



take time

PREGNANCY & ARTHROGRYPOSIS

A guide for parents expecting a
pregnancy affected by arthrogrypsis
and the doctors caring for them



WHAT IS ARTHROGRYPOSIS?

Arthrogyrosis Multiplex Congenita (AMC) or “arthrogyrosis” for short is a term used to describe contractures (or stiffness) in two or more body areas that are present at birth. There are over 400 different diagnoses or conditions that can lead to a baby being born with arthrogyrosis, but luckily it is relatively rare, occurring in approximately 1 in 3000 liveborn pregnancies. During pregnancy, arthrogyrosis can be detected by observing decreased or absent movement of an extremity or an abnormally shaped limb. Common ultrasound findings include clubfoot deformity, elbows or knees that do not move much or at all, or clenched hands. Unfortunately, in many pregnancies, these findings are not detected on routine ultrasound and are not discovered until birth.

WHAT CAUSES ARTHROGRYPOSIS?

In the most common type of arthrogyrosis, known as Amyoplasia, the exact cause is unknown. Some babies have an underlying neurologic or muscle disorder, or a specific gene mutation that leads to arthrogyrosis. Arthrogyrosis occurs when there is a lack of normal movement early in the pregnancy (around 8-11 weeks). In Amyoplasia, a prevailing theory is a disruption of bloodflow to the developing fetus at a critical time during development of the limbs. Some mothers may have experienced bleeding or a viral illness or fever during this time. Other risk factors include conditions that crowd the uterus, such as fibroids or twins.

It is important for parents to understand that they did nothing wrong during pregnancy that caused arthrogryposis to develop in their child.

When arthrogryposis is detected during pregnancy, it can be difficult to tell how severe the joint contractures are and what other body systems may be affected. Sadly, some babies are so profoundly affected that they are stillborn or do not survive to their first birthday. It is very difficult for even the most experienced providers to predict a baby's medical course after birth based on ultrasound findings alone. In some situations, parents may be offered the option of pregnancy termination after careful consideration of all the available information. Other tests, such as amniocentesis, fetal MRI, or genetic testing may help to gain insight into a baby's overall health and possible outcomes.



HOW IS ARTHROGRYPOSIS TREATED?

There is no cure for arthrogyrosis, but there are many therapies that can help improve the shape and function of affected areas of the body. Treatment options include:

- Stretching
- Casts or splints
- Braces and orthotics
- Physical therapy
- Occupational therapy
- Aquatherapy

Surgery can help correct abnormally shaped bones and joints. Surgical treatments include:

- Tendon lengthening or repositioning
- Osteotomy (cutting bone to reshape it)
- Placing hardware (screws, plates, rods) to straighten bones or direct how they grow
- Soft tissue release (loosening tendons and ligaments attached to joints)
- External fixators



WHO ARE WE?

Take TIME for AMC is an organization dedicated to improving the prenatal detection of arthrogyriposis and helping parents and their doctors navigate the pregnancy and delivery process. Our mission is to support research on prenatal diagnosis of arthrogyriposis, to raise awareness of AMC among families and medical professionals, and to advocate for improved protocols and guidelines for prenatal care of affected pregnancies.

Take TIME for AMC was founded by Ian and Sara Lemin after their son was born with AMC in 2017. Even as a critical care nurse and an OB/GYN physician, Ian and Sara had not heard of arthrogyriposis before their own pregnancy was affected. They want to use their experience at the intersection of AMC families and obstetrical medical professionals to help other expectant parents and their doctors during their pregnancies.

MY BABY HAS ARTHROGRYPOSIS — WHAT CAN I DO?

STAY HOPEFUL

Most expectant parents have not heard of arthrogryposis prior to being told their baby has it. It can be a lot of new and confusing information, and much of what is available on the internet projects a dismal outlook. There is a wide range of challenges that AMC babies may face, but most of them do very well at birth and beyond. Contractures look their worst at birth, but many joints relax with time, stretching, and therapy. Keep a positive outlook and seek information from reputable medical sources. In addition to all the physical uncertainty, soon-to-be AMC parents worry, “Will my baby be happy?” The answer is YES! Your baby will receive so much *LOVE* and *ATTENTION* from you, and that’s what really matters for a child to be happy. Your child will teach you more about strength, perseverance, joy, ingenuity, and love than you ever thought possible.

