

Chiari Can Make It Hard To Move

The human balance system is a delicate, complex system which involves several parts. To maintain balance, the body integrates input from three sources: the eyes which provide information about the body's position relative to their environment and detects motion; muscles and joints which provide information about the body's position relative to itself and the ground, which is known as proprioception; and the inner ear, or vestibular system which has fluid-filled structures that detect head movements and position. All of this information is sent to the cerebellum, which integrates the information, sends control signals to the muscles, and evaluates and corrects for errors which enable smooth, coordinated movements. Unfortunately, with Chiari, the cerebellum and its connections to the brainstem are compressed and under strain which disrupts the complicated actions of the balance system. In fact, according to the Chiari1000 more than 70% of all Chiari patients – adults, kids, males, and females, report balance issues as a significant symptom at the time of diagnosis.

Conquer Chiari's Physical Impact study explored this topic further by using the Activities Balance Confidence Scale – Six, which asks people to rate their confidence in performing six different balance related activities. The specific activities are standing on tip toes reaching for something above your head; standing on a chair reaching for something; being bumped into by people as you walk through the mall; walking onto or off an escalator while holding onto a railing; walking onto or off an escalator while holding onto something such that you cannot hold onto the railing; and walking outside on an icy sidewalk. Each activity is rated from zero to one hundred percent confident with the responses averaged for a final confidence score. Sixty-two percent of the Chiari patients scored 50% or lower which equates to a Low Level of Physical Function and very high risk of falling.

In addition to cerebellar issues, loss of ankle stiffness may also play a role in Chiari balance issues. The ankles are an important part of how humans maintain an upright position. When muscles are activated around the ankle during movement, the stability provided is referred to as stiffness. The ankle stability provided when standing still is called quasi-stiffness. One Conquer Chiari study which used force pressure plates found that the quasi-stiffness of Chiari subjects was significantly less than that of the controls

Conquer Chiari has previously reported on the high levels of pain and neck weakness that many Chiari patients live with. These factors, plus balance issues, result in many Chiari adults disengaging from physical activities. Conquer Chiari's Physical Impact project showed that an astonishing 84% of patients surveyed scored above the clinical cut-off for kinesiophobia. Kinesiophobia translates literally as fear of movement and is a recognized condition where someone has a debilitating fear of physical movements due to a sense of increased pain or risk of injury. Of course, as someone avoids physical activity and movement the worse their physical condition can become over time, thus perpetuating the cycle and leading to high levels of depression and anxiety.

Sources: Unpublished Conquer Chiari data

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<https://www.conquerchiari.org/donate>

Conquer Chiari's research updates highlight and summarize interesting publications from the medical literature while providing background and context. The summaries do contain some medical terminology and assume a general

understanding of Chiari. Introductory information and many more research articles can be found in the [Conquer Chiari Library](#).

Conquer Chiari is a 501(c)(3) public charity dedicated to improving the experiences and outcomes of Chiari patients through education, awareness and research.