



**Cavernoma  
Alliance UK**

Helping the Cavernoma Community

## **Information booklet**

**Pregnancy, childbirth and cavernoma**

For people interested  
in pregnancy and birth  
who are affected  
by cavernoma

[www.cavernoma.org.uk](http://www.cavernoma.org.uk)  
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**LOTTERY FUNDED**

Registered charity number 1114145

This booklet is for people affected by a cavernoma, which is also known as a ‘cavernous angioma’, ‘cavernous haemangioma’, or ‘cavernous malformation’.

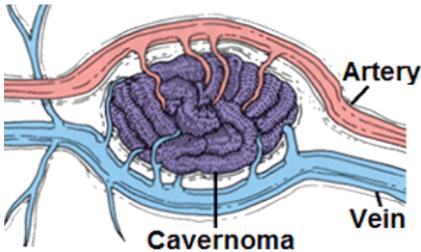
In particular, this booklet is for women who are pregnant or want to become pregnant, and their partners.

**There are other booklets in the Cavernoma Alliance UK series.**

**They are for:**

- people who have symptoms due to their brain cavernoma;
- people who do not have symptoms from their brain cavernoma;
- people concerned about genetic causes of brain cavernoma and whether cavernomas run in families; and
- people with spinal cavernomas.

# What are cavernomas?



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Cavernomas are clusters of abnormal blood vessels through which blood flows slowly – these are the caverns that give the condition its name. They are found in the brain, brainstem, spinal cord and, rarely, in other areas of the body. The cells that line these caverns sometimes ooze small amounts of blood into surrounding brain tissue, which sometimes causes symptoms. A cavernoma can range in size from a few millimetres to several centimetres. On a scan, a cavernoma looks like a piece of popcorn and under the microscope it looks like a raspberry.



# Are there increased risks during pregnancy for women who have a cavernoma?

**This booklet discusses four concerns associated with pregnancy for women with cavernomas.**

- Risk of brain haemorrhage (bleeding)
- Seizures and epilepsy
- The safety of MRI scanning
- Genetic testing and counselling

## Does pregnancy increase the risk of brain haemorrhage from a cavernoma?

Many women with a cavernoma ask if their cavernoma might be more likely to bleed during pregnancy or the six weeks after birth (the 'postpartum' period). Women and their doctors are also concerned that normal (vaginal) delivery may increase the risk of a bleed.

Until recently, a lack of information has made it difficult to deal with these concerns.

Two major studies, completed in 2012 and 2013 (see page 9), looked at whether the risk of brain haemorrhage from a cavernoma changed during pregnancy, delivery and the six weeks after birth. Both studies, one in Canada and one in the USA, showed that:

- the risk of bleeding from a cavernoma does not change significantly during pregnancy;
- there was no increase in risk associated with vaginal delivery; and
- there was no increase in risk in the six weeks after delivery.

**The studies therefore concluded that the method of delivery should be based on general pregnancy and delivery considerations only.**

# What are the risks of seizure from cavernoma in pregnancy?

Some patients with a cavernoma have epilepsy and have seizures, and most of these women take anti-epileptic medication. There are no studies specifically about the risk of seizure from cavernoma in pregnancy. However, there is a lot of knowledge and experience about caring for pregnant women with epilepsy and who are at risk of seizures.

If you have epilepsy or are concerned about the risk of seizures, it is important that your neurologist or epilepsy nurse specialist advises you early on in your pregnancy, alongside the antenatal care provided by your obstetrician. Women with epilepsy should take folic acid at the higher dose of 5mg daily, to reduce the risk of the baby developing birth defects such as spina bifida. A neurologist or epilepsy nurse specialist will know whether you should adjust the dose of your anti-epileptic drugs and will be able to give you other guidance about motherhood and epilepsy.

**The Royal College of Obstetricians and Gynaecologists has more information in their leaflet 'Epilepsy in Pregnancy' at**

[www.rcog.org.uk/globalassets/documents/patients/patient-information-leaflets/pregnancy/pi-epilepsy-in-pregnancy.pdf](http://www.rcog.org.uk/globalassets/documents/patients/patient-information-leaflets/pregnancy/pi-epilepsy-in-pregnancy.pdf).

