CdLS Walking and Orthopaedic Issues

By Thomas Renshaw, M.D., Yale University School of Medicine and former CdLS Foundation Clinical Advisory Board member

Family gatherings and other Foundation meetings host people with CdLS who display a variety of physical challenges. Older individuals in wheelchairs are occasionally among those present. Parents or caregivers of young children with CdLS may look at someone in a wheelchair and wonder if having CdLS means their child won't walk. They may even be told by uninformed medical professionals that their child will never walk as a result of CdLS.

While it is unrealistic to say that all children with CdLS will walk, the large majority of those with CdLS will walk. It just is not predictable as to when. While walking is often delayed (occurring at about three years of age on average), walking is the rule. Orthopedic problems seen in children with CdLS such as small feet, webbing between toes, and tight heel cords have little or nothing to do with the delay in walking that most people with CdLS experience. The delay in walking has more to do with neurological challenges such as delays in general development, fine and gross motor skills, and central nervous system factors influencing coordination and balance. Those individuals who never walk likely never reach a developmental level that makes walking possible. In general, if a child is not walking by three years of age, it is a good idea to confer with the child's pediatrician. An additional opinion from a pediatric neurologist or orthopedist familiar with CdLS would be beneficial if the pediatrician has little experience with children having the syndrome.

While orthopedic issues affecting the lower limbs may not automatically inhibit walking, they may need to be treated for other reasons. Scoliosis, hip problems, tight heel cords, and bunions number among the issues that may affect the lower body in people with CdLS. While none of these conditions is particularly common among individuals with CdLS, their incidence is higher among those with CdLS than it is in the general population. For example, scoliosis (a curvature of the spine) large enough to require treatment occurs in only 0.3% of the general population. However, while researchers are unsure of the actual incidence of scoliosis, it does appear more frequently in children with CdLS (perhaps in as many as 5-8% of cases).

Parents and/or caregivers can help identify scoliosis in a child with a careful physical examination. Scoliosis may be present if the exam reveals that one shoulder or shoulder blade is noticeably higher than the opposite one or, when looking at a person's waist, one side of the waistline is flatter or indented when compared to the opposite side of the body. A final test consists of observing someone who is standing while bending forward. If the person's body or posture appears asymmetrical (uneven when looking at both sides), spinal curvature could exist.

If scoliosis is not treated, the individual may experience back pain or even difficulty breathing in more severe cases. Treatment options include bracing and surgery in more extreme situations. Bracing is often used if the person is still growing and the curve is

moderate in nature. If the individual will not tolerate the brace and the curvature is significant enough, surgery may be necessary to remedy the situation.

Hip problems are more common in neurologically involved individuals than in the general population and could occur in as many as one out of every ten people with CdLS. Limping is the most direct sign that a hip problem could exist, but detecting hip problems in people who do not walk is more difficult. Children are well served by regular screenings (every year or two) in which a doctor may observe a child's gait and posture. Medical professionals have various techniques to enable them to detect asymmetry, developmental dysplasia, and even Perthe's Disease (condition causing degeneration of the upper femur in children).

Heel cord (also known as the Achilles' tendon) tension is evident if a child tends to "walk on his toes." Upon closer inspection, if the individual's range of motion in the ankle appears limited or the angle to which the ankle can be brought up tends to be restricted, the heel cords may be too "tight" or "short." While this condition presents no threat to walking, it provides an unstable base for walking. This instability could contribute to a general clumsiness or decreased control in walking and possibly result in arthritis in later years. Among the treatment options are stretching programs, casting, and a brief cord-lengthening procedure (surgery).

Everyone possesses a natural angle between their joints as evidenced by the graceful curve of a relaxed hand. Bunions occur when this angle becomes exaggerated between the foot and the base of the large toe, resulting in a bony "bump" on the outside of the big toe. The big toe may be so misaligned as to angle distinctly inward toward the other toes. Bunions are generally treated with good, comfortable shoes unless pain makes it necessary to explore other treatment options.

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