



AWARENESS



ADVOCACY



ADVANCEMENT

House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Hearing Title: FY2024 Public Witness
Written Testimony of: Lauren Stiles, JD, President, Dysautonomia International
Submitted: March 22, 2023
Subject: Research Funding for Postural Orthostatic Tachycardia Syndrome (POTS) to Advance Treatments and Cures

Thank you for the opportunity to submit this testimony on behalf of Dysautonomia International and millions of Americans living with debilitating autonomic nervous system disorders, collectively known as dysautonomia. Dysautonomia International is a New York based 501(c)(3) non-profit with a global scope. We have active support groups in all 50 states and 60 other countries. Our Medical Advisory Board members include leading autonomic neurology experts from Harvard, Stanford, Mayo Clinic, Vanderbilt, UT Southwestern, Johns Hopkins, and other respected medical centers. **We are seeking bipartisan support for FY2024 appropriations language directing the National Institutes of Health (NIH) to allocate \$50M from the NIH's existing budget to fund a new multi-institute Notice of Special Interest, to spur new research on postural orthostatic tachycardia syndrome (POTS) in accordance with previous direction from Congress to stimulate the field of POTS research.**

What is POTS?

Postural orthostatic tachycardia syndrome (POTS) is a debilitating autonomic nervous system disorder that causes symptoms such as lightheadedness, a racing heart beat upon standing, fainting, shortness of breath, chest pain, cognitive impairment, difficulty standing and walking, exercise intolerance, gastrointestinal dysmotility, temperature dysregulation, pupil dysfunction, and much more. All of these symptoms are the consequence of the autonomic nerves not working properly in people with POTS.

POTS impacted an estimated 3 million Americans prior to the COVID-19 pandemic, making it more common than well-known diseases like multiple sclerosis and Parkinson's, which each impact an estimated 1 million Americans. The most common age of onset of POTS is age 14, and >90% of patients are females between the ages of 12 and 50. POTS most often begins after a viral infection, but can also be initiated by a concussion, pregnancy, surgery or unknown causes. Recent research suggests the POTS population has at least doubled to 6M Americans as a result of the COVID-19 pandemic.

POTS is so debilitating that half of 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 POTS symptoms.¹ Half of adult POTS patients are unable to work, and of the patients who can work, 68% would work more hours if not for their POTS symptoms.² 19% of US adult POTS patients rely on government disability benefits as a result of their disabling POTS symptoms.³ People with POTS need more effective treatments, so they can attend school, work, raise their families, and get back to living their lives.

Due to a lack of physician training on POTS and related autonomic disorders, there are fewer than 100 doctors in the US who specialize in POTS. As a result, POTS patients endure an average five-year diagnostic delay, and see an average of seven doctors prior to being diagnosed with POTS. About half of POTS patients have to travel more than 100 miles from home for POTS specialty care. Many Americans cannot afford to get seven second opinions and cannot afford to travel far from home for medical care, so there are likely many people suffering with undiagnosed POTS without any treatment.

¹ 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.

² <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9156448>

There is no cure for POTS and FDA-approved treatment options specific to the disorder are non-existent. POTS is very debilitating despite optimized care with current treatment options. Mayo Clinic researchers have found that the disability seen in young people with POTS is similar to the disability seen in older adults with COPD or congestive heart failure.

Our Appropriations Request

Since 2017, Congress has made six appeals to the NIH to invest more in POTS research.³ In the Fiscal Year 2019 bill, Congress directed the National Heart, Lung, and Blood Institute and National Institute of Neurological Disorders and Stroke to work with stakeholders to prepare a report for Congress on the most pressing POTS research priorities and the estimated cost of implementing these research priorities.⁴ An NIH symposium⁵ was held in July 2019 and produced a two-part report outlining what was needed to advance research on POTS.^{6,7} The report recommended several major priorities for POTS research intended to deliver more effective treatments and improved clinical care, and recommended the NIH allocate a minimum of \$10,000,000 annually for five years to fulfill these priorities.¹⁰ To date, Congress and NIH have not acted on this recommendation, yet millions of Americans with POTS continue to suffer with no FDA-approved treatment options and substandard clinical care.

