

22 July 2021

Our ref: FOI/24907

Jimmy Hamill

Email: request-766734-b2d31989@whatdotheyknow.com

Dear Mr Hamill,

Re: Central Hypoventilation Syndrome – Diagnosis and Management - Adults

I refer to your Freedom of Information (FOI) request received on 20 June 2021 and follow-up query of 20 July 2021. Outlined below is Belfast Trust's response, which I hope you find helpful.

Questions:

- 1) How many living patients within the Trust are currently diagnosed with CHS?
- 2) How many patients within the Trust have been diagnosed with CHS since 1st Jan 2010?
- 3) What diagnostic procedures are used to identify CHS?
- 4) Is treatment for CHS managed at local (i.e. Trust) or tertiary level?
- 5) What medical specialities are involved in the management of patients with CHS?
- 6) Does any, one medical speciality have a primary lead in the management of patients with CHS?
- 7) What are the treatments used within the Trust to manage patients with CHS?
- 8) What home support is offered by the Trust to patients with CHS and to their families (including but not limited to 24-hour contact, home oximetry, training, family support)
- 9) For patients with CHS who are on ventilation, what oxygenation rates should be achieved?
- 10) How many patients in the Trust with CHS are currently on ventilation?
- 11) How many patients in the Trust with CHS are currently receiving daytime oxygen?
- 12) What are the ongoing review steps in place in the Trust for patients with CHS?

Response:

We have no patients with Central Hypoventilation Syndrome in the adult sleep service and, as such, the service cannot offer any input on the other questions.

There is no specific protocol for this and it would be managed on a case-by-case basis, using the Sleep Multi-Disciplinary Team meeting, as required.

If you are dissatisfied with the way in which we have handled your Freedom of Information (FOI) request you may wish to complain. You should write to: Public Liaison Service, Belfast Health & Social Care Trust, Nore Villa, Knockbracken Health Care Park, Saintfield Road, Belfast BT8 8BH or alternatively e-mail: publicliaison@belfasttrust.hscni.net within two months of the date of this response and your complaint will be considered and a response provided, usually within 20 working days of receipt.

Should you still be dissatisfied with the outcome, you can proceed to the second review stage by contacting the Information Commissioner, The Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, SK9 5AF who will undertake an independent review. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's review process to try to resolve the matter with the Trust in the first instance.

If you require any further information or wish to discuss, please do not hesitate to contact me.

Yours sincerely

A handwritten signature in cursive script, appearing to read "Hayley Kern".

Public Liaison Officer