

NIGHTWALKERS: RESTLESS LEGS SYNDROME

by Frank Roman MD JD



Night walkers, not to be confused with sleepwalkers, is a term used to describe people who walk most of the night, many nights, trying to obtain relief from restless legs syndrome.

Restless legs syndrome (RLS) is defined as a neurological condition characterized by an urge to move, usually associated with paresthesia that occurs or worsens at rest and is relieved by activity. It seems to follow a circadian rhythm, worsening at night, with the maximum severity of leg discomfort occurring after midnight. Involvement of the arms is not uncommon and unfortunately is associated with a greater overall severity.

The first description of RLS as a distinct clinical disorder has been attributed to the Swedish neurologist, Dr. Carl Ekbom, in a published article from 1945 presenting 53 cases and subsequently expanded in a series of articles from 1945-1970. However, like many other conditions in medicine, if you look back far enough you may find early descriptions of the same disorder. In this case, RLS was first described by Sir Thomas Willis (for you anatomy scholars the "Circle of Willis guy" in 1685). Coincidentally, this was about the same time that coffee was introduced into Europe. It is well established that caffeine is a significant aggravating factor to this condition. Sir Willis also suggested effective treatment—opioids—which is still used today but not first line.

Additionally, in medicine many a condition is named after the person who first described it and RLS is no exception being called Ekbom Syndrome, also called Wittmaack-Ekbom Syndrome, Anxietas Tibialis, and Hereditary Acromelalgia.

However, it is important that RLS not be confused with Ekbom Syndrome II.

Part of the difficulty with the diagnosis of RLS, is the lack of awareness in the medical community and the public at large. As one of my patients is fond of saying, "It doesn't even have a serious name". This same patient, who has been with me for over ten years and is a dear friend, has struggled with her severe RLS all of her life and has difficulty in many situations including her trips to the pharmacy to obtain legally prescribed opiates for her RLS. A few years ago, she attempted to start a doctor patient relationship with a new family practitioner in town. In an effort to impress upon him the seriousness of her condition, during the initial evaluation she told him that she suffered from Ekbom syndrome. From her description the doctor was not familiar with Ekbom syndrome and excused himself from the room. Upon his return he quickly and rudely dismissed my patient and her companion telling them never to return again. In retrospect it seems that the good doctor instead of reading on Ekbom syndrome I, or RLS, came upon Ekbom syndrome II, which is Delusional Parasitosis. This is a form of psychosis in which sufferers hold a delusional belief that they are infested with parasites. It commonly presents as the sufferer reporting parasites existing under the skin, around or inside bodily openings including the anus. Moreover, stimulant drug abuse, particularly amphetamines

continued on page 70

Hk 9 B 9LH; 9B 9F 5H C B

=B G 9B GC F H97 < B C @C ; M" " "

Focus Booth 917

fDc `mj]bm]XYbY`Zi cf]XYL

ij`FYUW`5<=gcbYf

ij`7cbg]ghYbh`CfU`UbX`B`UgU`U]fZck`XYhW]cb

ij`Bc`Wbbi`U`cf`fUbgXi`Wf`Vcl`fYeI`fYX

ij`AcfY`UWW`fUHy`h`Ub`U]f`dfYggi`fY`fUbgXi`Wf`

ij`7ca`dUfYg`k`jh`U`dbYi`a`cHJW`&`

ij`7ca`dUfYg`k`jh`Ub`Ygcd`U[`YU`VU`ccb`

D<CB9', , , !&%&! %%%S S

: 5L`+*`!+,`%!(`%&S

k`k`k`"Xma`YX]l`"Wa

%`H`XX9`_yZFDG`H`G`Yd`Fy`]k`|`G`dH`&S`S`

&`F]WUXG`Yf`n`z`A`8!`7<`g`HG`dH`&S`S`

`K`]"La`C`f`i`Z`D`8!`5`D`G`&S`S``

CIRCLE READER ACTION CARD # 40

This button might do more for the Sleep profession than *anything* else!



3" x 2" \$2.50 per button

Outfit your entire staff with these friendly, professional and memorable (to patients and) buttons. Order directly from FOCUS by calling 800-661-5690 *(minimum order 5 buttons) their families

Nightwalkers...continued from page 42

and cocaine can lead to delusional parasitosis as part of a stimulant psychosis and therefore could somewhat explain the family practitioners behavior in immediately kicking out my patient, possibly labeling her as a psychotic drug seeker.

