

Sleep Disorders and Huntington's Disease

Ask an HD person or family member about HD and sleep and you will probably get many different responses. Parents of children with Juvenile HD complain their children have odd sleep patterns, ranging from 24 hours awake to 24 hours asleep. This pattern makes it difficult to maintain schoolwork or plan for family events. Some families say there is no movement at night from an adult HD patient that experiences much chorea during the day. Others say the person moves all the time at night and needs to sleep alone to keep from disturbing his/her partner. Sleep problems are common in patients with neurologic disorders like HD. Lack of sleep (or disturbed sleep) has an enormous impact on one's quality of life. These sleep problems may arise from changes in the brain regions that control sleep or from drugs used to control symptoms. Lack of sleep can worsen the symptoms of the illness. The disruption of sleep seems to increase as the disease progresses.

A section of the brain called the hypothalamus helps to maintain the body's status quo (for example; sleep, hunger and thirst). It also

creates changes in a person's biological "clock". Circadian rhythm is the name given to the body's "internal clock". You may have heard this term in reference to people with jet lag or people that do shift work who have trouble regulating their internal clock. Many biological activities operate in a 24 hour cycle that includes 8 hours of sleep. Brain activity, hormone production and cell regeneration are some biologic activities that occur in a daily cycle. The hypothalamus is one area of the brain that shows some shrinking or atrophy with HD. This may help explain sleep disturbance as a feature of HD.

In the *Journal of Neuroscience*, 2005, a study used an HD mouse to show disturbed internal sleep cycles. In this model, increased daytime activity resulted in reducing the targets that are used to transfer genetic information; making RNA from DNA (transcription). There are apparently molecular abnormalities that explain sleep changes. Knowledge of how to treat sleep problems will benefit HD patients.

Sleep patterns and disorders research continue; as subjects and re-

searchers are looking for biomarkers to evaluate future therapies. Do discuss sleep patterns with your physicians. Use the suggestions on the back page of this newsletter for ideas on how to improve your sleep.



Jane Paulsen

Excellence in Medicine Award

I hope you are lucky enough to attend the HDSA Chapter dinner on Saturday, November 3rd at the Des Moines Marriott. The Chapter is planning a gala event to raise funds for the HD Center of Excellence. Seven honorees will get awards at this dinner including Dr. Jane Paulsen who has been involved in HD research for 15 years. Dr. Paulsen is a major grant receiver at the University of Iowa and is known internationally for her creative HD research. Many of you know her as the Primary Investigator for the Predict project that is assessing early signs of HD in a group of 994 across the globe. Yeah Jane! This award is well deserved. We are lucky to have her in Iowa.



Iowa HDSA
Celebration of Hope Dinner
 Saturday, November 3, 2007
 Des Moines Marriott
 6-10:30 pm



Our local families and professionals are being honored at a annual dinner to raise funds for the HDSA Center of Excellence at the University of Iowa. Questions? Call the Iowa chapter at 1-800-865-4342. Come join the fun with live and silent auctions, dinner and honoring a wide range of HD supporters.

SUPPORT GROUP in FONDA

First support group meeting in Fonda, IA on Sunday, November 11 at the Fonda Nursing & Rehab Center at 1:30 p.m. Wilma Frey, the administrator of Fonda Rehab will be the leader. For more information or if you would like input on further meeting times, contact Wilma at 712-288-4441.

FDA and the Orphan Drug Program

The U.S. Food and Drug Administration (FDA) is an agency within the Department of Health and Human Services. The FDA's mission is to protect public health by assuring "safety, efficacy (meaning efficient or useful) and security of human and veterinary drugs, biological products (for example, blood), medical devices, our nation's food supply, cosmetics and products that emit radiation". They are also responsible for "advancing the public health by speeding innovation that make medicines and foods more effective, safer and more affordable; and helping the public get the accurate, science-based information they need to use medicines and foods to improve their health". This is a very large mission with eight Centers to address all these concerns.

In 1983, the Orphan Drug Act was enacted to assist medical research and development of drugs for diseases affecting fewer than 200,000 people in the U.S. Because it is less financially advantageous for drug companies to find drug solutions for a small population, the act will reward companies with tax reductions and other market advantages. Huntington's Disease is listed as one of the rare or "orphan" diseases. The path to getting a drug to market is still the same, though some statistical burdens have been reduced. For example, the number of patients participating in a clinical trial might be less because there are fewer participants that have the disease. To date, there are 309 drugs (non HD) that have gone to market since the law was enacted. This year 11 orphan drugs have been approved. For the decade prior to 1983, the number of medications for "orphan" diseases was 10. Progress has been made.

