Tetrabenazine
One Step Closer to Approval

An Advisory Committee to the Food and Drug Administration (FDA) voted unanimously to recommend approval of tetrabenazine. If passed by the FDA, this will be the very first drug in the U.S. specifically approved for people with HD.

The HD community came through with personal testimony, written statements, and attendance making clear to the committee members that they should vote their approval for this drug.

Two hundred family members were present at the hearing and, at times during the day, the large room was standing-room only. Many took time to add their names to HDSA’s letter of support and more than 1,500 affirmations were presented to the committee, showing that there is widespread support for tetrabenazine.

Though committee members had little experience with HD before this hearing, the presence of many supporters sent a strong message for the investigating and approving HD treatments.

The Advisory Committee does not have the final say in approving the drug, but the FDA tends to follow their advice. “This was a great example of how working as a community, we can accomplish our goals,” says Barbara Boyle. Barbara Boyle, National Executive Director of HDSA, congratulates everyone for their assistance.

For some patients, tetrabenazine has helped treat chorea symptoms. A clinical trial was completed in the US at 16 HSG (Huntington Study Group) sites. The results of the study were published in the journal Neurology in February 2006. The medication is currently approved for use in several European countries as well as Canada and Australia.

Huntington Study Group
HSG Boston, MA

November, 2007

More than 200 HD research investigators and coordinators met in Boston for an educational and training program covering HD issues. A new format this year gave attendees a chance to be involved with the HSG working groups and learn from experts on how to select treatments for clinical testing, clinical trial design and HD clinical assessments. The working groups’ missions are to find ways for researchers with similar interests to work together for common goals.

For example, the clinical trials working group is trying to support and foster innovative research that will lead to clinical trial pilot studies and early phase trials. The working groups continue to push forward the best science by using the data collected in numerous projects. The groups include the clinical correlates group which advocates infrastructure to better use collected information. The genetics correlate group is creating better ways to define genetic factors. The neuropsychology working group continues to fine tune the best measures that monitor subtle change in HD. The behavioral working group continues to explore ways that improve behavioral measures. And the new biomarkers group discussed the need to increase the number of biological samples currently collected.

The format of the meeting was changed this year to foster needed education and training that helps ensure competence in planning an increasing number of HD clinical trials.

This year a research symposium was added to the agenda that included both researchers and interested families learning about the latest research in HD clinical trials. This symposium will continue to follow the HSG meeting next November in Florida.
Behind the Scenes in the Paulsen lab

Many have heard of or know something about Jane Paulsen’s Predict study aimed at better understanding early signs of HD by assessing MRI scans, blood data, cognitive and behavioral tests and any subtle motor movements. This multi site study (30 sites in the US, Canada, Australia and five European countries) is producing a mass of data. The study currently has 1000 participants across these sites. Many professionals are sorting through this data. Neuropsychologists are looking at behavioral and cognitive data while other professionals with expertise in imaging are sorting through more than 1000 MRI scans. Blood samples are being studied to identify early HD biomarkers. But there is a local Iowan that has been involved with the study since 2000, who assisted in the design of the study, and continues to help to interpret results. Enter the biostatistician Dr. Douglas Langbehn. A biostatistician uses statistical methods to analyze biological data. Dr. Langbehn has both his MD degree with a psychiatry specialty and a PhD in biostatistics. Doug understood that there was both a need and opportunity for the kind of research that Jane envisioned. He understood that helping find treatments for families was needed. But he also saw that “HD is an important model for the challenges that will also be faced in better understanding and treating other genetic neurological illnesses in the future.” Dr. Langbehn likes the ideas of “building mathematical models into results that have practical meaning in battling a disease.” Dr. Langbehn was first author on the 2004 paper in Clinical Genetics focusing on the prediction of “age of onset” based on CAG repeat length. This model and the information that is learned from Predict will help answer questions about when the disease starts.

So what does a man like this do when he’s away from statistics and formulas? Doug is a professional musician who plays piano, other keyboard instruments and the trumpet. He and his wife have what he calls a “geezzer rock band” and have produced some CDs that can be found on itunes. The HD community appreciates his efforts in his day job.

