

EB ERN-Skin Thematic Group Web Conference
24th February 2023
Agenda

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_ 14h-14h20 -EB Clinical Outcomes, by Marieke Bolling

The International project and ERN-Skin contribution

_ 14h20-14h40, by Martin Laimer

A systematic review on immunomodulatory/disease modifying mediators hitherto reported in the literature (stratified based on preclinical/clinical data, subtype, level of „evidence“), with the perspective to match data with drug/compound libraries and identify promising/feasible candidates.

_ 14h40-15h : RDEB Clinical Severity Score : (Christine and Cristina)

Goal : Create an severity score for dystrophic EB easy to use in clinical practice and in clinical trials : with Delphi method

>> state of play :

on going bibliography studies / estimated delay : end of summer 2023

Waiting for a quote for Delphi Method (organizing aspect)

+ if remaining budget : possible de visu meeting for 2nd part of this work

15h-15h20 Dental Practical Guidelines (Cristina)

“Dental care pathways for patients with epidermolysis bullosa: consensus clinical position statement from the European Reference Network for Rare Skin Diseases

>> state of play : manuscript in preparation

Practical guidelines "management of newborn and infants with EB (Maya, Giovanna)

>> state of play : under development

Plan to be discussed

1st part : draft to be proposed & discussed

15h20-15h30 CPMS: calendar of panels (Valérie)

15h30

More proposals : research studies or any other study, please feel free to propose, you're very welcome!