Amniotic Banding/Missing Limb

FACTS:

• When a baby is developing inside her mother, he or she is in a fluid filled “bag of waters” called the amniotic sac. This sac is made up of strong fibers that are usually hard to break. Sometimes, however, this sac will tear open, and the sticky strands can wrap around parts of the developing baby. When this happens amniotic banding can occur. The most common effect of amniotic banding is seen when the fibers wrap around the arms, legs, fingers or toes. The fibers cause a deep groove which looks like the baby has a tight rubber band on him or her. If the banding during development is severe, it may even cause the complete amputation of the limb.

• Amniotic Band Syndrome is a common birth defect. Children with amniotic banding can have conditions such as missing limbs, fused fingers and toes, hemangiomas, club feet and cleft palate.

• This is a randomly occurring defect; it is not genetic. It is not inherited from the parents, nor passed down to future children.

• Sometimes tight banding can impair circulation, causing areas below the band to be inflamed or swollen.

• There is no effect on intellect. Children with amniotic banding are normal in every other way.

Amniotic banding can cause a child’s limbs to not develop correctly.

Amniotic banding often looks like a rubber band is placed tightly on a child’s skin.
• For missing limbs, fused digits, hemangioma and cleft palate, please see the corresponding section in this manual for treatment options.

• If a child has constriction bands on his or her body or extremities, please consult a physician. Impaired circulation can often be improved with surgery to release the bands. In rare cases amputation of a digit or limb may be the only option.

Many forms of Amniotic Band Syndrome require no treatment at all.

My family loves me so much!
Arthrogryposis

FACTS:

• Arthrogryposis is characterized by multiple frozen joints and is usually diagnosed at birth. This condition has multiple causes and is extremely rare.

• During pregnancy, motion of the fetus is essential for the normal development of a baby’s joints. Anything that restricts fetal movement causes extra tissues to gather around the joint. The joint then becomes difficult to move or frozen in place.

• Conditions that decrease fetal movement include uterine malformations, having twins or triplets and inadequate amniotic fluid. The deformities are most severe at birth and do not progress.

• Children born with this condition may have other joint and limb problems.

• Children with this condition may also have a disorder of the nervous system or muscles.

This condition most often affects the hands and feet.

• These children may have medical problems with the heart, lungs or kidneys.

• Joints of the hands and feet are most often involved.

• The muscle groups around these joints are often weak due to lack of movement.

• These children usually have normal intelligence.

A child’s joints may be “frozen” in place.
TREATMENT:

• Very gentle movement of the stiff limbs after birth and as the child grows improves motion of the limb. Joint manipulations during the first few months of life may produce considerable improvement.

• The doctor may prescribe physical therapy to improve joint motion and to prevent muscle wasting.

• Some children need splinting of the limbs, and others need surgery.

• It is important for these children to be evaluated by a physician to determine if they have problems with the heart, lungs, kidneys or nervous system.

• Many of these children are able to live active and happy lives.
Brachial Plexus Injury

FACTS:

- This condition is caused by an injury during birth. The nerves and muscles of one side of the neck and arm are severely stretched and may tear.

- It causes weakness or paralysis of the affected arm.

- In some cases the injury will recover in three to six months if the arm is protected from further damage. In many cases the damage may be permanent.

- It affects only one arm and hand. If other parts of body are affected, consider other disorders.

- Children are able to learn activities of daily living using one arm and are of normal intelligence.

Children with brachial plexus injury are of normal intelligence.

In some cases the damage isn’t permanent.
Brachial Plexus Injury

TREATMENT:

- Wrap the infant with his or her weak arm across the upper abdomen and secure with a blanket. This holds the arm in proper position and prevents further injury.

- Take care that the infant does not lay on the weak arm.

- In an older infant or child, the sleeve of his or her clothing can be pinned across the lower chest.

- Moving the arm and hand gently several times a day will prevent it from contracting and being further damaged.

- Medical and surgical treatment may help in some cases. Please consult with a doctor familiar with this injury.

Medical or surgical treatment may be needed.

I can do ANYTHING!
FACTS:

- Cerebral Palsy (CP) means difficulty with movement, muscle control and/or balance.

- The child's muscles may be too stiff (high tone), too floppy (low tone) or both in different areas (trunk floppy, but tight limbs). Both arms and legs may be affected, or just the legs, or the arm and leg on one side of the body.

- CP is caused by damage to the part of the brain that controls the muscles. The damage can happen before the baby is born, during birth or right after birth (especially if the baby is born too soon). It does not get worse over time. It is not contagious.

