



# Proclamation

**WHEREAS**, approximately 14,000 people around the world are living with Batten Disease and 2 to 4 in every 100,000 births is diagnosed with one of the 13 known forms of Batten Disease, it is still is relatively unknown to the public; and

**WHEREAS**, Batten Disease is a heritable disorder, requiring both parents to carry the defective gene, there are significantly more (known and unknown) unaffected siblings who are carriers. Batten Disease essentially affects all populations equally, regardless of race, ethnicity, or gender; and

**WHEREAS**, symptoms of this fatal disease typically include vision loss leading to blindness, the inability to walk, talk, or swallow, often requiring surgical insertion of a g-tube for nourishment, personality and behavioral changes, frequent seizures, intellectual decline, disruption and loss of speech, dementia, and other debilitating ailments; and

**WHEREAS**, the disorder currently has few treatment options available and clinical trials and research endeavors have been significantly delayed or stopped altogether due to the global pandemic and current landscape of the biotech industry; and

**WHEREAS**, the Batten Disease Support, Research, & Advocacy Foundation (BDSRA) and Batten families are always advocating for and connecting the unconnected, leading the way through innovative and inventive approaches to scientific advancement and improved patient care, revamping systems to accelerate the path from discovery to treatment; and

**WHEREAS**, much remains to be done in raising public awareness of Batten Disease to help promote early diagnosis, carrier testing, proper management and treatment, and support for as research.

**NOW, THEREFORE**, I, Casey Hancock, Mayor, do hereby proclaim June 9, 2024 as

***“BATTEN DISEASE AWARENESS DAY”***

in the City of Hartsville in recognition of this important initiative.

**IN WITNESS THEREOF**, I hereunto set my hand and cause to be affixed the Seal of the City of Hartsville.

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Casey Hancock, Mayor

ATTEST: \_\_\_\_\_  
Andrea D. Crenshaw, CMC, City Clerk