Key Points

1. Restless Leg Syndrome (RLS) is characterized by unpleasant sensations in the legs and the urge to move them.
2. Symptoms occur when a person is lying down and trying to go to sleep.
3. RLS can be treated with a number of different drugs.
4. RLS can be due to other conditions or occur for unknown reasons.
5. A report identified 5 people with RLS who also turned out to have Chiari.
6. All had RLS at a relatively young age and had tried drugs with no effect.
7. This report is too small to say whether Chiari and RLS are linked, but studies have indicated the cerebellum and brainstem may be involved with RLS.

Chiarì & Restless Leg Syndrome

March 31, 2008 -- As if there weren't already enough symptoms related to Chiari, a recent publication in the journal Clinical Neurology and Neurosurgery by Turkish physicians (Kaplan and Oksuz) suggests a possible link between Chiari and Restless Leg Syndrome (RLS).

According to the National Institute of Neurological Disorders and Stroke (NINDS), RLS is, "a neurological disorder characterized by unpleasant sensations in the legs and an uncontrollable urge to move when at rest in an effort to relieve these feelings. RLS sensations are often described by people as burning, creeping, tugging, or like insects crawling inside the legs... The most distinctive or unusual aspect of the condition is that lying down and trying to relax activates the symptoms. As a result, most people with RLS have difficulty falling asleep and staying asleep."

The unpleasant sensations are referred to as Sensory Leg Discomfort (SLD) and are often accompanied by Periodic Limb Movements (PLM). PLMs are involuntary twitching or jerking movements during sleep which can occur several times a minute.

The prevalence of RLS has not been accurately determined, but estimates range from 12 million all the way up to 30 million Americans who may suffer from it. In general, RLS becomes more prevalent with age, and while some children do suffer from it, the average age of onset is more often around middle age. There is no single diagnostic test for RLS, however the International Restless Leg Study Group has established four criteria for the diagnosis of RLS:

1. A desire to move the limbs, often associated with paraesthesias or dysesthesias.
2. Symptoms that are worse or present only during rest and are partially or temporarily relieved by activity.
3. Motor restlessness.
4. Nocturnal worsening of symptoms.

The distinguishing feature of RLS of course is the fact that the symptoms occur when people lie down or are trying to relax. Long car rides and airplane flights can also trigger symptoms.

RLS can occur on its own (primary RLS) or can be caused by other things (secondary RLS), such as anemia, pregnancy, medications, multiple sclerosis, and rheumatoid arthritis. The underlying mechanism of primary RLS is not known, but it has been shown to run in families. Interestingly, imaging studies of restless leg patients has also implicated the cerebellum and upper brainstem as potentially playing a role.

Depending on the cause and severity, there are several ways to treat RLS. For less severe cases, many physicians will recommend certain lifestyle changes, such as eliminating caffeine, nicotine, and alcohol. Moderate exercise has also been shown to have some benefits, although heavy exercise can actually make the symptoms worse. In addition, RLS can be treated with a variety of drugs, including dopaminergics (which act like the neurotransmitter dopamine), opioids, and anti-convulsants. In 2005, the US FDA approved the drug ropinirole - originally a Parkinson's drug - specifically for the treatment of moderate to severe RLS. However, patients and doctors have found that not one medicine works for all cases.

In the Turkish report, the doctors identified five patients with RLS who also turned out to have Chiari. Four of the patients were women and one was a man. All had developed RLS early in life, yet none had a family history of RLS (which you might expect with primary RLS). And perhaps most significantly, each patient had tried at least two RLS drugs which failed to provide any symptom relief. Sleep testing showed that none of the group had apnea, but all suffered from Periodic Limb Movements and took a significant amount of time to fall asleep.

As the doctors examined these patients, they realized that 4 of them mentioned occasional pain in the back of the head, suggestive of Chiari. Follow-up MRIs confirmed that the patients all had herniations greater than 5mm. Given the high prevalence rate of RLS, it is possible that the patient group they saw with Chiari and RLS was just a coincidence, but given the potential role of the cerebellum and brainstem in RLS, it is also possible that there is a more significant link between the two. The authors do feel that at a minimum, the Chiari contributed to the treatment difficulties these patients encountered. It is important to note however, that 4 of the patients responded well to opioids.

The brainstem and cerebellum are involved in a great number of bodily processes, so it should not be surprising that Chiari can cause so many problems, but that very fact is one reason Chiari is so difficult on patients.

Author's Note: Though I have not pursued diagnosis or treatment, I have no doubt that I would meet the criteria...
Cerebrospinal fluid (CSF) - clear liquid in the brain and spinal cord, acts as a shock absorber.

Chiari malformation I - condition where the cerebellar tonsils are displaced out of the skull area into the spinal area, causing compression of brain tissue and disruption of CSF flow.

Syringomyelia - condition where a fluid filled cyst forms in the spinal cord.

Source:

Some nights I end up getting out of bed many, many times because I just have to move my legs. I also have periodic limb movements which can be pretty dramatic at times. In addition, there are many nights where my legs hurt terribly. However, I have not found that it disrupts my sleep so much that I am overly fatigued during the day. I have dealt with this since I was a young child, so I guess my body has adapted.