



## **PODIATRY**

**Footwear advice for parents caring for a child living with epidermolysis bullosa (EB)**

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



#### **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.**

**Júlia da Costa Landim, living with EB, aged 6, Brazil  
(photo credit: Rodrigo Landim Alves)**



Eden Hummerston, living with EB simplex, aged 6, United Kingdom

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## Who is this booklet for?

This booklet is for parents caring for a child 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 advice on footwear for parents caring for a child living with EB.

Topics covered in this booklet include:

- ▶ pre-walking stage of your baby
- ▶ why is footwear important for EB?
- ▶ footwear advice
- ▶ cushioning materials, insoles, and socks
- ▶ other considerations
- ▶ your child's environment
- ▶ wound care and pain management
- ▶ staying active and mobile
- ▶ how your child's 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 31.



When your child is learning to walk, it is advisable to allow your child to walk barefoot as much as possible. This encourages natural development of the foot and aids the development of walking by amplifying the feeling of different sensations and textures through the soles of the feet; often this is referred to as the motor skills development stage.

**These different sensations and textures through the soles of the feet can be reduced if footwear is worn too early.**

The benefit of barefoot walking does need to be considered alongside blister development. During this development time minor or even major accidents can occur. With an EB child, an accident often involves the development of blisters followed by pain (we will cover this later in the booklet). As parents, understandably you want to protect your children against all accidents and pain, as you do not want to see them suffer. However, it is also important for your child to find out for him or herself what their physical abilities are and learn his or her own boundaries.

### Tips to help with your child's motor skills development

- ▶ Allow your child to walk barefoot.
- ▶ Your child can wear just socks indoors.
- ▶ Shoes are not always necessary indoors.
- ▶ Use thick dressings on top of the usual layer to create extra padding for the knees and feet to minimise blistering when your child starts crawling/walking.

Special considerations for a child with severe EB would be to not walk barefoot but have layers of protective dressings.



### Recommendation from the occupational therapy CPG

Infants and children with EB should be encouraged to explore their environments with efforts to minimise blister formation.



Theo-Muzzi, living with EB, aged 1, Brazil (photo credit: Márcio Rodrigues/Lumini)



“ After some years of experience, I know that shoes have to fit perfectly before buying them. If not, it’s just a waste of money. If new shoes are painful I will not use them. New shoes have to feel perfect when I’m buying them. If not I can buy something else. Shoes for my son is difficult. If he gets blisters from wearing some shoes, he stops wearing them and we have to buy some new ones. When he gets new shoes I buy the same brand that I know works for me, and hope that it works for him too... ”

Kari Anne Bø, mother to Adrian living with EB simplex Oigna, aged 5, Norway

EB is a genetic skin blistering condition. Depending on the EB type and severity, it can affect any area of skin. Typically, it is prone to blistering and scarring in areas exposed to repeated application of pressure or friction. It is therefore not surprising to find that EB typically affects the feet. Although, due to the nature of EB, blistering in the feet is often inevitable, there are certain methods that can limit their creation, and the pain and discomfort that they bring.

**EB feet are typically affected by the footwear your child wears.**

### Recommendation

Have your child wear suitable footwear.

