



Dearadh agus Nuálaíocht Chliniciúil, Oifig an Príohoifigeach Cliniciúil  
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27<sup>th</sup> November, 2023

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

**RE: PQ 51586/23**

**To ask the Minister for Health if he will invest in additional home care, outreach care and mental health supports for people living with epidermolysis bullosa; and if he will make a statement on the matter.**

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 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, Dublin (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 a 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. A Consultant Dermatologist was appointed to lead the EB Adult Service in St James's Hospital in 2023 and this will facilitate the delivery of multidisciplinary care for adult patients.

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

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**Anne Horgan**  
**General Manager**