



PODIATRY

Hyperkeratosis (callus) care for adults living with epidermolysis bullosa (EB)



**This is how life feels
to people with EB.**

LOWE GKK

WHAT IS EPIDERMOLYSIS BULLOSA?

EB is a group of rare genetic disorders characterised by fragility of the skin and mucous membranes and mechanically induced blistering. EB comprises four main types - EB simplex (EBS), junctional EB (JEB), dystrophic EB (DEB), and Kindler EB (KEB), with more than 30 subtypes. EB is clinically heterogeneous including a broad spectrum of severity.

**Cover photo: Juliene Matos Fernandes, living with EB simplex, aged 29, Brazil
(photo credit: Suelen Szymanski)**



Fábio Ramos dos Santos, living with EB simplex, aged 42, Brazil (photo credit: Suelen Szymanski)



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The images below show blisters healing on feet.



Diane Laverne Inns, living with EB simplex, aged 53, United Kingdom

Who is this booklet for?

This booklet is for adults (16+ years old) living with any of the following types of EB:

- ▶ EB simplex (EBS)
- ▶ dystrophic EB (DEB)
- ▶ junctional EB (JEB)
- ▶ Kindler EB (KEB)
- ▶ EB acquisita (EBA) - autoimmune, not genetic*

*There was no evidence found in this population group for the CPG. However, it is assumed that they would require the same support.

What is this booklet about?

This booklet provides information on hyperkeratosis (callus) care for adults living with EB.

Topics covered in this booklet include:

- ▶ what is hyperkeratosis (callus) in EB?
- ▶ what are corns in EB?
- ▶ neurovascular hyperkeratosis
- ▶ wound care and pain management
- ▶ staying active and mobile
- ▶ how your podiatrist can help

Where does the information in this booklet come from?

The information and recommendations in this booklet are derived from the “Foot care in Epidermolysis bullosa: Evidence-based Guideline”. The guideline was written in 2018 by a group of EB healthcare professionals, individuals living with EB, and family members. The information and recommendations in the guideline come from a variety of sources including clinical research and expert opinion.

There are three different types of recommendations in this booklet:



