

Caroline Lamb
The Scottish Government
St Andrew's House
Regent Road
Edinburgh EH1 3DG

Dear Ms Lamb,

We are writing to discuss the low rates of prescription of a vital medicine, **Pancreatic Enzyme Replacement Therapy (PERT)**, in Scotland. Scotland has taken considerable steps already to improve this; as such, we write to outline what has been committed to, and what we believe needs to happen next.

As you will know, pancreatic cancer is the deadliest common cancer in Scotland. 813 people are diagnosed with pancreatic cancer every year in Scotland, with three in five diagnosed at a late stage. Most people will receive no treatment, and one in two will die within three months. These three short months are extremely distressing, with people often unable to digest their food, leading to rapid weight loss and unpleasant nutritional and digestive symptoms. But PERT, already a widely available prescription, can make a significant positive impact on the most debilitating of symptoms.

PERT replaces the digestive enzymes that people with pancreatic cancer can no longer produce, allowing food to be digested and absorbed by the body. It helps people gain the strength to undergo treatment, and gives them a better quality of life for the precious time they have left.

Currently, only a third of people with pancreatic cancer in Scotland are being prescribed PERT. But Scotland is leading the way in transforming the UK's PERT prescription rates. It is head and shoulders above the other UK nations in its work thus far, having already committed to a number of actions to rectify low prescription levels:

- Delivering a two-year project focusing on redesigning the first six weeks of the diagnostic pathway for pancreatic cancer, including prescribing PERT and supporting patients in how to take it
- Developing a checklist to ensure that all elements of pancreatic cancer care, including nutrition and PERT, are discussed with patients and delivered
- Undertaking a retrospective baseline audit to measure PERT prescription
- Measuring PERT prescription from diagnosis onwards, as part of a new 'best care package' pathway
- Investing £1.15 million into a prehabilitation programme, with access to timely treatment being a key priority.

We warmly welcome the above actions and would expect to see a dramatic improvement in PERT prescription rates for those diagnosed with pancreatic cancer as a result. But we need a concerted, long-term, system-wide effort to affect the greatest change. Moving forward, Pancreatic Cancer UK is calling on health policy makers in Scotland to build on Scottish Government's commitments, and other recent progress, by undertaking the following:

- Introducing a national PERT target through a Quality Performance Indicator (QPI) in the 2022 review, to consolidate and track progress of the recent commitments and ensure a *Once for Scotland* approach.
- Health Boards in Scotland should review their current guidance on PERT and share and promote Pancreatic Cancer UK PERT tools and resources, with a specific focus on channels, networks and outreach within the non-specialist care setting.
- Ensuring that every health professional involved with the care of people with pancreatic cancer is aware of PERT.
- All health professionals involved with the initial pancreatic cancer diagnosis need to pro-actively prescribe PERT.
- To improve local awareness and training, healthcare professionals should access Pancreatic Cancer UK's online PERT hub with training and resources on PERT.
- To ensure that no one falls through the gaps, there should be a nominated local health professional to champion PERT, who can ensure that colleagues are aware and trained to prescribe PERT and track that every person in the MDT has been considered for PERT.

To support this work, Pancreatic Cancer UK has launched a new campaign – **Transform Lives: Prescribe**. We are working in partnership with the clinical community to improve PERT prescription rates, whilst developing resources and training to support the healthcare community in understanding and prescribing PERT. We've developed an online training course, endorsed by the British Dietetic Association to increase healthcare professionals' knowledge of PERT, alongside a PERT Hub to help everyone treating people with pancreatic cancer to improve their practice.

We strongly welcome the progress already made in Scotland and are keen to work with you to ensure this continues so that everyone with pancreatic cancer has the opportunity to live the time they have left with the greatest possible comfort and dignity. Ultimately, there is no good reason why so many people in Scotland are missing out on a life-changing treatment such as PERT – together we can change this.

We look forward to meeting with you to discuss how we can keep up the momentum, and build on recent progress, so that all people with pancreatic cancer get access to the best possible treatment. Please contact Emily Waller, on emily.waller@pancreaticcancer.org.uk, who will be happy to make the suitable arrangements.

Yours sincerely,
Pancreatic Cancer UK and our undersigned supporters.