- Most children with CP have normal intelligence. Some may have difficulty with speaking or eating because the muscles in their mouths are affected, but they have normal understanding.

- These children are at slightly higher risk for seizures, which can usually be controlled with medication. If the child has a seizure, see a doctor!

Cerebral palsy affects a child's ability to use his or her muscles.

Most children have normal intelligence even if they can’t speak clearly.
The brain damage cannot be treated, but the child's ability to take daily care of himself or herself can be improved.

Physical therapy, braces and other treatments can help the child be more independent.

Talk normally to the child and encourage him or her to be as independent as possible. These children are usually bright and eager.

Help the child with poor balance to sit securely by using chairs with arms, pillows, rolled up blankets, etc.

Gentle twisting and stretching can help the child with tight muscles move more easily. Softly bouncing the "floppy" child on your lap or a big ball before an activity can help him or her have more control.

With therapy, children with CP can live happy and productive lives.

These children are usually bright and eager to learn!
FACTS:

- Club foot is a condition that causes one foot (unilateral) or both feet (bilateral) to be twisted inward and often pointing downward.

- The club foot does not form properly when the baby is growing in the womb. The affected foot is often smaller and the leg thinner than normal, which may not be as obvious if both feet are affected.

- Club foot occurs more often in boys.

- Children with club foot have normal intelligence and can lead active and normal lives.

- After treatment children can have healthy and pain-free feet and be able to wear regular shoes. They can walk, run, jump and play sports like other children.
A child born with a club foot should be seen by a doctor. There are several options for treatment.

One method of treatment involves a series of manipulations of the foot, which is held in place with a full leg plaster cast. This does not hurt the child. Each cast is left on for four to seven days as the muscles and ligaments relax and the bones grow into the corrected position. The doctor must be specially trained in this method.

Surgery is another method used to treat club foot. The method used is best determined by the doctor.

After surgery or casts, the doctor may have the child may wear an adjustable brace to which a special shoe is attached. This brace usually doesn’t interfere with learning to walk.

Following treatment children can wear normal shoes and enjoy their beautiful, straight and pain-free feet.
• Dwarfism is a medical or genetic condition that results in an adult height of 4'10" or shorter.

• There are over 200 forms of dwarfism. The most common form results in arms and legs that are disproportionate to head and trunk size.

• Most children with dwarfism are born to parents of normal height.

• Dwarfism does not affect a child’s intelligence.

• There is no cure for dwarfism; however, some of the associated medical problems can be treated.

• With some adaptations being made for their height difference, children and adults with dwarfism lead normal lives, even having children of their own.
Dwarfism

TREATMENT:

- Treat children with dwarfism as you would any other child that age. Do not treat them as babies because of their small stature.

- Modify the child’s surroundings to help them be as independent as possible. This is very important for development of a positive self-esteem.

- Children with dwarfism should be strongly encouraged to be as active as possible. This helps to develop the muscles that support the body and aids in weight management.

- Children with dwarfism many have moderate to severe orthopedic difficulties that can result in deformities that lead to a loss of mobility. A good relationship with a doctor who is knowledgeable about dwarfism is very important.

- The following three serious conditions can be related to dwarfism. Please have doctor check a child with dwarfism to rule out these conditions. If these symptoms arise, see a doctor immediately.

- **Compression of the brain stem.** Symptoms include failure to thrive and apnea (breathing stops momentarily during sleep).

- **Hydrocephalus.** Excess fluid on the brain causes the head to be abnormally enlarged.

- **Obstructive apnea.** Symptoms include failure to thrive, sleep apnea, sweats, snoring due to a partially blocked airway, frequent night awakenings, excessive sleepiness during the day and inattentiveness.
Fibular/Tibular Hemimelia

FACTS:

- Fibular/tibular hemimelia is the most common cause of leg length differences.

- Children are usually missing the outside toe and/or have a short or missing fibula (one of the bones between the knee and ankle) on one leg.

- These children usually have a small foot on the short leg. Often they are missing one or more toes on the outside of the foot.

- The ankle and/or hip joint may be affected. Other leg bones or joints may also be involved, including the hip, thigh bone or ankle.

- This condition is caused by a problem during pregnancy; it is not passed on from mother to child.

- Other than the leg length difference, these kids are normal in all other areas of growth and development.

- These children learn to walk, run, ride a bike and do almost anything—even with the short leg.

Special shoes can help a child walk more easily.

Children with this condition can do anything!
Children with leg length differences should be seen by an orthopedic doctor who deals with leg length differences.

A child’s leg length should be evened out to avoid developing problems with the hip or back later in life. Shoes may be built up to even the leg difference.

