



AMCSI

Arthrogryposis Multiplex Congenita Support, Inc.

PR
PACKET

FOR IMMEDIATE RELEASE





Arthrogryposis Multiplex Congenita Support, Inc.

FOR IMMEDIATE RELEASE

Contact: amcsupport.org
Phone: (805) 552-6274
Email: amcsibod@gmail.com

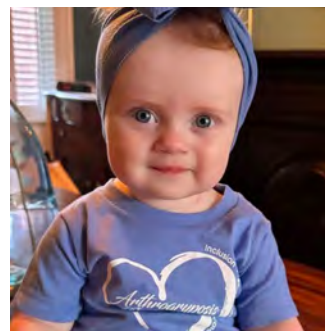
ARTHROGRYPOSIS SUPPORT GROUP HOSTS 15TH ANNUAL AWARENESS DAY

SPARTANBURG, SC, January 1, 2024— On June 30th, families across the globe will be wearing the color blue to honor those affected by Arthrogryposis Multiplex Congenita (AMC). This will be the fifteenth annual AMC Awareness Day sponsored by Arthrogryposis Multiplex Congenita Support, Inc. (AMCSI), a 501(c)(3) nonprofit organization.

Quick Facts About Arthrogryposis Multiplex Congenita

- Arthrogryposis is defined as multiple congenital (from birth) joint contractures or multiple joints that are stuck in one position and have very little flexibility.
- Arthrogryposis is an umbrella diagnosis, which means that it is part of many other conditions and syndromes. These conditions and syndromes are usually referred to as the type of arthrogryposis. Currently there are 400 identified types of AMC. Amyoplasia, Distal and Escobar Syndrome are the more common types (but they are still relatively rare within the general population). Some individuals never have their type of AMC identified.
- Arthrogryposis is not a newly identified condition. Adolph Otto officially described it in 1841. Literary evidence of arthrogryposis dates back as early as the 12th century. In 1642, a painting entitled “the clubfoot” located in the Louvre, portrays a beggar believed to have a form of AMC, though the specific type is still debated among experts.
- Stretching, various therapies (physical, occupational, speech, etc.) and some surgical interventions can help improve someone’s independence level and quality of life.
- Most children and adults who have a diagnosis of arthrogryposis are cognitively typical, meaning their IQ scores are normal or above normal. Some people with AMC will have some level of cognitive impairment.

Questions regarding the support group or to request more information about arthrogryposis should be directed to the organization’s Board of Directors by emailing amcsibod@gmail.com.



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To learn more: www.amcsupport.org

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Arthrogryposis Multiplex Congenita Support, Inc.

#BLUEForAMC



Dear AMC Family Members,

WHEN: AMC Awareness Month starts June 1st.
Wear #BlueForAMC on June 30th.

WHO: Arthrogryposis Multiplex Congenita Support Inc. (AMCSI) celebrates their 15th year raising awareness for arthrogryposis multiplex congenita.

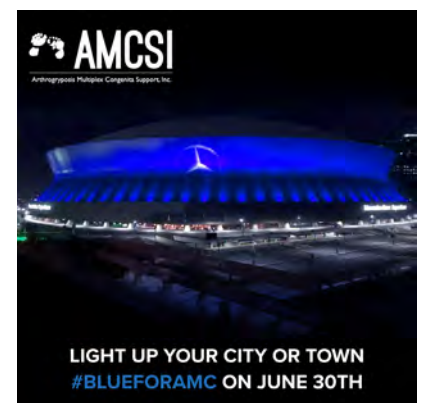
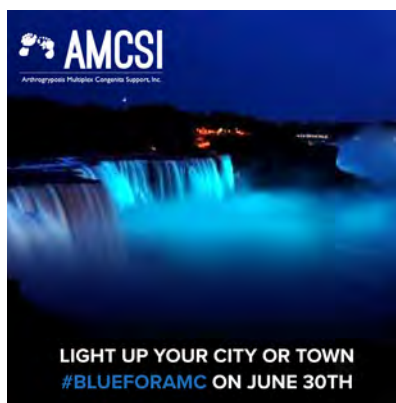
WHAT: You will find the press release for AMC Awareness Day attached to this email. Please use it to help AMCSI promote AMC Awareness Day and reach as many people as possible.

