

*The Bev Hartig
Huntington's
Disease Foundation*

*Educating * Funding * Believing*

The First Ten Years

2010 - 2019

A Note from the Hartig Family

We welcome you to the incredible journey of Bev Hartig and The Bev Hartig Huntington's Disease Foundation (TBHHDF). Our story began in 1998, when shortly after we were married, Bev learned that her birth father had Huntington's disease. Bev had a 50% chance of having the disease and passing it to our children. After careful thought, Bev was tested and found to be gene positive. For more than ten years she lived in secret fear and silence. In 2008, she nervously confided in a group of friends that she had HD and implored them to join her in starting a cause in search for a treatment and cure.

The resulting, now annual, event to raise awareness of this dreaded disease and money to fund research to find a cure was the seed for TBHHDF, and it continues to be the catalyst for raising monies for research. The event is the result of Bev's inspiration and the conviction of a group of men and women who support her in her cause. For the love of Bev, it is now our cause.

Thanks to the very generous contributions of time, effort, talent and money from volunteer family, friends, and donors, the event blossomed into what is currently a \$1.5 million foundation which funds promising research nationwide and across our borders in pursuit of a cure. It has humbled our expectations exponentially.

Today Bev, symptomatic for a decade now, requires assistance in everything she does. She has not driven for 5 years. She falls frequently and has difficulty holding conversations. Fearful of choking she requires all of her food to be cut into small pieces. She is in the grip of this hideous disease which has no shortage of psychological and physical challenges. Yet, she remains hopeful and optimistic that a breakthrough is on the horizon.

We are more than grateful to all who have joined us, past and present, in support of our mission to find a cure for HD. We ask for and covet your continued contributions to our cause. We dream of the day when the TBHHDF has fulfilled its mission and future generations will no longer suffer from living with and dying from Huntington's Disease.

In 2019, we celebrated our Tenth Annual Huntington's Disease Fundraiser, "A Musical Celebration of Giving". An elegant dinner and entertainment by The Warren Brothers and Tim Nichols, singer-songwriters from Songwriter City, Nashville, Tennessee highlighted the evening of giving. Our heartfelt thanks to all who support the foundation! ~ *Bob Hartig*

The Foundation's Story

The Bev Hartig Huntington's Disease Foundation was founded in 2011 as a vehicle for funding research to find a cure for Huntington's Disease. The Foundation has a three-pronged mission to educate, fund and believe that one day Huntington's Disease will be eradicated. HD is a relatively rare, inherited, neurodegenerative disease that causes the progressive breakdown of nerve cells in the brain impairing a person's functional abilities. Symptoms include deterioration of coordination, involuntary movements, loss of memory, impaired cognitive thinking, and results in psychiatric disorders, depression and death. Huntington's Disease, while present in an individual's genetic make-up from conception, most frequently becomes symptomatic in mid-life.

Inspired by her own diagnosis and the gradual on-set of symptoms, Bev Hartig gathered friends and neighbors to form a committee to help her fulfill her dream of creating a fundraiser to raise awareness of Huntington's Disease and money to help find a cure. The inaugural event was held in 2010 and raised over \$88,000 in a single evening. The Foundation was formed as the vehicle for awarding those monies to researchers with cutting edge approaches to seeking a cure. In the past 10 years the TBHHDF has awarded nearly \$1,500,000 to help find a cure.

