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Project title: Changes in the Socio-economic Burden of Epidermolysis Bullosa in Europe - BUR-EB research project (2022-2025)”

RESEARCH REPORT

Changes in the Socio-economic Burden of Epidermolysis Bullosa in Europe - BUR-EB research project (2022-2025)

Project description

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ÓBUDAI EGYETEM
ÓBUDA UNIVERSITY



NATIONAL RESEARCH, DEVELOPMENT
AND INNOVATION OFFICE
HUNGARY

PROJECT
FINANCED FROM
THE NRDI FUND

CHANGES IN THE SOCIO-ECONOMIC BURDEN OF EPIDERMOLYSIS BULLOSA IN EUROPE

BUR-EB RESEARCH PROJECT (2022-2025)

PARTICIPATING PARTNER FROM HUNGARY

Health Economics Research Center (HECON), University Research and Innovation Center, Óbuda University

Leader: Prof Márta Péntek DSc

Researchers: Prof László Gulácsi DSc, Dr Zsombor Zrubka PhD

FUNDING

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BACKGROUND

Epidermolysis Bullosa (EB) is a rare genetic skin disorder with no cure that places an enormous social and economic burden on patients and their families. Studies on this burden are scarce.

RESEARCH AIMS

This international research project (BUR-EB) funded by the European Union's Horizon 2020 programme and NRDI Fund (Hungary) aims to estimate the socio-economic burden of EB in 7 EU countries (Spain, France, Germany, Italy, Hungary, Austria and Bulgaria), and to compare it to data collected 10 years ago in a previous project (named BURQOL-RD).

Data related to the impact of EB on every-day life are collected from affected persons and their caregivers via an anonymous survey in collaboration with clinicians and patient organizations (DEBRA). The economic burden takes into account costs of healthcare and informal care, financial burden for families and productivity losses of all affected persons. Quality of life and family burden are also measured. Besides, affected persons will co-create a map of their trajectories of care and needs. Based on these needs, information materials will be developed to help patients and their families cope better with the illness.

HECON team (Óbuda University) leads the data analysis and cost-of-illness assessment in all the 7 countries of the project and participates in all work packages offering health economics expertise.

EXPECTED RESULTS AND IMPACT

BUR-EB offers an opportunity to observe how the social and economic impact of EB has changed over the last decade and how these changes could be connected to the health and social policies implemented during that period. The project will provide tools that could be used in clinical studies of novel therapeutic options. BUR-EB is backed-up by a balanced multidisciplinary group of internationally recognized clinical dermatologists, health economists, qualitative research experts, biostatisticians and representatives from patient organizations.

PROJECT HOMEPAGE

<https://www.bur-eb.com/>