



## **Charlotte & Gwennyth's Building Blocks Scholarship Fund Guidelines and Background Information**

### **ABOUT THE CHARLOTTE & GWENYTH GRAY FOUNDATION TO CURE BATTEN DISEASE**

The Charlotte and Gwennyth Gray Foundation to Cure Batten Disease (the "Foundation") was founded in 2015 to save the lives of all children impacted by Batten disease by accelerating the research for a cure and providing financial support for patient therapies and equipment critical to their wellbeing and rehabilitation. Since its inception, the Foundation has convened the world's leading researchers in Batten and other neurodegenerative diseases to promote collaboration and idea sharing to lead to a cure. Promising treatment options have been identified and receive funding from the Foundation, including a first of its kind investigational gene transfer clinical trial for children with Batten CLN6 at Nationwide Children's Hospital.

### **ABOUT CHARLOTTE & GWENYTH'S BUILDING BLOCKS SCHOLARSHIP FUND**

In addition to addressing the urgent need for funding research into transformative treatment options to cure Batten disease, founders Gordon and Kristen Gray quickly realized the vital role outpatient therapies also play in improving the quality of life for children with Batten disease and supporting children in reaching their full potential. Sadly, they were also made aware of the extremely high costs associated with many of these critical therapies, equipment, and other benefits, when not, or only partially, covered by insurance or other means. Charlotte and Gwennyth's Building Blocks Scholarship Fund was created to provide financial assistance to children with Batten disease CLN6 to help offset some of these costs associated with supportive rehabilitative and developmental therapies and equipment.

### **SCHOLARSHIP GUIDELINES**

The scholarship is open to children diagnosed with Batten disease CLN6. Funding may be requested to cover costs associated with therapies (occupational, physical, speech, behavioral, etc.), equipment, and other programs critical to the child's wellbeing and development/rehabilitation. Applicants should discuss whether alternate funding sources have been researched and attempted, including insurance, school districts, and others.

All requests are acknowledged via email upon time of receipt to the patient or responsible family member. As funding allows, applications will be reviewed bi-annually and awarded on a rolling basis within the two application windows: January 1 – February 1 and April 1 – April 30. Applicants are encouraged to apply early as a limited number of scholarships are available each period and will be reviewed on a first come, first served basis. Applicants may apply for a scholarship award during each bi-annual cycle, regardless of whether they have received scholarship awards previously; however, the Project Committee will give priority to first-time applicants. Scholarship awards will be distributed in lump sums of up to \$5,000 each.

The Charlotte and Gwennyth Gray Foundation to Cure Batten Disease reserves the right to deviate from these Guidelines on a case-by-case basis when special circumstances arise.

The Foundation's primary contact is Reba Hoeschler. Any questions or correspondence should be directed to her at [rhoeschler@givingback.org](mailto:rhoeschler@givingback.org) or 310-649-5222.