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HUNTINGTON'S DISEASE SOCIETY OF AMERICA HOSTS ITS 33RD ANNUAL CONVENTION IN LOS ANGELES WITH RECORD NUMBER OF ATTENDEES

New York, NY, June 13, 2018 -- The Huntington's Disease Society of America (HDSA) hosted its 33rd Annual Convention from June 7th-9th at the Los Angeles Airport Marriott in California. With 1,046 attendees, this was the largest Convention in the 50 year history of the organization breaking the previous record of 1,001 in Minnesota back in 2011. The HDSA Convention is the world's largest conference for families affected by Huntington's disease (HD).

"On behalf of the HDSA Board of Trustees, staff and volunteers I would like to thank everyone who supported and attended the 33rd Annual HDSA Convention," said HDSA's President & CEO Louise Vetter. "Throughout the entire Convention there was a clear message to follow in Marjorie Guthrie's footsteps to "do something" about this devastating disease. Fifty years ago Marjorie began her crusade against HD, and today we continue her legacy by bringing together the entire community to provide help and hope to all families affected by Huntington's disease."

This year's HDSA Convention kicked off on Thursday with its ceremonial Team Hope Walk and carnival-themed Welcome Reception. Guests were greeted by a surprise video greeting from actress Bryce Dallas Howard who donated four tickets to the LA premiere of her latest film, *Jurassic World: Fallen Kingdom*. The excitement did not stop there, Bryce then introduced an HDSA Convention exclusive sneak peek and extended trailer of the film.

Friday morning's opening ceremony featured powerful keynotes from Anna Canoni and Bill Johnston, respectively. Anna, who is the granddaughter of Woody and Marjorie Guthrie, shared her family story on how the Guthries were impacted by HD and Marjorie's extraordinary determination to establish the Committee to Combat Huntington's Disease (now known as the Huntington's Disease Society of America) fifty years ago. San Diego Padres' executive and HD family advocate Bill Johnston then discussed his family's battle against this devastating brain disorder and encouraged families to follow in Marjorie's footsteps to get involved and "do something".

Immediately following the Opening Ceremony, the HDSA Convention featured workshops led by world-class researchers, caregivers, social workers, clinicians and other experts.

On Friday night at the annual HDSA National Youth Alliance (NYA) Talent Show attendees were entertained with magic, dance, stand-up comedy and singing. The show raised more than \$30,000 to support the NYA Convention Scholarship Fund which sends youth to Convention each year.

The much-anticipated Research Forum on Saturday featured a first-of-its-kind panel which presented the history of the discovery of the HD gene and how it has led to the development of a promising new potential therapy for HD using antisense oligonucleotides. The panel included Dr. Jim Gusella, Dr. Anne Smith, Dr. Holly Kordasiewicz, Dr. Robert Pacifici, Dr. Doug Macdonald, Dr. Ed Wild, Dr. Blair Leavitt, Erik Lundgren, Dr. George Yohrling and HD family advocate Amy Fedele. Dr. Jeff Carroll and Dr. Wild from HDBuzz.net also delivered an informative and highly entertaining update on HD research.

Saturday night's Awards Dinner and Gala closed out this memorable Convention with amazing food, entertainment and dancing. National awards were presented to Dr. Jim Gusella (Researcher of the Year), the Johnston Family (Marjorie Guthrie Award), HDSA's Greater New York Chapter (Chapter of the Year), HDSA's Central Maryland (Affiliate of the Year), Anna Lunsford (HDSA Youth Award), Frances Saldana (Woody Guthrie Advocacy Award), HDSA Center of Excellence Partner Kaiser Permanente of Northern California (Excellence in HD Care) and Jeannette Garcia (HDSA Person of the Year).

For the 20th year, Marie Nemec and Charlotte Reicks led a team of dedicated advocates who once again rode bicycles to the HDSA Convention while raising money for HDSA. To date, Bike For The Cure has raised more than \$730,000!

The 33rd Annual Huntington's Disease Society of America Convention was made possible by the generous support of its sponsors: Archcare, BioTek reMedys, Broda, Enroll-HD, Genentech, Huntington Study Group, Ionis Pharmaceuticals, Lundbeck, Mass Mutual, PTC Therapeutics, Tagi Pharma, Teva Pharmaceuticals, uniQure, Vaccinex, Voyager and WAVE Life Sciences.

Please visit HDSA.org and follow HDSA's social media channels for more information on recorded sessions and photos from this past year's Convention. Also, visit HDSA.org/convention in the coming months to learn more about the 34th Annual HDSA Convention in Boston on June 27th-29th, 2019.

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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.