

10 THINGS POLITICIANS SHOULD KNOW ABOUT PoTS

- 1. Postural tachycardia syndrome (PoTS) is an abnormal response by the autonomic nervous system to upright posture. On standing up,** patients experience [multiple symptoms](#) that include rapid palpitations, chest pains, light-headedness, blackouts, nausea, fatigue, difficulty thinking, excessively rapid gastric emptying, chronic headache, tremulousness, sleep abnormalities, cognitive impairment and much more!
- 2. Disability caused by PoTS is severe** - equivalent to Congestive Heart Failure and Chronic Obstructive Pulmonary Disease (conditions that usually affect older people).
- 3. Onset of PoTS is typically in young adulthood;** 50% of patients are unable to attend work or school. The costs are enormous, both economically to the country and personally to sufferers and their families, given that many educational and career opportunities at this critical stage are irrecoverably lost.
- 4. PoTS is often misdiagnosed.** Mean time to diagnosis in the UK from symptom onset is 7 years.
- 5. 27% of patients with Chronic Fatigue Syndrome actually have PoTS** - yet most remain undiagnosed and untreated.
- 6. 85% of POTS patients are told it's "all in their head"** and given psychiatric labels of anxiety and depression, but research shows that POTS patients are no more likely to have psychiatric disorders than healthy controls.
- 7. Few healthcare professionals are aware of PoTS** (approximately 10% of GPs).
- 8. Many patients are denied access to NHS specialists and treatments.** Management is complex and requires an experienced and informed physician. Many hospital consultants decline to see such patients as they feel they do not have sufficient expertise. Those that do are seeing their clinics closed or reduced to providing only local services as GP commissioners do not know about PoTS or understand the need to provide for such patients, and NHS England declined to provide services under Specialised Commissioning.
- 9. Over 90% of patients will respond to treatment,** thus heightening the tragedy of delays in diagnosis and treatment. As it affects so many body systems, a multidisciplinary approach is recommended, but there is no such service available in the NHS for UK patients.
- 10. What a politician can do to help**
 - Ensure that PoTS patients have equitable access to healthcare
 - Raise awareness
 - Ensure that affected patients do not fall between the cracks of GP and specialised commissioning

You can learn more about PoTS from our website www.potsuk.org