

# The Importance of Movement for Individuals with CHARGE Syndrome

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This is the first in a series of articles focused on the importance of movement for individuals with CHARGE syndrome. The articles will provide information and strategies to enhance and increase movement through different opportunities. Let's start this series out with a question:

## **Why is movement important for individuals with CHARGE Syndrome?**

CHARGE syndrome often results in developmental delays, including motor delays (Dammeyer, 2012; Smith, Smith, & Blake, 2010). In addition, many children with CHARGE syndrome spend much of their infancy and childhood in and out of the hospital for various surgeries, which can cause motor (e.g., rolling, sitting, walking) delays due to the restricted environment (Hartshorne et al., 2011; Salem-Hartshorne & Jacob, 2004). The loss of both distant senses of vision and hearing and time hospitalized greatly affects and presents challenges to overall motor development. For instance, balance and mobility depend on vision and vestibular function, which are affected by vision and hearing loss (Poggrund & Fazzi, 2002).

For movement to occur, children must have a minimal level of balance. Characteristics present in children with CHARGE syndrome result in delays in balance and mobility development (Hartshorne et al., 2011; Thelin, Curtis, Maddox, & Travis, 2007). There are many benefits to moving, such as increased:

- Social Skills
- Self-esteem and self-determination
- Common bond with non-disabled peers
- Perceptions
- Sense of belonging
- Ownership
- Independence
- Orientation and Mobility Skills
- Physical endurance and fitness
- Spatial awareness
- Gross motor skills

Previous research has indicated a strong relationship between the attainment age of independent walking in children with CHARGE syndrome and the acquisition of symbolic communication (Thelin & Fussner, 2005), language (Petroff, 1999), adaptive behavior scores (Salem-Hartshorne & Jacob, 2004), and executive function behaviors (Hartshorne et al., 2007). Therefore, with the increase of movement and ability to walk independently, communication and language skills increase and his or her ability to adapt to the environment improves.

Children with deafblindness have fewer opportunities to participate in physical activities, are overall less active than their peers, and have motor skill delays (Lieberman, Bryne, Mattern, Watt, & Fernandez-Vivo, 2010; Lieberman & Houston-Wilson, 1999; Sherrill, 2004). Specifically, for children with deafblindness, movement provides a means to explore the world around them. Movement allows the child to explore new objects, people, and environments. This exploratory movement has been shown to be associated with perceptual and cognitive development (Gibson, 1988).

A child's mobility is affected by his or her ability to process the environment, to know when and how to move, and how to interact with the surrounding environment (Levtzion-Korach et al., 2000). A child with deafblindness not only has decreased sensory input but also limited motivation needed to stimulate purposeful movement within the environment. Motivation is thought to trigger movement (von Hofsen, 2004). Exploration and movement throughout the environment broadens a child's perspective of his or her world and increases knowledge; movement is crucial for the overall development of children with deafblindness. Acquiring independent movement is a stepping-stone to gaining independence, knowledge, and experience about the world around them.

## Reference List

- Dammeyer, J. (2012). Development and characteristics of children with Usher syndrome and CHARGE syndrome. *International Journal of Pediatric Otorhinolaryngology*, *76*, 1292-1296. Doi: 10.1016/j.ijporl.2012.05.021
- Gibson, E. J. (1988). Exploratory behavior in the development of perceiving, acting, and the acquiring of knowledge. *Annual Reviews in Psychology*, *39*, 1-41. Doi:10.1146/annurev.psych.39.1.1
- Hartshorne, T. S., Hefner, M. A., Davenport, S. L. H., & Thelin, J. W. (2011). *CHARGE syndrome*. In Shprintzen, R. J. (Ed.) San Diego, CA: Plural.
- Hartshorne, T. S., Nicholas, J., Grialou, T. L., & Russ, J. M. (2007). Executive function in CHARGE syndrome. *Child Neuropsychology*, *13*(4), 333-344.

- Levtzion-Korach, O., Tennenbaum, A., Schnitzer, R., & Ornoy, A. (2000). Early motor development of blind children. *Journal of Pediatrics: Child Health*, 36, 226-229.  
Doi: 10.1046/j.1440-1754.2000.00501.x
- Lieberman, L. J., Byrne, H., Mattern, C., Watt, C., & Fernandez-Vivo, M. (2010). Health related fitness in youth with visual impairments. *Journal of Visual Impairments and Blindness*, 104, 349-359.
- Lieberman, L. J., & Houston-Wilson, C. (1999). Overcoming the barriers to including students with visual impairments and deaf-blindness in physical education. *RE:view*, 31, 129-138.
- Petroff, J. (1999). *National transition follow-up study of youth identified as deafblind: Parent perspectives* (Doctoral dissertation). Retrieved from ProQuest Dissertations Publishing. (9921190)
- Pogrud, R. L., & Fazzi, D. L. (Eds.). (2002). *Early focus: Working with young children who are blind or visually impaired and their families* (2nd ed.). New York: AFB
- Salem-Hartshorne, N., & Jacob, S. (2004) Characteristics and development of children with CHARGE Association/Syndrome. *Journal of Early Intervention*, 26, 292-301.  
Doi: 10.1177/105381510402600405
- Sherrill, C. (2004). *Adapted physical activity, recreation, and sport: Crossdisciplinary and lifespan* (6th ed.). New York: McGraw-Hill.
- Smith, K. G., Smith, I. M., & Blake, K. (2010). CHARGE Syndrome: An educator's primer. *Education and Treatments of Children*, 33, 289-314.
- Thelin, J. W., Curtis, S. E., Maddox, J. F., & Travis, L. S. (2007). Balance and mobility. In Shprintzen, R. J. (Ed.), *CHARGE Syndrome* (pp. 55-62). San Diego, CA: Plural.
- Thelin, J. W., & Fussner, J. C. (2005). Factors related to the development of communication in CHARGE syndrome. *American Journal of Medical Genetics*, 133, 282-290. Doi: 10.1002/ajmg.a.30550
- von Hofsten, C. (2004). An action perspective on motor development. *Trends in Cognitive Sciences*, 8, 266-272. Doi: 10.1016/j.tics.2004.04.002