CHDI - The Drug Hunters

The three step process of finding the cure and drugs to slow progression begins with “basic” science researchers in the laboratory trying to understand what happens with a mutated gene. The second step, the applied phase, is finding a compound to stop the disease and/or fix symptoms and, third, clinical trials ensure the compound or drug is safe and effective.

CHDI is the second step. Now in its third year, they have a mission to move forward the process of drug development. Robert Paci-fici, PhD, Chief Scientific Officer of CHDI, Inc. described the group as drug hunters. With funding from the High Q foundation, they are able to focus specifically on finding companies to work on HD treatments. Though they have no chemistry labs of their own, they are able to partner with big and small drug and bio tech companies that target compounds for HD. Because clinical trials are costly; this critical phase helps select the best compounds to move forward. The “hunters” must ask the right questions, poke holes in old and new theories of HD and look at drugs that may be used for other diseases or symptoms to have the best targets. They hope to report on their progress in the coming year.

We are learning more from the PREDICT study about HD onset markers that can be used for clinical trials. This fall, our scientists will publish a study validating the formula for onset estimates based on CAG repeat length. This finding will help design clinical trials for very early (and pre-symptomatic) HD. The Federal Drug Administration (FDA) wants to know how drugs will work in this pre-symptomatic population. With a symptomatic patient, we are able to measure chorea or changes in functional capacity. This is harder to pinpoint in a pre-symptomatic population. But measures of cognition, behavioral changes or changes in the brain are evident in this pre-clinical population. Treatments might be quite different depending on the stage of a person’s illness.

Dr. Gusella spoke of hope and progress as the basic science researchers continue to learn more about how brain cells are affected by the HD expansion: how they are altered and eventually die. This information is then shared with the drug hunters (CHDI).

We wish all our scientists a productive year. With knowledge, luck and perseverance we look forward to good news about fighting this devastating disease.
Dr. Vickie Wheelock, HDSA Center of Excellence Director, University of California-Davis presented a talk at the national HDSA meeting in Oklahoma City, June, 2007 on “Complementary and Alternative Therapies”. She described methods to improve quality of life for individuals with HD. She described the HD Treatment Triad created by the late Jerry Lampson of the website HD Lighthouse, which incorporates spirituality, exercise and diet. Mouse models of HD have shown that a stimulated or enriched environment delays the onset of motor symptoms and prevents associated brain changes. Exercise is certainly one form of enrichment. Diet can also have a positive influence on living a healthy life with HD. Dr. Wheelock suggests a diet that includes blueberries considered to be leaders in antioxidant activity. Blueberries and other foods classified as polyphenols (for example; green tea, cocoa, berries) seem to have a positive impact on memory, balance and coordination. In addition, other over the counter supplements may show benefits. Research projects continue to ask questions about the supplements including CoQ10, creatine and omega 3 fatty acids.

Arizona Retreat

Jane Paulsen, Anne Leserman and Stacie Vik recently returned from the 8th Annual Arizona Retreat in Prescott, AZ. This expanding state meeting had attendance of more than 150 persons. The group included families with juvenile HD (jHD), residents and staff of Terrace Heights nursing home in Boulder, Colorado and families impacted by HD from many southwestern states. The jHD group had sessions with Jane, Anne and Stacie to share information about jHD to not only help each other but add to the knowledge base of jHD. Phil Hardt continues to coordinate this meeting and bring a variety of events and speakers to entertain and educate the different groups that attend. The Saturday evening session called the “pinecone ceremony” gave attendees an opportunity to dedicate a pinecone to someone special. This was a moving event for all.

Please contact Stacie Vik for updates on jHD research at (319) 353-3716 or stacie-vik@uiowa.edu.

Elizabeth Penziner
Bids Farewell

I celebrated over ten years at the HD center in Iowa City where I have been so fortunate to interact with an amazing community of families and an inspiring team of colleagues. To achieve training in the area of yoga and other healing arts, one needs balance, courage and strength, and I feel no other work could have better prepared me for success in this new field. I have gained so much from the enriching encounters and opportunities I have shared with all of you. I’ll forever give of myself to promote and support the advancement of care and research in HD and plan to stay connected through national and international HD events. Local friends may also spend time with me practicing stress reduction yoga at the Iowa City Huntington’s disease support group meeting on Sunday, August 26.

We thank you Elizabeth, for all your contributions to HD research and care and wish you the best in your new endeavors.

SAVE the DATE!

Iowa Hope Dinner
Saturday, November 3rd
Des Moines Marriott
for more information: see the Iowa chapter website www.hdsaiowa.org

Midge Toole Donation hits the local wire service

Gift provides relief for Huntington’s Disease patients, families at UI

Check out the link on the UI Foundation website http://www.uifoundation.org/news/2007/apr02.shtml
**CIT- HD**

Abbreviation for Citalopram

CIT-HD is a study to see whether this drug can improve cognitive or thinking processes affected by HD.