Lifts that are worn in the shoe or build up the sole of the shoe is a common, non-surgical correction.

There are two possibilities for surgical correction. Many children can have their legs lengthened. For some amputation of the foot or part of the leg allows the child to use an artificial foot.

I can ride my scooter!

My leg difference does not stop me from playing.
Funnel Chest/Pigeon Breast

FACTS:

- The child with a funnel chest has a depression in the center of their chest, which may appear quite deep.
- See a doctor if the depression is deep as the heart and lungs may be affected.
- Funnel chest can be caused by rickets or may be passed down from birth parents. In most cases the cause is unknown.
- With pigeon breast, a child’s breastbone and chest are pushed forward.
- Pigeon breast affects more boys than girls. It usually appears in girls early in life and in boys later as they grow.
- Pigeon breast is less common than funnel chest, and the cause is unknown.
- Both funnel chest and pigeon breast may be mild or severe and can be associated with scoliosis, respiratory problems and heart defects.
- Both conditions may cause difficulty playing and exercising. Growing children may experience chest pain, tenderness and pain in the breastbone area.

Funnel chest is where a child’s chest “goes in.”

Pigeon chest is where a child’s chest “pushes out.”
Funnel Chest/Pigeon Breast

TREATMENT:

• If a child has either chest condition, he or she should be seen by a doctor.

• These conditions can be diagnosed with an x-ray.

• Mild cases may correct themselves as the child grows.

• Surgery is advised if the chest defect is moderate to severe or the child experiences breathing difficulties or chest pain from exercise. See a doctor immediately if this happens.

These conditions are very common.

Children with these conditions are easily adopted.
FACTS:

- A hernia occurs when an organ (usually intestines) protrudes through a weak point or tear in the thin muscle wall that holds the abdominal organs in place.

- A hernia may become larger when the child coughs, bends, lifts or strains. In infants and small children it may only be seen when the child is crying.

- Umbilical hernias, or “belly button hernias,” are caused by the incomplete closure of the muscle surrounding the belly button at birth. It is a soft swelling that protrudes and may enlarge with crying or straining.

- An umbilical hernia usually will close on its own by age five years. It is painless and usually causes no problems.

- In rare cases bowel or blood vessels may protrude. If this is suspected, the child should be seen by a doctor.

- Inguinal hernias are caused by the weakness or an opening in the lower abdominal muscles and is felt as a soft bulge in the groin area. They are more common in boys than in girls.

- An inguinal hernia is more serious and can lead to bowel becoming trapped in the hernia. This loss of blood supply to the bowel can sometimes be life-threatening.

Many belly button hernias will close on their own.

Hernias are a very common birth defect.
Hernia

TREATMENT:

- Call a doctor right away if the child has a hernia and the contents cannot be pushed back into the abdomen using gentle pressure; the child develops nausea, vomiting or fever with their hernia; or the hernia becomes red, purple, dark, or discolored.

- Taping or strapping a hernia will not make it go away.

- Surgery is the only treatment for an inguinal hernia.

If a hernia becomes red, purple or dark, call a doctor immediately.

Children with hernias are easily chosen for adoption.
FACTS:

- Hip dysplasia is when a child’s hip is easily dislocated. This can occur at or after birth within the first year.
- Some infants are born with the hip dislocated; others may have a loose hip joint. The hip is unstable.
- The exact cause is unknown, but it can be caused by the child’s body makeup, the mother’s hormones and the position of the child in the uterus.
- More girls than boys have hip dysplasia.
- A doctor can test for hip instability by performing a test of the hips.
- Symptoms may include legs that are different lengths, uneven thigh skin folds and less mobility or flexibility on one side.
- If left untreated, the child may have a limp, pain, unequal leg length and decreased ease in movement.

Hip dysplasia is when the hip is easily dislocated.

The earlier the treatment, the better the outcome.
TREATMENT:

- Treatment will depend on the age of the child and degree of instability.
- The earlier treatment begins, the better the outcome.
- A child with this condition should see a doctor that specializes in bone disorders.
- A newborn may be treated by using two to three thick diapers to separate the hips and allow them to grow properly. This will work only in newborns.
- Don’t swaddle a baby too tightly.
- A child may be treated with a harness. Casting and surgery may be necessary.

If treated, a child should have normal movement.

Children might need to wear a cast to treat this condition.
Lymphedema

FACTS:

• Lymphedema is a condition where excess fluid becomes trapped in tissue and causes swelling.

• The problem may be caused by too few lymph nodes in a limb or a blockage of the lymphatic vessels. These vessels are small channels like blood vessels that contain a clear fluid called lymph.

