**Priority setting for treating epidermolysis bullosa**

Cochrane review Rev #22 Interventions for mucous membrane pemphigoid and epidermolysis bullosa acquisita

*Please note that although our Cochrane reviews may address some of the priorities identified in the priority setting process the poor quality of the studies found has generally meant that no definitive answers can currently be given to these questions.*

1. **Wound care**.
This was a fundamental issue for patients, carers and healthcare professionals and is the one with more unanswered questions about it.

2**. Itch.**

It is an important issue for all participants, leading to important discomfort and decreased quality of life.

3. **Pain.**

Pain is a big problem for DEB (dystrophic epidermolysis bullosa ) patients. It was felt by participants that part of it could be solved by proper application of current knowledge, and involvement of pain management specialists in DEB care. However, it was also felt that there are some questions about pain therapy that were specific for the disease, such as treatment of pain during baths or during cures, that might require specific research. (For example, some authors report decreased pain after adding salt to the bath water).

4. **Neoplasms**,

Especially issues of early detection and treating squamous cell carcinoma.

5. **Syndactyly (fusion of digits).**

There is a lack of knowledge about what the best method in preventing or delaying syndactyly is as well as in correcting syndactyly once it is established.

6. **New therapies**.

There was a shared thought about the importance of investigating new therapies in order to discover a cure for the disease and also find new techniques such as genetic engineering that could offer betters outcomes in the most common signs and symptoms of DEB. However these were rated lower than research on everyday problems