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.

**COHORT**

Cooperative Huntington’s Observational Research Trial

COHORT is a multi-site, long-term observational study. Our goal is to collect information and increase our knowledge about HD (such as potential treatments, planning of future experimental drug studies, and work toward postponing the onset or slowing the progression of HD). The study will be open to both adults and children who have clinically diagnosed HD and to adults who are part of HD families. Participation in COHORT is voluntary, and visits will be scheduled annually for as long as individuals are able (and choose) to participate. At the initial visit (year one) a blood sample will be drawn for HD genetic testing and other possible biomarkers. Medical and neurological evaluations will be performed at each yearly visit; these include standardized assessments of movement, thinking, memory, ability to perform everyday tasks and behavior.

For more information regarding this study, please contact Anne Leserman (319) 353-4307 (anne-leserman@uiowa.edu)

**The HD Family Study**

is looking for young adults 19-30 to volunteer to complete a survey about their teen years, living in a family where a person had HD. This information will be very important in helping devise ways to support teens in HD families who try not only to keep up with being a student and teenager, but also with being in an HD family. You may be contacted by mail to assist with this survey. If you would like to receive a survey, please contact Anne Leserman, anne-leserman@uiowa.edu or (319) 353-4307. Dr. Janet Williams in the College of Nursing at the University of Iowa is the Primary Investigator for this study.

**TREND-HD**

A Way Forward

On April 25, 2007 the Huntington Study Group (HSG) announced the results of their multi-site Phase III drug trial examining ethyl-EPA’s (i.e., Miraxion’s) affect on Huntington’s disease. Across 41 North American research centers, 316 people participated in this study; the University of Iowa followed 10 participants.

The trial’s primary aim was to examine the drug’s affect on specific motor symptoms. Unfortunately, the trial did not show any reasonable difference between ethyl-EPA’s effect and placebo (an inactive substance). However, it is important to note that ethyl-EPA appeared to be well-tolerated in study participants.

Dr. Ira Shoulson (Principal Investigator, University of Rochester) said, “We are disappointed by the preliminary results... We are grateful for the commitment of our research participants and are proud of the high quality data obtained in the trial.” Dr. Leigh Beglinger (University of Iowa Site Investigator) also indicated “It was a pleasure to work with everyone on this study. While this trial’s results were disappointing, we are very excited to begin offering three new drug trials in the near future. We remain committed to fighting HD at our Center of Excellence.”

The entire TREND-HD protocol was scheduled to last 12 months, and our investigators knew the trial’s clear answer in six months. Accordingly, the silver lining is participants received an answer in a timely fashion. And, because subjects generally only participate in one drug trial at-a-time, participants may now quickly move onto other therapeutic trials. As Dr. Beglinger indicated, we will begin offering three new trials very soon. One trial is scheduled to begin in Summer 2007, while two more are scheduled to begin in Summer 2008. All three will examine drug effects on motor symptoms. Additionally, the University of Iowa is currently hosting two drug trials aimed at improving attention and focus abilities in those who have Huntington’s disease. Both of those trials are currently recruiting.

Our HD Center of Excellence remains committed to investigating therapeutic treatments. While TREND-HD did not provide the answers we hoped for, it provided useful information for the future. We appreciate our participants’ energy and willingness to participate, and we thank everyone for their help in advancing our research.

Bill Adams (319) 353-4411
Clinical Trials Coordinator
The University of Iowa
Hospice Care

Hospice is a support care service that helps someone with a life-limiting illness or injury during their last days. It involves a team-oriented approach using hospice volunteers, registered nurses, social workers, home health aide, etc. The service is offered to patients of any age, religion, race or illness and can be found in hospitals, nursing homes, long-term care facilities, special needs facilities or at the home of the patient. Hospice does not offer a cure but provides assistance in medical care, pain management as well as offering emotional and spiritual support.

The hospice service is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations. More than 90% of hospices in the U.S. are certified by Medicare. Even if a person does not have insurance coverage hospice will work with the person and family members to ensure needed services are provided.

Hospice care usually begins approximately six months prior to a patients expected death. The starting date for hospice care is decided by the patient’s physician. The physician can also recommend the type of hospice care that may be needed: home care, impatient care, respite care, or continuous home care. It is important that a patient and their loved ones clearly understand and accept that the life-ending illness will not be aggressively treated.

Hospice is also beneficial for the patients loved ones by offering support during the patients last days. After the death of a loved one, hospice provides visits with the patients’ loved ones to assist with the grieving process. This may be through telephone calls, emails, visits, support groups, counseling, etc. Hospice care is available to help make the patient and their loved ones comfortable during this difficult transition.

Hospice is designed to fit the needs and wishes to comfort a patient during their last days. Support is offered in different forms to best suit each individual. If you have any further questions regarding hospice services, it is best to talk with your physician.

Reference: