Written by respected leaders in the field, and sponsored by the prestigious American Academy of Neurology, Restless Legs Syndrome: Coping with Your Sleepless Nights explains what is known about RLS, and what can be done to manage it.

Up to 8 percent of the population suffers from restless legs syndrome (RLS). If you are one of the millions who has experienced the creeping, crawling, burning, or aching that makes sleeping uncomfortable and sometimes impossible, then you know that this condition can wreak havoc on sufferers’ lives, causing chronic fatigue, career difficulties, and stressful personal relationships. Restless Legs Syndrome: Coping with Your Sleepless Nights will help you understand this condition so you can take control of your life and get the sleep you deserve.

TOPICS COVERED INCLUDE:
• Causes, symptoms, diagnosis, and RLS triggers
• Drug treatments and non-pharmacologic therapy
• Daily activities and lifestyle changes caused by RLS
• RLS in children
• Resources

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Harry J. Gould, III, MD, PhD

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This book is dedicated to Orren Hawley, Virginia Wilson, and Pickett Guthrie, who brought the Restless Legs Syndrome Foundation into being, and to Arthur Walter, who first realized that patients and physicians should work together to bring relief to the millions of RLS sufferers.

I would also like to dedicate this book to my mother and father, Rose and Norbert Buchfuhrer, holocaust survivors who passed on the determination and dedication necessary to write and edit this book on RLS.
This is a sample from Restless Legs Syndrome

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About the AAN Press
Quality of Life Guides

IN THE SPIRIT OF THE DOCTOR-PATIENT PARTNERSHIP

The better-informed patient is often able to play a vital role in his or her own care. This is especially the case with neurologic disorders, for which effective management of disease can be promoted—indeed, enhanced—through patient education and involvement.

In the spirit of the partnership-in-care between physicians and patients, the American Academy of Neurology Press is pleased to produce a series of “Quality of Life” guides on an array of diseases and ailments that affect the brain and central nervous system. The series, produced in partnership with Demos Medical Publishing, answers a number of basic and important questions faced by patients and their families.

Additionally, the authors, most of whom are physicians and all of whom are experts in the areas in which they write, provide a detailed discussion of the disorder, its causes, and the course it may follow. You also find strategies for coping with the disorder and handling a number of nonmedical issues.

The result: As a reader, you will be able to develop a framework for understanding the disease and become better prepared to manage the life changes associated with it.

ABOUT THE AMERICAN ACADEMY OF NEUROLOGY (AAN)

The American Academy of Neurology is the premier organization for neurologists worldwide. In addition to support of educational and scientific advances, the AAN—along with its sister organization, the AAN Foundation—is a strong advocate of public education and a leading supporter of research for breakthroughs in neurologic patient care.
More information on the activities of the AAN is available on our website, www.aan.com. For a better understanding of common disorders of the brain, as well as to learn about people living with these disorders, please turn to the AAN Foundation’s website, www.thebrainmatters.org.

ABOUT NEUROLOGY AND NEUROLOGISTS

Neurology is the medical specialty associated with disorders of the brain and central nervous system. Neurologists are medical doctors with specialized training in the diagnosis, treatment, and management of patients suffering from neurologic disease.

Lisa M. Shulman, MD
Series Editor
AAN Press Quality of Life Guides
Too often, the term “restless legs syndrome” (RLS) generates snickers of amusement from anyone who is ill informed about this puzzling condition. For years, most people with RLS suffered alone. It wasn’t until 1989 that eight RLS sufferers from across the US began exchanging letters. Medical knowledge about RLS was so limited that others afflicted with the strange-sounding disorder turned to this fledgling support group in search of coping methods and therapies. In 1992, this coalition of sleep-deprived amateurs launched the Restless Legs Syndrome Foundation, a non-profit organization, dedicated to alerting the world that restless legs syndrome is real and treatable.

Their grassroots effort soon attracted the attention of a small group of sleep researchers. This team of RLS pioneers became the nucleus of the foundation’s first medical advisory board and continues to lead the way in unraveling the mystery behind RLS.

Despite numerous studies estimating that as many as 10 percent of Americans have this potentially devastating disorder, RLS is still hardly a household word. Other than material published by the RLS foundation, people with RLS have had difficulty finding credible information about the condition. This book helps fill the need for reliable information and represents another milestone in the collaboration between patients, researchers, and clinicians. Patients and their families will appreciate the clear, concise descriptions of who gets RLS, what causes RLS, and how RLS is diagnosed. Even those who learned long ago the name of the culprit behind their sleepless nights will welcome this up-to-date review of treatment options.

Drs. Buchfuhrer, Hening, and Kushida are part of an effective partnership between patients and medical professionals that has spearheaded advances in treatment and improved life for RLS sufferers. All three have served on the foundation’s medical advisory board, written articles for the foundation’s quarterly newsletter, and answered hundreds of...
questions from patients who struggle with this potentially devastating condition. Along with impressive credentials, they each have the rare ability to translate medical and scientific terms into language that is accessible to any reader.