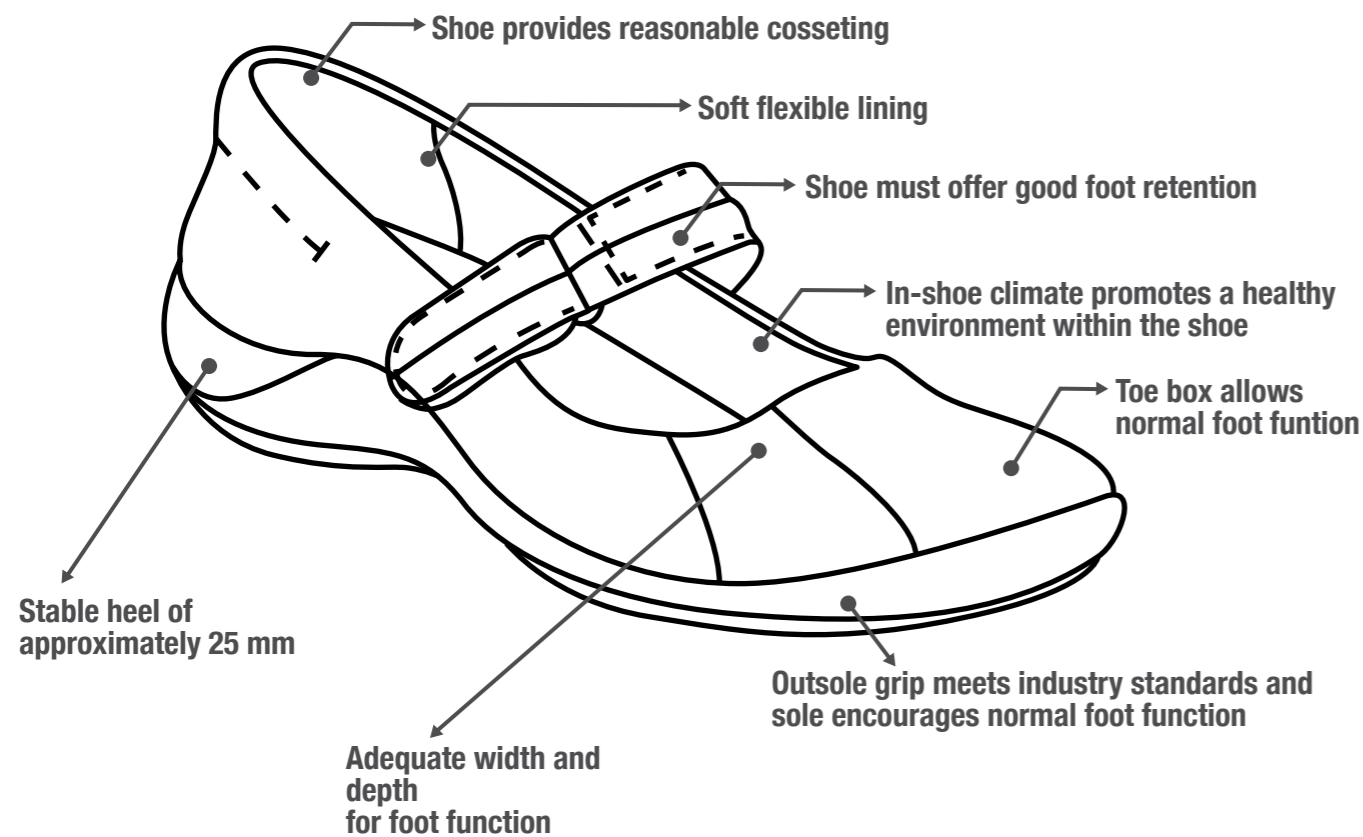
### Recommendation

Ensure that your child’s footwear is soft and breathable.

### Your child’s EB team/healthcare provider can:

- ▶ teach you protective bandaging techniques for:
  - the knees and elbows so that your child can crawl without causing serious injury
  - the feet when your child is first learning to walk.

This illustration shows key features of a suitable shoe.



The more active your child is going to be on any given day, the more likely the footwear advice above will be beneficial.

For your child to enjoy a healthy active life, taking good care of their feet is vital. Footwear can have a significant effect on the foot health and well-being of your child. Choosing suitable shoes is essential.

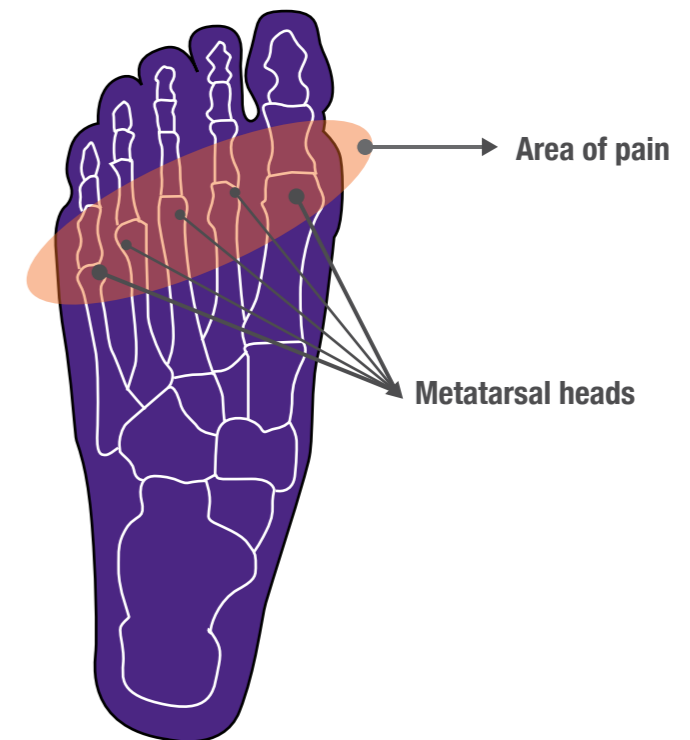
Feet are vulnerable areas of the body where footwear aims to protect, secure, and offer comfort through the changes of the day. Footwear is very specific to each child with EB. What works for one child may not work for another. However, symptoms in a fully developed foot are often improved if your child is able to support their feet with a stiff soled shoe or trainer.