³ See, Congressional Legislative History of POTS at <https://www.dysautonomiainternational.org/pdf/POTSLegHistory.pdf>

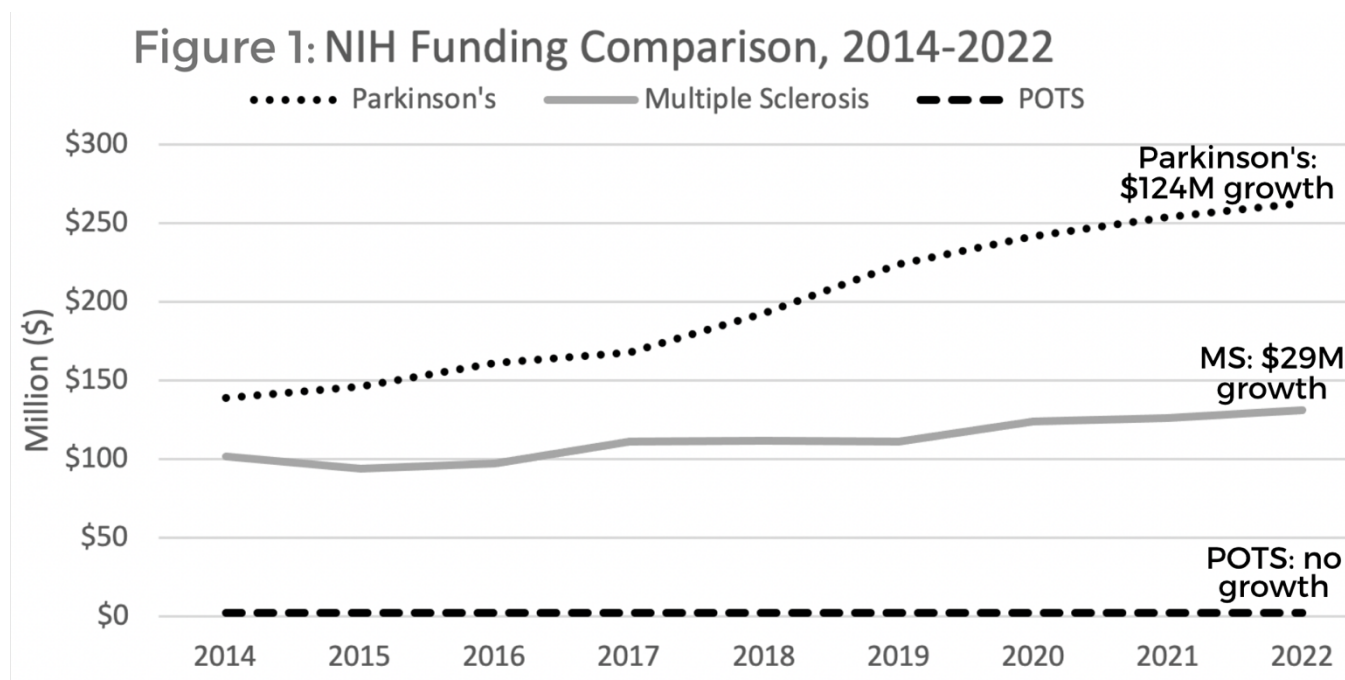
⁴ <https://www.congress.gov/115/crpt/srpt289/CRPT-115srpt289.pdf>

⁵ <https://www.nhlbi.nih.gov/events/2019/postural-orthostatic-tachycardia-syndrome-pots-state-science-clinical-care-and-research>