Topics covered in this book include non-pharmacological therapies (such as alerting activities and abstaining from caffeine, nicotine and alcohol); complementary and alternative medicine (vitamins, herbal remedies, chiropractic and acupuncture); intermittent drug treatment for those with sporadic symptoms; medications for those who contend with the disruptive symptoms of restless legs on a daily basis; and the future of RLS treatment.

In keeping with their philosophy of teamwork, the authors include material from two people directly affected by the disorder. The chapter on “RLS and Relationships” is written by Ann Battenfield, herself an RLS patient and volunteer moderator for one of the RLS online discussion boards. Her section offers tips for dealing with the stress of living with the disorder. Karla Dzienkowski is the mother of a 15-year-old with RLS. She is also a registered nurse and member of the foundation’s board of directors. Her chapter on “RLS in Children and Adolescents” outlines coping strategies for families dealing with the disorder in younger patients.

Fifteen years of collaboration between patients and medical professionals have improved RLS treatments and fueled rapid progress in unraveling the science that may someday lead to a cure. The authors and contributors to this book continue to prove that teamwork is the best hope for millions of men, women, and children who must live with restless legs syndrome.
Preface

“Restless Legs Syndrome: the most common disease you’ve never heard of.”

ROBERT YOAKUM
Former Board Member
Restless Legs Syndrome Foundation

If you are reading this book then it is very likely that you or someone close to you has restless legs syndrome (RLS). It is also likely that you understand how well Robert Yoakum’s quote typifies the lack of awareness about RLS. You have probably experienced the frustration of dealing with medical professionals, most of whom have very little knowledge about or ability to treat this disease, despite its high prevalence in the U.S. population. Until recently, RLS has been the “Rodney Dangerfield” of sleep and neurologic disorders, with little respect being given to patients or even to doctors treating or researching this trivial-sounding disease. It is common for an RLS patient to be told that the problem is “all in your head” or “doesn’t exist” or that “you are just too anxious.”

The RLS Foundation, which was created in 1992, has been working very hard to change this situation. This nonprofit organization provides support for RLS patients, doctors, educators, and researchers. It has been the driving force in the effort to increase awareness of this poorly known disease.

We are now at the dawn of a new age of RLS awareness and treatment. The FDA approved the first drug to treat RLS in May 2005, and several more are pending. Having an FDA-approved drug adds to the credibility of this disease. In the next few years, RLS should become much better known and gain the recognition and respect it deserves.

Although RLS is not a curable disease, its symptoms are very treatable. With proper care, most patients can achieve dramatic relief, if not
complete resolution of their symptoms. RLS patients should not despair, but rather take a proactive approach to managing their disease. This book helps guide RLS patients through the often very difficult path of managing their disease successfully.

All aspects of RLS and periodic limb movement disorder (PLMD) are discussed in this book. Readers will become more familiar with the presentation, diagnosis, course, and causes of RLS and PLMD. The chapter on management of RLS and PLMD covers all aspects of treatment extensively. It reviews all of the helpful drug and nondrug therapies. After reading this book, patients should become very familiar and comfortable with the management of this disorder.

Although this book is meant for RLS sufferers all over the world, the drug treatment of this disease varies from country to country due to the different availability of these drugs. Narcotics are more freely prescribed in the U.S., while drugs such as cabergoline are used more in Europe where they are less expensive. RLS patients in some countries do not have access to the newer drugs like Mirapex and Requip, while we here in the U.S. do not have domperidone, an inexpensive antinausea drug that does not worsen RLS. Clearly, the choice of RLS therapies can differ significantly based on the availability of drugs and the prevailing attitudes of their use.

RLS sufferers should take an active role in managing their disease. We discuss how they should work with their doctors to achieve optimal therapy. This book gives guidelines for the very difficult task of finding and choosing the right doctor to treat RLS.

Patients often have difficulties coping with their RLS symptoms and the limitations resulting from this disease. We discuss many techniques for coping with the different aspects of life affected by RLS and PLMD, including daily activities, recreational activities, emotions, psychiatric problems, and medical procedures. RLS sufferers will also learn how to deal with relationships that are often strained by this chronic disease.

RLS in children is quite common but is less well known and diagnosed than in adults. The book covers this topic as well as the treatment of children. We encourage parents of children with RLS to read the section on how to cope with RLS in young children and teenagers.
We encourage all RLS patients to become more educated about their disease. The Appendix contains information on other sources to continue your education. Included are resources for educating your health care professional. We also encourage all RLS patients to join the RLS Foundation and a local support group. By doing so, you will help both yourself and other RLS sufferers.

We hope this book will help those suffering from RLS or PLMD to manage and live with their disease. They will learn not to be embarrassed by their strange-sounding symptoms. Instead of suffering quietly, patients will learn how to get proper care, which should relieve the symptoms of most RLS sufferers.

The future for RLS sufferers looks much brighter now. We expect that over the next decade RLS will become a well-known disease. Patients will no longer have to struggle to be diagnosed and treated for their disruptive symptoms. As research accelerates, more therapies should make effective treatment even more accessible. Because of the fast pace of change in our knowledge about this disease, some of the therapies discussed in this book may be quite different in the next few years.