**There is also information at:**

[www.nhs.uk/Conditions/pregnancy-and-baby/pages/epilepsy-pregnant.aspx](http://www.nhs.uk/Conditions/pregnancy-and-baby/pages/epilepsy-pregnant.aspx)

[www.epilepsy.org.uk/info/women/having-baby/pregnancy](http://www.epilepsy.org.uk/info/women/having-baby/pregnancy)

[www.epilepsysociety.org.uk/pregnancy-and-parenting](http://www.epilepsysociety.org.uk/pregnancy-and-parenting)



# Is it safe to have an MRI scan during my pregnancy if I have a cavernoma?

MRI scans are safe in pregnancy, as they do not involve radiation. They are not carried out routinely in pregnancy. Gadolinium, the contrast agent used for brain MRIs, is usually avoided in pregnancy, if possible. Doctors will recommend an MRI scan if they are concerned that your cavernoma is growing or bleeding during pregnancy or if you need surgery during pregnancy. However, these incidences are unusual. In a major study carried out on 168 pregnancies in Phoenix, USA (see the reference on page 9), no patient needed surgery during pregnancy.

## A member's experience

*"I was diagnosed with cavernoma after suffering seizures and bleeding. Due to the position of the cavernoma, my consultants chose to monitor it instead of recommending surgery. After my condition stabilised and I adapted to my anti-antiepileptic medication, Keppra, I discussed with my consultants about getting pregnant. My epilepsy specialist suggested taking folic acid in preparation of pregnancy. The constant care I received from my doctors and hospital staff contributed enormously to ease my anxiety of pregnancy given my cavernoma.*

*I had a very smooth and happy pregnancy, and gave birth to a healthy 4kg boy under a C section. There were certainly more challenges to looking after my newborn than the pregnancy, mainly due to being a first time mother. Lacking sleep and constant worries may have contributed to increased seizures. Once again, I received lots of support from both hospitals. We managed in the end, and I really enjoy the new journey together with my son. For those of you thinking of pregnancy, planning ahead and arranging help from family and friends are definitely the essential steps in the plan."*

# Genetic testing and counselling

If you have the familial (genetic) form of cavernoma, or think that you or your partner may have this form of cavernoma, you may want to consider genetic counselling and genetic testing before trying to conceive. You may want to know your own genetic status or the chances of your child inheriting one of the genes associated with cavernoma. If one parent has a gene associated with cavernoma, each child they conceive has a 50% chance of inheriting that gene. This is the case whether or not you experience symptoms. Genetic testing and any decisions you make are personal, and your genetic counsellor or medical geneticist will be able to help you with information and support.

You can find general information on the genetics of cavernoma in our booklet 'The Genetics of Brain Cavernoma'. Also, there are two information articles about genetic tests specific to pregnancy (prenatal testing and pre-implantation genetic diagnosis (PGD)). You can read these at [www.cavernoma.org.uk/about-cavernoma/](http://www.cavernoma.org.uk/about-cavernoma/).

