DEBRA Ireland Submission, June 30th 2014

Public Consultation on Medical Card Eligibility

*On behalf of people living with epidermolysis bullosa (EB)*

**Answers to questions posed in the online submission form**

**Medical condition**: epidermolysis bullosa (EB).

**Reasons why this condition should be considered on the basis of medical need**: EB is a serious, chronic (genetic) and debilitating condition. *Please see the included ‘Guide to EB’ for more detail.* The medical requirements to manage the condition are numerous and costly. However, careful management is hugely beneficial in permitting the best possible quality of life for the patient and their family. It is also essential in order to minimise costs to the health service over the lifetime of a patient e.g. appropriate care minimises the number of hospitalisations required by severe patients. Failure to provide EB patients with a medical card would cause undue financial hardship to their families and, in many cases, would make it simply impossible for their essential medical needs to be met.

**GP Visits**: this depends on the severity of the individual’s EB and the extent to which they are cared for by the specialised hospital centres in Our Lady’s Children’s Hospital, Crumlin and St. James’s Hospital (severe cases often rely more on the hospital services, rather than their GP). It could range from twice a year to every 2 weeks.

**Medicines**: EB patients may take some or all of the following medication types: pain medications, anti-itch medications, antibiotics, nutritional supplements, treatments for reflux and nausea, laxatives, ophthalmic medications, antidepressants. *This list is not exhaustive.*

**Therapies**: this is best described by listing the range of specialists that an EB patient is likely to encounter: dermatologist, EB specialist nurse, nutritionist, occupational therapist, physiotherapist, psychologist, paediatrician, ophthalmologist, urologist, dentist, orthopaedic surgeon, podiatrist, microbiologist, general surgeon, ENT surgeon, oncologist, cardiologist, endocrinologist, clinical geneticist, haematologist, radiologist, pathologist. *This list is not exhaustive.*

**Aids and appliances**: the most frequently used and most expensive non-drug requirements of EB patients are dressings and bandages. Daily wound care routines require many different types of specialist dressings, bandages, syringes, creams, emollients and cleansers. Orthodontic appliances and specialist clothing and footwear are also often required. Wheelchairs and house appliances, associated with restricted mobility and dressing changes, are sometimes also necessary. *This list is not exhaustive.*
**In patient treatments:** in severe cases there are many complex treatments and diagnostic procedures that require hospitalisation. These include procedures relating to wound care, hand surgery, oesophageal dilations, iron infusions, skin cancer diagnosis and management, gastrostomy tube placement and management of infection. *This list is not exhaustive.*

**Respite care requirements:** it is difficult for carers of people with severe EB to avail of any form of respite, due to the expertise and experience required to manage the complexities of EB. What is desperately needed however, is nursing support for the incredibly painful, stressful and demanding wound dressing changes, which take approximately 3 hours every second day.

**Additional comments on behalf of people living with EB**

**Improving the constitution of the expert panel**

We welcome the strength of the medical expertise on the panel. However, we have serious concerns about the extremely limited patient representation among the group and we urge the panel to find a way to address this deficit. We would like to see representation from an umbrella organisation, such as the Disability Federation of Ireland (DFI), who have strong experience and knowledge in the relevant areas and who have the resources and capability to consult with, and gather opinions from, their many member organisations. We also view it is as essential that patients/parents, with ‘lived experience’ of the medical card processes, be included among your numbers.

**Reducing the bureaucratic burden**

As the panel will be very aware, there have been many publically-aired concerns, regarding the fact that patients with chronic, incurable conditions are required to renew/appeal their discretionary medical cards frequently. This entails enormous time and effort and places undue stress on families, who are already experiencing more than their fair share of worry. We are aware that this is largely as a result of medical cards being granted primarily on a financial means basis. However, we would like to see a move towards discretionary medical cards being granted completely on the basis of medical need. We hope that it will then be possible to grant discretionary medical cards on a permanent or long-term basis for people with EB.