The Gala Events

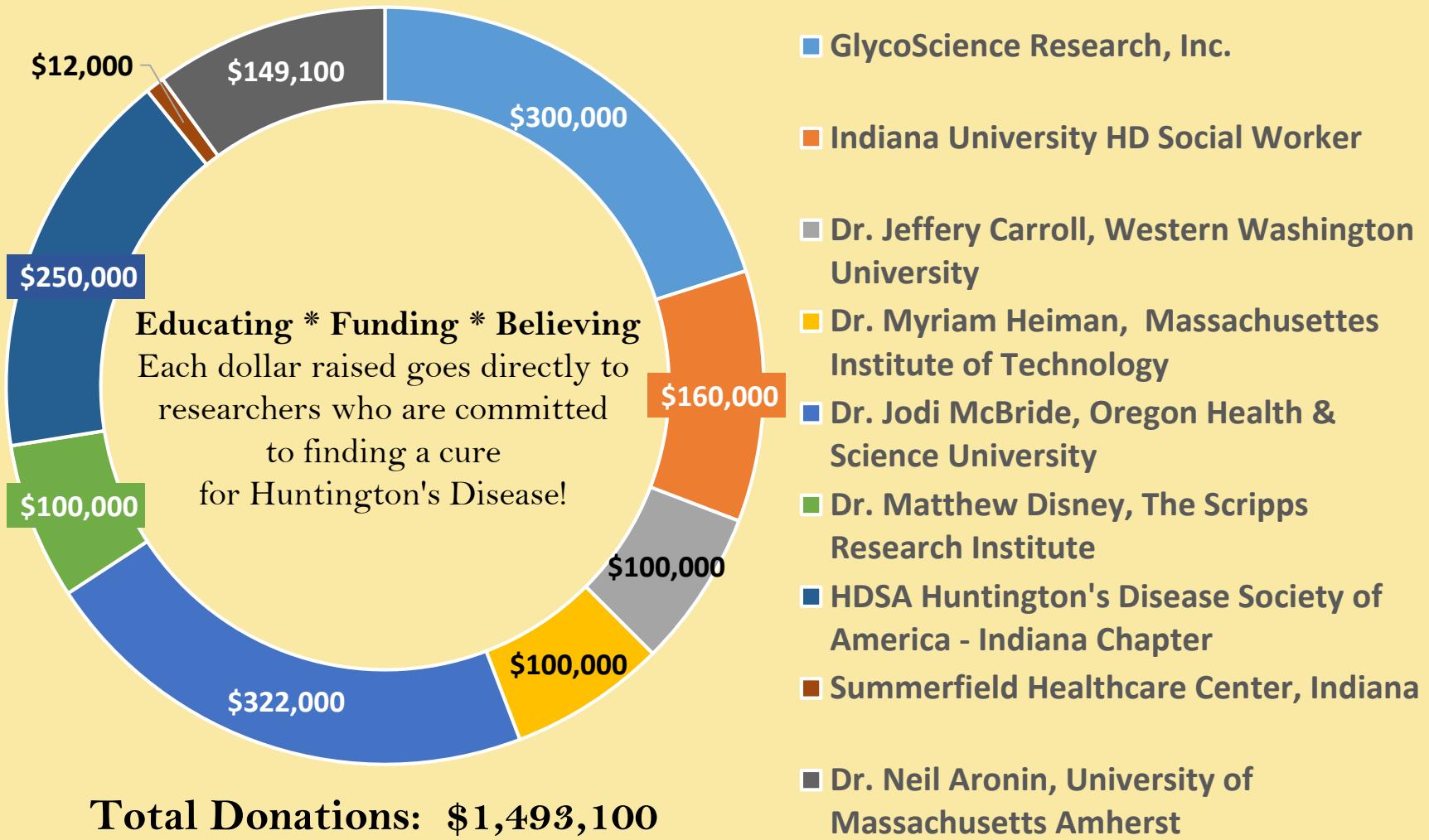
The Foundation monies come from the generous support of donors, mainly friends, family and admirers of Bev and Bob Hartig, who attend and contribute to an annual fundraising event planned and executed by an entirely volunteer committee. The humble beginnings of the Foundation started with the first annual fundraiser in 2010. A gala consisting of music, silent and live auctions, fun and food, also proved a wonderful opportunity to celebrate Bev as we raise money to help fund a cure. Initially, the fundraiser donated its income to the Huntington's Disease Society of America to support research for a cure. Three years after the first event, the TBHHDF became its own official 501c3 dedicated to finding the cure for Huntington's disease.

Annual events centered around fun themed evenings such as Night at the Derby, Mardi Gras, Hoedown for HD, Be a Superhero-Fight HD, Around the World in Search of a Cure, Wipe Out HD, and Team Bev-Go!Fight!Beat HD! have ensued annually. This year we celebrated our Tenth Annual Huntington's Disease Fundraiser, "A Musical Celebration of Giving!" on April 27, 2019. An elegant dinner and entertainment by The Warren Brothers and Tim Nichols, singer-songwriters from Songwriters City, Nashville, Tennessee highlighted the evening of giving.

Funding to Make a Difference

The funding arm of the Bev Hartig Huntington's Disease Foundation (TBHHDF) strives to seek out cutting-edge research that would not be funded without the Foundation that Bev inspired. The Foundation collaborates with The CHDI Foundation (<https://chdifoundation.org/>), a non-profit biomedical foundation whose aim is to rapidly discover and develop drugs that retard the progression of HD, and to identify up and coming researchers with promising studies. Upon organization, the Board of Directors of the TBHHDF sent out requests for proposal for consideration of funding to various researchers and research institutions. Subsequently, requests for funding from vetted researchers with unique and innovative approaches toward discovering a cure have been largely unsolicited.

Funds Raised and Application



Grant Highlights: Dr. Jodi McBride



The board is proud that its very first grant of \$142,000 was awarded to Dr. Jodi McBride of the Oregon National Primate Research Center at Oregon Health and Science University for her work creating a monkey model of Huntington's disease, whereby, a virus delivered to the blood stream or into the cerebral spinal fluid of a monkey, can carry a therapeutic gene to many parts of the brain otherwise unreachable. Dr. McBride's research has since been picked up by a pharmaceutical company for further study and expansion.

The board renewed funding to Dr. McBride in 2018, in the amount of \$100,000, for her work in developing and testing brain scanning techniques that can measure toxic huntingtin levels in the brain tissue. These methods, including PET scanning, must first be validated in monkey models and approved by the FDA before use in humans. A green light for human application will benefit all huntingtin lowering drug trials and therapies currently and futuristicly being conducted. You can learn more about her study by watching the video below.

