May 23, 2024

Statement from Louise Vetter, President & CEO

New York, New York – After careful thought and reflection, I have decided to resign from my role as President & CEO of the Huntington’s Disease Society of America effective July 12th in order to assume a new opportunity that will be communicated shortly.

Please know that this was a difficult decision. I am extremely proud of HDSA and I care deeply about the organization, its staff, volunteers, donors, partners and everyone who is touched by its work. During my tenure, HDSA’s mission impact has grown significantly. With strategic planning, we have increased our mission services, revenue and operational core as one unified HDSA. As a result, the organization’s Care, Cure and Community work has evolved and more families than ever before are helped by HDSA.

Words cannot express how grateful I am for the opportunities I have been given, the experience I have gained and the people with whom I have been lucky to meet and work. But, this is the right time for me to move on in my professional career.

There is an incredible amount of momentum at HDSA and in the HD community. I am working with the HDSA Board of Trustees to ensure that interim leadership is established to guide the Society after my departure and until such time that a new permanent leader for HDSA is identified.

Most importantly, thank you for welcoming me into the HDSA family fifteen years ago. I have been profoundly changed by the HD community. Strength, compassion and family have all taken on new meaning for me because of the HD families I have been fortunate to know.

As progress towards the development of new therapies to treat HD continues, I will move into the most sacred role at HDSA – volunteer, where I will continue my dedication to our mission to improve the lives of people affected by HD and their families.

With gratitude & hope,
Louise

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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.

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