

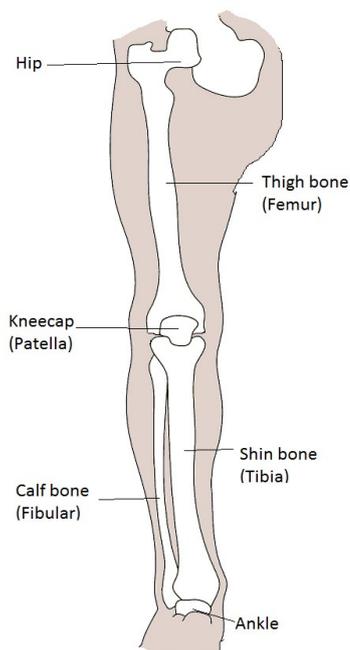
Fact Sheet



Tibial Hemimelia

What is Tibial Hemimelia?

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



Tibial hemimelia, is a deformity, partial or total absence of the tibia and is the rarest form of leg bone growth problems present at birth, it can also be associated with conditions affecting the arms, although any possible additional problems will be thoroughly investigated by your medical team. There are likely to be foot and ankle deformities and the foot may have additional toes. The knee may be twisted inwards and may be unstable or

completely dislocated. This instability is also due to an absence of ligaments attaching the tibia to the femur and absence or limited use of essential muscles in the area.

A leg affected by tibial hemimelia will look very different to an unaffected leg. It occurs either in one leg (unilateral) or, in around a third of cases, both legs (bilateral). In cases of unilateral tibial hemimelia, the condition most commonly affects the right leg, although it is unknown why this is.

The fibula may be deformed or it could be unaffected. Often, fibrous tissue is present at the lower end of the tibia. This is a developmental remnant, known as an anlage, which is extremely hard to detect on x-rays. The ankle is angled inwards, due to the shortness of the tibia in relation to the fibular bone and as such, mild cases that have not been detected on antenatal ultrasound may occasionally initially thought to be clubfoot.

In short tibial hemimelia is where one of the larger lower leg bones is shorter than in the other leg. In some cases, both legs are affected. There can also be problems with the knee, leg muscles and feet. In a few cases, there could also be problems with the arms.

Why does it happen?

Tibial hemimelia is extremely rare and is thought to affect only 1 in one million births. **In most cases of tibial hemimelia, the cause is unknown.** It can, occasionally, be passed on in families and is sometimes associated with other conditions, congenital deformities and syndromes (although in the majority of cases, a cause is simply not known). A thorough examination and diagnostic tests will detect the presence or absence of other such conditions.

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Diagnosis

Severe cases are likely to be seen at scans during pregnancy, sometimes as early as 16 weeks of a pregnancy, but many are not picked up at this stage. Milder cases may not be noticed straight away and only become apparent when the shortening of the leg becomes more noticeable and the leg is X-rayed. Most cases are thought to occur for no reason although it is possible that there is a genetic link in certain families.

Steps have produced a downloadable publication, about congenital lower limb length difference for expectant or new parents who have been told of a possible problem with their baby's legs.

Treatment

Treatment depends on the exact form of the condition; how much of the tibia is present, how much of the ankle has formed and the condition and stability of the foot, ankle and knee.

In most cases of tibial hemimelia, there is often little option for reconstruction and amputation is the most likely outcome for children affected by the condition. This may be through or below the knee depending on the condition of the knee joint and the presence or absence, of certain other parts of the upper leg.

Further investigations such as x-rays and MRI may be used to guide treatment, such as options around reconstruction and would depend on factors, including the stability and functionality of the knee.

For less severe forms, a fixator may be used to lengthen the leg and improve the position of the foot. Steps have produced a publication on 'Leg Equalisation', explaining the process of leg lengthening and shortening and covers aspects of caring for a child during this process.

When will treatment start?

The timing of treatment will depend on the treatment pathway, which again will be dictated by the severity of the condition. In mild cases, with a reasonably functioning ankle, a shoe raise can be used as your child begins to try

and cruise, until leg lengthening and correction of the ankle is attempted. Some of these cases may be managed by a shoe raise alone, without surgery.

Consultants will assess each child individually. Where possible a surgeon will attempt reconstruction but this can only occur if there is enough of the natural leg present. If this is not possible, an amputation is often considered the better option. If an amputation is to be performed most surgeons would aim to do this around the age of one.

How will it affect my child?

The emotional and physical effects of living with - and having treatment for - tibial 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, the condition is no barrier to success 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) is open from 9am until 5pm on weekdays, for any questions you may have about practical support. Medical enquiries to 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. The Steps closed Facebook Group <https://www.facebook.com/groups/1730693800550369/> is a friendly and safe way of discussing your worries with other parents, sharing tips and finding emotional support.

Our Family Contact service identifies someone else who has been through a similar situation and who's happy to talk about their experiences, on a one-to-one basis, to offer support and encouragement. For families also affected by limb difference of the arms reach.org.uk are very helpful.

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