STAY HEALTHY

As with any pregnancy, it is important to stay as healthy as possible. Follow a healthy diet with plenty of protein, fruits and vegetables. Take a prenatal vitamin that contains folic acid and DHA. Avoid tobacco use, vaping, alcohol consumption, and recreational drug use. Get an appropriate amount of sleep. Minimize stress where possible. If you have an underlying health condition, be sure it is under optimal control.

PROMOTE MOVEMENT

Although your baby may have limited ability to move inside the womb, research suggests you can help promote movement in your baby by:

- Exercising regularly
- Drink a caffeinated beverage 2-3 times per day
- Take a brief, brisk walk 2-3 times per day

GET ORGANIZED

You will have many questions during your pregnancy and after your baby is born. Many parents find it helpful to keep a notebook, computer file, or smartphone note. Write down questions you want to remember to ask your doctors. Print articles you find helpful. Often times, your doctors may not be very familiar with arthrogryposis yet and are learning alongside you, so bring information you find to share with them.

GET CONNECTED

Learning that your baby has arthrogryposis can be an uncertain, fearful, and lonely time in your pregnancy. **YOU ARE NOT ALONE!** There is a wonderful network of AMC families online and on social media that can be a very encouraging and informative source of support! The organization AMCSI (Arthrogryposis Multiplex Congenita Support Inc) is an excellent starting place that can direct you to online texts, support groups, specialists and events. Visit their website at www.amcsupport.org. You can also search “arthrogryposis” on Facebook to find support groups.

CELEBRATE THE NORMAL THINGS

It can be easy to get lost in the medical details, the unknowns, and the worry. Don't forget to take time to enjoy the beautiful things about your pregnancy too! Take a picture of your belly bump. Create a baby shower gift registry. Indulge in those weird food cravings. Let the little movements fill your heart with love and wonder.



HOW CAN MY DOCTOR HELP?

COORDINATE REFERRALS

A pregnancy affected by arthrogyriposis can benefit from a multi-specialty team approach. Your doctor should consider referrals to the following specialists as needed and when available. (Remember, every baby is unique and may not need ALL of these specialists, but this is a general list to use as a starting point.)

- Maternal Fetal Medicine
- Genetics
- Orthopedics
- Neonatology, including a tour of NICU
- Physical Therapy/Occupational Therapy
- Psychiatry
- Neurology
- Social Services and Financial Aid
- Early Intervention Programs funded by your state

RESEARCH MEDICAL LITERATURE AND CONSULT MEDICAL PEERS

Literature searches of medical databases can be a helpful source of up-to-date information for clinicians. Many excellent, well-trained physicians and midwives may have never encountered a pregnancy affected by arthrogyriposis before and are likely to be just as thirsty for accurate information as parents. A call to a Maternal Fetal Medicine specialist may provide helpful direction. Your doctor may also reach out to Take Time for AMC Inc or AMCSI for more information.



HOW CAN I PREPARE FOR DELIVERY?

DECIDE ON LOCATION

It is advisable to plan to deliver in a facility that has the capability to care for the needs of your newborn. As many as 60-70% of AMC newborns go to the Neonatal Intensive Care Unit (NICU). Your baby may not need much additional care, or he/she may need intensive support such as a ventilator or feeding tube. Since it is very difficult to predict how much care your baby may need, delivering in a hospital with a NICU available is something to strongly consider.

VAGINAL BIRTH OR CESAREAN?

Your doctor will help you decide on the most appropriate type of delivery for your baby based on your overall medical and prenatal history. Many babies with arthrogryposis are in the breech position (70-80%) due to their limited ability to move, and a cesarean delivery would be recommended. Babies with hyperextension of the neck should always be born by cesarean section. There are limited studies to evaluate whether a cesarean section protects AMC babies from broken bones or other injuries during delivery, but the overall incidence is low.

In a Facebook survey conducted by Take TIME for AMC of over 300 AMC pregnancies, a broken bone occurred in only 7% of all vaginal deliveries, and 11% of all Cesarean sections. If the baby is in a head-down position, a vaginal delivery may be appropriate.

