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Request for Information Reference: 07.19.27

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Email only

12 August 2019

Freedom of Information Act 2000 – Request for Information

Thank you for your request for information received on 15 July 2019 in relation to the County Durham and Darlington NHS Foundation Trust (Trust). We are dealing with your request under the provisions of the Freedom of Information Act 2000.

You requested information regarding Down syndrome. Specifically you requested information as follows:

Please find my questions requested under the Freedom of Information Act.

1 Do you have a care pathway for expectant women who receive a screen positive result for Down syndrome? If so, please provide a copy/link.

Answer: The Trust has the 'Screening for Down's, Edwards' and Patau's Syndromes' policy and also a combined screening pathway. For women with a screen positive result part of this pathway is to commence a Fetal Anomaly T21/18/13 screening in pregnancy contact sheet (attached) to be completed by the screening team.

2 When a pregnant woman receives a screen positive result for Down syndrome is she referred for counselling? If so, to whom and when?

Answer: When the screening team are informed of the high risk result we check the MSS report and her scan results to ensure all information is correct prior to contacting the woman. We would then contact her by phone and offer either counselling of her results over the phone or via face to face contact - which ever she prefers. If she opts for telephone consultation she is made aware that a face to face counselling appointment can still be arranged if she wishes.

The initial telephone call is within 3 working days of receiving the result from the lab (we do not contact women on a Friday), the face to face meeting would be arranged for a time convenient to the woman at her local hospital.

The screening coordinator or deputy are responsible for counselling the women over the phone or face to face. In their absence there are allocated PAU/ANC midwives at UHND, DMH, BAGH who would be asked to take on the role to ensure timely response.

Women are provided with the contact details for the screening office to contact with any queries and they are also given the details for ARC who also offer specialised information and counselling services.

3 What training do the staff providing counselling have appertaining to a) providing counselling & b) knowledge of Down syndrome?

Answer: Staff providing counselling receive counselling training from the Lead Screening Coordinator, employed by the Trust. They are also funded to attend genetic counselling courses which, whilst we acknowledge focuses mainly on Sickle Cell and Thalassaemia, still provides relevant skills to council families for a variety of genetic conditions. Staff members are also expected to complete online e-learning courses for combined screening and the conditions screened for through the Antenatal and Newborn Screening programme, and compliance with this e learning is monitored. ANNB screening is part of staff core essential training annually of which there is >95% compliance.

In line with the Information Commissioner's directive on the disclosure of information under the Freedom of Information Act 2000 your request will form part of our disclosure log. Therefore, a version of our response which will protect your anonymity will be posted on the County Durham and Darlington NHS Foundation Trust website.

If you have any queries or wish to discuss the information supplied, please do not hesitate to contact me on the above telephone number or at the above address.

If you are unhappy with the way your request for information has been handled, you can request a review by writing to:

The Chief Executive
County Durham & Darlington NHS Foundation Trust
Darlington Memorial Hospital
Hollyhurst Road
Darlington
DL3 6HX

If, you remain dissatisfied with the handling of your request or complaint, you have a right to appeal to the Information Commissioner at:



County Durham
and Darlington
NHS Foundation Trust

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

Telephone: 0303 123 1113
Website: www.ico.gov.uk.

There is no charge for making an appeal.

Yours sincerely

Joanna Tyrrell
Freedom of Information Officer