

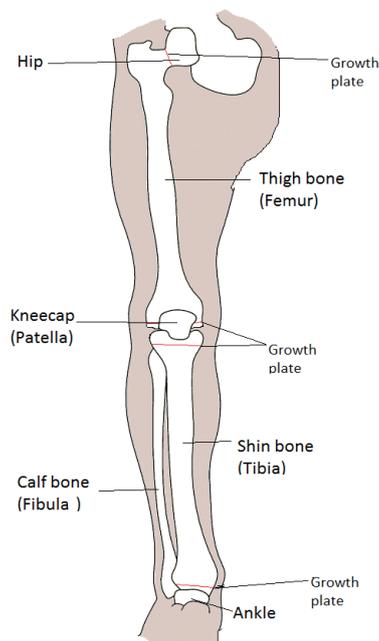
Fact Sheet



Fibular hemimelia

What is Fibular Hemimelia?

There are two long bones in the lower leg: the thicker one is called the tibia and the thinner one is the fibula.



Fibular hemimelia, or Congenital Short Tibia with an absent or hypoplastic fibula, is a congenital (present at birth) condition where the tibia is shorter than normal and the fibula is missing or underdeveloped.

There are associated limb length differences, foot problems, and knee ligament problems: the tibia may be bent; the foot may be smaller than normal and bent outwards at the ankle; and it may also have fewer than five toes.

The knee is often also misshapen and may not move properly. In addition, many children have a slower growing femur (thigh bone) on the affected side.

In short, Fibular hemimelia is where one shin is shorter than the other. In some cases, both legs are affected. There can be problems with the knee and there may be missing toes. In some cases, the femur (thigh bone) can be shorter too, the condition may affect soft tissue as well as bones.

Why does it happen?

The condition is rare, occurring in approximately 1 in 25,000 births, but is the most common form of leg bone problem present at birth. It is usually unilateral (affecting one leg) and bilateral Fibular hemimelia (affecting both legs) is much rarer.

Fibular hemimelia is not thought to be genetic in most cases, meaning it is not usually passed on in families, and the overwhelming majority of children born with this condition have no family history of birth defects.

Consequently, additional children born to the family have no more risk of the condition occurring than the general population: an exception to this is when the condition is associated with birth defects in both legs or problems with the arms.

In most cases it is unknown why Fibular hemimelia occurs.

It's thought that something happens during early growth of the leg.

Diagnosis

Severe cases may be picked up at scans during pregnancy, but not always. In milder cases, it may at first be thought to be a foot problem, but when the shortening of the leg becomes more noticeable and the leg is X-rayed, the full picture can be seen.

Treatment

Your child's medical team will use X-rays and measurements to try to estimate the difference between the leg lengths as your child grows older. Treatment is always tailored to individual children.

Some may require no treatment, others may require insoles to compensate for foot shape. In other cases, doctors may discuss lengthening a short leg or slowing down growth in the lower leg. Other operations may be necessary to improve the shape of the foot.

- In cases where the fibula is present and shortening is not severe, treatment is usually leg equalisation by lengthening the affected leg or by slowing the growth of the other leg (epiphyseodesis) or sometimes both.
- If the foot is reasonably normal, it may be possible to lengthen the leg using a frame.
- If the foot is twisted outwards, it may be possible to correct it enough using surgery.

If the foot is not at all normally formed and the tibia is too short, it may be best to amputate it through the ankle and fit a prosthesis (an artificial limb), but this is a less common option and sometimes the foot and lower leg can be fitted into a special prosthesis.

When will treatment start?

Early treatment is to help children to walk on their own, occasionally by providing insoles or shoes or an operation to bring the foot flatter to the floor. Children with Fibular hemimelia will usually learn to walk either at their normal age or with a slight delay. All children with the condition will walk, even in severe cases, and Fibular hemimelia will not stop your child from learning to walk.

Once a child starts to cruise or walk, a shoe-raise or lift is added to the bottom of their shoe to minimise the limb length discrepancy. Decisions over lengthening are made later in the process, after discussions with your child's medical team.

The type and timing of surgery will depend on many factors and will be discussed in detail with the child's medical team at regular consultations.

How will this affect my child?

The emotional and physical effects of living with - and having treatment for - Fibular hemimelia will vary with the type of treatment, from child to child and family to family.

Discussing your child's condition / treatment with them openly and in simple terms, promoting positive body image in both them and yourselves as parents will help them prepare for whatever the future holds.

As the many achievements of the children whose families we have supported demonstrate, even amputation is no barrier to a full and active life and the most important thing is to always encourage full participation in whatever your child shows an interest in.

Access to new technologies and advanced prosthesis means that your child should be able to participate fully in almost any activity.

Sources of support

Our helpline [01925 750271](tel:01925750271) is open from 9am until 5pm on weekdays, for any questions you may have about practical support.

Medical enquiries will be passed to our panel of NHS consultants. Email info@steps-charity.org.uk with a specific request or fill in a contact form on our website steps-charity.org.uk.

The Steps closed Facebook Group is a friendly and safe way of discussing your worries, sharing tips and finding emotional support.

Our Family Contact service identifies someone else who has been through a similar situation and who is happy to talk about their experiences, on a one to one basis, to offer support.

We don't take walking for granted...



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