Venous malformations

Information for families

Great Ormond Street Hospital
for Children NHS Foundation Trust

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

What is a venous malformation?

Venous malformations are abnormalities affecting blood vessels. Usually, the walls of a blood vessel contain smooth muscle cells, which hold the vessel in shape, becomes enlarged and slows down the pressure of the blood flowing through it. In venous malformations, this smooth muscle layer is abnormal, which means that the vessel does not hold its shape and slows down blood flow. This can lead to problems with clots forming within the abnormal blood vessel. Venous malformations can be very painful when this happens and repeated clots might damage the blood vessel wall. This feels like hard lumps within the malformation.

Venous malformation of the neck

What do they look like?

Venous malformations usually look like soft, lumpy, blue marks on the skin. They are present at birth, although they may not be obvious until the child grows. Some venous malformations become noticeable when blood flow to the area increases, for instance, if a baby cries or has a raised temperature or when an older child is playing sport. They grow in proportion with the child but may increase in size as a child puts on weight, if the malformation is traumatised or when hormone levels rise, for instance, at puberty and pregnancy or due to the contraceptive pill.

Enlargement of the area can cause mobility problems, particularly if the arm or leg is affected. As well as appearing on the skin, venous malformations can occur in the mucous membranes, such as the eyelids or inside the mouth, in muscles or internal organs. Venous malformations can be unsightly, particularly if on the face, arms or legs. While the blueness can be covered with cosmetic camouflage, the lumpiness of the affected area will still be noticeable. Our booklet *Bringing up a child whose face looks different* contains lots of suggestions from the Birthmark Unit at GOSH and from other parents.

Venous malformation of the foot

Venous malformation of the lip

How is a venous malformation diagnosed?

Venous malformations can be difficult to diagnose so we often have to perform some scans in the Radiology department to be certain of the diagnosis. Venous malformations have a characteristic appearance on these scans. An ultrasound scan show us the blood flow through the veins, as well as any clots, and an MRI scan shows us the extent of the malformation and which parts of the body are involved. Sometimes a dye injection is given during the MRI scan to highlight the veins.

What causes a venous malformation?

We do not yet know what causes them, although we are sure that it is not linked to anything that happened or did not happen during pregnancy. Fewer than five per cent of these children have a family history of venous malformations. If you have a family history of similar marks, please tell us so that we can discuss this further.

How common are they?

Venous malformations are relatively common compared to other vascular marks, but there is some confusion as they may have been misdiagnosed in the past. As with many conditions, they can be described as a 'spectrum', with some children having very small malformations but others having more widespread ones. At GOSH, we tend to see children with the more severe malformations and we have treated over 350 such children in the past 20 years.

Looking after your child's venous malformation

In most cases, venous malformations just need looking after carefully.

Venous malformations can be painful, mainly when knocked or a clot has formed. Regular pain relief such as ibuprofen and paracetamol are usually enough to deal with the discomfort, but stronger medicines can be prescribed if needed.

We advise children and young people to avoid contact sports if possible, to minimise the risk of damaging the venous malformation. However, depending on its location, some sport may be possible. Please discuss this with your doctor.

Extensive venous malformation of the hand (same child as on the front cover)

You may notice that your child bruises more easily around the venous malformation. The mark may look larger than a normal bruise and feel lumpier. This is a collection of blood under the skin, which will fade and disappear in time, although probably taking a bit longer than a bruise to go away completely.

Venous malformations can become infected. Signs of infection include discomfort, swelling and redness, and the mark will feel hotter than the surrounding skin. If you suspect infection, please see your family doctor (GP) as your child may need a course of antibiotics. A sore throat and raised temperature can be a sign of a specific infection called Streptococcus A (Strep A), which will also need treating with antibiotics once the doctor has confirmed the infection.

How can they be treated?

Venous malformations should be assessed and treated by a team of specialists including paediatric dermatologists, radiologists and/or plastic or vascular surgeons. The options for treatment depend on the size and location of the malformation and the blood vessels involved. Some or all of the following options are possible.

Watching and waiting

If a venous malformation is not causing any problems, treatment may not be needed. The doctors will suggest having regular check ups to make sure that it is not causing any problems.

Medicines

If there is concern about blood clotting problems in the malformation, anti-clotting medicines might be suggested. These can include aspirin or low-dose heparin. Rarely, clots may need dissolving using an injection of 'very low molecular weight' (VLMW) heparin. Regular blood tests will be needed to monitor any clotting problems to see how successful treatment is and adjust the dose if necessary. Mild heparin creams or gels can be used if a clot develops as these will help to reduce a superficial (surface) clot. However, deeper clots may increase the risk of deep

Venous malformation before sclerotherapy

Venous malformation after sclerotherapy

vein thrombosis and pulmonary embolus, especially during puberty, long haul flights and immobility.

Sclerotherapy

This is a procedure carried out by an interventional radiologist, who shrinks the blood vessels by injecting a special substance into them through the skin under general anaesthetic. Once a blood vessel has been blocked, it shrinks and becomes less noticeable. It may take several sclerotherapy sessions for the malformation to improve and even then, it might grow again. For more information about sclerotherapy, please see our separate leaflet.

Compression

Specially made compression garments should help swollen areas and reduce discomfort if worn for 8 to 12 hours a day. They work by stopping blood pooling in the abnormal big veins and encourages blood flow to the heart through normal veins. As they are made to measure, they need to be replaced regularly as the child grows. Compression garments can be helpful in making sport and exercise more bearable as they support the malformation and reduce swelling. Please see our *Looking after your child's compression garment* information sheet for further details.

Laser therapy

Small surface malformations can be treated with a laser, which shrivels up blood vessels using heat and light. For more information about laser treatment, please see our *Laser treatment for birthmarks* leaflet. Some deeper venous malformations can be treated using endovenous laser treatment (EVLT). Please see our leaflet for further information. As laser technology develops, other options for treating venous malformations may become available.

Surgical removal

Sometimes, small venous malformations can be removed safely in an operation. Detailed scans will be needed to plan the operation and it will only be carried out if the surgeon is confident that the operation will be successful. There will be some scarring after the operation, as with all surgery.

What is the outlook for children with a venous malformation?

Like the options available for treatment, this depends on the size and location of the malformation and the blood vessels involved. Whether clotting problems are present also has a bearing on the outlook. Anti-clotting medicines as gels or injections and compression garments can reduce pain and swelling significantly allowing a wider range of activity and also improve appearance to an extent. Most children treated at GOSH are now leading fulfilling lives, attending college and working.

Where to get further information

At Great Ormond Street Hospital

Birthmark Unit
Great Ormond Street Hospital
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Tel: 020 7405 9200 ext 5640

Support groups

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

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