COLLECT BLOOD FROM UMBILICAL CORD

After your baby is born and the umbilical cord is cut, there is still a fair amount of baby's blood in the cord and placenta. This blood can be collected (in EDTA tubes) and saved for later use if your pediatrician or neonatologist wants to order blood tests on the baby (i.e. genetic studies). If this sample has already been collected, it could spare your baby from an extra needle stick.

RESEARCH LOCAL RESOURCES

You can ask your pediatrician about their experience with caring for a child with arthrogryposis. They may feel comfortable caring for your child, or they may help connect you to colleagues at a larger regional center. Many children's hospitals in larger cities have an

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arthrogryposis clinic or a multi-specialty team already in place. Check the website of children's hospitals near you. Join social media AMC support groups and ask parents in your area where they take their children.

BUILD YOUR SUPPORT NETWORK

The days after your baby is born may be very busy. Some parents are saddened that they don't have as many opportunities to snuggle, nurse, or bond with a baby who requires extra equipment or care. If you have other children at home, it can be helpful to have extra childcare arranged ahead of time. Friends who can prepare meals or fill your freezer with premade dinners can be a wonderful help. Connecting with other AMC families online can be a huge source of support from parents who have been down the path you are on.

WILL I NEED SPECIAL SUPPLIES AT HOME?

Most babies with AMC are able to use typical baby care supplies such as car seats and bassinets/cribs. Clothing that does not need to go over a baby's head, such as kimono-style or wrap around shirts, can be very helpful. Many parents prefer sleep sacks or pajamas without feet

to accommodate casts or braces. Parent support groups online are excellent for answering questions about such preferences and places to shop.

WHAT WILL THE FIRST FEW MONTHS BE LIKE?

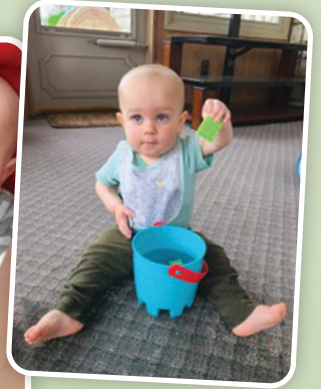
If we had to pick one word to describe the first few months, it would be OVERWHELMING!! Every child with arthrogryposis is unique, and your path will have its own course. It is reasonable to expect a possible stay in the Neonatal Intensive Care Unit. Once your baby comes home, he/she may have extra equipment such as casts, splints, monitors, oxygen, feeding tubes, etc. Don't panic! The hospital will be sure you understand how to care for these things before you come home.

Remember to take time to care for yourself and your close family relationships. Older children will benefit from keeping routines as close to normal as possible. Some family and friends may feel awkward about visiting or asking questions due to their own lack of understanding about arthrogryposis. Try not to be offended, but rather use opportunities to educate others in a positive way.

You can expect to have many appointments for your baby in the first few weeks, months, and years of life. Many parents are overwhelmed by the various types of appointments and providers their child may need, but it helps to focus on short term goals and take it one step at a time. Every child is unique and will require an individualized group of providers tailored to his/her specific needs. Some of the common types of doctors/therapists your child may see include:

Pediatrician
Neonatologist
Orthopedic surgeon
Geneticist
Occupational therapist
Physical therapist
Orthotist (makes braces)
Neurologist
Dietician
Speech therapist
Feeding therapist
Physiatrist / Rehabilitation

Pulmonologist
Cardiologist
Endocrinologist
Pain management
Psychologist
Chiropractor
Gastroenterologist
Ear/Nose/Throat specialist
Plastic Surgeon
Social Worker
Adaptive equipment specialist







QUESTIONS?

Please feel free to email us at info@taketimeforamc.org. We can direct you to resources that will help you find the information you are looking for. You can also visit our website at TakeTIMEforAMC.org.



Our co-founder, Sara Lemin MD, is a board-certified OB/GYN and an AMC parent. If your doctor has professional questions about your care plan, Dr. Lemin would be happy to speak with him/her. She can be contacted at AMCMamaDoc@gmail.com.



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Take TIME for AMC, Inc.
PO Box 2276 | North Canton, OH 44720

TakeTIMEforAMC.org



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