

Celebrating the season



photos by Sean Thompson



Left: (from left to right) Kevin Woods, Mary Woods and UI Research Assistant Stephen Cross partake in the food.

Top: (from left to right) UI Social Worker Anne Leserman, Carissa Gehl, Dixie Harrington, Aimee Brown, Erin Rogers and UI Clinical Trials Coordinator Nancy Hale enjoyed good food and great company at the HD support group holiday party on Dec. 13.

HD trials still enrolling

As the new year begins, Huntington disease studies continue recruiting

Despite difficulties in recruiting for HD trials (see article on Page 2), because of the tireless efforts of volunteers just like you, researchers are able to make breakthroughs.

You may be eligible for one or more of the following trials. If interested in participating, please contact the coordinator listed for more information.

Clinical Drug Trials:

- **HORIZON:** Must be at least 30 years old, have tested positive for HD, have some clinical features of HD and have some difficulty with thinking abilities. **Contact: Elijah Waterman, (319) 353-4131, elijah-waterman@uiowa.edu.**

- **2CARE:** Must be 16 years or older, in the mild to moderate stages of HD, able to independently walk and be fully self-sufficient in activities of daily living. **Contact: Nancy Hale, (319) 353-4537, nancy-hale@uiowa.edu.**

- **HART:** Must be at least 30 years

old, have tested positive for HD and have some clinical features of HD. **Contact: Nancy Hale (see previous).**

- **CIT-HD:** Must be between the ages of 18-65, have tested gene positive for HD or received a clinical diagnosis and notice a change in level of attention, focus and/or thinking ability. **Contact: William H. Adams, (319) 353-4411, william-h-adams@uiowa.edu.**

Observational studies:

- **PREDICT-HD:** Must be at least 18 years old, have been tested for the HD gene (positive or negative) and presymptomatic. **Contact: Anne Leserman, (319) 353-4307, anne-leserman@uiowa.edu.**

- **COHORT:** Must have tested positive for the HD gene; or be at risk for developing HD due to family history; or a caregiver/family member of a COHORT participant. **Contact: Anne Leserman (see above).**

GINA rules continue to be finalized

The rollout of the federal Genetic Information Non-Discrimination Act (GINA) continues, as interim rules on how health insurance discrimination will be regulated took effect in December.

According to the HDSA, the Interim Final Rules of the health insurance portion of GINA became effective on Dec. 7. Public comments on the rules were collected and will be reviewed, after which final rules will be issued. The rules are intended to protect people from insurers obtaining genetic information or using such information to determine eligibility or premiums.

Meanwhile, the portion of GINA meant to protect individuals from genetic information being used against them in the workplace went into effect Nov. 21. HDSA says specific regulations have not been issued.

GINA should still be effective in providing the protections legislators intended it to, said Cheryl Erwin, JD, Ph.D., professor at the John P. McGovern Center for Health, Humanities and the Human Spirit at the University of Texas.

It is not, however, a comprehensive protection against genetic discrimination, Erwin says. Moreover, people should consider more than just the potential for discrimination when deciding to get genetically tested for Huntington disease.

"Getting tested is not a legal decision," she said. "It's a life decision and a medical decision. It's great that we now have some protection against genetic discrimination, but the decision to get tested needs to be based more on your personal needs and family needs."

On the Web

For more GINA info featuring Cheryl Erwin, read a Web-exclusive article at www.uihealthcare.com/depts/huntingtondisease

HD Support Groups:**Des Moines**

Valley View Village Conference Room
2571 Guthrie Avenue
Third Sunday at 1:30 p.m.
Mark Hillenbrand
(515) 208-3511

Omaha, Nebraska

Perkins Restaurant
108 L. Street
Second Monday at 6 p.m.
Cathy McNeil
(402) 537-0739

Iowa City

University of Iowa Hospitals and Clinics
Della Ruppert Conference Room
Fourth Sunday at 1 p.m.
Anne Leserman
(319) 353-4307

Shooting hoops for a cure

Free-throw shooters across the state will be ripping the nets at a gymnasium near you as the Iowa Chapter of the HDSA's Hoop Tour 2010 kicks off in March.

The chapter's biggest fundraiser features food, silent auctions, entertainment and, of course, basketball. Participants will knock down as many free throws as they can in five minutes, with prizes for each age group. Shooters are asked to collect donations and pledges to benefit Huntington disease research.

T-shirts are available to all participants, and shooters are eligible for national prizes.

Organizers are hoping to top the over \$40,000 raised last year. To do so, volunteers are needed to help with planning and staffing various stations on the day of the event at the five sites. If you are interested in helping, please call 1-866-

Iowa Chapter of the HDSA Hoop Tour 2010

Storm Lake: March 20, 11 a.m. – 2 p.m., Storm Lake Middle School. Contact Amanda Damewood, (712) 200-3078.

