



**Case study:**  
**Guidelines for EB (epidermolysis bullosa)**

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*Eurordis Membership Meeting, 2014*

# Talk overview

**A little about EB**



**The need to develop clinical practice guidelines for EB**



**How we initiated the project**



**Challenges experienced**



**Efforts to improve the project**



**Some general thoughts on clinical practice guidelines in RD**

# EB (epidermolysis bullosa)



# Clinical care for EB



Our aim is to have a guideline that supports decision making, in each of the major aspects of care. They should be:

- The only such guideline
- Developed to the highest standards possible
- Available to all

# Why develop guidelines for EB?

A complex condition to treat

Being rare adds to this challenge

Limited guidance for clinicians

Varied clinical practice



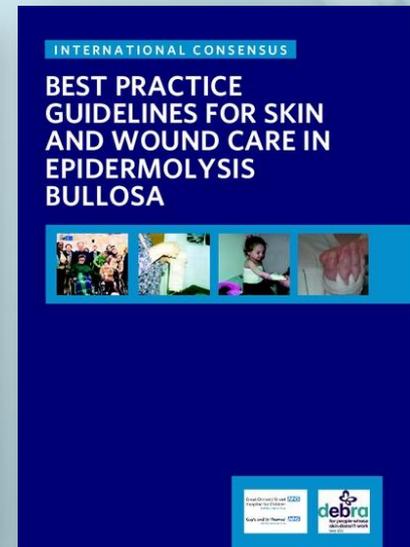
Who else would do it?

# Early experiences in the project



Dr Francis Palisson

Approached leaders in the EB medical field and encouraged them to develop guidelines.



# Challenges in the development of EB guidelines

Variation in adoption of a methodology

Very demanding for clinical leads

Duplication of effort

Lack of an evidence base

The need to be international



## UNORTHODOX METHODS OF WOUND CARE IN EB

While those with EB seen at centres in the UK are fortunate to have access to a great selection of dressings, others in less developed countries or where finances are limited must seek alternative methods of wound care.

Table 17 shows a few examples we have learned from resourceful families and healthcare professionals.

# Strengthening the project

## Refining the processes and providing more support

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



Developing a guideline for EB

What is the DEBRA International clinical practice guideline? DEBRA International embarked on a project in 2009 to improve patients, by creating a series of clinical practice guidelines (CPG) one guideline for each of the major clinical areas involved in EB. Each of the guidelines should be developed to the highest quality but each of the guidelines should be developed to the highest quality that but each of the guidelines should be developed to the highest quality that requires the use of an appropriate methodology, complete trial process and the involvement of a panel of experts and patient overview of the project's purpose, see [Clinical Practice Guidelines \(CPG\) for EB](#).

Hand Surgery in EB	high priority
Oesophageal Dilatation in EB	high priority
Eye Care in EB	high priority
Diagnosis of EB	high priority
Anaemia in EB	priority
Occupational Therapy in EB	priority
Renal Disease in EB	priority
Social and psychological care	under consideration
Physiotherapy in EB	under consideration

DEBRA International / Registered Charity No. ZVR 952763489

**debra**  
International

DEBRA International  
Clinical practice guideline submission form

Please read all sections of the [Developing a guideline for EB](#) page on the DEBRA International website, before completing this document.

