

FOR IMMEDIATE RELEASE Contact: Christopher Cosentino, Director of Marketing & Communications (212) 242-1968 ext. 229 ccosentino@hdsa.org

## HUNTINGTON'S DISEASE SOCIETY OF AMERICA LAUNCHES YOUTH SOCIAL WORKER PROGRAM

**New York, NY, January 16, 2019** – The Huntington's Disease Society of America (HDSA) is expanding its youth programming with the launch of its new HDSA Youth Social Worker Program. Over the next three years, HDSA will recruit and train Social Workers within its Huntington's disease (HD) network to serve young people and respond to the unique needs of children, teens and young adults impacted by HD.

"We are always working to develop new ways to provide meaningful resources for youth impacted by Huntington's disease," said Louise Vetter, HDSA's President & Chief Executive Officer. "In complement to the HDSA National Youth Alliance and our ongoing partnership with HDYO, HDSA's new Youth Social Worker Program will help us serve the needs of the youngest members of HD families and connect them to HDSA's vast community of support and resources."

Beginning on a part-time basis, the Youth Social Workers will provide case management, counseling and resources to young people nationwide impacted by HD. HDSA's first two Social Workers to join the program are Katie Dykman, LISW and Jessica Marsolek, LGSW. The HDSA Youth Social Worker Program is generously funded by The Griffin Foundation.

"Griffin Foundation focuses on expanding care and outreach to HD patients and families," said Jack Griffin, Chair of The Griffin Foundation. "This Youth Social Worker Program will be an important and much-needed piece to achieve this goal."

HDSA's National Youth Alliance (NYA) is a powerful network of children, teens and young adults between the ages of 9-29 who are impacted by Huntington's disease in the United States. The NYA includes all youth members of the HD community, including those who are at-risk, gene positive, gene negative, impacted by Juvenile-onset HD, caregivers and friends of those affected by HD. In addition to the new Youth Social Worker program, the NYA coordinates free Youth Retreats around the country, host an NYA Day at the Annual HDSA Convention, and manages its own Convention Scholarship Program to enables NYA members to attend the HDSA Convention at no cost.

For more information about HDSA's NYA and the Youth Social Worker program, please contact HDSA's Senior Manager of Advocacy & Youth Programs Jennifer Simpson, LCSW at jsimpson@HDSA.org or (212) 242-1968 x226.

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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 HD. Today, there are approximately 30,000 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 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 <u>www.HDSA.org</u> or call (800) 345-HDSA.