

# We Are HDSA!



Huntington's Disease  
Society of America

Support Group Newsletter • [www.hdsa.org](http://www.hdsa.org) • (800) 345-HDSA • Issue 8, July 2011



## Applying for Disability Benefits:

### HDSA launches new online information portal

Huntington's disease often robs a family of its financial stability. Symptoms of the disease, both physical and behavioral, will progressively interfere with the affected person's ability to continue in their accustomed profession. At some point, changes caused by the disease will make it will necessary for the person to stop working. This loss of income can have a devastating effect on the family and make a difficult situation even more stressful.

Social Security Disability Insurance (SSDI) is a program of the Federal Government that provides cash benefits to eligible people who are unable to work due to a disabling condition such as HD. Some benefits may also be available to family members. SSDI benefits can provide a financial lifeline to the individual or family facing the challenges of HD. However, not everyone is eligible for SSDI and the application process requires planning and careful effort.

#### New Online Resource Center

As part of our mission of assisting people and families affected by HD in coping with the problems presented by the disease, HDSA will launch a new webpage ([www.hdsa.org/disability](http://www.hdsa.org/disability)) in August designed to help the HD community understand the benefits that may be available to them through SSDI and provide advice on submitting a successful application.

Topics covered on the site include:

- The Social Security Disability Insurance (SSDI) Program
- Understanding Eligibility
- Building a Case for Disability
- Navigating the Application

The site brings together information from many sources to create a powerful online portal of information on disability benefits and the application process. Links are provided to checklists and screening tools that can help an applicant or caregiver prepare to file for benefits, as well as to online webinar presentations through Caregiver's Corner.

#### Caregiver's Corner – Disability Strategies Webinars

HDSA's Caregiver's Corner has sponsored a series of webinars on the Social Security application process, presented by disability claims expert Drew Yeannakis. The three webinars deliver practical guidance on the steps to take before, during and after applying for benefits in order to increase the chances of having the request for benefits approved. These webinars have been archived online and are available for viewing at any time, through links on the new site.

The Caregiver's Corner webinars include:

*Disability Strategies I: SSDI Basics:* This hour-long webinar contains an overview of the Disability application process and the criteria that the Social Security Administration (SSA) uses to determine disability for Huntington's disease, as well as information on filling out applications and list of the documentation you will need.

*Disability Strategies II: Disability Application & Questionnaires:* This hour-long webinar contains more details about the Disability application as well as step-by-step instructions on how to fill out the Adult Function Report and Fatigue Questionnaire.

*Disability Strategies III: Denials & Appeals:* This hour-long webinar contains an overview of what to do if your Disability claim is denied.

#### “Knowledge is Power”

It has been said that “knowledge is power.” HDSA's new webpage is an online resource dedicated to giving people with HD and their families the factual and useful information and guidance that can help them successfully apply for SSDI benefits.

If you have any questions about the new information portal please contact Jane Kogan at [jkogan@hdsa.org](mailto:jkogan@hdsa.org).

## A Caregiver's Guide to Huntington's Disease

In partnership with We Move, HDSA has printed a limited number of copies of this new guide for caregivers. If you are unable to pick up your free copy at the HDSA Annual Convention. Please visit [www.wemove.org](http://www.wemove.org) to download your free copy.

## Caregiver's Corner

If you missed the June 30 Caregiver's Corner on assistive technology resources, watch it anytime from the HDSA website at [www.hdsa.org](http://www.hdsa.org) in the "Frequently Used Shortcuts" section.

## HDSA Lunch n' Learn: Genetic Information Nondiscrimination Act (GINA)

Join HDSA on July 13 for a special hour-long webinar on GINA, presented by Peggy Tighe, JD. Contact Jane Kogan at [jkogan@hdsa.org](mailto:jkogan@hdsa.org) for more information.

## 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."

By Claudia Testa, MD, Ph.D.,  
Co-Director HDSA Center of Excellence at Emory University

Driving can be an emotionally charged subject for both the family and the person with HD. Families may delay having a conversation about driving to avoid conflict. Below are some suggestions on how to have a productive discussion about driving.

### Who starts the talk?

The conversation can be initiated by the family and friends or the doctor of the person with HD. While a doctor is a neutral authority and therefore can help the family avoid conflict, family and friends have a better feel of the person's driving ability. Many people are aware of changes in their driving ability and may understand when someone brings up the subject. If family and friends are hesitant to get into the car with the person with HD, it is time to talk about driving.

