

# NIGHT WALKERS



In Search of a Good Night's Sleep

## NIH Urged to Support Dopamine Research

### Birth of Workshop

Dr. Charlotte McCutchen, Program Director, Sleep Disorders Medicine, of the National Institute of Neurological Disorders and Stroke, (NINDS) at the National Institutes of Health (NIH) first proposed a workshop to discuss movement disorders affecting sleep, including RLS and PLMD, in 1996. The first scientific meeting of the RLS Foundation was held at the National Academy of Sciences in February 1997. At the conclusion of the workshop, the RLS Foundation was asked to submit research proposals to the Advisory Board of the National Center on Sleep

Disorders Research at their meeting the following month.

In February 1998, Dr. Sudhansu Chokroverty of our Medical Advisory Board, submitted a proposal for a workshop, similar to the one Dr. McCutchen had planned two years before, to the Research Committee of the National Center for Sleep Disorders Research. Later that same year, the House and Senate Appropriations Committee Reports accompanying the Fiscal Year 1999 Appropriations Act included specific language urging the NINDS to conduct research on RLS and PLMD (See *Night Walkers* Feb. 1999, p. 7).

With the strength of those recommendations, in August 1998, Dr. McCutchen approached Dr. Steven Groft, Director of the Office of Rare Diseases (RLS is not a rare disease; unfortunately, it is rarely diagnosed!) at the NIH, for support for a workshop. He agreed to give an initial grant, making it possible for the planning to begin. Subsequently, Dr. McCutchen's own institute, NINDS, as well as the National Institute of Mental Health, the National Institute on Aging, and the National Center for Sleep Disorders Research all committed funds. The RLS Foundation was involved throughout the process in both the planning of the workshop and its support.

Participants were excited about the workshop from the time they were first told about it. A number of those who were invited also asked to bring colleagues. Others heard about it and requested permission

to attend. Of those who were invited, only a handful sent regrets.

At the opening session, Dr. Mahlon DeLong, Chair of Neurology at Emory University and co-Chair of the Workshop, said, "I see a lot of unfamiliar faces here. That's a good sign!"

In his opening remarks, Dr. Gerald D. Fischbach, Director of the NINDS, said, "A great deal of interest is now focused on the central role of dopamine and related neurotransmitters in control of movement, mood and other activities of daily living. This is an exciting area of research and one that should lead to important clinical advances in the near future. Restless legs syndrome should bene-



Charlotte McCutchen, MD

*"The unanimous recommendation of the workshop participants was that the NIH should encourage and support research aimed at deciphering the role of dopamine systems in modulating sleep/wake phenotypes that are common to what superficially appear to be quite dissimilar disorders, e.g., restless legs syndrome, periodic limb movements, parkinsonism and narcolepsy/cataplexy."*

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Gerald Fischbach, MD  
Director, National  
Institute of Neurological  
Disorders and Stroke

fit from these advances and they should further stimulate interest in the area. In this regard, restless legs syndrome and periodic limb movement disorder have arrived.”

In addressing the workshop participants, Dr. Bruce Alberts, President of the National Academy of Sciences and member of the RLS Foundation's Scientific Advisory Board, said, “This meeting (with the format of bringing clinicians and basic scientists together to develop a research plan) is different. We need more like this because there are so many problems that are not being examined. This should be a prototype.”

In offering support for the workshop, Dr. Harold Varmus, former Director of the NIH, had previously written, “I firmly believe that efforts to bring together basic and clinical experts in divergent but complementary fields can refocus and catalyze research and lead both to new opportunities and to unprecedented advances.”

The Dopamine Connection Workshop clearly demonstrated that his words were prophetic. We've already had indications that we can expect both “new opportunities and unprecedented advances” as direct results. Enthusiastic feedback from participants suggests that new scientific directions are being taken and new collaborations are being forged.

