Q: What over the counter (OTC) medications would you recommend for HD and what are possible benefits? Does the level of illness affect your recommendations?

A: With regard to potential preventative or general health medications certainly no one can argue against a multivitamin daily and supplemental vitamin E. Vitamin E is a safe antioxidant, and perhaps part of the disease process in HD is oxidative damage. Both are very cheap and might contribute to general health independent of HD. For these reasons, I think a supplemental tablet of vitamin E with a multivitamin is fine.

For other OTC products, it comes down to a few things: What is the evidence the compound helps? Does its use have any down side? And how much will it cost me?

Of the three compounds I field most questions about, Coenzyme Q10 (CoQ) is the best studied. The HD-CARE study (Neurology 2001) was a carefully performed trial in people with HD. While CoQ did not show a statistically significant effect in slowing disease progression, in some measures it did show a trend toward slowing of progression over a two and half year period. Clearly CoQ proved to be safe at the dose taken (600 mg). Moreover a recent small trial in Parkinson’s disease suggested that a higher dose, 1500 mg a day, slowed that disease’s progression. Again, it was well tolerated and the results are not all that significant. Clearly more studies are needed. But in the meantime, for those who wish to take CoQ, doing so makes some sense and is not likely to harm you in any way. It may, however, pinch the pocketbook a bit.

Creatine is also an interesting over the counter product. In mouse models of HD, creatine has shown benefit but only at certain doses. We don’t know what the equivalent dose would be in people and we don’t have any strong clinical evidence yet that it helps people with HD. Hopefully the creatine trial will answer the question. In the meantime, I think people with HD or at risk for HD can take comfort in the fact that many bodybuilders take creatine and there are relatively few side effects. One does tend to bulk up a bit, and it is important to drink plenty of water when you take creatine. A teaspoonful a day (5 grams) would be reasonable if you choose to take this compound. I hope it helps, but I stress we do not yet know that it helps. Creatine will cost less on a per month basis than CoQ, but the data supporting its use are perhaps a little less numerous and strong at this time. I also do not recommend it for people who have very advanced disease.

Bile acids, in particular UDCA or ursodeoxycholic acid, have recently received lots of press, especially on the internet. There is one study in a mouse model of HD that suggested improvement (PNAS last year). Personally, I would like to see more evidence before I am convinced that this compound holds promise. That said, the literature I have read suggests it is relatively safe to take. In the absence of more data, I don’t feel comfortable making a recommendation on dosage.

Let’s revisit this question when more is known in one year. On a final note, isn’t it encouraging that we can cite data that provide some rationale for the use of the above compounds? Ten years ago, it was a much bleaker picture- things are looking up indeed for HD!

Thank you Dr. Paulson!
**New HDSA Volunteer Coordinator Hired**

Scott Suckow has been hired by HDSA as the new Upper Midwest Regional Coordinator. In this new position he will organize volunteers throughout the state at a community level to increase awareness of HD and raise funds to support HDSA’s mission.

Every day the society benefits from the success of volunteers who are making a difference. If you are interested in organizing a community walk, hoop-a-thon, dinner and auction or a wine and cheese reception, it can help fight HD. Help HDSA to continue its mission to fund HD research; provide services and referrals to our HD families and educate the public and healthcare professionals about this fatal genetic disorder.

To get involved in the statewide initiative, give Scott a call at 507-292-9488 or 800-865-4342 or email at umwhdsa@aol.com.

**A Successful hoop-a-thon**

was held in Bedford, Iowa on March 15, 2003 with 300-400 participants who raised $10,000 for the U of I HD Center of Excellence. Thanks to the Iowa Chapter of HDSA for their efforts. Another Iowa hoop-a-thon is planned for May 17, 2003 in West Des Moines at the Shepherd of the Valley Lutheran Church. Your participation would be greatly appreciated. Contact Karen Brown at 712-542-4976 or ksbrown@iowatelenet.net.

**Northeast Iowa hoop-a-thon**

planned for May 10, 2003 from 1-3 pm at Starmont Community Schools in Arlington, Iowa. Contact Tiffany at 563-933-4028 or at tkj96@hotmail.com.

Thank you Iowans for your support!

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**18th Annual Convention**

**Huntington’s Disease Society of America**

*Empowering the Family Through Knowledge*

Houston, Texas June 6-8, 2003

Inter Continental Hotel

Please join friends and professionals who have interest in learning more about HD at the annual convention in Houston, Texas. Workshops range from an introduction to HD (HD 101) to genetics of HD to grass roots fundraising and planned giving.

Special sharing sessions are designed to help people make contacts with people in similar situations and may cultivate a good support system.

Saturday’s activities begin with a walk for the cure for those early risers among you. The focus shifts to a research forum and then a wide variety of workshops dealing with HD issues at all levels. The day culminates in the Generation 2000 Gala dinner with the National Youth Alliance Silent Auction and awards and, finally, dancing.

The conference wraps up with roundtable discussions addressing research issues, genetics, medical issues and fundraising. Finally we disperse to bring hope and enthusiasm back to our local communities.

