

31 January 2014

Our Ref: 2013-154

Chris Miller

fyi-request-1362-3e1fe06c@requests.fyi.org.nz

Dear Chris Miller

Official Information Act Request 2013/154

Thank you for your Official Information Act (OIA) request of 12th December 2013, where you asked:

1. Does Capital and Coast District Health Board (CCDHB) offer testing to determine whether a fetus is at risk of Down syndrome?
2. What advice, information or counselling do you offer parents on a positive result.

CCDHB offers women in their care the option of 'first trimester combined screening' or 'second trimester maternal serum screening' to determine whether a fetus is at risk of Down syndrome or other conditions.

Whilst all pregnant women are offered screening for Down syndrome and other conditions it is optional. The screening test is made available so that women who wish to have this information about their baby are able to find out and plan accordingly. Women who choose to decline screening will not have their maternity care affected in any way.

For every 1000 women who undertake screening, approximately 50 will receive a result indicating that they are at increased risk and two women will have a fetus diagnosed with Down syndrome or another condition.

If a screening test result indicates that a fetus is at risk of having Down syndrome, the woman is offered further diagnostic testing to see if the condition is present or not. With the woman's consent a referral is made by her Lead Maternity Carer (LMC) to a Maternal Fetal Medicine specialist.

During this consultation the specialist talks with and counsels the woman and her partner. The specialist offers diagnostic testing that may include chorionic villus sampling or amniocentesis.

If the woman is unsure whether to proceed with diagnostic testing she is able to talk to a CCDHB counsellor and a further appointment with the specialist will be made.

The results of chorionic villus sampling and amniocentesis take between one and three weeks to confirm. However, the QF polymase chain reaction (PCR) result is usually available within 48 hours and is able to detect the three most common chromosomal anomalies. The Maternal Fetal Medicine Coordinator obtains the PCR result and contacts most women and informs them of their result. If the woman is being cared for by an LMC obstetrician this information is passed on to the LMC who will inform the woman accordingly.

If the karyotype result is positive the woman will be offered a further appointment with the Maternal Fetal Medicine specialist. At the appointment the woman and her partner are provided with information that may help them prepare for the birth of their baby: the option of birthing in a setting that has access to specialist surgical or medical care; the possibility of considering termination; or palliative care in the newborn period.

The woman and her partner must ensure that the decision they reach is right for them. There is no need to rush. If required further counselling sessions can be provided.

This data in this response has been provided under the Official Information Act 1982. If you have any concerns about the information we have not been able to provide, you have the right to complain to the Ombudsmen.

Yours sincerely



Delwyn Hunter
Executive Director Operations
Surgery, Women & Children's Directorate

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