⁶ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8455420>

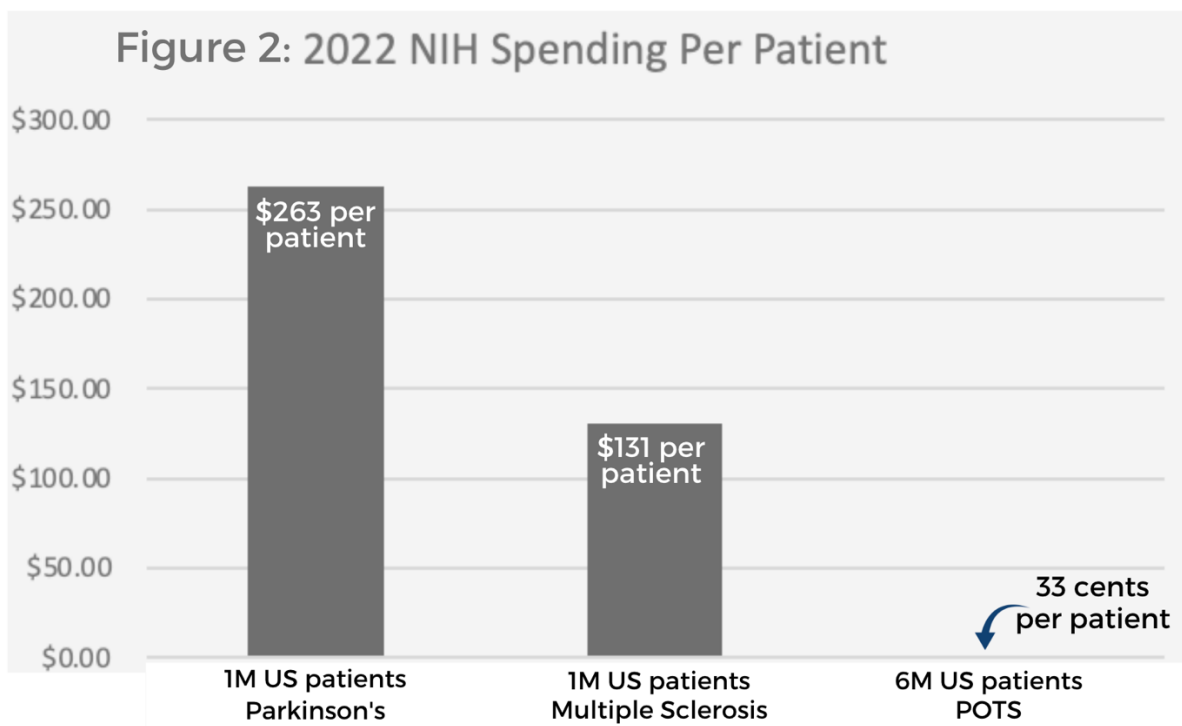
⁷ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8455430>

Despite eight years of increases in the NIH budget, and six years of Congress urging NIH to invest more in POTS research, NIH investment in POTS research has remained stagnant at less than \$2M annually, while other neurological disorders have seen substantial increases in NIH research funding (Figure 1).⁸



NIH is investing about 33 cents per patient in POTS research (Figure 2).⁸ For comparison, NIH invests \$131 per multiple sclerosis patient each year and \$263 per Parkinson’s patient each year, which has led to major advances in research and improvements in clinical care for Parkinson’s and multiple sclerosis patients. NIH’s investment in research in these diseases has also led to the establishment of clinics with substantial expertise in Parkinson’s and multiple sclerosis at nearly every academic medical center and large hospital system in the US, reducing diagnostic delays and improving access to high quality care for these patients. The 6 million Americans who have had their lives ruined by POTS, who are enduring years of diagnostic delay, suffering with no effective treatments, who have to wait years and travel hundreds of miles to see a POTS specialist, deserve that NIH research investment too.

⁸ Data Sources: NIH Research, Condition, and Disease Categorization (<https://report.nih.gov/funding/categorical-spending#>); NIH RePORTER Database (<https://reporter.nih.gov>)



Given the large underserved POTS population before the pandemic, and the growing numbers of post-COVID POTS patients, experts in our research field recommend that Congress fully commit to a \$50,000,000 investment in POTS research at the NIH in FY2024. These funds are warranted and desperately needed to identify more effective treatment options and potentially a cure.

Thank you for your time and consideration. Our organization is available to answer any questions you may have. I can be contacted at lstyles@dysautonomiainternational.org or 631-202-1720.