Mark J. Buchfuhrer, MD, FRCP(C), FCCP
Wayne A. Hening, MD, PhD
Clete A. Kushida, MD, PhD
I would like to thank the Restless Legs Syndrome Foundation, its founders, board of directors, advisors, and staff members, who have worked for so many years to increase the awareness of RLS, which has resulted in the demand for this book. The RLS Foundation has been integral in educating the public and medical professionals, raising money, and spearheading research on this perplexing disorder.

I would like to thank Elizabeth “Bill” Tunison, previous RLS Foundation board member and founder of the Southern California RLS Support Group, for gently but persistently guiding me into the field of RLS.

I would like to thank the family members of all the authors who supported us during the writing of the book.

I also thank my wife, Laurie Buchfuhrer, MD, for her patience and her support and her many helpful suggestions while writing this book.
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CHAPTER 1

What Are Restless Legs Syndrome and Periodic Limb Movement Disorder?

If you are reading this book you probably already know something about restless legs syndrome (RLS) and periodic limb movement disorder (PLMD). You may even know more than most physicians about these two common conditions. Despite being poorly known and understood, approximately 10 percent of the Caucasian population in the U.S. has RLS. There is a lot of confusion about RLS and PLMD, with many physicians and people mistaking one for the other. This misunderstanding arises because they often appear together, but in fact they are two separate and distinct disorders.

RLS is a neurologic sleep and movement disorder characterized by an almost irresistible urge or need to move the limbs, usually related to uncomfortable limb sensations, which are worse during inactivity. Movement of the limbs occurs in order to relieve the uncomfortable sensations. A person with RLS must be awake and conscious to be bothered by RLS. In order to relieve their RLS symptoms and fall asleep, people with RLS often move their limbs and toss and turn in bed, which may disturb their bed partners (Figure 1-1).

People who experience periodic limb movements (PLM) have limb muscle jerks that occur mostly when they are asleep and occasionally when they are awake. People with PLMD and their bed partners are usually able to sleep in spite of the leg movements, as long as the movements are not too vigorous. RLS is an awake sensory phenomenon with
movement due to the sensations, whereas PLM is a sleep (and only occasionally an awake) movement phenomenon that usually has no sensory component. Confusion can arise because RLS and PLM often occur together; however, they are not identical, and it must be remembered that either can exist without the other.

Despite extensive research, the cause of RLS and PLM is still unknown. The leading hypothesis at this time involves problems with dopamine function and iron in the brain. This is discussed further in Chapter 6. Although there is no cure for RLS or PLM, current therapies should relieve most people’s symptoms, as discussed further in Chapter 4.

Most cases of RLS and PLM are primary and occur in otherwise normal healthy individuals. Secondary RLS and PLM occur in association with certain underlying medical conditions, as discussed in Chapter 3.

FIGURE 1-1
My wife tells me that my legs were restless again last night. She said that she didn’t sleep a wink, but I slept fine.

RLS = urge to move with unpleasant limb sensations occurring while awake.

Published by Demos Health
RESTLESS LEGS SYNDROME

Uncomfortable Limb Sensations

Although most people with RLS have difficulty describing their uncomfortable sensations, many do not describe any abnormal sensation other than the almost irresistible urge to move the affected limb. Abnormal sensations are not necessary, however, to establish the diagnosis of RLS. The medical term for these sensations is *dysesthesia*, which is defined as a “disagreeable or abnormal sensation.” Many people with RLS do not agree with the use of this term, but it is the most accurate word available to describe the sensations. RLS sufferers often describe such sensations as like ants crawling in their legs, creepy-crawly feelings, pulling sensations, water running inside their legs, or electricity in their legs. Some can only describe the sensation as an urge to move their legs. Although RLS usually starts in the legs, it can also occur in the arms or other muscles in the body as the condition progresses. Most people with RLS do not describe these sensations as painful. To better understand this, consider the analogy of how it feels to be tickled. Most of us would not describe being tickled as painful. However, if the tickling continues for too long, it can become quite bothersome and so unbearable that we might begin to consider it painful.

A minority of people experience painful symptoms, which are often described as burning, aching, or simply painful. These symptoms may occur in addition to the more typical sensations. However, in some people the painful symptoms may be the result of some separate but associated problem, such as *neuropathy* (disease of the nerves).

The large variability of the uncomfortable sensations and the difficulty in describing them contributes to problems in communicating with physicians. Many people are even reluctant to mention their symptoms because they feel they are “just too weird.” Therefore, it is not surprising that physicians often miss the diagnosis of RLS. People often diagnose themselves, typically after reading a description of RLS.
What’s in a Name?

Many people with RLS and their families have made up their own names for the disorder. Table 1-1 lists some of the colorful terms that people use to talk about the condition before they learn the commonly accepted name, RLS. Many people do not agree with the use of the term “restless legs syndrome,” because they feel it makes the condition sound trivial, which results in physicians and others not taking it seriously.

