Recruitment and Retention for the PREDICT study:

What is PREDICT-HD?
PREDICT-HD (Neurological Predictors of Huntington’s disease Onset) is an international, longitudinal study under the direction of Dr. Jane Paulsen comprising of 32 sites across the US, Canada, Australia and Europe. The goal of the study is to define the earliest changes in HD and help researchers judge the effectiveness of future treatments. Individuals who are at least 26 years old, have been genetically tested and not diagnosed are encouraged to enroll. Participants are seen once a year for four years, with neuropsychological tests and MRI scans administered during the visits. Compensation and travel reimbursement is available for participants.

The PREDICT study currently has 570 participants who dedicate time from their busy lives to contribute to the study– nearing the anticipated enrollment figure of 750!

What activities do the Recruitment and Retention Team perform?
PREDICT is unique to many other studies by having a recruitment and retention team who focuses 100% of their time and attention to reaching out to HD families and individuals, answering questions, and keeping participants posted on the latest study findings.

Recruitment efforts for the study were initiated by building relationships with HD professionals, such as social workers, doctors, genetic counselors and support group leaders. By maintaining these relationships, the recruitment team has been able to distribute information to professionals, who in turn educate and inform their patients, group members or clients about this important study! Presentations are an effective way of reaching out directly to HD families. Our presentations are done world-wide. We speak to support groups at conventions, forums, fundraising events, and other venues where we have been invited to attend. We answer any questions that people may have relating to research and HD symptoms. Our research team relies on individuals already involved in the study who, depending on their family situations, talk openly about their experience with others who may be interested in enrolling. Most of all, the HD community has made our recruitment efforts a success! We sincerely thank all of you who have assisted us in this effort!

What motivates people to join and return yearly for research?
According to a recent survey our team conducted, many participants have discovered that being part of a research project is very rewarding. One-to-one contact with HD professionals and researchers has helped to answer questions and concerns. The research visit gives them an opportunity to talk openly about HD related issues in a comfortable environment, and solidifies their understanding that they are truly making a difference in HD research! Below are a few quotes from PREDICT participants:

“I appreciate being able to do something to help in the fight against HD, so thanks for allowing me to participate.”

“I enjoyed my visit – gives me a lot of hope.”

Participants also appreciate our newsletters featuring international HD updates and PREDICT news and research happenings. Our goal is to keep our participants informed about the areas that they are contributing so generously to!

For those of you considering volunteering for any research, feel free to contact one of the recruitment team members with questions at any time.

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GENETIC NONDISCRIMINATION ACT

On February 17, 2005, the US Senate unanimously approved a bill that would prevent employers from using genetic information to discriminate against their employees. The Senate passed the bill called the Genetic Information Nondiscrimination Act of 2005 (S. 306) by a 98-0 vote. First introduced by Senator Olympia Snowe (R-ME), the bill protects millions of vulnerable individuals who are genetically predisposed to certain illnesses or diseases from health insurance or employment discrimination on the basis of genetic information. The bill also amends existing medical privacy and confidentiality rules to prohibit the disclosure of genetic information. The Bush administration supports this legislation, promising to work with the Congress to prohibit discrimination by employers and the insurance industry. The House needs to pass similar legislation to create this law.

Dietitian Talks to Support Group

Betty Loan, a dietitian at Mercy Hospital in Iowa City, has worked in the dietary field for 35 years. She spoke to the HD support group at UIHC on February 27, 2005. She enjoys working with oncology patients and those that have a chronic disease. Her talk focused on food choices in mid to late stage HD that minimize aspiration (getting liquid in their lungs) and aspiration pneumonia. People with HD have a higher calorie need than the average person, because their involuntary movements and metabolic changes are not yet understood. Research has suggested that a 10-15% increase in a HD patient’s weight can increase stamina and maintain functioning. To boost calories eat frequently with mid-afternoon snacks and calorie-laden after-dinner desserts.

Oftentimes an assessment of swallowing is helpful with an HD affected person. Different consistencies of food are used to understand how a person is swallowing and what consistencies of food might cause choking problems. Swallowing is a very complex process involving many muscles. It is important to determine how the back of the throat opens and closes in relation to the esophagus. Liquids and solids are divided into different consistencies to aid caregivers in proper diet. Liquids are either thin, nectar-like, honey-like or spoon-thick. Food consistencies range from a regular diet to variations of minced, ground, chopped or pureed items.

The environment where the person eats is also important. For example, sitting upright in a chair is beneficial. Eliminate distractions like television or excess conversation. Encourage the person to pace him/herself with small bites. One technique is eating a bite and then putting the utensil down before eating again. Have the person take one sip of liquid and then swallow. Dietician Loan does not endorse using a straw, because a hard suck takes in too much liquid; this makes swallowing difficult.

