



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Bae Abertawe
Swansea Bay University
Health Board

Cadeirydd/Chair: **Emma Woollett**
Prif Weithredwr/Chief Executive: **Mark Hackett**

gofalu am ein gilydd, cydweithio, gwella bob amser
caring for each other, working together, always improving

Rydym yn croesawu gohebiaeth yn y Gymraeg neu'r Saesneg. Atebir gohebiaeth Gymraeg yn y Gymraeg, ac ni fydd hyn yn arwain at oedi. We welcome correspondence in Welsh or English. Welsh language correspondence will be replied to in Welsh, and this will not lead to a delay.

Cais Rhyddid Gwybodaeth / Freedom of Information request **Ein Cyf / Our Ref: 22-J-042**

You asked:

1. The number of people in your Health Board area who have been diagnosed with Epidermolysis Bullosa during the past five years.

I can confirm that this information is not held centrally. Patients seen under Dermatology as an Outpatient are not "coded" on our system. To obtain this information would involve a manual trawl and search of records which we have estimated would significantly exceed the 18 hours limit set down by the FOI Act as the reasonable limit. Section 12 of the FOI Act and The Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulation 2004 provides that we are not obliged to spend in excess of 18 hours in any sixty day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time.

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.

Please see Q1

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.

I can confirm that the Health Board does not hold this information. GPs are independent practitioners, and you would need to contact the individual practices for this information.



Pencadlys BIP Bae Abertawe, Un Porthfa Talbot, Port Talbot, SA12 7BR / Swansea Bay UHB Headquarters, One Talbot Gateway, Port Talbot, SA12 7BR

Bwrdd Iechyd Prifysgol Bae Abertawe yw enw gweithredu Bwrdd Iechyd Lleol Prifysgol Bae Abertawe
Swansea Bay University Health Board is the operational name of Swansea Bay University Local Health Board