

## **PREDICT-ing a Brighter Future for HD Research**

We at the University of Iowa's HD Center of Excellence are pleased to announce the beginning of a new research study called 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](http://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](mailto:elizabeth-penziner@uiowa.edu).

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If you would like to be involved in a clinical trial, or just learn more about research at the Center of Excellence, see pages 6-7 for information!

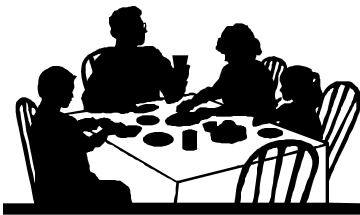
## *HD and Nutrition: Ideas for the HD Kitchen*

(Adapted from Anna Gaba, *Nutrition and Huntington's Disease*)

Having the right equipment can make preparing and serving meals for the person with HD much easier. Of course, what becomes "essential" is a matter of individual needs and preferences, as well as budget. These guidelines might be useful in the kitchen as you prepare healthy food for the HD patient with an eye to weight gain from high-calorie foods.

And always remember that food should be enjoyed!

- **Blender and/or food processor:** When a softer consistency is needed, these can help with pureeing, as well as for preparing shakes, soups, and sauces. If possible, get one that has more than one container, to allow for preparation of multiple foods quickly.
- **Juicer:** A juicer can be useful for a person with dental problems, who cannot chew fruits and vegetables well. If swallowing is a problem, try adding thickening powder, or mix the juice into a thick shake or soup for some needed calories.
- **Cappuccino maker:** This may seem like a luxury, but switching from regular coffee to cappuccino, made with whole milk and added cream (or vanilla ice cream!), can add some needed calories.
- **Pastry cutter and/or potato masher:** These can serve many purposes in mixing and mashing foods. These are also useful for adding "extras" like butter or sour cream into a dish.
- **Dishes with sides** (aka "soup plates" or "pasta dishes"): Dishes with sides can make picking up food much easier and less messy, and they are readily available in most department, house ware or medical supply stores. You might also consider using "sports" cups with covers and straws to help prevent spills.
- **Rubber sleeves and larger handles** on spoons, forks, and other utensils make picking up food easier. Rubber handles can be bought at medical supply stores.
- Using a **heated "baby dish"** for a warming tray can keep food warm throughout a meal for a slow eater.



### **Huntington's Disease**

#### SUPPORT GROUP MEETING SCHEDULE

**January 27** we will discuss individuals with HD and caregivers

**February 24** Elizabeth Penziner will lead a discussion on death and dying

**March 24** we work on pieces to contribute to the travelling HD Quilt

#### **Location**

**University of Iowa Hospitals and Clinics**  
Adult Outpatient Waiting Room  
1<sup>st</sup> Floor John PappaJohn Pavilion,  
near elevator I

#### **Time**

All meetings are held from 1:00-3:00 p.m.  
Snacks provided

#### **Questions**

Please call Elizabeth Penziner at  
319-353-4307

## *HD Center's "Celebration of Hope"*

To celebrate having been designated a HD Center of Excellence we held our first "Celebration of Hope" dinner on Monday, 16 April 2001. This dinner honored local service leaders in the fight against HD and recognized the efforts of the researchers and staff of the HD Center of Excellence. The Celebration of Hope dinner included an Awards Ceremony presenting "Distinguished Leadership Awards" and the "HD Humanity Award." All proceeds from the dinner went directly toward maintaining and promoting research and care services at our HD Center of Excellence.

The Celebration of Hope dinner was a wonderful opportunity for the center directors to reach out and share their experiences with researchers, politicians, and the corporate communities of Iowa. It was also a celebration of the advances in HD care and research that continue to inspire persons with HD, their families and the health care professionals working in the field.



In 1993 the gene for Huntington's Disease was discovered, which made it possible to begin testing for the disease in persons at-risk to develop the disease. For those at risk, who have family members who have HD, the test will show if the individual has the gene for HD or not. If they do not have the gene, they will not develop HD symptoms, and will not pass the disease on to their own children. Testing early for the disease is a good way to plan for the future. One should only be tested at a specialized HD Center. In order for one's genes to be tested for HD, one need only provide a blood sample at the test site. If you think you might be at risk and wish to be tested, please contact the Iowa Regional Genetic Consultation Service toll-free at 1-800-260-2065.



## *For your health...*

Do you know the difference between recreation and relaxation? While recreation can be relaxing and fun, there are ways to learn to relax that also promote a healthy mind and body. Some examples include yoga, meditation, Tai Chi, and breathing exercises. Often, community colleges and recreation centers have listings for courses in relaxation techniques. In addition, light exercise is a great way to relax, feel good, and stay healthy!

