

EB-DD-HHD group meeting Minutes
EB Gp Meeting during BOARD Meeting
11.12 December 2025

Ongoing tasks: Where we are?

1. **DEB score** Christine B – manuscript draft will be circulated to all participants to the Delphi process in January 2026
2. **Practical EB Guidelines:** Literature review and expert advices for updating “older” EB guidelines: Christine B
Input from the group:
Update of existing guidelines is needed, in particular for wound management
 - i. This should be in the form of a practical approach and recommendations
 - ii. Add existing national specific therapy plans to the material used for recommendations
 - iii. The European consensus for therapies should also serve for discussions with regulatorsRecommendations for follow-up and management of specific EB types would be useful in centers and should be developed as a future task.
A scoring system for EBS would be necessary and should be developed as a future task.
3. **Delayed puberty in RDEB:** Sophie G and her team in collaboration with Endo-ERN conceived a questionnaire to identify the need for research on this topic. This questionnaire was circulated in the group. Clinical research should figure out if and which treatment should be given in such cases.
4. **EB trial failures.** Christine Maria Wagger and collaborators (Salzburg, Groningen and Bucharest) designed a study to identify which factors influence /determine EB trials to be successful or to fail. The study is based on the analysis of the literature and on questionnaires. Questionnaires can be still completed in case the group members wish to participate. The results are expected soon.
5. **COSEB: an update** Martin Laimer and his international collaborators initiated this study to identify and harmonize endpoints in EB. The methodology is well established and based on analysis of the literature and different rounds of Delphi in working groups. The work is ongoing.
6. **Training and education – ongoing**
7. **Scientific eLearning with clinical cases:** Maya EH (Cristina H., Anna-Lena Hillebrecht) – ongoing
8. **eTraining for patients:** Carmen S. – will be discussed in next meetings