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EJ GARNER APPOINTED CHAIR OF THE NATIONAL BOARD OF TRUSTEES AT THE HUNTINGTON'S DISEASE SOCIETY OF AMERICA

Kamran Alam, Dr. Leslie Thompson & Dr. Vicki Wheelock Join HDSA's Board of Trustees

New York, NY, December 10, 2018 – The Huntington's Disease Society of America (HDSA) National Board of Trustees has elected EJ Garner as new Chair replacing Dr. Arik Johnson who completed his two-year term. Dr. Johnson will now serve as Past Chair for a two-year term, and Dr. Victor Sung, Director of the Huntington's Disease clinic at the University of Alabama at Birmingham, has been appointed Chair-Elect.

Mrs. Garner has been an active HDSA volunteer since 2006 and has served on HDSA's National Board of Trustees since 2015. She was on the board of HDSA's Orange County Chapter from 2008 to 2013 and served as Chapter President from 2010 to 2012. She was named the Chapter's *Volunteer of the Year* in 2011 and was recognized as one of the top fundraisers of HDSA Team Hope Walk in 2013 and 2015. In tribute to her son and grandson and in an effort to raise awareness and funds for the fight against HD, EJ embarked on the 554 mile Camino de Santiago pilgrimage in mid-August 2015. Walking the entire route with a 23-pound backpack, she raised more than \$16,000 for HDSA Team Hope Walk. Her next trek will be walking to the 21 California Missions (approximately 800 miles).

EJ has been deeply affected by Huntington's disease. She is the grandmother of twin granddaughters who are at-risk of HD. Her husband passed from Huntington's disease in 2002, and her son Scott died at age 44 from complications of HD in 2015. Additionally, her grandson, brother to her granddaughters, Matthew, died at age 6 from Juvenile HD in May 2008. A long-time resident of Southern California, she recently moved to Olympia, WA with her husband, Art, to be close to her granddaughters and daughter-in-law. After 40 years with Toyota Motor Sales, U.S.A., Inc. she retired from a career of various management positions including, administration, marketing, merchandising, and distribution/logistics. EJ holds a Bachelor's of Science degree from University of Redlands in California.

"It is an honor and a privilege to be appointed Chair of HDSA's Board of Trustees," said EJ Garner. "The Board is made up of a fantastic group of doctors, scientists, researchers, family members and others committed to finding a cure for Huntington's disease. Having lost a son and grandson to HD, I feel a special responsibility to help represent the thousands who face the challenges of the disease every day. Just as those fighting HD daily inspire me, I hope to inspire others to support and get involved with their local HDSA Chapters and Affiliates. As advances in HD research and treatments reach market and the hope for a cure grows, HDSA must continue to grow and continue to assist those dealing with the disease on a daily basis, those with HD and the families and friends that support them. I also look forward to working with HDSA's National Youth Alliance and supporting their mission and inspire them to get involved in the battle against HD."

In addition to Mrs. Garner's appointment, Kamran Alam, Dr. Leslie Thompson and Dr. Vicki Wheelock have been elected to join HDSA's National Board of Trustees. Mr. Alam is currently the Deputy Chief Financial Officer at AveXis, Inc., a Novartis Company in Bannockburn, Illinois. Dr. Thompson is a world-renowned HD researcher and currently a professor at the

University of California-Irvine School of Medicine. Dr. Wheelock is a beloved and well-respected neurologist at HDSA's Center of Excellence at the University of California-Davis.

Special thanks to Dr. Jang-Ho Cha, Dr. Michelle Gray and Arvind Shreedharan who have completed their terms on HDSA's National Board of Trustees. Each will remain involved in advisory roles within the organization.

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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 www.hdsa.org or call 1-800-345-HDSA.