

The power of networks

Clinical practice guideline development

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This is Casey. She has EB



We need guidelines to improve care for patients....
and to support clinicians

Caring for someone with EB is.....



Nerve-racking
Humbling
Emotional
Tough
Hard
Difficult
Overwhelming
Fearful
Upsetting
Frightening

Clinical practice guidelines

– a major project for DEBRA International

Pain management

Cancer care

Oral Health Care

Wound care



The screenshot shows the DEBRA International website. The top navigation bar includes 'DEBRA Epidermolysis bullosa Patients Med. professionals Research News & Events'. The main content area features a banner with the text 'This is how life feels to people with EB.' and an image of a person's back with a large, colorful, textured lesion. Below the banner, the text reads: 'Clinical Practice Guidelines (CPGs) for EB DEBRA International is driving the development of a series of clinical practice guidelines (CPGs) for EB. These guidelines will help improve the medical care of EB patients across the globe.' To the right, there is an image of two healthcare professionals. The left sidebar menu is circled in black, with 'Clinical Practice Guidelines (CPGs) for EB' highlighted. Other menu items include 'DEBNET', 'Developing a guideline for EB', 'Oral health care', 'Wound care', 'Pain management', 'Cancer management', 'Nutrition', 'Occupational therapy', 'Professional training', and 'DEB Patient registry'. At the bottom, there is a section titled 'How life feels with EB' with an image of a person's face.

Acknowledging the challenges



Providing solutions





Understanding the priorities

Building a community

Applying best practice

... And a large dose of GWP

The way forward

EB-CLINET – an example of the value of a clinical network



Have your say in the future of clinical practice guidelines for EB

Why complete this survey?

How could the ERNs facilitate?



European
Reference
Networks

Gathering
experts

Providing
guidance on
methodology

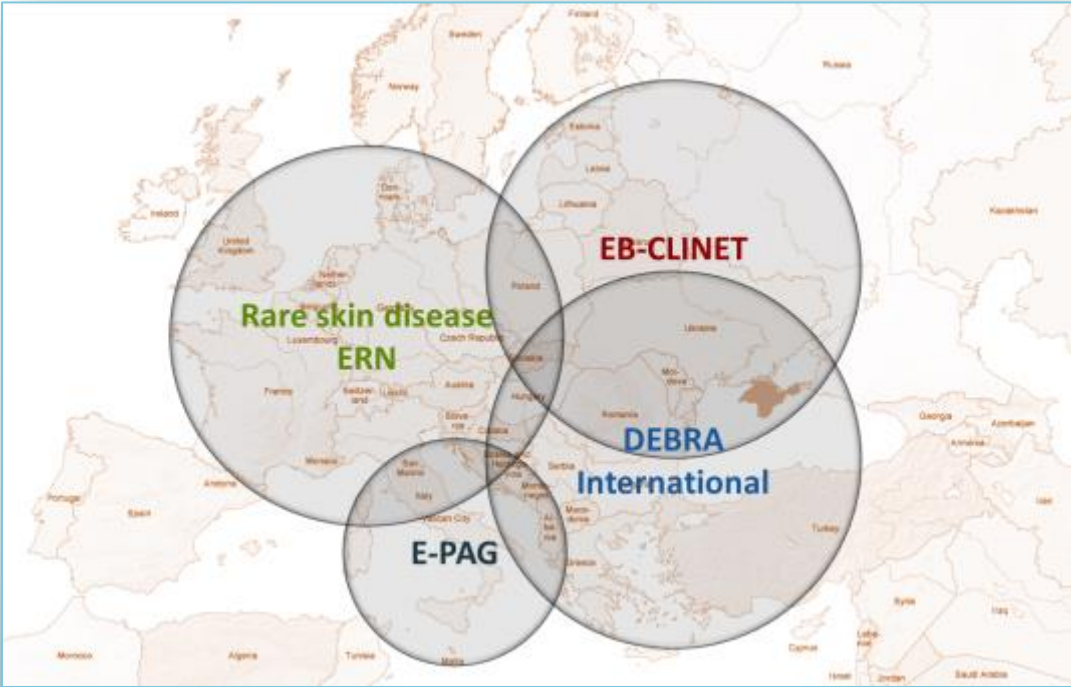
Disseminating

Implementing

Addressing
evidence gaps

Providing
Funding

Looking to the future



Thank you!

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