A simple relaxation technique you can try on your own is to contract, and then release, your muscles. This causes a sense of release and relaxation throughout your body. Another technique is this: sit or lay down comfortably. Then begin to consciously think of relaxing your toes, followed by the soles of your feet, and up through the rest of your body. As you think of each part of your body, mentally relax it. Regular practice, like regular exercise, can have long lasting benefits.

When applying for Social Security Disability Insurance (SSDI) for the first time, you should note that only one-third of all initial applications are approved. When rejected, always appeal – over half of initially denied applications are accepted on appeal. You may wish to consider hiring a lawyer for the appeal, but this is not necessary. Be aware that this process may take several months, however. Social Security defines disability as an inability to work, so your medical records will be examined with particular attention to the nature and extent of disabilities, with an eye to the degree of impairment suffered.

With Medicare, bear in mind that Medicare home care is only to provide “skilled care” and not “custodial care.” Thus the individual must require the care of a nurse or therapist, and during the provision of that care they may qualify for a home health aide whose assistance is supposed to focus on personal care (bathing, dressing vs. shopping and cleaning) for a few hours a day, a few days a week. And while Medicare is normally eligible for people over the age of 65, it is available on a temporary basis for some disabled persons under 65 as well. Contact Medicare for more information.

When applying for financial assistance, such as Social Security and Medicare, you consider organizing and putting together the following documents to use as needed:

- Social security number and proof of age of person applying
- Names, addresses and phone numbers of doctors, hospitals, clinics and institutions treated the individual and dates of treatment
- Names of medications that are being taken
- Medical records from doctors, therapists, hospitals, clinics and caseworkers
- Laboratory and test results
- A summary of employment: locations and types of work.
- A copy of W-2 form and/or tax returns of past year.
- Documents granting power of attorney for health care as well as financial matters

Keep these contacts handy for reference:

**Social Security** - National toll-free number: 1-800-772-1213  
Website: [www.ssa.gov](http://www.ssa.gov)

**Medicare** - National toll-free number: 1-800-MEDICARE (1-800-633-4227)  
Websites: [www.hcfa.gov](http://www.hcfa.gov) (also has Medicaid info)  
[www.medicare.gov](http://www.medicare.gov)

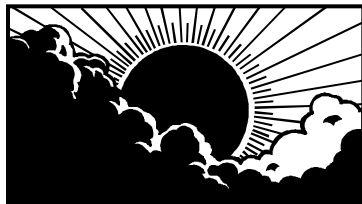
**Iowa Consumer and Legal Affairs:**  
Toll-free number: 1-877-955-1212  
Website: [www.state.ia.us/ins/legal/legal.htm](http://www.state.ia.us/ins/legal/legal.htm)

**Senior Health Insurance Information Program (SHIIP):**  
Toll-Free number: 1-800-351-4664  
Website: [www.state.ia.us/ins/shiip/shiip.htm](http://www.state.ia.us/ins/shiip/shiip.htm)

Have you thought about using hospice services? Did you know that November was National Hospice Month? Hospice care is a community based care system that provides symptom management and health maintenance. It greatly facilitates the level of quality in a patient's care as well as decision-making regarding the patient's care. Hospice care is not simply health care: it is about enhancing the quality of life.

Before choosing to pursue hospice care, consult with your doctor about your needs. It may be helpful to ask him or her for a referral to a local hospice program. While most hospice care patients live at home, hospice care is still available at hospitals or nursing care facilities. Your doctor can still provide care in addition to hospice services. Oftentimes, Social Security and Medicare, as well as commercial insurance, can help pay for hospice services.

If you decide hospice care might be right for you, and wish to locate a nearby provider, first check your Yellow Pages, under "hospice." You may also try calling the Hospice Foundation of America toll-free at 1-800-854-3402 (10:00 AM – 6:00 PM, EST). For more information about hospice care, or to use an online hospice locator, see the Hospice Foundation of America Website at [www.hospicefoundation.org](http://www.hospicefoundation.org).



When selecting a hospice, remember that communication is important. When you speak with a hospice representative, if you don't understand something he or she says, try asking again. For example, hospice services are available 24 hours a day, 7 days a week. This does not mean that hospice provides 24-hour care. Some important questions to ask when meeting a hospice admissions representative are:

- ✓ Does the hospice serve the area where the patient lives?
- ✓ Is the hospice licensed and (where applicable) Medicare/Medicaid certified?
- ✓ Does the hospice provide the services you want/need?
- ✓ What does the hospice expect from you and your caregiver support system?
- ✓ Will your insurance plan work with the hospice?
- ✓ Does the hospice have a support program for caregivers?
- ✓ Where is needed inpatient or respite care provided?
- ✓ Are the hospice's positions on resuscitation, hydration and antibiotics similar to yours?
- ✓ What out-of-pocket expenses should you anticipate?
- ✓ Is there a sliding scale payment plan for services not covered by insurance?  
*(Questions reprinted from "Choosing Hospice," copyright Hospice Foundation of America)*

*Hindsight\** newsletter is a not-for-profit service of the HD community of care.  
This issue was compiled by Matthew Bingley.

