Ethics and Research: Concluding Thoughts

Most researchers are very sensitive to the ethical dimensions of their studies. All researchers are required to be familiar with the legal and ethical requirements of research. At the University of Iowa a formal course is offered in the ethics of clinical research which goes beyond the legal requirements imposed by state or federal law. This is rapidly becoming the norm at major medical centers. It is our hope that participants in HD research become equally sensitive to the ethical dimensions of the studies they are involved with. It is our belief that ethics is everyone’s business, and requires constant attention to future risks and past mistakes in order to achieve our goals together.

Research with HD raises important ethical issues that both researchers and participants should be aware of. The potential loss of confidentiality concerning genetic status or family history does not fit easily within the traditional framework of risks associated with new drugs or procedures, but it can be analyzed using the principles of respect for persons and beneficence. The most commonly mentioned risks involve insurance and employment issues. Yet, the need to control private information about oneself should not conflict with the desire to contribute to research on HD, if both researchers and participants are aware of the risks and the desires of the participant to limit access to this information. In addition, new risks may be discovered but this discovery may be facilitated if everyone is aware of the ethical importance of risk in the conduct of clinical research.

More work remains to be done on the issue of confidentiality in HD and the effect of the risk of lost confidentiality and control over genetic information. Little is known about the perspectives of participants, as few studies have directly examined the concerns and experiences of individuals who live with the knowledge they are at risk for developing HD. It is our hope that in the future we can conduct studies that examine the perspectives, experiences and effects of laws that regulate the disclosure and use of genetic information. These studies may help illuminate the needs of participants for information prior to consent, or may help us identify harms which have not yet been documented. In this way we can better meet the demands of respect for persons, increase the benefits of participation and more equitably recruit future participants.

This is Part III of a three part series on ethics and HD research.

Written by Cheryl Erwin, JD, PhD, Assistant Professor, The University of Iowa College of Medicine

Thank you Dr. Erwin!
The 19th Annual HDSA Convention was held at the Adams Mark Hotel in St Louis, Missouri on June 11-13, 2004. The attendance of 450 people included families affected by HD as well as researchers and professionals working with HD families, such as neurologists, neuropsychologists, social workers, speech pathologists, occupational therapists and genetics counselors.

The research forum was well attended as usual, as families are eager to hear the latest in medication updates and to hear about research heading towards a cure. There have been changes in the research coalition towards a cooperative method of partnering to share information across different laboratories throughout the country and the world. Teams of scientists are working together to address major questions about HD and designing projects to answer these questions. Translational research will determine how specific therapies in animal models may translate to humans. It is clear that there are many questions to ask and answer to promote our understanding of HD and create avenues where medications can be used for treatment. How impressive to have the HD research community come out of their individual laboratories and work together to ask the right questions about what causes HD. The continued hope is that this collaboration will lead to a cure and make this the last generation of HD.

The list of clinical trials has increased in 2004. Tetrabenazine, COQ 10, Minocycline, Riluzole, phenylbutyrate, creatine are some of the drugs that are being studied. Visit huntingtonproject.org for a list of unique nominations of medications that have been recommended for study. Observational studies, like PREDICT, are still enrolling new members. All of these studies give us more information to better understand HD. There are lots of important ways to contribute.

Practical workshops about speech, swallowing and nutrition were interspersed with support and networking groups for affected persons with HD. The National Youth Alliance (NYA) again had a large presence and was active in a talent show. Several Iowa families brought teenagers to participate in this supportive and inspirational group.

Eight staff from the HD Center at the University of Iowa were fortunate to attend the National meeting. It was an enlightening event for all who attended, whether for the first or the seventh time.

Congratulations to our own Iowa HDSA chapter that won the award for “Chapter of the Year”. Karen Brown, president, and her active board have worked hard to increase awareness and have been very successful in fund raising events (hoop a thons). $30,000 has been raised this year to support the chapter and the Iowa Center of Excellence. Thank you Karen!

Plan to attend the next national HDSA meeting in Atlanta, Georgia on June 24-26, 2005.

State and Local News
Iowa HDSA Conference
July 17, 2004 8am-4pm
Airport Holiday Inn, Des Moines
Contact: Amy McClain
(402) 533-1031

1st Annual Golf Classic
August 23, 2004
Willow Creek Golf Course
West Des Moines
Contact: HDSA Regional Office
1-800-865-4342

Music at the Mill
October 8, 2004 8pm-12am
Iowa City
Contact: Anne Leserman
(319) 353-4307

HDSA Support Groups:
Des Moines
Iowa Lutheran Hospital
University Ave at Pennsylvania
4th Friday at 6:30 pm

