

HIND-Sight

Huntington's Information & New Discoveries

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PREDICT-ing a Brighter Future for HD Research

The University of Iowa's HD Center of Excellence are pleased to provide an update of our newest research study, PREDICT-HD.

The purposes of the study are to determine the factors that signal the onset of HD. PREDICT-HD will also refine the measures that physicians use to detect the onset of HD. Better detection and measurement of the earliest signs of disease will ensure that treatments are given to patients at the best time for the greatest benefit. The study focuses on individuals who are at risk for HD, but who have not been diagnosed with the disease. Currently, the Paulsen lab is recruiting individuals who are between 30-55 years of age, who are at-risk and have been tested for the

HD gene, and who have not yet been diagnosed with HD.

If you are eligible, then we welcome you to participate in this study. While there are no direct benefits to participating in this study, the information gathered will help scientists better understand the onset of HD in persons at risk for the illness. If you are interested in learning more about this study, please contact the Huntington Study Group toll free number (1-800-487-7671) or visit the website at: www.Huntington-Study-Group.org. If you would like to participate in the study, please call the center coordinator, Elizabeth Penziner, at 319-353-4307, or email her at elizabeth-penziner@uiowa.edu

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Want to get more involved?

If you would like to be involved in a clinical trial, or just learn more about research at the Center of Excellence, see page 5 for information!

- A new study shows that a drug called cystamine alleviates tremors and prolongs life in mice with the gene mutation for Huntington's disease (HD). The drug appears to work by increasing the activity of proteins that protect nerve cells, or neurons, from degeneration. By enhancing the brain's natural protective response to the disease, researchers were able to alleviate the uncontrollable tremors and prolong the lives of mice that were artificially carrying the gene that causes HD. The study suggests that
- In a study published in the August issue of Nature Neuroscience (and available online July 1), HDSA-funded Coalition for the Cure investigator, J. Timothy Greenamyre of Emory University in Atlanta GA found that the mutant protein disrupts the mitochondria of nerve cells in the brain. Mitochondria are the 'power plants' within each cell, which provide the energy necessary for all cell functions. They are the principal sites where energy is generated from the oxidation of food we ingest. Mitochondria normally have a membrane potential, like the charge of a battery. Dr. Greenamyre and colleagues found that mitochondria from blood cells of people with HD have a lower membrane potential ("charge") than

a similar treatment may one day be useful in humans with HD and related disorders. In the study, lead scientist Marcela Karpuj, Ph.D., and colleagues injected cystamine into mice with an abnormal huntingtin gene. The mice that received the drug had fewer tremors and other abnormal movements and less weight loss than the untreated mice. They also lived about 20 percent longer. However, cystamine did not reduce the number of huntingtin clumps found in the brain. - *NINDS*

normal. In addition, mitochondria normally take up calcium when it enters nerve cells and, in this way, prevent cell damage and death that may be caused by excessive calcium levels. The scientists found that HD mitochondria could not take up calcium as efficiently as normal mitochondria. Dr. Greenamyre believes that understanding exactly how mutant huntingtin protein harms mitochondria may lead to new ways to protect the nerve cells that die in HD. And, if drugs can be found that improve mitochondrial function, they may be useful to slow or stop disease progression. It is also possible that these findings could help to explain why people with HD have difficulty gaining or retaining body weight despite eating high calorie diets.



***New Additions:
HD Center to Hire Social Worker!***

In the new year, a trained social worker will be joining the HD Center staff. Our HD Center is finally in a position to hire a trained social worker to assist with family services. The most exciting update about this new position, is that a social worker will bring new skills and information to our families (the new hire will be trained in providing information about disability services, Medicaid programs, and residential facility placement issues, -specifically related to HD).

Wherever you are on the wide spectrum of those affected by Huntington's disease, whether you live with the disease yourself, the possibility of possessing the gene, or if you are the family member of someone who is suffering from Huntington's, the degenerative nature of this neurological disorder can leave many people with an overarching feeling of hopelessness. Compounded with the normal difficulties of day-to-day living, coping with Huntington's may seem at times an act of futility. It is not uncommon for people with fatal illnesses to turn to drugs and alcohol as a coping mechanism. Because it is of paramount importance to cultivate physical as well as mental health in order to maintain an active role in fighting the progression of the disease, we here at the Huntington's disease Center of Excellence thought it might be useful to illustrate some of the warning signs associated with substance abuse, in order to help you pinpoint, if necessary, any behavior counterproductive to prolonging your health and well-being.

The following are some diagnostic guidelines that can be helpful in recognizing drug/alcohol addiction signs. Understand that drug/alcohol addiction signs can vary depending on the drug used.

- ✓ Drug/alcohol is often consumed in larger quantities and for longer periods than planned. Increasing inability to control or decrease drug/alcohol use.
- ✓ Life begins to center around obtaining and using and recovering from drug/alcohol.
- ✓ Family, friends, work and hobbies are neglected in favor of the drug/alcohol.
- ✓ Drug/alcohol use continues despite physical and mental problems that are caused by using.
- ✓ Increased tolerance as it takes greater quantities of the drug/alcohol to achieve the desired effect.
- ✓ Withdrawal symptoms are felt when drug/alcohol use is stopped and drug is taken to prevent withdrawal.
- ✓ Overwhelming desire and compulsion to use the drug/alcohol.

Prevention/Safety:

- ✓ Learn how having a disability/disease poses unique risk factors for the development of alcohol, tobacco, and other drug (ATOD) problems, and, conversely, how ATOD use poses unique risks for the disabled.
- ✓ Ask your doctor about the over-the-counter and prescription drugs that you take. Alcohol, in combination with some medications, may cause serious physical reactions. The safest option is to not drink alcohol while using these medications.
- ✓ If you are of legal age and choose to drink, recognize that your physical condition may reduce your tolerance to the effects of alcohol.
- ✓ This may put you at greater risk for accidents and injuries.
- ✓ Be aware that alcohol and other drugs can interfere with learning and developing social skills, decreasing a person's ability to be independent.
- ✓ Your body's immune system is affected by alcohol, tobacco, and other drug use. Any indication of deteriorating health should be taken as cause to halt drug/alcohol abuse.

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*Laura Stierman, University of Iowa College of Medicine, Psychiatry
Research MEB 1-174, Iowa City, IA 52242-1000*

Jane Paulsen, Ph.D.
University of Iowa
Psychiatry Research 1-293 MEB
Iowa City, IA 52242-1000
503260023