### What to ask?

It is best to focus on specific questions, such as: Have there been any changes in your driving? Have you had any small fender benders recently? Avoiding certain driving tasks like highways or left turns? Have other people expressed concerns about your driving?

Asking about the person's needs is helpful. This includes practical points like where do they regularly drive – lunch, church, work – and emotional needs like feeling in charge. Acknowledging that reducing driving feels unfair and is difficult can help avoid feelings of being punished, isolated, and frustrated.

Many people are happy to hear others are concerned about them but are still very willing to put themselves in danger. It may be more helpful emphasize how continued driving puts other people at risk. For example, "it's just me in the car" doesn't acknowledge small children in the neighborhood or the family in the other car.

When there is uncertainty about driving skills, a rehabilitation driving assessment can be very helpful. A specialist, usually an occupational therapist, conducts a detailed assessment geared towards identifying what the person can and cannot do in regular driving situations and whether the car or the person's behavior can be modified to allow some driving. Your doctor and medical social worker can help set this up.

### How will my loved one get around?

Many areas do not have adequate public transportation. Families may not be able to afford an alternative driver. However, there are solutions. Working with your medical social worker can help identify resources in your area. Human resource departments at work can provide carpool information. Talking to other HD families may uncover suggestions from their experience. Simply asking friends to pitch in gives people a chance to step up and maybe surprise you with willing support. Seeing how others want to help can diffuse the sense of loss around reducing driving.

### The scary part: What if this talk doesn't go well after all?

In the end, some people simply do not recognize that their driving is dangerously impaired. This is the most stressful situation for all involved. That person's safety and public safety become serious issues. Removing access to a working car may be necessary.

Doctors can report a person to their state's Department of Motor Vehicles, which will lead the DMV to determine the ability to the driver. Making peace with this conflict can be hard for families. Reaching out for support from the community and HDSA Social Workers may ease family burden in these cases.

**Upcoming Educational Days****July 9**

New Orleans, LA

**July 15**

Eastport, ME

**July 30**

Kirkland, WA

**August 13**

Lawton, OK

**September 17**

Englewood, CO

If you would like any information about upcoming educational days, please contact Jane Kogan at [jkogan@hdsa.org](mailto:jkogan@hdsa.org).

**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.

*Karen Baker, MSW, LICSW, HDSA New England Regional Social Worker*

Advance directives are instructions given by an individual specifying their wishes regarding end of life medical care and designating who should make medical decisions for them in the event that they can no longer communicate or make decisions. While various states use different language and procedures, this article covers some of the issues that are common to all.

There are many benefits to completing your advanced directives. First is the protection of your rights to make your own decisions of what medical treatment you would or would not want. With advance directives in place, you will feel increased peace of mind knowing your opinions are known and your rights are protected. In the event of a medical emergency, medical professionals can immediately provide the level of care you have chosen, because they have been provided with written legally recognized directions in advance. Finally, tension and disagreement between your friends and family can be decreased if they do not have to question, wonder, or worry about medical decisions you would want to be made. Completing routine advanced directives while you are still healthy may prevent the need for a costlier, more time-consuming or more stressful legal intervention such as the designation of a Guardian in the future.

There are several steps that can be taken to work towards completing your advanced directives. First, research the legal specifics in your state. You can start by asking your HDSA Social Worker or other Social Workers involved in your care for details regarding your state's requirements. Several states' government websites include information or even a printable copy of the Health Care Proxy form. States vary in the requirements regarding witness signatures. Some health care facilities may allow staff to sign as witnesses, others may not. Research the difference between a Health Care Proxy (designating who will speak for you when you cannot), a Living Will (written details of your general wishes), and more specific forms.

Once you understand the legal requirements in your state, you can begin to research and discuss your desired medical options. Speak to your doctor, neurologist, and other health care professionals. Utilize the information available on the HDSA website to educate yourself regarding potential health issues. The major medical interventions one may or may not desire include artificial resuscitation, feeding tube, ventilator, and tracheotomy. Other treatments may involve psychiatric or pain medications. Also research the Hospice services available in your area. Consider your personal opinions regarding these interventions, and how your age, or cultural, ethnic, or religious background may influence your comfort with different options. We need to respect that different individuals will elect different choices.