## The Emerging Story in RLS Research: The Dopamine Connection

**Bruce Ehrenberg, MD**

Tufts-New England Medical Center

A workshop was held at the National Institutes of Health (NIH) in Bethesda, Maryland, on November 10-11, 1999, to stimulate research into the cause of RLS and related disorders. Dr. Charlotte McCutchen, program director for sleep disorders at the National Institute of Neurological Disorders and Stroke, brought together prominent researchers and clinicians from the United States, Canada, and Germany to discuss their work and to develop a forum for the exchange of ideas gleaned from the study of RLS, Parkinson's disease, narcolepsy and PLMD.

These four conditions have at least one thing in common: they all respond to drugs that mimic the effects of dopamine. However, on further exploration, it turns out that there are other “crossover links” between some of these conditions that provide deeper insights. One group of such links involves the disorders that have PLMS as a common additional finding. Although RLS is accompanied by PLMS in 70% to 90% of patients, PLMS are also found in a high proportion of patients with narcolepsy and Parkinson's disease, and both of these diseases are treated effectively with drugs that affect the dopamine system in the brain.

Dr. David Rye has studied patients with Parkinson's disease who had surgical treatments such as pallidotomy or implantation of subthalamic stimulators (electrically destroying, or stimulating a small part of the brain, using a deep penetrating wire). After the operation, these patients had a marked improvement not only in their Parkinson's symptoms, but also in their PLMS.

The dopamine system refers to all of the nerve cells in the brain and spinal cord that either produce or respond to the neurotransmitter dopamine. Dopamine is related to epinephrine (“adrenaline”) but does not have quite the same ability to create a full-fledged fright/flight/fight or fear response. Nevertheless, dopamine is a powerful stimulant when taken in large doses and is mimicked by amphetamine in this regard. Interestingly, dopamine can lower your blood pressure (sometimes a little too much) when taken in low doses, but in higher doses it is used to keep the blood pressure from dropping to zero in patients who are in shock.

Dopamine is deficient in people with Parkinson's disease, but we now know that it is also the key missing ingredient in RLS. In fact, some of the dopamine-like drugs developed for Parkinson's disease, for example pramipexole and ropinirole, seem to work better for RLS! Similarly, these drugs seem to work exceedingly well in controlling PLMD, the sleep-related “partner” of RLS.

The long view: our best bet for fully understanding RLS/PLMD would be to find the gene or genes AND explain how it (or they) can cause the disorder. All of the above information will be relevant since the final answer(s) will have to fully explain each of the facets and clinical manifestations we see. To that end, everyone affected can participate in finding the answers because all of your observations and family histories are important in the final effort.

—Bruce Ehrenberg, MD

## NightWalkers

is the official publication of the Restless Legs Syndrome Foundation

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*NightWalkers* is published in February, May, August, and November by the Restless Legs Syndrome Foundation, Inc. Ask the Doctor questions, Bedtime Stories, address changes, contributions, and membership inquiries should be sent to *NightWalkers* Editor, RLS Foundation, 819 Second Street SW, Rochester MN 55902-2985. The RLS Foundation does not endorse, sponsor, or advertise any products or services.

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**Warning and Disclaimer** Persons suspecting that they may be afflicted with RLS or PLMD should consult a qualified healthcare provider. Literature concerning RLS and PLMD that is distributed by the Restless Legs Syndrome Foundation, Inc., including this newsletter, is offered for information purposes only and should not be considered a substitute for the advice of a healthcare provider.

Iron-deficiency anemia is associated with some cases of RLS, and from basic research it has been known that the production of dopamine in the brain cells is dependent on a sufficient supply of iron. A few years ago Dr. Sean O'Keeffe found that even if elderly RLS patients had normal iron storage (measured by the ferritin test), there was still some benefit to taking supplemental iron if the ferritin level was in the lower end of the normal range. Most recently, Drs. Richard Allen and Christopher Earley at Johns Hopkins University have shown that regardless of the ferritin level in the blood, it may be even lower in the spinal fluid, suggesting that the amount available to the brain, where it is needed for dopamine production, is almost nil. If this were true of all patients with RLS, it would mean that iron therapy should work for everyone. However, it appears that just taking iron pills by mouth is not enough, and research is currently under way to determine if giving the iron intravenously will yield better results, but even then, the amount actually reaching the brain would only be slightly greater. But since the brain is protected from what is in the blood, even intravenously administered iron may not work. This is not very convenient, so a better way is needed.

