Arthrogryposis

What is Arthrogryposis?

Arthrogryposis is a rare condition that occurs in one out of 3000 births. It involves curved or hooked joints and limited range of motion for joints of the hands, wrists, knees, feet, shoulders and hips. Most children with arthrogryposis have normal intelligence and a sense of touch.

The full name is Arthrogryposis Multiplex Congenita.

- Arthro = joints
- Grypo = curved
- Multiplex = different forms
- Congenita = present at birth

Arthrogryposis is also known as Multiple Congenital Contractures.

- Multiple = many
- Congenital = at birth
- Contractures = limited joint motion

In some cases only a few joints are affected and the range of motion is nearly normal. In severe cases many joints are involved, including the jaw and back.

The most common form is Amyoplasia.

- A = absent
- Myo = muscle
- Plasia = abnormal growth or development

This condition involves multiple contractures in all of the limbs. The joint contractures are often severe and affect the same joint in both limbs.

What are the causes?

In most cases the cause cannot be identified. Joints that are unable to move before birth can result in joint contractures. When joints are not moved for a period of time, extra connective tissue develops. This fixes the joint in a stiff or locked position. It also causes the tendons connecting to the joint to not stretch to their normal length making normal joint movement difficult.

The causes for limitation of joint movement are:

- muscles do not develop properly.
- muscle diseases.
- fever during pregnancy and viruses that may damage cells that transmit nerve impulses.
- decreased amount of amniotic fluid.
- the central nervous system and spinal cord do not form correctly.
- the tendons, bones, joint or joint linings may develop abnormally.

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- a genetic cause in 30% of the cases.
    - Several genetic patterns have been recognized, but most cases are rare and recurrence varies with the type of genetic disorder.

What are the goals?

To assist your child in developing and achieving goals to maximize independence in activities of daily living and accessing his or her environment.

What is the treatment?

Treatment is tailored to the individual by a multi-disciplinary team of physicians (pediatrician, orthopedic surgeon, neurologist, geneticist), nurses, physical therapists and occupational therapists.

Treatments may include physical therapy, occupational therapy and/or surgery.

1. The goal of **physical therapy** is to increase the range of motion and strength through functional activities and exercises. Assistive devices to help achieve goals may include splints, braces, crutches and wheelchairs. Parents are encouraged to become active participants in a therapy program and to continue therapy at home on a daily basis.
2. The goal of **occupational therapy** is to learn activities of daily living such as feeding, bathing, toileting and dressing with assistive devices. These assistive devices include long handled utensils, hairbrushes, toothbrushes, bath brushes, toileting aids, etc.
3. The goal of **surgery** is to correct the alignment of the upper and/or lower extremities so that the activities of daily living, such as standing and walking are possible. In some cases tendon transfers are done to improve muscle function. For severely affected children the extremities are positioned in a fixed standing or sitting position. The pros and cons for both positions will be discussed prior to scheduling surgery.

What to expect?

In most cases, the outlook is a positive one. The condition does not worsen with age. Therapy and other available treatments can bring about substantial improvement. The vast majority of children survive and live a normal life span. Many excel because they become experts at meeting and tackling challenges and are able to lead productive, independent lives as adults.

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