10 Facts Doctors Should Know About POTS

1. POTS is a disorder of the autonomic nervous system. Approximately 50% of POTS patients have sudomotor neuropathy, and 20% have cardiac dropout on MIBG scans, which may be due to cardiac autonomic neuropathy.(1-4)

2. POTS is not rare. POTS impacts an estimated 1,000,000 to 3,000,000 Americans;(5-10, 30) 80-85% female, most commonly women of childbearing age.(7,8,11,12) POTS occurs around the world, but estimates are not available for other countries.

3. Research indicates that POTS may be an autoimmune condition. Antibodies targeting alpha1, beta1, and beta2 adrenergic receptors, muscarinic3 receptors,(12) g-AchR receptors,(3,13) and numerous cardiac lipid raft proteins(14) have been identified in POTS patients. Preliminary studies are underway exploring the use of IVIG in POTS.(15)

4. POTS or POTS like symptoms can appear secondary to other autoimmune conditions, such as Sjogren's syndrome, lupus, antiphospholipid syndrome, celiac disease, ankylosing spondylitis, sarcoidosis, Lambert Eaton myasthenic syndrome, myasthenia gravis, and mulitple sclerosis.(9,12,16-21)

5. POTS can cause symptoms throughout the body including tachycardia, palpitations, chest pains, lightheadedness, fainting, nausea, fatigue, gastroparesis or rapid gastric emptying, migraines, blood pooling in the extremities, Raynaud's, tremulousness, sleep abnormalities, cognitive impairments and more.(9,12,22)

6. The majority of POTS patients are hypovolemic despite adequate hydration. Standard blood and urine tests may not detect this hypovolemia, as the patient is typically deficient in plasma and RBCs. Blood volume analysis with a radio-tracer can be used to evaluate a POTS patient for hypovolemia.(23)

7. POTS is often misdiagnosed. The average time to diagnosis is 5 years and 11 months.(24) 85% of POTS patients are told it's "all in their head" or given similar psychiatric labels prior to receiving a POTS diagnosis,(24) but research shows that POTS patients are no more likely to have psychiatric disorders than healthy controls.(25,26)

8. Most teens do not "outgrow" POTS. A 10 year retrospective study of Mayo Clinic's pediatric POTS patients found that 60% had improved symptoms but still had POTS, 20% had recovered, and 20% had worsened or stayed the same since the time of diagnosis.(27)

9. The severity of POTS symptoms varies. Approximately 25% of POTS patients are so disabled that they cannot work or attend school.(9) The disability seen in POTS has been compared to COPD and congestive heart failure.(9)

10. Patients with suspected POTS should be referred for autonomic function testing including tilt with heart rate variability, Valsalva and QSART. In some cases, supine/upright catecholamine testing, blood volume analysis with a radio tracer, and skin biopsies to screen for sudomotor and sensory small fiber neuropathy may be used. An investigation should be made to search for underlying or contributing conditions such as autoimmunity, Ehlers-Danlos syndrome(28) or mast cell disorders.(29)

For further information on POTS, please visit our POTS medical journal article collection or this informative lecture from Dr. Satish Raj, noted POTS researcher from Vanderbilt University's Autonomic Dysfunction Center.

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