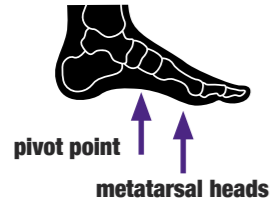
## Tips

- ▶ Make sure you are aware of your child's correct foot size (this can vary over time and between shoe brands or manufacturers).
- ▶ Footwear with fastenings provides the greatest support.
- ▶ Check there is enough room in the shoe for your child to wiggle their toes (6 mm between the tip of their longest toe and the end of the shoe).
- ▶ There should be enough width in the shoe to accommodate the whole foot; there should be no pressure points.
- ▶ Shoes should not slip at the back (if they slip whilst walking, slide your child's foot to the back of the shoe and readjust the laces/straps).

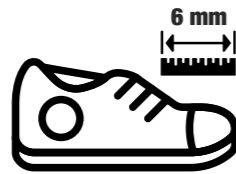
A supportive shoe can reduce the range of movement within the foot that results in blisters from friction. It is typically along the pivot point of the balls of the feet/metatarsal heads where blistering tends to be most prevalent.



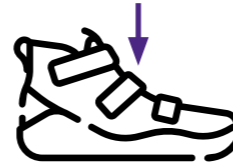
The images below demonstrate things to consider when choosing shoes.



The pivot point of the balls of the feet and metatarsal heads are where blistering tends to be most prevalent



There must be a minimum of 6 mm in front of the longest toe



Styles with a lace, touch and close fastening, or buckle provide most adjustment



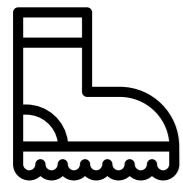
The heel must not slip up and down at the back



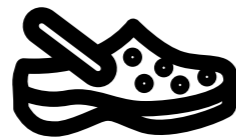
Ideally the tread pattern should extend over the whole sole and heel area



There should be enough width in the shoe to accommodate the whole foot; there should be no pressure points



Shoes with sheep skin inside can offer cushioning. Be aware of overheating



For summer choose shoes that let the feet breathe



Healthcare professionals and people with EB have reported the benefit of using corn starch on the soles of the feet and in between the toes to help control excessive moisture and reduce friction

Changes in temperature and weather

Rigid soled, supportive footwear is easier to wear in colder periods; however, it can also cause the feet to get hot.

Footwear is problematic in hot weather when rigid soled footwear tends to be heavier and provides less ventilation than softer, more flexible shoes. There are options in the summer that will be preferable to a standard sandal.

In this case, you need to decide what contributes more to blistering of your child's feet: heat or friction, and choose the more appropriate footwear accordingly. In certain cases, we find that footwear that provides a certain amount of support along with a lightweight/ventilated upper is a good compromise. One recent example of these are memory foam trainers.

Flexible footwear in warmer weather will often provide the most amount of ventilation as well as being the most lightweight. Both of these characteristics mean that this type of footwear is most often used in the hotter times of the year.



Isaque do Nascimento Gomes, living with EB Simplex, aged 5, Brazil (photo credit: Suelen Szymanski)





“ Since new shoes are always painful for Ira, I used to rub olive oil or Vaseline into the leather when she was a baby but now just try to wear them for her to break them in. Thankfully, we are now the same size. ”

Ritu Jain, mother of Ira living with EB simplex, aged 20, Singapore

Your child's shoe size does not stay constant throughout life. It is recommended that feet are measured every 2-4 months during childhood. If you do not have facilities close by, you could use the easy shoe size guide. Have your child's foot measured if they are feeling discomfort with their normal shoe size.

#### Tips from EB experts

- ▶ Make sure shoes are a comfortable fit: appropriate length and width, flexible, rounded end with plenty of room for the toes.
- ▶ A flat heel is better for heel support.
- ▶ Laces or straps prevent excessive movement or slipping of the foot inside the shoe.
- ▶ Seams should be flat or absent.
- ▶ The upper covering of the shoe should be made of leather or fabric mesh to allow air to circulate, rather than plastic or synthetic.

#### Tips from the EB Community

- ▶ Shoes have to fit perfectly before buying them.
- ▶ Wear shoes little and often at first around the house and garden.
- ▶ Rub oil or Vaseline into leather shoes.



Children are also exposed to peer pressure as they want to fit in and make friends even very early on in life. With a child that lives with EB this can be enhanced due to the visible nature of their EB if they have recessive dystrophic EB or the more invisible nature of their EB if they have EB simplex for example.