Lincoln, Nebraska
daVinci’s Restaurant
120 N. 66th Street
1st Tuesday at 7:00 pm

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

SW Iowa
600 N. 21st
Clarinda, IA
1st Monday at 7:00 pm

Iowa City
University of Iowa Hospitals and Clinics
Della Ruppert Conference Room
4th Sunday at 1:00 pm
<table>
<thead>
<tr>
<th>DISORDER</th>
<th>ACQUIRED</th>
<th>SYMPTOMS</th>
<th>BRAIN AREA</th>
<th>CHEMICAL</th>
<th>ONSET</th>
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<tbody>
<tr>
<td>Parkinson’s</td>
<td>Slow, progressive degenerative disorder of the central nervous system</td>
<td>Slowness of movement (bradykinesia), rigidity, postural instability, and tremor primarily while at rest.</td>
<td>Progressive loss of nerve cells within a certain region of the</td>
<td>Depletion of the neurotransmitter dopamine.</td>
<td>Around 60</td>
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<td>shuffling, unbalanced manner of walking; “mask-like” facial expression; weakness of the voice; small, cramped</td>
<td>substantia nigra of the brain</td>
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<td>handwriting; depression</td>
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<td>Huntington’s</td>
<td>Hereditary progressive neurodegenerative disorder</td>
<td>Chorea–or involuntary, rapid, irregular, jerky movements that may affect the face, arms, legs, or trunk–as</td>
<td>Loss of neurons in certain areas of the brain, including the</td>
<td>Result of abnormally long sequences or “repeats” of coded instructions</td>
<td>Evident during the</td>
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<td>well as the gradual loss of thought processing and acquired intellectual abilities (dementia). There may</td>
<td>basal ganglia and cerebral cortex.</td>
<td>within a gene on chromosome 4</td>
<td>fourth or fifth decades of life</td>
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<td>be impairment of memory, abstract thinking, and judgment; improper perceptions of time, place, or identity</td>
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<td>(disorientation); increased agitation; and personality changes (personality disintegration)</td>
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<td>Alzheimer’s</td>
<td>Progressive disease of the brain that is characterized by impairment of memory</td>
<td>Memory loss that affects job skills, difficulty performing familiar tasks, problems with language,</td>
<td>Increase in the production or accumulation of a specific protein</td>
<td>Disruption of nerve cells, abundance of abnormal structures (tangles</td>
<td>Typically over age 65</td>
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<td>disorientation to time and place, poor or decreased judgment, problems with abstract thinking, misplacing</td>
<td>(beta-amyloid protein) that leads to nerve cell death.</td>
<td>and plaques) protein tau is chemically changed, threads, nerve cells</td>
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<td>things, changes in mood or behavior, changes in personality, loss of initiative</td>
<td></td>
<td>of the hippocampus and cerebral cortex, the regions that are</td>
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<td>Onset of AD is usually very slow and gradual.</td>
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<td>devastated by AD</td>
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<td>Amyotrophic Lateral Sclerosis</td>
<td>Motor neuron disease. Motor neuron diseases are progressive chronic diseases of the</td>
<td>Progressive muscle weakness and wasting. tripping and falling, loss of motor control in hands and arms,</td>
<td>? excess of brain chemical, glutamate in the motor neurons</td>
<td>Specific nerve cells in the brain and spinal cord that control voluntary</td>
<td>Mid-life, 50-70</td>
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<td>(ALS or Lou Gehrig’s disease)</td>
<td>nerves that come from the spinal cord responsible for supplying electrical stimulation</td>
<td>difficulty speaking, swallowing and/or breathing, persistent fatigue, and twitching and cramping, sometimes</td>
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<td>movement gradually degenerate.</td>
<td>Men are about one-and-a-half times more likely to have the disease as</td>
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<td>to the muscles. This stimulation is necessary for the movement of body parts.</td>
<td>quite severely. Lower extremity muscle wasting (atrophy) and weakness generally follows wasting of the arms,</td>
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<td>women</td>
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<td>Progressive and fatal.</td>
<td>hands, and shoulders.</td>
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HealthSmart

Ted Mitchell, MD
from USA Weekly March 27, 2004

Checklist for your brain

Losing the car keys is one of the most common complaints of Dr. Mitchell’s patients. He tells them not to worry but to start taking care of their brain for the long term.

How many of these brain boosters do you do? Add more and maybe you’ll never lose your keys again.

Physical enhancers

- the basics: Eat a balanced diet, drink lots of water, sleep well, exercise regularly.
- Don’t smoke (it hurts blood flow)
- Limit alcohol, over the counter drugs and other mind-altering substances.

Mental exercises

- interact with people, play games, talk.
- Take up hobbies that require thought.

- Work for info: read a paper instead of watching the news. Read the book before seeing the movie.

Fixes for memory loss

- reduce mental clutter. Write reminders on sticky notes; do one thing at a time, establish daily routines and habits.

- look for false dementia. Beta-blockers and other common drugs can cause symptoms that mimic dementia.

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