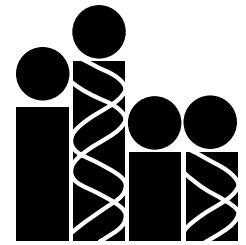


# Northwest HUNTINGTON'S News

HUNTINGTON'S DISEASE SOCIETY OF AMERICA • NORTHWEST



## Flowers for the Cure

HDSA has a new preferred Teleflora service. Using HDSA's new floral affiliate, FTD, you can order a wide variety of beautiful flower arrangements. Fifteen percent of each purchase will be donated to HDSA's research, education and family service programs.

FTD is a renowned international Teleflora with a long tradition of excellent service. FTD offers a wide variety of arrangements for holidays and special occasions, or they can create an arrangement that fulfills your requirements. FTD can deliver flowers and gifts all over the world!

There are two easy ways to order:

- 1: Via the Internet at [www.ftd.com/hdsa](http://www.ftd.com/hdsa)
- 2: Via telephone at (800) SEND-FTD (800-736-3383), using reference code 3015. This code guarantees that 15 percent of your purchase will be donated to HDSA.



Please visit our new floral partner, FTD, and give a gift that gives all year long!



## Centers of Excellence

Centers of Excellence is an exciting new HDSA program meant to create stable regional centers providing high quality clinical care and services for individuals affected by HD and their families. In addition to clinical and family services, Centers of Excellence provide professional and lay education and are involved in HD clinical research.

Centers of Excellence are 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.

**The University of Washington (UW), in Seattle, WA, has applied to be a Center of Excellence. HDSA is currently considering the application and will make a decision early March 2001. Think about it—a specialized HD clinic dedicated to providing services to the Northwest.**

**Please help make this dream come true. A center of Excellence requires funding. An anonymous donor has already pledged \$10,000 towards UW becoming a Center of Excellence. Please consider making a matching donation to the chapter to support this exciting initiative.**

## WINTER 2001

Serving  
Alaska  
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Oregon  
Montana  
and  
Idaho

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

**HELPLINE**  
**(206) 464-9598**



## President's Letter

I Hope everyone had a safe and peaceful holiday season. The beginning of a new year is always an exciting time, filled with hope and possibility. I think there is much to be hopeful for; more and more money and attention is being focused on Huntington's Disease research. We seem to be getting closer and closer to a real treatment for HD and perhaps even a cure. HDSA is expanding at an exciting rate and now offering a wide variety of services for HD persons and their families.

Your chapter is also filled with hope and possibility for 2001. We are particularly excited that the University of Washington in Seattle, Washington is being considered for a HDSA Center of Excellence. More information about what a Center of Excellence can be found elsewhere in the newsletter. If the University of Washington is selected, it will benefit the entire Northwest.

We are also hoping to expand the services provided by our social worker Catherine Kendall, MSW. We are hopeful that we can raise enough funds in 2001 to increase her availability from 20 hours a week. Catherine can be reached at 206-221-5390 or through our chapter help line at 1-888-264-4372.

We plan to put on some exciting events in 2001. We'll be having a hoopathon in April or May and also will likely be putting on a Cajun music concert in the first half of 2001. We also hope to hold a HD symposium where a wide variety of experts will discuss the various aspects of HD. Details will be coming about all these events. And of course, we'll be holding our auction again!

All the above takes time and energy. There continue to be a variety of ways to become involved with the chapter and help yourself and others. All of the above events will benefit from volunteers. We are also continuing to expand our board. We are currently looking for new board members who have skills in any of the following areas:

- Finance
- Fund-raising
- Marketing/Public relations
- Legal
- Social work

If you would like to volunteer or be considered for a board position, please give me a call at 206-789-7941. Let's have a great year and cure HD!!!

## Persons needed for PHAROS study

Dr. Thomas Bird, the medical advisor for our HD chapter, needs persons between the ages of 30 - 55, who have never been tested for the HD gene, for an observational study at the University of Washington.

During the study, subjects will be evaluated every nine months for a total of three years, using a short neurological examination and brief testing of concentration and memory. Each evaluation takes approximately one hour. A blood sample is taken at

the beginning of the study and confidentially tested to determine if the participant has the gene for HD. Neither the study subject nor any of the physicians or nurses in PHAROS will ever learn the results of individual gene tests. This study will provide essential information for future trials of experimental drugs to postpone onset of HD.

If you are interested or have any questions, please phone the study coordinator, Hillary Lipe, RN, at (206) 277-1825 or (800)329-8387 X61825.

## Internet Support Group Formed

The chapter is pleased to announce the formation of a new Internet support/informational group hosted by our social worker, Catherine Kendall, MSW. The first group will meet on the Internet on February 1, 2001 on Thursday at 11:00 a.m. PST. This free group will meet weekly.

