

An introduction to best practical EB-guidelines

Francis Pallison ,M.D. , Chili

History

During the International EB meeting in Belgium 2008, the President of DEBRA International, Mr. Graham Marsden, defined:

«One of the best form to improve the quality of life in EB patients is to develop best clinical practice guidelines in every aspect that they need»

Starting to develop this initiative there was first a need to think about the protocol concerning the development of these guidelines. These thoughts led tot the following outcome;

“We want to resolve specific clinical problems in the best way, based on a systematic and careful review of all the literature published in the field. This is reviewed by an international committee of experts and a consensus of recomendations is generated, all approved by an international group of EB patients/parents. Finally, these are re-checked by the group of experts and published for world wide use.”

Of course this kind of approach caused problems :

- It was a huge amount of work.
- It had to be on an international level, multi-centered, involving not only a group of experts, (because that could be a partial view) but also EB-patients and their care-takers.
- There are many items concerning EB that are not published and even not studied yet.
- There is new evidence coming, so there is a constant need to re-check the guidelines periodically
- It takes almost 2 years to develop a guideline; it is expensive.

But the advantages were and are:

- In this way you can standarise the best care treatments and recomendations for EB
- It provides teaching opportunities for professionals and patients /relatives about the clinical problem
- This approach stimulates the interaction between different specialists from different EB-centers, helps to share experience and define new protocols for Clinical Research.
- It creates the possibility to receive the feedback from the leaders of the different EB-groups, working on these topics on their current recommendations.
- Welcomes the comments from a patient perspective to integrate those comments into the draft guidelines.
- Stimulates all the persons concerned to ask all type of questions to define future guidelines.

The next presentations will be based on (the development of) the following guidelines:

- Dental care (Is published: see presentation of Susanne Krämer)
- Pain Management (Is going to be developed; see K.Goldschneider)
- Occupational Therapy (Will be published in 2012; see Florian Prinz)
- Cancer in EB (Is gong to be developed; see J.Mellerio)