

# Patient information on Hereditary Haemorrhagic Telangiectasia (HHT) & Pregnancy

## Who is this information for?

This information is for patients, families and carers with hereditary haemorrhagic telangiectasia (HHT).

## Why could HHT affect pregnancy?

- During pregnancy, the circulating blood volume increases by 60%.
- This means fragile blood vessels can be more prone to bleeding.
- The body copes with extra blood by making many of the mother's blood vessels dilate. These blood vessels do not always return to their pre-pregnancy size.
- The majority of HHT pregnancies are safe for a mother with HHT and the baby, but they are always treated as "high risk" by obstetricians due to potential risks associated the disease process and the pregnancy state.

## Can I have children if I have HHT and how do I need to be managed?

- Women with HHT do have children.
- If you know you have pulmonary AVMs (PAVMs) or cerebral AVMs (CAVMs) you will need to see a specialist obstetric doctor to discuss the possibility of pregnancy.
- Before pregnancy: undertake PAVM and CAVM screening and ideally treat PAVMs before becoming pregnant. You will be advised to use antibiotics prior to dentistry or surgery.
- During pregnancy: the mode of delivery will be decided by your health professional and will be guided by your general health and particular features of your pregnancy. If PAVMs are present you will require prophylactic antibiotics. If CAVMs are present, you may be offered a caesarean section to avoid excessive straining.
- Following pregnancy: PAVM screening may need to be repeated, even if it was initially normal.

## If a pregnant woman has HHT will the baby be alright?

- Miscarriage rates are comparable in HHT and non-HHT pregnancies.
- There is no evidence for additional abnormalities developing more commonly than in non-HHT pregnancies.
- If a pregnant female has pulmonary arteriovenous malformations (PAVMs), the baby should still develop normally.
- Premature birth of small healthy babies is more common with women who have HHT.

- If you have low oxygen levels, your baby's growth will be carefully monitored by your obstetrician.

## Will the mother be at risk during and after pregnancy?

- Most pregnancies result in no serious HHT-related complications for the mothers but they are always treated as "high risk" by obstetricians.
- Nosebleeds may get worse and new telangiectases often develop.
- Some women report an improvement in nose bleeds and new skin lesions often improve post pregnancy.
- PAVMs may develop or enlarge during pregnancy.
- There is a very small risk that a pregnant HHT patient can have a life threatening bleed from a PAVM in the last trimester of pregnancy. If blood is coughed up in late pregnancy that cannot be accounted for by a nose bleed, **urgent medical management is required**.
- There is no good data available to indicate that cerebral AVMs in HHT or non-HHT patients are more likely to bleed during delivery or even pregnancy.
- Most anaesthetists will not undertake a spinal or epidural anaesthetic because of the small risk of a spinal AVM (1-2%). Alternative analgesia will be offered. However, if referred early, an MRI scan could be undertaken to exclude spinal AVMs and allow epidural analgesia. Anaesthetists and the delivery health practitioner (obstetrician or midwife) need to be made aware of your HHT status as early as possible in your pregnancy.

## What is the risk of passing HHT onto my children?

- Children of one HHT parent have a 50:50 chance of having HHT with the same genetic mutation. This can be tested for in childhood by a blood test if the parent's mutation is known.

## Concerns or questions?

In an emergency please present to the nearest emergency department or call 000.

You can contact your ENT Specialist at the Melbourne ENT Group (MEG):

- Phone: 1300- 952-808
- Email: [admin@melbentgroup.com.au](mailto:admin@melbentgroup.com.au)
- Website: [www.melbentgroup.com.au](http://www.melbentgroup.com.au)



Your GP is also the best contact for ongoing care and concerns.

## Further information

Further information about HHT can be obtained from the Australian HHT Alliance website [www.hht.org.au](http://www.hht.org.au) or from the Cure HHT (previously the HHT Foundation) website [www.hht.org](http://www.hht.org)

[www.hht.org.au](http://www.hht.org.au)



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