AMCSI Annual Conference

Once a year we meet, bringing together professionals, doctors, physical therapists and occupational therapists. We provide workshops and invite people throughout the world to learn, share, laugh, cry and grow as one community.

Our Mission

To provide and encourage more understanding and mutual support among anyone affected with the diagnosis of arthrogryposis multiplex congenita (AMC).

To create a higher standard of AMC awareness by means of conferences, meetings, and studies.

Our Vision

To provide educational material to new parents, or soon-to-be parents regarding the diagnosis of arthrogryposis multiplex congenita (AMC). To provide a resource of information to the medical field to include, but not limited to, occupational therapists, physical therapists to assist them in the treatment of a child or person with the diagnosis of AMC.

Our Support

We encourage you to join our online support group. There you will find information and support not only from parents whose children were born with AMC, but also from adults living with AMC.

For research articles and more information go to our website www.amcsupport.org

You can join at www.amcsupport.org/support forums

www.facebook.com/amcsupport
www.twitter.com/amcsupport
www.instagram.com/amcsupport

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What is (AMC)?

Arthrogryposis multiplex congenita — Rather than an actual diagnosis, the term “arthrogryposis multiplex congenita” is more of a description for someone born with multiple joint contractures. The word arthrogryposis is derived from the two Greek words “arthro” (meaning “joint”) and gryposis (meaning “crooking”); “multiplex” and “congenita” are Latin words meaning “many” and “existing at birth,” respectively. Therefore, the loose translation is “many crooked joints at birth.”

What causes AMC?

There are many different types of AMC (in excess of 400) and in most cases the exact cause is unknown. However, all the different forms of AMC have one thing in common; the baby did not move his or her joints fully during pregnancy. This in turn can be caused by abnormal development of the spinal cord, muscles or nerves going to the muscles. The most common types of arthrogryposis are not hereditary and other types are individually very rare.

What is the outlook for people with AMC?

The experience of arthrogryposis is unique to each individual. However, unlike many other syndromic conditions present at birth, arthrogryposis does not worsen with age. Therefore, the outlook for those with arthrogryposis is positive. With treatment, significant improvement in functional skills is possible. Furthermore, more than two thirds of children who are born with arthrogryposis are of normal intelligence and are able to lead productive, independent lives as adults. On this brochure, you will find side-by-side examples of before and after pictures of a number of our members.

What if I am pregnant with a baby with AMC?

If you are pregnant, and arthrogryposis is diagnosed through ultrasound findings, Dr. Judith Hall, one of the most knowledgeable geneticists on the subject recommends “in-utero therapy” during the third trimester, if cleared by your obstetrician:

- Drink Coffee or Tea 3x a day.
- Take 10 deep breaths 3x a day.
- Keep Moving - Exercise.
- Take 10 minute fast walks at least 1x a day.

She also suggests discussing with your obstetrician the possibility of delivering the baby 2-3 weeks early, if the baby is healthy enough (lungs are developed). That will allow the contractures to be treated sooner. You may also want to talk with your doctor about delivering by C-section to reduce the risk of fractures, to which babies with AMC are more prone during the newborn period. Not all patients have the same medical and pregnancy history. Always talk with your physician before changing medications or lifestyle changes.

Early Intervention

Early Intervention services are crucial to the healthy development of children with disabilities such as AMC. Over the years, early intervention services have proven to be vital to the healthy development of infants and toddlers with AMC, minimizing their potential for developmental delay. With early intervention, a child can decrease the extent of delay relative to their peers. Services may include occupational therapy (OT) to improve upper extremities (fine motor skills), physical therapy (PT) to improve lower extremities (gross motor skills), and speech therapy (ST) to help children learn to eat, speak, and improve oral motor skills. Service coordination through a local agency (e.g., Department of Mental Health, Mental Retardation and Developmental Disabilities, and Department of Education) is provided as well. Some states also offer developmental therapy (DT) provided by an Educational Specialist or Developmental Therapist who can track general developmental progress and work on pre-academic skills. Most early intervention services take place in the child’s Natural Environment; this could be the child’s home, daycare facility or babysitter. Parks and other community facilities are also considered part of the child’s natural environment.

AMC Awareness

Help raise awareness by wearing BLUE on June 30th!