HOW: Craft a personal message about your own story/experience with Arthrogryposis and send it to your local news/media sources (*on-line, television, newspaper, etc.*) with our press release attached to your message. You will find many local news sources that love to report on special interest stories or events. Local reporters/new anchors have worn #BlueForAMC. Have connections with celebrities or social media influencer's? - Tag them to support AMC Awareness Day!

If you are submitting applications to light up local bridges, hotels, buildings, tourist staples, or arenas #BLUEFORAMC please submit ASAP! There may be permits that need to be approved before a lighting event and most of them have deadlines well in advance of the date you're requesting. Any news/media publications would just need to run prior to awareness day on June 30th.

DON'T FORGET: let us know if you are successful in receiving a response from any media outlets and be sure to email us a link to news reports once they air or articles once they are published. Please TAG @AMCSUPPORT in all #AMCAwareness posts! We would love to share your efforts with our community!

THANK YOU for helping us make AMC Awareness Day a success!



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Arthrogryposis Multiplex Congenita Support, Inc.

AMC AWARENESS DAY

Proclamation FAQ

What is a proclamation?

A proclamation is a formal public statement. It is a major statement made in front of an audience or the authoritative word on some subject. It's most often used in an official or government context. Proclamations can be created at the local, state, and federal level.

Why do I have to request a proclamation every year?

A proclamation is an official document to commemorate a specific time period (day, week, or month) for the purpose of raising awareness about an issue, or celebrating milestones. Therefore, if a proclamation has been issued in the past, a new request still needs to be requested each year.

Why is it important to obtain proclamations?

Proclamations are a great way to raise awareness within your community about Arthrogryposis. You can use the proclamation for media outreach and social media.

Where do I request proclamations from?

Municipalities include: Governor's office, Town, Cities, Boroughs, Counties or Parishes. A city or county website may list appropriate contacts.

Who do I request proclamations from?

A state Governor, Mayor, First Selectman, City Council or County Commission's office

How do I get started in obtaining a proclamation?

Email amcsibod@gmail.com to sign up for your state. We will maintain a list so our volunteers don't duplicate efforts. If there is another volunteer working on your state, we can put you in contact with them to join forces.

Most states request submission of a request 2 months prior to AMC Awareness Day, June 30th. Follow up 10 to 14 days after you submit the request.

What happens when I get the proclamation?

Share with AMCSI and the AMC community and flood the Internet with photos. Don't forget to add hashtags: #BlueForAMC #AMCAwareness #Arthrogryposis and #AMCAwareness2024

Write a letter, post on official Facebook and/or Twitter account to the mayor, governor or legislators and thank them for their support in bringing official attention to Arthrogryposis.

Thank you for all helping us making June 30th the best AMC Awareness Day ever!!



State of South Carolina Governor's Proclamation

WHEREAS, arthrogryposis multiplex congenita is a condition that causes many joints to be stiff and crooked at birth, resulting in a lack in the normal range of motion in the affected joints; and

WHEREAS, arthrogryposis is present in approximately 1 in 3,000 births; and

WHEREAS, any and all joints, including the hands, feet, hips, knees, elbows, shoulders, wrists, fingers, toes, jaw, and spine, can be affected, and some may not be affected; and

WHEREAS, while arthrogryposis is not curable, there are effective treatments that help promote independence in the activities of daily life.

NOW, THEREFORE, I, Nikki R. Haley, Governor of the great State of South Carolina, do hereby proclaim June 30, 2016, as

ARTHROGRYPOSIS AWARENESS DAY

throughout the state and encourage all South Carolinians to work together to raise awareness of this condition and the available treatment options.



