

What can be found on the web at
www.iuhdclinic.org & www.hdsaindiana.org

www.iuhdclinic.org

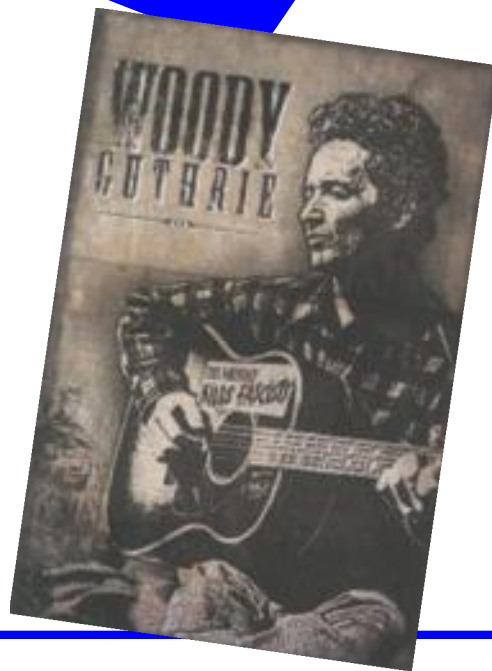
- **More About The Center**
get to know the staff and other information about the IU Center of Excellence
- **Research**: information about current HD research at IU
- **News**: current news and information about HD
- **Helpful Web Links**: useful links to more information available online
- **Directions & Maps**: see where the clinic is located
- **E-Mail and Mail List**:
receive the latest information about the IU HD Center of Excellence

www.hdsaindiana.org

- **Added to the mailing list**: join the chapter's mailing list
- **What is HD?** a brief explanation of the disease
- **Who's Who**: a listing of people in the local chapter
- **Event Calendar**: local upcoming events
- **Publications & Links**: web resources
- **Statistics**: general stats about HD
- **General Info**: local chapter information
- **Research**: information about current HD research
- **Support Groups**: groups in and near Indiana
- **In-Service Training**: training about HD is available to any medical facility
- **E-mail**: send the chapter a message
- **HDSA**: the national organization's website

Welcome to the

Indiana University
Huntington's Disease
Clinic



Indiana University Medical Center in Indianapolis is home to a Center of Excellence for Huntington's Disease

Through a multidisciplinary health care team, the Center provides comprehensive services for people affected by Huntington's Disease

- **Medical evaluation and treatment**
- **Social services**
- **Genetic counseling**
- **Research opportunities**

For More:

info@iuhdclinic.org
www.iuhdclinic.org

Social Worker: (317) 271-0624

Toll-free 866-488-0008

Nurse: (317) 278-5450
Toll-free 866-740-1941

Overview of Huntington's Disease

Every generation lives on a frontier...
simply because we are, we must
move up,
 move out,
 move in and challenge the darkness.
That which once unknowable becomes known,
 even more commonplace.
This has been a man's nobility-
 his intellectual mobility.

Michael Paul Fitzgibbon — Poet, HD Patient from Indiana

Huntington's Disease (HD) is a progressive neuropsychological disorder for which there is no cure. HD affects the ability to think, to speak, and to walk. Many patients have emotional symptoms such as depression, anxiety, and sleep disorders. Motor control becomes impaired and patients drop things, stumble and slur their words. They often develop poor concentration and impaired judgment. As the disease progresses, patients lose the ability to work, drive a car and live independently. In the late stages of HD, the weakened individual succumbs to pneumonia or other complications of immobility that ultimately result in death.

HD afflicts not only the patient, but everyone in his or her family. HD is hereditary, and each child of an affected parent has a 50% chance of inheriting the HD gene. Everyone who inherits the gene will develop the disorder. HD strikes individuals in the prime of their lives. The average onset is between the ages of 30-50 and the duration of the illness is approximately 10-25 years. Children as young as 2 and adults as old as 80 have developed HD.

HD is named after Dr. George Huntington, an American physician, who first described the disease in an article published in 1872. However, the HD gene was not identified until 1993. This dramatic discovery has simplified the testing process, made it much more financially realistic to be tested and has increased the accuracy of the diagnostic process. The cause of dying brain cells was discovered in the fall of 1997. This exciting breakthrough has enabled drug trials to begin and given renewed hope of finding a way to possibly slow the progression or prevent the onset of HD.

Huntington's Disease, once thought of as rare, is now recognized as one of the more common hereditary diseases. In the past, affected individuals and their families rarely spoke of the disease, feeling ashamed and hopeless. This fact, coupled with frequent medical misdiagnosis of HD, has led to an underestimation of its prevalence.

Indiana has the second highest recorded HD population in the country. Current estimates are that up to 1 in 10,000 people in the United States have the disorder. HD creates a ripple effect because relatives are likely to experience the disease and its varied consequences. It is therefore estimated that 1 in 1,000 Americans are directly affected by HD.



Huntington's Disease Society of America



Clarian Health