

WHAT IS BATTEN DISEASE?

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



In 2008, Beyond Batten Disease Foundation was formed by Charlotte and Craig Benson in response to their daughter's diagnosis of Batten disease and supported by a community who shared the belief that something had to be done. BBDF was established to eradicate juvenile Batten disease by raising awareness and funds to accelerate research for a treatment or cure. Today we are the world leader in juvenile Batten disease research funding.

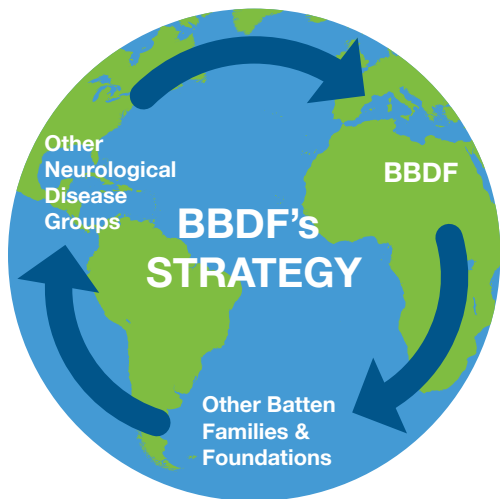
BBDF has matched every donation

DOLLAR
FOR
DOLLAR

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

HOW DOES THIS HAVE AN IMPACT BEYOND BATTEN DISEASE?

BBDF'S strategy has been successful by partnering and receiving co-funding from Batten 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 within 24 months.

BBDF SPENDS

84%

ON PROGRAMS

According to The American Institute of Philanthropy most highly efficient charities spend 75% or more on programs

WHY \$6 MILLION WITHIN 24 MONTHS? Here's the math:



100% of your Be Project donation will go directly to funding this effort.

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

PREPARE FOR CLINICAL TRIAL SUCCESS

Support development of an international patient registry	\$400,000
Further critical biomarker studies	\$300,000
FDA regulatory consultation and clinical trial preparation	\$200,000

CONTINUE TO SUPPORT RESEARCH FOR A CURE

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

TOTAL: \$6,000,000

HOW WILL WE DO IT?

WHO WILL YOU BE?



a donor

make a financial commitment to the campaign or pledge a monthly gift



a connector

host a gathering to engage others in our mission or connect us to other major donors and foundations



a hero

act now to save lives