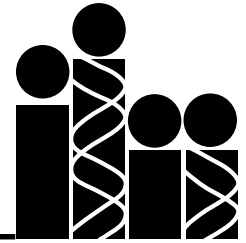


Northwest HUNTINGTON'S HUNTINGTON'S DISEASE SOCIETY OF AMERICA • NORTHWEST News



Chapter General Meeting

You are invited to attend the Huntington's Disease Society of America Northwest Chapter's general meeting on Saturday March 23, 2002. The meeting will be at Greenlake United Methodist Church at 6415 1st NE, 1 block from Green Lake in Seattle, WA. The meeting is open to all people either living with or interested in Huntington's disease. Come and enjoy good food (bring a dish, salad, or dessert) and meet your Northwest Chapter board members as well as old and new friends from around our area.

This year we will welcome national speaker, **Phil Hardt**, BA, MA, and "Phd" (person with Huntington's disease), to our meeting. Mr. Hardt has written many articles on how to apply for Social Security disability, the benefits of volunteering, and how HD affects marriages and relationships. He has spoken at many HDSA support groups and annual meetings, and was honored with the HDSA "Person of the Year" award at the 2001 national convention. He is on the board of directors of the Arizona HDSA chapter and serves as president of the Dementia Advocacy and Support Network. Mr. Hardt enjoys speaking on how to "Live Positively with HD," "The Importance of "Caring When There is No Cure," and "How to Prepare if You are At-Risk."



In addition to our Seattle meeting, Mr. Hardt will be attending the joint Open-Caregiver HD support groups meeting on Thursday, March 21 at 6:30 PM. It is located at Oregon Health Sciences University, CDRC Building, Room 3200, 707 SW Gaines Rd, Portland, OR. (Call Karen Kovak at 503-494-5606 for directions.) We are also in the process of arranging meeting(s) in the Centralia-Olympia-Tacoma areas on Friday, March 22 for people interested in meeting Mr. Hardt. Contact Russ Kastberg at 360-425-9338 if you would like to participate in the meeting.

Home Safety / Fall Prevention Reprinted from the Delaware Valley Chapter

By **Bettie Neal, RN**

Home safety is always important, but it is really critical to individuals with Huntington's disease and their caregivers. Remember these basic safety precautions:

- ◆ Keep stairways, hallways and pathways free of clutter
- ◆ Remove loose scatter rugs and use non-skid mats with throw rugs
- ◆ Keep stairs, especially at the top and bottom, well lit
- ◆ Install handrails on stairways and in bathroom shower and tub areas
- ◆ Place non-skid mats or strips in the bathtub
- ◆ Keep all electrical and telephone cords out of traffic areas.

Making a home or environment safe is more than just the things above. It is also an attitude and a willingness to make accommodations for those we love.

When discussing safety, one needs to look at the entire picture—the environment, the person with HD, and the caregiver. One is safe only if all three are safe. The environment is not safe if it is dark, cluttered, or poorly equipped. The person with HD is not safe if the

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Chapter Address
P.O. BOX 33345
Seattle, WA 98133
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HELPLINE
(206) 464-9598
(888) 264-HDSA



caregiver is working in that environment. Both are at risk for falls and serious injuries. The caregiver is also at risk for various sprains and strains trying to move and twist in a tight environment.

So, what can you do? Look at your environment and decide that maybe it's time to rearrange the furniture. Put the dining room table in the basement, move the bookcase out of the bedroom, or put the laundry hamper in the closet. Get rid of the clutter, brighten the lights and try something new!

Now is the Time to Speak Your Mind...

By Brian Giddens

For those of you struggling on a day to day basis managing health and care-giving concerns, the last thing needed is more demands on your time. Unfortunately, this legislative session is going to be quite a contentious one, given that the state is looking to cut 1.2 billion dollars from the budget, impacting health and human services funding substantially.

It is clear that our state is in a recession, and that the revenues have dropped significantly. It is also clear that with the passage of recent initiatives, there are limits on how to raise additional revenue to make up the difference. Where does that leave lawmakers? Faced with tough decisions, now more than ever they will be vulnerable to persuasion from voters. Interestingly enough, legislators don't hear much from individual voters. What they do hear from are organized associations and special interest groups who are politically savvy, and who know that they can influence decision-making by huge call-in and letter-writing campaigns.

Do these groups represent your interests? Perhaps they do, and if so, you can rest assured that they do have influence. But if you are not sure that they do, or you want to make sure that your voice is heard, you may want to follow some simple steps to ensure that your opinions are expressed:

1) Keep in mind that "government" is composed of several parts. It encompasses all of public education, a large share of health services to vulnerable populations such as low-income moms, the disabled and elderly, basic public services such as transportation, public programs such as libraries and community centers, and support services such as chore services, community mental health, COPES, food stamps, and payments to nursing homes for low-income residents. Many of these programs directly affect people with HD, and their caregivers.

2) Keep abreast of the news and let your legislators know what you think is important, whether it is to totally revamp the tax structure, support human services, or provide more assistance to caregivers. You may think that they are working for you, but they respond to who contacts them. If everyone they heard from pressed them with the same

opinion, their natural assumption is that this is how the entire electorate feels.

3) It is SO EASY to contact your legislator. All you do is call the Legislative Hotline at 1-800-562-6000, state your name and address (you don't even have to know who your legislators are, or what your district is—they can find that out through your address), and give a brief statement about how you feel. It helps to be succinct, and it is helpful to be clear, i.e., "As a taxpayer I support my taxes going for..." With this one call, you can leave the message for your senator, your representatives, AND the governor!

4) If you see in the papers, or on TV that the status of the budget or a specific bill is changing direction, it is ok to call again, or to call the legislator's office directly, and reinforce your earlier message.

