Bev Hartig

HUNTINGTON'S DISEASE

Foundation

Educate. Fund. Believe.

A Note from the Hartig Family

The Bev Hartig Huntington's Disease Foundation hopes that you and your family had a healthy and safe 2021 and are looking forward to a great 2022! Your generous donations have helped the foundation support excellent research in 2021 and we are hopeful that together we can make 2022 even better. Thank you simply does not seem to be adequate for all that our family, friends, sponsors, and donors have done throughout the years. Your time, energy and efforts have helped create a $2.5 million foundation which funds promising research nation-wide and across our borders in pursuit of a treatment and one day a cure. TBHHDF is proud to be in our Thirteenth year. All of this is possible because of the courage, strength and inspiration from my wife, Bev.

Today, Bev, symptomatic for over 13 years, fights her HD every day. She is confined to a wheelchair and requires care 24 hours a day. All the things so many of us take for granted like bathing, dressing, eating, walking and talking, Bev needs assistance with daily. Her eating and communication continue to be a challenge because she is losing coordination with her tongue and swallowing. But the most challenging part is that she knows she is declining. The psychological strain is leading to physical challenges. Her chorea, involuntary movements, are more pronounced than ever before and put her at constant risk for falling and severe injury. Her chorea has caused her to damage her wheelchair multiple times and keeping her calm has become our primary focus. Trying to find the right balance of medications has been difficult. Amazingly, through it all, she remains optimistic. If you were to visit Bev and ask her how she is doing, she would immediately respond, "I'm doing great!" She is truly an inspiration to me and so many others and I am proud to be her husband.

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

On April 30th, we will come together and celebrate Bev with our 13th annual Event ~ Thirteen and Thriving! Please join us for an elegant dinner and entertainment at the Forum Events Center. We're looking forward to seeing you there!

From the bottom of our hearts, Thank You for the support of our foundation! ~ Bob Hartig

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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 12 years the TBHHDF has awarded nearly $2.3M to help find a cure.