STRONG RECOMMENDATION
based on good-quality
research evidence



RECOMMENDATION
based on research
evidence

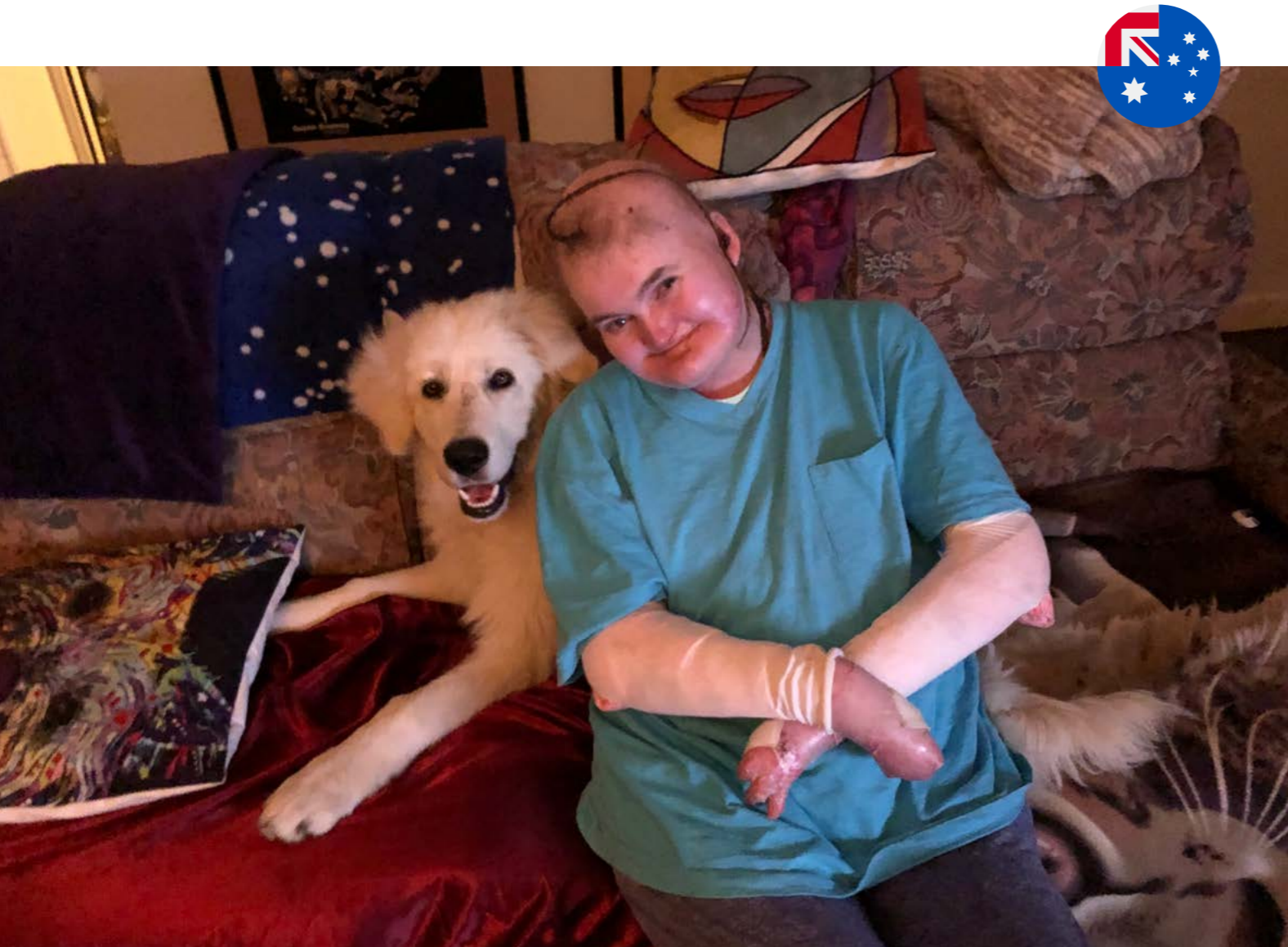


RECOMMENDATION
based on clinical
experience



This icon signposts to recommendations that overlap with those from other EB clinical practice guidelines (CPGs). These are referenced to on page 25.

WHAT IS HYPERKERATOSIS (CALLUS) IN EB?

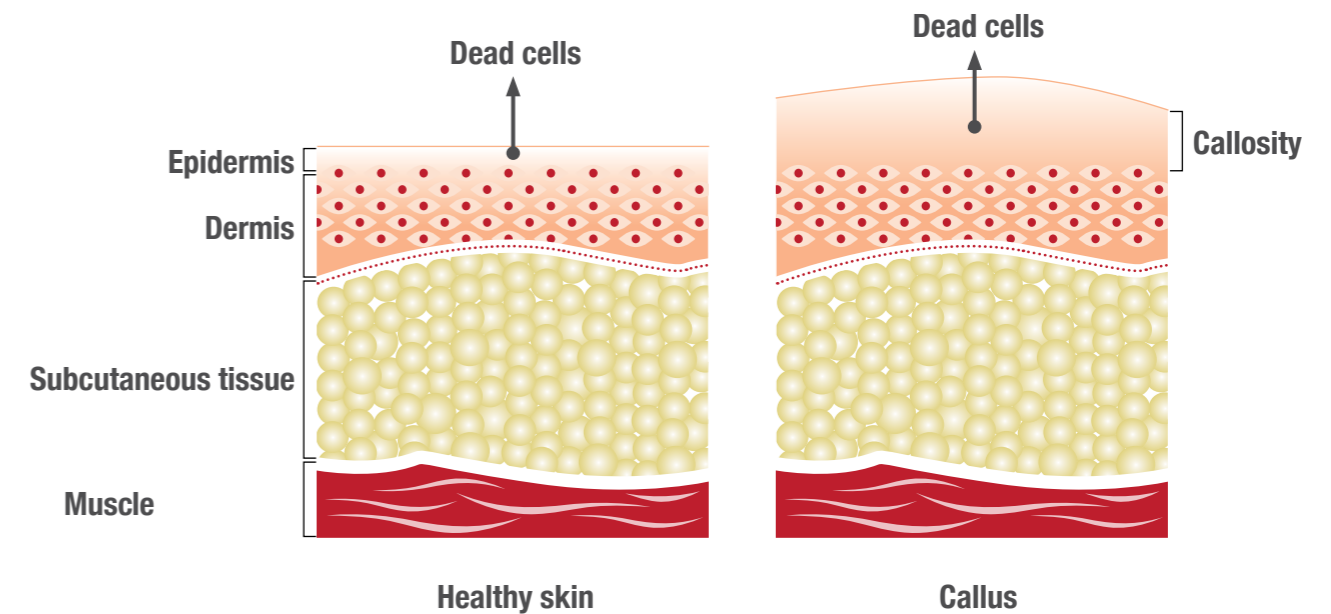


“ After having my calluses seen to by my podiatrist the pain in my feet decreases substantially and walking becomes a pleasurable activity once more. ”

Lisa Brains, living with recessive dystrophic EB, aged 48, Australia

WHAT IS HYPERKERATOSIS (CALLUS) IN EB?