**Simplifying access to medical requirements**

This may be outside the remit of the panel but, in the hope that it might influence some of the panel’s decision-making, we would like to air a huge concern about the number of ‘hoops’ that patients can be required to jump through, to access their health entitlements. We provide the example of EB patients who, having been granted a medical card, are not then able to access their largest and most expensive requirement, dressings and bandages, through the scheme. Instead, they are required to subsequently access these ‘non-drug’ requirements through the
unfortunately-named ‘Hardship Scheme’. This is a non-transparent, inequitable scheme and the cause of much additional bureaucracy and stress for many families. We call for access to all medical requirements for people with EB to be streamlined and simplified.

**Avoiding listing and prioritising medical conditions**

The HSE website states that ‘the Expert Panel will identify a range of medical conditions, in priority order, that would benefit most from medical card eligibility’. In representing a rare disease and in the knowledge that there are more than 6,000 other rare diseases and many more patients with no diagnosis, this concerns us hugely. Even without consideration of the rare diseases, we wonder about the appropriateness of prioritising one serious medical condition over another. With this approach you would be in danger of recreating an expanded version of the inequitable Long-Term Illness Scheme. We recognise that there are those among you on the panel, Prof. Eileen Treacy included, who are very aware of the particular challenges of rare and undiagnosed conditions and whose voices will hopefully be heard. However, if you haven’t already, we urge you to move away from this idea of attempting to put medical conditions into neat boxes. Ultimately, discretionary medical cards should only be granted on the basis of an individual patient’s medical needs and not on the basis of whether a medical condition is on a list or not.

*Avril Kennan, PhD*

*Head of Research and Advocacy, DEBRA Ireland*

**DEBRA Ireland**

Butterfly Cottage, 8 Clanwilliam Terrace, Grand Canal Quay, Dublin 2

T: + 353 1 412 6924

E: avril@debraireland.org

W: www.debraireland.org
Guide to EB

What is EB?
Epidermolysis bullosa (EB) refers to a group of distressing and painful genetic conditions that cause the layers of the skin and internal mucous membranes to separate and blister at the slightest touch.

How is EB caused?
EB is a genetic condition and is inherited in either a dominant or a recessive fashion. It is chronic and debilitating.

How common is EB?
EB is very rare. An estimated 1 in 18,000 babies born are affected by it.

What genes cause EB?
There are a number of genes associated with the structure of skin, that can cause EB if they have a genetic fault in them. These include genes coding for collagen, keratin and integrin proteins.

Are there different types of EB?
Yes, there are different forms of EB which vary in severity. Broadly, there are three major subtypes: EB simplex, junctional EB and dystrophic EB. EB simplex tends to be a less severe form of the condition (although still very debilitating) but there are exceptions and some subtypes of EB simplex are very severe. Babies born with junctional EB rarely survive. Dystrophic EB ranges in severity but usually has a huge impact on quality of life and, at the severe end of the scale, is a truly devastating condition. Severe forms are progressive, due to, among other things, the build-up of scar tissue.

How is EB diagnosed?
If EB is suspected, a biopsy is usually taken. Microscopy and antigen mapping are used to guide the diagnosis. In Ireland, the diagnosis is almost always confirmed by genetic testing.

Is it only the skin that is affected in EB?
In less severe cases, the symptoms of EB are localised to the skin. In more severe cases the mucous membranes (mouth, oesophagus and anal tract) are often badly affected, along with many other parts of the body, including teeth, nails, eyes and bones. In severe cases there is almost no part of the body that remains unaffected and the care of EB requires a large multidisciplinary team of medical specialists.

Are there effective treatments for EB?

No, there are no effective treatments for EB. Current care involves the management of symptoms, which has improved dramatically over the years. There is much research being undertaken world-wide however, into developing effective treatments.

How are EB patients cared for in Ireland?

EB patients are cared for by specialist, multidisciplinary teams in Our Lady’s Children’s Hospital Crumlin and St. James’s Hospital. This care is supplemented by support from a variety of specialists in the primary care setting, including GPs, community nurses, OTs, physiotherapists, dentists etc.

What financial costs are associated with EB?

There are a variety of costs associated with EB. The largest expense is usually that associated with dressings and bandages which, in severe cases, can run to several thousand euro a month. There are also many medications involved in the care of EB including pain relievers, anti-itch medications, nutritional supplements, anti-depressants, antibiotics, laxatives, ophthalmic treatments and emollients. Finally there is often a broader financial impact on the family, relating to loss of earnings and travel to specialist care providers.