

2023-2024 LOSNA Special Project – Supporting AMC

Arthrogryposis from the Greek simply means joints (arthro) that are stuck or crooked (gry) as part of a condition (posis). So if someone has limited range in their joints (arthrogryposis) from birth (congenita) in at least two or more areas of the body (multiplex), they get this diagnosis of arthrogryposis multiplex congenita (AMC). Children often refer to this as "my bendy parts don't bend."

AMC affects 1 in 3,000 births. That's very similar to the number of babies born redheads! So, it's rare, but not as rare as people think; you're likely to have someone with AMC in your community! But redheads usually have other redheads in their family to look up to whereas those with AMC will often be the only one in their family. The most common type of AMC (called amyoplasia) doesn't have any genetic component to it. That leaves a big need for community. The conferences are a solution to that need.

The Project for this year has three parts.

1. Money will be raised for Shriner's Greenville to Support the Mini Conference held each year. The funds will be used for the AMCer and one care giver to travel to this conference. At this conference the AMCer has access to doctors, therapists as well as the networking with other AMCs. Who best to teach a child with AMC but another child with AMC. This conference is held in conjunction with AMC Support.
2. Money will be raised for AMC Support to support the Annual Weeklong Conference held each year. The funds will be used for the AMCer and one care giver to travel to this conference. At this conference the AMCer will also have access to doctors, therapists as well as the networking with other AMCs. You may also see at this conference expectant parents of a future AMCer. This shows the parents that AMCs can do anything. They just do it a little differently.
3. Courts can designate their funds for the purpose of purchasing an OBI Robotic Spoon Independent Feeding System. These systems cost \$8,000 but are an invaluable tool to feed some of the AMCs that do not have muscle tone to lift a spoon.

Donations for the Special Project can be made by sending your checks to our Grand Recorder made payable to **'Grand Council, LOSNA'** and 2023-2024 Special Project on the memo line.

Donations for tax purposes can be sent to Lady Charlene Carpenter, Treasurer of the Grand Council LOSNA Foundation by making your checks payable to **'Grand Council LOSNA – Foundation'** and 2023-2024 Special Project on the memo line.

Both Addresses are in the Book of Proceedings.

Lady Karen Przytula
Grand High Priestess