



# Northwest Chapter HD News

What a busy and exciting fall we have had!!

Our 6<sup>th</sup> Annual Dinner and Auction raised a record \$36,000 to support family services and research. For the first time we engaged a professional auction house, and their energy and expertise had a lot to do with the success of the evening. It also enabled me to spend some time saying "hi" to many of you, and that was wonderful.

HDSA also sponsored Dr. Bird's bi-annual educational symposium last month. It was the most successful one thus far, and I would like to thank Gretchen's Shoebox Express for the wonderful box lunches that they did for us for a significantly discounted price . . . they have been a very good friend to us over the years.

But hold on to your hats, because we are absolutely thrilled to be doing our Mardi Gras dance again in February. For those of you who missed it last winter, this is simply not to be missed! *Les Femmes D'Enfer* will again be rocking the house, and dance instructor, Marylee Lykes will be there to help those of us with two left feet. It was such fun last year that we are going to change very little . . . but we will have a bigger and much nicer location at the Mt. Baker Community Club. And we are so grateful to have The New Orleans Creole Restaurant in Pioneer Square catering much of the food. Please, please mark your calendars and come join the fun!

Sincerely,  
Edward Morgan  
President  
Northwest Chapter HDSA

## Save the Date for Our 2nd Annual Cajun Mardi Gras Dance

**When: Sunday, February 13, 2005  
5:30 to 10:00 pm**

**Where: Mt. Baker Community Club  
Seattle, WA**

## Cure HD Auction A Success

Our 6<sup>th</sup> Annual Cure HD Auction was held on Saturday, October 9, at the Redhook Brewery in Woodinville, WA.

Once again, we had many great items donated for the auction including art work, hand-built furniture, massage, weekend getaways,



sports memorabilia, jewelry, sailboat rides, Pearl Jam guitars, a luxury cruise, a wine tasting tour, a tour of the Seattle Times printing facility, and a tour of Nintendo. This year's auction consisted of two silent auctions, an Italian dinner buffet, a live auction, fund a cure, and ended with the popular dessert dash. Over 200 people attended the auction.

We also hired a professional auctioneer to run the auction, which actually helped us to raise more money and to have a more professional event.



Thank you to all the volunteers who worked so hard to make this

event a success! Also, please make a note of those businesses who donated items for our cause. We hope that you will patronize these businesses if the opportunity arises.

## HD Educational Symposium

The University of Washington HD Center of Excellence and the Northwest Chapter of HDSA presented a public symposium on Huntington's disease at the Seattle VA Medical Center on November 13, 2004. This all day symposium with 100 persons in attendance was a tremendous success.

Ted Morgan, President of the Northwest Chapter, introduced the proceedings. The keynote speaker was Dr. Penelope Hogarth from the Department of Neurology at the Oregon Health Sciences University in Portland. Dr. Hogarth has outstanding professional credentials in the Huntington's Disease field. She gave an impressive overview of the history, diagnosis, management and contemporary research in HD. Dr. Hogarth described the Venezuelan HD connection and emphasized the research on the new animal models of HD in mice and fruit flies. Two



*Barbara Isenhouer, Hillary Lipe, Catherine Kendall, Amelia Schultz, Dr. Bird, Dr. Rebecca Logsdon, and Sarah Elmore (left to right)*

studies have even reported that in the mouse model of HD there may be benefit from physical contact (hugging?) and environmental stimulation. Hillary Lipe, Neurology Nurse Specialist, presented details of the many HD-related research projects occurring at the University of Washington. These include the national longitudinal studies of PHAROS, PREDICT, and the Huntington's Study Group Database. She also mentioned biomarker studies that have required collection of spinal fluid and muscle biopsies. She thanked many local participants in these projects.

Rebecca Logsdon, Ph.D. and Catherine Kendall, M.S.W., facilitated a panel of individuals participating in local HD support groups. Five volunteers discussed what it is like to be a member of these group meetings. The com-

ments of the panel members concerning their personal experiences with HD were very enlightening.

In the afternoon, there were three smaller breakout sessions. The first was Catherine Kendall discussing organization and facilitation of HD support groups. There is a need for more support groups in many local communities. The second was Barbara Isenhour, J.D., discussing the highly relevant topic of financial issues and estate planning in HD. We were honored to have Ms. Isenhour's participation because of the multitude of financial problems faced by HD families including questions regarding employment, pensions, social security, insurance and living wills. The third was Dr. Thomas Bird discussing genetic testing and genetic counseling in HD. There are many complex issues surrounding this topic including interpretation of test results and potential for "genetic discrimination."

Throughout the day Mr. Rob Hopping interviewed several participants for a video documentary on HD that he is producing. Sarah Elmore from the VA Medical Center provided expert technical assistance. This fourth Seattle HD Symposium was highly informative, generated a tremendous number of positive comments and was generally considered the best symposium to date.