It is easy to be complacent about our democratic process, because we have had the opportunity to vote all of our lives, and freedom of speech. But a minority of the population showed up to vote last election, even after our country was shaken by such a tremendous assault on our freedom. There is also the impression that money is more important than voters. The reality is that a politician can gather all the money they can, but if they don't get the votes, they won't make it into office. So please take a moment to influence the decision-making process and let your legislators know how you feel.

Shoot for the Cure Hoop-a-thon!

The Northwest chapter's 2nd annual Shoot for the Cure Hoop-a-thon will be held April 27, 2002 11-2 PM at the Ballard Community center in Seattle, Washington. The center is located at 6020 28th Avenue NW. We are delighted to report that sportscaster, Brian Prawitz, will again emcee the event and that Amica Insurance is once again a corporate sponsor.

This fun-filled basketball event involves sponsored individuals shooting from the foul line and sinking as many baskets as possible in a 10-minute period. The hoop-a-thon is open to all ages and skill levels. Teams and individuals are invited. Prizes will be awarded in several categories including the most baskets sunk in 10 minutes and the most funds raised.

Prevent Dehydration in People with Huntington's Disease

Reprinted from NC Nucleus

People with HD may be more prone to dehydration. People with HD who have difficulty organizing their thoughts and actions may be unaware they are thirsty or not know to drink extra fluids on hot days. Motor abnormalities and chorea may prevent some people from getting access to sources of fluids.



Chorea may interfere with getting a drink to their mouth. Difficulties with swallowing can also be a risk factor.

There are several signs to tell if someone is dehydrated—increased heart rate, dry mouth and concentrated urine. As dehydration worsens, symptoms can become more severe—sunken eyeballs, decreased blood pressure and change in mental status (delirium or confusion).

Dehydration can be prevented. A person with HD may not ask for fluids or tell you they are thirsty. This means that caregivers, family and friends need to anticipate this need and plan accordingly. Always have fluids available when out and about. Sports bottles are a great way to do this. Drinking water is best. Drinks with caffeine, such as soda, can actually make dehydration worse.

Frequently remind the HD person to drink their fluids. Eight ounces every few hours should be adequate during the waking hours.

Pedal for Huntington's Disease!

Ride the Seattle to Portland (STP) bicycle ride and help those affected by Huntington's Disease. The ride is July 13 & 14, 2002 and goes 200 miles from Seattle to Portland.

Pedal for a Purpose provides the opportunity to ride the STP and raise funds for the Northwest chapter. Raise more than \$350 and you'll ride STP for free—we'll reimburse your \$70.00 registration fee.

All fund-raising is strictly voluntary and is not a requirement to participate in the STP ride.

Sounds good, how do I get started? First, register with the Cascade Bike Club at <http://www.seattletoportland.com/registration.htm>. Next, call 1-888-264-4372 and let

us know you've chosen to help raise funds. Then, just collect pledges. Donations must be collected by you personally and checks should be sent to us.

When you collect donations, send them with your sponsor sheets to the chapter. You don't have to wait for the sponsor sheet to be full. We will send tax statements to your sponsors for pledges over \$50. You can copy the sponsor sheet for even more pledges.

Raise \$500 and you'll receive a \$50 bike shop gift certificate. Raise more and you'll earn even larger bike shop gift certificates!

To have your registration fee reimbursed and to earn other incentives, your donations must be turned in by August 1st, 2002.

Complete details about Pedal for Huntington's Disease and sponsor sheets can be found at <http://www.geocities.com/nwhdsa/pedal.htm> or by calling 1-888-264-4372.

HDSA's A+ Rating

The American Institute of Philanthropy (AIP), a national charity supervisory service that assists donors in making well informed giving decisions, has designated HDSA as one of the top rated charitable organizations. Ranked with large health organizations, such as the American Heart Association, and the American Liver Foundation, HDSA was the only health organization to receive an A+ grade. If you would like to find out more about AIP, and their grading system, you may log onto www.charitywatch.org.

YES! I want to help.

CLIP THIS FORM NOW AND SEND IT IN RIGHT AWAY!

Enclosed is my donation

\$100 Benefactor \$15 Individual \$25 Family

Name: _____

Phone: _____

Address: _____

City: _____ State: _____ Zip: _____

Send to: Huntington's Disease Society of America
Northwest Chapter, PO Box 33345, Seattle, WA 98133

Northwest Chapter Services Provided

- Public Education
- Nursing Home Staff Education & Consultation
- HELPLINE (206) 464-9598 – Information and Support
- Individual & Family Counseling
- Newsletter
- Funds for Research
- Area Support Groups
- HD Information & Consultation for Medical Specialists

The HDSA is a non-profit agency. All donations are tax-deductible.

VOLUNTEERS MAKE IT HAPPEN!

The N.W. Chapter is always available to help you. And, if **YOU** would like to be involved, the Chapter could always use your help! Here are ways you can volunteer a few hours of your time to the N.W. Chapter. Please let us know your area of interest or expertise.

AREAS OF INTEREST/COMMITTEES:

- | | | | |
|------------------------------------|--|---------------------------------------|-----------------------------------|
| <input type="radio"/> Board Member | <input type="radio"/> Nominating | <input type="radio"/> Speakers Bureau | <input type="radio"/> Other _____ |
| <input type="radio"/> Finance | <input type="radio"/> Volunteer Development | <input type="radio"/> Advocacy | _____ |
| <input type="radio"/> Fund-raising | <input type="radio"/> Family Services | <input type="radio"/> Newsletter | _____ |
| <input type="radio"/> Publicity | <input type="radio"/> Advisory Legal Medical | <input type="radio"/> Computer Skills | _____ |