Hyperkeratosis (callus) may be defined as hard, thickened areas of the skin as a result of friction, pressure, or irritation. Calluses can be located on the tips of the toes, between the toes, and soles of the feet. It can also occur on the hands and other body areas that may have constant pressure or friction.



The image above and to the left shows the structure of the skin with the upper layer being the epidermis, and then progressively lower, the dermis, and the subcutaneous tissue (fat), which is on top of the muscles. The image on the right shows the callus formation.

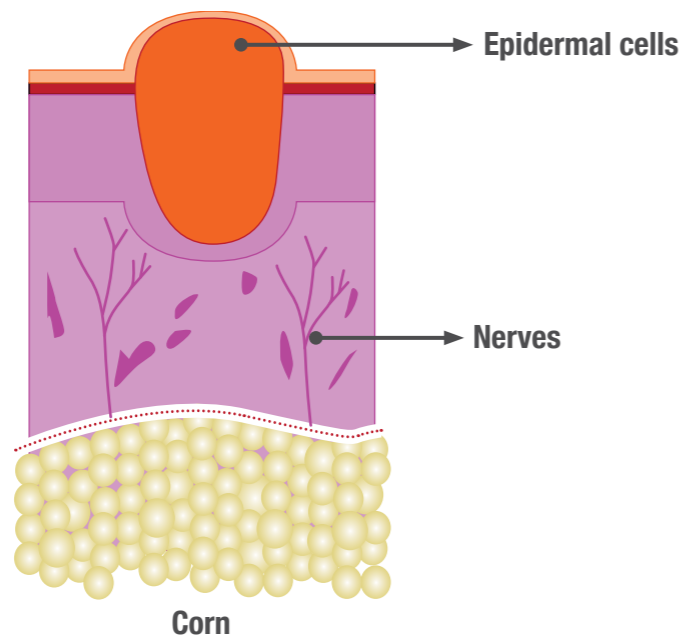
Recommendation

Get specialised podiatry support to help with pressure redistribution and cushioning to prevent hyperkeratosis development.

Callus and corn development in EB can significantly impact an individual's quality of life due to the associated pain and impact on mobility.

Heloma Durum (the common corn) refers to the central core of the hard, yellow skin that extends downwards in a cone-shaped point into the dermis skin layer, and can cause notable pain and discomfort.

Heloma Molle (seed corns) are frequently seen in EB due to toe and foot deformity. Seed corns can be found amongst calluses, usually scattered around the heel or non-weight bearing areas of the sole of the feet. A seed corn is usually found between toes and is spongy/white in appearance as it absorbs moisture from sweat.



The image above shows the structure of the skin with a corn formation in the epidermal cells.

During initial appointments with your new podiatrist, it is always preferable to request that the podiatrist doesn't remove as much as the corn/callus as they normally would in someone without EB. This is because a certain amount of the hard skin can protect the vulnerable skin underneath. Over time, with regular communication, you can instruct your podiatrist as to which areas may require more or less debridement than previously provided.



The images above show a recessive dystrophic EB mitten foot with plantar hyperkeratosis (callus) before and after debridement.

WHAT ARE CORNS IN EB?



Tips

- ▶ Healthcare professionals and people living with EB alike have reported the benefit of applying dry corn flour on the soles of the feet and in between the toes to help control excessive moisture and reduce friction. This can help control blistering and callus development on a day-to-day basis. Prevent the corn flour from getting wet or turning into a paste-like consistency as this can cause blisters.
- ▶ Many people living with EB have also reported bad experiences regarding podiatrists who have no understanding of the nature of the condition. Those with access to a specialist EB trained podiatrist can pass on the podiatry service contact details to provide any additional support/information/advice to their local podiatrist.
- ▶ Please direct your podiatrist to the areas of treatment you wish to be managed and instruct them as to how much you would like the area to be debrided. A more conservative approach is recommended as over-debridement can make the underlying skin more likely to blister, and become painful and tender.
- ▶ Never treat your corns with corn plasters because dressings need to be non-adherent to the corn and surrounding skin. They also have a central area which is acidic to burn away the corn, but this can often cause localised maceration and ulceration.
- ▶ Take EB-friendly dressings to all podiatry appointments in case they do not have any.