The problem may be solved when the genetic basis of RLS is worked out, since those who have a predisposition to develop RLS could be genetically deficient in one of the iron-transport proteins that are needed to bring iron from the blood stream into the brain. Dr. Guy Rouleau reported that RLS is extremely prevalent in French-Canadians and an effort is underway to trace lineage back to a potential "founder" in northern France.

Another remarkable finding in RLS has been the strong interaction

with circadian rhythms. Dr. Wayne Hening and others have data showing that patients who travel to distant time zones will find that their daily symptoms begin at the usual time in the old time zone and only after a few days do they re-adjust the starting time to the new time zone. Dr. Claudia Trenkwalder noted that one study of gender among RLS patients over age 65 found a 2:1 ratio of women to men with the disorder. This study also found a remarkable 9.8% of this age population have RLS. Other studies have ranged from 2.5% to 15%.

## Dopamine and Sleep Disorders

**Emmanuel Mignot, MD, PhD**  
 Stanford University School of Medicine

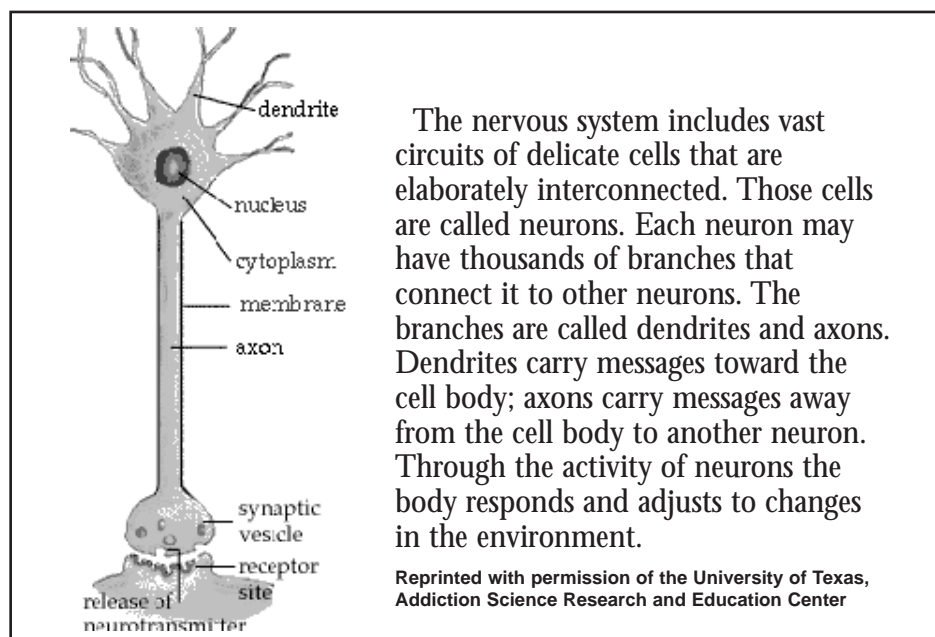
For me, this workshop achieved two main things. First, it was extremely useful to put dopamine back on the map of neurotransmitters that may be important to further study in sleep regulation and sleep disorders. Second, it emphasized the importance of studying RLS more intensively and developing animal models for this condition.

