



University of Washington Center of Excellence Needs Your Support

The Northwest has a tremendous local resource in the battle against Huntington's Disease. It's the Center of Excellence at the University of Washington.

The University of Washington Center of Excellence is a stable regional center providing high-quality clinical care and services to individuals affected by Huntington's Disease (HD), their families and caregivers. In addition to clinical and family services, the Center provides professional and lay education and is involved in HD clinical research. The center is designed to provide comprehensive multidisciplinary diagnostic and therapeutic services for HD individuals and their families. Services are centered around an organized HD clinic in which an individual's needs are determined; plans are made to fulfill those needs and sufficient follow-up is provided.

What does this mean for you and your family? Personalized high-quality HD care in one location.

The University of Washington Center of Excellence is committed to providing the best possible care and resources to Northwest HD persons and their families. With your help, this commitment to care can be maintained and expanded.

You can make a lasting difference in the battle against Huntington's Disease by making a tax deductible financial gift to the HDSA Center of Excellence at the University of Washington.

Your gift can be sent directly to the Northwest chapter. Please call 206-464-9598 or e-mail nwhdsa@yahoo.com if you have any questions about supporting the University of Washington Center of Excellence.

Thank you for your support!

The NW Chapter's 3rd Annual 2003 Shoot for the Cure Hoop-a-thon

Date: Saturday, May 3, 2003
Time: 11 AM to 2 PM
Location: Ballard Community Center
6020 28th Ave NW
Seattle, WA
For more details, see page 5.

My Personal History and Goals as President-Elect at Northwest HDSA

By LaVonne Veatch Goodman, M.D.



Personal experience with Huntington's disease has shaped much of my adult life, as Huntington's will have affected most of the readers of this newsletter. I hope to bring the strength and knowledge gained over the years to bear on the problems that

we in the Huntington's community face in the coming few years. I am "between Huntington's." My first special husband died with this disease, and we have children at risk. So I am highly motivated and in the years of my life when all energy is not taken just to survive. I am also a physician, an internist by training and choice. My present special husband is a researcher with both personal and professional history with HD. I hope to put this combination of history to good use as your upcoming president.

Over the last year, I've worked at formulating goals that are worthy of this Northwest HDSA group and the patients and families it represents. I believe these goals can be accomplished, but not without your support and hard work. Note also that these are my personal goals, and that I don't assume these are the only chapter or member goals unless they are agreed upon by all of you. I certainly need your input to be an effective leader. Information from the upcoming survey will be most welcome and useful.

There will be continued primary focus to promote and fund the services of our Center of Excellence at the University of Washington Medical center. In addition, I will work on additional goals, which I list below. I have studied research literature, and have spoken with research neurologists, drug developers, and most important with HD families. I

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have planned meetings with medical policy makers in late January, and will be meeting with National HDSA in February.

While these goals are just the tip of the iceberg, I have faith they are achievable. I am willing, and I hope able, to start the chipping. So here we begin:

Goal 1) to get out into your neighborhoods, and give patient education about drugs available now for potential treatment of HD. I'll try to help you "wade through" the often contradictory drug information. There could also be newsletter contributions. This involves education for HD families first, but will progress to the medical community and medical policy makers as well. I will endeavor to bring you the most up-to-date information. There will be a community lecture for patients and families given on Saturday, February 15 from 10 to 11 a.m. at the Everett Clinic, which is located in the Gunderson Bldg., 3901 Hoyt Ave., Everett, WA.

Goal 2) to give patients and their families education about drug development strategies that our researchers are working on, (b) to plan a researcher-given symposium in the Northwest (for sometime spring of 2003) by our local "world class" researchers in Seattle and Vancouver. (See the article on page 5.) c) to work on strategies for quicker sharing of research data as drugs are developed. (d) to work on strategies for rapid drug screening.

Goal 3) to initiate and facilitate education on gene research (which would include stem cell research) through informal lecture discussions with HD families. (b) To promote political activity and to push through Washington State legislation for stem cell research. (See the article on page 3.)