HD Hope Dinner Successful

On November 3rd, 150 people came together at the Des Moines Marriott for fun, food and community to honor those who give and continue to give to the HD community. There was both a silent and live auction raising more than $17,000 to help support the HDSA Center at the University of Iowa. Jane Paulsen was honored with the Excellence in Medicine award. Barbara Boyle made her first trip to Iowa and has a better appreciation of why Iowa has a special reputation. Please plan to join the HD Iowa chapter next year to raise funds and honor those who make a commitment to the HD community. Check out the pictures on the Iowa chapter link at www.hdsaiowa.org.

At Risk Group?

Are you 18 or older and at risk for HD? Would you be interested in a support group to talk about your experience? Would you be willing to come to Iowa City? Would a Saturday, Sunday or evening time work? This could be a one time group or possibly meet every few months. Please email me if you are interested.

anne-leserman@uiowa.edu

HD Support Groups:

**DES MOINES**
Valley View Village Conference
2571 Guthrie Ave
3rd Sunday at 1:30 pm
Mark Hillenbrand
(515) 208-3511

OMAHA, Nebraska
Village Inn Restaurant
78th and Dodge
2nd Monday at 6:00 pm
Cathy McNeil
(402) 537-0739

**IOWA CITY**
University of Iowa Hospitals and Clinics
Della Ruppert Conference Room
6th floor, elevator H
4th Sunday at 1:00 pm
Anne Leserman
(319) 353-4307

FONDA
Fonda Nursing and Rehab
607 Queen
2nd Sunday 1:30 pm
Wilma Frey
(712) 288-4441
The HD Family Study

We are looking for teens between 13-18 and young adults 19-30 to volunteer to complete a survey about their teen age years, living in a family with 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.

Citalopram & HD
A New Clinical Trial

This summer, the University of Iowa launched a new drug trial called Citalopram & HD. Dr. Leigh Beglinger and her HD Clinical Trials Team are managing the clinical trial. Citalopram is a medication that may be familiar to our readers, as it is also known as Celexa (a medication sometimes used when treating depression). Based on previous research, we believe the medication may improve cognition and are now evaluating its use for treating HD symptoms.

A clinical trial is a study that evaluates promising experimental treatments. They are designed to learn if new medications are safe, tolerable and effective. These studies differ from an observational study where people are examined over time without receiving any experimental drugs or treatments.

Professionals from Neuropsychology and Psychiatry are evaluating citalopram on HD symptoms using a standard double-blind procedure. This means neither researcher nor participant know if the person is taking citalopram or placebo during the trial. Over 16 weeks of treatment, we evaluate the drug’s effect on participants’ daily activities such as working, attention span, global thinking abilities and motor movements.

Interested persons must have an HD diagnosis and be between 18 and 65 years old. Additionally, they cannot be taking any antidepressant medication when they enroll. There are eight outpatient visits for study, and each one generally lasts about 1-3 hours. Compensation and some travel reimbursement are also available.

For additional information, please contact the HD Center of Excellence at (319) 353-4411 or email William-H-Adams@uiowa.edu

Eye Tracking:
Establishing a Biomarker for HD

Eye Tracking is a study designed to utilize advanced eye-tracking methods to establish a biomarker for HD by investigating subtle motor and cognitive eye tracking problems in individuals tested for HD. Participants 18 years of age or older who have completed an HD gene test are invited to participate in this 60 minute eye tracking session. Participants will include people who have tested both positive and negative for the HD gene. Compensation is available to study participants. For more information call Jana Hanson at (319)353-4537 or email jana-hanson@uiowa.edu.

RESEARCH
Caregivers Recommendations on Relieving Caregiver Burden

1. **Compromise**- work hard to avoid family fights and resentments. Try not to let old issues pull you apart. This is a time to stick together.
2. **Coordinate**- Offer your services if you have skill with insurance forms or other legal documents. Try to create a game plan when the illness becomes severe or fatal. Adult kids often avoid that conversation.
3. **Encourage**- Help the caregiver find some type of professional support. A support group or an online chat room could help.
4. **Facilitate**- Ask somebody who can be objective to act as a negotiator in stressful situations. This may be a social worker or clergy person.
5. **Investigate**- Find books, go to websites or get in touch with organizations that can help caregivers learn about the illness of the person.
6. **Organize**- Work with the caregiver to make a list of people who can be called upon for different duties.
7. **Discuss**- Ask the caregiver to tell his or her story or keep a journal.
8. **Plan**- Think about the specific services that you can offer the caregiver to make it easier for that person to ask for your help.
9. **Socialize**- Include the caregiver and person they are caring for in community and family activities.

Information from AARP magazine 2007