## Amniotic Band Syndrome BIRTH DEFECT RESEARCH FOR CHILDREN

## What is Amniotic Band Syndrome?

ABS refers to abnormalities caused by fibrous strands that can entangle or confine developing parts of the fetus. These strands are believed to arise from membranes that form outside the placenta. If the amniotic sac ruptures during gestation, the protective barrier of the sac is removed from the area between the placenta and the developing fetus, and the strands can be exposed and trap parts of the fetus. Symptoms associated with amniotic band syndrome include limb or skull abnormalities, cleft lip/palate, scoliosis, and other, more complex abnormalities. The most common symptoms of this syndrome include a circular, indented type of scar (constriction ring) around the arms, legs, fingers, or toes, or complete amputation of arms, legs, fingers, or toes.



## Amniotic Band Syndrome

How Many Children Have Amniotic Band Syndrome?

ABS happens in approximately eight out of every 10,000 live births. The most severe form of this syndrome usually results in a miscarriage of the fetus. In this case, the rate can be as high as 178 out of every 10,000 live births.

What Causes Amniotic Band Syndrome?

ABS has been linked in some studies to prenatal exposure to drugs such as methadone or LSD. Injury to the fetus or abdominal trauma may also play a role, but neither drugs nor trauma have been definitively linked to this syndrome. In addition, no definite genetic factors have been established; recurrence is extremely rare. The most severe symptoms of ABS occur when the placenta ruptures in early pregnancy.

How Can You Help Your Child With ABS?

Medical Examination: It is important for every child with ABS to have a complete medical evaluation to look for possible internal problems. However, since the most severe abnormalities usually result in miscarriage or stillbirth, live born children usually have only limb abnormalities.

Prosthetics: Since some children with ABS may have limb amputations, it is important to consult a prosthetist as early as possible. Advances in prosthetics have now made bionic (myoelectric) arms available for some children with missing hands or forearms. A bionic arm has a lifelike hand that can open and close through nerve impulses in the child's upper arm. Great improvements have also been made in artificial legs and feet. A more flexible prosthetic foot has been developed that aids children in better walking and running.

Surgery: Children with partially formed fingers or hands may benefit from new advances in surgical reconstruction. Surgeons now use a variety of techniques including transfer of bone and skin from other parts of the body to perform reconstruction. In addition, a new in-utero surgery has been developed that can release constricting bands from the fetus, thus allowing normal limb development to resume.

Living with an ABS: Children with ABS constriction rings or limb amputations must learn to cope with looking different than others. The parents' attitude about their child's birth defect has a major impact on how the child feels about his/her differences and how he/she responds to the curiosity of others. Parents can help their children feel good about themselves and explain their birth defect in a matter-of-fact way to other children. The teenage years can be more difficult for children with ABS than early childhood. It helps if the teenager has been encouraged to develop a variety of interests and abilities that allow them to interact with their peers on many levels.

Sports and Physical Activities: ABS should not prevent children from participating and even excelling in many sports and physical activities. Several professional athletes with limb amputations have played in major league sports.

Can Amniotic Band Syndrome Be Prevented?

Although the specific cause(s) of ABS is not known, it is essential to avoid unnecessary exposure to drugs or other chemicals during pregnancy. If detected early, in-utero surgery may be an option to correct band restrictions. Genetic counseling may be helpful to some families, even though recurrence is rare.

Fact Sheet by:

Birth Defect Research Children, Inc. www.birthdefects.org