These first three education goals could be accomplished by mini informal "symposiums" that could accompany a support group meeting or other format. If your group would like to talk about scheduling such an event, please call our Northwest Chapter business line at 206-464-9598, or e-mail me at llvg@attbi.com.

Goal 4) to utilize all of the above to promote more effective patient involvement in decisions regarding drug development strategy. Patient-driven drug development will achieve the goal of drugs and treatment faster for this generation. Timely treatment for those with or at risk for Huntington's disease is the overriding goal.

Northwest Huntington's Disease Research Studies

PHAROS (Prospective HD At Risk Observational Study) - An observational study to advance knowledge about the experience of being at risk for HD, and to lay the groundwork for future studies of treatments to delay onset. The requirements for volunteers are: 26 - 55 year of age, at risk for HD (an affected parent) and never had gene testing. Volunteers are evaluated by two neurologists and a nurse practitioner every nine months. We have over 25 subjects enrolled at the University of Washington and are still enrolling new subjects. There is no financial compensation to subjects.

PREDICT - HD (Neurobiological Predictors of HD) - An observational study of the behavioral and MRI predictors of HD onset. This study differs from PHAROS in having more detailed testing of concentration and memory in addition to neurologic examination, which is videotaped, and a MRI of the brain. The requirements for volunteers are: 26 years of age and older, tested for the HD gene (both negative and positive), never diagnosed with onset of HD by a physician, and able to bring a companion along to each visit.

Volunteers are evaluated by a movement disorder specialist and a nurse practitioner every year. We have begun enrolling subjects and need more. Subjects are compensated for visits.

Family Health in HD - The focus groups arranged for late November had to be canceled. The team from the University of Iowa School of Nursing will be coming to Seattle in March 8, 2003, to learn about the health and behavioral management concerns of family members related to a person affected with HD or who has tested positive for HD. Both adults and adolescents are invited to participate. Subjects are compensated for participation.

Spinal Fluid Biomarkers in HD - A study of spinal fluid in persons affected with early symptoms of HD and unaffected persons as controls, to determine whether there are changes in spinal fluid that will be useful in understanding the biologic events occurring in the brains of persons with HD. Biomarkers might be useful in identifying the earliest stages of HD, following the progression of the disease, or in monitoring the effects of treatments. We recently started enrolling subjects, and especially need controls. Subjects are compensated for participation.

If you have questions or are interested in being a volunteer for any of the above studies, contact Hillary Lipe, ARNP, Study Coordinator, at (800)329-8387 X61825 or (206)277-1825.

Tips for Coping with Huntington's Disease

Reprinted from HDSA Central Ohio Newsletter

Promote security—Establish and maintain consistent routines and rituals so that the HD person knows what to expect each day and can count on something familiar and meaningful.

Celebrate remaining capacity—Reinforce what the HD person can still do well and don't exaggerate impairment.

Don't struggle to make the HD person behave in old familiar ways. Instead, make time for fun and togetherness. Make taking pleasure in the moment a goal in itself.

Substitute for lost ability. Do things for instead of with the HD person if he or she can no longer do them, but be discreet in offering help. Protect their self-esteem. Don't argue with, or test the person in public.

Make up for the fact that the HD person may no longer be able to control impulses. Try to divert him or her or get the person to think about something else if he or she is about to do something embarrassing or disruptive.

Watch out for situations that trigger disruptive behavior. For example, do not expose the HD person to large crowds or too many choices if these scare, upset or frustrate them.

Build self-esteem. Let your relative feel productive by finding tasks that he/she can do, such as carrying grocery bags.

Listen to the HD person. Learn to hear and respond to the feelings behind the words. For example, a confused or frightened person may ask for his or her mother who died years ago. Instead of saying "Your mother has been dead for twenty years" which initiates a grief reaction every time you say it, say something like, "You must really miss your mom," or "Your mother was a wonderful lady."

Know where to get help. Ask your doctor to help you find assistance. Find out what your community has in the way of education, support, counseling and respite care.

