



News from the Hereditary Disease Foundation

Partners in Research

The Future Is Now at NJ Cure HD

For John Stevens, as for so many others, Huntington's disease is not an esoteric illness that you read about in books, it is a disease that impacts every aspect of daily life. John's wife, Patty, was diagnosed with HD in 2009. He had been caring for her at home until last year when he had to admit her to a nursing home. John is President of NJ Cure HD, a statewide New Jersey organization made up of passionate individuals united as a community in the fight against Huntington's disease.

NJ Cure HD is a generous Partner in Research with HDF. Their Annual Golf Classic has raised over \$250,000 to fund HD research. This year's Golf Classic will be held on Monday, August 13, at Echo Lake Country Club, in Westfield, NJ, with proceeds benefitting organizations such as HDF. njcurehd.org

A father of three, and grandfather of six, John says, "Research is the future. I pray and hope that there is a cure in my lifetime, or significant progress that helps people along the way. It's essential that we raise money for an organization such as HDF that is funding important research."



Dr. Sarah Tabrizi

John is particularly inspired by gene silencing and its potential to slow, stop, prevent or reverse HD.

"It's wonderful to hear about exciting new research that is going on at places such as Ionis Pharmaceuticals. I was fascinated to meet Dr. Sarah Tabrizi at last year's HDF Gala and to learn more about her work as global Principal Investigator of the world's first gene silencing trial in HD."

David Zwally, Chairman of the Board of HDF, is also a board member of NJ Cure HD. He too believes that the future is in research, and that now is the time to redouble our efforts to fund HD scientists.

David Zwally has HD in his family. He says, “A good way for me to give back was to join the NJ Cure HD Board and be active in the HD community.”

Founded in 2011, NJ Cure HD has no paid employees and very limited expenses. David says, “We are all volunteers focused on raising money to find a cure. It’s very important to us that monies we raise go to support research, and the Hereditary Disease Foundation is all about research.”

HDF Makes \$1Million+ Commitment to Trailblazing Research Programs

We are thrilled to announce grant and postdoctoral fellowship awards to six researchers who are conducting dynamic research focused on finding treatments and cures for HD.

Nancy Wexler, President of HDF said, “Each year, we provide funding to support brilliant researchers who are working to bring hope and healing to HD families. It is only through research conducted by the best minds in laboratories around the world that we will achieve our goal of conquering HD.”



Scientists at an HDF Conference

The awards are made following a rigorous process, in which the HDF Scientific Advisory Board, composed of distinguished international scientists, reviews hundreds of grant and fellowship applications and selects the most promising research projects to fund.

The 2018-2019 award recipients are:

- Anne Ast, PhD, Max Delbrück Center for Molecular Medicine in the Helmholtz Association, Berlin-Buch, Germany
- Piere Rodriguez-Aliaga, PhD, Stanford University
- Alejandro Mas Montey, PhD, The Children’s Hospital of Philadelphia
- Ellen Penney, MD, PhD, Massachusetts General Hospital
- Anna Pluciennik, PhD, Thomas Jefferson University
- Kenneth Matthew Scaglione, PhD, Medical College of Wisconsin

Collaborative research is the key!

This year HDF is sponsoring a number of opportunities, totaling over \$1,000,000, to support HD scientists. In addition to grants and fellowships, over 250 scientists from around the world will come together to share their latest discoveries and develop new ideas at our Milton Wexler Biennial Conference in Boston this month. We also are organizing a Scientific Workshop in New York City on October 22, at the Harvard Club. Renowned molecular biologist Shirley M. Tilghman, President Emeritus of Princeton University, and C. Frank Bennett, Senior Vice President of Research at Ionis Pharmaceuticals, whose work made possible the first clinical trials in HD, will be featured at the Symposium.

Stay tuned for updates in the months ahead!

Join Us for October Events!

Walk 4 HD

Jackie Hamilton fought a long battle with Huntington's disease, but she left a legacy of love and compassion to her family and friends. In honor of Jackie, her daughter, Gabrielle Hamilton will hold the 2nd Jackie's Walk 4 HD on Sunday, October 14, at 10am, at Glen Island Park in New Rochelle, NY. Visit hdfoundation.org to learn more and register. Proceeds will benefit the Hereditary Disease Foundation and the Huntington's Disease Society of America Center for Excellence at Columbia University.

HDF Symposium and Gala

We'll celebrate our 50th Year at our 2018 Symposium and Gala on Monday, October 22, at 6 pm, at the Harvard Club in New York. Please mark your calendar!

For more information, visit [Hereditary Disease Foundation](http://HereditaryDiseaseFoundation.org)

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