



Future development of the postal USO team

Ofcom

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Dear Sirs

Please accept this letter as a formal response to the call for input in relation to the future of the universal postal service.

We are writing on behalf of the National Society for Phenylketonuria (NSPKU) which is the UK wide charity for people with the rare metabolic condition phenylketonuria (PKU). This condition is characterised by the inability to metabolise the amino acid phenylalanine which will build up in the blood and brain causing permanent brain damage unless the condition is carefully managed by either specialist dietary treatment or medication. About 1 in 10,000 people are diagnosed with PKU in the UK, although some parts of the UK (Northern Ireland and Scotland) have higher prevalence. Most people with PKU achieve normal educational outcomes. However, a substantial number of people with PKU have cognitive impairments related to the condition. People with PKU and their carers may also be at risk of having lower household incomes than the UK average.

The postal service is part of the overall treatment pathway for patients with PKU. Patients are monitored by home blood sampling; patients or carers take a dried blood spot sample which is mailed to hospital laboratories for analysis of the patient's blood phenylalanine levels. The phenylalanine levels are then reviewed by metabolic specialists who will then provide guidance on the treatment regime to the patient.

Patients are instructed to have blood phenylalanine measurements regularly; between three times a week and once monthly depending upon age or other characteristics. The current medical consensus guidelines<sup>1</sup> stipulate that the time between blood sampling and patients/parents receiving the results should be minimised, aiming for less than 5 days. In special situations (infancy and the care of pregnant women with PKU) the results should be available within 2-3 days of sampling.

This background information therefore informs our response to this consultation. Patients with PKU rely upon a fast, reliable and reasonably priced postal service to achieve good outcomes from their treatment. We have the following observations:

1. Lost or delayed post will mean patients do not have their blood phenylalanine levels monitored in a timely way. Patients may then be exposed to high phenylalanine levels for extended periods of time. Exposure to high phenylalanine levels can cause brain damage to

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young children, and adults may experience symptoms such as cognitive impairments or brain fog. We are already aware that patients are experiencing a decline in the reliability of the postal service which impacts their health.

2. It is also important that the postal service is accessible to people with PKU and their carers. The treatment regime for PKU is already burdensome. Shifting to alternative means of transporting the blood spot samples to the laboratory (e.g. couriers or accessing a special means of delivery via a post office counter) would be likely to increase the administrative burden. Some vulnerable patients/families or carers may not cope with this. The postal service is local and easy to use.
3. The post service should be financially accessible. The huge increases in the cost of first-class stamps are difficult for patients who need to use first class post very frequently. As a charity we are aware that some lower income families/patients are reducing the frequency of blood phenylalanine monitoring for cost reasons.
4. Finally, it is essential that patients with PKU can use a postal service which is both reliable and fast, with no reduction in collection or delivery days and no reduction in the target delivery time.

We hope that the team at OFCOM will have regard to the experiences and needs of the vulnerable minority group of people with PKU in making its determination on the future of the postal service.

Yours sincerely

**ANDREW THOMPSON**

**Chairman, on behalf of the Council of Management of the National Society for Phenylketonuria**

cc.

Dr James Davidson, Consultant in Paediatric Metabolic Medicine, Great Ormond Street Hospital and Chair of the British Inherited Metabolic Disease Group.

Kirsty Hoyle, Metabolic Support UK.

Liz Twist MP, Liz Saville-Roberts MP, Peter Aldous MP, Paul Girvan MP, Patrick Grady MP

Medical Advisory Panel of the National Society for Phenylketonuria