



# Northwest Chapter HD News

Issue 6

[www.geocities.com/nwhdsa](http://www.geocities.com/nwhdsa)

HELPLINE 888-264-HDSA

Business line 206-464-9598

## Greetings from Our Chapter

Please join us for our first spring/summer fashion show -- THAW, which will be held at the Western Bridge in Seattle, WA on Thursday, May 3, 2007 from 7:00 to 10:00 pm. This is a great opportunity to have fun while supporting our local Huntington's Disease community. Also, a big thank you to everyone who is donating items for this event and to those who plan to volunteer for it. It wouldn't be possible without you. For more details, see the ad in this newsletter or refer to the web site at: <http://www.thawfashionshow.com>

## HDSA Convention Scholarships Available

If you are interested in attending this year's HDSA 22nd Annual Convention in Oklahoma City, OK, June 15 to 17, 2007, scholarships of \$1,000 each are still available. Please contact Liz Weber, our Northwest Chapter President, at 206-235-5871 by April 15, 2007.



## Volunteers Wanted

If you are interested in volunteering to help set up and take down for THAW, our spring fundraiser, call Liz Weber at 206.235.5871 for details. The first ten people to sign up will get a free ticket to the show.

## THAW

A spring/summer fashion show featuring independent designers from Seattle, Portland, New York and LA benefiting the Huntington's Disease Society of America (HDSA).

**WHEN:** Thursday, May 3, 2007

**WHERE:** Western Bridge, 3412 4th Avenue South

**TICKETS:** \$100/person – reserved seat, martinis, wine and dessert bar

\$500/person – table seating with wait staff providing drinks, includes discounts starting at 20% for Tulip, Errice', Sway and Cake, Les Amis, Carmilia's and Bowie Salon

\* ALL guests receive a 15% discount at Julep Nail Parlor.

### DESIGNERS:

A Broken Spoke - <http://www.abrokenspoke.com/>

Liza Rietz - <http://www.lizarietz.com/>

Kate Towers - <http://www.katetowers.com/>

Elizabeth Dye - <http://www.elizabethdye.com/>

Emily Ryan

Frocky Jack Morgan

Peeta Tinay

Pinkham Millinery - <http://www.pinkhammillinery.com/>

Thread

Alica + Olivia

### LIVE AUCTION

NYC Fashion Week for Two: Marc by Marc by Jacobs runway show, Nobu, Bliss Spa and more...

Giselle Bundchen gift bag: Some of the model's favorite things selected personally for this event, Gucci handbag, Roberto Cavalli sunglasses and more...

Photo shoot with L.A. Fashion Photographer Michael Dar, including professional hair styling and makeup application.

### SILENT AUCTION (continued)

Accessories by independent designers, including Mineral by Lisa Kinoshita, Dana Faith, Cero Designs, Kimberly Baker, Peeta Tinay, Amy Tavern, Pinkham Millinery, Demimonde by Rachel Donaldson, Patricia No, Emily Nemesi, Lasposa, Crystalyn Kae, Alisha Louise, Flora and Fawn and more...

### ABOUT HUNTINGTON'S DISEASE (HD)

Huntington's Disease is a devastating, hereditary, degenerative brain disorder for which there is, at present, no effective treatment or cure. HD slowly diminishes the affected individual's ability to walk, think, talk and reason. Eventually, the person with HD becomes totally dependent upon others for his or her care. HD profoundly affects the lives of entire families — emotionally, socially and economically.

Each child of an affected parent has a 50% chance of inheriting the HD gene. For more information, please go to [www.hdsa.org](http://www.hdsa.org).

