RESEARCH
Here and There

The Huntington Study Group (HSG) is a non-profit group of health care professionals in the United States, Canada, Europe and Australia, experienced in the care of Huntington’s disease (HD) families. The HSG was formed in 1993, prompted by the recognition that HD clinical research and care required the participation of large numbers of research participants under the cooperative care of skilled and experienced researchers. The HSG aims to advance knowledge about the cause(s), disease progression and treatment of HD. The HSG is committed to: a) open communication within the scientific community; b) full disclosure of research results in scientific journals after independent expert review; c) revelation of conflicts of interest of each HSG member and the group; d) democratic governance of its organizations and activities.

What Makes the HSG Unique?
The HSG has carried out cooperative research since 1993, beginning with the Unified Huntington’s Disease Rating Scale (UHDRS) Natural History’s database. Since then, they have carried out several multi-center studies examining the symptomatic and neuroprotective effects of experimental interventions in HD. The HSG has partnered with pharmaceutical companies, private foundations, and The National Institutes of Health (NIH) in these studies. The HSG publishes their research in internationally recognized peer-reviewed journals in an effort to make all of their knowledge in HD available to the public.

Where are the HSG and its Members Located?
The core resource of the HSG is a network of experienced people in the United States, Canada, Europe and Australia. Membership in the HSG is based on active participation in HD research, the UHDRS Natural History database, or through active participation on committees of the HSG. The HSG now includes more than 269 active investigators, coordinators and scientists from approximately 62 HSG sites. Research is conducted at all of these sites in an effort to find new treatments (e.g., medications) for HD, as well as new ways to understand and detect early HD. Sites are selected for participation in HSG studies on the basis of their experience and performance in conducting clinical HD research.

This information comes, in part, from the HSG website. Many HD researchers from the University of Iowa are members of the HSG. University of Iowa staff who just attended an HSG meeting was educational and informative. It was exciting to see how the group coordinates all the HD research. I am more aware of how our efforts in Iowa make a difference to people with HD everywhere on a daily basis. I found it rewarding to have personal meetings with people that I usually interact with only by phone or email.”

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“The HSG opened my eyes to multiple research advancements surrounding Huntington’s Disease. It allowed me to learn from passionate researchers whose enthusiasm offers hope to the HD community.”

“If it was a great experience to see so many people focused on a collective cause as important as HD.”

http://www.huntington-study-group.org/
Fall Fund Raising in Iowa

In October, *Music at the Mill* in Iowa City brought 125 people together to hear the music of the Letterpress Opry, Ben Schmidt, Sam Knutson and Flying Bacchus. $6,000 was raised by donations, ticket sales, raffles and a silent auction. These funds will help support services at the HD Center of Excellence at the University of Iowa.

*Jam for Hope*, in November, was another music event with 6 bands donating their time and talent to promote HD awareness and help benefit the Center of Excellence. Tim Hobert took on the giant task of planning and organizing this music event to support his longtime girlfriend, Aimee Brown, who is diagnosed with HD. Tim’s Davenport event at the Col Ballroom raised about $8,000.

Watch for more music in eastern Iowa in the fall of 2005. The regional coordinator of HDSA, Leigh Peterson, hopes to continue our local fundraising.

## HD Support Groups:

### DES MOINES

- **Iowa Lutheran Hospital**
  - University Ave at Pennsylvania
  - 4th Friday at 6:30 pm

- **Lincoln, Nebraska**
  - Perkins Family Restaurant
  - 48th and O St
  - 1st Monday at 7:30 pm

- **Omaha, Nebraska**
  - Village Inn Restaurant
  - 78th and Dodge
  - 2nd Monday at 6:00 pm

### IOWA CITY

- **University of Iowa Hospitals and Clinics**
  - Della Ruppert Conference Room
  - 6th floor, elevator H
  - 4th Sunday at 1:00 pm

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SAVE THE DATE!! February 14, 2005. **Support the HD Center.**

Consider lunch or dinner at Thai Flavors.

340 E Burlington St, Iowa City, 52240, (319) 339-8900

Thai Flavors will donate 20% of the day’s proceeds to the UIHC HD Center.
RESEARCH SPOTLIGHT
Interview with Bill Adams-
New PHAROS Coordinator
University of Iowa:

**Anne:** How many people are in PHAROS?

**Bill:** While the University of Iowa has 26 active participants, over 1,000 participants are currently donating their time and energy to PHAROS across the United States and Canada.