<table>
<thead>
<tr>
<th>Table 1-1</th>
<th>Patient’s Names for RLS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Achy knees</td>
<td>Having butterflies in my legs</td>
</tr>
<tr>
<td>Achy legs</td>
<td>Hopping legs</td>
</tr>
<tr>
<td>Aerobic sleeping</td>
<td>Hot legs</td>
</tr>
<tr>
<td>Alien legs</td>
<td>Itchy blood</td>
</tr>
<tr>
<td>Ant legs</td>
<td>Itchy chin-bone</td>
</tr>
<tr>
<td>Antsy legs</td>
<td>Anxious feet</td>
</tr>
<tr>
<td>Anxious legs</td>
<td>Jello legs</td>
</tr>
<tr>
<td>Bone itch</td>
<td>Jiggles in my legs</td>
</tr>
<tr>
<td>Bugs crawling in my legs at night</td>
<td>Jiggy legs</td>
</tr>
<tr>
<td>Bugs in the bones</td>
<td>Jumpy knees</td>
</tr>
<tr>
<td>Busy legs</td>
<td>Jumpy legs</td>
</tr>
<tr>
<td>Butterfly twitches</td>
<td>Jumpy life</td>
</tr>
<tr>
<td>Crawly legs</td>
<td>Kickies</td>
</tr>
<tr>
<td>Crazy leg thing</td>
<td>Kicky legs</td>
</tr>
<tr>
<td>Crazy legs</td>
<td>Last nerve disease</td>
</tr>
<tr>
<td>Dancing legs</td>
<td>Lead legs</td>
</tr>
<tr>
<td>Day crawls</td>
<td>Leaping legs</td>
</tr>
<tr>
<td>Dead legs</td>
<td>Leg thrashies</td>
</tr>
<tr>
<td>Edgy legs</td>
<td>Legitis</td>
</tr>
<tr>
<td>Eeky</td>
<td>Legs are mad</td>
</tr>
<tr>
<td>Feet cramps</td>
<td>Legs want to break dance</td>
</tr>
<tr>
<td>Fidgety legs</td>
<td>Magic legs</td>
</tr>
<tr>
<td>Flapping legs</td>
<td>Mom's leg thing</td>
</tr>
<tr>
<td>Floggin legs</td>
<td>Muzzy legs</td>
</tr>
<tr>
<td>Funny bone legs</td>
<td>My hands and feet are nervous</td>
</tr>
<tr>
<td>Funny legs</td>
<td>Nervous leg syndrome</td>
</tr>
<tr>
<td>Grasshopper legs</td>
<td>Night crawls</td>
</tr>
<tr>
<td>Great RLS boogie</td>
<td>Night thrashers</td>
</tr>
<tr>
<td>Happy feet</td>
<td>Nighttime jitterbug</td>
</tr>
<tr>
<td>Heebee-jeebees</td>
<td></td>
</tr>
</tbody>
</table>
Groups of people with RLS have lobbied to change the name to *Ekbom’s syndrome*, after Dr. Karl Ekbom, who first described RLS in 1944. Dr. Ekbom first called it *irritable legs*, but changed it to *restless legs syndrome* in 1945. Since then, the medical and scientific world has accepted and used this term, and it would be confusing to change the name again.

The Urge to Move the Affected Limb

This cardinal symptom of RLS must be present to establish the diagnosis. Many people with RLS do not have uncomfortable limb sensations, but they all have an almost irresistible urge to move the affected limb when at rest. Many people with RLS have some control over this urge and can usually delay moving for a short time as well as choose the type of movement (walking, shaking, or rubbing their leg). This is quite similar to the urge to scratch a mosquito bite. We can voluntarily stop ourselves from scratching using our willpower but, if distracted, will immediately scratch the itchy spot. However, with RLS, if the urge to move is suppressed for too long, it becomes so intense that the person loses control and must move.

Many people say they move their affected limb because it brings complete or partial relief of the uncomfortable sensations; however, the RLS symptoms and the urge to move the limb often return once the limb is at rest again. The length of time that a person can sit or lie down before feeling the urge to move decreases as RLS worsens. This can make it impossible for them to perform sedentary activities, such as watching television or going to bed and falling asleep.

Early in the disorder, the symptoms may occur only at bedtime and can be relatively mild. Once the patient is tired enough, falling asleep at bedtime may not be a problem. However, as the disorder progresses, the RLS symptoms can become intense enough that sleep is almost impossible. As the disorder progresses, symptoms usually occur earlier in the day. People with severe RLS may even have symptoms upon awakening. RLS symptoms usually start in the legs, but as the condition worsens, the symptoms move to the arms and other muscles of the body, such as the abdomen, chest, back, neck, and even the facial muscles.
How Does Your RLS Rate?

Many people with RLS wonder how their RLS problems compare with others’. Often the only reference point is a comparison to the level of RLS early in the course of the disorder. Speaking to other people with RLS may be helpful, but it may not help you define the level of your RLS within the spectrum of the disorder.