While a lawyer may not be required to complete a Health Care Proxy (HCP) form in your state, you may benefit from legal advice if your family situation is more complicated with non-married partners, divorce or separation. A Living Will is a longer narrative describing your wishes. A helpful tool is the "Five Wishes" a check list listing specific ideas, see the website [www.agingwithdignity.org](http://www.agingwithdignity.org). Currently this tool is considered legal in only 42 states, but even if not legal in your state you may find it helpful to spark thought and conversation.

Consider who will make the best Health Care Proxy for you. It may not be your spouse, best friend, or closest relative. Someone may love you dearly, but if they are the type of person who becomes very anxious or uncomfortable in a medical emergency they might not be the best candidate. Ideally, a good candidate to be a HCP is someone who understands how modern health care works, who can be reached quickly in an emergency, who will not "faint at the sight of blood," and can respect your wishes. I believe it is best to ask someone if they will agree to be your HCP so that you can communicate your wishes. Your state's policy may also give the

*(Continued on page 4)*

## **We Are HDSA!**

*We Are HDSA!* is going green! Starting in October, 2011, issues will be published in electronic form and, along with being available on our website, will be sent out via e-mail. Don't wait until we stop printing *We Are HDSA!*. Sign up for the electronic version today! Send an e-mail to Seth J. Meyer at [smeyer@hdsa.org](mailto:smeyer@hdsa.org) with your name, e-mail address, and city and state so you can be added onto our *We Are HDSA!* e-mail list.

## **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!*"

## **HDSA National Convention**

Did you miss the HDSA National Convention? Was there a workshop that you were unable to attend? Convention presentations will be made available online [www.hdsa.org/convention](http://www.hdsa.org/convention).



option of a "second" or "back-up" HCP in the event that your "primary" HCP is unreachable, injured, or incapacitated. Often spouses select each other as HCP but may be injured together in an emergency.

Carefully follow your state's directions for completing your HCP form, as well as the more general Living Will or more specific forms. Once completed, give copies to your doctors, home care staff, family and friends. EMT's often look for medical forms on the refrigerator. You can also keep a copy in your car. Other communication ideas include listing ICE ("in case of emergency") in your cell phone, purchasing a medical alert bracelet, or placing a contact information card in your wallet.

Your final step is to review and update your advanced directives as needed. You may change your mind about an intervention. The HCP you chose may no longer be the best candidate should a relocation, divorce, or illness occur.

While this is an emotional project, the completion of your advanced directives will bring peace of mind to you, your family and friends, and your health care providers.

## **Advocacy Corner:**

### 5 ways YOU can Advocate for S. 648 and H.R. 718

*The Huntington's Disease Parity Act (S. 648/H.R. 718) is important to everyone who is impacted by HD. The Bill would make it easier for people who are disabled by Huntington's Disease to receive Social Security Disability and Medicare benefits. This legislation has the power to improve lives – financially, socially, and emotionally!*

Your Representative and Senators need to hear from YOU to know that the *Huntington's Disease Parity Act* is important! Here are five ways you can participate!

1. Use the HDSA E- Advocacy Center, [www.hdsa.org/takeaction](http://www.hdsa.org/takeaction) to contact your Representatives and Senators about cosponsoring the HD Parity Act (S. 648/H.R. 718) with just a few mouse-clicks!
2. Call Congress for HD! Go to [www.hdsa.org/callcongress](http://www.hdsa.org/callcongress) to get the phone numbers for your Senators and Representative, as well as talking points. Then, tell up to 10 friends to also call by using the Tell-A-Friend link at the bottom of the page.
3. Educate the Media! Use the HDSA E-Advocacy Center, [www.hdsa.org/takeaction](http://www.hdsa.org/takeaction) to send a letter to the editor of your local newspaper to educate the media, your community, and Congress about HD. You can also contact Jane Kogan at [jkogan@hdsa.org](mailto:jkogan@hdsa.org) for a printed letter you can adapt, and local newspaper information.
4. Make your contact more direct! Send a copy of your letter to the staff person responsible for healthcare. Contact Jane Kogan at [jkogan@hdsa.org](mailto:jkogan@hdsa.org) for Congressional health staffer information.
5. Make it local! Schedule a District meeting with your Representative or Senators. Contact Jane Kogan for information about setting up a local meeting

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## **Thank you**

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