ANNUAL HSG MEETING

On November 8-11, 2006, approximately 225 professionals attended The Huntington’s Study Group’s (HSG) 14th annual meeting in St. Louis, Missouri. This is incredible attendance, especially compared to 14 years ago when researchers required only a small meeting room for HD research. The HSG is a non-profit group comprising physicians, psychologists, nurses, social workers and other healthcare providers.

This collaborative team works to create and manage HD research projects. Professionals from the US, Canada, Europe, and Australia discussed the latest HD projects and possibilities. Several predominant studies are outlined below:

PREDICT and COHORT are both large, multi-site, observational studies. Currently there are 945 participants enrolled in PREDICT throughout North America, Europe and Australia. COHORT currently enrolls participants throughout 45 sites in North America and Australia. University of Iowa is a COHORT site and is looking for both adults and children with clinically diagnosed HD. All family members are also encouraged to participate. The data from these studies is used to better understand disease onset triggers and potential treatments.

Therapeutic trials explore drug treatments that may benefit individuals with HD. Trials that are currently enrolling include DOMINO, a long term safety study of Minocycline and DIMOND, a study that examines the antihistamine, Dimebon. This drug was also used as an Alzheimer’s medication. A new study called 2CARE will examine the effects of Coenzyme Q10 (CoQ10). Look for 2CARE to begin in 2007.

The HSG science forum focused on biomarkers. Biomarkers are used to help trace disease and encode information. With the use of new technologies, researchers are able to identify ways to measure biochemical changes. Understanding biomarkers may shorten clinical trials, require fewer participants, and help researchers learn more about the course of the disease.

To find the nearest research facility and, to learn more about these studies, review the HSG website at http://www.huntington-study-group.org/.

We anticipate a great year in HD research with promising outcomes that bring us closer to ending this devastating disease.

Shield Family Endowment Supports HD Center of Excellence

A family endowment was founded to support the University of Iowa HD Center of Excellence mission and to assist HD families in need. The Shield Family Endowment was established by Midge Toole of Des Moines, Iowa. The interest from this account will be used to help HD families with special circumstances.

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Midge Toole shared with our Center staff the story of her uncle who suffered with HD. She arranged to visit him in another state and have lunch in a restaurant. Her uncle’s HD was prevalent, and he was quite unsteady on his feet. A pedestrian commented that an old drunk man should not be seen with a young woman. Ms. Toole was angered by this comment and argued with the pedestrian. The memory of her uncle’s continuous struggle stays with her. She hopes that her gift to the HD Center will help families improve their quality of life. She also hopes that others will feel compelled to add to this gift, ensuring more families are served.

This is the largest private gift that the HD Center has received, and we are THRILLED!

New Research Assistants join the Paulsen lab

It’s transition time in the Paulsen Neuropsychology Lab as old research assistants leave for advanced training in their desired fields of study. We thank them for their commitment and for helping to train those that take their place. We are pleased to welcome the following new assistants:

Andrew R. Juhl is the Imaging Coordinator for the PREDICT study. He graduated from the University of Iowa in 2005 with dual science baccalaureates (psychology and sociology) and has worked in research continuously since the autumn of 2000. In his spare time, he enjoys writing, performing comedy, and adding entries to the long list of movies he’s seen.

Diem Phan graduated from the University of Iowa in 2005, with degrees in psychology and English. She helps coordinate PREDICT recruitment and retention and coordinates a study involving patients with mild cognitive impairment. She loves to cook (especially Vietnamese dishes), play sports (mainly tennis and disc golf), and spend time with her family, friends and boyfriend—whom she adores. She also loves to relax by watching a movie or listening to Michael Buble.

Jana Hanson graduated in 2006 with a M.A. in psychology from Boston University. She is involved in the RESPOND study which examines discrimination and, the

Bone Marrow Transplant (BMT) study, which assesses cognitive functioning. “I think the best part about the lab is how welcoming everyone is. In addition, I have really valued the resources and trainings that have been provided to all the new Research Assistants to help us transition easily into our new roles.”