The image above shows a foot with a callus and a corn.



Diane Laverne Inns, living with EB simplex, aged 53, United Kingdom

This is a form of callus in which the nerve endings and blood vessels become prominent in the epidermis skin layer in response to trauma and treatment. The area is sensitive, painful, and difficult to treat as normal treatment by sharps debridement (cutting away at dead skin) causes pain and bleeding. Although rare, it is very debilitating in the small number of people with EB affected.



The image above shows a foot with neurovascular hyperkeratosis.

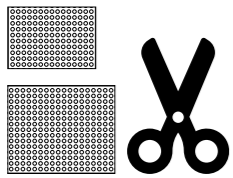
Calluses, corns, and fissuring (cracks in the skin) of the feet have been reported in all subtypes of EB. If not treated, the constant friction can cause EB blisters to form under the thickened tissues and painful fissures can develop. This can result in possible infection if left untreated. Individuals with dystrophic EB have been found to have increased callus and corn development due to the deformities associated with the mitten deformities and contractures, which lead to areas of high pressure.

Painful calluses and corns can have a big impact on a person's gait, posture, and reduce the ability to walk and eventually, increase wheelchair use.

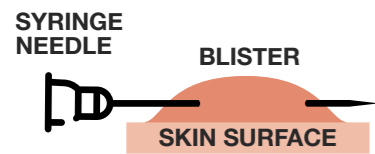


The image above shows a recessive dystrophic EB mitten foot.

Bigger blisters = bigger wounds! Pop a blister as soon as you see it. Cleaning and removing debris/dead tissue helps to reduce bacteria in wounds and promote wound healing.



01 Prepare all dressing material in suitable sizes and amounts in advance to keep dressing changing times shorter.



02 Use a clean needle to create an entry and exit hole so the fluid can escape



03 Roll a soft clean cloth over the blister to expel fluid



04 The roof should be left on the blister to protect the wound



05 Remove dead skin around the open wound

As EB blisters are not self-limiting and can spread, intact blisters should be lanced and fully drained even at the areas of the feet and toes. Your specialist EB trained podiatrist or EB team may have shown you how to do this but you can also find advice in the skin and wound care CPG and from the illustration on page 16 of this booklet.



Recommendation from the skin and wound care CPG

You should lance intact blisters and fully drain them or they will refill.



Wound dressings, insoles, and socks will also need to be considered when using footwear. If dressings are worn daily on the feet then foot size should be measured with dressings in place when choosing suitable footwear.

Painful feet and neuropathic pain are common complaints with EB. Neuropathic pain is caused by damage or injury to the nerves that transfer pain information. This pain is often described as a 'burning' pain on the soles of the feet. Some of these issues are addressed in the pain management CPG. They emphasise that an important aspect of pain care for individuals is to have careful or professional attention to their footwear, nails, orthotics, and hyperkeratosis management. Hyperkeratosis refers to thickening of the outer skin layer made of keratin protein.



Strong recommendation from the pain management CPG

Discuss how to optimise your pain control with your specialist EB trained podiatrist or EB team.



Recommendation from the pain management CPG

Discuss with your specialist EB trained podiatrist or EB team to see if there are any topical therapies you could use.





Gemma Jaega, living with recessive EB simplex, aged 28, United Kingdom; Mike Jaega, born with recessive dystrophic EB (1971-2019), United Kingdom

Problems such as blistering, hyperkeratosis, nail loss, altered gait, and deformity can result in reduced mobility and, eventually, increased wheelchair use. Preventing these problems can help you to stay mobile for longer and improve your quality of life.



Recommendations

- ▶ Preventing these problems can help adults of all subtypes of EB to stay mobile for longer and improve their quality of life.
- ▶ Podiatric treatment can help you stay active and mobile for longer.
- ▶ Discuss how to access programs to optimise mobility with your specialist EB trained podiatrist or EB team.



How your podiatrist can help

Specialist EB trained podiatrists should be available to:

- ▶ examine your feet
- ▶ develop podiatry treatment plans and recommend suitable footwear
- ▶ offer treatment at a specialist clinic, such as for the development of bespoke footwear
- ▶ recommend appropriately trained podiatry services near your home
- ▶ carry out regular manual sharps debridement to treat lesions, corns, and calluses
- ▶ assess and monitor weight distribution
- ▶ help with appropriate cushioning to prevent hyperkeratosis
- ▶ provide socks with silver impregnated
- ▶ encourage regular emollient/moisturiser application to help your skin's integrity.

