Valley, MN
St. Louis, MO
Albany, NY
New York, NY
Memphis, TN
Kirkland, WA



What is the Reach2HD Trial?

- ◆ To study whether PBT2 (an investigational drug) is safe and effective
- ◆ To determine PBT2's effect on cognition (thinking abilities) and other symptoms including movement and overall functioning

What are the study requirements?

- ◆ You will have 8 in-person visits over 6 months
- ◆ Your participation includes study-related examinations at no cost to you

Who can participate in Reach2HD?

If you or someone you care about can answer "yes" to the questions below, please talk to your healthcare team today!

- ◆ Do you have early to mid-stage Huntington disease?
- ◆ Are you at least 25 years old?
- ◆ Do you have a study partner who can come with you to some of the research visits?

**HDSA Annual Convention:
27th Annual HDSA Convention
June 8-10, 2012**



For more information or to register, please visit www.hdsa.org/convention.

Three Easy Ways to Access HDSA Publications & Newsletters

1. Order publications on the HDSA website, at www.hdsa.org/publications. Publications are available for free or for a nominal fee.
2. Download publications for free by visiting the HDSA website at www.hdsa.org/publications.
3. Contact Anita Mark Paul, HDSA's Information and Fulfillment Coordinator, at 800-345-4372, ext 219 or via email at amarkpaul@hdsa.org.

