



Podiatry care in epidermolysis bullosa

DEBRA International is undertaking a long-term initiative to develop clinical practice guidelines (CPGs) for EB. These guidelines will help improve the clinical and social care of EB patients across the globe.

This guideline is specifically focused on providing insight and recommendations into the topic of Podiatry in Epidermolysis bullosa.

Your responses to the following survey will directly affect the questions and issues addressed in the International Clinical Practice Guidelines for Podiatry in people living with Epidermolysis Bullosa.

This survey is designed for people living with EB, families, carers supporting people living with EB.

Confidentiality

Participation in this survey is voluntary. No compensation will be provided for completion. Any identifying information you provide will be used solely for interpretation of survey results to direct the clinical practice guideline process. By completing this survey, you consent to the use of any information you provide in this process.

1. Do you require feet care/podiatry care due to EB?

- yes
- no

2. What are your problem areas? (Select all that applies)

- Dystrophic nails
- Blistering and Wound management
- Mobility
- Shoes
- Hyperkeratosis (thickening of the outer layer of the skin.)
- Fusion of toes
- Dry and hardened areas
- Other (please specify)

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3. How often problems with your feet affect your activities?

	Never	Rarely	Sometimes	Often	Always	N/A
walking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
doing sports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
working	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
independence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
socialising	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
relying on others for help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4. Which problem areas do you think the guideline should concentrate on the most?

<input type="checkbox"/>	<input type="checkbox"/>	Dystrophic nails
<input type="checkbox"/>	<input type="checkbox"/>	Blistering and wound management
<input type="checkbox"/>	<input type="checkbox"/>	Mobility
<input type="checkbox"/>	<input type="checkbox"/>	Exploring the most suitable shoes for EB
<input type="checkbox"/>	<input type="checkbox"/>	Hyperkeratosis (thickening of the outer layer of the skin)
<input type="checkbox"/>	<input type="checkbox"/>	Fusion of toes

5. Do you have any other concerns relating to feet care that could be relevant to the guideline?

6. What do you use on your feet to prevent blistering? (Select all that applies)

- dressings
- vaseline gauze wrap
- seamless socks
- custom made shoe
- creams
- insoles or orthotics
- don't use anything

Other (please specify)

7. How do you think EB patients could be best supported relating to feet care?

- supported in the community by local health professionals
- supported in the hospital during regular hospital check-ups
- supported in patients own home by community staff and referred to hospitals if necessary
- Other (please specify)

8. What type of EB do you have? (for easier analysis only using the main types not the subtypes)

- EB Simplex
- Junctional EB
- Dystrophic EB
- Kindler Syndrome

9. What age group do you belong to?

- 0 - 5 years
- 5 - 10 years
- 10 - 18 years
- 18 - 25 years
- 25 - 35 years
- 35 - 45 years
- 45 - 55 years
- above 55 years

10. Where do you live?

- Europe
- North America
- South America
- Asia
- Australia Oceania
- Africa
- Other (please specify)



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Thank you!

Thank you for taking the time to complete this survey; your feedback will be used by the Podiatry CPG panel to develop the guideline.

DECLARATION

I understand that the information I provide will be used only for the discussion, direction, and development of the Podiatry Clinical Practice Guidelines.

I understand that all data collected through this survey will be anonymised and will not become identifiable in the guideline development process. For more details on how DEBRA International uses your information, please visit www.debra-international.org.