<https://www.youtube.com/watch?v=XKhZsSgHouk&t=23s>

Grant Highlights:

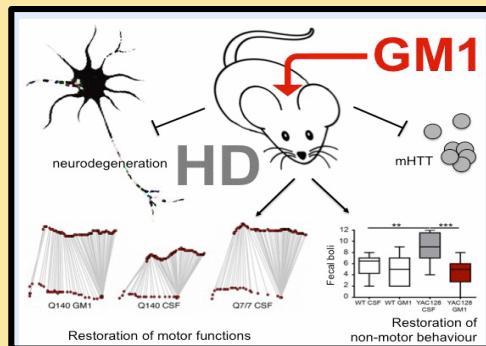
Dr. Larry Holler and

Dr. Gary Dunbar

GM1 Sheep Study



GM1 Ganglioside is a molecule which occurs naturally in the human nervous system. Too much or too little of the molecule is harmful. People with HD have too little of the molecule. Increasing the amount of GM1 has been proven to reverse the symptoms of Huntington's disease in mice. Veterinarian Dr. Larry Holler, has successfully genetically modified sheep to produce 40 times the normal amount of GM1 ganglioside which could be harvested and used to treat humans. The foundation's monies, in the form of two separate grants for \$150,000 and \$50,000 have enabled research to continue during a crucial timeline to human testing. This study is currently being reviewed by the NIH and approval will result in the commencement of human trials.



Grant Highlights: Dr. Matthew Disney, PhD

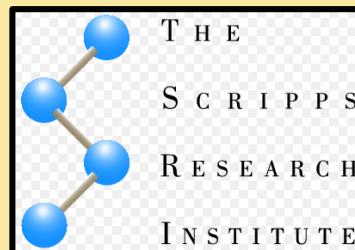


Dr. Disney is studying a series of compounds that they believe are brain entrant that affect many aspects of HD by targeting the CAG repeat. The Scripps Research Institute is near a real breakthrough, and will use funds from TBHHDF to see if the compound can indeed be a breakthrough to treat HD.

Famine, drug abuse and even stress can “silence” certain genes, causing health problems in generations to come. Now scientists are wondering—could therapies that change gene expression in parents help their children?

A new study from scientists at The Scripps Research Institute (TSRI) suggests this is possible. The research showed that the offspring of mice treated with a drug also had delayed onset and reduced symptoms of Huntington’s disease, an inherited, degenerative disease that causes a loss of motor skills, cognitive impairment and death.

This was the first time scientists have shown that drug compounds that benefit parents can also cause changes in genetic expression that benefit offspring—in this case, improved memory and motor skills.

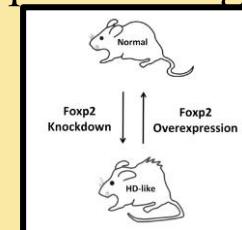


Grant Highlights: *Dr. Myriam Heiman*



Dr. Myriam Heiman of the Massachusetts Institute of Technology is studying two genes that they believe regulate the toxic accumulation of mutant Huntingtin in the brain. Funding from The Bev Hartig Huntington's Disease Foundation allows them to perform the necessary therapeutic test studies in mice.

The mammalian brain is composed of myriad cell types integrated into complex circuits. To help overcome this complexity and study the molecular profiles of distinct CNS cell types *in situ*, our lab makes use of the Translating Ribosome Affinity Purification (TRAP) methodology. In HD, medium-sized spiny neurons (MSNs) of the striatum are earliest and most dramatically affected. Through our TRAP and genetic screening studies, we have recently identified genes that either enhance or suppress mutant Huntingtin toxicity in MSNs, and hope to use this knowledge to identify new therapeutic targets for Huntington's Disease.



Grant Highlights: Well-Being Grants



In addition to the research grants, the Foundation annually provides \$20,000 toward the salary of a Social Worker at **Indiana University Hospital** to counsel and provide resources for Huntington's Disease patients and their families (in Indiana).

Summerfield Healthcare Center in Cloverdale, Indiana is one of only 4 facilities nationwide that care specifically and exclusively for patients with Huntington's Disease. Following a visit to the center by the TBHHDF board of directors, two separate grants of \$1,000 and \$5,000 have been awarded to fund special social activities and experiences to its residents over and above what their budget allows. The funds have allowed individual residents to attend a concert, go horseback riding, receive a birthday gift and groups of residents to enjoy entertainment and parties. In addition, they were able to purchase a specialized recliner for their social room at the Center.



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Join our Journey to Find a Cure

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* *Attend our Annual Gala: Saturday, April 25, 2020*

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* *Shop using Amazon Smile for your purchases and choose The Bev Hartig Huntington's Disease Foundation as your charity*

* *Share information (like this video below) to help Educate friends about HD*

<https://www.youtube.com/watch?v=5qU1OAc5OII>



<https://bevhartighuntingtonsdisease.com/>