

# We Are HDSA!



Huntington's Disease  
Society of America

Support Group Newsletter • [www.hdsa.org](http://www.hdsa.org) • (800) 345-HDSA • Issue 7, June 2011

## THANK YOU!!!

HDSA would like to thank all of the Support Groups that helped make the *Let's Talk About HD* campaign a success. They include:

Bangor, ME  
Milwaukee, WI  
Newton, MA  
East Islip, NY  
Tri-City, MI  
Atlanta, GA  
Seattle, WA  
Cleveland, OH  
Indianapolis, IN  
Mt. Vernon, WA  
Mt. Pleasant, MI  
Farmington, CT  
Baltimore, MD  
Sacramento, CA  
Nashville, TN  
Louisville, KY  
Austin, TX  
Santa Monica, CA  
Wichita, KS  
Hershey, PA  
San Antonio, TX  
Minneapolis, MN  
Rochester, MN  
Newark, DE  
Plymouth Meeting, PA  
Lawrence, KS  
Muncie, IN  
St. Louis, MO  
Denville, NJ  
Jacksonville, FL

Barrington, RI  
Vancouver, WA  
Templeton, CA  
San Diego, CA  
Kalamazoo, MI  
Everett, WA  
Las Vegas, NV  
Denver, CO  
Grand Rapids, MI  
Eastport, ME  
Alexandria, VA  
Manchester, NH  
Albany, NY  
Erie, PA  
Olympia, WA  
Flint, MI  
Akron, OH  
Lawton, OK  
Providence, RI  
Stratford, NJ  
Portland, OR  
Clearwater, FL  
Rockland, MA  
Renton, WA  
Baton Rouge, LA  
Colorado Springs, CO  
Cleveland, OH  
Dover, NH  
Palo Alto, CA

Rochester, NY  
Chevy Chase, MD  
Boise, ID  
Sarasota, FL  
Tewksbury, MA  
New York, NY  
Cook County, IL  
Raleigh, NC  
Miami, FL  
Chico, CA  
Tampa, FL  
Grand Forks, ND  
Sioux Falls, SD  
Charleston, WV  
Geneva, IL  
Northridge, CA  
Phoenix, AZ  
West Los Angeles, CA  
North Vernon, IN  
Lodi, CA  
Ventura County, CA  
Tiburon, CA  
Virginia Beach, VA  
Fargo, ND  
Iowa City, IA  
Orlando, FL  
Charlottesville, NC  
Brooksville, FL  
Delray Beach, FL

If you would like someone to talk to your support group about advocacy and the *Huntington's Disease Parity Act*, please contact Jane Kogan at [jkogan@hdsa.org](mailto:jkogan@hdsa.org).

## Going, going, gone

Do you enjoy *We Are HDSA!*? Then don't forget to sign up for the electronic version before HDSA publishes its last print copy in September, 2011. Just send an e-mail to Seth J. Meyer at [SMeyer@hdsa.org](mailto:SMeyer@hdsa.org) with your name, e-mail address, zip code, and the name of the support group you belong to.

## New Support Group Application:

Are you interested in starting up a new support group in your area? Then fill out the new support group application at [www.hdsa.org/sgapp](http://www.hdsa.org/sgapp). If you have any questions about starting a support group, please e-mail Seth J. Meyer at [SMeyer@hdsa.org](mailto:SMeyer@hdsa.org).

## Ask the Social Worker:

HDSA is excited to introduce a new column to our website, *Ask the Social Worker*. Check out the latest Ask the Social Worker column on the HDSA website at [www.hdsa.org/atsw](http://www.hdsa.org/atsw) to gain insight into the various services HDSA Chapter and Center of Excellence Social Workers provide. If you have a question you would like to ask a social worker, send an e-mail to Seth J. Meyer at [SMeyer@hdsa.org](mailto:SMeyer@hdsa.org) with the subject line "Ask the Social Worker."

