

## **GUIDELINES FOR ACTIVITY FOR CHILDREN WITH SPINAL MUSCULAR ATROPHY WHO ARE AMBULATORY, WITH OR WITHOUT BRACES OR ASSISTIVE DEVICES**

### **BACKGROUND:**

SMA is associated with decreased lean body mass. In stronger SMA patients, muscle weakness most noticeably affects the hip and shoulder girdles, making it more difficult to arise from the floor without assistance, and sometimes associated with a somewhat wide-based unsteady gait. Joint contractures (decreased range of motion around a joint) are much less common in ambulatory SMA children. However, development of contractures can occur during periods of decreased activity or illness. In ambulatory children, contractures most commonly affect the hips and ankles. Associated tightness of the hamstrings also often occurs in this setting. Toe-walking is often a sign of developing ankle contractures. Ankle contractures can lead to an increased probability of tripping, since tightness of the Achilles tendon can limit how far the foot can flex upward to clear the ground. Tightness of the hips over time, in association with weak abdominal muscles, can lead to an enhanced lumbar lordosis, or “swayback” position. Muscle weakness, particularly of the quadriceps muscle group which helps to stabilize the knee, can also contribute to an increased risk for falls.

### **IMPORTANCE OF STRETCHING:**

Development and progression of lower extremity contractures can be prevented or delayed with a combined exercise and stretching program. Stretching should target the hips, thighs, low back, hamstrings and ankles on a daily basis if possible. Building this into a child’s routine is important to establish early. Learning to stretch properly under the guidance of a physical or occupational therapist is best. The frequency with which such stretching can be incorporated into the daily and weekly routine is a primary key to success. Performing such routines following exercise, after a warm bath, or just before bedtime can help maximize benefit and acceptability. Sometimes just a few days in bed can weaken the quadriceps sufficiently due to muscle atrophy to really impair ambulatory capacity and result in dangerous falls. Don’t forget the daily stretching, even if your child is ill or recovering from surgery, and early ambulation is advisable to help maintain function.

### **PHYSICAL ACTIVITY:**

Just as important as stretching, or even more so, is some form of regular exercise to help maintain muscle strength. Daily physical activity is important, and this can be supplemented with more specific focused therapy with your PT or OT to target weak muscles and work on specific functional goals. Using a wheelchair to minimize fatigue over longer distances is fine. However, encourage them to stand or walk on their own at home and at school as much as possible. Stairs can be viewed as exercise opportunities rather than obstacles (with proper technique and monitoring!). Cycling, swimming and walking are excellent sources of aerobic exercise. However, be creative and have fun! Tai Chi or dance can provide children with a great experience that incorporates elements of stretching, balance, strengthening and activity in a setting where self-image is likely to be enhanced. Use of light weights with no more than moderate repetition frequency can help maintain strength in the upper extremities. Sit-ups or other abdominal strengthening exercises – with or without an exercise ball or peanut, and performed following proper instruction by your therapist to avoid back injury, can be helpful in maintaining good posture and minimizing back pain. The most important thing is to find a routine that works for you and your child. They will be much more likely to want to participate if it is fun.