

Does your child have Epidermolysis Bullosa?

Do you also have a child without EB?

Are they between 7 and 16 years old?

Would you be willing to share your experience?

What is it about?

I would like to invite **you and your child** to take part in a research study which aims to explore the family experience of EB, with a specific focus on the experience of **siblings** living with a brother/sister with EB.

Why take part?

To our knowledge, no research has specifically focused on the experiences and views of siblings.

This research provides the opportunity to have yours and your child's voice heard. **This can help professionals better understand what support families affected by EB need.**

I have worked closely with **DEBRA UK** and families impacted by EB to develop the research.

What should I expect?

You and your child will be asked to complete separate one-to-one interviews about family life and the experience of having a child/sibling with EB.

Participants will receive a £20 voucher as a thank you!

Contact: downeys1@cardiff.ac.uk

Sarah Downey, Trainee Clinical Psychologist

Supervised by Dr Andrew Thompson, Dr Nicola Birdsey and Dr Gary Burgess