The potential role of dopamine in the regulation of normal sleep and in sleep disorders has long been overlooked. One of the main reasons is the old observation that the activity of dopamine-containing neurons in the brain stem does not change dramatically across the sleep cycle. This, together with the well-established role of dopamine in the regulation of the motor system, has led most investigators to believe dopamine had nothing to do with sleep. This workshop demonstrated this thinking was most probably wrong. Only a few papers substantiate the claim that dopamine is not important for sleep regulation. In contrast, disorders with known

*Research—continued from previous page*

dopaminergic lesions, such as Parkinson's disease, were shown to have major disturbances of REM and non-REM sleep. Amphetamines, the most potent wake-promoting compound known, were demonstrated to act by increasing dopamine in the brain. Dopaminergic drugs, usually used to treat Parkinson's disease or RLS, were shown to produce sleep attacks. Clearly, dopamine is important in sleep regulation!

A second personal impression was the fact that steady progress is being made in understanding the pathophysiology of RLS (in spite of limited funding) and that an animal (rodent) model should now be developed. The observation that narcoleptic dogs have PLMS demonstrates that it is possible to look at species other than humans. Considering the exciting new data that connect iron deficiency and RLS, experiments should be conducted to see if iron deprivation can produce an animal model for RLS/PLMS. A possibility would be to start with an animal model that is easier to "understand" behaviorally (for example dogs) and then to move to rodents. Based on my experience with dogs, it should be possible to see if dogs or other large animals have trouble staying still when trying to fall asleep, the hallmark of patients with RLS. From there, similar experiments could be done in rodents to try to determine if something similar can be detected. Having a widely available and well-defined animal model would facilitate pharmacologic, pathophysiologic and genetic studies.



The nervous system includes vast circuits of delicate cells that are elaborately interconnected. Those cells are called neurons. Each neuron may have thousands of branches that connect it to other neurons. The branches are called dendrites and axons. Dendrites carry messages toward the cell body; axons carry messages away from the cell body to another neuron. Through the activity of neurons the body responds and adjusts to changes in the environment.

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## NIH Workshop Emphasized Iron and Dopamine Connection in RLS

**James R. Connor, PhD**

Penn State University College of Medicine

At the NIH-sponsored workshop on dopamine and neurologic disorders, there was a strong emphasis on RLS, including topics of genetics and pathology. There were, in particular, several presentations and considerable discussion among the participants on the relationship of iron to dopamine and RLS. RLS is frequently associated with iron deficiency; estimates suggest as many as 25% of RLS patients may have an iron deficiency. Furthermore, serum iron levels undergo a daily fluctuation (circadian rhythm) and are lowest at night when RLS symptoms are worse. Serum ferritin, which is frequently used as an indicator of the body's iron status, correlates with the severity of RLS symptoms. When serum ferritin is low, suggesting body iron stores are low, the RLS symptoms are worse. These observations strongly suggest that there is a direct relationship between iron and RLS. The relationship between iron and

dopamine is also direct. Iron is essential for the synthesis of dopamine. The enzyme tyrosine hydroxylase regulates the biochemical step that is most responsible for making dopamine, and it does not function properly if iron is not available. In experimental models of iron deficiency, there is a loss of dopamine in the brain. Furthermore, there are reports that the activity cycle of mice (normally awake at night and asleep during the day) is reversed when the animals are iron deficient. These two observations—lower dopamine and lower activity during the normal resting period, which result from iron deficiency—are hallmarks of RLS. Thus the connection between iron status and RLS appears real and ready for rigorous scientific analysis.

In the brain, iron is found in abundance in those areas that are rich in dopaminergic nerve cells. Thus the brain does not have an even distribution of iron, and the uneven distribution maps closely with the dopaminergic system. The question that faces us is how does the iron accumulate in these brain regions. More importantly in the context of RLS, the question is whether there is enough iron in these regions to keep dopamine at

normal levels. The research questions facing those of us in this area are: (i) What are the iron levels in the brains of RLS patients? and (ii) What is the transport mechanism for iron into the brain?

