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27th March, 2024

Deputy Bernard J. Durkan, TD
Dáil Éireann
Leinster House
Kildare Street
Dublin 2

PQ 10635/24

To ask the Minister for Health the extent to which treatment is planned for those that suffer with epidermolysis bullosa; the extent to which plans are in hand to provide these people access to the support required, including homecare support and mental health support, with particular reference to addressing their quality of life; and if he will make a statement on the matter.

Dear Deputy Durkan.

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 HSE National Rare Disease Office (NRDO) and the National Clinical Programme for Dermatology on your question and have been informed that the following outlines the position.

Inherited Epidermolysis Bullosa (EB) is a group of rare genetic conditions caused by disease-causing variants in over 21 known genes, which lead to fragility of the skin and other tissues. The estimated prevalence in Ireland is around 1/20,0000 with around 300 Irish patients. Management of EB requires intensive multidisciplinary care, with the Specialist Dermatologist as the key co-ordinating specialist.

There are currently no effective therapeutics. Patient management remains based on preventive measures, together with symptomatic treatment focusing on protection against trauma, dressings for wound care, intensive nutritional support and early medical or surgical interventions to manage skin fragility, wound infections, growth, pain, pruritis and mobility.

Management of this debilitating condition remains supportive through a range of supports. In Ireland, the specialist clinical service for EB is the National Skin Fragility Service based at Children's Health Ireland, Crumlin (Paediatric – EB & skin fragility patients) and St James' Hospital Dublin (Adult - EB 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

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, in line with Sláintecare Policy.

The National Rare Diseases Office has developed an integrated care pathway for EB, which includes input from the national patient organisation 'Debra Ireland' and multiple health and social care professionals including occupational therapy, physiotherapy, speech and language therapy, dietetics, social work, psychology and genetic counselling. This EB care pathway sets out the recommended steps in care as a national paediatric and adult care pathway. It is available on the HSE website at the following link:
https://www.hse.ie/eng/services/list/5/rarediseases/care-pathways/inherited-epidermolysis-bullosa-eb-paediatric-and-adult-care-pathway.pdf

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