

HIND-Sight

Huntington's Information &
New Discoveries

HDSA Center of Excellence
University of Iowa



JUVENILE HD

This newsletter generally focuses on information and research updates on adult HD, but did you know that 10% of HD cases occur before age 20? Patients and their caregivers have first-hand knowledge of the differences between adult and juvenile HD. The diagnosis of juvenile HD (JHD) can include changes in behavior, psychiatric symptoms, decline of cognitive functioning, rigidity, clumsiness and a higher likelihood of developing epilepsy. In about 70-80% of JHD cases, the affected parent is the father (Brewer, et al., 2008). In addition, the affected child is likely to have longer CAG repeats (50 +) than those found in the adult onset population.

When faced with the possibility of JHD, families have reported difficulty getting an HD diagnosis for someone with early HD signs. Distinguishing teenage behavioral disturbances versus JHD signs is sometimes difficult to ascertain. It requires the involvement of a knowledgeable HD professional who is familiar with JHD. This may mean a pediatric neurologist or a movement disorder neurologist. The diagnosis of JHD might take more than one visit. A medical professional will want to

learn more about family history, look at test records from the school and assess data from cognitive testing to assist in understanding the abnormal features the patient presents. The MD will also want evidence of JHD-like symptoms during the neurologic exam before requesting a blood test to confirm her/his suspicions. Genetic testing guidelines require a person to be 18 years or older prior to testing. An MD can request HD testing for a child with clear clinical symptoms or a pattern of symptom progression over 6-12 months.

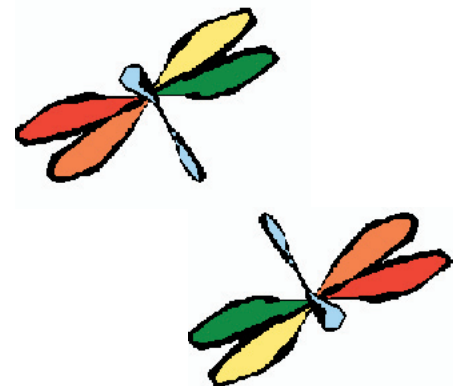
At the University of Iowa, in partnership with the European Huntington's Disease Network (EHDN), two studies are recruiting individuals who are affected by JHD. One study is recruiting the parents/guardians of children with JHD. An informal interview will be conducted to examine the views and opinions of families affected by JHD regarding their healthcare needs and their experiences with JHD. This study also hopes to understand the various coping mechanisms families affected by JHD may use, in addition to other support systems through family, friends, professionals, etc. The second JHD study is recruiting both parents and individuals affected by JHD to research the

effectiveness of clinical measurements. This study will compare the current adult version of the Unified Huntington's Disease Rating Scale (UHDRS '99) with a new modified version specifically developed for the JHD population. The purpose of this research study is to better understand JHD and to improve the currently available tools that evaluate the course of the disease. For more information about these studies, contact Stacie Vik at Stacie-vik@uiowa.edu or 319-353-3716.

For more information about JHD, the following websites are helpful.
<http://www.stanford.edu/group/hopes/basics/juvenile/e0.html>

<http://hdlighthouse.org/abouthd/juvenile/>

<http://www.hdac.org/jhd/>



HD Radio Show

On January 23, 2008, Dr. Jane Paulsen participated as the HD expert on a live radio show called Patient Power. "Patient Power programs feature renowned experts and inspiring patients who talk about the latest and most relevant information to make important decisions about health concerns. Often the discussions focus on illnesses that have not received the attention deserved."

"Patient Power is based in Seattle and founded by two health communications pioneers, Andrew and Esther Schorr. They previously founded HealthTalk, a leader in support for people with chronic illnesses and cancer. Patient Power is devoted to helping you and your family through knowledge, to get the best medicine and return to good health. Andrew was diagnosed with leukemia in 1996. By reaching out to other patients and connecting with doctors who specialize in his illness, he participated in a clinical trial, received "tomorrow's medicine today" and, now 9 years after diagnosis, remains in deep remission and takes no medicines."

In the 1/23/2008 program, "Andrew was joined by renowned expert Dr. Jane Paulsen, Professor of Psychiatry, Neurology, Psychology and Neurosciences at the University of Iowa Healthcare.