Several RLS rating scales are used to assess severity in medical studies. You can rate your RLS using the simple rating system shown in Table 1-2, which is based loosely on the validated Johns Hopkins restless legs severity scale that assigns severity based on the time of day that symptoms begin. This crude severity rating scale rates most people with RLS fairly well, but it does not take into account the intensity of the RLS symptoms and their effect on sleep and daytime functioning. It also excludes people who do not get symptoms at bedtime, but experience them only with prolonged sitting, such as on a long airplane trip.

<table>
<thead>
<tr>
<th>Severity</th>
<th>Time of day when symptoms usually start (&gt;50 percent of the time)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>Bedtime symptoms only</td>
</tr>
<tr>
<td>Moderate</td>
<td>Evening symptoms starting after 6 P.M.</td>
</tr>
<tr>
<td>Severe</td>
<td>Afternoon symptoms starting after 12 P.M. (noon)</td>
</tr>
<tr>
<td>Very severe</td>
<td>Morning symptoms</td>
</tr>
</tbody>
</table>

The International RLS Study Group Rating Scale

The International RLS Study Group rating scale can be used to determine a more accurate severity rating. This scale, validated in 2003, is currently considered the standard scale by most RLS specialists. To evaluate the severity of your RLS, simply answer the questions below, add up the appropriate number of points, and find your severity level in Table 1-3. Use the average symptoms you experienced during the most recent 2-week period for evaluating symptom severity.
1. How would you rate the RLS discomfort in your legs or arms?
   - Very severe: 4 points
   - Severe: 3 points
   - Moderate: 2 points
   - Mild: 1 point
   - None: 0 points

2. How would you rate the need to move around because of your RLS symptoms?
   - Very severe: 4 points
   - Severe: 3 points
   - Moderate: 2 points
   - Mild: 1 point
   - None: 0 points

3. How much relief of your RLS arm or leg discomfort do you get from moving around?
   - No relief: 4 points
   - Slight relief: 3 points
   - Moderate relief: 2 points
   - Complete or almost complete relief: 1 point
   - No RLS symptoms: 0 points

4. How severe is your sleep disturbance from your RLS symptoms?
   - Very severe: 4 points
   - Severe: 3 points
   - Moderate: 2 points
   - Mild: 1 point
   - None: 0 points

---

Table 1-3 Overall Severity of RLS from IRLS Rating Scale

<table>
<thead>
<tr>
<th>Severity</th>
<th>Total points from 10 IRLS questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>1-10</td>
</tr>
<tr>
<td>Moderate</td>
<td>11-20</td>
</tr>
<tr>
<td>Severe</td>
<td>21-30</td>
</tr>
<tr>
<td>Very severe</td>
<td>31-40</td>
</tr>
</tbody>
</table>
5. How severe is your tiredness or sleepiness from your RLS symptoms?
   Very severe: 4 points
   Severe: 3 points
   Moderate: 2 points
   Mild: 1 point
   None: 0 points

6. How severe is your RLS as a whole?
   Very severe: 4 points
   Severe: 3 points
   Moderate: 2 points
   Mild: 1 point
   None: 0 points

7. How often do you get RLS symptoms?
   Very severe (6–7 days a week): 4 points
   Severe (4–5 days a week): 3 points
   Moderate (2–3 days a week): 2 points
   Mild (1 day a week or less): 1 point
   None: 0 points

8. When you have RLS symptoms, how severe are they on an average day?
   Very severe (8 hours per 24-hour day or more): 4 points
   Severe (3–8 hours per 24-hour day): 3 points
   Moderate (1–3 hours per 24-hour day): 2 points
   Mild (less than 1 hour per 24-hour day): 1 point
   None: 0 points

9. How severe is the impact of your RLS symptoms on your ability to carry out your daily affairs, for example, having a satisfactory family, home, social, school, or work life?
   Very severe: 4 points
   Severe: 3 points
   Moderate: 2 points
   Mild: 1 point
   None: 0 points

10. How severe is your mood disturbance from your RLS symptoms, for example: angry, depressed, sad, anxious, or irritable?
Very severe: 4 points
Severe: 3 points
Moderate: 2 points
Mild: 1 point
None: 0 points

PLMD

What exactly is PLMD? Initially, this condition was called nocturnal myoclonus because the leg jerks occurred mainly at night (nocturnal) and involved contractions of a group of muscles (myoclonus). Many physicians still use this phrase, but the more current and accepted term is periodic limb movement disorder. Table 1-4 contains definitions of the terms related to PLMD.

PLM are the leg kicks or jerks experienced by more than 80 percent of people with RLS. However, PLM most often occurs without RLS.

PLM = limb muscle jerks mostly while asleep (PLMS).

Some people will develop RLS in the future, but most will experience only PLM and never have any RLS symptoms. The two disorders are separate and distinct entities, but they are linked in many ways. Aside from being common in people with RLS, PLM are thought to result from mechanisms similar to RLS and to respond to the same therapy.

Periodic limb movements in sleep (PLMS) are also common in other sleep disorders, including sleep apnea and narcolepsy. Some sleep specialists think that PLMS are a nonspecific response to disturbed sleep, rather than a distinct disorder. They are also more prevalent in older people who usually have no sleep complaints or problems from leg kicks. PLMS are also more common in conditions associated with secondary RLS, including pregnancy, iron-deficiency anemia, and kidney failure (see Chapter 3).

