

Ref: FOI/GS/ID 6573

**Please reply to:**  
FOI Administrator  
Trust Management  
Maidstone Hospital  
Hermitage Lane  
Maidstone, Kent  
ME16 9QQ  
Email: [mtw-tr.foiadmin@nhs.net](mailto:mtw-tr.foiadmin@nhs.net)  
[www.mtw.nhs.uk](http://www.mtw.nhs.uk)

01 March 2021

## **Freedom of Information Act 2000**

I am writing in response to your request for information made under the Freedom of Information Act 2000 in relation to Down Syndrome.

*You asked:*

- 1. Letters sent to expectant women advising of screening tests following combined/quadruple screen testing for Down Syndrome. I understand the letter may be different depending on whether results are low or high chance so please send examples of each.*
- 2. Letters/results from Non-Invasive Prenatal Testing (NIPT), again high and low chance examples if different.*
- 3. Examples of information eg. letters, leaflets, signposting etc. shared with expectant women about these tests (combined/quadruple screening and NIPT).*
- 4. Any information shared with expectant women about Down Syndrome itself (including guidance on pregnancy/care when given an antenatal diagnosis).*

Trust response:

Under Section 21 of the Act we are not required to provide information in response to a request if the information is already reasonably accessible to you.

A large part of the information you requested is available from the trust website using the following link/s:

<http://www.mtw.nhs.uk/wp-content/uploads/2019/10/Down-Syndrome.-300719.pdf>

<http://www.mtw.nhs.uk/wp-content/uploads/2019/05/Ante-natal-screening-or-diagnostic-results-for-Down-syndrome.-100519.pdf>

The following letters have had slight amendments to them since the previous response:

Women's & Children's, Level 0  
Tunbridge Wells Hospital  
Tonbridge Road  
Pembury, Kent  
TN2 4QJ

Dear

**Screening Result from  
Combined Screening for Down's, Edwards and Patau's syndrome**

Please find enclosed a copy of your Combined Screening Test Result which is reported as "screen negative". This means there is a low chance that your baby has Down's, Edwards or Patau's syndrome and therefore further testing is not indicated at this stage.

A "screen negative" result does not exclude the possibility of Down's, Edward's or Patau's syndrome because screening does not detect all affected pregnancies.

If you require any further information relating to this result or any other screening matters, please do not hesitate to call on the number below.

Yours sincerely

Sarah Clarke, Carolyn McMahon and Samantha Firth  
Antenatal & Newborn Screening Midwife

Tel 01892 633391

**Please file the enclosed report in your hand-held Maternity Records  
(The information will be required when you attend for you anomaly scan)**

Antenatal Clinic 3  
Maidstone Hospital  
Hermitage Lane  
Maidstone, Kent  
ME16 9QQ

Women's & Children's, Level 0  
Tunbridge Wells Hospital  
Tonbridge Road  
Pembury, Kent  
TN2 4QJ  
Tel 01892 633391

Dear

**Screening Result from  
Combined Screening for Down's syndrome**

Please find enclosed a copy of your Combined Screening Test Result which is reported as "screen negative". This means there is a low risk that your baby has Down's syndrome and therefore further testing is not indicated at this stage.

A "screen negative" result does not exclude the possibility of Down's syndrome because screening does not detect all affected pregnancies.

If you require any further information relating to this result or any other screening matters, please do not hesitate to call on the number below.

Yours sincerely

Carolyn McMahon, Sarah Clarke & Samantha Firth  
Antenatal & Newborn Screening Midwife

**Please file the enclosed report in your hand-held Maternity Records  
(The information will be required when you attend for you anomaly scan)**

Antenatal Clinic  
Maidstone Hospital  
Hermitage Lane  
Maidstone  
Kent  
ME16 9QQ

Antenatal Clinic  
Level 0  
Women's & Children's  
Tunbridge Wells Hospital  
Pembury, Kent  
TN2 4QJ

Dear

**Screening Test Result – Nuchal Translucency Only Screening for  
Down's, Edward's and Patau's Syndrome**

Please find enclosed a copy of your Nuchal Translucency Screening Test Result which is "screen negative". This means there is a low chance that your babies have Down's, Edward's or Patau's syndrome and further testing is not indicated at this stage.

A "screen negative" result does not exclude the possibility of Down's, Edward's or Patau's syndrome because screening does not detect all affected pregnancies.

If you require any further information relating to this result or any other screening matters, please do not hesitate to call on the number below.

