

Orthopedic Center

Hand and Orthopedic Upper Extremity Program

Macroductyly

Whether your child or loved one suffers a broken arm, a sports-related injury or the most complex spine condition, the Orthopedic Center at Boston Children's Hospital is committed to providing comprehensive and compassionate care. Established in 1903, we are among the world's most experienced pediatric orthopedic programs, treating a high volume of some of the most complex orthopedic conditions. And with 13 specialty clinics, we are the largest in the country. We are also one of the busiest. Each year, our staff attends to about 100,000 patient visits and conducts about 6,000 surgeries.

The Hand and Orthopedic Upper Extremity Program provides comprehensive care for infants, children and adolescents with a wide range of complex upper limb conditions. Multidisciplinary care involving occupational and physical therapy, splinting, casting and reconstructive surgeries is provided for congenital, neuromuscular, sports-related oncologic, traumatic or post-traumatic conditions.

What is macroductyly?

Macroductyly is an uncommon birth defect in which toes or fingers are abnormally large due to overgrowth of underlying bone and soft tissue—particularly the nerves, fat and skin of the involved digit or digits. As with the majority of birth defects, scientists do not know why macroductyly occurs, but information that is known about the condition indicates that it does not result from the mother's lifestyle or anything the mother did during her pregnancy.

Macroductyly is more commonly considered static, with the enlarged digit (finger or toe) continuing to grow at the same rate as the normal digits of the hand, but it can be progressive, with the affected digits growing faster than the rest of the hand. In the static type, the involved digits are generally about 1 1/2 times the normal length and width of the normal digits. If the condition is progressive, the involved digit or digits can become enormous. Hands are more commonly involved than feet. Most of the time, only one hand or one foot is affected, but usually more than one digit is involved. It may coexist with syndactyly, a condition in which two fingers or toes are fused together.

Macroductyly can be associated with other conditions or can occur on its own. Although it is a benign condition, it is deforming and can be cosmetically displeasing to the child and family. Surgery, usually involving multiple procedures, can help the problem.

What causes macroductyly?

Several theories exist about the cause of macroductyly. Some believe that the condition is due to an abnormal nerve supply to the affected digit while others blame an abnormality in the blood vessels and blood supply in the area. Although neither theory have been proven, some evidence does suggest that nerves have some control over the

growth of tissue. Although it occurs at birth, macroductyly is not an inherited condition. It can occur in association with neurofibromatosis and vascular malformations. Children with multiple echondromatosis, Maffucci syndrome and tuberous sclerosis can have enlarged digits.

How is macroductyly diagnosed?

Most cases of macroductyly are apparent soon after birth, although occasionally, the progressive type may not be detected until later in infancy, when relentless enlargement occurs. Your baby's doctor will want to perform diagnostic tests of the affected area to note the underlying layers of tissue that are enlarged.

How is macroductyly treated?

Specific treatment for macroductyly will be determined by your child's physician based on:

- your child's age, overall health, and medical history
- whether the condition is static or progressive
- the severity of the condition
- any associated conditions
- your child's tolerance for specific medications, procedures, or therapies
- your opinion or preference

The goals of treatment also depend on whether the macroductyly occurs in the hand or foot. For instance, if in the hand, the goal would be optimal function, and hand function can tolerate a digit with a certain degree of increased width and length. In the foot, however, even the slightest amount of enlarged width may make shoe wearing difficult.

In mild cases, treatment for macroductyly may involve observation or, in the case of an enlarged foot, shoe modification alone. Most of the time, however, surgery is required. It is important to understand that surgery to correct macroductyly is complex because

it involves multiple layers of tissue. It may take several different surgical procedures to achieve the desired result. Size altering surgery will involve extensive observation and planning, because doctors will want to be able to plot the rate of growth of your child's normal digits versus the enlarged digits. Your child's doctor may recommend some combination of the following surgical procedures:

Soft tissue debulking— To help correct width, this procedure involves the surgical removal of the thickened layers of skin and fat and the replacement of skin with skin grafts harvested from healthy skin in the proximal region. This procedure is usually performed in several stages around three months apart. It is more often used to treat the milder forms of macroductyly or as a part of the treatment of the more progressive forms.

Shortening procedures: To help correct length, shortening procedures usually involve either surgical excision (removal) of one of the phalanges of the finger or toe, or removal of a metacarpal (hand bone) or metatarsal (foot bone).

Ray resection— Surgical removal of the entire digit or digits is sometimes necessary, particularly when the condition is progressive. It is also an option if there is excessive widening of the forefoot, where digital shortening and debulking procedure may not be effective.

What is the long-term outlook for a child with macroductyly?

The long-term outlook for a child treated for macroductyly varies from child to child, depending on how severe the problem is. Generally speaking, you and your child can expect an overall improvement in appearance and function. However, it is rare to attain perfect size and function of the involved digit(s).

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