Congressman Josh Gottheimer Champions Rare Diseases by Sponsoring Bill - H.Res.1039 - for Charcot-Marie-Tooth Disease

Bipartisan resolution introduced to the House on International Rare Disease Day is a significant step to advocate for much needed funding for CMT research.

From Left: Congressman Josh Gottheimer (NJ-5), Congressman Don Bacon (NE-2)

SCARSDALE, NEW YORK, USA, April 10, 2024 /EINPresswire.com/ -- On February 29, 2024, International Rare Disease Day, U.S. Congressman Josh Gottheimer (NJ-5), a dedicated member of the Rare Disease Caucus, took a significant step to advocate for rare disease research by leading a bipartisan resolution with Congressman Don Bacon, H.Res.1039, entitled, "Recognizing the significance of Charcot-Marie-Tooth disease and the need for robust funding of the National Institute of Neurological Disorders and Stroke at the National Institutes of Health." The resolution underscores the urgency of addressing the challenges of individuals diagnosed with Charcot-Marie-Tooth disease (CMT) and the need for robust research funding.

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>
> *U.S. Congressman Josh Gottheimer (NJ-5)*

“We must do more to provide hope and support to the families who struggle every day managing Charcot-Marie-Tooth disease and provide opportunities for our cutting-edge research institutions to finally get us desperately needed cures,” said Congressman Josh Gottheimer (NJ-5). “By collaborating with experts and advocates, we can give everyone struggling with Charcot-Marie-Tooth Disease hope. Even with all of the challenges we are facing, I remain optimistic and hopeful.”

The initiative behind resolution - H.Res.1039 - was led by Alexander Zaken, a Junior Board

member of Hunters CMT4B3 Research Foundation and a high school junior who served as a summer intern for Congressman Gottheimer. Zaken's dedication reflects the grassroots efforts of young individuals committed to making a difference in the fight against rare diseases.

Hunter Schultz, CMT4B3 Patient, Age 6

Charcot-Marie-Tooth disease (CMT) stands as the most prevalent inherited peripheral neuromuscular disorder, affecting an estimated one in every 2,500 individuals, comprising approximately 126,000 Americans and over 2.6 million people globally. CMT causes damage to the peripheral nerves, which transmit information and signals from the brain and spinal cord to the rest of the body, and can also directly affect the nerves that control the muscles.

CMT's progressive nature leads to the degeneration of nerve cells, resulting in debilitating symptoms that impair normal motor and sensory functions, often necessitating multiple surgeries and causing significant disabilities. This disease strikes people of all ages, genders, races, or ethnicities, impacting individuals across diverse demographics.

Caused by mutations within specific genes impacting nerve signal transmission, CMT presents over 100 recognized gene mutations and various sub-types. CMT4B3 represents an ultra-rare form of CMT, also known as Childhood CMT, and is characterized by severe symptoms, including loss of mobility, limb deformities, loss of sight and/or hearing, as well as a shortened lifespan.

Regrettably, despite its profound impact, federal funding for CMT research witnessed a decrease in 2022 compared to 2021. This concerning trend underscores the critical need for increased investment in research to unlock potential treatments and cures for CMT and related neuromuscular disorders. Congressman Gottheimer's sponsorship of the resolution - H.Res.1039 - signifies a beacon of hope for individuals grappling with CMT and their families, offering the promise of improved outcomes and enhanced quality of life.

Hunters CMT4B3 Research Foundation proudly supports H.Res.1039 and extends its sincere

appreciation to Congressman Gottheimer for his unwavering commitment to advancing legislation aimed at addressing the needs of individuals with rare diseases.

LEARN MORE: visit www.cmt4b3research.org and follow @hunt2cureCMT on X, instagram, facebook
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