

**Freedom of Information Act 2000 - Request Reference FoI/22/513**

**Epidermolysis Bullosa**

**Information Requested:**

1. The number of people in your ICB/ICP area who have been diagnosed with Epidermolysis Bullosa during the past five years.
2. The number of people with Epidermolysis Bullosa referred to one of the UK's specialist EB treatment centres in the past five years.

*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.

**Response details:**

- Cardiff and Vale University Health Board (the UHB) does not hold this information. Under Section 16 of the FOIA, which provides us with the duty to advise and assist, the UHB can inform you that the UHB have not diagnosed or referred epidermolysis Bullosa in the last 5 years.
- The UHB does not have formal training program for GPs and frontline health care professionals on EB. However, the UHB have a dermatology on call service and all our trainees and consultant colleagues are familiar with management and referral process for suspected EB patients.