Sample letter to send to your local GPs/CCG.

Dear [*insert name of your GP/local CCG (Clinical Commissioning Groups)]*

I am writing to you to ask for your help in improving local services for people suffering from Postural Tachycardia Syndrome (PoTS). As you may know it is a disabling condition which mostly affects young adults. With an average time to diagnosis of 7 years, it is vital that GPs can refer people to good local services.

PoTS is an abnormal response by the autonomic nervous system to upright posture. On standing up, people experience multiple **symptoms that include rapid palpitations, chest pains, light-headedness, blackouts, nausea, fatigue, difficulty thinking, gut problems, headaches, tremulousness and sleep abnormalities.**

I have suffered from PoTS for x years. This means that...[*insert some examples of how it affects your life].*

TIP: You may wish to add a paragraph about your diagnoses and treatment history, with examples of how the pandemic has affected this. Include comments about your local services or lack of them. Try to keep this concise as the letter is more likely to be read if it isn't too long.

PoTS UK, of which I am a member, says that Awareness Day this year is particularly important for two reasons:

First, the pandemic has meant that sufferers like me have found it even harder to access the support and services we need. PoTS continues to be misdiagnosed and mislabelled as a psychological problem such as anxiety in half of patients. As recognition slowly grows, scarce services are becoming even more overwhelmed and waiting lists longer.

People with PoTS are often heavy users of NHS emergency services until they can access appropriate diagnostic tests and treatment, after which most will respond to treatment. Meanwhile many are unable to work or attend school. There are few specialists in the UK and existing services are overwhelmed with waiting times of around a year. In some parts of the UK there are no services, and it is especially difficult for children to access healthcare.

Second, PoTS appears to be a common symptom in people with long COVID. Clinicians and charities working with people experiencing PoTS have a great deal to offer in understanding the needs of the long Covid population. However, despite NICE guidance recommending tests for PoTS in people with postural symptoms, this does not always occur. So, we are asking for your help in campaigning for clinics with appropriate assessments and specialist multidisciplinary care to speed up recovery and support the well-being of those affected by long COVID.

These services would also be well-placed to serve the unmet needs of many people with PoTS who do not have local access to the services they need. We have an opportunity from the enhanced understanding of complex post-viral conditions brought by the pandemic, and the experiences from managing PoTS, for a long-overdue reinvention of healthcare provision for those with long-term conditions like this - with a huge impact on quality of life, and on the economy.

With the Government's recent publication ***Build Back Better: Our Plan for Health and Social Care*** the time is right for this reinvention.

The following documents may also be useful to look at:

https://www.potsuk.org/UserFiles/File/Sept_21_covid_update_PIF_PoTS_on_a_Page_GP_guide_V2.0_docx_3_.pdf

https://www.potsuk.org/wp-content/uploads/2021/10/PoTS_10_things_you_need_to_know_Oct2021.pdf

I am very willing to talk to you further about this and to discuss how local services could be improved. [*Include your contact details if you wish to].* PoTS UK is also very happy for you to contact them: info@potsuk.org.

Yours sincerely