## Getting to Know Our HD Investigators



Dr. Peskind is a professor in the UW Department of Psychiatry and Behavioral Sciences and the head of the Mental Illness Research and Clinical Center (MIRECC) at the VA Puget Sound Health Care System. She is an experienced researcher with an interest in the cerebrospinal fluid (CSF)

biomarkers of neurodegenerative brain diseases. She has done more than 500 lumbar punctures in her 20 year research career to collect CSF for various studies. She runs the largest CSF bank in the US. Dr. Peskind attended medical school and completed her residency in psychiatry at the UW. Then, she did a VA research fellowship in geriatric psychiatry. She enjoys photography and caring for her Doberman puppy and two cats. Dr. Peskind is collecting spinal fluid samples in persons with HD to determine if there are biochemical changes useful in tracking the progression of symptoms. Results could be useful in identifying the stages of HD or monitoring the effects of treatment. If you would like to find out more about Dr. Peskind's HD spinal fluid project, call Hillary Lipe, ARNP at 206-277-1825.



### Suman Jayadev, MD

– Dr. Jayadev attended New York Medical College for her basic medical education, then attended the University of Washington for a residency in neurology, followed by a fellowship in neurogenetics with Thomas Bird, MD. She is now part of the faculty in the Department of Neurology at the

UW. Dr. Jayadev cares for patients in the Medical Genetics Clinic at the UW and teaches medical students and neurology residents at Harborview Medical Center. Her research interests include the biology of brain cells in neurodegenerative disorders. She has an infant daughter and enjoys hiking. Dr. Jayadev currently has a research project entitled **Retinal Degeneration as a Biomarker for HD** evaluating whether mild alterations in the retina of people with HD can be used as an early biomarker of disease. She measures retinal function by an electroretinogram or "ERG". This is a test that has been used by ophthalmologists for decades and is a standard and safe procedure. The test takes about 1–2 hours and requires wearing a measuring electrode on the eye that is similar to a contact lens. If people with HD have measurable differences in retinal function compared to controls, the ERG might serve as a means to follow response to new drug treatments and for following progression of HD. If you would like to speak with Dr. Jayadev, she can be reached at 206/221-2930 or email [Sumie@u.washington.edu](mailto:Sumie@u.washington.edu).

## HD Symposium

The HD Symposium, held on Saturday, October 21, 2006 at the UW Medical Center, was a great success! It was sponsored by the HDSA NW Chapter, UW HD Center of Excellence, and the VA Puget Sound Health Care System. The purpose was to provide the latest information for HD families and care providers.

Pierre's Story, a moving film documentary about HD, was shown by producer Rob Hopping. An update on the latest in genetic research was presented by Vicki Wheelock, M.D.

The afternoon breakout sessions included the following topics:

- Genetic testing and counseling — Genetic Counseling Staff, University of WA Medical Genetics Clinic
- How to Secure Help: The ABC's of Connecting to Programs and Services – Donna Ross, M.S.W.
- Finances and Estate Planning – Sean Bleck, J.D.
- Approaches to Behavior Issues – Rebecca Logson, Ph.D. and Hillary Lipe, A.R.N.P. VA Puget Sound Health Care System

## 10,000 Mile Walk for HDSA

It's another walk in the park for ultra-walker Don Stevenson of Auburn, WA. Just three months after completing a 2,400 mile charity walk in Ohio for the American Cancer Society, Don began a ten thousand mile walk in the Auburn's Game Farm Park at 9:00 A.M on Monday, January 9<sup>th</sup>, 2007.

Don will be averaging 34 miles a day Monday through Saturday. It will take twelve months to complete the walk.

Don will be joined by triathlete, Jack Meteyer, who besides being the event and public relations coordinator, will contribute several hundreds of miles of running and walking himself.

This Huntington's Disease (HD) Awareness Walk is dedicated to the memory of Jack's natural mother and three siblings who died with HD. By God's grace, Jack was spared from being infected with the HD gene.

Everyone is welcome to visit and walk with Don and Jack at the Game Farm Park throughout the year, between 6 a.m. and 2 p.m. Monday through Saturday. There will be free coffee, snacks and information about HD. If you have a chance, please come out to support these great people!

