

# Down Syndrome and Therapeutic Riding

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Down Syndrome is the most common and readily identifiable chromosomal condition associated with mental retardation. It is caused by a chromosomal abnormality: for some unexplained reason, an accident in cell development results in 47 instead of the usual 46 chromosomes. The extra genes cause certain characteristics known as Down Syndrome. Individuals with Down Syndrome also have all the other genes given to them by their parents. As a result, they have a combination of features typical of Down Syndrome on top of the individual features from their parents. This includes some degree of mental retardation, or cognitive disability and other developmental delays. The extra chromosome changes the orderly development of the body and brain. In most cases, the diagnosis of Down Syndrome is made according to results from a chromosome test administered shortly after birth.

Approximately 4,000 children with Down Syndrome are born in the U.S. each year, or about one in every 800 to 1,000 live births. Although parents of any age may have a child with Down Syndrome, the incidence is higher for women over 35.

There are more than 50 clinical signs of Down Syndrome, but it is rare to find all or even most of them in one person. Common characteristics include: poor muscle tone; slanting eyes with folds of skin at the inner corners (epicanthal folds); hyperflexibility (excessive ability to extend the joints); short, broad hands with a single crease across the palm on one or both hands; broad feet with short toes; flat bridge of the nose; short, low-set ears; short neck; small head; small oral cavity; and/or short, high-pitched cries in infancy.

Individuals with Down Syndrome are usually smaller than their peers without disabilities, and their physical as well as intellectual development is slower.

Besides having a distinct physical appearance, children with Down Syndrome frequently have specific health-related problems. A lowered resistance to infection makes these children more prone to respiratory problems. Visual problems such as crossed eyes and far- or near-sightedness are higher in individuals with Down Syndrome, as are mild to moderate hearing loss and speech difficulty.

Some people with Down Syndrome also may have a condition known as Atlantoaxial Instability -- a misalignment of the top two vertebrae of the neck. This condition makes these individuals more prone to injury if they participate in activities that overextend or flex the neck. Parents are urged to have their child examined by a physician to determine whether or not their child should be restricted from sports and activities that place stress on the neck.\* Although this misalignment is a potentially serious condition, proper diagnosis can help prevent serious injury.

*\* NARHA Standards require all NARHA operating centers to have their riders with Down Syndrome examined annually by a physician for Atlantoaxial Instability.*

*From Down Syndrome Fact Sheet, National Information Center for Children and Youth with Disabilities, 1-800-695-0285.*

## **Medical Considerations for Therapeutic Riding**

*By Liz Baker, PT, Medical Committee Chairman*

Serving people with Down Syndrome in the therapeutic horseback riding setting can be a source of great joy and satisfaction to riders, instructors, therapists and volunteers. These riders are often among the most talented and competitive a program may ever serve. It is helpful to be familiar with a few characteristics of Down Syndrome which will influence the operating center's

decisions as to how to best serve this population.

People with Down Syndrome are more likely than most people to have Atlantoaxial Instability. This is a condition in which the first two vertebrae of the spine, the atlas and the axis (C-1 and C-2), are loosely connected by the corresponding ligaments that are supposed to hold the vertebrae together. This results in dislocation of the C1-C2 joint, placing pressure on and even completely disrupting the spinal cord at that level. It is presumed to be a result of the generally low muscle tone and lax ligaments commonly found in people with Down Syndrome. AAI is potentially life-threatening. A person with Down Syndrome with AAI may or may not demonstrate neurological symptoms.

The following is quoted from the NARHA Precautions and Contraindications, found in the NARHA Guide and the NARHA Operating Center Standards & Accreditation Manual: "Specific x-rays are needed to rule out this instability before riding is permitted. This condition can occur in adults with Down Syndrome even though previous x-rays during or after childhood may have been interpreted as negative. At present, it is not known how often adults with Down Syndrome should be tested to rule out atlantoaxial instability. Operating centers should not rely on x-rays taken before the age of 2 and 1/2 to 3 years, as [this area of the spine] has not [become fully formed bone] at this early age. A set of films taken just prior to riding is advisable."