Outside of work she enjoys making stain-glass art, playing jazz music and caring for her 2 kittens named Miles and Ella. (Get the jazz theme?)

Nick Doucette spent two years in the inpatient pharmacy at the University Hospital prior to starting in the lab. He graduated in 2004 from Cornell College (Mt. Vernon, IA) with a B.A. in Psychology, Sociology and Women’s Studies. He helps coordinate the PREDICT-HD study, an additional study called PERFORM-HD and he assists with COHORT. He enjoys political debate, sampling new area restaurants and wines, and spending time with his roommate and their sassy cat, Zorra.

Nicole Ramza earned a psychology degree from Saint Ambrose University in 2005. She was trained to perform image analysis in the neuropsychology lab. She is the current Startle coordinator which tests the startle reflex. She will soon begin an Eye Tracking study, which comprises three different groups of HD participants. Nicole is a wine enthusiast who enjoys great food and loves to cook and spend time with friends. She enjoys physical activities like walking, jogging and softball.
Things to know when buying Herbal Supplements

Many physicians treating patients with HD are cautiously recommending over the counter (OTC) medications as a way to slow disease progression. But not all OTCs are the same. Since supplements are defined as dietary, they are not subject to the same standards as drugs evaluated by the FDA (Federal Drug Administration). Some supplements do not list all of their ingredients, what you believe is pure CoQ10 (for example) may be combined with other ingredients. Some companies use different names of the supplement. To be a savvy consumer, consider the following:

Look for standardized herbal supplements. The USP symbol verifies that the supplement matches what is in the bottle, that the product doesn’t contain contaminants and the supplement was made under good manufacturing conditions. Other groups use similar (but not exact) measures to provide some quality control. Good Housekeeping has a research institute that evaluates products as well as NSF International (a not for profit organization committed to safety) and Consumerlab.com. These companies examine safety issues; they do not claim that the supplement will help.

Beware of claims that sound too good to be true. No one supplement can tackle or repair a wide range of health concerns.

Buy only single-herb products. Some products are mixtures, and the label may not have the exact percent of product in the bottle.

Be sure to tell your health care worker about all the medications you are taking, both prescribed and over the counter. All medications and supplements can have side effects or could interact with other medications.

Remember to be a concerned and cautious consumer!

WORMS?

What do worms, Andrew Fire and Craig Mello have to do with each other? And what does this have to do with HD? Andrew Fire from Stanford University in Palo Alto, California and Craig Mello of the University of Massachusetts Medical School won the Nobel Prize for medicine in 2006. Using nematode worms, they discovered a method to control the flow of genetic information in a cell. This method is called RNA interference. This was the first work to silence a gene by turning it off. This gene therapy is being used in many diseases, including HD. We applaud their work and the scientists that have put this method to use in HD research including our own UIHC faculty: Beverly Davidson, Ph.D. and Henry Paulson, M.D., Ph.D. We await further news of RNAi in HD research.

CIT-HD

Abbreviation for Citalopram

Do you know someone that is diagnosed with HD? Is that person NOT taking an anti-depressant medication? The HD Center at the University of Iowa is looking for 20 such people. The CIT HD study assesses results of thinking tasks in participants with early symptoms of HD. This is a double blind study of citalopram, a medication sometimes prescribed for depression. For more information call Bill Adams at (319) 353-4411 or email william-h-adams@uiowa.edu
Home Health Products Improved

For more than forty years Michael Graves and Associates have designed buildings, interior spaces and created consumer products for home and office. You may remember the company product designs for Target in early 2000 like clocks, toasters and teapots. His latest designs are of medical products, inspired unfortunately, because of his own need. Throw out those old hand held shower massagers, because Mr. Graves has turned his creativity towards the design of products that are both functional and attractive. New grip reachers and light weight canes are taking the place of the standard fare. Look for more information on his products at http://www.aarp.org/bulletin/yourlife/ and more information about Michael Graves and Associates creative designs at www.michaelgraves.com.