Communication Strategies for Huntington's Disease

By Jeff Searle, MS, Kansas University Medical Center

Huntington's Disease affects many skills that are necessary for effective communication. Cognitive language skills, or the thoughts we need to formulate what we say, are affected by the disease. Difficulties include such things as:

- ◆ Initiating conversations, putting thoughts into words
- ◆ A reduced number of words available
- ◆ Understanding complex information
- ◆ Slow response time, impaired reading/writing skills

People with HD may also have problems:

- ◆ Learning new information and new skills
- ◆ Reduced short term memory skills
- ◆ Poor attention and concentration abilities
- ◆ Lack of ability to organize, reason, problem solve

As a caregiver, it is important to understand that the person with HD has no control over this; they are not being stubborn or making a conscious choice not to remember or repeat a task. It is the degenerative, unpredictable nature of HD that is the root of the problem.

Strategies for Communication

The listener should accept responsibility for conversation. The HD patient often needs to rely on guidance from the listener to achieve communication. Speak with a speech/language pathologist to help you implement, monitor and adjust the following strategies:

- ◆ Speak slowly
- ◆ Repeat or re-phrase the message
- ◆ Simplify the message... limit options
- ◆ Use Yes/No questions
- ◆ Refocus person on the topic
- ◆ Monitor behavior and provide feedback
- ◆ Allow adequate time
- ◆ Reduce distractions
- ◆ Provide a predictable environment

Stem Cell Research Legislation Coming to WA State

Stem cell therapy research for Huntington's is active in Europe, with Sweden in the forefront. Most exciting are the human studies progressing with Huntington's patients who have undergone stem cell transplant therapy. These people have had significant benefit. While these are admittedly preliminary results, and the study (unpublished as yet) includes only a few individuals, it is the best we've heard for any human Huntington's treatment. These studies are occurring right now in Europe where stem cell research is alive, well, and active.

Unfortunately for the Huntington's families here in the United States, stem cell research is not active. It is not even alive. Our research institutions are crippled by the federal government, which has tightly restricted stem-cell use in federally funded studies. Researchers are allowed to use only stem cell lines in existence in the year 2000. These cell





lines are few, are not easily available to, and are known to not work well for those researchers brave enough to use them. Stem cell scientists have been financially and politically driven away from this research. So this kind of research can't happen in the U.S. unless big changes are made. But wouldn't it be worth working on big changes if Huntington's could be treated?

Fortunately for us, California has taken the first big steps to change this situation. Hopefully, Washington State will soon follow. As of January 1, 2003, California became the first state to endorse stem cell research, by enacting a new law (SB 253). By so doing, it freed up state and private funds to support state universities and biotechnology companies. This was California's political response to the national ruling severely limiting stem cell research. Shortly after, Stanford University in California launched a privately funded stem cell research project with solid state political backing.

Closer to home, Washington State representative Brian Sullivan (from the 21st district southwest Snohomish County) will be sponsoring a similar bill in our state legislature in early 2003. This bill would authorize stem cell research in Washington State in its state-sponsored institutions and biotechnology companies. This would be similar to the California bill: promoting stem cell research from human embryos for therapeutic medical purposes, which includes transplant therapy for Huntington's (and other diseases). The state law (California, and the proposed Washington) specifically bans its use for reproduction (such as cloning a human baby). The present federal law does not prohibit reproductive cloning. Promoting therapeutic stem cell research is very important to the Huntington's community. Wouldn't it be great to have it this close to home and perhaps available to our families!

Stem cells are embryonic cells that are extracted from 4 day old fertilized egg cells grown in a laboratory. These cells are donated from couples undergoing fertility treatment; cells that would otherwise be discarded. These cells can then be selectively grown in cell culture and stimulated to develop into brain cells that could then be transplanted into patients with Huntington's. Stem cell therapy in Huntington's involves injections of these cells into basal ganglia of the brain. This is done through tiny tubes which are placed into the brain using MRI three-dimensional targeting by the neurosurgeon.