The purpose of the group is to provide support and information to individuals with HD, family members and friends, and health professionals. You must preregister for the group a day before the first session you would like to attend. Preregister by sending Catherine an e-mail at [ckendall@u.washington.edu](mailto:ckendall@u.washington.edu) or calling 1-877-264-HDSA. For step-by-step instructions, visit <http://hometown.aol.com/catjon7> and click on the hyperlink next to the HD group announcement.

## Hoopathon To Be Held May 19

A Shoot for the Cure hoopathon will be held May 19, 2001 11-3 p.m. at Ballard community center in Seattle, Washington. The center is located at 6020 28th Avenue NW.

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 hoopathon is open to all ages and skill levels. Teams and individuals are invited. Prizes will be awarded in many categories including most baskets sunk in 10 minutes and most funds raised.

To register or volunteer for this exciting event, please call 1-888-264-4372. We look forward to seeing you there!

## Second Annual Auction a Success!

The chapter's 2<sup>nd</sup> annual cure HD auction, held October 14, 2000 at the Red Hook Brewery in Woodinville, Washington was a great success with over \$9,000 raised, twice as much as last year. The auction was hosted by well known DJ Tim Hunter and local band Nowhere Band provided lots of great music.

While enjoying hors d'oeuvres & drinks, attendees bid on a wide variety of items, including vacation trips, works of art and services. Bidding was fast and furious on many items.

A good time was had by all. Planning has already started for next year's auction which we expect to be even bigger and better.

## HD Support Groups Report

Catherine Kendall, MSW

The **Seattle Caregivers Group** meets the second and fourth Wednesday of the Month at the Greenwood Senior Center at 9:00 a.m. The facilitators are Amelia Schultz, Ph.D., MSW and Karin Mack. Occasionally, I have substituted as a facilitator when Amelia or Karin are out of town. This is a strong and dedicated support group. Many in the group talk about the meaning of knowing others that have been through the emotional terrain of caring for a loved one with HD. If you are interested in attending this group call Amelia Schultz at 206-363-4304.

The **Portland Support Group**, for individuals affected by HD and their loved ones, meets the first Thursday of each month at Oregon Health State University at 7:00 p.m. It is facilitated by Karen Kovac, Medical Genetics Counselor. I attended in September. Karen had sent out announcements to group members that I was planning to attend and over 20 people came! In addition, Penny Hogarth, the new neurologist at OHSU, attended the meeting. The group lasted for almost two hours. I was impressed by the vitality of this support group and their generosity in welcoming me. The group boasts a married couple who met at the group and have been married for several years. They both have HD and live in an assisted living facility near Portland. The couple is grateful for HD because it assisted them in meeting one another! I would recommend this group to anyone living in Southern Washington and Northern Oregon. Please contact Karen Kovac at 503-494-5606 for more information.

On Tuesday September 12, 2000 I was invited to attend the **Tacoma Support Group** by Jane Gidney, group facilitator. The group meets the second Tuesday of the month in the Stillacum Lutheran Church. Jane has been a group facilitator for many years. She also is an Occupational Therapist who works with many HD patients at

Western State Hospital. This group is small and intimate with a dedicated core of membership. It is a good group for individuals who may be too shy to attend large gatherings. Please contact Jane Gidney at 253-588-1233 if you would like to attend. On October 18, 2000, I was invited to attend the **Spokane Support Group** by Cindy Dolan, Medical Genetics Counselor. The group meets every other month on the third Wednesday of the month. Cindy had sent notices the month before and the group came out in force. This group has been meeting for several years and the members celebrate many special occasions together.

The members of the group were quite interested in talking about Social Security eligibility and other state programs that they or their loved one may qualify for. The staff at University of Washington regularly advocates for patients experiencing difficulty qualifying for benefits. This is done most effectively by scheduling affected individuals for a consultation with Dr. Thomas Bird. Dr. Bird will send a clinic note to a patient's regular local medical team. Dr. Bird and Catherine Kendall regularly collaborate to send documentation of a patient's disability from HD to the Social Security Administration. If you are interested in attending this group, please contact Cindy Dolan at 509-473-7115.

### New Support Group!

Announcing the formation of our first support group in Anchorage, Alaska! Facilitated by Marti Bradley, the group is a small but dedicated support group with five members. Call Marti at 907-258-5665, write her at PO Box 200704, Anchorage, Alaska 99520, or email her at Alaskashield@gci.net. Way to go Marti!

If you are interested in having Catherine Kendall, MSW attend your support group, or want to start one, contact her at UWMC, PO Box 357720, Seattle, WA 98195, or 1-888-264-HDSA, or ckendall@u.washington.edu.



### 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 | _____                                |