



## **Physical Needs of Children with CHARGE Syndrome**

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Children with CHARGE syndrome have physical characteristics which affect their gross motor performance. These characteristics interact with each other to affect the child's balance and ability to interact with their environment. The following is a brief discussion of these characteristics, their interactions and some accommodations for them:

### **Low muscle tone**

Muscle tone is defined as the "resistance to passive stretch." What this means is, when the muscle is moved, does it resist the movement (high tone), does it go along with the movement (normal tone), or move quickly without tension (low tone)? Muscle tone is involuntary and should not be confused with strength. Low tone muscles are slower to contract and unable to maintain a contraction for as long as normal tone muscles. This means children with CHARGE syndrome may not be able to sit for as long as their peers. They need position changes approximately every 30 minutes. These changes may include standing and working at a higher surface (so they do not have to bend over), lying on their stomachs on the floor (for a more stable position) with work in front of them, and sitting in a more supportive chair such as a bean bag or recliner to decrease the amount of physical effort required to sit up.

### **Visual Impairments**

Decreased visual field (blind spots, loss of upper visual field with retinal colobomas) and decreased acuity are among the visual impairments that affect motor performance. Visual information is used to guide muscle performance and movement as well as being a component of balance. When there is decreased visual information, the quality and/or ability to move will be affected. Consultation with a vision specialist can help in understanding the visual impairments and in planning for specific accommodations. Accommodations may include adequate lighting, increased contrast for edges/ borders of objects, and special paper with large lines.

### **Skeletal Anomalies**

Spinal anomalies are sometime present, including congenital cervical spine fusions, kyphosis and scoliosis. Many have torticollis and decreased use of the shoulders. These will affect the ability to:

- rotate the head, resulting in having to turn the trunk as a whole to see from side to side
- raise the head to look up (to accommodate for loss of upper visual field)
- maintain an upright trunk with the head in midline
- raise arms – often they cannot raise their arms above the shoulders

Materials should be presented within the physical limits of the child's posture. Adaptations to the classroom seating will be necessary to allow full access to materials. Consultation with physical and occupational therapists for modifications specific to the student would be helpful.

## **Vestibular System Impairments**

The nearly ubiquitous vestibular system impairments in children with CHARGE inhibit the ability to detect body motion and position in space. This is important for maintaining an upright posture and is an integral part of the balance system.

### **Balance**

The body's ability to balance is a complex mechanism, normally using input from vision, muscles, joints and the vestibular system. All of this information must be processed by the brain and translated to motor output (movement). Children with CHARGE syndrome have impairments in all of these areas. They have decreased visual and vestibular information. Because of the low muscle tone and skeletal anomalies, the information from the muscle and joint receptors is also decreased. The ability to process this information may also be decreased. The resultant motor output is also affected by the decreased muscle tone and visual impairments. The motor response time may be increased. The stability of the joints is decreased and difficult to maintain. The visual information is not present to direct movement. Sometimes the kids just fall down or need to lie on the floor for a while! Ability to move about may be different indoors (with walls to serve as visual cues) and outdoors, due to differences in visual cues (walls, doorways) and surface changes (floor vs. grass).

Accommodations can be made to increase the sensory information available which can in turn increase the ability to balance. These include increased lighting and the use of contrasting colors to define the edges of stairs, curbs, or other surface changes to increase the visual information. Provide safe environments with increased physical assistance to ensure success while performing activities that require balance, such as walking on a balance beam (which has been modified to increase visual information), roller skating, scooters. Help enable success and repetition with decreasing assistance, effective balance reactions can be "learned." Consultation with physical therapists to provide student specific accommodations can be helpful.