

Our Ref: PW/AKB/FOI-04-359

3rd May 2023

Stafford Education & Enterprise Park
Weston Road
Stafford
ST18 0BF

Telephone: 0300 123 1461

Sent by email

Dear

FOI-04-359

Your request for information under the Freedom of Information Act 2000

Thank you for your request for information received on the 28th April 2023. We can confirm that the Staffordshire and Stoke-on-Trent Integrated Care Board can provide the following information.

Please see our responses in blue below:

My question is:

1. How many individuals were identified to have a CACNA1C gene change as a result of genetic testing during the year 2022 and during the year 2021?

When a genetic change is found it is categorised according to the ACGS Guidelines (Association for Clinical Genomic Science). Ideally your response to how many individuals identified would indicate the classification of the findings with regard to number of individuals ie. Pathogenic, Likely pathogenic, Variant of Uncertain Significance, Likely benign and Benign.

The ICB do not hold this information. Genetic testing does not fall under the commissioning responsibility of the ICB and rests with NHS England. The contact details for NHS England are as follows:

NHS England - https://www.england.nhs.uk/contact-us/foi/

Right of Appeal

Should you require any further information or clarification regarding this response please do not hesitate to contact us. If you are dissatisfied with the response, you are entitled to request an internal review which should be formally requested in writing and must be within two calendar months from the date this response was issued.

Chair: David Pearson MBE Interim Chief Executive Officer: Peter Axon



To request an internal review

You can request an internal review by contacting the Staffordshire and Stoke-on-Trent Integrated Care Board FOI team by emailing the team at StaffsStokeFOI@staffsstoke.icb.nhs.uk or by post to the address at the top of this letter.

If you are not content with the outcome of your internal review, you may apply directly to the Information Commissioner's Office (ICO) for a decision. Generally, the ICO cannot make a decision unless you have exhausted the Staffordshire and Stoke-on-Trent Integrated Care Board's FOI complaints procedure.

The ICO can be contacted at:

Information Commissioner's Office Wycliffe House Water Lane Wilmslow Cheshire SK9 5AF

www.ico.gov.uk

Yours sincerely

Paul Winter
Associate Director of Corporate Governance

Chair: David Pearson MBE Interim Chief Executive Officer: Peter Axon