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To:
Compassionate Allowances Program Office
Social Security Administration

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Proposed Condition Name

Dysautonomia – Postural Orthostatic Tachycardia Syndrome (POTS)

Alternate Names

- Postural Orthostatic Tachycardia Syndrome
- Chronic Orthostatic Intolerance
- Hyperadrenergic POTS (subtype)
- Neuropathic POTS (subtype)
- Dysautonomia (general autonomic nervous system dysfunction)

Summary

Postural Orthostatic Tachycardia Syndrome (POTS) is a disorder of the autonomic nervous system characterized by an excessive heart rate increase upon standing, in the absence of orthostatic hypotension, accompanied by symptoms of cerebral hypoperfusion and sympathetic overactivity [1,2]. POTS is one of several forms of **dysautonomia**, a broader category of disorders in which the autonomic nervous system (ANS) fails to regulate key functions such as heart rate, blood pressure, temperature regulation, gastrointestinal motility, and sweating [3].

POTS can be idiopathic or secondary to autoimmune disease, post-viral syndromes, neuropathies, or other systemic illnesses [4,5]. In autoimmune or post-infectious cases, immune-mediated damage to autonomic nerve fibers or receptors is suspected [5]. The condition is chronic, often disabling, and significantly limits daily functioning.

Description of Condition

POTS is defined by a sustained **heart rate increase of ≥30 beats per minute (≥40 bpm in adolescents) within 10 minutes of standing or head-up tilt**, without a drop in blood pressure meeting orthostatic hypotension criteria [1].

Symptoms typically include lightheadedness, palpitations, tremulousness, visual blurring, fatigue, exercise intolerance, and cognitive impairment ("brain fog") upon standing [2,4]. Many patients also have comorbid gastrointestinal dysmotility, chronic pain, small fiber neuropathy, and other forms of dysautonomia [3,5].

Diagnostic Testing

Orthostatic Vital Signs:

- Measurement of HR and BP after supine rest, and during 10 minutes of standing [1].

Tilt Table Testing (Gold Standard):

- Objective demonstration of HR increase ≥30 bpm within 10 minutes of head-up tilt, without significant BP drop [2].

Autonomic Function Testing:

- Quantitative sudomotor axon reflex test (QSART)
- Heart rate variability
- Valsalva maneuver
- Plasma norepinephrine levels (hyperadrenergic subtype) [3,5]

Laboratory Screening for Secondary Causes:

- ANA, thyroid function, serum B12, autoimmune panels [4]

Physical Findings

- Excessive postural tachycardia on tilt or standing
- Cool, mottled extremities
- Acrocyanosis
- Tremulousness upon standing
- Hypohidrosis or hyperhidrosis (subtype dependent)
- Generalized fatigue and orthostatic intolerance during exam [2,4]

ICD-10 Codes

- **G90.9** — Disorder of autonomic nervous system, unspecified
- **G90.3** — Multi-system degeneration of autonomic nervous system
- **I95.1** — Orthostatic hypotension (if present with other dysautonomia features)

Onset

POTS often begins **abruptly following a viral illness, immunization, surgery, or pregnancy**, though gradual onset cases occur [3,5]. The condition is most common in women aged 15–50 but can occur in all ages and sexes [1,4].

Course / Progression

- **Early Stage:** Episodic lightheadedness, palpitations, fatigue, especially after standing [2].
- **Progressive Stage:** Symptoms present with minimal upright activity, causing reduced mobility and work capacity [4].
- **Chronic Stage:** Persistent autonomic instability, frequent presyncope, exercise intolerance, and severe quality-of-life impact [3,5].
- Some patients experience partial remission; many have persistent symptoms for years [5,6].

Treatment

Non-Pharmacologic:

- Increased fluid and salt intake
- Compression garments
- Physical reconditioning (recumbent exercise programs) [3]

Pharmacologic:

- Fludrocortisone for volume expansion
- Midodrine for vasoconstriction
- Beta-blockers or ivabradine for heart rate control

- Pyridostigmine for autonomic modulation [1,4]

Rationale for Compassionate Allowance

- **Objective diagnostic criteria** with gold-standard testing [1,2].
- **Severe functional limitation**—patients often unable to stand or walk for normal daily activities [3,4].
- **Chronic disability**—many require work accommodations or complete disability benefits [5,6].
- **High economic and quality-of-life burden** comparable to congestive heart failure and COPD [6].

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