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The Gala Events

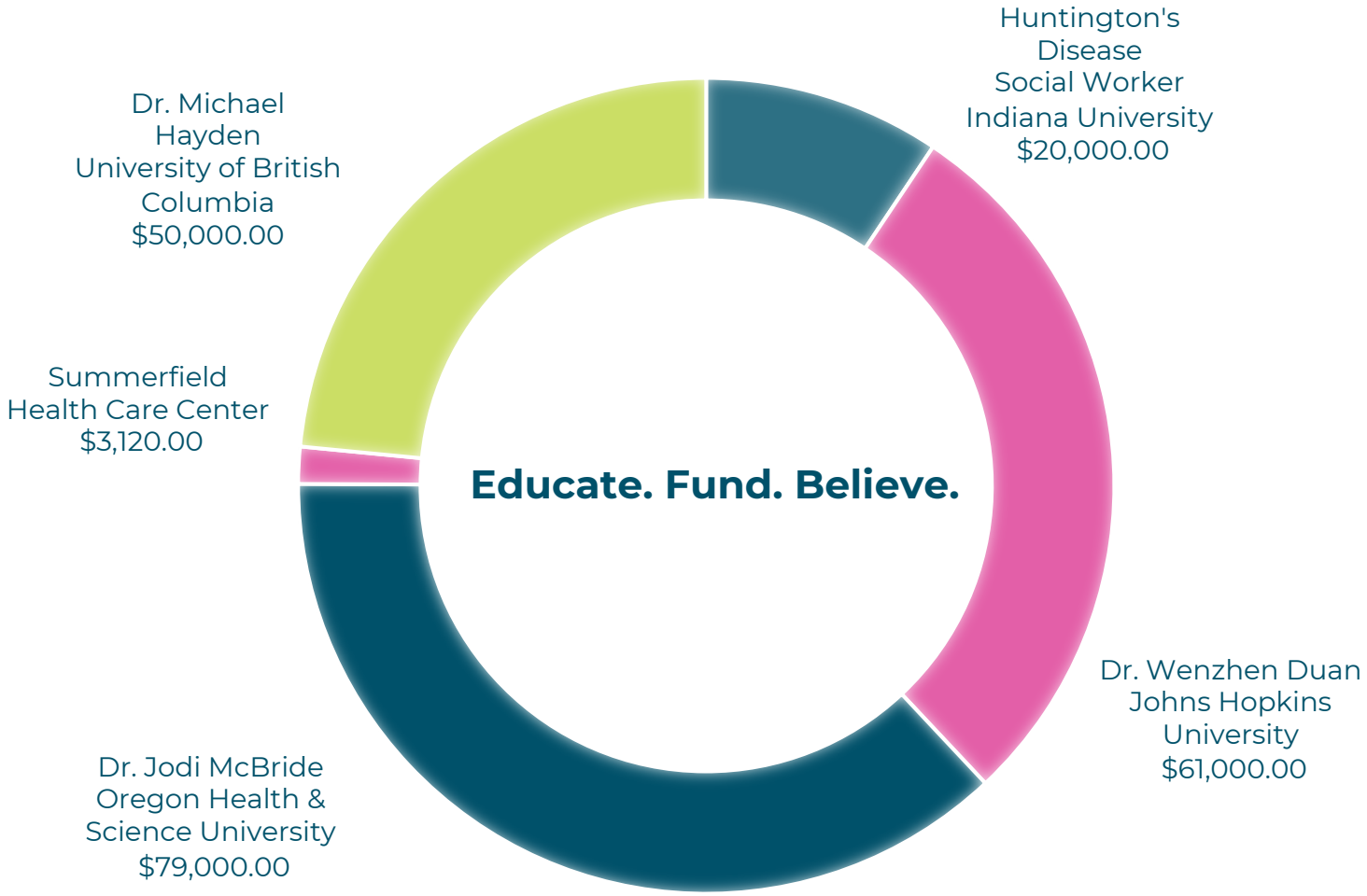
The Foundation monies come from the generous support of donors, mainly friends, family and admirers of Bev and Bob Hartig, who attend and contribute to an annual fundraising event planned and executed by an entirely volunteer committee. The humble beginnings of the Foundation started with the first annual 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. Our Tenth Annual Huntington's Disease Fundraiser, "A Musical Celebration of Giving!" was elegant dinner and entertainment by The Warren Brothers and Tim Nichols, singer-songwriters from Songwriter City, Nashville. In 2020 we went virtual, and felt the love of our generous supporters. In 2021 we were back together to celebrate the success of the foundation that Bev built and to continue to fund research.

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.

2021 Funds Raised and Application



OREGON HEALTH & SCIENCE UNIVERSITY

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Grant Highlights: Dr. Jodi McBride

Dr. Jodi McBride is an Associate Professor of Neuroscience at the Oregon National Primate Research Center and also holds a joint faculty position in the Department of Behavioral Neuroscience at the Oregon Health and Science University in Portland, Oregon.

Research: The McBride Laboratory is working to evaluate therapeutics that slow or prevent the progression of Huntington's Disease. As part of this work, she and her research team developed a new rhesus macaque model of HD. The HD monkey model shows many of the same cardinal symptoms of HD experienced by human patients, including balance and gait alterations, chorea and working memory impairment. She and her team are using brain imaging, including MRI and PET, to characterize HTT-mediated disease pathology in this animal model. Using MRI, they have detected degeneration in specific white matter tracts and gray matter brain regions in this model. Additionally, using PET imaging, they have characterized a widespread reduction in brain metabolism and altered dopamine neurotransmission in the HD macaques. Dr. McBride and her team are currently working to correlate pathology seen via brain imaging to changes in specific proteins found in the cerebral spinal fluid, in order to define a comprehensive set of biomarkers of disease progression in this model.