Bedford: March 27, Noon – 3 p.m., Bedford High School. Contact: Karen Brown, (402) 533-4693.

Audubon: March 28, 1-4 p.m., Audubon High School. Contact: Carrie Tibben, (515) 563-4181.

Des Moines: April 10, 1-4 p.m., AIB College. Contact: Sarah O'Neil, (515) 707-4229.

Iowa City: April 11, 1-4 p.m., West High School. Contact: Sean Thompson, (319) 384-4094

248-IAHD, e-mail mail@hdsaiowa.org or contact the organizer at your site (see graphic).

This marks the first year that a Hoop-A-Thon has been held in Iowa City, home of the UI HDSA COE. For the latest details, visit www.uihealthcare.com/depts/huntingtonsdisease.

Volunteers key to HD research

By Sean Thompson
HIND-Sight Editor

With several clinical trials and observational studies of Huntington disease underway and others that will begin enrolling in the near future, the need for study volunteers persists.

In a Nov. 28 article, *The Washington Times* reports a general shortage of clinical trial participants. Such shortages result in longer clinical trials, and ultimately, delays in drug manufacturing.

In the HD community, there is no lack of passionate volunteers willing to take part in research. But with at least eight clinical drug trials and several other

observational trials like PREDICT-HD currently underway, participants' time can get stretched thin.



Megan Smith
 UI Assistant Professor

That's why researchers work hard to develop the best measures that identify the earliest changes in HD, says University of Iowa Assistant Professor of Psychiatry Megan Smith.

Studies like PREDICT-HD are developing new measures to be used in clinical trials. Once researchers are confident that a measure will allow them to assess if a drug is effective at treating HD, they can design clinical trials requiring fewer participants. And fewer participants mean faster trials and less of a burden on the HD community.

HD researchers design trials always with the participant in mind in an effort to make volunteering as easy and convenient as possible, Smith said. But even the most well-designed trial won't go anywhere without an amazing group of HD study participants.

"We thank you for taking the time to participate in clinical trials," Smith said. "It's the only way we're going to move forward with treatments for Huntington disease."

Aside from participating themselves, Smith hopes volunteers will share their experiences with others in an effort to encourage more participation.

"A lot of people are hesitant about taking part in a clinical trial, so if they can talk to other people they know, more people might be willing to volunteer," Smith said.

"Molecular switch" may hold key to preventing HD

New HD research suggests a molecular switch that prevents the disease in mice may lead to a treatment for humans.

According to a University of California, Los Angeles news release, researchers discovered that chemically modifying the huntingtin protein prevented the onset of symptoms of HD.

"This finding suggests an exciting new avenue to develop therapeutics for Huntington's disease," said X. William Yang, associate professor of psychiatry and behavioral sciences at the Semel Institute of Neuroscience and Human Behavior at UCLA.

The article is published in the Dec. 24 edition of *Neuron*. For more information, visit www.newsroom.ucla.edu.

From the Editor

You hear a lot about the need for HD study volunteers. The need is real, but we also want to thank those who do give their time. You are making a difference!

As is always the case, feel free to contact me with feedback at sean-thompson@uiowa.edu or (319) 384-4094. Also, if you want to write something for HIND-Sight, please contact me with your ideas!

Sean Thompson, HIND-Sight Editor

Benefits of HD? Support group's atypical list

By **Anne Leserman**
UI HDSA COE Coordinator

Typically, the monthly UI HDSA Center of Excellence HD Support Group in Iowa City features either a speaker or a chance for the group to split to discuss



Anne Leserman

either caregiver or person-with-HD issues. Recently, a topic for the full group centered on personal lessons of HD. This topic gave the group an opportunity to think about what they have learned or benefits that have come from living with HD.

The idea that there might be a benefit from HD is an unusual one, but the discussion was certainly enlightening.

Please read through the list we generated to see if you share any from our list:

- Patience towards loved ones
- Patience towards others
- Sacrifice
- Knowledge
- Education
- Faith
- Hope
- Persons with HD (PHDs) are heroes
- Acceptance
- Find your true friends
- Empathy toward others
- Learning to find the good
- Knowing you are not alone
- Stamina
- Awareness of differences
- Persistence
- Humor
- Understanding
- Dealing with anxiety and depression

- Opportunities
- Appreciating what you have
- Inner strength
- Love

If you have a benefit or lesson learned from living with HD that you would like to add, please let me know. It is very clear that a supportive group environment is important to our support-group members. I thank them for their openness.