(A) GENERAL INFORMATION

APPLICANT

Title	Surname	First names

INSTITUTION

Department	Post held by Applicant

Full official postal address of Applicant

Telephone number

(B) PROPOSED GUIDELINE TOPIC

PROPOSED TOPIC

PROPOSED DURATION

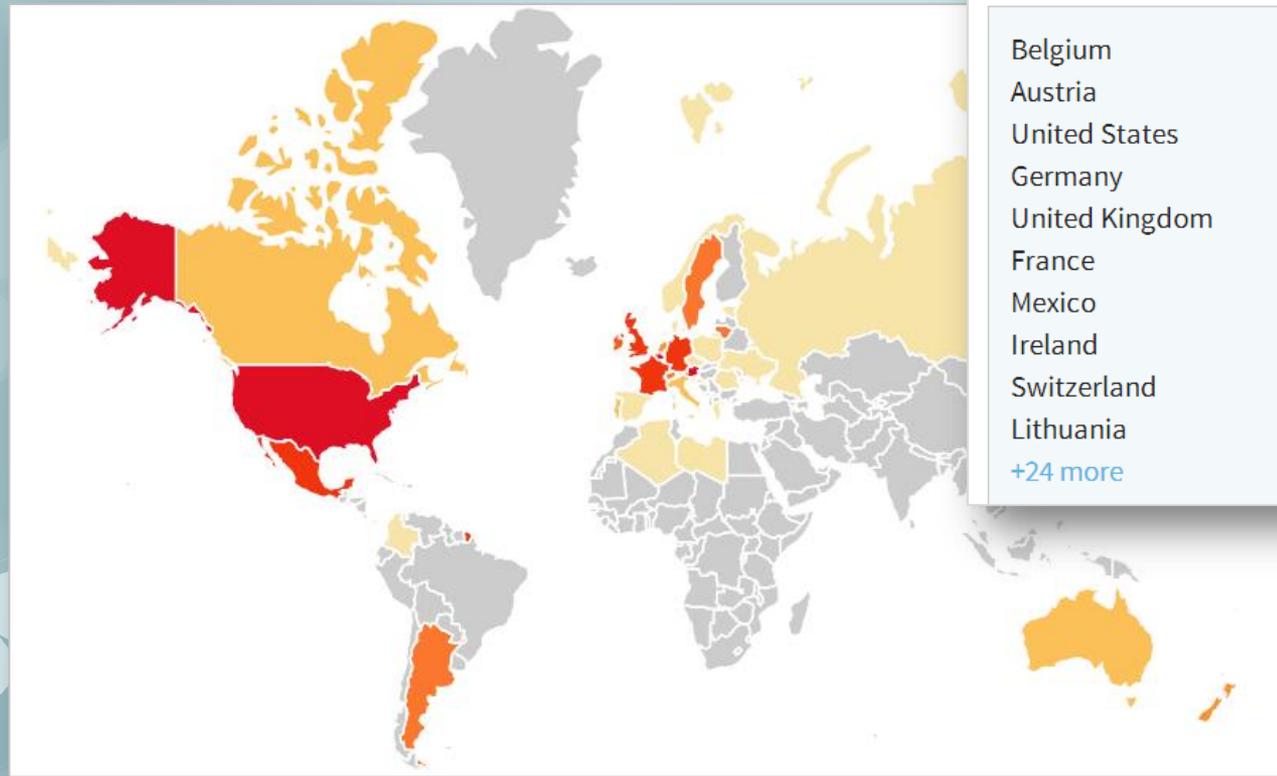
PROPOSED START DATE  
DD / MM / YYYY

Guidance notes

Prioritising topics

Application form

# Putting out a call



Top Countries (clicks / % of total)

Belgium	9	9%
Austria	8	8%
United States	8	8%
Germany	7	7%
United Kingdom	7	7%
France	7	7%
Mexico	6	6%
Ireland	5	5%
Switzerland	4	4%
Lithuania	4	4%
<a href="#">+24 more</a>		

# Challenges that have arisen

Do interested groups really understand what is involved?

How to we persuade people to be guideline leaders?

How do we manage expectations around DEBRA's involvement?

What to do if more than one person wants to lead?



# What do we still need to work on?



Providing guidance on methodology

Formalising patient involvement



Considering issues around implementation

Ensuring they are accessible for all



Ensuring they influence future research



# Are CPGs in RD possible and meaningful?

Force  
consensus

Encourage  
patient  
input

Point to  
gaps in the  
research

Provide  
something  
to build on

Principled but pragmatic

# Thank you!



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