To make a contribution, call: 206-464-9598. Or send your check to:

Huntington's Disease Society  
P.O. Box 33345  
Seattle, WA 98133

Please indicate that your contribution is for the "Park Walk." Don's email is: [donlssixty-two@juno.com](mailto:donlssixty-two@juno.com). Jack's email is: [jackmeteyer@comcast.net](mailto:jackmeteyer@comcast.net).

## 2007 Drive Toward A Cure BMW Sweepstakes!



Help us raise funds for HD research. Give yourself and your friends a chance to **win...**

**Grand Prize:** 2007 BMW 328i Sedan or \$25,000

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

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

**Fourth Prize:** \$750 cash

**Fifth Prize:** \$500 cash

\$100 donation requested per ticket. Buy 2 and get the third one free!

Remember that all proceeds will benefit HDSA Research Programs.

### RSVP Immediately!

Winners will be drawn at the HDSA National Convention on June 16, 2007 in Oklahoma, OK.

For additional tickets or more information, call 800-345-HDSA ext. 210.

**Good luck!**

**We would like to thank BMW of North America for helping to make this annual sweepstakes possible.**

## Latest Research News

### University of British Columbia Lab Prevents HD in Mice

**Article Date : 09/13/2006**

*The next step is finding a drug to create the same effect.*

Lead researcher Dr. Rona Graham examines an x-ray showing the fragments of huntingtin protein from the brain of a person with HD (photo by Alexandra Howard, UBC).

The cure for Huntington's disease may be one step closer.

Researchers at the University of British Columbia (UBC) have demonstrated that they can prevent HD from occurring in mice that carry the same harmful genetic mutation as humans.

One of the biggest research advances since the identification of the HD gene in 1993, the discovery involves a scissors-like enzyme called caspase-6. Caspase-6 snips the mutated huntingtin protein inside a brain cell in a way that releases a toxic fragment of the protein and thus contributes to cell death. The researchers altered the huntingtin protein in their mice so that caspase-6 could no longer cut it.

Upon examination these mice showed no symptoms of Huntington's and displayed normal brain function. In addition, exposure of their brain cells to harmful substances thought to cause problems in HD did not lead to any negative consequences.

"Basically what we've been able to do is identify a target that we can go after for a therapeutic approach to Huntington's disease," said Rona Graham, Ph.D., the lead author of the research study, which was published in the June 16, 2006 issue of the journal *Cell*. "It's like a system of locks and keys. We changed a lock so that the key doesn't fit anymore. Caspase-6 is the critical player. When you block it, you don't get the symptoms."

"This is a monumental effort that provides the most compelling evidence of [the fragment] hypothesis to date," said Dr. Marian DiFiglia, a professor of neurology at Harvard Medical School and one of the world's leading HD experts.

The next stage in the research involves finding a drug that can be implemented in the mice to produce the same effect as the genetic engineering performed by Dr. Graham and her fellow researchers at UBC's Centre for Molecular Medicine and Therapeutics. The UBC team has already begun this task. So has the CHDI, Inc., the nonprofit HD drug development organization. According to Dr. Robert Pacifici, CHDI's chief scientific officer, the organization hopes to have a caspase-6 inhibitor ready for testing in mice by the end of 2006.

If safe and effective inhibitors can be found for animals, the next goal would be human testing. Another possible treatment would involve the use of gene therapy to produce a caspase-6-blocking antibody.

"Our findings are important because they tell us exactly what we need to do next," said Dr. Graham, who added that caspase-6 is implicated in Alzheimer's disease. "We're starting to see that there are certain proteins involved in more than one disease. That's where the implications of this research could be very large."

Dr. Graham declined to forecast a timeline for a human caspase-6 treatment, because research is often a slow and painstaking process. Arriving at the caspase-6 discovery was like finding the proverbial needle in a haystack, she said. Aside from finding caspase-6 inhibitors, she and other researchers must still answer many other questions about the interaction between caspase-6 and the huntingtin protein, the role of other caspases, and the effects of cleavage in the cell. Researchers must also be sure that blocking caspase-6 will not cause harmful side effects.