• This problem usually affects the legs but can also affect the arms. It may only affect one limb or several.

• A significant increase in swelling may occur over time, resulting in limbs that are clearly enlarged.

• Infection is the most common complication.

• Some children might have difficulty in wearing shoes or pants or in using an affected limb in daily activities.

It is important to keep skin moisturized and free of infection.

Swelling in an arm or leg may be an indication of lymphedema.
Lymphedema

TREATMENT:

• Usually swelling becomes less pronounced with age. The majority of children only need supportive treatment, but approximately one-third of patients will need surgical intervention.

• Elevating a limb to help drain fluid is often helpful.

• Look for looser clothing for a child and shoes that allow the swollen foot to be comfortable.

• Excellent foot care is essential. Make sure there are no ingrown toenails, that toenails are cut straight across and the skin between the toes is kept dry and very clean to prevent fungus from developing.

• Exercise and activity help lymph fluid decrease. Swimming is excellent, as is riding a bike, using a trampoline or walking up steps.

• Supportive stockings and elastic garments worn throughout the day over the affected limb, may decrease swelling.

• If available, overnight use of an intermittent pneumatic compression pump (a device that moves fluid from the end of a limb upwards toward the heart) can be very effective.

Children should be encouraged to be active.

• Skin care is extremely important. Infection should be promptly treated with antibiotics and bed rest.

• Consult with a doctor if fever, redness and tenderness are present in the affected limb.

• When supportive measures fail and a limb becomes too heavy to maneuver during daily activities, or when normal clothing or shoes cannot be worn, surgical options may be considered.

• Patients with recurrent infections may also benefit from surgery.

Lymphedema does not have to stop a child from having a happy life.
FACTS:

- Osteogenesis Imperfecta is an inherited disorder that affects the bones and joints in which the bones may break easily. There are very mild to severe cases of this disorder.

- Children with mild disease may be of short height. Children with severe disease may look they have dwarfism.

- This condition is not curable; however, there are some medicines that will decrease how often the bone fractures occur and will help to increase gross motor development.

- Children with this disease may develop scoliosis (spinal curvature) and other bone deformities.

- Some children may be normal in appearance, stature and development. Children with more severe disease have limited and delayed motor skills, high rate of deformity and extremely short stature.

- Intelligence is not affected.
TREATMENT:

• It is important for these children to have a good calcium and vitamin D intake. A diet with lots of dairy products and time spent out in the sun are helpful.

• These children need to avoid activities where injury may happen but should be as active as possible since muscle strength decreases bone breakage.

• Broken bones need to be set by a doctor to prevent bone deformities. If a child is cranky or irritable for no reason or in obvious pain, a fracture may be present—even if there was no trauma to the bones. Consult a doctor about pain medication if the child has continued irritability.

• Physical therapy is helpful for proper movement and muscle development.

• Some children may need assistive devices, such as braces, walkers or crutches to walk.
Radial Club Hand

FACTS:

- This is a very rare condition where the inner bone of the forearm does not form properly.
- The wrist clubs inward and may be limited in movement; the thumb may not work properly or may be missing.
- Sometimes this disorder can be accompanied by other problems. The child should be evaluated by a doctor to rule out associated syndromes.
- There is usually diminished function of the affected arm and hand as the child grows older.
- Children with radial club hand find different ways to do everyday tasks of daily living and are seldom limited by this limb difference.

Radial club hand affects the lower arm of a child.

I can figure out how to do things for myself!
TREATMENT:

- Occupational and physical therapy are helpful in improving the function of the hand in teaching a child different methods of doing fine motor tasks.

- Encourage a child with radial club hand to try everything other children do. They will usually find a way to do it that works for them.

- In early infancy the wrist may be straightened using casts.

- Surgery may be used to lengthen the forearm, correct the angle of the wrist and create a thumb by moving a finger into this position.
FACTS:

• Rickets is a bone disorder caused by a lack of enough calcium and vitamin D. This disease can be prevented by the use of a good formula containing adequate amounts of calcium and vitamin D.

• Physical signs include bow legs, pigeon chest, delayed teething, and abnormal fractures. Children with rickets have bones that are soft and weak.

• If not corrected while the child is growing, skeletal deformities and short stature may be permanent.

• The physical signs of rickets can also be signs of other bone or kidney diseases. Children with suspected rickets should be seen by a doctor to determine if these other possible conditions are present.

Bowed legs are a sign of rickets.

Children with rickets have bones that are weak.
Rickets

TREATMENT:

• Foods high in calcium should be offered to children with rickets. Calcium is found in milk, dark green vegetables, tofu, sesame seeds, cheese and yogurts.

