



Dearadh agus Nuálaíocht Chliniciúil, Oifig an Príohoifigeach Cliniciúil
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Deputy Colm Burke, TD
Dáil Éireann
Leinster House
Kildare Street
Dublin 2

RE: PQ 53565/23, 53567/23, 53568/23, 53569/23 & 53570/23

PQ 53565/23 - To ask the Minister for Health what action his Department is taking to ensure that people living with epidermolysis bullosa have access to additional services such as physiotherapy and occupational therapy in the community, given that it can be difficult for those affected with EB to access these services; and if he will make a statement on the matter

PQ 53567/23 - To ask the Minister for Health if he will consider the provision of funding for an epidermolysis bullosa specific bandaging and dressing scheme, given that those effected by EB incur a significant financial burden annually in the purchasing of bandaging and dressing materials; and if he will make a statement on the matter

PQ 53568/23 - To ask the Minister for Health if he will consider the provision of additional funding to help appoint a clinical psychologist dedicated to supporting adults living with epidermolysis bullosa, given that those affected by EB exhibit higher than average frequencies of psychiatric symptoms; and if he will make a statement on the matter

PQ 53569/23 - To ask the Minister for Health if he will consider the provision of additional funding for regular and reliable home nursing care for those living with more severe epidermolysis bullosa, to ensure a greater quality of life for those living with EB in Ireland and those who care for someone with EB; and if he will make a statement on the matter

PQ 53570/23 - To ask the Minister for Health if greater research will be undertaken by his Department into the quality of life of people living with epidermolysis bullosa in Ireland; and if he will make a statement on the matter

Dear Deputy Burke,

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 (NCP) for Dermatology on your question and have been informed that the following outlines the position.

Epidermolysis Bullosa (EB) is the collective term for approximately 30 different diseases characterised by a hereditary propensity to develop blisters on the skin and, in some cases, the mucous membranes.

All types and subtypes of EB are rare. The overall incidence and prevalence of the disease in the United States are approximately 1/53,000 live births and 1/125,000 respectively. Similar estimates have been obtained in some European countries.

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 Children's Health Ireland (CHI) Crumlin (for children) and St. James Hospital, Dublin (for adults). Hospital-based multidisciplinary EB teams work closely with Community Services multidisciplinary teams 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.

The current configuration of services for EB is for paediatric patients to attend the EB clinic in Our Lady's Children's Hospital in Crumlin, which is a multidisciplinary clinic and for adults to attend the EB Clinic in St James's Hospital, which again is a multidisciplinary clinic and has an EB Nurse.

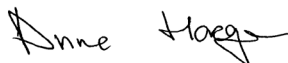
With respect to home nursing care for patients with EB, EB nurses are in place to provide outreach to patients, especially in the area of wound care and dressings. A permanent EB outreach nurse was appointed last year, with a remit to cover both children and adult services. A Candidate Advanced Nurse Practitioner (cANP) post has also been recently allocated to the EB service. Psychological support is provided to patients through multidisciplinary teams - at Children's Health Ireland (CHI) Crumlin for paediatric patients and St James's Hospital for adult patients.

A Consultant Dermatologist was appointed to lead the EB Adult Service in St James's Hospital in 2023. This appointment will facilitate the delivery of multidisciplinary care for adult patients. With respect to research into the quality of life of people living with epidermolysis bullosa (EB) in Ireland, NCP Dermatology understands that the remit for this new Consultant Dermatologist role at St James Hospital includes research in EB.

Because of the propensity to develop blisters, skin care and dressings are a daily requirement for patients. NCP Dermatology acknowledges that Epidermolysis Bullosa (EB) specific bandaging and dressings can be expensive. Patients with EB can apply through the Hardship Scheme to the HSE's Primary Care Reimbursement Service (PCRS) for re-imburement of same.

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