She said, however, that the response from the HD community has been "incredible."

"We got so many e-mails from patients. The patients did understand. They know that this is a major breakthrough, but that a pill is not ready yet."

## Caregiver's Resources

Government Dept. of Health & Human Services has a link to the National Family Caregiver Support Group Program: [http://www.aoa.gov/press/nfc\\_month/2003/how\\_to\\_use.asp](http://www.aoa.gov/press/nfc_month/2003/how_to_use.asp) <[http://www.aoa.gov/press/nfc\\_month/2003/how\\_to\\_use.asp](http://www.aoa.gov/press/nfc_month/2003/how_to_use.asp)>

The left-hand column has resources on:

### Help! Where To Find It

[http://www.aoa.gov/press/nfc\\_month/2003/how\\_to\\_use.asp](http://www.aoa.gov/press/nfc_month/2003/how_to_use.asp) <[http://www.aoa.gov/press/nfc\\_month/2003/how\\_to\\_use.asp](http://www.aoa.gov/press/nfc_month/2003/how_to_use.asp)>

Using the Eldercare Locator, State and Area Agency on Aging, State Family Caregiver Support Program Contacts, State Caregiver Websites and other resources. For example I clicked on the State Caregiver Websites, then Florida and got the link to Florida's Department of Elder Affairs. Granted, most are for seniors but there are some good resources and info to.

### Taking Care of Others

[http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking\\_care\\_of\\_others/taking\\_care.asp](http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking_care_of_others/taking_care.asp) <[http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking\\_care\\_of\\_others/taking\\_care.asp](http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking_care_of_others/taking_care.asp)>

Provides list of caregiving resources that have been developed through the National Family Caregiver Support Program and AoA, but also has booklets in PDF format for downloading.

These are really well written and informative *free* booklets!/  
Jean

Advance Care Planning - Making Choices Known  
<[http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking\\_care\\_of\\_others/docs/ECHO1.pdf](http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking_care_of_others/docs/ECHO1.pdf)>

- A workbook to document the kind of care you want if you are unable to make decisions for yourself. Includes web addresses to find your state's forms.

Planning Ahead - Funeral and Memorial Services  
<[http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking\\_care\\_of\\_others/docs/ECHO2.pdf](http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking_care_of_others/docs/ECHO2.pdf)>

- A workbook to document your funeral or memorial service preferences ahead of time. Includes tips for consumers.

Preparing to Say Good-Bye - Care for the Dying  
<[http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking\\_care\\_of\\_others/docs/ECHO3.pdf](http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking_care_of_others/docs/ECHO3.pdf)>

- Learn about common symptoms experienced by dying people and what you can do to make the dying person more comfortable

When Death Occurs - What to Do When a Loved One Dies  
<[http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking\\_care\\_of\\_others/docs/ECHO4.pdf](http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking_care_of_others/docs/ECHO4.pdf)>

- Learn about the common expressions of grief, the healing process, and when to get help

Help For The Bereaved - The Healing Journey  
<[http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking\\_care\\_of\\_others/docs/ECHO5.pdf](http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking_care_of_others/docs/ECHO5.pdf)>

- Learn about the common expressions of grief, the healing process, and when to get help.

### Taking Care of You

[http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking\\_care\\_of\\_you/taking\\_care\\_of\\_you.asp](http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking_care_of_you/taking_care_of_you.asp) <[http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking\\_care\\_of\\_you/taking\\_care\\_of\\_you.asp](http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking_care_of_you/taking_care_of_you.asp)>

Taking care of your health is important, no matter what your age. This is especially true for caregivers who often overlook their own health needs as they care for loved ones. The section below is just for you! Take a few moments to read through the basic health tips and special health conditions highlighted in this section for a healthier you! Scan down for a whole section on **Managing Your Stress**.