PLMS differ from the hypnic jerks, or “sleep starts,” commonly experienced by normal people. These jerks are involuntary local or general
muscle contractions that take place during the transition from wakefulness to sleep. They are often described as an electric shock or falling sensation and can cause significant body movement in bed. Stress, irregular sleep patterns, and discomfort may increase the occurrence of sleep starts. Many people confuse hypnic jerks with the leg jerks of PLMS. However, hypnic jerks occur only once or twice a night, whereas PLMS recur frequently throughout the night.

The leg kicks of PLM typically consist of a rhythmic extension of the big toe (the big toe moves upwards) and dorsiflexion of the ankle (the foot moves upwards at the ankle), with flexion at the knee and hip. Flexion at the knee and hip, which can result in vigorous leg kicks, only occurs occasionally. People vary considerably in how their leg muscles jerk, with most

| Table 1-4 Periodic Limb Movement: Acronyms and Definitions |
|---------------------------------|---------------------------------|
| **Acronym** | **Definition** |
| PLM | Periodic Limb Movement(s)—One or more leg movement in a series of rhythmic repetitive leg movements manifested by extension of the big toe, dorsiflexion of the ankle with or without flexion of the knee and hip occurring in wake or sleep. The movement can also occur in the arms. This term can also be used as the plural form for many limb movements. |
| PLMS | Periodic Limb Movement(s) in Sleep—One or more PLM that occur during sleep. Usually used in the plural form, referring to all the leg movements occurring during sleep or to the condition of having these leg movements during sleep. |
| PLMW | Periodic Limb Movement(s) during Wakefulness—One or more PLM that occur while the patient is awake. Usually used in the plural form. |
| PLMA | Periodic Limb Movement(s) with arousals—Leg movements that occur during sleep and result in a shift from deeper to lighter sleep. |
| PLMI | Periodic Limb Movement Index—Number of PLM per hour. Usually refers to the number of PLMS per each hour of sleep. |
| PLMAI | Periodic Limb Movement Arousal Index—Number of PLMS associated with an arousal per hour of sleep. |
| PLMD | Periodic Limb Movement Disorder—A medical disorder resulting from a significant frequency of PLMS during sleep with a related clinical complaint such as daytime sleepiness. The PLMS cannot be due to another disorder (sleep apnea, narcolepsy or RLS). Therefore, people with RLS cannot have PLMD. |
having unnoticeable contractions. The movements last from 1/2 second up to 10 seconds and occur about every 20–40 seconds, although there may be intervals of 5–90 seconds. They can occur in one leg at a time or both legs simultaneously. At times, the arms may also be involved.

PLM follow a circadian (24-hour, or daily) rhythm identical to that of RLS symptoms. They increase during the evening and night and improve in the morning. PLM occur more frequently in NREM (non–rapid eye movement, or nondreaming) sleep during the first half of the sleep period. Although typically these leg kicks are noticed by bed partners, a sleep study in which the leg muscles are monitored with (EMG) electromyography electrodes and the brain waves are monitored by EEG (electroencephalogram, or brain wave) electrodes is necessary to diagnose the extent of PLMS and whether they cause arousals.

The term PLMD is used only when PLM cause significant enough problems to result in a recognized medical disorder; however, whether or not PLMD is a real disorder is still quite controversial. Many sleep specialists do not believe that PLMS—even when associated with arousals—can cause a significant enough sleep disturbance to decrease the patient’s daytime alertness. There is insufficient evidence to prove definitively that frequent leg kicks (with or without arousals) cause a real disorder that would warrant the term PLMD. Many sleep specialists, however, believe that PLMD does exist and should be treated.

All sleep specialists agree that the term PLMD should not be used if there are only a few leg kicks and they do not cause any sleep disruption. As discussed above, these leg kicks are called PLMS when they occur during sleep and periodic limb movements during wakefulness (PLMW) when they occur while awake.

Many people notice that their bed partner kicks occasionally, and they may be concerned that their bed partner might have PLMD. However, a few leg kicks do not necessarily confirm a diagnosis of PLMD. For true PLMD to exist there must be more than five PLM per hour for children and more than 15 per hour for adults. In addition, the movements must disturb the patients’ sleep sufficiently to affect their ability to stay awake during the day. A sleep study to record even the minutest of leg muscle contractions is necessary to quantify the PLM, because many
of the leg jerks may be minimal and imperceptible to an observer. In addition, the sleep study can count the number of PLM that cause arousals (brief awakenings from sleep) and thus prevent deep, restorative sleep.

Most people experience weak leg muscle contractions that are hardly apparent and may not bother the patients or their bed partners. The movements may consist of only a raised toe or foot. These people do not know they have PLM except when monitored in a sleep lab that can record these barely perceptible leg muscle contractions. However, the leg jerks can be violent enough to kick a patient’s bed partner out of bed or break the patient’s toe—luckily, these are rare events. PLM can also cause leg muscle soreness the next day. People with PLMS have complained of getting up in the morning feeling as if they have been vigorously exercising all night.

