



HR0344

LRB104 13625 LAW 26254 r

1 HOUSE RESOLUTION

2 WHEREAS, Giant Axonal Neuropathy (GAN) is a rare,
3 terminal, inherited neurodegenerative disorder that affects
4 both the central and peripheral nervous systems, leading to
5 progressive muscle weakness, impaired coordination, and other
6 severe symptoms; and

7 WHEREAS, GAN primarily manifests in early childhood and
8 progressively worsens over time, significantly impacting
9 mobility, motor function, and overall quality of life; and

10 WHEREAS, GAN is caused by mutations in the GAN gene, which
11 disrupts the proper function of nerve cells, ultimately
12 leading to the deterioration of the nervous system; and

13 WHEREAS, GAN currently has no cure, and treatment options
14 remain limited to symptom management and supportive care; and

15 WHEREAS, Approximately 75 known people have been diagnosed
16 with GAN worldwide, including Ethan Tkalec of Riverside; and

17 WHEREAS, Increased awareness, research funding, and early
18 diagnosis are critical to improving outcomes for individuals
19 affected by GAN and their families; and

1 WHEREAS, Advocacy organizations, medical researchers, and
2 healthcare providers are working diligently to advance
3 scientific understanding and explore potential therapies for
4 GAN; and

5 WHEREAS, It is imperative that the State of Illinois
6 recognizes the challenges faced by individuals living with GAN
7 and their caregivers and supports initiatives to enhance
8 research, education, and awareness of this rare disease;
9 therefore, be it

10 RESOLVED, BY THE HOUSE OF REPRESENTATIVES OF THE ONE
11 HUNDRED FOURTH GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, that
12 we declare May 28, 2025 as Giant Axonal Neuropathy Awareness
13 Day in the State of Illinois to raise public awareness of Giant
14 Axonal Neuropathy (GAN), encourage research efforts, and
15 support affected individuals and their families; and be it
16 further

17 RESOLVED, That we encourage the collaboration of public
18 and private entities, healthcare professionals, and research
19 institutions to advance medical research and treatment options
20 for GAN; and be it further

21 RESOLVED, That a suitable copy of this resolution be
22 presented to organizations dedicated to GAN awareness and

1 advocacy as an expression of the State of Illinois' commitment
2 to improving the lives of those affected by this condition.