Although this patient's experience is extreme, it is not uncommon for many a patient with restless legs to be diagnosed with a psychiatric disorder since there is no biological marker or radiological study to make the definitive diagnosis of RLS. It is well known that symptoms worsen in association with a decrease in CNS activity leading to a decrease in alertness, thus the nighttime association. However it must be noted that the patients see the doctor during the day and during that time is very anxious and focused in attempting to describe their symptoms. Despite their descriptions of never being able to sit still, they sit quietly as they describe their inability to do so. To make matters worse their description varies tremendously from creepy crawly to ants and bugs under the skin to Coca-Cola in the veins, to a dull toothache and even significant pain. I have three patients who have seriously requested that both lower extremities be amputated due to the severe discomfort and pain caused from RLS. Part of the difficulty with this neurological disorder is the perception that you will not die from RLS or be admitted to the hospital for management and treatment of RLS. However, it has a significant impact on the lives of these very patients. It is difficult to believe in this day and age how these patients have avoided going to movie theaters, seeing a play or a concert, taking long car trips, or traveling by plane due to the severity of this condition. One of the most panic inducing events in these patients is being admitted to the hospital for an unrelated elective procedure, knowing that they will be on strict bed rest. On many occasions I've had to call or write the surgeon to explain the impact of RLS and the importance of giving them medications for this treatment. Fortunately, even with the skepticism of the surgeons, many of the pain medications used to treat the post operative pain serendipitously also take care of the restless legs. Moreover, trying to get certain accommodations at work for

some patients, for example later start times since it seems patients describe getting their best sleep in the morning hours most likely from falling asleep just from pure exhaustion, has been met with sarcasm. It doesn't help when one of my favorite programs, Seinfeld, also trivializes RLS. There was one particular episode where my favorite character, Cosmo Kramer, was dating a girl with "jimmy legs". He was very upset over it since it was affecting HIS sleep and was torn in explaining to her that he didn't want to spend the night since it was disrupting HIS sleep. At the end of the episode they reconciled but no mention was made on how the issue of RLS was fixed.

The most important mandate for us in the past 10 years or so has been to increase awareness in the medical community in the public at large of this serious and debilitating neurological disorder. It is with great satisfaction to know at this time that for a sleep center to get accredited through the American Academy of Sleep Medicine it must present a case of RLS. Say what you may of direct consumer advertising, the commercials regarding RLS and the first DFA approved treatment Ropinirole HCL (Requip) do serve the community in addressing this mostly unrecognized sleep disorder.

The second edition of the International Classification of Sleep Disorders Diagnostic and Coding Manual presents the criteria necessary to make the diagnosis of RLS. For the diagnosis in adult patients (older than 12 years) the following must be met: A.) The patient reports an urge to move the legs, usually accompanied or caused by uncomfortable and unpleasant sensation in the legs. B.) The urge to move or the unpleasant sensations begin or worsen during periods of rest or in activity. C.) The urge to move or the unpleasant sensations are partially or totally relieved by movement, such as walking or stretching, at least as long as the activity continues. D.) The urge to move or the unpleasant sensations are worse, or only occur in the evening or night. E.) The condition is not better explained by another current sleep disorder, medical or neurological disorder, mental disorder, medication use, or substance use disorder.

What is new in this classification is the inclusion of criteria for diagnosis in pediatric patients ages 2-12. In this patient population A alone or B and C satisfy the criteria.

A. The child meets all four essential adult criteria for RLS listed above and relates a description in his or her own words that is consistent with leg discomfort.

OR

B. The child meets all four essential adult criteria for RLS listed above but does not relate a description in his or her own words that is consistent with leg discomfort.

AND

C. The child has at least two of the following three findings:

- I. A sleep disturbance for age.
- II. A biological parent or sibling with definitive RLS.
- III. A polysomnographic documented periodic limb movement index of 5 or more movements per hour of sleep.

The pediatric criteria is extremely important as our expanding knowledge base suggests in retrospect that many cases of "growing pains" were really RLS and the probable association of ADHD and RLS in this population.

Frank Roman MD is a diplomat of the American Board of Sleep Medicine and a Partner, Neurosurgery and Neurology Associates of Massillon, OH. Dr. Roman also received his law degree from the University of Akron Law School.