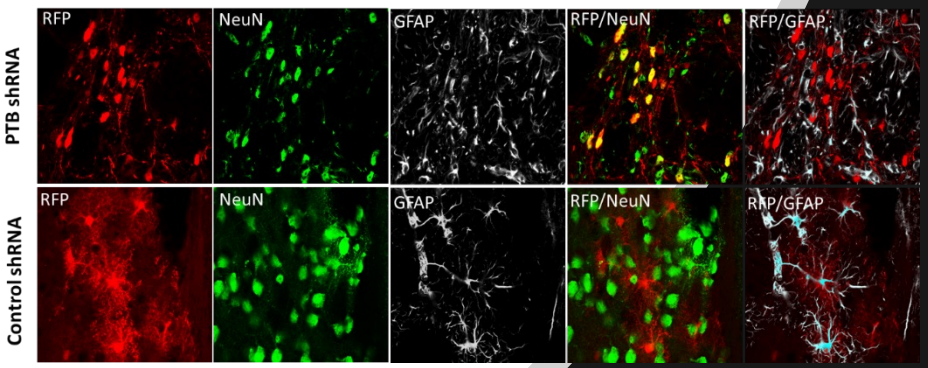
Grant Highlights: Dr. Wenzhen Duan

Synopsis: Recent *in vivo* cell conversion technology provides a promising approach to regenerate functional new neurons in adult brains by directly reprogramming local glial cells into neurons. Using endogenous glial cells for neurodegeneration has emerged as a powerful cell replacement therapy that would avoid transplantation of external cells and therefore minimize potential immune rejection caused by foreign cells. A recent breakthrough in the regenerative medicine reveals that knocking down of polypyrimidine tract binding protein (known as PTB or hnRNP) by shRNA has converted native astrocytes into neurons that rescued Parkinsonia symptoms induced by a neurotoxin induced Parkinsonia mouse model. Astrocytes offer several advantages for *in vivo* reprogramming in the brain. These cells are abundant, proliferate upon injury, and are highly plastic with regards to cell fate.

In this TBHHDF funded project, the Johns Hopkins Translational Neurobiology Research Team led by Dr. Wenzhen Duan aims to determine the capacity of direct converting astrocytes into neurons by knocking down of PTB by shRNA in the striatum of a mouse model of Huntington's disease. The team used an astrocyte-specific promoter Aldh1l1 to drive expression of PTB shRNA in the striatum. The results indicated successful conversion from astrocytes to neurons by PTB shRNA in the striatum

(**Figure 1**). The PTB shRNA-treated HD mice displayed improved motor function on the balance beam, though the survival and body weight of HD mice were not affected by PTB shRNA treatment. The preliminary findings provide insights into further exploring a potential therapeutic approach for HD by focusing on promoting endogenous neuron regeneration, though application of this approach to humans will need to overcome a variety of obstacles.

Figure 1. Successful astrocyte-to-neuron conversion in the striatum by AAV_2-Aldh1l1-PTB shRNA in mice. Representative images of mouse striatum injected with PTB shRNA (with red fluorescent protein reporter, RFP) or control shRNA (RFP reporter).



Grant Highlights: Dr. Michael Hayden

THE UNIVERSITY OF BRITISH COLUMBIA

Neurofilament light chain in biofluids are stabilized in response to mutant huntingtin lowering in the brain of Huntington disease mice

Preclinical studies in rodent models of Huntington disease (HD) have shown that pharmacological lowering of mutant HTT (mHTT) in the brain can prevent regional brain atrophy and improve HD-like behavioural phenotypes. These findings have led to the clinical development of multiple analogous HTT lowering therapeutic approaches for HD. Neurofilament light chain (NfL) is a neuron-specific component of the cytoskeleton that is released into the cerebrospinal fluid (CSF) and blood following neuronal injury. In HD, NfL in CSF and blood increases with disease stage, and its elevated levels are a prognostic biomarker of clinical progression and brain atrophy.

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). This is an annual commitment of the Foundation.

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, grants have been awarded to fund special activities and experiences to its residents, over and above what their budget allows. As our funds have allowed, we have grown to providing specialized recliners as well as wheelchairs that can accommodate their patients and offer the most comfort.

IU HEALTH

summerfield HEALTH CARE CENTER

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Join our Journey to Find a Cure

- Follow us on Facebook
- Follow us on Instagram
- Attend our Annual Gala in April
- Donate Funds
- 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/

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