# NSW Gestational Trophoblastic Disease Multidisciplinary Team clinical service pilot – Patient information

**The information provided here is intended as a guide only. If you have any questions, please talk with the medical professionals looking after you.**

## What is the NSW Gestational Trophoblastic Disease (GTD) pilot service?

This pilot program is an initiative of the Agency for Clinical Innovation (ACI), in conjunction with the ACI GTD working group. The pilot offers a statewide service to support best practice in the diagnosis, and management of GTD. During this pilot, Chris O'Brien Lifehouse (COBL) is providing a clinical support service to assist with monitoring and support of patients with GTD. This service is available to patients living anywhere in New South Wales (NSW).

### Here's how it works

Blood testing and monitoring: Patients have blood tests at the pathology service of their choice. These tests measure pregnancy hormone levels, which are monitored regularly by the Nurse Practitioner at COBL.

Telehealth support: The Nurse Practitioner at COBL will review the blood test results and contact the patient. The monitoring process is done through telehealth/telephone, so patients do not need to travel to COBL. The Nurse Practitioner will liaise with the patient's local treating medical professional. Otherwise, the patient's care will remain with their treating medical professional.

Frequency of blood tests: Blood tests will be done weekly until the hormone levels return to normal. Testing will continue for a period of time after that, to check that levels remain normal.

Treatment if necessary: If the hormone levels do not return to normal, treatment may be needed. If treatment is required, patients will be referred back to their referring team for this.

Specialist Consultant, Clinical Associate Professor Trevor Tejada-Berges and Nurse Practitioner Shannon Philp are supervising the NSW GTD pilot.

If you have further questions, you can contact the COBL Nurse Practitioner (details at the end of this form).

## Molar pregnancy is a common type of GTD

### Hydatidiform moles (also called molar pregnancy)

This happens in approximately one in every 1000 pregnancies and is caused by abnormal fertilisation of the egg. In a normal pregnancy, the placenta (which is made up of millions of cells known as trophoblastic cells), feeds the growing baby and removes its waste products.

In GTD, the trophoblastic cells are abnormal and cause the placenta to overgrow. This is known as a “hydatidiform mole” or “molar pregnancy”.

There are two different types of hydatidiform moles, partial and complete.

- Partial Mole: This is where only part of the placenta is growing abnormally. There may be some fetal development, but the fetus will never survive and will miscarry early in the pregnancy.
- Complete Mole: This is where the whole placenta is abnormal and usually grows very rapidly. There is no fetus present in these pregnancies.

## How is a molar pregnancy diagnosed and what is the treatment?

In a normal pregnancy, the placenta produces a hormone called hCG (human chorionic gonadotrophin) to support the growth of a fetus. In the case of hydatidiform mole, the overgrowth of the abnormal placenta produces a large amount of hCG, which can be measured in the blood.

Most of the time, a molar pregnancy is discovered in the first three months of pregnancy, often because it ends in a miscarriage. It may also be discovered when you have an early pregnancy ultrasound. It is treated by a minor operation called a dilatation and curettage (D&C). This is when the placenta is surgically removed from your uterus.

This operation is usually carried out after miscarriages. This is normally all that is required for treatment of hydatidiform moles. To make sure that there are no abnormal cells remaining, we will measure your hCG levels every week by testing your blood until these levels are normal and then for a period of time thereafter, depending on what type of hydatidiform mole you have. Your specialist will let you know when you’re OK to start trying for a pregnancy again.

## What do you need to do?

You will need to do some blood tests to check your pregnancy hormone levels (beta-hCG). This will help us know if you need any further treatment. We will give you pathology forms for your blood tests. Sometimes you might also need to do a urine test.

You can do your tests at a pathology service that you choose. You should do the tests at the same place each time. We will contact you after we get your results and tell you what else you might need to do.

**For how long will you need to provide samples?**

- If you are diagnosed with a partial mole, your hCG levels will be monitored until the level becomes normal and is normal for 3 consecutive weeks.
- If you are diagnosed with a complete mole, your hCG levels will be monitored until the level becomes normal and is normal for 3 consecutive weeks. We will then monitor you monthly for a total of 6 months.
- The GTD service will advise you if a different follow-up is required, depending on your individual circumstances.

**Why might you need more treatment?**

You are more likely to need more treatment if you had a complete molar pregnancy compared to a partial molar pregnancy.

In some cases, the hormone levels do not go down to normal and might start to go up. There might also be a growth which could spread to other parts of your body, but this is rare. This is called persistent GTD, or Gestational Trophoblastic Neoplasia.

We will find out what treatment you need by doing more tests. You might need:

- blood tests
- chest X-ray
- ultrasound
- other scans like a CT scan or an MRI.

## Can you get pregnant again?

You should not get pregnant again until you finish all your follow-up testing. A new pregnancy raises your pregnancy hormone levels which makes it hard to know if you need treatment for your molar pregnancy or not.

Pregnancy and miscarriage rates for women who have had a molar pregnancy are the same as for the general population.

## What contraception should you use?

It is important that you use an effective form of contraception whilst being monitored. This will depend on your circumstances but both hormonal contraception and barrier is effective. You should talk to your medical professional about what is best for you.

## What are the chances of another molar pregnancy?

There is a very low chance that you will have another molar pregnancy. If you get pregnant again you should:

- have an early pregnancy ultrasound.
- tell your doctor/midwife that you have had a molar pregnancy.

Your doctor/midwife should do a beta-hCG blood test 6 weeks after you have your baby to check that the hCG level has returned to normal.

## COBL contact details

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Feedback

- We are always interested in feedback regarding our service. If you would like to provide feedback during business hours, please call (02) 8514 0000. After hours, please fill out this form or email feedback@lh.org.au.

## Useful links

- COBL website - https://www.mylifehouse.org.au/
- Cancer Australia - https://www.canceraustralia.gov.au/cancer-types/gestational-trophoblastic-disease/overview
- Charing Cross Gestational Trophoblast Disease Service - www.hmole-chorio.org.uk