## UW Research in HD

*By Hillary Lipe, A.R.N.P.*

### **PREDICT-HD (Neurobiological Predictors on Huntington Disease)**

This study is taking place at 26 sites across the United States, Canada and Australia, with the UW being one of highest enrolling sites for study subjects. The study subjects have been tested for the HD gene and have not been diagnosed with HD onset of symptoms. The study is looking for markers to determine when treatment for HD should begin, how to measure efficacy of the treatment and prepare for clinical trials of medication to postpone onset of HD. Subjects are seen once every year for four years, and have an examination by a neurologist, an MRI, detailed testing of concentration and memory, blood samples, and complete questionnaires about mood, behavior, stress, and other environmental factors. The goal is to enroll 600 subjects from all the participating sites. About 90% of that goal has been reached.

### **MRI studies in HD**

Elizabeth Aylward, Ph.D., continues her study of brain structures using MRI brain imaging in persons with HD and at risk. Dr. Aylward is one of the main investigators for the PREDICT-HD study.

## **P.H.A.R.O.S. (Prospective Huntington at Risk Observational Study)**

This study is being conducted at 43 sites in the U.S. and Canada. Study subjects are at risk for HD and have not been tested for the gene. The goals of P.H.A.R.O.S. include determining the first signs of HD and determining which tests are most effective at detecting onset. There are also surveys about environmental influences such as smoking, stress, diet, etc. Enrollment of 1001 subjects, total, has been completed for the P.H.A.R.O.S. study, with the UW being among the top sites for enrollment and retention of study subjects. Study visits are every nine months and include an examination by two neurologists, brief testing of thinking, and a blood sample at the beginning of the study. Some publications have been released about P.H.A.R.O.S. showing that there have been minimal adverse events, such as study subjects dropping out of the study because of depression, and most subjects agreeing to have the blood samples saved for other HD studies in the future.

## **U.H.D.R.S. 99 Data Collection (Unified HD Rating Scale)**

Data is collected from patients with HD who are seen at the UW Medical Genetics Clinic and shared with a coordinating center at the University of Rochester in Rochester, NY. The U.H.D.R.S. monitors medications prescribed by the physician, the neurological examination, brief tests of thinking, and questions about mood, behavior, and everyday activities. Jin Do, RN, MN, did a preliminary analysis of the data from the UW group, as part of her master's thesis. From a group of 83 subjects with a mean age of 48, 61% were male, 89% white ethnicity, and 43% married. The parent affected with HD was the mother in 47% of subjects and the father in 42%. For 11% the affected parent was unknown, either because the parent died prior to showing signs of HD or in the event of adoption. In this group, age 41 was the mean age of onset reported by the patient. The initial symptoms of HD reported by the patient were motor, meaning coordination or chorea, in 45%; cognitive in 16%, behavioral in 14% and mixed in 24%. The motor symptoms fluctuated over time, especially chorea, gradually getting worse in the early years of the disease, then lessening and sometimes disappearing later in the disease. Stiffness of muscles, or dystonia, was more prominent later in the course of HD. Gait and eye movement abnormalities were progressive.

## **Muscle Biopsy Study in HD**

Studies in HD mice have suggested the possibility of changes in the muscle. In this study, a small piece of muscle is removed under local anesthesia from persons

with HD to look for markers of HD in the muscle tissue. Because measures of HD progression, such as the U.H.D.R.S., can fluctuate over time and are not consistently reliable, it is important to find other objective measures of HD progression.

## **Spinal Fluid Biomarkers in HD**

This study used spinal fluid from persons with HD and control subjects without HD to look for biomarkers of HD.

## **Family Health after Predictive HD Testing**

Janet Williams, R.N., Ph.D., based at the University of Iowa, is the main investigator on this study. The UW was one of several sites where focus groups of family members were assembled with structured interviews of the groups. Several issues have been identified as important to families, such as how to interpret behaviors in the person who has been tested, changes in relationships within the family, secrecy, and feeling isolated.

## **Hypothermia in a Transgenic Mouse Model of HD**

Questions to be answered in this study include whether temperature regulation is affected during the course of HD and if so, whether temperature could be used as a biomarker of HD progression.

## **Dopamine Neurotransmission in Mice**

Basic science studies of nerve cell physiology noting that the neurotransmitter, called dopamine, filters the input to nerve cells and reinforces sets of nerve connections. This has potential implications for several neurologic diseases including HD.

A heartfelt "thank you" to all the individuals who take part in HD studies. Progress depends upon your willingness to give of your time and energy. In response to the problem of timely communication with the public about research, The Huntington Study Group is launching a new website for HD research, starting in 2005:  
[www.HuntingtonProject.org](http://www.HuntingtonProject.org)

## Prop 71: California May Become Biotechnology Magnet — Stem Cell Research Will Lure Scientists

SEATTLE POST-INTELLIGENCER

[http://seattlepi.nwsource.com/national/198932\\_stem10.html](http://seattlepi.nwsource.com/national/198932_stem10.html)

Wednesday, November 10, 2004

By PAUL ELIAS

THE ASSOCIATED PRESS

SAN FRANCISCO -- A 21st-century gold rush is on in California after the voters approved \$3 billion for human embryonic stem cell research.

