



Advancing Care for POTS: A Silent Crisis for Women and Children

There are **over 20 million Americans living with various autonomic nervous system disorders**, collectively known as dysautonomia. The autonomic nervous system controls our heart rate, blood pressure, digestion, pupil function, temperature control, immune function, and all of the other “involuntary” functions of the body – the things our body is supposed to do for us automatically to maintain good health.

An estimated **six million Americans are suffering** from postural orthostatic tachycardia syndrome (POTS), a common form of dysautonomia, and the number of Americans impacted by POTS is growing. In fact, researchers have found that **67% of Long COVID patients are developing POTS and other forms of post-viral dysautonomia**. Notably, **over 90% of POTS patients are female**, with the most common age of **onset at the young age of 14**. This underscores the necessity to treat POTS as a priority women's health issue.

Additionally, the debilitating nature of POTS cannot be emphasized enough. Research demonstrates that the disability seen in POTS is **akin to the disability seen in congestive heart failure or COPD**. A recent study highlighted the profound socio-economic repercussions of this condition, revealing that many patients with POTS **face challenges in completing their education, attending college, or even entering the workforce**. As a result of this significant disability, many people with POTS are **forced to rely on government benefits for subsistence**.

Despite the high prevalence of POTS, it may be **one of the most misdiagnosed conditions of our time**. POTS patients take on average **five years to get accurately diagnosed**, and patients have to see an average of seven physicians before their POTS is recognized and diagnosed, due to a lack of awareness within the medical profession. In fact, **21 percent of POTS patients have seen more than 10 physicians** before they were accurately diagnosed with POTS.

Once diagnosed, patients have a hard time accessing care to treat POTS. POTS is most often and most effectively treated by autonomic disorders specialists. However, there is a severe autonomic disorder specialist shortage in the country, partly attributed to the lack of fellowship training sites for autonomic disorders. There are **only six autonomic disorders fellowship sites in the United States**, including one housed at the National Institute of Neurologic Disorders and Stroke (NINDS), that are accredited by the United Council for Neurologic Subspecialties. There are **fewer than 75 doctors in the country** who hold a board certification in autonomic disorders – trying to serve a population of over 20 million Americans with POTS and other dysautonomias.

A glaring example is **the Military Health System**, which serves our nation's service members and their

families, over 10 million Americans. It **has only one autonomic disorders specialist** at Walter Reed National Military Medical Center. Unfortunately, we are told this clinic is bursting at the seams with POTS and other autonomic disorders patients. As a result, **many of our nation's servicemembers and their families in need of this expertise are left unable to access specialty care.**

Similar problems face the general population, where the **average wait time to see an autonomic disorders specialist is nine to twelve months**, and many waitlists are so overwhelmed that clinics are not accepting new patients. But, this is in states that actually have specialists. **28 states** – Alaska, Arizona, Arkansas, Colorado, Connecticut, Delaware, Hawaii, Idaho, Indiana, Kentucky, Louisiana, Maine, Michigan, Montana, Nevada, New Hampshire, New Jersey, New Mexico, North Carolina, North Dakota, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Dakota, Vermont, Wisconsin and Wyoming, as well as Puerto Rico -- **do not have a board-certified autonomic disorders specialist** especially for those who can least afford it. **Over 50 percent of POTS patients travel more than 100 miles from home** to receive POTS specialty care and 20 percent travel more than 500 miles from home, with patients in **rural areas particularly underserved.**

Finally, while clinical care is difficult to find, treatment options are even more elusive. There is no cure for POTS and no FDA-approved treatment for POTS. While some POTS patients can mitigate their symptoms with the use of non-pharmacological approaches and off-label use of medications, for most patients the condition is very debilitating despite optimized care with current treatment approaches.

This combination of diagnostic difficulties and lack of an adequate provider network to treat the growing POTS and dysautonomia patient population, **emphasizes the critical need for investments in the clinical and research workforce**, so patients have access to appropriate medical treatment and the best chance at a better quality of life.

Potential Solutions:

- Establish clinical education and advocacy programs on POTS and other forms of dysautonomia to increase awareness and knowledge to reduce diagnostic delays and increase access to care for patients.
- Provide scholarships or student loan repayment awards to individuals who commit to engage in clinical practice or research related to POTS and other forms of dysautonomia for a period of obligated service as physicians.
- Develop curriculums on POTS and other forms of dysautonomia in coordination with institutes of higher education that have an accredited medical school to encourage medical students to enter the autonomic medicine field.