Please contact your national DEBRA group for more information on your local EB specialist clinic.

Recommendation

Have your podiatrist monitor and manage your EB hyperkeratosis.

When people want to go privately we advise them to check the podiatrist is registered with their governing body.



Janaina Rodrigues Pereira, living with recessive dystrophic EB, aged 40, Brazil (photo credit: Suelen Szymanski)



Tell us what you think

Have your say in the future patient versions of clinical practice guidelines (CPGs) for epidermolysis bullosa (EB)

The purposes of this survey are to:

- ▶ assess the quality of the information, presentation, and delivery of the patient versions
- ▶ help us to develop a standard for all patient versions now and in the future.

The data collected will help us to improve the information provided and experience of the user in all future CPG patient versions. The data may be used to report the development steps taken to improve their quality; this may be done through conference presentations, posters, abstracts, or studies.

We want to make sure that all patient information provided meets the needs of everyone living with EB.

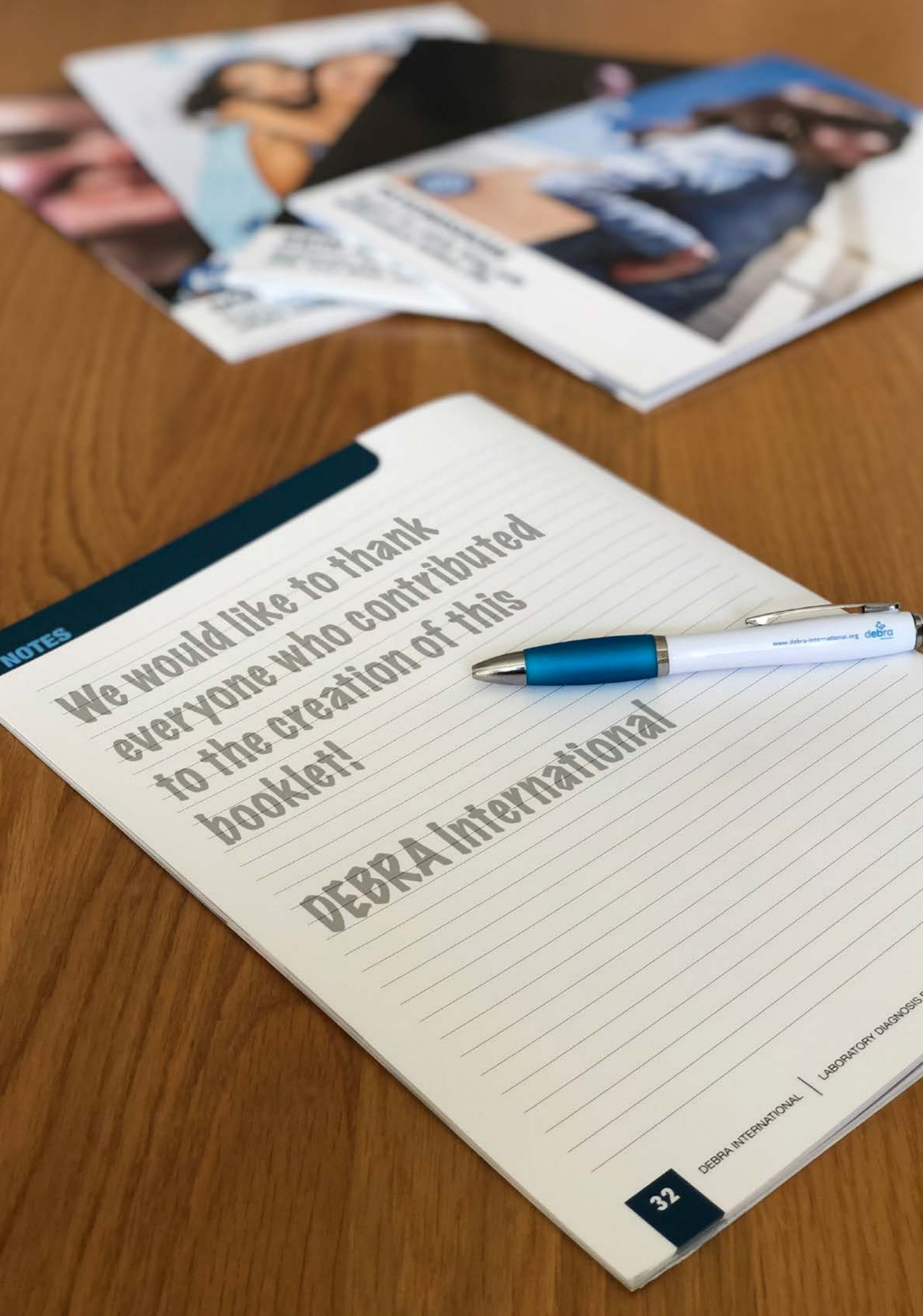
Help us create new CPGs and patient versions

