



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

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

RE: PQ 37397/22

To ask the Minister for Health his plans to extend services and supports to patients with epidermolysis bullosa in Budget 2023; 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.

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