Genetic testing and genetic research for inherited diseases are becoming more readily available. Parents may face decisions about whether or not to have a child tested to see whether or not she/he carries an affected gene. Often, parents are unsure about their own feelings and thoughts about DNA testing. They may also be confused about what kinds of policies are in place regarding children, testing and research. Further, they may wonder what kinds of questions to ask before enrolling a child in a research study. In the HD world, only symptomatic children (those who have received an HD diagnosis in the context of a positive family history) are tested for the Huntington’s gene. However, children who are not affected or whose gene status is unknown could potentially still be useful participants in a study of genetic disease in the family.

Before involving a child in research, the researcher must decide whether that young person is capable of giving informed consent to participate. Traditionally, parents have made the decisions about whether and under what circumstances a child’s consent is obtained. Recently, however, researchers have recognized that a child’s ability to understand not only the procedures involved in a research project (what will happen to me?) but also the long term implications of that participation (what might be the long term effects of my doing it?), vary greatly depending both on the child’s age in years and her/his level of maturity.

**Younger than 7 years old**

For the reason stated above, many research review boards require that children younger than 7 participate only via parental consent. Very young children lack the maturity to understand the concepts of time, cause and effect, and sequencing necessary for such decision-making. While young children are likely to ask questions about what will happen to them, such as having blood drawn or taking a medicine, they are not ready to think about what it will mean to them in the future to have participated in research or to consider the fact that there might be both benefits and risks for themselves and others as a result.

**Ages 7-12**

Between the ages of 7 and 12, children’s thinking becomes more complex and sophisticated, and they are more ready to become partners in making decisions about whether or not to participate in research. However, some of their thinking processes are still not well developed, such as the ability to think ahead about the long term consequences of an action. For this reason, researchers generally require children in this age range to give their assent (to show that they understand important parts of the study) to participating, but also ask that parents sign an informed consent on behalf of that child.

**13 years old and older**

Older teens (13+) are usually asked to give written assent but their parents are still involved in signing the consent form. Only after age 18 are people considered ready to make independent decisions about participating in research. Parents must weigh the risks and benefits of participation for that individual child as well as for the larger community. There are three major areas to consider before signing a consent form for your child or adolescent. First, you need to consider the physical and emotional effects of the procedures that will take place, the energy and time involved, and any life situations that may make that child’s participation difficult to maintain. Second, you need to consider the potential benefits to that child and all people affected by the outcome.
of the research. Will your child feel good about doing something to help the doctors learn more about Daddy’s illness and be proud of his involvement, or is she likely to be embarrassed by having to miss school in order to come to her appointment? How will other family members react to that child’s participation? Is it possible that having that child involved might contribute to the eventual discovery of a cure for a disease? Is this important to the child? Do the benefits outweigh the risks?

Research guidelines also require that all people who participate in a study give voluntary consent. This means that they must understand what will happen at each visit, what kinds of information will be gathered and disclosed, how their confidentiality will be protected, any risks and benefits involved in the research, and who exactly might have access to their personal information and records. For children, this may mean explaining the study in simple but accurate terms, allowing the child to ask questions, and then asking the child to respond to some specific questions to be certain she understands what is being asked of her.

Sometimes children may want to end their participation in research. When a child has very strong negative feelings about continuing, even if the parents feel that it is worthwhile, researchers are bound to consider and honor that child’s wishes. If this occurs, it is important to listen carefully to the child’s reasons for wanting to stop and to have a discussion that involves adults and the child together.

**Spring Hoop-a-Thons 2006**

*proved to be a fun and successful way to support a worthy cause.*

A hoop-a-thon is a free throw basketball shooting event for all ages and abilities. Shooters get their friends, neighbors, family and co-workers to sponsor their shooting.

Your friends and family raised over $50,000 for the HDSA Iowa chapter. Seven hoop-a-thons took place around the state of Iowa and eastern Nebraska. Funds support chapter events and assist the University of Iowa Center of Excellence in its mission to support families with HD.

Donations to the Iowa chapter are always welcome. Or maybe you would like to sponsor a hoop-a-thon in your community for 2007? Contact the Iowa chapter at mail@hdsaiowa.org.