All responses to the above survey are confidential unless you decide to join the DEBRA International CPG network. Please consider joining the network if you are interested in becoming involved in the development of CPGs and patient versions in the future. To join the network, please complete question 1 on page 7. If you do not complete this question, we will not receive any of your personal details and you will remain anonymous. Joining the CPG network is entirely voluntary and you may choose to opt out at any time by contacting DEBRA International.

If you have any questions when completing this survey or about joining the CPG network, please contact the DEBRA International CPG Coordinator, Kattya Mayre-Chilton by email at: kattya.mayre-chilton@debra-international.org

TELL US WHAT YOU THINK!

Answer the survey to help us improve the patient versions of the CPGs:
www.surveymhero.com/c/PatientVersionsSurvey





Matt Lightfoot, living with dominant dystrophic EB, aged 26, United Kingdom

Disclaimer

The information contained in this booklet does not indicate an exclusive course of action or serve as a standard of medical care. Variations, taking individual circumstances into account, may be appropriate. The authors of this booklet have made considerable effort to ensure that the information contained within accurately reflects the content of the guidelines on which it is based. The authors, DEBRA UK, and DEBRA International accept no responsibility for any inaccuracies, information perceived as misleading, or the success of any recommendations, advice, or suggestions detailed in this booklet. The information provided on the following pages is subject to change without notice. For the most up-to-date information on available clinical practice guidelines, booklets, and contact information, please visit: www.debra-international.org

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Development source

Foot care in Epidermolysis bullosa: Evidence-based guidelines

This CPG was approved by DEBRA International and funded by DEBRA UK.

To access the following CPGs and patient version booklets, please visit: www.debra-international.org



Podiatry booklets

- ▶ Podiatry dystrophic nail care for people living with epidermolysis bullosa (EB)
- ▶ Podiatry footwear advice for parents caring for a child living with epidermolysis bullosa (EB)
- ▶ Podiatry footwear advice for adults living with epidermolysis bullosa (EB)



Other CPG topics referred to in this booklet



- ▶ International Consensus Best Practice Guidelines for Skin and Wound Care in Epidermolysis Bullosa
- ▶ Pain care for patients with epidermolysis bullosa: Best care practice guidelines

Other CPG topics

- ▶ Clinical Practice Guidelines for Epidermolysis Bullosa Laboratory Diagnosis
- ▶ Management of Cutaneous Squamous Cell Carcinoma in Patients with Epidermolysis Bullosa: Best Clinical Practice Guidelines
- ▶ Occupational therapy for epidermolysis bullosa: clinical practice guidelines
- ▶ Oral Health Care for Patients with Epidermolysis Bullosa - Best Clinical Practice Guidelines
- ▶ Psychosocial recommendations for the care of children and adults with epidermolysis bullosa and their family: evidence based guidelines

Other languages

We are happy to consider requests for this booklet to be provided in other languages. Please send all enquiries to: office@debra-international.org

How was the Foot care guideline produced?

- ▶ The CPG development group consisted of EB experts: podiatrists, dermatologists, a physiotherapist, a dietitian, and patient representatives.
- ▶ All panel members completed written conflict of interest and code of conduct declarations.
- ▶ During guideline development, they conducted several panel meetings where six to nine members would meet in person and virtually. They discussed the clinical questions and methodology; reviewed the evidence (publications in the field of EB podiatry research); formulated recommendations; and agreed on the guideline's structure and wording.
- ▶ CPGs are based on a critical, extensive, and exhaustive review of the most relevant publications in the field of EB podiatry and foot care research together with the personal experiences of the panel members.
- ▶ To identify publications, seven electronic search engines were accessed, including Wiley Online Library, Google Scholar, Athens, ResearchGate, Net and PubFacts.com. The search period ended in December 2018.
- ▶ Out of 46 papers appraised, 36 were chosen for the final recommendations by six panel members according to the Critical Appraisal Skills Programme (CASP) and Scottish Intercollegiate Guidelines Network (SIGN) quality rating.

