

BUR- EB


*Changes in the Socio-economic Burden
of Epidermolysis Bullosa in Europe*

Kick-off meeting

AGENDA



7th March 2022. 9.30h (CET time)

 Zoom (online). Link to the event:

<https://us02web.zoom.us/j/88248891381?pwd=Z2NEYWI6T29pMDVGRFNXNHh0d2J2UT09>



[Open session to all members and patient associations]

09.30 – 09.40	Welcome	Renata Linertová (BUR-EB Project Coordinator, FIISC)
09.40 – 10.30	Introduction of partners	All partners – max. 5 min/partner
10.30 – 10.45	European Joint Programme on Rare Diseases presentation (EJP RD)	Diana Dèsir Member of EJP RD's Coordination Team
10.45 – 11.00	Background of BUR-EB: BURQOL-RD, burden of rare diseases	Renata Linertová (BUR-EB Project Coordinator, FIISC)
11.00 – 11.15	Coordination and organization	Michelle Perello (CE) / Renata Linertová (FIISC)
11.15 – 11.45	Coffee break	

[Open session for official project partners only]

11.45 – 12.00	WP1 – Methods revision and Situational analysis	Verónica Alonso (IIER)
12.00 – 12.15	WP2 – Development of tools	NEMH
12.15 – 12.30	WP3 – Data collection – Survey	Samira Oulahsein (DEBRA International)
12.30 – 12.45	WP4 – Data analysis	Márta Péntek (HECON)
12.45 – 13.00	WP5 – Qualitative study: Patient Journey Map and co-creation of capacity building materials	Alezandra Torres (FIISC)

13.00 – 14.00		Lunch break
14.00 – 14.15	WP7 – Communication & Dissemination	OPBG
14.15 – 14.45	Ethical issues	Cristina Has (UKF)
14.45 – 15.00	Follow-up tasks and discussion	Renata Linertová / All
15.00		Kick-off meeting closure