

ERN Support and Training programme- WP17- EJP RD

Report Workshop “Epidermolysis bullosa: from genes to translation into therapies”

Date/Venue/Format

23-24.03.2023 / Biology I Haupstr. 1, 79104 Freiburg, Germany / hybrid

Numbers (participants, speakers, ERNs represented, patient representatives)

54

Participants 39

Speakers 15

ERN represented 38

Patient representatives - none

Analysis of the workshop satisfaction survey

20 participants filled the survey, 15 had attended in person and 5 online

Rating

Programme: excellent 17, good 2, fairly good 1

Organisation: excellent 19, good 1

2-3 participants' testimonials

The insights into the workflow in other EB outpatient clinics, as well as preclinical work models were very interesting. The limited number of participants clearly enabled a low-threshold exchange with Expert.

Combining both clinical care and research in EB, within a relatively 'small' setting so you had the opportunity to talk to experts and raise questions. Good program and nice social event with a very nice hotel. It give me a lot of ideas for both research and our clinical care so I'm grateful for the opportunity to attend the event!

That it was really focused on EB and especially EB research

If applicable a main result of the workshop (e.g. working group created to do)

A good balance between the workshops and enough time to meet other people and to connect with them.



« This project has received funding from the European Union's Horizon 2020 research and innovation programme under the EJP RD COFUND-EJP N° 825575”

Conclusions, lessons learned, best practice to keep in mind.

The format was effective because the workshop was focused on one group of disorders and included both clinical and scientific aspects. In particular, juniors had the chance to meet senior scientist and know each other. It would be important to organize such meetings every 3-5 years to form the future generations.