Panel group

- ▶ M T Khan - CPG Lead (United Kingdom / Australia)
Specialist EB Paediatric Podiatrist - Great Ormond Street Hospital for Sick Children, London; Royal London Hospital for Integrated Medicine, UCLH, London; St George Hospital, Sydney, NSW; Barts and The London NHS Foundation Trust, London
- ▶ M O'Sullivan - CPG Co-lead (United Kingdom)
Specialist EB Adult Podiatrist - University Hospitals Birmingham NHS Trust, Solihull Hospital, Solihull
- ▶ B Faitli - CPG Member (United Kingdom)
Person living with EB
- ▶ J E Mellerio - CPG Member (United Kingdom)
Consultant - St John's Institute of Dermatology, Guy's and St Thomas' Hospital NHS Foundation Trust, London
- ▶ R Fawkes - CPG Member (United Kingdom)
Specialist EB Podiatrist (Retired) - St Thomas' Hospital NHS Foundation Trust, London
- ▶ M Wood - CPG Member (United Kingdom)
Specialist EB Paediatric Physiotherapist - Great Ormond Street Hospital for Sick Children, London
- ▶ L D Hubbard - CPG Member (United Kingdom)
Principal dietitian in adult EB - St Thomas' Hospital NHS Foundation Trust, London

- ▶ A G Harris - CPG Member (Australia)
Dermatologist - St George Hospital, Sydney, NSW; Department of Dermatology, Concord Hospital, Sydney, NSW
- ▶ L Iacobaccio - CPG Member, CPG patient version Lead (Australia)
Specialist EB Adult Podiatrist - The Royal Melbourne Hospital, Melbourne, VIC
- ▶ T Vlahovic - CPG Member (United States)
Specialist EB Podiatrist - Temple University, Philadelphia, PA
- ▶ L James - CPG Member (United Kingdom)
Specialist EB Adult Podiatrist - University Hospitals Birmingham NHS Trust, Solihull Hospital, Solihull
- ▶ L Brains - CPG Member; Patient version Co-lead (Australia)
Person living with EB
- ▶ M Fitzpatrick - CPG Member (Australia)
Person living with EB, DEBRA Australia
- ▶ K Mayre-Chilton - Methodologist, CPG Member (United Kingdom)
DEBRA International CPG Coordinator; Specialist Adult Research Dietitian - Guy's and St Thomas' Hospitals NHS Foundation Trust, London

External review group

- ▶ C Pankhurst (UK)
Clinical Specialist - Guy's and St Thomas' Hospitals NHS Foundation Trust, London; Clinical Network: Foot Care (Co-chair); British Association of Prosthetists and Orthotists; (Professional Affairs Committee Co-vice-chair); Foot in Diabetes UK (Vice-chair)
- ▶ K A Bø (Norway)
Person living with EB
- ▶ S Woolcock (UK)
Specialist EB Adult Podiatrist - Guy's and St Thomas' Hospitals NHS Foundation Trust, London

DEBRA International project team

- ▶ K Mayre-Chilton - CPG patient version project lead (United Kingdom)
CPG Coordinator - DEBRA International
- ▶ O Mullins - Editorial and format lead (United Kingdom)
Business Manager - DEBRA International
- ▶ L A Taguchi - Branding and design lead (Brazil)
Mother of a person born with EB; Marketing Director - DEBRA Brazil
- ▶ M Cardoza - Graphic designer (United Kingdom)
- ▶ A Winter - Design assistant (United Kingdom)
Fundraising Events Coordinator - DEBRA UK

DEBRA International

DEBRA International is the umbrella organisation for a worldwide network of national groups that work on behalf of those affected by the rare genetic skin blistering condition, epidermolysis bullosa (EB). The first DEBRA was created over 40 years ago and is present in over 50 countries around the world.

www.debra-international.org
office@debra-international.org

EB Without Borders

EB Without Borders is a key initiative of DEBRA International. Its mission is to help patients, families, and doctors in countries where there is no DEBRA structure to support them, and to assist new groups to form and develop.

ebwb@debra-international.org

EB-CLINET

EB-CLINET is the global clinical network of EB centres and experts.

www.eb-clinet.org
office@eb-clinet.org

Lined area for notes on page 29.