To obtain the answer to the first question we have undertaken two approaches. The first approach is to obtain magnetic resonance images (MRI) from brains of individuals with RLS. Iron can be visualized but not quantified on an MRI, so this type of analysis will give us some indication of the relative amounts of iron in the brains of RLS patients. Whenever possible, RLS patients should encourage their neurologist to ask for an MRI. The second approach we are taking to determine the iron levels in the brains of RLS patients is to assess the iron and iron-protein concentrations in the cerebrospinal fluid (CSF). The CSF is a nutrient-rich solution that bathes the brain and spinal cord. The CSF can be "tapped" in the spinal column and can provide an indirect assessment of the amount of iron in the brain.

To obtain the answers to our second question regarding transport mechanisms for iron in the brain, we are hoping to develop animal models. The basic questions we have regarding iron in the brain are how did it get there and how much is needed. In some diseases such as Alzheimer's, Parkinson's and Huntington's, there is too much iron in the brain. RLS is currently the only disorder of which we are aware that is associated with too little iron. Our current hypothesis is that there is a "set-point" for iron transport into the brain that is set shortly after or even before birth. This set-point for iron transport allows a continuous but regulated flow of iron into the brain. Iron not used is stored for challenges that require more dopamine (for example) that individuals will face during their lives. In RLS, we hypothesize, the

set-point for iron transport into the brain is too low. Thus, although normal activity is unaffected, there is no extra iron for challenges. The challenges may be as simple as the daily fluctuations in iron levels in the blood or more challenging such as iron deficiency. The result of a challenge to a low set point for iron transport would be temporary insufficient dopamine synthesis. We hope we have identified potential animal models for our RLS studies. One animal model lacks the iron-transport protein transferrin, and another animal model we have makes only one-half of the amount of ferritin that it should. A third potential animal has a defect in a recently discovered iron-transport mechanism that results in abnormally low amounts of iron in the brain. All of these models are better



than using an iron-deficient diet as a model for iron transport because the brain tries to compensate for low iron by increasing the number of its iron transporters. We believe that RLS patients may not be able to increase the number of iron transporters.

The NIH-sponsored workshop was tremendously successful in bringing scientists together to recognize ties between observations that were not previously clear and to share new ideas. The future for understanding the biologic disorder underlying RLS is hopeful and appears to have iron as part of its solution.

## NATIONAL SLEEP AWARENESS WEEK

March 27 to April 2 is NATIONAL SLEEP AWARENESS WEEK, sponsored by the National Sleep Foundation. The focus of the Sleep Awareness Poll this year is on Fatigue in the Workplace. Everyone is encouraged to arrange events in their own locality on a day most convenient to the sleep centers, support groups and others who may be involved or to generate local publicity about RLS and its impact on sleep. Please consult the National Sleep Foundation's Web site at [www.NSAW.org](http://www.NSAW.org) for the latest details.

## RLS In the News

The following articles have been published in the medical literature since the November 1999 issue of *NightWalkers*. We do not have copies of these articles, but have provided the authors' addresses (when available) so that you can contact them for reprints.

*Duroni C. Restless legs have sufferers losing sleep. Intelligencer Journal Lancaster, PA October 21, 1999*

*Restless Legs Syndrome Enjoying Good Health RPS September - October 1999;2:5*

*Picchiatti DL, Underwood DJ, Farris WA, Walters AS, Shah MM, Dahl RE, Trubnick LJ, Bertocci MA, Wagner M, Hening WA. Further studies on periodic limb movement disorder and restless legs syndrome in children with attention-deficit hyperactivity disorder. Mov Disord 1999;14:1000-1007*

Fourteen consecutive children who were newly diagnosed with attention-deficit hyperactivity disorder (ADHD) and who had never been exposed to stimulants and 10 control children without ADHD underwent polysomnographic studies to quantify Periodic Limb Movements in Sleep (PLMS) and arousals. Parents commonly gave both false-negative and false-positive reports of PLMS in their children, and a sleep study was necessary to confirm their presence or absence. The prevalence of PLMS on polysomnography was higher in the children with ADHD than in the control subjects. Nine of 14 (64%) children with ADHD had PLMS at a rate of >5 per hour of sleep compared with none of the control children ( $p < 0.0015$ ). Three of 14 children with ADHD (21%) had PLMS at a rate of >20 per hour of sleep. Many of the PLMS in the children with ADHD were associated with arousals. Historical sleep

