

Atlantoaxial instability (AAI) Information

Atlantoaxial instability (AAI) is a common co-morbidity (the existence of more than one disease or condition within your body at the same time) among patients with Down syndrome/trisomy 21.

Atlanto-axial instability (AAI) is a condition that affects the bones in the upper spine or neck under the base of the skull. The joint between the upper spine and base of the skull is called the atlanto-axial joint. In people with Down syndrome, the ligaments (connections between muscles) are “lax” or floppy. This can result in AAI where the bones are less stable and can damage the spinal cord.

What Are the Symptoms of AAI?

- Change in the way your son/daughter walks;
- Gets tired easily when walking;
- Pain, numbness or tingling in the neck, shoulder, arms or legs;
- Head tilting to one side;
- Trouble moving the neck or holding it up;
- Weakness in the arms or legs;
- Loss of bladder control (having accidents).

How Do Doctors Test for AAI?

If your child has symptoms of AAI, the doctor will suggest an X-ray. If the X-ray results are abnormal (different than usual), the doctor will order another imaging test, like a computed tomography (CT) scan or magnetic resonance imaging (MRI) test.

Is it safer to get just an X-ray?

In previous years, doctors thought all people with Down syndrome should have regular X-rays to check for AAI. This is no longer true. An X-ray is low-cost and low-risk, but it does not always tell whether a person has AAI or not.

Sometimes, an X-ray shows AAI when there are no symptoms. If this X-ray is repeated, the AAI might go away. This means routine X-rays are not helpful. It is better to let your doctor know if your son/daughter is having symptoms.

How Do Doctors Treat AAI?

Treatment depends on your son/daughter’s symptoms. In severe (very bad) cases, your son/daughter might need neck surgery. In less severe cases, physical therapy can also help.

If your son/daughter does not need surgery, it is important for him/her to be very careful playing sports or doing other physical activities. The doctor will tell you which sports and activities are safe for your son/daughter.

The above information is intended to provide health information so that you can be better informed. It is not a substitute for medical advice and should not be used to treatment of any medical conditions.

Participation in Special Olympics activities by Individuals with Down Syndrome who have Atlanto-axial Instability

In light of medical research indicating that up to 15% of individuals with Down syndrome have a mal-alignment of the cervical vertebrae C-1 and C-2 in the neck, known as Atlanto-axial instability, exposing such individuals to possible injury if they participate in activities that hyperextend or radically flex the neck or upper spine,

parents/guardians must take the following precautions before permitting athletes with Down syndrome to participate in certain physical activities:

- (1) Athletes with Down syndrome may participate in most Special Olympics sports training and competition but shall not be permitted to participate in any activities which, by their nature, result in hyper-extension, radical flexion, or direct pressure on the neck or upper spine unless the requirements of subsections (g)(2) and (g)(3) below are satisfied.

Such non-permitted sports training and competition activities include butterfly stroke and diving start in swimming, pentathlon, high jump, squat lifts, equestrian sports, artistic gymnastics, football (soccer), alpine skiing, snowboarding, adapted judo, and any warm-up exercise placing undue stress on the head and neck.

- (2) An athlete with Down syndrome may be permitted to participate in the activities described in section (1) above if that athlete is examined (including x-ray views of full extension and flexion of the neck) by a physician who has been briefed on the nature of the Atlantoaxial instability condition, and who determines, based on the results of that examination, that the athlete does not have an Atlanto-axial instability condition.

- (3) An athlete with Down syndrome who a physician has diagnosed as having an Atlanto-axial instability condition may nevertheless be permitted to participate in the activities described in section (1) above if the athlete, or the parent or guardian of a minor athlete, confirms in writing his or her decision to proceed with these activities notwithstanding the risks created by the Atlanto-axial instability, and two (2) Licensed Medical Professionals to certify in writing that they have explained these risks to the athlete and his/her parent or guardian and that the athlete's condition does not, in their judgment, preclude the athlete from participating in Special Olympics. These statements and certifications shall be documented and provided to Special Olympics Ireland using the standardised form, entitled "**Special Release for Athletes with Atlantoaxial Instability**," ([include link to the form](#))

This form should only be completed if symptoms of spinal cord compression or Atlanto-axial instability were found in a pre-participation examination and a doctor then provided clearance for participation following a neurological evaluation.