



Venous malformations

This information sheet provides information about venous malformations and how they can be treated. It also explains what to expect when your child comes to Great Ormond Street Hospital (GOSH) for diagnosis and treatment.

What is a venous malformation?

Venous malformations arise from genetic changes that cause certain veins to have an abnormal shape, to be abnormally located, or to be abnormally numerous and bulky.

What problems may arise from a venous malformation?

These structural abnormalities can change the blood flow in the affected veins, usually slowing it down, which can sometimes lead to formation of small clots. These are trapped within the malformation so they cannot spread around the body but they can be painful when they form.

Very large, extensive venous malformations may lead to the development of so many small clots that levels of normal clotting factors in the blood are reduced, leading to poor clotting in other parts of the body.

Large venous malformations can also cause problems because of their size. They can swell when blood pools in them and is slow to return to the heart. This is more common in parts of the body affected by gravity such as the legs. Such venous malformations can be uncomfortable after long periods of standing or walking. This swelling or discomfort is usually made better by rest or by raising the affected area, or by using a special compression garment.

What do they look like?

Venous malformations may appear as raised blue marks on the skin, others can be hard to see from the outside. Though they are present at birth, they may not be obvious until later. Some venous malformations become more noticeable when blood flow to the area increases, for instance, with exercise or crying.

Venous malformations can occur in any tissue including the mucous membranes, muscles and internally. Large venous malformations may cause functional problems, particularly if the arm or leg is affected.

Venous malformations usually grow in proportion with the child but may enlarge following trauma or when hormone levels rise, for instance, at puberty and during pregnancy.

How is a venous malformation diagnosed?

Most venous malformations can be diagnosed in the clinic, though scans in the Radiology department may be required to be certain of the diagnosis, and to assess the extent of the malformation.

What causes venous malformations?

Venous malformations are the result of a mutation (change) occurring early in foetal life in one of the genes controlling the growth and development of veins. These mutations are not known to be linked to anything that happened or did not happen during pregnancy. Only rarely do venous malformations arise as a result of the abnormal gene being inherited, in which case there may be a family history of blue marks.

How common are they?

Venous malformations are relatively common compared to other vascular malformations.

Looking after your child's venous malformation

Pressure garments are very helpful for preventing discomfort arising in venous malformations of the arms and legs. Pain arising following injury or clot formation will usually respond to paracetamol.

How can they be treated?

Venous malformations are assessed and treated by a team of specialists including paediatric dermatologists, interventional radiologists and plastic surgeons. The options for treatment depend on the size and location of the malformation. If a venous malformation is not causing any problems, treatment may not be needed.

If there is concern about blood clotting problems arising from the malformation, anti-clotting medicines, such as low dose heparin may be required. Regular blood tests may be needed to monitor clotting problems.

Sclerotherapy is carried out by interventional radiologists to keep the main symptoms of a malformation well controlled. A medicine is injected into the veins, which irritates them encouraging them to scar and shrink. It may take several sclerotherapy sessions for the malformation to improve. For more information about sclerotherapy, please see our separate leaflet.

Specially made compression garments help prevent enlargement of venous malformations of the arms and legs, and reduce discomfort if worn for 8 to 12 hours a day. They work by preventing pooling of blood in the abnormal veins. They need to be replaced regularly as your child grows. Please see our Looking after your child's compression garment information sheet for further details.

It may be possible to surgically remove certain venous malformations. As with all surgery, there will be a scar and sometimes, the malformation can grow back.

Further information and support

The **Birthmark Support Group** is the main organisation in the UK offering support and advice. Email them at info@birthmarksupportgroup.org.uk or visit their website at www.birthmarksupportgroup.org.uk

Changing Faces supports anyone affected by a visible difference. Call them on 0845 4500 275 or visit their website at www.changingfaces.org.uk