## Caregivers Corner:

HDSA is pleased to announce that on June 30 at 12:00 p.m., Kathleen Samulski will be presenting a webinar entitled "Facilitating Access and Communication Through the Use of Assistive Technology." For more information, please contact Jane Kogan at [JKogan@hdsa.org](mailto:JKogan@hdsa.org).

## How do I ask for help with caregiving?

By: Lynn Ross, LMSW, Social Worker

HDSA Center of Excellence at Emory University, Atlanta, GA

When someone asks, "How are you?" do you automatically say, "fine"? If they ask, "Is there anything I can do to help?" do you always reply, "Thanks, but we're doing OK"?

That may be the polite answer, but are there times you wish that you could say, "I'm exhausted. I could really use a hand"?

We all have a strong desire to maintain the status quo; to try and keep things the way they were. But where is it written that you have to do it all alone? Everyone needs help at times, especially when caring for someone with HD. In the beginning, you may have been able to fulfill your daily responsibilities and meet the needs of the person with HD, but their requirements change over time. By trying to do it all – and all alone – you may be making it harder on everyone.

Think about the following list of questions and how they apply to your family. Have there been...

- Any changes in our family?
- Any physical/emotional/behavioral changes in the person with HD?
- Are their personal care needs increasing?
- Have there been changes in my health?
- Do I feel overwhelmed or stretched to the limit?

If you answered, "yes" to any of these questions, it's time you seriously considered allowing others to help. By seeking outside help and support from other family members, friends and local agencies, you may be surprised at what is available.

Does even thinking about asking for help make you feel guilty? First, recognize that admitting you need assistance and seeking help is not a sign of weakness or personal failure. You are still the primary caregiver. You are not abandoning anyone; you are in this for the long haul. Getting help may actually be the path to better care for the person with HD. Second, realize that allowing others to help you will give you the freedom to be a more vital and caring emotional companion to your spouse or child. Isn't that what's really important?

While the hardest step may be acknowledging that help is needed, actually asking for help can also be challenging. Where do you start? Begin by making a list of personal care needs or household tasks that could be done by someone else. Nothing is too small if it will provide physical and emotional relief to you and allow you freedom to spend quality time with your loved one. Next, show your family members and friends the list and ask if there is something they would be willing to take over for you. Be specific (i.e. "Don needs a ride every Thursday morning. It takes about an hour.") and then be willing to accept what they can offer (i.e. "I can do that, but only twice a month."). Many times others are ready to help, if they know what's needed.

Due to pride or sheer willpower, some caregivers go beyond their limits. They get to the point where depression and fatigue cloud their judgment and they feel crushed by their responsibilities. That does not have to happen to you. You know your needs and those of your loved one better than any one else. You have the wisdom to know what tasks can be handed off. Give yourself the freedom to ask your friends and family for help with caregiving, because admitting you need a hand is a sign of strength and good judgment.

Go to page four where we will look at some of the services available to you in the community and from outside agencies.

## 2011 Drive Toward a Cure Sweepstakes

**Grand Prize:** 2011 BMW 328i Sedan or \$25,000 Cash

**Second Prize:** \$5,000 Cash

**Third Prize:** \$2,500 Cash

**Fourth Prize:** \$750 Cash

**Fifth Prize:** \$500 Cash

**Tickets:** \$100 each.

For every two tickets you buy at \$100 each, you receive a third free! Sweepstakes limited to only 2,500 tickets.

Drawing will be held on Saturday, June 25, 2011 at HDSA's 26th Annual Convention in Minnesota.

All proceeds will support HDSA's research and programs to fight Huntington's Disease.

For more information, to get tickets and for official rules please visit our website at [www.hdsa.org/bmwsweeps](http://www.hdsa.org/bmwsweeps).

## A Physician's Guide

Thanks to a generous educational grant from Lundbeck, HDSA is able to provide a complimentary copy of *A Physician's Guide* to every HD family when they send or call the HDSA national office with the name, address and phone number of both the neurologist and primary care provider seen by your loved one with HD.