Given that a fall from a horse (or even excessive motion to the neck from the movement of the horse) could be life-threatening to a person with Down Syndrome-related AAI, it is imperative that all programs serving these individuals be completely familiar with this section of the Precautions and Contraindications. In short:

- If the individual is younger than 2 and 1/2 to 3 years, it is impossible to tell whether AAI is present; (thus it is inappropriate to allow children with Down Syndrome to ride until AAI can be definitively ruled out).
- Once past this age, this area of the spine has become fully formed bone and the x-ray is reliable.
- Once the x-ray has been read as negative for AAI by a physician experienced in this problem, research suggests it is unlikely that the individual will develop AAI. However, current research has not gone on long enough to make this a "sure thing" (hence the recommendation for an x-ray before beginning riding).
- Research suggests that certain symptoms (which can be tested for by the physician annually) are enough to document that AAI is not present. Thus, when the operating center updates medical forms on its riders annually, there is no need for another set of x-rays. You can simply request the physician to again give the date of the last x-ray and its result, and indicate that the symptoms of AAI are not present.

In the Operating Center Standards and Accreditation Manual, the current form entitled "Rider's Medical History and Physician's Statement" allows the physician to indicate the positive or negative status and the date of the last x-ray taken for AAI. An upcoming modification of this form will allow the physician to simply indicate the continued lack of symptoms of AAI.

For the benefit of operating center staff, these symptoms are detailed in the NARHA Precautions and Contraindications. Instructors, volunteers and therapists are sometimes the first to notice a change in the rider and may recognize these symptoms, which include:

- Loss of head control--head tilt, stiff neck, torticollus
- Loss of hand control--fisting, change of dominant hand, progressive weakness, tremor
- Change in gait--toe walking, scissoring(walking with the knees close together or crossing one over the other), progressive clumsiness, posturing abnormally
- Loss of bowel and bladder control

The presence of atlantoaxial instability (that is, a positive x-ray and/or the presence of signs and symptoms of this condition) are an absolute contraindication to participation in riding at a NARHA Operating Center. It has not been established that this is a contraindication to therapeutic driving; it is generally not considered a contraindication to stable management and horse care activities, although good judgment should be used by the riding instructor and/or therapist as to the level of risk to the participant.

People with Down Syndrome may also have a greater tendency to degenerative "wear and tear" of the spine, resulting in a form of arthritis. This also may produce neurologic symptoms such as those encountered when atlantoaxial instability is present, or the arthritis may be a problem in the lower spine. This can result in pain or instability in the spine wherever the degeneration occurs. It is helpful to remember that the observations of the person's abilities and function at the operating center, and changes in function, are useful information to the physician and parent/guardian; the program staff again may be the first to detect a change that can be diagnosed and treated.

Additionally, people with Down Syndrome may have related problems such as learning disabilities, mental retardation, congenital heart defects, premature aging, deafness, and the development of Alzheimer-like changes in the brain later in life. Make sure the physician, parent/guardian and rider understand the physical activity and risk of horseback riding.

### **Inclusion**

In most instances operating centers will be able to accept and serve individuals with Down Syndrome in a wide variety of equestrian activities. However, it is appropriate to give some thought to the concepts of just what therapeutic riding is, and what "inclusion" is. Many people providing services under the umbrella of "therapeutic riding" would agree that a person with a disability should be able to go to a public stable that offers safe, quality riding instruction, with appropriate accommodations for their physical impairments, and participate in whatever level of riding or equestrian activities are desired and most enjoyable. After all, we would certainly agree that individuals with disabilities who wish to play tennis should be able to go to a public tennis court and play, whether they play with disabled or non-disabled peers!

However, our realization of both the tremendous therapeutic benefits of equestrian activities, in all areas, and our concurrent understanding of the risks involved in riding, particularly at a public stable have led to the establishment of therapeutic riding centers. Our centers provide a safer, more therapeutic setting for most riders. But we should also work toward inclusion of our riders, whenever safe and appropriate, into a "normal" riding setting. It is our responsibility, however futuristic, to promote the integration of riders with disabilities into non-disabled riding settings. Thus, an operating center serving a capable and independent rider with Down Syndrome can look at whether this rider could participate equally well in equestrian activities at the "non-therapeutic" public riding stable down the road; or whether it should integrate people with a wider variety of abilities and disabilities into its own sessions.

Liability insurance should not be the driving force which compels capable independent riders with disabilities to ride at NARHA centers rather than public stables! Inclusion and community integration are more than concepts--they are methods by which NARHA Operating Centers and staff continually look for the best way to bring the joy of the horse to the person with Down Syndrome.