

Dear **(Insert name of Member of Parliament)**

I’m writing to you, as your constituent, to highlight an urgent issue affecting **(me/my partner/spouse/family member)**

As you may be aware there is a critical medicines shortage of Pancreatic Enzyme Replacement Therapy medication, that is currently affecting more than 60,000 people across the UK, including those with neuroendocrine cancer.

Neuroendocrine Cancer is a group of rare cancers that can arise almost anywhere in the body – the most common primary sites include lung, pancreas, and small bowel.

Approximately 6,000 people in the UK are diagnosed each year (incidence 8.87:100,000 – 2018 (1). However, it is a highly prevalent cancer – 10th most prevalent of all cancers, 2nd most prevalent gastrointestinal cancer: meaning many more than 6,000 are currently living with it: even though, less than 30% are diagnosed at an early stage (1)

Neuroendocrine cancer and / or it’s treatment can lead to Pancreatic Enzyme Insufficiency (PEI).

Pancreatic Enzyme Replacement Therapy (PERT) is the gold standard treatment for PEI: and is a medicine that **(I/my partner/spouse/family member)** require**(s)** every day to replace digestive enzymes that **(I/my partner/spouse/family member)** am unable to make.

Without PERT, **(I/my partner/spouse/family member) (am/is)** unable to absorb fats, proteins, carbohydrates, and essential vitamins, that are crucial for retaining a healthy weight and controlling associated symptoms like bloating, diarrhoea, extreme lethargy and malnutrition.

Inability to absorb nutrients can also adversely impact on **(my/my partner’s/spouse’s/family member’s)** ability to be suitable for and/or undergo life-saving or life-extending anti-cancer treatment.

Over the past nine months, there have been intermittent shortages of PERT across the UK which has made it difficult, sometimes impossible, to get a PERT prescription filled.

I have been told that these shortages will continue until at least 2026, with little fore-sight or scoping, as to whether current expectations of a resolution will actually meet current need or any future increase in demand: all of which I find incredibly worrying.

**(insert personal information about the role PERT plays in your daily life – and the impact that shortages have had on you/your partner/spouse/family member).**

All I ask is that you write to the Secretary of State for Health & Social Care and highlight this as an issue requiring urgent national action?

If you have any questions, you can contact Nikie Jervis, Support Service Lead, Neuroendocrine Cancer UK – nikie@nc-uk.org

Thank you in advance for all your help.

**(Name and postcode)**

**(It is important you include your postcode so that your MP/MSP/MLA/MS knows you are their constituent).**

References:

1. White et al (2022) Incidence and survival of neuroendocrine neoplasia in England 1995-2018: A retrospective, population-based study. Lancet Reg Health Europe;23: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9513765/>
2. PSGBI Position Statement June 2024: <https://www.psgbi.org/position-statement-pert-shortage/>
3. Pancreatic Exocrine Insufficiency (PEI) & Pancreatic Enzyme Replacement Therapy (PERT): <https://www.neuroendocrinecancer.org.uk/pancreas-pei-pert/>.
4. Phillips et al (2021) Consensus for the management of pancreatic exocrine insufficiency: UK practical guidelines. BMJ Open Gastroenterology: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8212181/>
5. Clement et al (2019) Nutritional and vitamin status in patients with neuroendocrine neoplasms. World J Gastroenterology: <https://pubmed.ncbi.nlm.nih.gov/30886501/>