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

Congenital haemangioma

This information sheet from Great Ormond Street Hospital (GOSH) explains the causes, symptoms and treatment of congenital haemangiomas – rapidly involuting congenital haemangiomas (RICH), non-involuting congenital haemangiomas (NICH) and partially involuting congenital haemangiomas (PICH) – and where to get help.

What is a congenital haemangioma?

A haemangioma is a collection of small blood vessels under the skin. A congenital haemangioma is one that is present from birth and has grown to its maximum size while the baby is developing in the womb. Congenital haemangiomas are less common and behave very differently to the more common infantile haemangiomas.

Congenital haemangiomas are classified into three types: rapidly involuting congenital haemangiomas (RICH), non-involuting congenital haemangiomas (NICH) and partially involuting congenital haemangiomas (PICH).

- Rapidly involuting congenital haemangiomas (RICH) have reached their maximum size by the time the baby is born and start to shrink quickly, and have usually flattened within 12 to 18 months, often leaving little sign that they were ever present. However some may leave behind an indentation and prominent veins, which may need treatment at a later stage to improve their appearance.
- Non-involuting congenital haemangiomas (NICH) may continue to grow after birth in proportion with the baby. Unlike the RICH type or infantile haemangiomas, NICH do not have a shrinking stage.
- Partially involuting congenital haemangiomas (PICH) are a combination of both RICH and NICH type lesions. For example,

what might have initially appeared to be a RICH may start to shrink but then stop or one that appeared to be a NICH might start to shrink after some time. We do not know why a PICH behaves in this way.

What causes a congenital haemangioma?

We do not know what causes a congenital haemangioma. We know that they are not inherited and, unlike infantile haemangiomas, they affect males and females equally. More research is needed to confirm the causes of congenital haemangiomas. One theory is that it is related to placental tissue. The placenta is divided into segments, similar to a flattened orange which has pith separating each segment. It is possible that congenital haemangiomas arise from the 'pith' like tissue in between each segment of placenta while the baby is developing in the womb.

What are the signs and symptoms of a congenital haemangioma?

Congenital haemangiomas are immediately visible at birth. They may be raised or fairly flat, and are usually pink or purple in colour. Sometimes they have a waxy look or the surface may contain thread veins (telangiectasia). The affected skin may feel quite warm because the abnormal blood vessels are close to the surface. Congenital haemangiomas

commonly appear on the head, neck or limbs. Sometimes, they have a paler area of skin around the birthmark.

In severe cases, the blood flow through the congenital haemangioma is so rapid that it can affect how hard the heart has to pump to keep blood circulating through the body, which can, in rare circumstances, lead to heart failure.

How is a congenital haemangioma diagnosed?

Occasionally, congenital haemangiomas can be diagnosed before birth if they are visible using prenatal ultrasound scanning. This is more likely if the haemangioma is on the head or neck.

Congenital haemangiomas are clearly visible immediately after birth. However, there may be some confusion as to the diagnosis because they are comparatively rare. A full physical examination by doctors at a specialist centre is recommended, alongside ultrasound scanning and other imaging techniques to show the extent of the haemangioma and the blood flow through it. Sometimes biopsy (a tiny sample of tissue to examine under a microscope) is required to help confirm the diagnosis.

While congenital haemangiomas can be diagnosed visually, deciding whether it is a RICH, NICH or PICH type may be difficult in the short term, although this will usually become obvious over a matter of weeks or months as the RICH type will shrink but the NICH type do not.

If doctors suspect that the blood is flowing too fast through the haemangioma and is affecting the heart, they may suggest imaging scans such as magnetic resonance imaging (MRI) using contrast, a liquid that shows up well on scans, or angiography.

How is a congenital haemangioma treated?

Treatment options will depend on whether the birthmark is a RICH-type or NICH-type.

Propranolol, a beta blocker medicine often used to treat the more common infantile haemangiomas, is not effective in treating RICH, NICH or PICH type birthmarks. In very severe cases, and depending on the location, embolisation – a procedure to block certain blood vessels so that blood flow through the haemangioma is reduced – may be suggested.

Following this, surgery may be used to remove the birthmark, although inevitably this will leave some scarring.

What happens next?

Depending on the size and location of the congenital haemangioma, there may be little sign it ever existed once it has shrunk.

The majority of RICH type birthmarks disappear completely within 12 to 18 months. Sometimes, the area of skin affected may be slack or sunken as there is no layer of fat under the skin (lipoatrophy), which may later require correction with plastic surgery, fat transfer and sometimes laser therapy.

Occasionally the affected area of skin might be a bit lighter in colour than the rest of your child's skin. Thread veins are also common. These are tiny red veins on the surface of the skin and are easily treated with a laser later on in childhood.

If the haemangioma has been removed surgically there will always be a scar. The degree of scarring will vary depending on the location and size of the haemangioma. There are several options for reducing the appearance of scars if necessary, including plastic surgery, laser treatment and cosmetic camouflage.

Vascular birthmark research is an area of medicine that is continually advancing. Studies have already given us improved options for treating haemangiomas and continue to tell us more about how and why they develop.

Further information and support

At Great Ormond Street Hospital (GOSH), contact the Birthmark Unit.

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

Changing Faces is the support organisation for anyone affected by visible difference. Telephone their helpline on 0845 4500 276 or visit their website at www.changingfaces.org.uk. They also have a specific website for teenagers and young adults at www.iface.org.uk

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