As your child grows older, how they dress themselves is a form of self-expression, which nowadays may start even before they are a teenager. In the case of children living with EB from birth, they mature earlier than their peers and may look for this self-expression earlier. This is a part of growing up, knowing themselves, and becoming aware of their body image. As stated before, your child will need to explore their boundaries even with footwear including footwear that is for the more fashion conscious.

**If you are a parent currently experiencing these changes with your child, it is important to at least restrict your child's activity as much as possible in this type of footwear due to the lack of support that they provide.**

Iasmin Santos Martin, living with EB simplex, aged 7, Brazil (photo credit: Suelen Szymanski)



In conjunction with appropriate footwear, specialised cushioning insoles have proven to help reduce pressure and friction underneath the foot, which can stop or reduce the development of blisters.

In EB clinical centres with dedicated specialist EB trained podiatrists, they may examine your child's feet and walking style using a plantar pressure readout system. If you do not have access to a specialist EB trained podiatrist then it would be useful to try and find a local, certified podiatrist who can liaise with your child's EB team about what type of insole may help your child. In some cases, you may find that anything that takes up additional room in your child's footwear (even a thin insole) may contribute to symptoms getting worse due to an increase in localised heat and/or a reduction in ventilation. It is always advisable to discuss this with your child's EB team prior to using something new.

There are certain accessories available that can help maintain comfortable feet. These include double layer socks, *Coolmesh* socks, silver socks, and silk. Silver socks can conduct heat away from the feet and help reduce friction; they also have antimicrobial properties. Silk, *Coolmesh* socks, and double layer socks also help to reduce friction. However, in some cases the extra layer of the double layer socks can increase heat and is therefore detrimental to some users.

Using dressings or barriers to prevent blisters can also be effective. Materials such as bi-stretch soft silicon *Spycra*, *Mepitel*, fixation bandage *Soft-One*, or hydrogel sheets *Kerralite Cool* can help cool the skin and reduce pain. Access to these materials will vary depending on where in the world you are. These materials can be easily cut to wrap around toes or cover larger areas where repeated blistering or scarring is a concern.



### Recommendations

- ▶ Wear suitable footwear and appropriate insoles for all types of EB.
- ▶ Suitable footwear should be supportive and minimise blistering by reducing friction.

Dystrophic (thickened) toenails are also a common development. If this is the case, it can also cause significant discomfort when wearing footwear as the thick nails can be squeezed by the shoe. This injury to the toe/toenails makes it more likely that the nails will continue to thicken over time and make the problem worse. In this case it is advisable to find a qualified podiatrist to provide professional care. Toenail removal may be possible for some people but in the majority of cases, ongoing professional nail care will provide the best outcome.

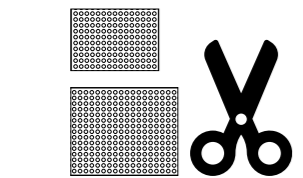
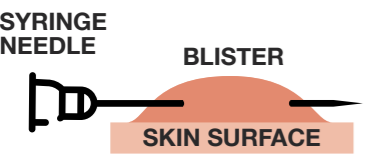
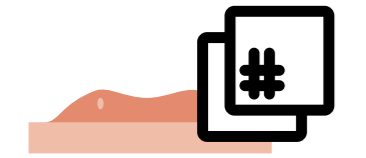


Unfortunately, once a nail is thickened, the damage is irreversible so will need ongoing attention. If your child does not have access to regular podiatry care, self-management by filing across the top of the nail can help relieve the symptoms of pressure within footwear.



### Tip

Healthcare professionals and people living with EB 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.

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

Before choosing whether or when your child should start wearing shoes, wound care and pain management need to be addressed. As EB blisters are not self-limiting and can spread, intact blisters on your baby or child should be lanced and fully drained even at the areas of the feet and toes. Your child's 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 22 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 child's pain control with their specialist EB trained podiatrist or EB team.



## Recommendation from the pain management CPG

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





“ Despite constant pain he still plays football and is a goalkeeper for a local team. Eden also does Jujitsu and he has the most amazing football coach (Dan) and jujitsu Sensei (Luke). They have both embraced Eden’s condition and made sure they have a good understanding of it to enable him to continue to do what he loves. As parents it is heartbreaking knowing he is in pain but also so reassuring knowing that he has the support to succeed! ”

Laura Hummerston, mother of Eden living with EB simplex, aged 6, United Kingdom

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

**Recommendations**

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

**Recommendation**

Exploring the environment and staying active are important at any age; you should start this with your child as soon as possible.



### How your child's podiatrist can help

Specialist EB trained podiatrists should be available to:

- ▶ examine your child's 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.