Dr. Paulsen is also the director of the Huntington's Disease Center where a wealth of information is available for patients with HD. As a neuropsychologist with over 15 years of active research in Huntington's disease, she is one of the leading authorities on this topic. Andrew and Dr. Paulsen discussed issues that have many HD families concerned such as discrimination

against HD patients, juvenile HD, and the status of Food & Drug Administration (FDA) drug approval. Dr. Paulsen also talks about the excitement surrounding research and clinical trials, in addition to information about supplements. She talked about coenzyme Q10 and what it is doing for people with Huntington's disease, Parkinson's disease and how far we have come since the HD gene was discovered. Patients are now able to receive a simple blood test that clears up all uncertainty." The show also offered a patient perspective from Karen Milek, a participant in the Iowa research program and a vocal HD advocate.

The response from this radio program was enormous and Andrew promised another show on HD to cover the many unanswered questions and concerns from the listening audience. The HD Center also noted an increase in our website hits at <http://www.uihealthcare.com/depts/huntingtonsdisease/> and an increase of emails to Dr. Paulsen and her staff. Thank you, Andrew, for continuing to educate the public about rare diseases. You can listen to the broadcast or read the transcript at <http://www.patientpower.info/listenhealthtopic-details.asp?showid=HR012308&Topic=Huntington's%20Disease>.

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?

Are you 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

Hoop-a-Thons

Join the Iowa HDSA chapter in spring hoop-a-thons to raise money and create awareness of HD. Shoot some hoops and support the Iowa chapter of HDSA that, in turn, helps fund the HDSA Center of Excellence at the University of Iowa.

March 15, Des Moines

AIB College Activities Center 1-4

March 29, Bedford

Bedford High School 11-2

March 30, Audubon

Audubon High School 1-4

April 5, Storm Lake

Storm Lake Middle School 11-2

May 3, Marion

Vernon Middle School 11-1

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

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 RESEARCH

fMRI

In this study, functional Magnetic Resonance Imaging (fMRI) scanning will be used to examine brain changes in HD during cognitive tasks. **Participants currently enrolled in the PREDICT-HD study are being invited to participate in an fMRI study at either the University of Iowa or the Cleveland Clinic in Cleveland, Ohio.** Participants will undergo fMRI scanning for three visits with 12 months between each visit. This 5-6 hour study takes place over the course of two days. Compensation is available. Questions? Please contact Andrew Juhl by email at andrew-juhl@uiowa.edu or (319) 353-5451.



Citalopram & HD

The University of Iowa launched a new drug trial called Citalopram & HD in summer, 2007. 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.

Currently, we do not know if anyone with HD will benefit from participating in this trial. However, by enrolling, participants are helping us evaluate future treatment strategies for HD. 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

RESEARCH



The HD Family Study

continues to look for young adults 19-30 to volunteer to complete a survey about their teens years living in a family where a person had/has HD. Dr. Janet Williams in the College of Nursing at the University of Iowa is the Primary Investigator for this study. This information will be very important in helping to develop support for teens in HD families. You may be contacted by mail to assist with this survey. If you would like to receive a survey, please contact Anne Leserman at (319) 353-4307 or anne-leserman@uiowa.edu.

RESEARCH RESEARCH

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Complimentary and Alternative Medicine

Alternative medicine treatments ranging from herbal remedies to acupuncture have become more popular as people seek greater control of their own health. The idea of integrated care is that people heal best when doctors include biology, psychology, spirituality and lifestyle to treat disease. Many treatments, both conventional and unconventional, have risks and side effects. It is always useful to let your doctor know what you are taking.

Alternative medicine is the use of practices that aren't typically used in conventional medicine being used instead of conventional methods. **Complimentary medicine** uses alternative practices but in addition to conventional therapies.

Acupuncture: A technique of inserting and manipulating very fine needles into points on the body with the aim of restoring health and well-being, e.g. treating pain and diseases. Acupuncture is thought to have originated in China and is most commonly associated with Traditional Chinese medicine (TCM).

Biofeedback: A form of alternative medicine that involves measuring a subject's bodily processes such as blood pressure, heart rate, skin temperature, sweat response, and muscle tension and conveying this information to a person in order to raise awareness and conscious control of these physiological activities.

Herbs and Supplements: The use of plants for their therapeutic qualities

Meditation: A discipline in which the mind is focused on an object of thought or awareness. It usually involves turning attention to a single point of reference. Meditation is recognized as a component of eastern religions, where it has been practiced for over 5,000 years.

Yoga: A series of postures, breathing, concentration and meditation in a physical practice to strengthen the body, calm the mind and increase one's sense of peace and well-being.

for more information try www.mayoclinic.com or www.nccam.nih.gov (the National Center for Complimentary and Alternative Medicine)