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**University of Iowa, Paulsen neuropsychology lab staff enjoy the Marion hoop-a-thon. From left: Chris Werling, Carissa Nehl, Anne Leserman, Bill Adams and Kimberly Bastic**

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**HD Bike for the Cure**

Marie Nemec and Charlotte Reicks of Colorado and Sherri Kole of Idaho spent a day in Iowa City on May 29 as they rode their bicycles as part of “Midwest meander” raising funds and awareness for Huntington’s disease on their way to the national HDSA convention in Milwaukee June 9. This was their 7th ride to convention complete with t-shirts, sponsors and media coverage. The HDSA Center of Excellence was happy to host them in our homes and show them the University of Iowa facilities where they met our research staff.

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Thank you again for your interest in HD and willingness to help the cause. Marie shares a daily account of their adventures through her website www.bikeforthecure.org.
PREDICT HD
Neurobiological Predictors of Huntington’s Disease Onset

The University of Iowa coordinates this multi site project with sites across the US, Canada, Australia, England, Spain and Germany. This trial will help to define the earliest changes in HD. This information will help researchers judge the effectiveness of future treatments more accurately. Individuals who have been genetically tested and are pre-symptomatic are encouraged to enroll. Compensation is available for study participants.

The PREDICT-HD team was pleased to announce during the Huntington Study Group (HSG) meeting that the study received a superior review from the National Institutes of Health and was renewed at 100% for three years.

Recently the study received approval to invite an additional 100 gene negative subjects to become part of this important project to gather further control test measures. Participants are asked to return once a year for a minimum of 4 years and will complete thinking and feeling tests and an MRI. If you are interested in learning more and for a list of participating sites the Huntington Study Group (HSG) website can give you more information. http://www.huntington-study-group.org/h-s-g.

HDSA National Convention
Milwaukee Wisconsin
June 9-11, 2006

Six hundred people came to Milwaukee for the 21st annual HDSA convention. The University of Iowa staff was well represented with talks by Jane Paulsen, Elizabeth Penziner, Anne Leserman, Janet Williams and Cheryl Erwin. Topics are geared towards all levels of HD from those at risk to those exhibiting symptoms. The National Youth Alliance (NYA) had a strong presence at convention with a talent show and silent auction. Families got the opportunity to talk to researchers about their concerns and hear the latest in research news like the integrating of bio technology companies to focus on HD. The convention culminated in a dinner and dance on Saturday evening. It was moving to see the banquet hall with no lights other than individual glow sticks representing loved ones with HD. Next year the convention is in Oklahoma City, June 15-17, 2007.

Iowa Conference

Please join the Iowa chapter at the state meeting on Saturday, July 15, 2006. The keynote speaker will be Dr. Henry Paulson, co-director of the HDSA Center of Excellence at the University of Iowa. Dr. Paulson will share his expertise as a neurologist that sees HD patients and does research. Other University of Iowa speakers are Ann Sporman-Link, a speech pathologist and Anne Leserman, the clinical social worker for the HD Center. Hear an update on how successful the chapter has been at raising funds. Contact the chapter for details at mail@hdasiowa.org or (866) 248-4243.

New Social Worker

The Iowa HDSA chapter, with assistance from the Iowa Center of Excellence, has hired social worker Myke Selha to facilitate the Des Moines support group. Please note the new Sunday afternoon time. Myke is a licensed social worker and is currently in the residency program at the Des Moines Pastoral Counseling Center. He has experience facilitating groups of different age ranges that focus on health and rehabilitation issues. Introduce yourself to Myke at the state meeting on Saturday, July 15.

HD Family Study

The first phase of the HD Family research project, which was intended to better understand HD family needs is now complete. University of Iowa registry members may be invited to participate in this survey for family members (teens between 14-17 and adults).
How to stay younger
Brain activities to keep your mind active

Neuroscientists once thought that cognitive decline was inevitable because of the natural process of brain-cell death which is caused by aging. Recent studies show the brain as capable of reorganizing and rebuilding. There are things you can do to maintain and improve your functioning.

The 1996 “Nun Study” by David Snowdon, *Aging with Grace: what the nun study teaches us about leading longer, healthier, and more meaningful lives*, showed that mental stimulation kept a group of nuns living well into their 90’s with less than the average amount of diagnosed Alzheimers. What did they do? Try some of the list below:

- Brain teasers
- Puzzles
- Listening to music
- Reading
- Traveling
- Gardening
- Farming
- Bicycling
- Walking
- Sports
- Odd jobs
- Hobbies
- Knitting
- Learn a new language
- Go to the theater
- Take a course
- Learn to play an instrument
- Learn to repair something
- Start a journal
- Play scrabble
- Play bridge

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