

Researcher (s):	DDr Gudrun Salamon
Research Institution:	Sigmund Freud University Vienna, Austria
Project Title:	Burdens and helpful aspects for achieving and maintaining quality of life with epidermolysis bullosa
Research Area:	Psychosocial/Advocacy
Start Date: June 2022	End Date: June 2023
Funded by:	DEBRA Austria and Ireland
Lay Summary	
<p>Apart from the medical aspects, quality of life is a crucial factor in the well-being of those living with a chronic condition, such as EB. The balance between individual burdens and resources is essential. In the study, a special focus is placed on what was or still is perceived as helpful assuming that EB does not only have an impact on those affected themselves, but also on their relatives.</p> <p>Since summer 2019, DDr Gudrun Salamon, researcher in the faculty of psychology at the Sigmund Freud University Vienna has been leading a research team of six people on the project of "Burdens and helpful aspects for achieving and maintaining quality of life with epidermolysis bullosa".</p> <p>In cooperation with DEBRA International, DEBRA Austria, and the EB-Haus Austria, the team are currently conducting an online survey on burdens and resources in EB with the international EB population (in German and English).</p> <p>Participation in the study will provide valuable experience and will help the team to build a better understanding on burdens and helpful factors in dealing with EB with the aim of being able to provide better support to people living with EB as well as their relatives.</p>	
Project Abstract	
Not provided as we only funded an Irish analysis of the data set, DEBRA Austria funded main project	
Blog post written about project for website	
None	

Quotes we have from Researchers

None

Researcher (s) Bio

None