NIKKI R. HALEY
GOVERNOR
STATE OF SOUTH CAROLINA

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HOW TO CELEBRATE AMC AWARENESS



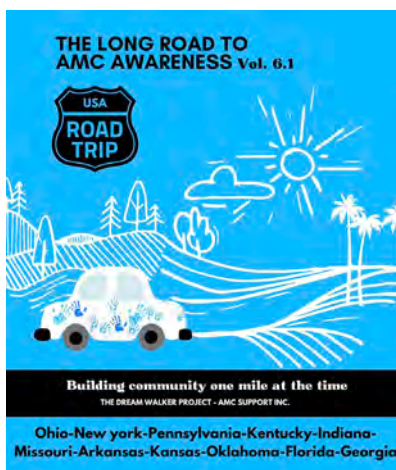
Fundraising 101

- Yard-sales, Bake-sales, Lemonade Stands
 - Pancake Breakfast/Lunch/Dinner
 - Corn-hole Tournament
- Restaurant Partnership/Wine Tasting:
 - Pub Crawl
 - Sip'n Paint
 - Host An Event:
 - Hip Hop Festival, Comedy Night, Val's AMC Music Festival, Val's Bowl-A-Thon, Reach out to local musicians
- Organize a 5K (run, walk or roll):
 - Bike Race - 253 For AMC, Color Run
- Motorcycle Run (Ride for AMC Charity)
 - Golf Tournament
- Employment Donor Match Programs
 - Crazy Hat Day At School



Want to make your celebration a donation to AMCSI, please email us at info@amcsupport.org

Donations help fund our community give-back grants and our annual conference.



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WHERE AS STATEMENT EXAMPLE:

Organization: AMC Support
Website: AMCSUPPORT.ORG

Arthrogryposis Awareness Day Proclamation

Organization: AMC Support Website: AMCSUPPORT.ORG
Arthrogryposis Awareness Day Proclamation



Whereas:

Arthrogryposis Multiplex Congenita (AMC) is a condition that causes many joints to be stiff and crooked at birth. A newborn with Arthrogryposis lacks the normal range of motion in one or more joints. This condition develops prenatally and can be caused by an underlying condition or syndrome; and

Whereas:

Arthrogryposis Multiplex Congenita is an umbrella diagnosis, meaning that it is a part of many other conditions and syndrome. There are over 400 different types of AMC of which Amyoplasia, Distal Escobar Syndrome is the most common; and

Whereas:

A newborn has to have three contracted joints in two different body areas to be diagnosed with arthrogryposis. This occurs in 1 in 3,000 births; and

Whereas:

Joints that can be affected by AMC include the joints in the hands, feet, hips, knees, elbows, shoulders, wrists, fingers, toes, as well as the jaw and the spine. Though all joints can be affected, some may be unaffected as no two people experience the same symptoms; and

Whereas:

Though arthrogryposis is not curable, it is treatable. Treatment goals aim to allow those living with the condition as much independence in their daily lives as possible; now

Therefore:

I, Phil Murphy, Governor of New Jersey do hereby proclaim June 30, 2024, as ARTHROGRYPOSIS AWARENESS DAY in New Jersey.



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Arthrogryposis Multiplex Congenita Support, Inc.

AMCSI ANNUAL CONFERENCE

Once a year, we bring 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.

COMMUNITY SUPPORT

Our mission is to always support our community through our resources and grant programs. Below are some that we provide:

- Research Fund
- Adoption Grants
- Mini Meet-Up Grants
- College Scholarship Grants
- Medical/Travel Grants

Visit amcsupport.org/grants to learn more about our grant programs.

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, 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.

BECOME A MEMBER

All of our programs are fully funded by our AMC community. We could not do any of this without the help of our membership, donors, sponsors, fundraisers, friends and family. We appreciate each and every one of you.

MEMBERSHIP BENEFITS INCLUDE:

- Discount on registration fees to the AMCSI yearly conference.
- Access to annual public meetings and monthly BOD meeting minutes.
- Ability to apply to serve for a vacant spot on AMCSI’s Board of Directors.
- Ability to participate in various volunteer and board committees.
- Ability to apply for grants such as the Mini Meet-up, Research, Bereavement, and College Scholarships.

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 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 groups and social media platforms. You will find information and support not only from parents whose children were born with AMC, but also from adults living with AMC



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