• Make sure all infant formula contains Vitamin D. Milk and yogurt for older children should be enriched with Vitamin D.

• Sunlight is a source of Vitamin D for the body. Children should be outside daily and exposed to the sunlight to obtain Vitamin D. Sunbaths may also help.

• If corrected while a child is young and still growing, any skeletal deformities usually disappear over time.

• Severe cases of rickets can cause scoliosis and may require surgery.
FACTS:

- Scoliosis is a curve in the spine.
- One shoulder may be higher than the other or one hip higher than the other, affecting sitting or walking.
- Scoliosis can be caused by rickets, a spinal defect or unknown causes.
- This condition affects more girls than boys.
- People who have scoliosis need treatment by a doctor. Severe scoliosis can affect the ability to breathe or walk easily and can cause pain in daily activities.
Scoliosis is best treated when a young person’s body is still growing and can respond to treatments. Treatments include physical therapy to keep muscles flexible and strong, lifts on a shoe or a body brace.

- Severe cases may require surgery.

Scoliosis should be treated when a child is still growing.

Children with scoliosis are loved by their families.
Syndactyly

FACTS:

- Syndactyly is a condition where a child has finger or toes that are joined together or not formed completely.

- Fingers and toes can be short or curved or formed together.

- Syndactyly can be genetic—passed down by the parents. It can also happen while the baby grows inside the mother.

- Children with syndactyly can usually do anything that a child with normal appearing fingers and toes can do. They may need help learning how to do daily activities like dressing.

- Children with syndactyly can live long and healthy lives.

Syndactyly affects a child’s fingers and/or toes.

These children can learn to do everything when given encouragement.
**TREATMENT:**

- Check with a doctor to see if treatment is needed.
- Surgery may or may not be needed to correct the involved fingers or toes.
- Physical therapy can help children learn to do daily tasks with ease. Children should be encouraged to engage in normal play and other activities. This will give them a chance to develop and improve their motor skills. With practice children with syndactyly can do everything!
- Children may prefer to wear clothes without buttons. Shirts with zippers or pants with elastic waists make getting dressed easier.
- Cups and bowls with handles may be helpful at mealtime.
FACTS:

- A teratoma is a congenital (present at birth) tumor formed in all three layers of tissue. It can contain bone, teeth or hair fragments.

- A sacral teratoma, located on the tail bone, is the most common form of teratoma and is usually visible from outside the body.

- Although less common, teratomas can occur in the sex organs (testes and ovaries).

- Although most teratomas are benign, some are malignant. ALL have the potential to become malignant.

- Symptoms of teratomas include a tumor, swelling or mass that can be felt or seen; constipation or incontinence; and leg weakness if a sacral tumor.

- Teratomas can be diagnosed through biopsy, blood test, CAT scan or MRI, x-ray and/or ultrasound.

Teratomas are present at birth.

They should always be checked by a doctor.
Surgery to remove the tumor is the most common treatment.

Chemotherapy to interfere with the cell’s ability to grow or reproduce is used with both benign and malignant teratomas.

Radiation therapy is used to kill cancer cells and shrink tumors.

Supportive care is also given to prevent and treat any side effects of treatment or complications and to keep the child comfortable during treatment.

Once the teratoma has been treated or removed, the child should be given regular health checks.

Surgery is the most common treatment option.

Many families have adopted children with teratomas.
FACTS:

- Torticollis is a tightening of the neck muscles on one side. This causes the head to turn to one side and usually to tilt to one side or the other.

- It may be caused by an injury to the neck muscles during birth, position in the uterus during pregnancy or may be caused by the joining together of neck vertebrae. It can also be caused by lying in one position for long periods of time, causing the muscles to become stiff and tighten.

- Without treatment one side of the head may flatten and cause the face to be asymmetrical. This can also cause the child to avoid looking to one side and can result in not developing skills in that side of his or her body (eyes, hands, etc.).

Torticollis often causes a child to tilt his or her head to one side.

Torticollis can be caused by the way a child lies inside the mom’s uterus.
Physical therapy is used to gently stretch the neck muscles on the tight side and strengthen the muscles on the opposite side.

Placing toys where the infant has to turn his head to see them will gently stretch the muscle. Position the child to encourage him or her to turn the tight side of the neck to look at other children, caregivers or the door and window.

Do not allow the child to lie in the twisted or tilted position for feeding, and do not prop the child’s bottle. Hold the bottle so the head is looking straight forward.

Early treatment produces excellent results.

Physical therapy can gently stretch the neck muscles.

The results of treatment are usually EXCELLENT!