

DYSAUTONOMIA INTERNATIONAL



AWARENESS



ADVOCACY



ADVANCEMENT

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October 17, 2023

Hon. Representative Brian Higgins
2459 Rayburn House Office Building
Washington, D.C. 20510

Hon. Representative Brian Fitzpatrick
271 Cannon House Office Building
Washington, D.C. 20510

Dear Representatives Higgins and Fitzpatrick:

On behalf of Dysautonomia International and the patient community we serve, I am writing to thank you for the introduction of the SSI Savings Penalty Elimination Act (H.R. 5408).

Dysautonomia International is a U.S. based non-profit patient advocacy organization with a global scope, representing individuals diagnosed with autonomic nervous system disorders, which are collectively referred to as “dysautonomia.” The autonomic nervous system controls the automatic functions of the body that we do not consciously think about, such as heart rate, blood pressure, digestion, dilation and constriction of the pupils, kidney function, the immune system and temperature control.

Dysautonomia is not rare, affecting over 70 million people worldwide before COVID-19. Recent research suggests that millions of Americans are developing dysautonomia, most commonly presenting as postural orthostatic tachycardia syndrome (POTS), after COVID-19 infections.¹ Pre-pandemic, POTS was estimated to impact approximately three million Americans, but with ongoing COVID-19 infections, millions more are developing POTS. The most common age of POTS symptom onset is age 14, and approximately 90% of people with POTS are women and girls.

POTS is extremely debilitating with impairment in quality-of-life and functioning comparable to individuals with heart failure and chronic obstructive pulmonary disease. Approximately half of all patients postpone or delay enrollment in college due to their POTS symptoms, and 23% who do attend college have to drop out due to their symptoms.² Half of adult POTS patients are unable to work, and of those who can, 67% would work greater hours if not for their illness. According to a recent community survey, 19% of POTS patients report having had to rely on government benefits to provide for themselves and their families.³

¹ <https://www.frontiersin.org/articles/10.3389/fneur.2022.1012668/full>

² Stiles LE, Bourne K, Ng J, Shaw BH, Green EA, Shibao CA, Okamoto LE, Garland EM, Gamboa A, Peltier A, Diedrich A, Biaggioni I, Robertson D, Raj SR. Educational & Social Impacts of Postural Tachycardia Syndrome: Insights from a Cross-Sectional Community-Based Survey. *Clin Auton Res* (2017)27:332.

³ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9156448>

The Supplemental Security Income (SSI) program was established to be a safety net for disabled Americans, but the program has not been updated in nearly 40 years. Currently SSI limits beneficiary assets to \$2,000 for individuals and \$3,000 for married couples with the average current monthly benefit at \$585. For reference, as of January 2023, the average rent in the U.S. is \$1,325 per month.⁴ With financial experts recommending individuals keep at least three to six months of expenses in savings, disabled individuals relying on SSI are in a precarious financial state. This is particularly alarming for people with POTS who often experience medical emergencies resulting in even more monthly expenses.

Today, SSI is a program that traps disabled Americans in poverty by discouraging work, savings and even marriage. Dysautonomia International strongly supports the SSI Savings Penalty Elimination Act, which would raise the asset limitations to \$10,000 for individuals and \$20,000 for married couples, and index them to inflation moving forward. This legislation will have a significant impact on not only beneficiaries' economic well-being, but their quality of life.

Thank you for your dedication and work on this important issue for patients living with POTS and other forms of dysautonomia, and all disabled Americans who rely on SSI to support themselves and their families. We look forward to supporting your efforts as you move forward with this important legislation.

Sincerely,

A handwritten signature in black ink, appearing to read "L Stiles".

Lauren Stiles, JD

President & CEO, Dysautonomia International

⁴ <https://worldpopulationreview.com/state-rankings/average-rent-by-state>