Rt Hon Keir Starmer
Prime Minister
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Mary Phillips
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5th February 2025

Dear Prime Minister,

The ongoing impact of the PERT Shortage from Pancreatic Clinicians and leading Digestive Health Charities: an open letter.

Further to the letter of July 2024 from the group of leading digestive health charities to the Secretary of State for Health and Social Care, we write to ask if your office can facilitate an urgent meeting with the Secretary of State and our clinical and charitable organisations, to discuss how we can alleviate the medicine shortage that is currently affecting more than 60,000 people across the UK.

Together, our ten organisations support patients with diseases that affect the function of the pancreas. These include pancreatic cancer, neuroendocrine cancers, pancreatitis and those who have undergone surgery to their pancreas, stomach and duodenum. **We need your help!**

Pancreatic enzyme replacement therapy (PERT) allows people with pancreatic exocrine insufficiency to digest and absorb food. Without it, people experience horrendous bowel symptoms, poor diabetes control, malnutrition and reduced absorption of other medications, all of which have a massive impact on their health and quality of life.

I am sure you have seen the media coverage and have likely had correspondence from your constituents regarding the shortage of the main brand of PERT called Creon®. These shortages started in 2023 and are predicted to continue until at least mid-2026.

It is no exaggeration to say the absence of PERT can have a devastating impact on people’s lives. Without access to PERT, people’s chances of survival, their physical and mental health, and their ability to work and play an active role in society are under threat.

Patient support lines and clinicians are inundated with requests for help from desperate patients. We are seeing patients who:

- Are unable to work due to uncontrollable diarrhoea
- Have deteriorated clinically due to malnutrition, to the extent they have been unable to have chemotherapy (with a survival impact)
- Have had to revert to an artificial diet consisting predominantly of prescribed supplement drinks
- Have experienced potentially life-threatening hypoglycaemic (low blood sugar) episodes due to malabsorption
- Are frail and have fallen when rushing to the bathroom.

Unlike other medications currently experiencing shortages, there is no easy alternative to taking PERT. As such, patients are taking desperate measures to cope with the shortages.

Pancreatic Cancer UK surveyed 572 people affected and found that 82% have struggled to obtain their usual PERT prescription on more than one occasion, 19% have frequently gone without taking PERT, and 71% are either taking a lower dose of PERT than they need or have restricted their diet.

Neuroendocrine Cancer UK surveyed 148 people and found that: 38% have run out completely at least once and 42% have gone without eating, 66% report an adverse/negative impact on functionality and quality of life.

Similarly, Guts UK surveyed 208 patients with pancreatitis and found that 24% had no PERT supply for more than one month, and 9% were admitted to hospital as a direct result of the shortage.

PERT shortages are Europe-wide, and manufacturing and raw materials play a significant part in these shortages. However, the UK has been hit particularly hard due to several policy and procedural challenges. For example:

1) **Lack of diversity of products available.** There are multiple brands available in other countries, whereas in the UK, Creon® holds a very high market share.

2) **Lack of a national response from the NHS**. We have asked the NHS medicines supply chain for centralised importing during this severe shortage but have been advised that this is not possible. Instead, each individual ICB is going through the same process of obtaining approvals, approving translated patient information, and then ordering in limited supplies of medication with long delays. As healthcare professionals at the 'coalface' of this issue, it is clear to see that this is a highly ineffective process.

3) **Lack of uptake of imported equivalents** due to the financial restraints on community pharmacies and system challenges:
    a. Additional costs of importing medicines (in some cases more than ten times the price of licensed medications in the UK) take two months to be reimbursed, which presents a cash flow issue for community pharmacies who are already under significant financial pressure.
    b. Prescribing systems are slow to update with unlicensed products, meaning hand written prescriptions of imported medicines are required.
    c. There is a lack of understanding amongst primary care clinicians and pharmacists about the clinical and quality of life impact of these shortages resulting in lack of prioritisation in an already overwhelmed NHS.

4) The VPAG scheme. We are concerned supply to the UK may be worsened by the introduction of the new VPAG scheme, which will further reduce the price of PERT in the UK by 35% and so may disincentivise companies from prioritising the UK for supply as to do so is of less financial benefit to them.

We are calling for a common-sense approach to this shortage: a national process to import PERT and introduction of imports into the normal wholesalers. This would make PERT accessible to all patients, we need reimbursement for imported medications to be processed in a more timely fashion to prevent cash-flow penalties for community pharmacies.

We also ask that the Government reviews the impact of the VPAG on the supply of medicines in times of shortage and undertakes a review of all medicines where one product dominates the UK supply to prevent issues like this from occurring again.

We would hugely appreciate if you could raise this with Wes Streeting and do what you can to facilitate a meeting to discuss the actions that can be taken both in the short and longer term.

Thank you

Yours sincerely,

Mary Phillips, Advanced Clinical Practitioner (HPB Dietetics) and Senior Specialist Dietitian, Chair of the Nutrition Interest Group & Past President of the **Pancreatic Society of Great Britain and Ireland**, Clinical Lead (Pancreas) Gastroenterology specialist group, **British Dietetic Association** and Vice Chair, Optimal Care Pathway Committee, **Pancreatic Cancer UK**

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