Upon receipt, HDSA will send you one free copy of the all new *A Physician's Guide* to you as well as a copy to your neurologist and primary care provider.

Call Anita Mark Paul at **800-345-4372** extension **219** or email Anita at [amarkpaul@hdsa.org](mailto:amarkpaul@hdsa.org).

**Please Note:** Your correspondence with HDSA is completely private. HDSA does not share any information with Lundbeck nor the Doctors.

*By: Lauren Dennis, MS, CGC, Certified Genetic Counselor, HDSA Center of Excellence at the University of California, San Diego, CA*

Genetic counselors are health professionals trained to speak with individuals and families on all aspects of genetic disorders, including: how genetic disorders are inherited within families, the risks and benefits of genetic testing, and how genetic conditions and test results will impact the family.

You may have wondered if and when you should speak to a genetic counselor. There is no one "best" time to do so, but here are some reasons you might consider scheduling a consultation:

### If you have questions about how HD runs in families.

There are many myths about how HD is inherited in families and a genetic counselor can provide you with accurate information about the genetics of HD.

### If you are wondering whether or not you are "at-risk" for HD.

A genetic counselor will review your family history to identify who may be at-risk.

### If you are considering predictive genetic testing.

There are many considerations to take into account when deciding whether or not to have genetic testing for HD. A genetic counselor, often as part of a multi-disciplinary team, can speak with you about the pros and cons of genetic testing and help you explore how it will affect your life decisions and family dynamics. There is generally both pre and post-test counseling. There are many reasons why an individual may or may not pursue genetic testing. It is very important that you do not undergo genetic testing until you are ready.

### If you have had genetic testing and would like to discuss the implications of your result.

### If you are planning a family.

The optimal time to discuss family planning is BEFORE a pregnancy. A genetic counselor can inform you of the risks to your children and the reproductive options that are currently available.

### If you would like to discuss how to speak with family members about HD.

### If you need assistance identifying additional resources, such as written information, support groups, research studies, etc.

The above are just some of the ways a genetic counselor may be able to help answer your questions about genetic disorders and genetic testing. Genetic counselors are dedicated to providing accurate information that can help you as you make important life decisions.

### How do I find a genetic counselor or genetics clinic in my area?

#### The HDSA National Website ([www.hdsa.org](http://www.hdsa.org))

All HDSA Centers of Excellences have genetic counselors. If there is no HDSA Center of Excellence in your area, your local Social Worker can help you find a genetic counselor close to you. Click on "Find HDSA in your Community" on the main page and chose either "HDSA Centers of Excellence" or "Social Workers" and click on the state you live in.

#### National Society of Genetic Counselors ([www.nsgc.org](http://www.nsgc.org))

Click on "Find a Genetic Counselor" tab to search by specialty or zip code

#### Genetests ([www.genetests.org](http://www.genetests.org))

Click on "Clinic Directory" tab to search

## Share your feedback!

Is there an article you would like to see in *We Are HDSA*? Is there a topic you would like to see discussed. Please send all feedback concerning *We Are HDSA!* to Seth J. Meyer at [SMeyer@hdsa.org](mailto:SMeyer@hdsa.org) with the subject line "We Are HDSA."

## NYA Silent Auction

The NYA Silent Auction at the HDSA Convention is the largest fundraising activity for the group. Items are brought from all over the country and organized by the NYA Silent Auction Committee during the convention. We are looking for YOUR help to provide items for the silent auction.

### Including:

- Anything that can be used by anyone across the country. (No local gift certificates)
- Past donations include: Sports memorabilia, handmade items, jewelry, airline tickets, artwork,

\*The NYA Silent Auction has been moved to FRIDAY June 24th (originally Saturday) before the HDSA Convention Reception and Chapter Awards.