## UW Research Volunteers Wanted

### Department of Radiology Research Subjects Needed

Researchers at the University of Washington are doing a study to see if some non-invasive methods can be used to judge the progress of Huntington's Disease in patients. The researchers will study both brain and muscle. In the future these methods could help doctors decide when to prescribe medications and help determine how well treatments are working. This is not a treatment trial, and no medications will be prescribed or tested. Males and females ages 18 – 65 years who have the gene mutation for Huntington's Disease are invited to participate as subjects. The gene mutation must have been confirmed by genetic testing, and volunteers must have either no symptoms or mild symptoms of the disease. Volunteers

are not eligible if they have a heart condition, pace-maker or other implants, or diabetes. They must not be obese or shorter than 5 feet 2 inches tall, and must not have had a blood clot or recent major surgery on the abdomen, hip or legs. Females cannot be pregnant or in the first year of oral contraceptive use. Research subjects will have magnetic resonance scans (MRI) done as part of the testing. Participation involves attendance at 7 testing sessions ranging from 1 - 4 hours per session. Testing will be done in Seattle at a baseline time (4 sessions) and then follow-up one year later (3 sessions). Subjects will receive \$50 per session, so \$350 if all sessions are completed. Compensation for some travel-related expenses may be available to subjects who do not live in the greater Seattle area. For more information, please contact Mercy Laurino at (206) 598-8771.

## New Support Group in Renton, WA

A caregiver support group has been formed.

Date: 1st Saturday of each month, 10-11:30am.

Location: Valley General Hospital, Renton. First floor, Medical Arts Center Building, room D.

Questions: Call Craig Williams, group facilitator, 253-735-4103

Directions: Driving north or south on I-5, take the northbound I-405 exit. At Renton, take the southbound Hwy 167 (Kent/Auburn) exit. From 167 **southbound**, take the first exit, South 180th. Off the exit, turn left at the signal on East Valley Rd, then turn left at the next light, heading east on SW 43rd Street. If you're **northbound** on Hwy 167, take the 43rd Street exit. Turn right off the exit onto 43rd Street South. To reach the main entrance, turn left at Talbot Road South, then left again onto the campus.

The campus is located just east of Hwy 167 at the intersection of SW 43rd Street and Talbot Road South.

## Group Health Seattle to Portland Classic

My father James Lee had Huntington's Disease and passed away on 8/22/05. He was a hard working man and a dedicated father and husband. I wanted to do something in his memory, so I am training for this two day event. Approximately 200,000 people are at risk for inheriting the gene that causes this disease. I am one of them.

The bike ride is a 200 mile ride from Seattle to Portland and takes place on July 14th and 15th. Please consider supporting my friends and I in our efforts to raise awareness and funding for the NWHDSA. We are collecting pledges for the bike ride with a goal of raising at least \$5,000. Please e-mail me at [Mandy5lee@yahoo.com](mailto:Mandy5lee@yahoo.com) if you would like to pledge money towards our bike ride. You can also contact the NW HDSA at 206-464-9598 and donate money towards this event. Any pledge amount will be truly appreciated.

Mandy Kipfer (Lee)



Mandy and her dad

## ORDER FLOWERS FROM HDSA

Now when you order flowers at [hdsa.flowerpetal.com](http://hdsa.flowerpetal.com), 12% of each purchase goes to HDSA. There are no fees delivery!