Interested in joining our group? We meet monthly on the fourth Sunday in the Della Ruppert conference room in the John Pappajohn Pavilion of the University of Iowa Hospitals and Clinics. For more information, please contact me at (319) 353-4307 or anne-leserman@uiowa.edu. You can also visit us on Facebook by searching for "Iowa Huntington's Disease Society of America Center of Excellence."

Paulsen's professional philosophy: collaborate

UI HDSA Center of Excellence Director Jane Paulsen, Ph.D., was recently profiled by the UI Carver College of Medicine. Paulsen spoke candidly on a number of topics related to medical research and health care. Some excerpts:

Q: How does your work help translate new medical discoveries into patient-centered care and education?

Jane Paulsen: I see research that simply does not get translated into people's lives. Patients started describing this breakdown between what we knew in the neurosciences and what they witnessed in their day-to-day lives. So the first thing I did was simply write more

lay articles. I spent a lot of time teaching families and patients.

It became clear that there were a lot of components of science that could change other aspects of patients' daily lives, and the most notable component right now is clinical trials. We've known a lot about certain brain diseases for decades and yet have been unable to treat them. Now we can test many more chemical compounds,

which is good timing because there are a lot of chemical compounds right now that we want to test. In addition to just drug trials, there are

other methods that we want to try, like gene therapy and stem cell treatments. I think the only way to facilitate trying more treatments for persons with brain damage or disease is really improving the methodology so we can do that in the most efficient and ethical manner.

Q: What philosophy guides your professional work?

JP: There are some basic philosophies that I feel pretty strongly about, and one is to always strive for excellence. Secondly, I really am an advocate for collaborative work. I find that progress has been hindered by tunnel vision and that our best work comes forth when

On the web

To read the full profile, visit www.medicine.uiowa.edu and click on "faculty profiles."



Photo by Susan McClellen/University of Iowa
Dr. Jane Paulsen in her office on campus

we're challenged not just by colleagues in our own profession, but colleagues in many different professions and walks of life. So a basic philosophy for me really is a collaborative spirit where we include all views, all opinions, all methodologies and all paths.

For more information on the UI HDSA Center of Excellence, visit our Web site at:

www.uihealthcare.com/depts/huntingtonsdisease/

And, we are now on **Twitter!**

Follow us at:

UIowa_HDCenter

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Doctor's order: Look on the bright side

Excerpts from "Why Optimism Is Powerful Medicine" by Dr. Ranit Mishori, published Nov. 15, 2009 in Parade Magazine.

I write a lot of prescriptions—for pills, creams, and physical therapy. One thing I can't dictate a dose of—though I wish I could—is a positive attitude. Patients who "look on the bright side" seem quicker to seek help when they need it and more motivated to follow doctors' orders.

Perhaps most important, they appear to believe they're going to get healthier. A recent issue of the journal *Circulation* provides hard evidence that optimism and health are connected. Researchers studied nearly 100,000 women over eight years, tracking how many heart attacks they suffered and how long they lived. The conclusion? Optimism is good for you.

"Optimists had a 16% lower risk of having heart attacks," says the lead author, Dr. Hilary Tindle of the University of Pittsburgh School of Medicine.

The reverse seems to hold true, too.

"Optimism and pessimism affect health almost as clearly as do physical factors."

Dr. Martin Seligman, director of the Positive Psychology Center at the University of Pennsylvania

Pessimists—who were followed in a 30-year Mayo Clinic study—ran a 19% higher risk of early death than optimists.

Being an optimist also has been associated with a healthier immune system and an ability to better cope with physical pain. Still other studies have connected a positive attitude to a quicker recovery from heart surgery and a reduced likelihood of re-hospitalization.

"Optimism and pessimism affect health almost as clearly as do physical factors," says Dr. Martin Seligman, director of the Positive Psychology Center at the University of Pennsylvania.

What is it about optimism that seems to allow some people to live longer, healthier lives?

Optimists are generally disposed to "positive future expectations," Dr. Tindle says, and they are less likely to blame themselves when something bad happens.

"They expect good things to happen and work toward them."

By contrast, Dr. Seligman says, a pessimist "habitually views setbacks as permanent, unchangeable, and pervasive." Pessimists often feel helpless when things go wrong and tend to believe that bad luck repeats itself. Such an attitude can increase stress and contribute to depression.

If you're naturally a pessimist, it doesn't mean your disposition is unalterable. The key is learning to recognize negative patterns of thinking. You can learn to challenge them and replace them with positive alternatives. Will optimism lead to better health? Perhaps. But it's also its own reward. After all, who wouldn't prefer to wake up on the right side of the bed every morning?