-  ▶ **Argentina**
www.debraargentina.org
info@debraargentina.org
+54 (011) 3965 4298
-  ▶ **Australia**
www.debra.org.au
admin@debra.org.au
+61 (0) 427 937 003
-  ▶ **Austria**
www.debra-austria.org
office@debra-austria.org
+43 1 876 40 30
-  ▶ **Belgium**
www.debra-belgium.org
info@debra-belgium.org
+32 (0) 4 267 54 86
-  ▶ **Bosnia & Herzegovina**
www.debra.ba
djeca.leptiri@hotmail.com
+387 33 328 284
-  ▶ **Brazil**
www.debrabrasil.com.br
web@debrabrasil.com.br
+55 (047) 3237 6243
-  ▶ **Bulgaria**
www.debrabg.net
contact@debrabg.net
+359 (0) 882 919 167
-  ▶ **Canada**
www.debracanada.org
debra@debracanada.org
+1 800 313 3012
-  ▶ **Chile**
www.debrachile.cl
info@debrachile.cl
+56 2 22 28 67 25
-  ▶ **China**
www.debra.org.cn
debra_china@163.com
+86 139 1850 3042
-  ▶ **Colombia**
www.debracolombia.org
info@debracolombia.org
+57 1 62 365 09

-  ▶ **Costa Rica**
www.debracr.org
info@debracr.org
+506 2244 3318
-  ▶ **Croatia**
www.debra.hr
info@debra-croatia.com
+385 1 4555 200
-  ▶ **Cuba**
debra_cuba@yahoo.com
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www.debra-cz.org
info@debra-cz.org
+420 532 234 318
-  ▶ **Finland**
www.allergia.fi/suomen-eb-yhdistys-ry
suomenebyhdistys.debrafinland@gmail.com
+358 9 473351
-  ▶ **France**
www.debra.fr
contact@debra.fr
+33 (0)7 78 95 83 44
-  ▶ **Germany**
www.ieb-debra.de
ieb@ieb-debra.de
+49 (0) 6461 9260887
-  ▶ **Hungary**
www.debra.hu
posta@debra.hu
+36 1 266 0465
-  ▶ **Ireland**
www.debraireland.org
info@debraireland.org
+353 1 412 6924
-  ▶ **Italy**
www.debraitalia.com
info@debraitalia.com
+39 02 3984 3633
-  ▶ **Italy (Südtirol - Alto Adige)**
www.debra.it
info@debra.it
+39 335 10 30 23 5

-  ▶ **Japan**
www.debra-japan.com
info@debra.sakura.ne.jp
+81 (0) 11 726 5170
-  ▶ **Malaysia**
www.debramalaysia.blogspot.com
debramalaysia@gmail.com
+60 12 391 3328
-  ▶ **Mexico**
www.debra.org.mx
debramexico@gmail.com
+81 8008 0352
-  ▶ **Netherlands**
www.debra.nl
voorzitter@debra.nl
+31 030 6569635
-  ▶ **New Zealand**
www.debra.org.nz
debra@debra.org.nz
+64 04 389 7316
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www.debra.no
-  ▶ **Poland**
www.debra-kd.pl
sekretariat@debra-kd.pl
+48 501 239 031
-  ▶ **Romania**
www.minidebra.ro
contact@minidebra.ro
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-  ▶ **Russia**
www.deti-bela.ru
info@deti-bela.ru
+7 (495) 410 48 88
-  ▶ **Serbia**
www.debra.org.rs
office@debra.org.rs
+381 (0)64 308 6620
-  ▶ **Singapore**
www.debrasingapore.com
debrasingapore@gmail.com
+65 9237 5823

-  ▶ **Slovakia**
www.debra-slovakia.org
debra.slovakia@gmail.com
+421 940 566 667
-  ▶ **Slovenia**
www.debra-slovenia.si
info@debra-slovenia.si
+386 31 348 303
-  ▶ **Spain**
www.debra.es
info@debra.es
+34 952 816 434
-  ▶ **Sweden**
www.ebforeningen.se
malin.ch.net@gmail.com
+46 (0)703 146 048
-  ▶ **Switzerland**
www.schmetterlingskinder.ch
debra@schmetterlingskinder.ch
+41 62 534 16 90
-  ▶ **Taiwan**
www.eb.org.tw
taiwaneb2010@gmail.com
+886 03 5734493
+886 0966 521836
-  ▶ **Ukraine**
www.debra-ukraine.org
info@debra-ukraine.org
svitdebra@gmail.com
+380 50 331 94 97
-  ▶ **United Kingdom (UK)**
www.debra.org.uk
debra@debra.org.uk
+44 (0)1344 771 961
-  ▶ **United States of America (USA)**
www.debra.org
staff@debra.org
+1 (212) 868 1573
+1 (855) CURE-4-EB

Get involved with **DEBRA International**

THE WORLD'S LEADING EB PATIENT ADVOCACY AND SUPPORT NETWORK

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