Huntington's Disease
Society of America

For Immediate Release

Amy Gray Appointed as New President & CEO of HDSA (Huntington's Disease Society of America)

New York, NY — February, 3, 2025 — The Huntington's Disease Society of America (HDSA) is pleased to announce the appointment of **Amy Gray** as its new President and Chief Executive Officer, effective immediately. Amy brings over two decades of extensive experience in fundraising, operations, and patient advocacy, having held senior leadership roles in several national nonprofit health organizations. Her background in advancing patient-centered initiatives and strengthening nonprofit infrastructure will guide HDSA in its mission to improve the lives of individuals and families affected by Huntington's disease.

Amy joins HDSA after serving as CEO of the Undiagnosed Diseases Network Foundation (UDNF), where she successfully led the organization's efforts to improve access to diagnosis, research, and care for individuals with undiagnosed and ultra-rare conditions. Under her leadership, UDNF developed its inaugural strategic plan, launched a groundbreaking patient navigation program with support from the Chan Zuckerberg Initiative, and secured multi-year funding from the National Institutes of Health (NIH) for the Undiagnosed Diseases Network.

"Amy's passion for advancing patient care and her proven track record in leadership and strategic growth make her the ideal choice to lead HDSA into its next chapter," said **Jenne Coler-Dark**, Chair of the Board of Trustees at HDSA. "Her deep experience in both the rare disease and nonprofit sectors will be invaluable in accelerating our mission to provide support for families impacted by Huntington's disease, while advancing critical research efforts. We are thrilled to welcome her to our team."

Prior to her work at UDNF, Amy served as the CEO of the Charcot-Marie-Tooth Association (CMTA), where she successfully tripled the organization's annual revenue and launched transformative programs to support research and community engagement. She has also held executive roles with the Parkinson's Foundation, Crohn's & Colitis Foundation of America, and the Muscular Dystrophy Association, where she worked on strengthening organizational operations and cultivating strong relationships with stakeholders and donors.

"I am honored to join the Huntington's Disease Society of America, an organization with a long history of dedication to families and individuals affected by Huntington's disease," said **Amy Gray**, President & CEO of HDSA. "I look forward to working closely with the HDSA team, its board, and the broader Huntington's disease community to continue to drive forward progress in research, advocacy, and support for families. Together, we will work toward a brighter future for those living with Huntington's disease."

Amy's leadership and advocacy have also extended internationally, as she has served on multiple committees and advisory boards, including the NIH's Rare Disease Clinical Research Network and the Undiagnosed Diseases Network's executive and steering committees. She has been invited to speak at major global conferences, such as the Global Genes Rare Summit and the World Orphan Drug Conference, on the importance of patient engagement and innovation in drug development.

As HDSA's new President & CEO, Amy will work closely with the board, staff, volunteers, and community stakeholders to continue HDSA's mission of providing support, education, and advocacy for families living with Huntington's disease, as well as advancing research to find a cure.

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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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