If you have any items, please contact Mynelly Perez ([mperez@hdsa.org](mailto:mperez@hdsa.org)) with an item description. Any questions can be directed to BJ Viau ([hoopathon@yahoo.com](mailto:hoopathon@yahoo.com)).

## HDSA Convention

Have you signed up for the 26th Annual HDSA National Convention? It's not too late. The Convention will run from June 24th-June 26th in Bloomington, Minnesota. For more information, please visit [www.hdsa.org/convention](http://www.hdsa.org/convention).



## What resources are available and how do I find them?

By: Lynn Ross, LMSW, Social Worker

HDSA Center of Excellence at Emory University, Atlanta, GA

Now that the decision to seek outside help has been made, what next? Depending on where you live, resources may be available that will make your job as primary caregiver easier. Services, both affordable and not so affordable, are there if you know where and how to look.

Knowing what is offered and how to access them is one of the primary tasks of the social worker at the HDSA Centers of Excellence or HDSA Chapter in your local area. They are knowledgeable and ready to assist you in finding resources. To find one closest to you, go to ([www.hdsa.org](http://www.hdsa.org)) and press on the "Living with Huntington's Disease" tab or call (800) 345-4372.

Below are just a few of the resources you can contact to find help:

### Caregiver Resources

**National Family Caregivers Association**  
[www.nfacares.org](http://www.nfacares.org) (800) 896-3650

**Caregiver.com (Magazine)**  
[www.caregiver.com](http://www.caregiver.com) (800) 829-2734

**Caring Connections**  
[www.caringinfo.org](http://www.caringinfo.org) (800) 658-8898

**Lotsa Helping Hands/HDSA**  
[www.hdsa.org/carecoordination](http://www.hdsa.org/carecoordination)

HDSA, in partnership with Lotsa Helping Hands, has launched the Care Coordination Portal, a service that allows family, friends, neighbors and colleagues to create a community and assist with daily tasks.

### Disability Resources

**US Department of Labor**  
[www.dol.gov](http://www.dol.gov)

[www.disability.gov](http://www.disability.gov)

### Government Resources

**Center for Medicare & Medicaid Services (CMS)**  
[www.medicare.gov](http://www.medicare.gov) 1-800-MEDICARE  
 (800-633-4273)

**Department of Health & Human Services**  
[www.health.gov](http://www.health.gov) (240) 453-8280

**Center for Disease Control**  
**Listing of State Health Departments**  
[www.cdc.gov](http://www.cdc.gov) (404) 498-1150

**Service of National Council on Aging**  
[www.benefitscheckup.org](http://www.benefitscheckup.org)

**Social Security Administration**  
[www.ssa.gov](http://www.ssa.gov) (800) 772-1213

### HD Websites

**Huntington's Disease Society of America**  
[www.hdsa.org](http://www.hdsa.org) (800) 345-4372

**Huntington's Disease Advocacy Center**  
[www.hdac.org](http://www.hdac.org)

**HD Lighthouse**  
[www.hdlf.org](http://www.hdlf.org)

**Huntington's Outreach Project for Education**  
<http://hopes.stanford.edu>

### State Resources

*Locate information and resources by State*  
[www.carepathways.com](http://www.carepathways.com) (877) 521-9987

**National Association of Area Agencies on Aging**  
[www.n4a.org](http://www.n4a.org) (800) 677-1116

### Other Resources

**Assistance with Advance Directives**  
**National Association of Elder Law Attorneys**  
[www.naela.org](http://www.naela.org) (703) 942-5711

**Visiting Nurses Association of America**  
[www.vnaa.org](http://www.vnaa.org) (617) 737-3200

**National Adult Day Services Association, Inc.**  
[www.nadsa.org](http://www.nadsa.org) (866) 890-7357

**Patient Advocate Foundation**  
[www.patientadvocate.org](http://www.patientadvocate.org) (800) 532-5274

## Thank you

HDSA thanks Lundbeck for the educational grant that made this newsletter possible.

