I want to have a child without HD . . . .

**Question:**
Hi. I am a 26 year old person at risk for HD. My father has it. So I have a 50-50% chance of getting it and my children that I would like to have one day have a 25-25% chance, right? I am married and would like to start a family next year, but how do I have a child without passing on HD? I have thought about 1) getting the blood test, but I am not sure if I or my significant other can handle the results 2) doing in-vitro to get rid of the “bad DNA”. What can I do? How can I have my own children without passing HD to them?

**Answer:**
Thank you for your question. Please use the following information as a reference point and I encourage you to speak with a genetics counselor about your unique situation.

First of all, it is important to understand autosomal dominant inheritance, the method by which the HD mutation is passed through generations. If you have a parent with HD you have a 50% chance of inheriting the mutation and developing the disease. As you are aware, because your biological father is a carrier, there is a 50% chance that you are also a carrier. Because you do not know your gene status I can see why you would say there is a 25% chance that your children will get HD (50% chance for you multiplied by a 50% chance for your children equals a 25% chance). But that is a theoretical percentage. In reality there is either a 0% or 50% chance that your children will get HD, depending on whether or not you carry the mutation.

All of this does make the decision about having children difficult. It sounds like you are familiar with the options currently available for having biological children, but I will try to clarify.

- **In vitro fertilization with preimplantation genetic diagnosis (IVF with PGD)**

  I believe this is what you meant about using in vitro to get rid of the mutated DNA. The process of IVF means that both sperm and eggs are harvested from the parents and fertilization occurs outside of the mother. PGD involves testing the created embryos for the HD mutation. Only the “HD free” embryos are implanted into the mother. This method is useful for people who do not want to know their own gene status but want to be certain that they do not pass HD on to their children. The medical staff can perform both IVF and PGD without letting the couple know what the status of the embryos is. Unfortunately, this technique can be very expensive, up to $20,000 a cycle. For some couples it only takes one cycle to get pregnant, but for others it can take many.

- **Amniocentesis (prenatal testing of the fetus)**

  Another option is to create a baby in vivo (through intercourse) and have an amniocentesis performed sometime in the first trimester. This will tell you the gene status of the fetus. However, if the fetus is positive for HD, you will inadvertently know your own gene status and have to deal with the difficult decision about whether or not to terminate the pregnancy.

- **Genetic testing**

  Just to clarify, there are three types of genetic testing:
  - **Prenatal:** done in the first trimester of a pregnancy
  - **Confirmatory:** done when a doctor would like to confirm their clinical diagnosis of HD with a blood test
  - **Predictive:** DNA testing of people at risk but not symptomatic. Predictive testing involves a series of visits to a genetic counselor and can cost between $300 to $1000.

  The decision you are facing is a very personal one. I hope this information is helpful to you.

  **Rachel Conybeare**

  Research Assistant to Dr. Jane S. Paulsen
In Harmony for Huntington’s Disease

The first Iowa City music benefit to support the University of Iowa HDSA Center of Excellence took place Friday, September 19, 2003 at the Mill in Iowa City and was a resounding success! Four local bands donated their time to play to an enthusiastic crowd of music lovers and HD supporters. Local businesses donated gift certificates, jewelry and tickets for the raffle, and the Iowa HDSA chapter donated flower bulbs and candles. Periodically throughout the night, the crowd hushed in great suspense to hear raffle numbers announced, and many people went home with nice prizes. Both Drs Hank Paulson and Jane Paulsen had positive comments about the evening. “I was especially happy to see HD families truly enjoying themselves,” said Hank Paulson.

We would like to extend a special thank you to those of you who were able to join us! The four bands included: Big Wooden Radio, Ben Schmidt, Sam Knutson and Flying Bacchus. Those lucky enough to stay for the whole evening might have witnessed the Center of Excellence staff on the dance floor enjoying the music and basking in the glory of a job well done.

Thanks to our generous supporters including Pfizer Pharmaceutical and Integrated DNA Technology, the Departments of Neurology and Psychiatry, local Iowa City businesses, as well as friends, relatives, and the HDSA Iowa Chapter. We couldn’t have done it without you.

Welcome Dr. Peg Nopoulos

Peg Nopoulos, M.D. is the physician who oversees the psychiatric care of patients in the HD Center of Excellence. She is currently an Associate Professor in the Department of Psychiatry and has expertise in the neurobiology of major mental disorders. Her research focuses on evaluating brain structure using Magnetic Resonance Imaging (MRI). Dr. Nopoulos has recently begun to use MRI to study the structure of the brain in persons with HD and those who are at risk for developing the disease. Welcome scientist/practitioner, Dr. Peg Nopoulos.