At least one out-of-state biotech company is already making plans to move to California. Stem cell startup businesses are expected to emerge. And universities are hoping to recruit some of the field's brightest minds to take part in the biggest state-run research project in U.S. history.

Scientists elsewhere, including those at some of Seattle's leading research institutions, are concerned about a "brain drain" -- losing their best and brightest -- to California.

"We're going to lose people," said Dr. Beverly Torok-Storb of the Fred Hutchinson Cancer Research Center. Torok-Storb, who works with mature or adult stem cells, said embryonic stem cells represent the next "big wave" in biology.

The voters' 59 percent approval of the bond measure on Election Day represents a resounding rejection of Bush administration policy, which has sharply restricted federal funding for research that involves the destruction of human embryos.

Embryonic stem cells can potentially grow into any type of human tissue. Many scientists believe that stem cells could someday be used to repair crippling spinal cord injuries and treat an array of diseases, including diabetes and Parkinson's.

Proponents and critics alike expect the new agency created under the ballot measure, the California Institute for Regenerative Medicine, to serve as a state version of the National Institutes of Health.

But questions remain to be resolved as election night euphoria gives way to the hard work of creating an agency that can dole out \$300 million a year in grants for 10 years.

No one is sure when the first dollar will be allocated or where the agency will be located, although biotechnology booster groups from San Diego to the San Francisco Bay Area are working on their sales pitches.

"California will be the epicenter of stem cell research in the future," said Dr. Edward Holmes, medical school dean at UC-San Diego. "Many people were reticent to move into this field, but this will attract some of the best and brightest young minds."

Dr. Albert Berger, associate dean of research at the University of Washington Medical School, echoed Torok-Storb's concern that Seattle could lose some of its top scientists to California. But Berger said he hoped the passage of this measure would instead alert the public to the situation and stimulate the Washington Legislature to act in similar fashion to protect the region's existing and longer-term scientific leadership.

Worcester, Mass.-based Advanced Cell Technology said it will soon open a California laboratory so it can apply for grants. Its chief executive has already moved to the San Francisco Bay area, and the company is trying to line up financing from California investors. "It's a very favorable environment, and this could serve as a wake-up call for the rest of the country," said Dr. Robert Lanza, Advanced Cell's research chief.

Lanza also said he has been approached by California venture capitalists and other investors to begin a stem cell startup company. He said he declined the offer.

Opponents of Proposition 71 worry that long before any useful therapies are discovered, most benefits will go to venture capitalists and others with ties to the biotechnology industry, who contributed \$28 million to get the measure approved.

"Many questions remain unanswered about conflicts of interest among the scientist-entrepreneurs promoting Proposition 71, about the high cost of any treatments that are eventually developed, and about health risks to women from whom eggs for research cloning will be obtained," said Marcy Darnovsky of the Center for Genetics and Society in Oakland, which opposed the measure.

The newly created institute will be managed by a 29-member board to be appointed over the next 40 days. The board will name the agency's chairman and a vice chairman, key appointments that could devolve into political fighting.

Gov. Arnold Schwarzenegger, a Republican who broke ranks with his own party to endorse the measure, gets to appoint five people to the board. Other appointments will be made by UC's five medical schools, the lieutenant governor, the treasurer, the controller and the leaders of the Assembly and Senate.

Once the board is in place, it will appoint two key committees -- one responsible for doling out research grants, the other for funding laboratory construction.

P-I reporter Tom Paulson contributed to this report.  
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## Upcoming Events

### Sunday, February 13 - Mardi Gras Benefit Dance

The Cajun band, *Les Femmes d'Enfer*, will be playing another toe-tapping, benefit concert for the Northwest Chapter on February 13 from 5:30 pm to 10:00 pm at the Mt. Baker Community Club. Dance lessons will be provided by Marylee Lykes. And delicious Cajun food will be catered by The New Orleans Restaurant. We are looking forward to seeing everyone! We will post more information and a map on our web site soon.

## 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 Friedenberg 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

Seattle Amelia Schultz 206-363-4304

Seattle Catherine Kendall 206-221-5390

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

Tacoma Tony Hoyt 253-863-0217

Cosetta Stroud 253-402-4633

Tri-Cities –

W. Richland Carl Gallion 509-967-9161

Wenatchee Kathy Wolf 509-663-0399

509-548-7622

Vancouver Russ Kastberg 360-425-9338

Tom Gillihan 360-425-8477

Yakima Joyce Korevaar 509-225-4429

509-548-7622

### Adult Support Group

- 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 3:00-4:30 at the University of Washington CHDD building room 454.

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.

## Chapter Board and Officers

Edward B. Morgan, <b>President</b>	425-885-1916
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Rachel Mickelson, <b>Vice-President</b>	425-828-3198
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University of Washington - Center of Excellence  
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