

For Immediate Release

HUNTINGTON'S DISEASE SOCIETY OF AMERICA ENDORSES ENROLL-HD

New York, NY, February 21, 2014 -- The Huntington's Disease Society of America (HDSA) is pleased to announce its endorsement of the Enroll-HD prospective registry study, a global effort to collect a common set of clinical data and biological samples that will help scientists better understand the disease and support both the recruitment and conduct of clinical trials of potential new therapeutics for HD. Additionally, data collected from Enroll-HD will also help inform the standards of medical care for HD families.

"Enroll-HD has the potential to revolutionize HD science and accelerate development of therapies," said Steven V. Seekins, HDSA Chairman of the Board of Trustees. "In our mission to improve the lives of everyone affected by HD and their families, Enroll-HD distinguished itself as the platform from which future HD science will launch. It's simply too important to the lives of the HD community for us not to champion it and the potential it brings."

Enroll-HD is sponsored and managed by CHDI Foundation, a not-for-profit biomedical research organization dedicated to rapidly developing therapies that slow the progression of Huntington's disease. Launched in November 2010, Enroll has 52 currently recruiting sites internationally, 39 of which are in the United States. For a list of all current sites and more information about Enroll-HD, visit www.enroll-hd.org.

"Unlike other clinical studies that are testing potential drugs or observational studies that are smaller in scale, Enroll-HD is unique in scope and size," noted George Yohrling, PhD, Director of Medical & Scientific Affairs at HDSA. "A global repository of the most rigorously collected clinical data and samples offers countless opportunities to both academic and industry scientists."

Louise Vetter, CEO of HDSA stated that "In order to test potential therapies so that safe and effective drugs stop HD in its tracks, we need many thousands of HD family members participating in the scientific process. HDSA believes that Enroll-HD is a new breed of patient registry, with the highest levels of management, patient protection and commitment to sharing its data with scientists that can help make sure we understand HD better, test potential drugs more quickly and ensure that we are providing the highest quality of care for HD families."

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To support its endorsement, HDSA will be launching an educational campaign on Enroll-HD across its network of 54 Chapters and Affiliates nationwide. Clinical trial education is already a critical component of HDSA's educational, research and advocacy work. The Society's 170 support groups, 40 social workers and specially trained Clinical Trial Diplomats and Research Ambassadors provide ongoing education to HD families about the role of observational and clinical trials in finding treatments for HD.

"We know that HD families are under enormous pressures just to make it through each day, and that participating in research studies is often too much to consider. For those who are looking for one thing they can do to move the field of HD science closer towards treatment, we encourage them to consider Enroll-HD," added Ms. Vetter.

HDSA cautions families to be careful about where they share personally identifiable information about their HD heritage, genetic status, treatments, and research involvement. Limitations exist in today's genetic discrimination protection laws, and individuals are encouraged to participate in science conducted by reputable academic and medical institutions with strong review processes and patient protections. For more information about genetic discrimination and to find a clinical trials in your area, visit HDSA.org.

Huntington's disease is a hereditary, degenerative brain disorder that results in a loss of cognitive, behavioral and physical control, and for which, presently, there is no cure. Symptoms usually appear in an individual between 30 and 50 years of age and progresses over a 10 to 25 year period. Cases of juvenile HD have been diagnosed in children as young as two years of age. Eventually, a person with HD becomes totally dependent upon others for his or her care.

More than 30,000 people in the United States are currently diagnosed with HD. Each of their siblings and children has a 50 percent risk of developing the disease. Although medications can relieve some symptoms in certain individuals, science has yet to find a means of conquering or even slowing the deadly progression of HD.

The Huntington's Disease Society of America is the largest non-profit organization dedicated to improving the lives of everyone affected by Huntington's disease. Founded in 1968 by Marjorie Guthrie, wife of folk singer Woody Guthrie who lost his battle with HD, the Society works tirelessly to provide community services, education, advocacy and research to support everyone affected by HD.

To learn more about Huntington's disease and the work of the Huntington's Disease Society of America, visit www.hdsa.org or call 1-800-345-HDSA.

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