Receiving a pre-natal diagnosis is never easy. You will probably have many questions, but unfortunately not too many answers. Hopefully the following will answer some of your questions:

What is Arthrogryposis?

Arthrogryposis Multiplex Congenita (AMC) is a description of joint contractures (stiff or fixed joints). Joints may be fixed in a flexed (bent) or extended (straight) position and be present in just two or many different body areas. The joints become affected due to a lack of movement in the womb. This immobility can have several causes:

- Failure of muscles to form or function correctly
- Absence or incomplete formation of the nervous system
- Abnormal joints or connective tissue
- Decreased space in the womb

What are the affects of Arthrogryposis?

AMC is a diverse condition that affects babies very differently and this makes it difficult for consultants to give a clear idea of the future, even once the baby is born. A few babies may also be affected in other body areas, such as the jaw or spine, and a smaller number may have other complications affecting the central nervous system, respiratory system or digestive system. However, the majority of babies born with AMC do go on to lead full and active lives. Most children with AMC are able to walk, but may need the help of splints or other aids to do so. Physiotherapy plays a key role in the treatment of AMC and some babies will need surgery.

What can be learnt from scans?

With recent technological developments more and more cases of Arthrogryposis are being picked up during scans but it is usually very difficult to give expectant parents many answers from the information available from the ultra sounds. Never-the-less more is being learnt all the time and so it is very important that you:

- push for as much information as possible
- request a ‘real time’ hour long scan
• ask every question that comes into your head – make a list before the next appointment

It is essential when scanning to look for movement for at least an hour, rather than take the standard bone measurements. Movement starts between 11 and 34 weeks. Other tell-tale signs are extra fluid around the neck and thin under calcified bones. Due to the improved technology ultra sounds should be able to pick up bone abnormality at around 14 weeks.

What might consultants recommend?

• An early delivery of up to 4 weeks when everyone (family and consultants) is in agreement that this will be in the best interests of the baby. Physiotherapy is particularly important and effective in the first 3 to 4 months of life when the contractures tend to loosen significantly. This is known as the ‘Grace Period’ or ‘Catch up’. During this period the lungs continue to develop and the gut tends to improve in function and thus food is digested more effectively. Even some of the muscles that would appear to be unusually weak may significantly increase in strength and bones tend to increase in mineralization and growth.

• Encouraging baby to move in the womb: foetal movement relates to maternal movement and so the mother can encourage the baby to keep moving and thus possibly lessen the severity of the joint contractures by exercising regularly (gently) herself, by frequent deep breathing and drinking coffee – but only after the first trimester. In terms of prenatal diagnosis and the most up-to-date information on scanning, the organisation Antenatal Results and Choices (ARC) can offer excellent advice and they have supported many of TAG’s members who have had a prenatal diagnosis of Arthrogryposis.

You can contact them at:

ARC  www.arc-uk.org
Helpline 0207 631 0285

If you have any questions at all, or you just need someone to talk to, please do contact TAG