In Harmony for Huntington’s Disease  
Music at the Mill  

Iowa City’s Mill restaurant hosted the 3rd annual “In Harmony for Huntington’s” fundraiser on Friday, October 7th. More than 100 people enjoyed music from local bands Rock Lobster, Big Wooden Radio and the Letterpress Opry. Patrons bid on silent auction items and won prizes in a raffle. The fundraiser supports our family services program and the University of Iowa HD Center of Excellence. HD clinic staff thanked supporters for their ongoing contributions to the Center of Excellence. The audience included many families coping with HD. Members from the Iowa HDSA chapter also joined in the festivities.

Gifts from Carmen Leal  

Professional speaker, singer, and author Carmen Leal donated one hundred copies of her new book to the HD Center of Excellence at the University of Iowa and to other HD Centers across the country. The book is called “Portraits of Huntington’s” with the subheading “choosing joy through life lessons”. Carmen uses her own HD experience intermingled with other HD family stories and portrays a sense of hope and joy when dealing with adversity. The sections of the book examine knowledge, laughter, patience, compassion, faith, love, hope and joy in relation to living with HD. Carmen and the families she writes about choose to move forward and live with HD in their lives but manage to find special gifts in a family member that they dearly love. Thank you, Carmen, for this special book that offers hope and encouragement but also permits laughter and crying.

answer from back page- All of these countries are part of the International Huntington’s Association whose primary goal is to promote collaboration in the search for a cure for HD.
What does it mean?

**Apoptosis**: A form of cell death where the elimination of cells does not release harmful substances into the surrounding area. The human body replaces perhaps a million cells a second. Too little or too much apoptosis plays a role in many diseases. When programmed cell death does not work, cells that should be eliminated may hang around and become cancerous. When apoptosis overly works, the process kills too many cells and damages tissues. This is evident in strokes and neurodegenerative disorders such as Alzheimer’s, Huntington’s and Parkinson’s diseases.

**Benzodiazepines**: A class of drugs that act as tranquilizers by lowering the level of activity in the brain. They are commonly used in the treatment of anxiety. Benzodiazepines may cause drowsiness. They are effective in reducing anxiety, stress, agitation, promoting sleep, treating restlessness and relaxing muscles. Examples include the generic name with brand name in parenthesis: diazepam (valium), alprozalam (xanax), clonazepam (klonipin) and lorazepam (ativan). These medications are habit forming.

**Dopamine agonist** (DA): Dopamine is an important messenger in the brain. Dopamine agonists are drugs that increase dopamine amounts in the brain. These drugs help satisfy the brain’s need for dopamine. These drugs are thought to be neuroprotective and may slow the progression of some disease. For example, DA medications are being used to treat Parkinson’s disease.

**Neuroimaging**: Detailed images of the brain and spinal cord (central nervous system) through the use of computed tomography (CT) scanning, magnetic resonance imaging (MRI), positron emission tomography (PET) scanning, or other imaging techniques that assist in diagnosis, treatment decisions, or research. **CT** - data from multiple x-ray images that are turned into pictures on a screen. They can show structures not seen in conventional x rays. **MRI** scans use magnetism, radio waves, and a computer to produce images of body structures. The MRI scanner is a tube surrounded by a giant circular magnet. The patient is placed on a moveable bed which is inserted into the magnet. The image and clarity produced by an MRI is detailed and can detect tiny changes of structures within the body. **PET** - A highly specialized imaging technique that produces three-dimensional colored images of radioactive substances functioning within the body. PET scanning provides information about the body’s chemistry which is not available through other procedures.

Dr. Jane Paulsen and Dr. Henry Paulson enjoy dinner at the HD meeting in Manchester, England September 2005
Planning for your Loved One with Special Needs

This was the topic of the Iowa City support group on Sunday, October 23rd. Krisanne Hawes, a MetDesk specialist was the speaker. MetDesk is a specialized unit of the MetLife insurance company or the Division of Estate Planning for Special Kids (DESK). The unit assists families with a complicated process: planning for the future of a person with special needs. Though the primary focus is planning for children, Krisanne talked about future plans for a family member with HD. She emphasized finding an attorney that specializes in special needs estates. She stressed this point, because Iowa is very strict about the wording of trusts. There are 14 different kinds of special needs trusts. The services offered by MetDesk are free. Caregivers asked questions about how to arrange their retirement benefits to help their children in the future but not limit government services to their spouses. This was one of many concerns of the group. It was an informative session and we appreciate Krisanne Hawes traveling from Des Moines on a Sunday afternoon to speak with us.

TREND-HD is a new clinical trial that will begin in early December 2005. This study evaluates ethyl-EPA’s (found in omega-3 fatty acid) affect on HD symptoms. It will be conducted at 45 HSG Centers throughout the United States and Canada.

Participation in TREND-HD lasts 12 months, and each research center will enroll more than seven participants. During the first six months, participants are randomly assigned to receive either the active drug (ethyl-EPA) or an inactive look-alike (placebo). The last six months allow all participants to receive ethyl-EPA.

Study procedures include physical, neurological, mood and thinking exams. Blood samples are also taken for general health screening and to confirm that the HD gene is present.

We do not know if participants will benefit from participating in TREND-HD. However, participants will contribute to our growing HD knowledge.

More information about this study can be located at www.Huntington-Study-Group.org

An Exciting New Imaging Technique—Chemical Shift Imaging

Drs. Peg Nopoulos and Vincent Magnotta in the Department of Psychiatry are piloting a research study examining brain composition in those showing symptoms of Huntington’s disease using an imaging technique called Chemical Shift Imaging (CSI) or spectroscopy. The doctors hope to discover whether or not the brain’s chemical composition in those with HD is different from control participants who do not have the disease. If the researchers encounter any differences, they may design a larger study using CSI on many more participants with HD.

Chemical Shift Imaging is done using a Magnetic Resonance Imaging (MRI) machine. Using a very powerful magnet and radio waves, this machine can determine the concentrations of certain chemicals that are normally found in different areas of the brain. It is hypothesized that neurological (brain) diseases like HD may change the composition of certain chemicals in the brain, possibly causing some HD symptoms.

As with most of the research we complete at the HD Center of Excellence, we hope that information we learn from this and other imaging studies will help us slow the progression of the disease and find better ways to treat HD symptoms.

HD Support Groups:

DES MOINES
Valley View Village Conference
2571 Guthire Ave
3rd Tuesday at 6:30 pm
Kim Wesack
(515) 965-5469

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
What do these countries have in common?  
*see front page for the answer*

Argentina  
Australia  
Austria  
Belgium  
Brazil  
Canada  
Chile  
China  
Colombia  
Cuba  
Czech Republic  
Denmark  
Ecuador  
Egypt  
Finland  
France  
Germany  
Greece  
Hungary  
Iceland  
India  
Iran  
Ireland  
Israel  
Italy  
Japan  
Lebanon  
Lithuania  
Malta  
Mexico  
Moldova  
Netherlands  
New Zealand  
Northern Ireland  
Norway  
Oman and other African countries  
Pakistan  
Paraguay  
Peru  
Philippines  
Poland  
Portugal  
Romania  
Russia  
Scotland  
Slovakia  
Slovenia  
South Africa  
South Korea  
Spain  
Sweden  
Switzerland  
Taiwan  
Thailand  
Tunisia  
Turkey  
United Kingdom  
Uruguay  
USA  
Venezuela  
Yugoslavia  
Zimbabwe