

Concert for a Cure

LVH ALS Foundation Raises \$300,000 for ALS Research

The Larry Vance Hughes ALS Foundation (LVH ALS Foundation) has donated \$300,000 to the Duke ALS Clinic to support its research into therapies associated with “ALS reversals,” documented instances where the symptoms of amyotrophic lateral sclerosis (ALS) unexpectedly diminish and motor function returns.

Proceeds for the donation were raised through the LVH Benefit Concert for ALS Research, featuring country music artists Mark Wills and Taylor Hicks, held last October at the Millennium Center in Winston-Salem, North Carolina.

Established in 2014 by the family of the late Larry Vance Hughes, the LVH ALS Foundation is one of the largest ALS foundations in North Carolina. Through its partnership with Duke University, the foundation and its founder, Brett Hoge, are committed to raising funds and awareness to find a cure for ALS, also known as Lou Gehrig’s disease, a fatal nervous system disease that causes progressive loss of muscle control.

Brett Hoge, his family, and the foundation have provided significant annual support for ALS research at Duke. Through annual fundraising events, including golf tournaments, Kentucky Derby parties, and last year’s concert, the LVH Foundation has donated a total of more than \$1 million to support Duke’s research and search for a cure.

Thanks to this generosity, Richard Bedlack, MD, PhD, director of the Duke ALS Clinic, has established and expanded the clinic’s ALS Reversals Research program.

“I am very grateful for the support that the LVH foundation has provided over the past six years,” said Bedlack, a professor of neurology at Duke University School of Medicine. “This has allowed me to pursue a line of research that I think is very exciting but is also very controversial. It is unlikely that traditional granting agencies would fund my ALS reversals research, since the very idea that people can recover from this disease is still not widely accepted.”

In the vast majority of patients with ALS, symptoms inexorably worsen over time, resulting in death an average of 2-5 years after diagnosis.

Bedlack has thus far confirmed 48 cases of ALS reversals. In these cases, for unknown reasons, the progressive worsening of symptoms unexpectedly reverses course, and patients regain some or all of their motor function.

Bedlack is diligently investigating these cases in an attempt to identify why reversals occur and, ultimately, to develop techniques to induce reversals in other ALS patients. He has established two ALS reversal programs within the Duke ALS Clinic: Study of ALS Reversals (STAR), which gathers detailed data—including genetic, microbiome, environmental exposure, and other information—into a dedicated database in order to identify trends and shared characteristics among patients with ALS reversals; and Replication of ALS Reversals (ROAR), which involves small pilot trials of food supplements and other treatments associated with dramatic ALS reversals.

“Having pored over the medical records of these 48 patients, I am convinced that they had ALS, progressed to where they were disabled from it, and then recovered most or all of their lost motor function,” said Bedlack. “If I can figure out why these ALS reversals occurred, I should be able to make them happen more often. To me, this is the most exciting, most hopeful research I have ever been part of.”

The LVH ALS Foundation is a significant partner in the Duke ALS Clinic’s pursuit of a cure. The foundation looks forward to hosting its next in-person fundraising event to support Duke’s ALS research, tentatively planned for the fall of 2021.

For more information on the LVH ALS Foundation, visit <http://lvhalsfoundation.org>. To learn how you can make an impact and support ALS research at Duke, please contact Director of Development Whitney Martin at Whitney.W.Martin@duke.edu or 919-451-3758.