

Dearadh agus Nuálaíocht Chliniciúil; Oifig an Príohoifigeach Cliniciúil Ospidéal Dr. Steevens, D08 W2A8 R: clinicaldesign@hse.ie

Clinical Design & Innovation; Office of the Chief Clinical Officer Dr Steevens' Hospital, D08 W2A8 E: clinicaldesign@hse.ie

27th October 2021

Deputy Catherine Murphy, TD Dáil Éireann Leinster House Kildare Street Dublin 2

RE: PQ 50238/21

To ask the Minister for Health if he will seek the necessary finance for the establishment of a designated intestinal failure unit or service in Ireland in order that that the HSE fulfils its ethical and legal responsibility to reduce the unacceptably high rates of complications and mortality among persons with intestinal failure

Dear Deputy Murphy,

The Health Service Executive has been requested to reply directly to you in relation to the above parliamentary question, which you submitted to the Minister for Health for response. I have consulted with the National Clinical Programme for Gastroenterology and Hepatology on your question and have been informed that the following outlines the position.

Intestinal failure (IF) is a condition characterised by the inability to maintain a state of adequate nutrition or fluid and electrolyte balance due to an anatomical or a physiological disorder of the gastrointestinal system. IF can be an extremely debilitating condition, significantly affecting the quality of life of those affected.

The National Clinical Programme for Gastroenterology and Hepatology (NCP G&H) is actively working to develop models of care for all patients with gastroenterology and hepatology conditions. Within this programme (NCP G&H), a working group has been set up chaired by a consultant gastroenterologist, who is also Director of Irish Society for Clinical Nutrition and Metabolism (IrSPEN).

The IrSPEN has established a registry which has recently gone live. There are currently 90 adult patients in this cohort, comprising:

- 30% with Short Bowel Syndrome (SBS-IF) following an ischaemic event;
- 30% developing Intestinal Failure (IF) following a surgical episode, including patients with severe Crohn's disease;
- 30% transition from the paediatric service in CHI Crumlin, where they have been managed often from birth with congenital conditions including inborn errors of metabolism;
- Remaining 10% have a variety of miscellaneous reasons for developing IF.



There have been significant improvements within this service in recent times with the introduction of the drug Teduglutide, which works by improving the absorption of fluids and nutrients in the intestine. Improvement in access to Interventional Radiology services is an essential development to ensure access for feeding through intravenous routes.

The working group within NCP G&H aspires to provide a Model of Care to meet the needs of all patients with intestinal failure (IF). This Model of Care is currently work in progress and will have a multidisciplinary team approach to meet all the needs of people living with IF across Ireland.

I trust this information is of assistance to you, but should you have any further queries please do not hesitate to contact me.

Yours sincerely

**Anne Horgan** 

**General Manager** 