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**Support Group Schedule**

**Location:**

University of Iowa Hospitals and Clinics

Adult Outpatient Waiting Room

1st Floor John Pappajohn Pavilion, near elevator I

**Time:**

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

Snacks provided

**Questions:**

Please call Anne Leserman

319-353-4037

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**Meet the HD COE Staff**

The Huntington’s Disease Center of Excellence is a multidisciplinary team put together to offer the best clinical care and services for individuals with HD and their families. We are so fortunate in Eastern Iowa to have such a talented group of committed professionals. This includes physicians specializing in neurology and psychiatry, neuropsychologists, genetics counselors with nursing and advanced degrees in genetics, a rehabilitation therapist, physical therapists, an occupational therapist, speech pathologists and a social worker. Throw in a multi talented research coordinator and three hard working research assistants and the result is a great group of people trying to make a difference in the future of Huntington’s Disease.

Let me introduce you to our research coordinator.

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Conducted at 43 hospitals and medical centers around North America. To date, over 800 participants have been enrolled, including over 30 at the University of Iowa. This study is designed to discover what the first signs of disease are, and what tests are most effective at catching the earliest symptoms. The study involves visits to the University of Iowa every nine months for 4-7 years. Participants undergo motor and cognitive testing, and are asked to answer questions about their mood and behavior. Participants also complete surveys that ask about opinions and personal beliefs.

PHAROS is focusing on people who have not had the genetic test and do not want to know their genetic status. To be eligible, participants must be at least 26 years old and have a parent with the disease. The study will continue to enroll eligible persons through June. PHAROS is funded by the National Human Genome Research Institute and National Institute of Neurological Disorders and Stroke of the National Institutes of Health.

PET
Positron Emission Tomography, a type of brain scan, is being used to examine the activity of the brain in persons at risk for HD. The PET scanner is back up and running after a month of maintenance. Participants undergo PET scanning while performing simple tasks.

fMRI
Individuals at risk for Huntington’s Disease are continually being recruited for a 3-4 hour study, taking place in Milwaukee, Wisconsin. Participants will undergo Functional Magnetic Resonance Imaging (fMRI) scanning which will produce pictures of the brain. All ages are accepted. Mileage and hotel stay are compensated.

The primary goal of these research studies is to identify HD as early as possible. Much research is leading us towards possible treatment for HD and our goal is to postpone illness while you are healthy.

Thank you Dr. Paulsen

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Elizabeth Penziner is the Research Coordinator at the Huntington’s Disease Center of Excellence at the University of Iowa. Elizabeth earned a bachelor’s degree from Luther College in Sociology. Her graduate work was done at the University of Iowa where she completed a Master’s Degree in Health Promotion and earned certification as a Health Education Specialist. Elizabeth is a member of the Huntington Study Group and has been involved with Huntington’s disease research since 1997. Her interests include the promotion of healthy lifestyles among families with Huntington’s disease focusing on diet, nutrition, physical activity, stress management, sexuality and substance use. Elizabeth is actively involved in educational programming for the Huntington’s Disease community. Most recently, Elizabeth presented Nutrition and Huntington’s Disease: A Family Approach to Healthy Living at the Huntington’s Disease Society of America’s National Conventions of 2001 and 2002.

Thanks for all you do!

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**Research Flourishes**

**Neurobiological Predictors of Huntington’s Disease**

**PREDICT-HD**

The PREDICT-HD study has been underway since September 2002 and so far over 130 participants throughout the 20 study sites have enrolled. Here at the University of Iowa we have enrolled 14 participants and are eagerly looking for more people to get involved. **PREDICT-HD is looking for pre-symptomatic individuals who have completed genetic testing** to help answer the following questions:

- What are the earliest signs of HD and when do they start?
- How accurate are the measures that physicians use in detecting the onset of HD?
- What factors influence the age at which a person carrying the HD gene develops the illness?

Participants will be asked to come back once each year for MRI scan, Neuropsychological testing, PET study which involves scanning the brain, and Biomarker measures.

**PHAROS**

The Prospective Huntington At-Risk Observational Study (PHAROS) study was begun in 1999 by the Huntington Study Group (HSG), and is being conducted at 43 hospitals and medical centers around North America. To date, over 800 participants have been enrolled, including over 30 at the University of Iowa. This study is designed to discover what the first signs of disease are, and what tests are most effective at catching the earliest symptoms. The study involves visits to the University of Iowa every nine months for 4-7 years. Participants undergo motor and cognitive testing, and are asked to answer questions about their mood and behavior. Participants also complete surveys that ask about opinions and personal beliefs.

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**Interested in Clinical Trials?**

Visit the following websites:

- [http://www.clinicaltrials.gov](http://www.clinicaltrials.gov) - a listing of trials sponsored by the National Institutes of Health
- [http://www.centerwatch.com](http://www.centerwatch.com) - a listing of trials by government, universities and pharmaceutical companies
- [http://www.huntington-study-group.org](http://www.huntington-study-group.org) - the site of the Huntington study group
- [http://medlineplus.gov](http://medlineplus.gov) - consumer health information service providing links to information about 350 diseases and conditions
Caregiver’s Bill of Rights

I have the right...
To take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my loved one.

To seek help from others even though my relatives may object. I recognize the limits of my own endurance and strength.

To maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.

To get angry, be depressed, and express other difficult feelings occasionally. To reject any attempts by my loved one, either conscious or unconscious, to manipulate me through guilt, and/or depression.

To receive consideration, affection, forgiveness, and acceptance for what I do from my loved one, for as long as I offer these qualities in return.

To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my loved one.

To protect my individuality and my right to make a life for myself that will sustain me in the time when my loved one no longer needs my full time help.

To expect and demand that, as new strides are made in finding resources to aid physically and mentally impaired persons in our country, similar strides will be made towards aiding and supporting caregivers.

To be myself...

Author Unknown
Borrowed from Carmen Leal-Pock