WHAT IS BATTEN DISEASE? Batten disease is a rare, neurodegenerative, fatal disorder that affects children for which there is no treatment or cure.



HOPE www.willherndon.org

The Will Herndon Research Fund was established in 2009 by Missy and Wayne Herndon, in honor of their son Will, who was diagnosed with juvenile Batten disease at the age of 6. This rare, fatal, genetic disease attacks an otherwise healthy child, beginning with vision loss, declining cognitive and motor skills and seizures. Affected children become wheelchair-bound then bedridden. Batten disease is always fatal, most often by the late teens or early twenties. The Herndons partnered with Beyond Batten Disease Foundation with a goal to SAVE WILL, and the hundreds of other children stricken with juvenile Batten disease.



Beyond Batten Disease Foundation (BBDF) is the world's largest nonprofit organization dedicated to funding research for a treatment and cure for juvenile (CLN3) Batten Disease. Since 2008, over \$16 million has been invested in research by leveraging strategic partnerships. Today there is a treatment in sight. BBDF funded research has discovered a drug that slows the progression of the disease in Batten models. The foundation has launched a campaign to advance the treatment to clinical trials.

HOW DOES THIS HAVE AN IMPACT ON BATTEN DISEASE?

The Will Herndon Research Fund's strategy has been successful by partnering with BBDF and other neurodegenerative disease groups. While developing a treatment for Batten, BBDF funded discoveries have been able to inform and accelerate progress in other neurodegenerative conditions such as Parkinson's and Alzheimer's, additional rare diseases and more common illnesses.



MEDICAL BREAKTHROUGH Treatment now in sight!

• These efforts have resulted in a treatment which slows the progression in Batten disease models.

• This treatment needs to go through an expensive validation and development process in order to enter a clinical trial.

• To complete this project and prepare for clinical trial success we need to raise **\$6 million**



by leveraging partnerships and co-funding resulting in **\$16 million in Research** over the last 8 years

TODAY, TOMORROW, AND FOREVER Here's how:



TODAY: FUND THE TREATMENT

Validate initial academic work to pharmaceutical standards while determining optimal dosing, efficacy and safety information	\$3,000,000
Support critical science at Texas Children's Hospital to inform and complete validation studies	\$1,300,000
TOMORROW: PREPARE FOR CLINICAL TRIAL SUCCESS	
Support development of an international patient registry	\$400,000
Support development of an international patient registry Further critical biomarker studies	\$400,000 \$300,000

Continue to support other rapidly evolving technology in stem cell, gene therapy, and gene skipping	\$500,000
Provide scientists with important Batten specific research tools	\$300,000

HELP US TO #SAVEWILL

WILLHERNDON.ORG





Make a commitment to our capital campaign to be one of the 100 people raising \$1,000 to help us #SaveWill.

Individual

Host a gathering to engage others in our mission or connect us to other donors and foundations.

Corporate

Help us raise funds, spread awareness, and save children battling this fatal neurodegenerative disease.

Missy & Wayne Herndon Founders The Will Herndon Research Fund

Will Herndon

For more information, contact us at: hope@willherndon.org or call 713-557-0219

The Will Herndon Research Fund at Beyond Batten Disease Foundation is a registered 501(c)(3) nonprofit organization. Contributions are deductible to the extent allowed by law. Tax ID# 26-3223661.

