



Dearadh agus Nuálaíocht Chliniciúil, Oifig an Príohifigeach Cliniciúil
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25th July, 2022

Deputy David Cullinane, TD
Dáil Éireann
Leinster House
Kildare Street
Dublin 2

RE: PQ 37398/22

To ask the Minister for Health his plans to extend services and supports to patients with epidermolysis bullosa such as ring-fenced funding for home nursing care for those with severe EB, provision of an EB outreach nurse to support adults living with EB and increase mental health supports for people living with EB; and if he will make a statement on the matter.

Dear Deputy Cullinane,

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 Dermatology on your question and have been informed that the following outlines the position.

As currently there is no cure for Epidermolysis Bullosa (EB), management of this debilitating condition remains supportive through a range of supports between hospital services in CHI Crumlin (for children) and St. James Hospital (for adults). Hospital-based EB teams work closely with Community Services and Primary Care in arranging supports such as nursing home care, medical cards and supports like Special Needs Assistants (SNAs) through Education.

Significant investment in enhancing and re-configuring community-based health services and supports has been made in recent years and it is anticipated that such investments will continue, in line with Sláintecare Policy.

A permanent EB outreach nurse was appointed last year with remit to cover both children's and adult services. A Candidate Advanced Nurse Practitioner (cANP) post has also been recently allocated to the EB service. While the EB service is supported by hospital psychology departments, there is acknowledgement of a need to increase this capacity and relevant departments are currently pursuing business cases to this effect.

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