Support Group Schedule

**Location**
University of Iowa Hospitals and Clinics
Adult Psychiatric Outpatient Waiting Room
1st floor John Pappajohn, near elevator I

**Time**
1:00-3:00 pm
Snacks provided

**Questions?**
Call Anne Leserman
(319) 353-4307

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<td>September 28</td>
<td>Katrina Moran-Mabon, LMT, “Give yourself a hand”</td>
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<td>October 26</td>
<td>Carissa Nehl, “How do I know if I’m depressed?”</td>
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<td>November 23</td>
<td>Caregivers prepare for the holidays</td>
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<td>December 7</td>
<td>Holiday get-together</td>
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National Research Update

TETRA-HD: A Randomized, Double-Blind, Placebo-Controlled, Study of Tetrabenazine for the Treatment of Huntington’s Chorea. The Huntington Study Group (HSG), under the direction of Frederick Marshall, MD (University of Rochester), is conducting a multi-center, double-blind, placebo-controlled study of tetrabenazine. TETRA-HD is designed to assess and gather information on the optimal dosage of tetrabenazine. The HSG is looking to recruit at least 72 participants who are 18 years of age or older and who have significant chorea. For each participant the study will last approximately 15 weeks. At the end of the trial, participants will be offered the option to continue treatment for an additional 6 to 12 months.

The TETRA-HD therapeutic study is now accepting participants. See who to contact at:
http://www.huntington-study-group.org/TETRAHDParticipatingSites.html

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PHEND-HD: Stay tuned for more information on the Phenylbutyrate Development for Huntington’s Disease study. A clinical trial testing the safety, tolerability and clinical impact of the drug phenylbutyrate in people with HD will begin early Spring 2004. The University of Iowa is one of the six sites that will be participating in this study. Other sites include; Columbia University, Kansas University Medical Center, Massachusetts General Hospital, University of California San Diego and University of Rochester. Each site will enroll 10 participants for a duration of 20 weeks, with either a visit or phone contact every four weeks.

The Huntington Study Group has concluded a clinical trial investigating Minocycline for HD. Minocycline is an FDA-approved antibiotic that prolongs survival in HD mice. This was a study testing safety and tolerability of the drug. Longer, more extensive trials are necessary to determine whether Minocycline alleviates any of the symptoms of HD.

What did I miss in Support Group? “Give yourself a Hand”

Thanks to Katrina Moran-Mabon, Licensed Massage Therapist, for being the September support group speaker. Katrina talked about the benefits of therapeutic massage for HD on the whole body system including muscles, circulatory and lymphatic systems. She began her talk with a breathing exercise to get our blood flowing. This was just one of her examples to help us understand how our bodies function and begin to learn about the mind/body connection. She explained the licensing process in the State of Iowa and what to look for in picking a massage therapist. And she saved the best for last! She brought her new massage chair and several members of the support group were wowed by her massage technique in a five-minute back massage. Thank you, Katrina! Katrina Moran-Mabon, Licensed Massage Therapist, in Cedar Falls, Iowa can be reached at 319-266-7385.

Innovative Techniques in a Nursing Home

Linda Beck from Cedar Manor Nursing Home in Tipton was the August speaker for the Iowa City support group. Linda has been working in the field of long-term care for 20 years. She feels as if she was destined to work with older adults. The staff at Cedar Manor had been open to looking at fresh, “out of the box” ideas to aid their residents. Their alternative therapy room has been an award winner in the State of Iowa. They offer a soothing, calm room for residents who are having some behavioral disturbance. In a 10-15 minute session, residents are offered soothing music, gentle massage of hands and arms and one-on-one attention. The staff has noticed that they use less medication to control behaviors using this technique. There continues to be a waiting list to get into this facility. They are lucky to maintain a stable staff with over one third of the staff employed at Cedar Manor for over 15 years. Thank you Linda. Linda Beck can be reached at Cedar Manor in Tipton, Iowa 563-886-2133.

Long Term Care Ombudsman from the State of Iowa

Debi Myers traveled to Iowa City on a rainy July Sunday afternoon to talk with the HD support group about patient and family rights in a nursing home. The Ombudsman’s office can investigate and resolve complaints and grievances that may affect the health, safety, welfare, or rights of residents. Debi talked about resident advocacy committees of volunteers who assess local nursing homes and share information to improve the care for residents. Her office is important for residents who do not have family to speak on their behalf. You may want to talk with Debi if you have specific concerns about a nursing home or if you want information about how to choose a facility. The number of calls to this agency has sky rocketed due in part to public awareness that patients and families have rights. It is good that so many have found their voice. If you have questions for Debi Myers, Iowa Department of Elder Affairs in Des Moines, please call 1-800-532-3213.
Bathing
• Long-handled sponge or brush for hard-to-reach places
• Long-handled pad for applying hand lotion

Dressing
• Long-handled shoe horn
• Button hook for shirts and pants
• Zipper pull to grab the zipper tab
• Stocking aid to put on socks and hose
• Elastic shoe strings to make tying shoes unnecessary

Cooking
• Cutting board that holds food in place
• Knives with T-shaped handles for easier holding
• Device to open jars
• Special handle to grip awkward containers
• One-handed or no-handed electric can opener
• Electric vegetable peeler that eliminates painful wrist motion
• Material to build up utensil handles to make gripping easier

Hobbies
• A device to hold needlepoint hoops, crochet hooks, knitting needles, small hand tools, playing cards, card shufflers

Balance and Endurance
• Long-handled “reacher” for getting items off high shelves or the floor
• High stool with wheels that makes it easier for a person to work at a kitchen counter with less fatigue

Mobility
• Walker with a basket for carrying things, and a flip-down seat for a quick rest

(Courtesy of the University of Iowa Center for Disabilities and Development)

Time for a change?
Let’s not be HIND anymore. Help me think of a new name for the newsletter. Call or email Anne at 319-353-4307 or hdinfo@uiowa.edu