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1 HOUSE RESOLUTION

2 WHEREAS, Batten disease is progressive and devastating
3 neurodegenerative childhood disease, with symptoms including
4 developmental delays, dementia, cognitive decline, vision
5 loss, seizures, and loss of motor skills, ultimately resulting
6 in premature death; and

7 WHEREAS, Batten disease is a rare genetic disease wherein
8 most of those affected inherit a recessive gene from each
9 asymptomatic parent; the disease inhibits the production of
10 essential levels of cellular enzymes, leading to the
11 accumulation of metabolic waste in brain cells, causing the
12 cells to lose function over time and die; and

13 WHEREAS, At least 14 different variants of Batten disease
14 have been identified, and these variants are most often
15 referred to as CLN1 through CLN14; and

16 WHEREAS, Due to its rarity, sufferers of Batten disease
17 often experience significant delays in being properly
18 diagnosed, with an accurate diagnosis sometimes taking years;
19 and

20 WHEREAS, Only a single variant of Batten disease, CLN2,
21 currently has an FDA-approved therapeutic option, which is an

1 enzyme replacement therapy intended to delay disease
2 progression; currently, numerous variants of the disease have
3 genetic-based therapies either in development or are being
4 administered to patients on an experimental basis; and

5 WHEREAS, The burdens of rare childhood diseases, and
6 Batten disease in particular, are significant, requiring
7 extensive utilization of medical, financial, caretaking, and
8 emotional resources on affected patients, their families, and
9 their communities; and

10 WHEREAS, Due to many rare diseases being progressive,
11 including Batten disease, early diagnosis provides the best
12 chance of a successful treatment or therapy; and

13 WHEREAS, Illinois is home to Rush University Medical
14 Center, an institution recognized as one of only nine Batten
15 Disease Centers of Excellence in the United States in 2024;
16 and

17 WHEREAS, Dr. Elizabeth Berry-Kravis, a pediatric
18 neurologist and professor of Pediatrics, Neurological
19 Sciences, and Biochemistry at Rush University Medical Center,
20 is also the clinic director of the Rush University Medical
21 Center Batten Disease Center, where she works tirelessly on
22 cutting-edge medicine and science to advance novel genetic

1 treatments for children afflicted with rare diseases,
2 including Batten disease; and

3 WHEREAS, Charlie Sims, an energetic and loving
4 eight-year-old boy from Naperville, was diagnosed with Batten
5 disease at age six and is living with the CLN1 variant; and

6 WHEREAS, Charlie Sims has undergone first-in-the-world
7 experimental genetic treatments for his CLN1 Batten disease at
8 Rush University Medical Center, under the supervision and care
9 of Dr. Elizabeth Berry-Kravis, in an attempt to slow the
10 progression of his disease and to establish valuable research
11 data so that other children in the future may also receive
12 novel and life-extending genetic therapies for Batten disease;
13 and

14 WHEREAS, Following his diagnosis, Charlie Sims' family and
15 friends created Team Charlie in 2023, establishing an
16 organization committed to bringing awareness of Batten disease
17 and other rare pediatric diseases to the public, engaging in
18 philanthropy for the benefit of Batten disease and all rare
19 disease families, and assisting in the advancement of novel
20 genetic treatments for all children afflicted by rare
21 pediatric diseases, including Batten disease; therefore, be it

22 RESOLVED, BY THE HOUSE OF REPRESENTATIVES OF THE ONE

1 HUNDRED FOURTH GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, that
2 we declare June 9, 2025 as Batten Disease Awareness Day in the
3 State of Illinois in order to recognize and bring awareness to
4 the rare disease population, including those living with
5 Batten disease in Illinois, and to recognize the heroic and
6 tireless efforts of Dr. Elizabeth Berry-Kravis and her
7 esteemed colleagues at Rush University Medical Center as they
8 attempt to save children afflicted with Batten disease by
9 searching for treatments and a cure; and be it further

10 RESOLVED, That we commend Charlie Sims for advancing the
11 scientific development of treatments for Batten disease for
12 children everywhere, his family and friends for valiantly
13 facing the difficulties of Batten disease, and the ongoing
14 efforts of Team Charlie in their continued work of finding
15 hope, giving love, and being good.