

Date: 02 May 2024
Our ref: K: FOI/Ref: 2024-000159
Email: nss.pcf-foi@nhs.scot

Dear [REDACTED]

Freedom of Information Reference: FOI-2024-000159 – congenital hyperinsulinism (CHI) treatment.

I refer to your freedom of information request that we received on 15 April 2024 requesting the following information.

I am looking for:

Out of all the births that were registered in the whole of Scotland in the whole year from January 1st 2022 to December 31st 2022, how many babies received congenital hyperinsulinism (CHI) treatment?

Then likewise for the years 2019 and 2018. I do not wish for any personal details, I am looking only for numbers, no other details please.

We have now completed the search of our records and can provide you with the following information:

Under Section 17 of the Freedom of Information Act, 2002 (FOISA) an organisation does not have to provide that information if it does not hold it. NHS National Services Scotland (NSS) does not hold the information you have requested. NSS, National Services Division (NSD) do not commission or provide clinical services where infants are treated for hyperinsulinemia.

We can advise that NSS NSD manage the Scottish Paediatric Endocrinology Network (SPEG) which involves clinicians from Scotland collaborating on various pieces of work to improve the diagnosis and management of endocrinological problems in children and young people. Since SPEG was established, we are aware of approximately 50 children of various ages with a diagnosis of hyperinsulinemia across Scotland.

For more information I would advise you to contact each territorial health board. Email addresses are as follows:

Ayrshire and Arran - foi@aapct.scot.nhs.uk

Borders – foi.enquiries@borders.scot.nhs.uk

Dumfries and Galloway – dg.feedback2@nhs.scot

Fife – fife.foirequestfife@nhs.scot

Forth Valley – fv.freedomofinformation@nhs.scot

Grampian – gram.foi@nhs.scot

Greater Glasgow & Clyde – foi@ggc.scot.nhs.uk



Chair
Chief Executive

Keith Redpath
Mary Morgan

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Highland – nhsh.foirequestshighland@nhs.scot

Lanarkshire – foi@lanarkshire.scot.nhs.uk

Lothian – foi@nhslotthian.scot.nhs.uk

Orkney – ORK.FOIrequests@nhs.scot

Shetland – shet.foi@nhs.scot

Tayside – tay.informationgovernance@nhs.scot

Western Isles – wi.foi-requests@nhs.scot

I trust you will find the information of assistance and if you require any further information, please do not hesitate to contact me.

If you are unhappy with any aspect of how we have dealt with your request, you can make representations to us asking us to review the handling of your request. Please write to the

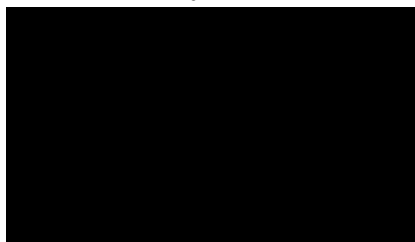
Head of Information and Cyber Security
Digital and Security
NHS National Services Scotland
Headquarters
Gyle Square
1 South Gyle Crescent
Edinburgh
EH12 9EB

or at the email address nss.foi@nhs.scot within 40 working days of the date of this correspondence.

If after a review you are still unhappy, you also have the right to apply to the Scottish Information Commissioner, who can be contacted at Kinburn Castle, St Andrews, Fife, KY16 9DS, or via their [online application form](#).

If you have any queries about this letter, please contact me at the above address.

Yours sincerely



Chair Keith Redpath
Chief Executive Mary Morgan

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Common Services Agency for the Scottish Health Service*