Huntington's Disease Society of America

FOR IMMEDIATE RELEASE

The Huntington's Disease Community Unites for April 13 Day of Action

Patient advocates stand together, calling for Congress to protect a rare-disease system that advances safe innovation without unnecessary delay

New York City, New York — 4/7/2026 — On 4/13/2026, the Huntington's disease (HD) community will unite in a national call to action, urging Congress to support a rare-disease development and regulatory system that reflects both scientific rigor and the urgent realities facing families living with Huntington's disease.

In support of this effort, the HD Community is standing together with patients, families, caregivers, researchers, clinicians, and advocates across the country to amplify one clear message: the Huntington's disease community cannot afford unnecessary delay.

Huntington's disease is a fatal, progressive neurodegenerative disease, and there are currently no approved disease-modifying therapies. While existing treatments may help manage some symptoms, they do not stop or slow the underlying progression of the disease. For families facing HD, every month without access to a potentially effective therapy may mean further progression, greater loss of function, and less opportunity to benefit when treatment may matter most.

The HD community has also shown an extraordinary commitment to research. Through ENROLL-HD, tens of thousands of individuals and families have contributed personal health data to help build a robust Huntington's disease natural history database. That commitment has helped create the scientific foundation needed to better understand the disease and support smarter, faster, and more effective clinical trials.

The message behind this day of action is clear: urgency must be grounded in scientific rigor, but rigor must not become a barrier to progress. Congress has directed the U.S. Food and Drug Administration to apply regulatory flexibility in rare diseases when traditional trial designs are not feasible or would unduly delay access. The HD community is calling on lawmakers to ensure that this flexibility is meaningfully applied in a way that upholds FDA's high standards while recognizing the realities of terminal rare diseases.

On April 13th, advocates across the country are being asked to contact their U.S. Senators and Representatives and raise their voices. Together, the Huntington's disease community is calling for a rare-disease system that protects scientific integrity while ensuring families facing terminal illness are not left behind.

Take action on April 13th. Contact your members of Congress and tell them the HD community needs a rare-disease system that works. Visit HDSA.org/HDDayofAction for more information.

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Huntington's disease is a fatal genetic disorder that causes the progressive breakdown of nerve cells in the brain. It deteriorates a person's physical and mental abilities during their prime working years and has no cure. Each child of a parent with HD has a 50/50 chance of inheriting the faulty gene that causes Huntington's disease. Today, there are over 41,000 symptomatic Americans and more than 200,000 at-risk of inheriting the disease. The symptoms of Huntington's disease are described as having ALS, Parkinson's and Alzheimer's – simultaneously.

The Huntington's Disease Society of America is the premier nonprofit organization dedicated to improving the lives of everyone affected by HD. From community services and education to advocacy and research, HDSA is the world's leader in providing help for today and hope for tomorrow for people with HD and their families.

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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