Yours sincerely

Carolyn McMahon, Sarah Clarke and Samantha Firth  
Antenatal & Newborn Screening Midwives

Tel. 01892 633391

**Please file the enclosed report in your hand-held Maternity Records  
(The information will be required when you attend for your anomaly scan)**

Women's & Children's, Level 0  
Tunbridge Wells Hospital  
Tonbridge Road  
Pembury, Kent  
TN2 4QJ

Dear

**Screening Test Result – Quadruple Screening for Down's Syndrome**

Please find enclosed a copy of your Quadruple Screening Test Result which is "screen positive" for Down's syndrome. You will see at the bottom of the report that most women with screen positive results will not have a baby affected by Down's syndrome. We have talked on the phone about what this result means to you and the options for further testing if you wish.

You will also see from the report, that your result is low chance for Edward's syndrome

I have sent you information about Amniocentesis and you are aware there is a 1% chance of miscarriage following this procedure. We will speak to you again in a few days to discuss your decision regarding further testing.

If you require any further information relating to this result or any other screening matters, please do not hesitate to call on the number below.

Yours sincerely

Sarah Clarke, Carolyn McMahon & Samantha Firth  
Antenatal & Newborn Screening Midwives

Tel. 01892 633391

**Please file the enclosed report in your hand-held Maternity Records  
(The information will be required when you attend for you anomaly scan)**

Cc Community Midwife

Antenatal Clinic 3  
Maidstone Hospital  
Hermitage Lane  
Maidstone, Kent  
ME16 9QQ

Women's & Children's, Level 0  
Tunbridge Wells Hospital  
Tonbridge Road  
Pembury, Kent  
TN2 4QJ  
Tel 01892 633391

Date

Dear

I have just been speaking with you on the phone, so with your consent to send this email, I am writing to enclose information about your screening result and options. I know there is a lot to take in, but below is a summary of our discussions today. Please take your time to read through this information and the attachments

The screening test has given a 1 in **xxx** chance of Down's syndrome - see attached. This is a chance of **xxx**% which means **xxx** % chance baby does NOT have Down's. Screening for Edwards and Patau's syndrome is low chance.

Just to re-iterate, the options are:

- 1) no further testing. Your next routine screening test would be your anomaly scan at 20 weeks. Please be aware it is not possible to rule out or diagnose Down's syndrome from ultrasound alone
- 2) CVS - see attachment. CVS is offered at Medway Hospital.
- 3) Amniocentesis - see attachment. Amnio offered at Medway Hospital between 16 - 18 weeks of pregnancy.

Results of CVS or amniocentesis usually take approximately 3 working days and give you a "yes" or "no" result as to whether baby is affected by Down's syndrome

Both the CVS and amniocentesis procedure has a 0.5% procedure related chance of miscarriage. Out of every 200 women having one of these invasive tests, 199 women will not miscarry, but one woman will miscarry as a result of the procedure. Unfortunately there is no way to predict who this will happen to, or to prevent it. Further information about CVS and amniocentesis can be found at [Chorionic villus sampling \(CVS\) and amniocentesis: information for parents](#)

A 4<sup>th</sup> option is Non Invasive Prenatal Testing (eg Harmony) which is currently only available privately (costs around £300 - £700). Some women are choosing to look into this before deciding about an invasive test as it is more accurate than the combined test and does not carry the risks associated with invasive tests.

The results take approximately 10-14 working days and it is not quite a 100% result. If the result of Non Invasive Prenatal Testing is positive, then an invasive test (amniocentesis) would be recommended to confirm.

Here is a link to information which may be helpful if you are considering private screening (section 4)

<https://www.gov.uk/government/publications/leaflet-thinking-of-having-a-private-screening-test/private-screening-important-facts>

Ultrasound alone cannot rule out or detect Down's syndrome, so if you feel you need to know for sure, then further testing is the only way to find out before the birth. On the other hand, if it wouldn't actually make any difference to how you proceed with the pregnancy, then you may prefer not to take the risk of an invasive test.

It can be difficult to decide whether or not to take testing further and there is an organisation called **ARC (Antenatal Results & Choices)** who offer information and support to parents throughout antenatal testing. They have a phone number which parents can call when they want someone else to talk things through with. It is **0845 077 2290** (or 0207 713 7486 from a mobile) and website <https://www.arc-uk.org/>. There is information about Down's syndrome on the website <https://www.nhs.uk/conditions/downs-syndrome/> or <https://www.downs-syndrome.org.uk/>

We respect any choice that you make and we are here to support you through the process in any way we can. Please let us know how best we can do this.

We will speak with you later to see how you feeling, however if you would like to meet with us please contact us at Tunbridge Wells Hospital on 01892 633391 and we can arrange an appointment.

Kind regards

Carolyn McMahon, Sarah Clarke & Samantha Firth  
Antenatal & Newborn Screening Midwives  
Monday – Friday 09.00am – 5.00pm