Ms. Loan had helpful hints to make pureed foods more palatable. Adding gravies and sauces (i.e. barbecue sauce) to ground or pureed meat adds flavor and color. The use of spices can also make food more appetizing. Adding cinnamon, jello powder, or kool aid to pudding is a creative way to enhance flavor.

For patients with more advanced HD, Ms. Loan talked about tube feeding. She favors tube feeding if a patient is regularly aspirating. The three basic types of feeding tubes are:

1) naso-gastric tube (NGT) threaded through a nostril, down the throat and into the stomach. This type of feeding is temporary but the disadvantage is that it can easily be pulled out.

2) peri-epigastric tube (PEG) is a tube that is implanted through the abdomen into the stomach. It is usually for long-term use. Patient can receive both tube feeding and an oral diet.

3) jejunostomy tube (J-tube) is implanted below the stomach, directly into the small intestine. The advantage is that it reduces the risk of aspiration or back up of fluid into the lungs.

Please speak with your healthcare provider for more information about tube feeding. Thank you, Betty Loan, for sharing your wealth of knowledge with the University of Iowa HD support group!
What does it mean when my doctor uses the word ________?

**Executive function** - A person’s ability to establish a goal, make decisions, and put into action activities to meet that goal. A person with HD may have difficulty carrying out the steps necessary to complete a goal.

**Glutamine** - An amino acid that is abundantly present throughout the body and is involved in many metabolic processes. It is the principle carrier of nitrogen in the body and is an important energy source for many cells. Huntington’s disease is caused by too many copies of the codon or chemical code C-A-G in human DNA, which causes elongated copies of glutamine in the huntingtin protein causing damage.

**Hallucinations** - A false perception with no relation to reality that occurs while the person is awake. The person reacts to this perception like it is real. Hallucinations may involve any of the senses, including hearing, vision, smell, taste, and touch. (Auditory and visual hallucinations are most common). Sometimes people experience hallucinations with organic disorders, like HD.

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**Hoop it up!**

Local hoop-a-thons raise money for HD research.

Hope you had a chance to make a few baskets and help raise funds for Huntington’s research in your local communities. Arlington, Des Moines, Marion, Clarinda, Audubon, Storm Lake, and Omaha, Nebraska hosted hoops in their local gymnasiums. Local “boy” and national spokesperson, Billy Aaron Brown, was around to sign autographs and support the activities. Stay tuned to find out how much money was raised for the cause.

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**HD Support Groups:**

**DES MOINES**
Valley View Village Conference
2571 Guthire Ave
3rd Tuesday at 6:30 pm

**LINCOLN, Nebraska**
Perkins Family Restaurant
48th and O St
1st Monday at 7:30 pm

**OMAHA, Nebraska**
Village Inn Restaurant
78th and Dodge
2nd Monday at 6:00 pm

**IOWA CITY**
University of Iowa Hospitals and Clinics
Della Ruppert Conference Room
6th floor, elevator H
4th Sunday at 1:00 pm

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**A Patient’s Perspective**

I have come face to face, and my reality has been checked

So many people in my family

Uncles, aunts, grandparents, brothers, and even my own children have been affected

I see the beauty in things I've never noticed before

It is unbearable to think about what is going to happen to me in the future

But it is researchers like you who will make the difference

Submitted by: Neuropsychology researchers at the University of Iowa to the Poetry in Public project for Johnson county residents.

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**Thank you** to Thai Flavors in Iowa City for donating 20% of their proceeds on February 14, 2005. It was a profitable day for the HD Center!
FENG SHUI

Feng Shui (fung shway) is the ancient (several thousand years) Chinese practice or art of placement in relation to energy. Feng Shui is about fine tuning your physical surroundings to balance with your inner energy or life force (chi). The art of placement is a unique way of looking at yourself and your environment to create balance, comfort and harmony. The thought is to create a supportive environment for fulfillment and success in all aspects of life. The imbalance of energies displaces good luck and brings about internal disorders.

Feng Shui combines words of wind (feng) and water (shui); two natural elements that flow, move and circulate everywhere. These are the basic elements of life: the air we breathe and the water needed to sustain. A balance is created from these natural energies. This practice is a holistic world view. All things are alive and in flux, ever moving and changing. The idea is to manage our home and work environments to create and promote positive energy and balance. There are many tools and guidelines for analyzing and correcting the flow of energy through the space we occupy.

Five elements are used to enhance, control or achieve balance. The interactions of these elements are also important. 1) wood- upward growth, 2) fire- excitement, intensity, quickness, 3) earth- settling down, serenity, 4) metal- sharpness, focus, 5) water- flowing, making connections.

Interested in reading more? There are hundreds of books on the topic.
Try:
Feng Shui by Pak Tin Li
Pocket Idiot’s Guide to Feng Shui by Stephanie Roberts
Feng Shui for Dummies by David Daniel Kennedy

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