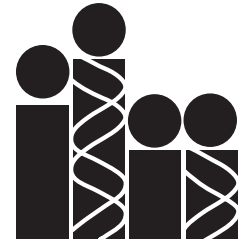


Northwest HUNTINGTON'S News

HUNTINGTON'S DISEASE SOCIETY OF AMERICA • NORTHWEST CHAPTER



Thank You to King County Council

The Northwest Chapter recently received a \$5,000 grant from the King County Council. The grant, coordinated through the Seattle-King County Department of Public Health, supports social services for persons with Huntington's Disease and their families. The Chapter will use the grant to provide continued funding for its family services coordinator position at the University of Washington.

Our current family services coordinator is Catherine Kendall, MSW (206-221-5390, or ckendall@u.washington.edu). Catherine is available to meet with individuals and families to discuss Huntington's Disease testing, provide consultation about the progression of Huntington's Disease and make referrals for medical care. Catherine is also able to provide information and training about HD to medical personnel and nursing homes.

The Chapter especially would like to thank King County council member

Second Annual Cure HD Auction

Our Second Annual Cure HD Auction will take place 7-10 PM, October 14, 2000 at the Red Hook Brewery in Woodinville, Washington. The auction will raise funds to support our family services coordinator position at the University of Washington. Tickets are \$35, which includes appetizers and drinks.

A wide variety of exciting goods and services will be up for bid, including a famous Ghiglieri bronze sculpture. Our goal is to have enough funds to make the family services coordinator position a full time position. Imagine – a highly trained

& experienced social worker available to provide a wide variety of services to you and your family 40 hours a week. If you're unable to attend the auction, please consider contributing an auctionable item or service or giving a donation. We're also looking for volunteers to help organize and run the auction.

To purchase tickets or if you're able to help with the auction, please contact Rachel Mickelson (rachel.s.mickelson@boeing.com, or 425-828-3198).

We look forward to seeing you there!

President's Letter

I'm just back from the 2000 Huntington's Disease Society of America Convention and I'm excited and energized. I'm excited about all the HD research underway and the number of scientists pursuing HD solutions. I'm excited about HDSA's recent partnerships with major pharmaceutical firms like AstraZeneca and Athena Diagnostics.

I'm also excited about what's happening with our chapter...your chapter. We continue to grow and expand our services. We just added a new person to the Chapter's board of Directors and are close to adding a second. Catherine Kendall, our family services coordinator at the University of Washington, is now providing services 20 hours a week to HD persons and their families. Our chapter web page (www.geocities.com/nwhd-sa) provides much information about HD and receives hundreds of hits each month. We also continue to offer support groups throughout the Northwest.

(Continued on page two)

SUMMER 2000

Serving
Alaska
Washington
Oregon
Montana
and
Idaho

Inside

2nd
Annual
Cure HD
Auction

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HDSA
Convention

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Thank You!

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Oregon
ManWins
Sweepstakes

Chapter Address
P.O. BOX 33345
Seattle, WA 98133

HELPLINE
(206) 464-9598
(888) 264-HDSA



President's Letter

(Continued from front page)

Perhaps most exciting of all, we have been working to establish a Center of Excellence at the University of Washington. Currently, the University of Washington has been invited to apply to be a Center of Excellence. Centers of Excellence are HD clinics that provide comprehensive multidisciplinary clinical services to HD persons and their families. The invitation to apply is the first of several steps for the University in becoming a Center of Excellence.

All of the above exciting activities take time, energy and money. Please help us to help you. We will be holding the Second Annual Cure HD Auction on October 14, 2000 at the Red Hook Brewery in Woodinville, WA. The event will raise funds to support our family services coordinator position. If you are unable to attend, please consider contributing an auctionable item or donation. We're also looking for volunteers to help organize and run the auction. If you're able to help, please contact Rachel Mickelson (rachel.s.mickelson@boeing.com, or 425-828-3198).

We're also continuing our search for people interested in joining the Chapter's board of directors. Board membership does not require lots of time and there are many opportunities to help HD persons and their families. If you are interested in being considered for the board of directors, please contact Steve Weil (206-789-7941, or steveweil@yahoo.com). Finally, please let the board of directors know how it can serve you better. Please direct any comments and questions you might have to Steve Weil at the above phone number or e-mail address.

Together, we can make this the last generation with HD.

Chapter General Meeting

You are invited to attend the Huntington's Disease Society of America Northwest Chapter's general meeting on Sunday October 8, 2000. The meeting will be at Greenlake United Methodist Church at 6415 1st NE, 1 block from Green Lake in Seattle, Washington.

Come talk with your chapter's board of directors and your fellow members. Share your ideas and learn about the exciting chapter events that are coming up. You will also have the opportunity to meet Carmen Leal, well known HD writer and speaker. More information about Carmen can be found at <http://www.writerspeaker.com>.