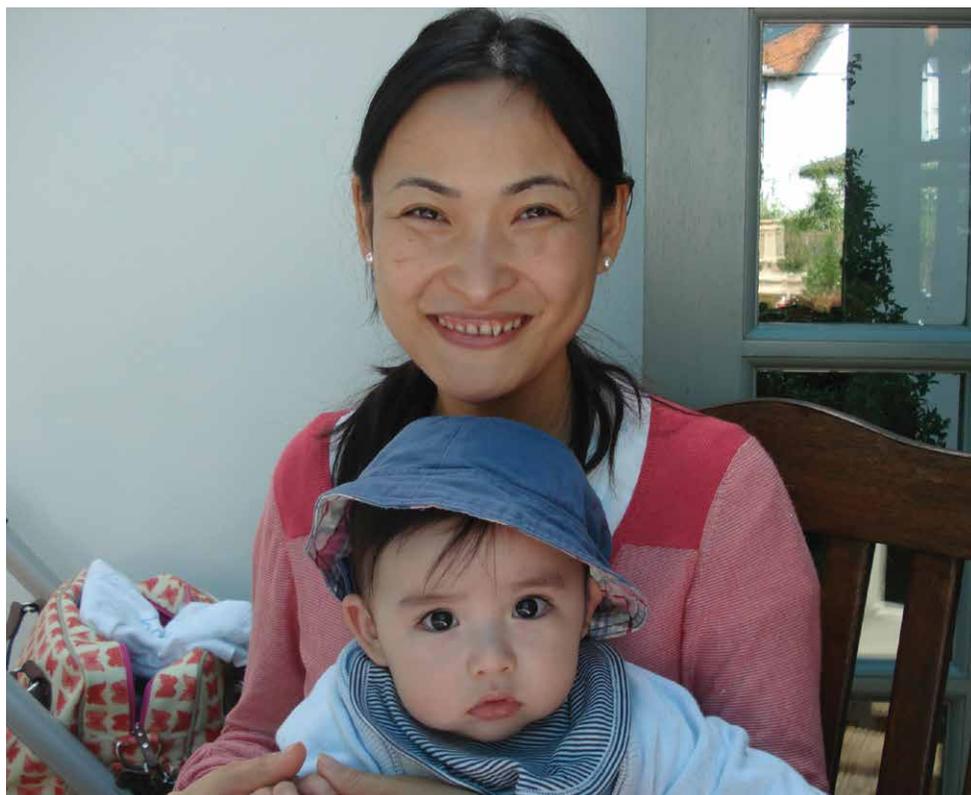


# Pregnancy and childbirth for women with a cavernoma – thinking about your pregnancy

The evidence from the two major studies mentioned earlier is that the risk of brain haemorrhage is not likely to change during pregnancy, delivery or the six weeks after delivery. These reassuring studies support women to choose for themselves what to do about their cavernoma and pregnancy. The studies were carried out on a wide range of women with cavernomas, but each patient has an individual health history. If you have a cavernoma and are pregnant or want to become pregnant, you should consult your neurologist or neurosurgeon as well as your obstetrician if you have questions about possible risks during your pregnancy. If your doctor recommends a procedure such as an MRI scan or Caesarean delivery because you have a cavernoma 'just to be on the safe side', this may be due to your personal health history or situation. If you are not sure why you have been advised to have a particular procedure, you may want to discuss the reasons further with your doctor, and show them this leaflet which refers to the best available evidence.

If you are at risk of seizures, have epilepsy or are on anti-epileptic medication, it is important to consult your neurologist or epilepsy nurse specialist about your medication and how to control seizures during your pregnancy.

If you have the inherited, familial (genetic) form of cavernoma and would like more information or support about genetic testing or inheriting the genes associated with cavernoma, you should get advice from your medical geneticist or genetic counsellor before becoming pregnant or early on in your pregnancy. This is especially important if you would like to have genetic testing.



## References

1. Witiw CD, Abou-Hamden A, Kulkarni AV, Silvaggio JA, Schneider C, Wallace MC. Cerebral cavernous malformations and pregnancy: hemorrhage risk and influence on obstetrical management. *Neurosurgery* 2012; 71(3):626-630.
2. Kalani MY, Zabramski JM. Risk for symptomatic hemorrhage of cerebral cavernous malformations during pregnancy. *Journal of Neurosurgery* 2013; 118(1):50-55.

**These research articles are available online.**

## This booklet

This booklet was written by Pat Spallone, compiled by David White and reviewed by Professor Rustam Al-Shahi Salman and Professor Catherine Nelson-Piercy, and members of Cavernoma Alliance UK.



# How Cavernoma Alliance UK can help

Cavernoma Alliance UK was set up by people affected by brain cavernomas to support those with the condition and their families.

Our website, [www.cavernoma.org.uk](http://www.cavernoma.org.uk), provides information about brain and spinal cavernomas, current members, and information about how you can become a member. Membership is free. Along with our affiliated organisation, Angioma Alliance, and associated groups throughout the world, we also provide updates on research.

## Our aims

- To make sure that every person with brain or spinal cavernomas, and their family, has access to clear information about the illness.
- To provide information, through our website, about others affected by brain and spinal cavernomas.
- To increase awareness of brain and spinal cavernomas so that those affected by the condition receive understanding and support.

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## Acknowledgements

We are very grateful to  
The Alice Ellen Cooper Dean Charitable Foundation  
for their financial support in producing  
this information booklet.



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