## FOR IMMEDIATE RELEASE

Huntington's Disease Awareness Month: A Month-Long Campaign to Educate and Empower, Culminating with the Annual HDSA Convention in Spokane, WA

New York, NY (April 24, 2024) – This May, the Huntington's Disease Society of America (HDSA) is celebrating 32 years of Huntington's Disease Awareness Month with a series of events across the country and an online initiative called **#letstalkabouthd**. This campaign seeks to raise awareness and support for those affected by Huntington's disease (HD), culminating in the HDSA Annual Convention, the largest gathering of HD families in the world, to be held in Spokane, WA.

The month-long observance encourages communities to come together to learn about HD, a hereditary neurodegenerative disease that currently has no cure. Through educational programs, fundraising activities, and community events, HDSA aims to foster a greater understanding of HD while providing support to those impacted by it.

A key component of this year's campaign is the online initiative, #letstalkabouthd, which invites people from around the world to share their personal stories and experiences with HD on social media. Louise Vetter, President & CEO of the Huntington's Disease Society of America, emphasizes the importance of this initiative, stating, "The #letstalkabouthd campaign is designed to personalize the profound effects of Huntington's disease. Since HD affects each person and family in unique ways, it's time to share our stories and raise awareness about the reality of living with this disease."

The roots of Huntington's Disease Awareness Month trace back to 1992, when President George H. W. Bush issued a proclamation in response to Senate Joint Resolution 251, designating May as "National Huntington's Disease Awareness Month." In his proclamation, President Bush declared, "In order to enhance public awareness of Huntington's disease and to express concern for those affected by it, the Congress, by Senate Joint Resolution 251, has designated May 1992 as 'National Huntington's Disease Awareness Month' and has requested the President to issue a proclamation in observance of this month."

Throughout May, various events and activities will take place at HDSA Chapters across the nation, focusing on education, advocacy, and community support. The culmination of these efforts will be the 39<sup>th</sup> Annual HDSA Convention in Spokane, WA, on May 30-June 1, 2024 bringing together HD families, advocates, and researchers for a weekend of learning and connection.

For more information about Huntington's Disease Awareness Month, the #letstalkabouthd campaign, and the Annual HDSA Convention, please visit the HDSA website at www.hdsa.org.

Huntington's disease (HD) 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. Every child of a parent with HD has a 50/50 chance of inheriting the faulty gene that causes HD. Today, there are approximately 41,000 symptomatic Americans and more than 200,000 at risk of inheriting the disease. The symptoms of HD 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 Huntington's disease. HDSA supports research to find a cure for HD, provides resources and support services to HD families, educates the public and healthcare professionals about HD, and advocates for legislation and policies that benefit the HD community.

## **MEDIA CONTACT**

Mynelly Perez
Director of Marketing & Communications
212-242-1968, ext. 214
mperez@hdsa.org