### Sales (to place a new order)

Toll Free: 1.800.976.2830 (24 hours a day, 7 days a week) Facsimile: 1.800.530.6059

Email: [florist@flowerpetal.com](mailto:florist@flowerpetal.com)

## HD Support Groups and Contact Persons

### Alaska

Marti Bradley 907-258-5665

### Idaho

Bay View Peggy Webb 208-683-2704

Boise Anne Spencer 208-334-2235,  
ext. 258

Coeur d'Alene Barbara Tucker 503-494-8307

Glenda Weaver 208-769-7896

Clarksfork Carolyn Vogel 208-266-0266

Sandpoint Sharon McCahon 208-265-7915

### Montana

Whitefish Joanne Friedenber 406-892-3179

Patty Morris 406-862-3977

### Oregon

Portland Karen Kovack 503-494-8307

CDRC Genetics 503-494-5606

### Washington

Centralia Ruth Tremblay 360-736-2294

Clallam County Joan Greiger 360-683-3798

Kitsap County Angie Gordon 360-697-6870

Mukilteo Bill Pew 425-745-9468

Hans Wold 425-353-4002

Linda Dixon

Renton Craig Williams 253-735-4103

Seattle Amelia Schultz 206-363-4304

Seattle Donna Ross 206-598-8753

Sequim Joan Geiger 360-683-3798

Southwest Russ Kastberg 360-425-9338

Spokane James or Patti Hook 509-276-8038

Rhea Kine 509-747-4735

Nick Suksdorf 509-838-6364

Tri-Cities –  
W. Richland Carl Gallion 509-967-9161

Wenatchee Kathy Wolf 509-663-0399

### Washington (continued)

509-548-7622

Vancouver Russ Kastberg 360-425-9338

Tom Gillihan 360-425-8477

Yakima Joyce Korevaar 509-225-4429

509-548-7622

### HD Support Groups

- On the second Monday of each month an HD Support Group meets at the Swedish Hospital (conference room 305) in Ballard. All are welcome.

- Additionally, a neurogenetics adult support group meets the first and third Thursday of each month from 2:00-3:30 at the University of Washington CHDD building room 365.

**The Northwest Chapter  
Can Use Your Help!**

### Contributions

We gratefully accept contributions. The Huntington's Disease Society of America is a non-profit agency and all donations are tax-deductible.

### Volunteers

For further information about volunteer opportunities, please call our chapter business line at 206-464-9598. You can also send us e-mail at [nwhdsa@yahoo.com](mailto:nwhdsa@yahoo.com). If you are interested, please contact Liz Weber, our chapter president, at [lweber@natlogic.com](mailto:lweber@natlogic.com).

All telephone calls and e-mail to us will be kept strictly confidential.

You can also write to us at:

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

*If you would like to send an article or editorial viewpoint for consideration in the newsletter, please send an e-mail to: [maxi@halcyon.com](mailto:maxi@halcyon.com).*

The Northwest Huntington's News attempts to report all items of interest relating to individuals with Huntington's Disease, their families, health care professionals, and interested friends and supporters. HDSA and the Northwest Chapter do not provide medical advice, nor do they promote, endorse or recommend any product, therapy or institution. Please check all drugs, treatments, therapies and products with your physician. Statements and opinions expressed in articles are not necessarily those of HDSA, Inc. and the Northwest Chapter.

Moving or no longer want to be on our mailing list? Call our Chapter HELPLINE at 206-464-9598 or 1-888-264-HDSA. This will help us conserve paper and postage.



**Huntington's Disease  
Society of America  
Northwest Chapter**  
Post Office Box 33345  
Seattle, WA 98133

**RETURN SERVICE REQUESTED**

## Chapter Board and Officers

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Jerry Mickelson, <b>Treasurer</b>	425-828-3198

University of Washington - Center of Excellence  
**HELPLINE Donna Ross 1-888-264-HDSA**

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Donna Ross, <b>MSW Social Worker</b>	206-598-8753
Dr. Thomas D. Bird, <b>Medical Advisor</b>	206-764-2021
Estelle Klasner, <b>MA, CCG-SLP</b>	206-362-9123
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**Helpline: 888 264 HDSA (4372)**

**Business: 206 464 9598**

**Website: [www.geocities.com/nwhdsa](http://www.geocities.com/nwhdsa)**

**Email: [nwhdsa@yahoo.com](mailto:nwhdsa@yahoo.com)**