

Freedom of Information Request	FOI 22-522	14 th November 2022
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I am writing to you under the Freedom of Information Act 2000 to request the following information from Aneurin Bevan Health Board.

Please will you provide me with the following information by reply in electronic format.

- 1. The number of people in your ICB/ICP area who have been diagnosed with Epidermolysis Bullosa during the past five years. During the past 5 years 6 patients were treated as an inpatient or daycase in one of the Health Boards hospitals with a diagnosis of epidermolysis bullosa. Please note the Health Board is unable to advise when a diagnosis was made as there is no outpatient data available.
- 2. The number of people with Epidermolysis Bullosa referred to one of the UK's specialist EB treatment centres in the past five years.

 The Health Board does not record this information.

Note: Specialist centres include children's services at Birmingham Women's and Children's Hospital, Glasgow Royal Hospital for Children and GOSH and adult services at Glasgow Royal Infirmary, Guy's and Thomas' Hospital and Solihull Hospital.

3. How many GPs and frontline healthcare professionals have received training on Epidermolysis Bullosa diagnosis and care within your area. Please refer to training undertaken where possible.

The Health Board does not hold this information for GP or frontline healthcare professionals. With regard to GP's, you may wish to contact each GP practice direct as they may hold the information.