It is most common for these movements to occur while the patient is asleep (PLMS). They can also occur when awake, especially when sitting in the evening or while in bed trying to get to sleep. This is an example of PLMW. We can also divide the problems caused by PLM into two groups: those that disturb the patient and those that disturb the bed partner.

**PLM That Disturb the Bed Partner, but Not the Person Who Kicks**

Most people with PLM produce few arousals and may have no problem with their nighttime kicks other than the complaints of their bed partners. Most people are not aware that they are kicking at night. Like those who snore loudly and vehemently deny it (even after hearing a tape recording of their snoring), people with PLM will also deny their nightly kicking. People with PLM may not retain any conscious memory of it because the movements occur while they are asleep. PLM are usually noticed first by bed partners, who complain about being kicked and may even have bruises to prove it.

The bed partner’s complaint of being kicked is often the main reason for seeking medical help, because maintaining harmony in a relationship that is affected by nighttime kicking can be an important issue. Many people with PLM that only bother their bed partners’ sleep will
demand medication so they can continue to sleep with their partners. However, physicians usually do not like to use medications to treat problems not directly affecting the patient. Helpful nondrug solutions will be discussed in Chapter 4.

PLM That Disturb the Sleep of the Person Experiencing Them

PLM can disturb sleep in two ways. The first is by preventing the person from falling asleep or by waking the person up from sleep and then preventing further sleep. The second way is by causing frequent sleep arousals (brief awakenings from sleep), which may result in nonrestorative sleep and daytime sleepiness.

The PLM may be frequent and vigorous enough to disturb a person’s sleep. If these more vigorous PLM occur while the person is still awake in bed (PLMW), they may result in insomnia. Vigorous leg kicks can also wake the person up in the middle of the night. If the kicks continue, the person may be unable to go back to sleep. Little controversy exists about treating PLM that are vigorous and frequent enough to prevent people from regularly getting to sleep or sustaining sleep. People experiencing these types of PLM usually seek medical attention.

Controversy arises with leg kicks that do not awaken the person experiencing them, but cause sleep arousals. Sleep arousals are brief awakenings from sleep that last a minimum of 3 seconds. The person will not be aware of sleep arousals because he or she is not awake and conscious when they occur. The only way to document sleep arousals is by performing a sleep study with EMG electrode monitoring of the legs, which can record minimal leg muscle contractions, and EEG electrode monitoring.
The reason for the controversy is that it has not been proven that sleep arousals from PLM really do cause daytime sleepiness. Many studies have shown that the frequent sleep arousals resulting from obstructive sleep apnea cause fatigue and excessive daytime somnolence, but this may not necessarily apply to arousals due to PLM. It is necessary to show that eliminating the arousals caused by PLM improves daytime functioning. Numerous studies have demonstrated this for sleep apnea, but not yet for PLMD. In fact, one study found no relationship between the PLM arousal index and the subjective complaint of disturbed sleep, an objective measure of daytime sleepiness, or awakening refreshed in the morning.

Thus, there is a difference of opinion among RLS specialists. Some experts believe that people with frequent PLM-related sleep arousals have a real disorder (PLMD); others do not believe that PLMD exists. To diagnose PLMD, most sleep specialists require one to have more than 15 PLM arousals per hour in order to explain any increased daytime sleepiness. Other causes of daytime sleepiness must be ruled out, including sleep apnea, narcolepsy, or the use of medications with a side effect of sleepiness. Once these criteria are met, many sleep specialists would agree that the patient indeed has PLMD and should be treated.

A BRIEF HISTORY OF RLS

When did RLS begin to affect humans? There are rumors that the great Roman orator Cicero was afflicted by the disorder and that an even earlier Indian sage wrote about it in one of the Hindu epics. Montaigne, the great French essayist, wrote about restlessness of the legs, which was sometimes aroused by sermons in church: “... so that though I was seated, I was never settled.”

In the Middle Ages people with RLS may have been thought to be possessed and underwent exorcism or were burned as witches. In the early modern era, the great physician and anatomist Thomas Willis described one case that many with RLS would probably recognize:

... whilst they would indulge sleep, in their beds, immediately follow leapings up of the tendons, in their arms and legs, with cramps, and such unquietness
and flying about of their members, that the sick can no more sleep than those on the rack.

Willis seems to be clearly on point as to many features of RLS: the leg discomfort ("cramps"), the periodic limb movement while awake ("leapings up"), the onset at night ("indulge sleep"), and the difficulty sleeping, which causes the greatest problem for many people with RLS. Was Willis describing RLS? We do not know for sure, but one supportive fact is that he was able to treat one patient with a medication drawn from a class that is still used today: laudanum, a preparation of opium. He claimed a cure from this treatment, but we do not know whether a single dose, a short course, or continued treatment was necessary to control his patient’s symptoms.

