

Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families

Haemangiomatosis

This information sheet from Great Ormond Street Hospital (GOSH) explains the causes, symptoms and treatment of haemangiomatosis and where to get help.

What is haemangiomatosis?

A haemangioma is a collection of small blood vessels that form a red mark or a swelling. The term haemangiomatosis is used when there are multiple haemangiomas. 'Cutaneous haemangiomatosis' refers to the condition when only the skin is affected and 'visceral haemangiomatosis' (also known as diffuse, disseminated or miliary haemangiomatosis) when internal organs are also involved.

What causes haemangiomatosis?

There is some evidence to suggest that haemangiomas may originate from placental tissue. We do not yet know how or why this might occur. More research is needed to confirm the causes of haemangiomas. Haemangiomatosis is a rare condition affecting 1 in 50,000 babies. It appears to be more common in babies born early

(premature) or as a multiple birth.

What are the signs and symptoms of haemangiomatosis?

Haemangiomas are not usually present at birth but develop after a few days or weeks. Most grow rapidly in the first three months, increasing in size and sometimes in redness. The growth phase is followed by a 'rest period' and then shrinkage. The haemangiomas of haemangiomatosis are usually very small, and show limited growth. The appearance of tiny new lesions may continue throughout the first year of life.

Visceral haemangiomatosis

The most common location for an internal haemangioma is the liver. Most liver haemangiomas are completely harmless, require no treatment, and will disappear on their own. Very rarely, liver haemangiomas may be large or numerous and can lead to increased work for the heart.

How is haemangiomatosis diagnosed?

As haemangiomatosis is a rare condition, diagnosis will usually only be possible at a specialist centre with input from different specialists, such as dermatologists (skin specialists) and radiologists (imaging specialists). Initially, imaging scans such as ultrasound will be used to locate any internal haemangiomas.



How is haemangiomatosis treated?

If haemangiomas are only located on the skin and are not causing any problems, treatment is not required.

Systemic beta-blockers, usually propranolol, may be required if a haemangioma is located near the eye, on the lips or in the nappy area. Further information about propranolol is available from the Birthmark Unit.

Internal haemangiomas will occasionally need treatment to speed up the rate at which they shrink. This is likely to be propranolol as for skin haemangiomas. If the increased work on the heart is causing problems, additional medicines to reduce this effort may also be prescribed.

Surgery to remove the haemangioma is rarely an option for those located in the liver, due to the complicated blood supply, but in some cases, a procedure called embolisation may be suggested. Embolisation is a way of blocking abnormal blood vessels. Various substances can be used to block the blood vessel, including medical glue, medical putty, tiny metal coils or plastic beads. The substance used depends on the area being embolised, the speed of the blood flow in that area and the size of the blood vessels. Sometimes two or more substances are used together to get the best result.

What happens next?

All haemangiomas shrink over time. Depending on the size and location of the skin haemangiomas, there may be little sign they ever existed.

Further information and support

At Great Ormond Street Hospital (GOSH), contact the Birthmark Unit on 020 7405 9200 ext. 1113.

The Birthmark Support Group offers support and advice to parents of children with all types of birthmark, including neonatal haemangiomatosis. Telephone their helpline on 0845 045 4700 or visit their website at www.birthmarksupportgroup.org.uk

Compiled by the Birthmark Unit in collaboration with the Child and Family Information Group Great Ormond Street Hospital for Children NHS Foundation Trust, Great Ormond Street, London WC1N 3JH www.goshfamilies.nhs.uk www.childrenfirst.nhs.uk