*\*Because hindsight is just foresight...  
with a story!*

This past year has brought tremendous advances in HD research. Numerous discoveries about Huntington's Disease have been made, including ways to delay onset of symptoms, halt the progression of the disease and even reverse brain cell death in animal models. Below is a list of projects and trials currently underway at the University of Iowa Hospital and Clinics and affiliated institutions.

**PHAROS: Pilot Huntington At-Risk Observational Study**

Individuals who participate in this trial will help researchers to define the natural history of HD in its earliest stages. This three-year study will give researchers a more complete picture of the initial signs of the disease and the factors that influence age of onset.

**HD MAPS Study**

As part of the HD MAPS study, study coordinators are seeking siblings that are affected by HD. HD MAPS (HD Modifiers in Age at onset in Pairs of Siblings) is investigating genetic factors that influence the age that people develop HD and the severity of the illness. The study examines brothers and sisters who are both affected by HD.

**Motor Assessment Battery**

Individuals who are at risk for Huntington's showing no symptoms, as well as symptomatic individuals, are being studied for a motor assessment

**General HD Battery**

Persons who are at-risk for or have already been diagnosed with Huntington's disease are continually being studied. HD patients undergo motor, psychiatric, cognitive, and behavioral assessments.

**MINO: MINOcycline in HD**

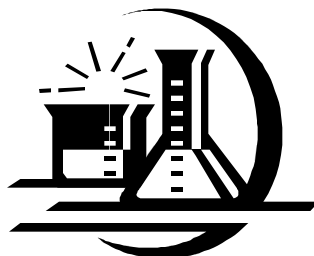
This clinical trial is a multi-center, double-blind, placebo controlled study of Minocycline. The study is designed to assess and gather information on the safety and tolerability of Minocycline. The focus of this study is on persons who are 18 years of age or older, and have early onset HD.

**FMRI and PET**

Laboratories in Milwaukee, WI, are continually using Functional Magnetic Resonance Imaging (fMRI) scanning to study individuals at risk for HD. The fMRI device produces pictures of brain activity. In addition, another type of brain scan, positron emission tomography (PET), is being used to examine the activity of the brain in persons at risk for HD.

**For additional information or to participate, please contact Elizabeth Penziner at (319) 353-4307.**

**If you are interested in learning about more research at other HD centers, visit the Huntington Disease Society of America's website at <http://www.hdsa.org>.**



Contributions and gifts to the HD Center are accepted throughout the year. If you wish to make a donation by check, please mail a check payable to HD Center of Excellence at the University of Iowa. Checks can be sent care of Elizabeth Penziner, 2-323 MEB, University of Iowa, Iowa City, IA 52242.

In addition, contact Elizabeth if you wish to make a contribution to the HD Center Wish List. Earmark a donation by specifying "Wish List" on the memo. The primary needs for the Wish List fund are for scholarships for summer camp for children of HD, as well as for Christmas gifts for children and families affected by HD. If you would like to contribute useful items instead of money, the following items would be of particular help:

- Prepaid telephone cards for HD patients who live away from their friends and family
- Weighted cups and silverware, and other utensils with good grips
- Wheelchairs
- Any other implements for assisted living
- Men's clothes, sizes S-M (a flannel would be fantastic!)

Thank you!

### *Finding out more about...*

In the fight to understand HD, scientists use different types of research. Generally speaking, the first phase is basic research, which explores the ways that cells and chemicals interact in order to see how things work. Clinical research is the second phase, which takes basic research data and determines how it can be applied to treat or cure a medical problem in humans. Before all of the amazing research being done in laboratories around the world will be of any use to people suffering from HD, researchers and doctors must use clinical trials to see which therapies work in humans and how to use them correctly. By volunteering to be part of clinical

### *Getting Involved*

research, you play a vital role in advancing scientific understanding. Clinical trials can be used to study drugs, surgical techniques or rehabilitation therapies. Observational trials can be an important precursor to therapy trials. These studies attempt to document the symptoms and progression of a disease or condition in order to later judge the effectiveness of a particular drug or treatment. Before being accepted for general usage, a promising drug or therapy needs to be carefully studied in a closely monitored test group (therapy trials) to determine whether it is safe and effective.

To find out more about clinical trials, take a look at the following web sites:

<http://www.clinicaltrials.gov> -- a listing of trials sponsored by the National Institutes of Health

<http://www.centerwatch.com> -- a listing of trials sponsored by government, universities and pharmaceuticals companies.

<http://www.huntington-study-group.org> -- the site of the Huntington Study Group

<http://medlineplus.gov> -- consumer health information service providing links to information about 350 diseases and conditions.

**Not getting your own copy? Moving?**

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