**PROCLAMATION Declaring June 9, 2023 as Batten Disease Awareness Day**

WHEREAS, BDSRA (Batten Disease Support, Research, & Advocacy) Foundation is observing June 9, 2023, as Batten Disease Awareness Day to educate the public globally about this ultra rare genetic disorder; and

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; and

WHEREAS, 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, BDSRA leads the collective effort, along with many Batten family foundations to promote and financially sponsor world-class medical research aimed at finding effective treatments, with the ultimate goal of finding a cure; and

WHEREAS, 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, BDSRA provides a wide variety of patient, sibling, family, and caregiver support through its information resources, Annual Family Conference, as well as various virtual activities and program offerings; 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 research;

Now Therefore, I, \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ **(Name)**,\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ **(Title & City/State/Other, such as** “**Mayor of the City of TBD or Official of the State of TBD, etc.**”**)**, in recognition of this important initiative, do hereby proclaim the June 9, 2023 as “Batten Disease Awareness Day.”

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