

# HIND Sight



## *Huntington's Information & New Discoveries*

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Experience exotic cuisine and support Iowa's Huntington's Disease Center of Excellence! On Tuesday, **January 14<sup>th</sup>**, Iowa City restaurant, Thai Flavors, will donate 20% of all of that day's revenue to the HD Center of Excellence. That means that a portion of every meal purchased on that day, (lunch 11-2; dinner from 5-9) will go to support HD Center services and research. The event, intended to support community services, is made possible by Pac, owner of Thai Flavors and local resident. Each month Pac selects a different community organization and generously contributes much of his time and daily profits, in an effort to raise money and awareness for important causes. The support provided the HD Center is a reflection of Pac's commitment to the Iowa City community and the services offered here. Please show our thanks by visiting his restaurant when looking to enjoy a

meal in Iowa City. Thai Flavors, located at 340 E. Burlington St., is handicap-accessible and parking is available at the Robert A. Lee Community Recreation Center parking lot/ramp. Telephone 339-8900 for reservations.



Uuhhhh... Pictured above is a sheepish Elizabeth Penziner after running down the ill-fated mailbox at the home of Ronald and Marlene Armstrong. Apparently, nothing stands in the way of the Center's statewide outreach efforts. Luckily, the owners are good friends to the HD Center and quite handy with the toolbox!

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- Public television to air program about the impact of genetics

***Families helping scientists identify new models for treatment: more about PREDICT-HD ahead***

- 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 protecting nerve cells, or neurons, from degeneration. By enhancing the brain's natural protective response to the disease, researchers were able to alleviate tremors and prolong the lives of mice that were artificially carrying the gene that causes HD. The study suggests that a similar treatment may one day be useful in humans with HD and related disorders. – *NINDS*
  
- In a study published in the August issue of *Nature Neuroscience*, Coalition for the Cure investigator, J. Timothy Greenamyre of Emory University in Atlanta GA found that HD's 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. 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. 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.
  
- The University of Iowa's HD Center of Excellence is pleased to provide an update of our newest research study, PREDICT-HD. Finally underway, the study has enrolled participants from across the country. Results of the PREDICT study will determine the factors that signal the onset of HD. Future models for HD treatment are reliant on this study for important information about when to begin drug therapies that are newly developed. The study focuses on individuals who have been gene tested for HD, but who are not yet showing symptoms of the disease. Currently, the Paulsen lab is recruiting individuals who are older than 26 years of age, who are at-risk and have been tested for HD, and who have not yet been diagnosed with HD.
  
- Privately-held Structural GenomiX, Inc. (SGX) and the Hereditary Disease Foundation (HDF) recently announced a collaboration agreement to utilize SGX's drug discovery technology to investigate the structure of the huntingtin protein responsible for Huntington's disease. This is the first-ever large-scale effort aimed at determining the structure of this protein since the huntingtin gene was discovered in 1993. The goal of the SGX-HDF collaboration is to advance the development of therapeutics for the treatment of Huntington's and other diseases.
  
- University of Iowa research team led by Beverly Davidson, combined gene-therapy and gene-silencing to identify method of altering gene expression in a way that "turns off" mutations in the genes of mice. This disrupts the chain of events that otherwise causes the cells to die. Future research is targeted on translating this discovery so that it is useful in humans.



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

A new social worker will be joining the HD Center staff. The HD Center has been eagerly awaiting the assistance of a social worker to enhance family services. The most exciting update about this new position is that a social worker will bring new skills and information to our families (she is trained in providing information about disability services, Medicaid programs, and residential facility placement issues). Please join us in welcoming Anne Lesserman at upcoming support group meetings held in Iowa City on the fourth Sunday of every month. This group meets from 1:00-3:00 p.m. in the Adult Outpatient Clinic, room 1911 JPP, on the first floor of the John Pappajohn Pavilion near elevator I.

***Premiering this winter on your PBS station:  
OUR GENES/OUR CHOICES***

A 3-part PBS series examining the impact of advances in genetics on the right to privacy, reproductive choices, and personal responsibility will air in Iowa on **January 19, 2003**.

Three timely and provocative programs in the PBS series OUR GENES/OUR CHOICES, produced by Fred Friendly Seminars, engage viewers in a critically needed dialogue about the implications of genetic information. The three programs in the series - Who Gets to Know?, Making Better Babies, and Genes on Trial - tackle personal, social, legal and ethical issues surrounding the development of genetic science.

**Program Schedule for Iowa broadcasting: Iowa Public Television**

Who Gets to Know?
Jan 19, 2003
3:00PM

Making Better Babies
Jan 19, 2003
4:00PM

Genes on Trial
Jan 19, 2003
5:00PM

The Robert Wood Johnson Foundation; the National Science Foundation; the Alfred P. Sloan Foundation; the National Human Genome Research Institute; the United States Department of Energy Office of Science and the Josiah Macy, Jr. Foundation provide funding for the OUR GENES/OUR CHOICES project. OUR GENES/OUR CHOICES is a production of the Fred Friendly Seminars at Columbia University Graduate School of Journalism in association with Thirteen/WNET New York.

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