In an Associated Press article from August 2007, there is concern that the FDA is exercising more caution on drug choices. The FDA is asking for more information before making their decisions. Drug companies worry about excessive delays after some prominent medications were pulled from the market. Drug application approvals have dropped since one year ago. "Drugs for life threatening diseases or conditions with no good current treatment are generally being approved". What will this mean for medications for HD? We will continue to offer clinical trials and keep you informed on advances in HD treatments.

(see CIT-HD on next page)

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

RESEARCH

COHORT

Cooperative Huntington's Observational Research Trial

Dehydration

Dehydration is a condition in which the body contains an insufficient volume of water for normal functioning. Symptoms of dehydration can differ from person to person, because everyone's body is unique. Dehydration can be caused by vomiting, diarrhea, blood loss, malnutrition and failure to take in liquids after excessive sweating and urination. This is the reason that people are advised to drink lots of liquids when they are ill. But the signs of dehydration can be identical to delirium. Correcting the dehydration can make new or quickly appearing dementia symptoms ease or disappear. The Family Service Coordinator, Anne Leserman, at the HD Center of Excellence, often gets questions about HD patients that have developed a rapid onset of confusion. She recommends being evaluated by the person's local physician to rule out the possibility of dehydration or other causes. In early stages of dehydration, there may be no signs or symptoms. As dehydration increases, the following signs and symptoms may develop: persistent fatigue, lethargy, muscle weakness or cramps, headaches, dizziness, nausea, forgetfulness and confusion. Dehydration is one of the most frequent causes of hospitalization after age 65. Correcting dehydration can help an older person return to their normal functioning.



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 future experimental drug studies, and work toward postponing the onset or slowing the progression of HD). The study is 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 occur annually. At the initial visit a blood sample will be drawn for HD genetic testing and other possible biomarkers. Medical and neurological evaluations are performed at each yearly visit; these include standardized assessments of movement, thinking, memory, ability to perform everyday tasks and behavior. For more information contact Anne Leserman at (319) 353-4307 or anne-leserman@uiowa.edu.

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 Functional Magnetic Resonance Imaging (fMRI) scanning for three visits with 12 months between each visit. Each visit takes place over the course of two days lasting 5-6 hours.

Compensation is available. For more information call Andrew Juhl at (319) 353-5451 or email andrew-juhl@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 45 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 Nicole Ramza at (319)384-9408 or email nicole-ramza@uiowa.edu.

CIT- HD

Clinical Trial

CIT-HD is a study to see whether citalopram (antidepressant) 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 56 such people to participate in this clinical trial. 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.

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10 Tips to Get Better Sleep

- 1. Cut caffeine.** Try cutting out caffeine four to six hours before bedtime.
- 2. Avoid alcohol as a sleep aid.** Alcohol may help you fall asleep but it can cause disturbances in sleep, making for less restful sleep.
- 3. Relax before bedtime.** Develop some kind of pre-sleep ritual to break the connection between the day's stress and bedtime. This might be as little as 10 minutes or as long as an hour.
- 4. Exercise at the right time for you.** Regular exercise can help you get a good night's sleep. The timing of your exercise seems to play a key role in its effect on sleep. If you get energized or more alert with exercise, you may not want to exercise in the evening.
- 5. Keep your bedroom quiet, dark and comfortable.** Find an ideal temperature for your room. A room that is too hot or too cold can disrupt sleep. Try earplugs if you are a light sleeper and window coverings to create an ideal sleep environment.
- 6. Eat right, sleep tight.** Don't go to bed hungry but also avoid heavy meals before bedtime. Some foods can help to promote sleep like milk, tuna, halibut, pumpkin, artichokes, avocados, almonds, eggs, peaches, walnuts.
- 7. Restrict nicotine.** Having a smoke before bed puts a stimulant into your blood stream.
- 8. Avoid napping.** Napping can make things worse if you are having trouble falling asleep. If you do nap, keep it to a brief 15-20 minutes. This can be rejuvenating.
- 9. Keep pets off the bed.** Pets can cause you to awaken during the night because of allergies or pet movements.
- 10. Avoid watching TV, eating and discussing emotional issues in bed.** The bed should be used for sleep and sex. If used for other activities, it can create a distraction and make sleep more difficult.