To get this "stem cell" ball rolling in Washington State, we need to get this bill passed. Call or write your state legislature member. Call the Legislative Hotline at 1-800-562-6000, state your name and address, and give a brief statement about how you feel about support (or otherwise) about therapeutic stem cell research. With this one call you leave the message for your senator,

representative, and the governor. If you are interested in volunteering for gathering signatures or wish to help in some other way in this effort please contact Hans Wold at 425-772-0940 (who has been instrumental in initiating this Washington State bill) and/or Northwest HDSA at 206-464-9598.

Organizations for Parkinsons disease and juvenile diabetes have also joined this effort. The Huntington's disease community who has for generations suffered this disease with no treatment does surely have the right to pursue research that might effect a treatment for this devastating disease.

Top Five Reasons to Attend a Support Group

The Northwest chapter offers support groups throughout the Northwest. These groups are a great source of support and information about Huntington's Disease.

1. If you are newly diagnosed with HD, you will meet people who have gone through the same things you are experiencing. They will understand. You can learn how others have coped with HD and the choices they have made.
2. If you or a family member has had HD for a long time, you can share your experience. Others will benefit from your years of living with HD. You are the expert.
3. If you are having a "bad time" because of HD, you can present your situation to a support group and get suggestions or ideas you may not have considered and that are helpful.
4. If things are going well, you'll have an opportunity to share your story. Your experience and ideas will benefit others.
5. Researchers and medical professionals periodically speak at support groups. The groups are a great place to learn about the latest research and treatments for Huntington's Disease.

Upcoming Events for 2003

The Survey is Coming

In January 2003, we will be sending out a survey to all of you who receive this newsletter.

The survey was generated by our HDSA chapter, with the assistance of our Center of Excellence professionals. The purpose of the survey will be to obtain your input into needed services and how to best supply them.

We will keep all responses confidential, with the method described in a cover letter that will come with the survey.

Upcoming Events for 2003 (continued)

PLEASE , PLEASE answer and return the questionnaire. Your responses will be taken very seriously and will make our organizations more responsive to local needs. We in advance, thank you.

Spring - Symposium on Drug Development Strategies in Huntington's Disease

There will be a symposium on Drug Development in Huntington's Disease coming to Seattle in late spring. The exact date and location is yet to be determined. We are extremely fortunate to have both Dr. Jim Olson from the Fred Hutchinson Cancer Research Center in Seattle and Dr. Michael Hayden of the University of British Columbia on the speakers list.

Once the date and time are finalized, the information will be announced in local papers, through our Web sites, and all support groups.

May - Shoot for the Cure Hoop-a-thon

The chapter's 3rd annual Shoot for the Cure Hoop-a-thon will be held on Saturday, May 3, 2003 from 11 AM - 2 PM at the Ballard Community Center, which is located at 6020 28th Ave. NW, Seattle, WA.

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 including most baskets sunk in 10 minutes and most funds raised.

To register or volunteer for this exciting event, please call 206-464-9598 or send e-mail to nwhdsa@yahoo.com.

Pledge forms can be downloaded at <http://www.geocities.com/nwhdsa>. We look forward to seeing you there!

July - Pedal for Huntington's Disease!

Ride the Seattle to Portland (STP) Bicycle Classic and help those affected by Huntington's Disease. Pedal for a Purpose provides the opportunity to ride the STP and raise funds for the Northwest chapter. Raise \$350 and you'll ride STP for free—we'll reimburse your \$70.00 registration fee. Raise more than \$350 and you'll earn REI gift certificates.

Complete information about Pedal for a Purpose can be found at <http://www.geocities.com/nwhdsa/pedal.htm> or by calling 206-464-9598.

Cure HD Auction a Success!

The chapter's 4th annual Cure HD auction, held October 19, 2002 at the Red Hook Brewery in Woodinville, Washington was a great success, raising over \$15,000 in support for the University of Washington Center of Excellence. About 125 persons attended the event.

While enjoying delicious food, drinks and music, attendees bid on a wide variety of items including works of art, restaurant meals and hotel stays. Bidding was fast and furious on many of the items. Attendees were also able to participate in a special ribbon cutting ceremony for the University of Washington Center of Excellence and meet the Center's staff.

A great time was had by all. A big thank you to all the individuals and companies who provided items for the auction.



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 1-888-264-HDSA – 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.

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