As mentioned earlier, Karl Ekbom, a Swedish physician, presented an almost complete picture of RLS in 1944, noting that RLS was common and could be easily diagnosed if the physician was aware of its typical symptoms. He described restlessness and movements during sleep and the difficulties his patients had with leg discomfort if they remained seated for a sustained period of time. He noted that RLS could cause difficulties with employment, the disorder ran in families, it could be increased in pregnancy or with anemia, and it could be provoked by stomach surgery that reduced the ability of the body to absorb vitamin B₁₂. It is still worthwhile to read his writings in order to get a clear picture of the various faces of RLS. Dr. Ekbom also named the disorder. At first, he considered a proper Latin name: either asthenia crurum paraesthetic or, for the kind of RLS with painful symptoms, asthenia crurum dolorosa. After some thought he settled on the simple term the disorder is known by today.

After Ekbom, RLS assumed a small niche in the medical field, and periodically another study or paper written was about it. The next major advance came from Italy, where Drs. Lugaresi and Coccagna were helping to develop the field of sleep medicine in the 1960s. One patient, a monk, came to them complaining of difficulty sleeping and jerks in his legs. Dr. Coccagna stayed up all night to monitor the patient and heard repeated scratches of the polygraph, a device used to continuously record brain waves, breathing, and muscle contractions. He peeked in at
the patient and found that every 20–30 seconds the patient’s legs would move. Starting with this one patient, these physicians from Bologna discovered that many people experienced the same type of movements.

Drs. Guilleminault, Weitzman, and Coleman developed a scheme for counting the movements, which they first called periodic movements in sleep, then periodic leg movements in sleep, and most recently periodic limb movements. Periodic limb movements were initially thought to cause major problems by disrupting sleep, and initial treatment was aimed at reducing these movements. Sometimes little distinction was made between RLS and PLMD without RLS.

A major advance was made in the early 1980s with the discovery by Sevcet Akpinar in Turkey that medications that increase the brain’s dopamine activity could benefit people with RLS. Dr. Akpinar was consulted by a colonel in the Turkish military who could not sleep at night because of leg discomfort and leg jerks. He tried many different medications and found that levodopa and pergolide, a dopamine agonist (a chemical that can substitute for the brain chemical dopamine and cause a similar action), worked quite well. He was also impressed by the benefits of narcotic painkillers. A few years later, it was discovered that anti-convulsant medications such as carbamazepine (sold in the U.S. first as Tegretol®) could also benefit people with RLS. Even earlier, sedatives such as clonazepam (Klonopin®) were found to improve the quality of sleep in people with either PLMD or RLS.

In the 1990s two organizations were founded that have had a major impact in increasing education about RLS and moving the study of RLS forward: the RLS Foundation (RLSF) and the International RLS Study Group (IRLSSG). Begun as a small group that exchanged a newsletter, the RLSF was legally established in 1992 as a nonprofit corporation by Virginia Wilson and Pickett Guthrie. The RLSF has helped increase public awareness of RLS, provided public advocacy, and sponsored medical and scientific advances.

Around the same time, Dr. Arthur Walters founded the IRLSSG, which began with a few researchers in seven or so countries. By 2006 it had more than 170 members worldwide in more than two dozen countries. The first major project of the group was a standardized definition
of RLS, which made it easier for physicians to determine who had RLS and who did not. This is critical for research, because you cannot study a condition unless you can decide if someone has it. The RLSF and IRLSSG collaborated and developed a medical advisory board. In 2004, under the direction of Dr. Michael Silber of the Mayo Clinic, the medical advisory board published treatment recommendations.

As it became apparent that RLS was not a rare condition, but instead a common neurological disorder, pharmaceutical companies became interested in the condition. By the early 2000s, several companies had begun trials to see if medications they owned would be effective for RLS. Most of the trials focused on dopamine-enhancing medications. The first to be approved was a levodopa compound (Restex®) in Germany and Switzerland. In 2005 the dopamine agonist ropinirole (Requip®) was approved for use in the U.S. and Europe. The involvement of the pharmaceutical industry definitely benefits people with RLS. Physician and patient education has begun, improving the chances that RLS may be more readily recognized and effectively treated.

It was first reported in 2001 that some families are likely to share the genes that cause RLS. The site of such a gene (on the number 12 chromosome) was first identified by the Canadian geneticist Guy Rouleau, who worked with Jacques Montplaisir, a prominent RLS researcher. Several more genetic sites have since been identified. Although no specific gene has yet been found to cause RLS, at least seven different groups are conducting genetic research.

Another development is the explanation of the connection between iron deficiency and RLS. Researchers from Johns Hopkins and Penn State Universities are working together to understand this connection, assisted by the RLSF “brain bank.” A number of people with RLS have been willing to have their brains harvested after death and saved for scientific research. Using this brain tissue, researchers have been able to show that the amount of iron in the brain cells of people with RLS is low; that the brain proteins that keep iron at the right level are not functioning correctly; and that the lack of iron leads to difficulties in developing the contacts between brain cells that are needed for correct brain function.
We now know that RLS is not a degenerative brain disease, such as Parkinson’s disease, Alzheimer’s disease, or amyotrophic lateral sclerosis (ALS, or Lou Gehrig’s disease), but that it probably represents a disturbance in the way the brain works. Future research holds the key to answering the question as to the cause of RLS and treatment.