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

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



Elis Reque Ruiz, living with EB simplex, aged 6, 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.

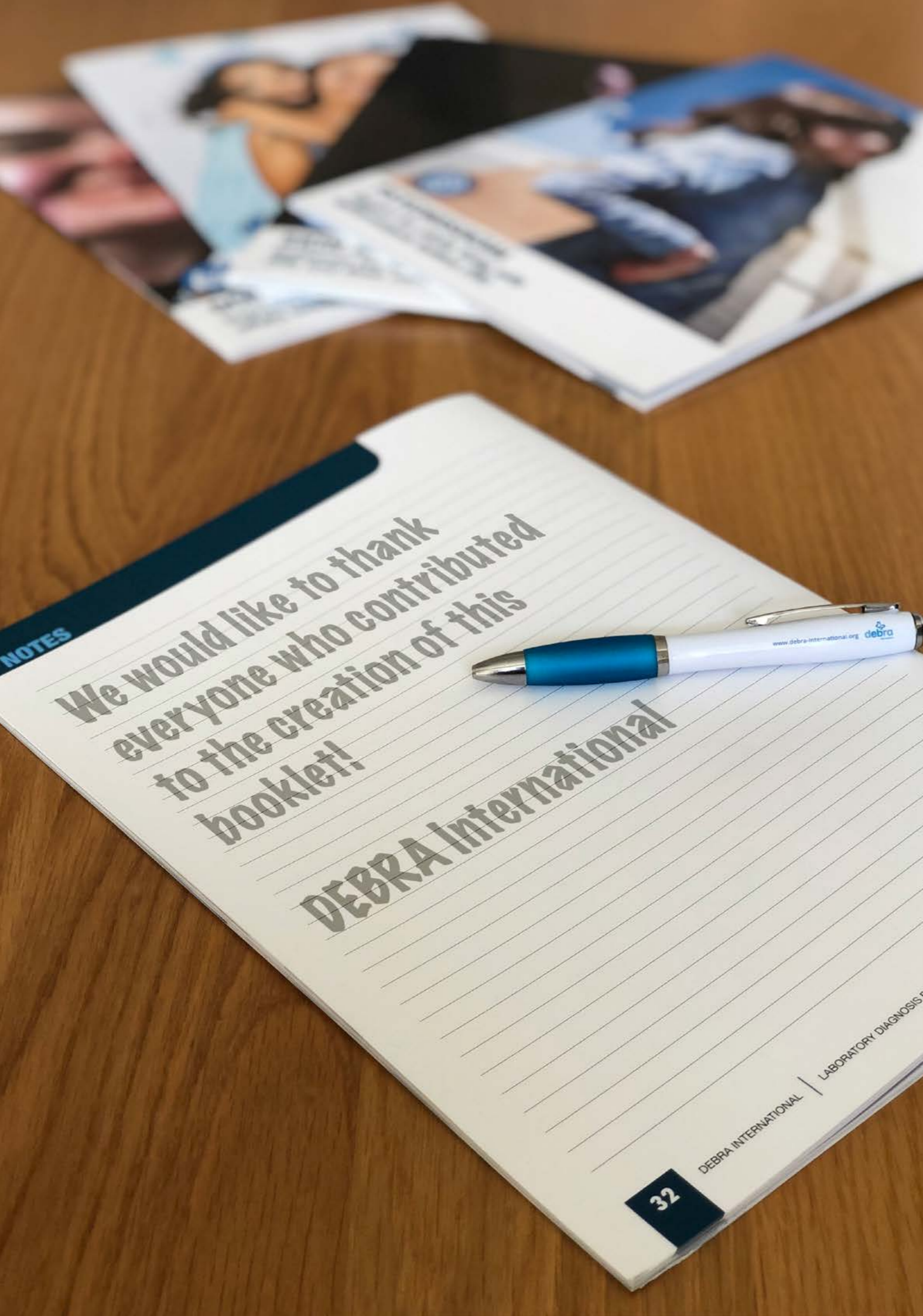
### Help us create new CPGs and patient versions

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](mailto: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](http://www.surveymhero.com/c/PatientVersionsSurvey)





**Gustavo Xavier Shibata, living with recessive dystrophic EB, aged 9, Brazil**  
(photo credit: Adrieli Carolina Fotografia)

**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](http://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](http://www.debra-international.org)



**Podiatry booklets**

- ▶ Podiatry dystrophic nail care for people living with epidermolysis bullosa (EB)
- ▶ Podiatry hyperkeratosis (callus) care for adults 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
- ▶ 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](mailto: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
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Person living with EB
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Person living with EB

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