The meeting will be potluck so please bring food or drink. We look forward to seeing you there.

Own a Famous Ghiglieri Bronze Sculpture!

A lovely Ghiglieri bronze sculpture will be up for bid at our 2nd annual Cure HD auction. Ghiglieri sculptures are displayed throughout the world and owned by many celebrities and public officials. More information about Ghiglieri sculptures can be found at <http://www.finearttrust.com/index2.html>.

Come to our October 14, 2000 auction at the Red Hook Brewery in Woodinville, Washington and you could walk away with a wonderful sculpture.

HDSA Convention

The 15th annual Huntington's Disease Society of America convention was held June 9-11, 2000 in sunny Orlando, Florida. Approximately 750 persons attended the convention. They came from all over the United States and a few were even from other countries.

The convention began with the keynote address from the Editor-in-chief of Today's Caregiver Magazine. He presented statistics indicating that many Americans are or will be caregivers. The main focus of his talk was encouraging caregivers, particularly HD caregivers to become "Advocate Caregivers."

Following the keynote address, the first annual Athena diagnostics family services and care forum took place. A panel of HD persons and medical experts discussed how to maintain the integrity of the person with HD and the HD family. The persons with HD discussed how they cope with HD and the medical experts offered many suggestions for living with HD.

Next came a wide variety of workshops and panels. Topics covered were learning about Huntington's Disease and family services & care. Within each topic, a wide variety of HD experts and non-experts provided much encouragement and useful information to their audiences.

Saturday began with the AstraZeneca pharmaceuticals research forum. The forum began with an address by James Gusella, Ph.D., one of the discoverers of the HD gene. Following Dr. Gusella's address, a variety of HD doctors and researchers, including Nancy Wexler, Ph.D., presented their work.

In the afternoon, a wide variety of workshops on issues for the HD family took place. The workshops were followed by "Ask the Professionals" sessions. Professionals from a wide variety of fields answered questions from HD persons and their families. The day concluded with the always fun convention dinner. A number of awards were given out and the dinner ended with dancing till midnight.

I really enjoyed attending this year's HDSA convention and encourage everyone to attend next year's convention in San Diego. It was exciting to hear about all the current HD research and to see many persons and families coping with HD in dignified, caring ways.

The conventions are very well organized and designed to be "HD friendly." I came away with much useful information about HD. The conventions offer a great opportunity to meet with HDSA national staff and to exchange ideas with HD persons and their families from all over the world. See you in San Diego!

— Steve Weil

Thank you Blakely Elementary School!

Blakely Elementary School on Bainbridge Island recently conducted a fundraiser called "The Blakely Fitness Challenge" and raised \$3162 for HD research and support services. The school graciously donated half to research conducted by Dr. Thomas Bird at the University of Washington and half to funding our chapter's family services coordinator (206-221-5390 / ckendall@u.washington.edu).

Karen Evans, the school's physical education specialist was instrumental in organizing the "Blakely Fitness Challenge," where kids walked around their school track and adults pledged up to ten cents a lap. Two children "won" with 132 laps and 116 laps respectively.

Great job to all the teachers, parents and children who participated and contributed to the fundraiser. A big thank you from the Chapter!

HDSA Makes NCIB List-Again!

We are pleased to report that the Huntington's Disease Society of America has once again met all the standards of the National Charities Information Bureau (NCIB) and has been included in its list of not-for-profit organizations. NCIB is considered the watchdog of charitable organizations. Corporations, foundations and individuals considering making donations use its list as a resource. The NCIB's evaluation of a national charity is based on the assessment of the organization's policies, practices and operations, in accordance with the Bureau's high standards of philanthropy.

Oregon Man Wins HD Sweepstakes!

On June 10, 2000, the holder of a ticket sold by our chapter was drawn as the winner of the Grand Prize in the 2000 Cure HD sweepstakes, a 2000 BMW Z3 roadster 2.3. The winning ticket was purchased by a Beaverton, Oregon man who wishes to remain anonymous. When contacted, the man expressed shock and delight at having won the car. He is currently considering what to do with his exciting prize.

Second prize was a \$10,000 U.S. Savings Bond. Third prize was a \$5,000 U.S. Savings Bond and three fourth prizes of \$1,000 U.S. Savings Bonds were awarded. This year, the Northwest Chapter sold 38 Cure HD Sweepstakes tickets, raising nearly \$1000 for Huntington's Disease research.

Maybe you'll be next year's winner!



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="checkbox"/> Board Member | <input type="checkbox"/> Nominating | <input type="checkbox"/> Speakers Bureau | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Finance | <input type="checkbox"/> Volunteer Development | <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__Medical | <input type="checkbox"/> Computer Skills | _____ |