**Anne:** Is PHAROS still enrolling?

**Bill:** PHAROS closed to enrollment when the number hit 1,000. However, there are many HD studies actively recruiting. Please contact the local HD Center of Excellence to learn about the many opportunities for research participation.

**Anne:** How long will PHAROS continue?

**Bill:** Participants complete ten visits, and each visit is separated by nine months. We anticipate study completion by 2007. It is important to note that even after participants complete visit ten, there are additional research opportunities available for our PHAROS participants.

**Anne:** 2007 seems like a long time. Why is the study so long?

**Bill:** There are many benefits to a longitudinal study, and this allows us to gather an impressive amount of data over several years.

**Anne:** What are the goals of PHAROS?

**Bill:** There are two main goals. We are primarily interested in accessing specific symptoms and their onset. Discovering what symptoms manifest early and which symptoms are prolonged allows researchers to better focus their investigational drug studies. Additionally, we are interested in accessing doctors’ diagnostic accuracy.

**Anne:** Bill, what can you tell our readers about confidentiality?

**Bill:** Of course, we hold our participants’ confidentiality with extreme importance. Participants’ DNA, medical history, and data contributions are coded with unique number sequences. We believe this keeps our participants’ anonymity secure and safe.

**Anne:** Regarding a participant’s DNA sample, what happens with his or her sample at the end of the study?

**Bill:** When participants reach visit ten, we present them with their informed consent, remind them that their DNA sample contains no identifying information, and ask them if they will donate their DNA sample for future HD-related research. If participants do not wish to donate their DNA sample, it is destroyed. However, if the participant does donate his/her sample, the Huntington Study Group will keep the DNA in a secure location and use it in future studies. Participants are also reminded that they are free to change their mind at anytime.

**Anne:** Can PHAROS participants receive a gene test while actively participating in the study?

**Bill:** Yes. If a PHAROS participant decides to undergo genetic testing for Huntington’s Disease, our center is prepared to help him or her with the experience. We simply ask our participants to keep the results from our independent raters (Dr. Robert Rodnitzky and Dr. Henry Paulson); it is important that they remain blind to the participant’s test results. However, our center staff may know the results and, accordingly, help the participant with any questions and concerns.

**Anne:** What about the study’s results?

**Bill:** The study is nearing completion. The Huntington Study Group will release the results when the study is completed and all the data is carefully analyzed. The research participants will be among the first to see the results. All readers of this newsletter will also see the results.

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RESEARCH NEEDS YOU

**STARTLE**

in Pre-symptomatic HD

The purpose of this study is to characterize the startle reflex (an eyeblink to a startling stimulus). Participants listen to varying decibel levels of sound through headphones, and their eye blink activity is measured.

**PREDICT-HD**

This trial will help define the earliest changes in HD and this information helps researchers evaluate the effectiveness of future treatments more accurately. Predict comprises individuals who are gene tested and are pre-symptomatic. Participants are evaluated once a year. Evaluation includes computerized touchscreen testing and brain scans.

**Study Controls**

Individuals who have tested negative for the HD gene expansion are needed to volunteer as comparison participants for various studies. By serving as a control, you provide us with important information on brain functioning.

**fMRI/MRI**

Brain scans will examine both graphic pictures of brain activity and measure regions of the brain. This will provide useful information about normal and disease process in HD.

**Differential Treatment Study**

This research survey asks about individual experiences and perceptions regarding discrimination. Adults who are genetically tested and pre-symptomatic are eligible.

for more information, please call Anne at (319)353-4307 or email at anne-leserman@uiowa.edu
QUACKERY could be broadly defined as “anything involving overpromotion in the field of health.” This definition would include questionable ideas and dubious products and services, regardless of the sincerity of their promoters.

Avoid Being Quacked

1. Remember that quackery seldom looks outlandish.
2. Ignore any practitioner who says most diseases are caused by faulty nutrition or can be cured only by taking supplements.
3. Be wary of anecdotes and testimonials.
4. Be wary of pseudomedical jargon.
5. Don’t fall for paranoid accusations.
6. Forget about “secret cures.”
7. Be wary of herbal remedies.
8. Be skeptical of any product that claims to be effective against a wide range of unrelated diseases—particularly diseases that are serious.
9. Ignore appeals to your vanity.
10. Don’t let desperation cloud your judgment.

www.quackwatch.com
founded by Dr. Stephen Barrett