times were less for children with ADHD. The children with ADHD who had PLMS chronically got 43 minutes less sleep at home than the control subjects ( $p = 0.0091$ ). All nine children with ADHD who had a PLMS index of >5 per hour of sleep had a long-standing clinical history of sleep onset problems (>30 minutes) and/or maintenance problems (more than two full awakenings nightly) thus meeting the criteria for Periodic Limb Movement Disorder (PLMD). None of the control children had a clinical history of sleep onset or maintenance problems. The parents of the children with ADHD were more likely to have restless legs syndrome (RLS) than the parents of the control children. Twenty-five of 28 biologic parents of the children with ADHD and all of the biologic parents of the control children were reached for interview. Eight of twenty-five parents of the children with ADHD (32%) had symptoms of RLS as opposed to none of the control parents ( $p = 0.011$ ). PLMS may directly lead to symptoms of ADHD through the mechanism of sleep disruption. Alternative explanations for the association between ADHD and RLS/PLMS are that they are genetically linked, they share a common dopaminergic deficit, or both.

**Arthur S. Walters, MD**  
New Jersey Neuroscience Institute  
JFK Medical Center  
65 James Street  
Edison NJ 08818

*Winkelmann J. Restless legs syndrome. Arch Neurol 1999;56:1526-1527*

It was not until 1995 that the International Restless Legs Syndrome (RLS) Study Group agreed on criteria for the definition of the diagnosis of Restless Legs Syndrome, although the clinical features of the "syndrome which causes such suffering that it should be known by every

physician" had been known for several centuries. However, it was not until the 20<sup>th</sup> Century that it was recognized as an independent neurological disorder. This article cites a number of quotations from the early history of RLS to the beginning of the 20<sup>th</sup> Century when the Swedish Neurologist Karl Ekbom investigated the syndrome extensively and presented the broad clinical picture of the disease for the first time.

**Juliane Winkelmann, MD**  
Max Planck Institute of Psychiatry  
Kraepelinstrasse 10  
D-80804 Munich, Germany

*Rye DB, DeLong MR. Amelioration of sensory limb discomfort of restless legs syndrome by pallidotomy. Ann Neurol 1999;46:800-801*

**David B. Rye, MD, PhD**  
Emory University School of Medicine  
Department of Neurology  
Woodruff Memorial Building  
Suite 6000, PO Drawer V  
Atlanta GA 30322

*Hening WA, Walters AS, Wagner M, Rosen R, Chen V, Kim S, Shah M, Thai O. Circadian rhythm of motor restlessness and sensory symptoms in the idiopathic restless legs syndrome. Sleep 1999;22:901-912*

**STUDY OBJECTIVES:** To determine if motor restlessness in the Restless Legs Syndrome (RLS) shows a circadian rhythm with maximum at night, as previously found for subjective discomfort and periodic limb movements (PLMs), and to correlate RLS peak intensity with the core temperature cycle.

**DESIGN:** Subjects underwent two days of normally timed wakefulness and sleep followed by a night and subsequent day of sleep deprivation. Activity was standardized through modified suggested immobilization tests (mSITs).

**SETTING:** The study was conducted in a laboratory environment with a bedroom equipped for polysomnography during sleep and the mSITs.

**PATIENTS:** Nine patients (mean age 59.8+/-11.3 years [range: 33-72]; 4 males, 5 females) with clinically severe idiopathic RLS.

**INTERVENTIONS:** Patients were monitored with continuous ambulatory activity and core temperature recording. The mSITs were performed every three hours while subjects were awake. During the mSITs, subjective discomfort was measured every 15 minutes while motor restlessness was assessed through activity monitoring.

**MEASUREMENTS AND RESULTS:** Subjective discomfort and motor restlessness increased from a trough in the morning to a maximum at night in the hours following midnight. Peak intensity was found on the falling phase of the core temperature cycle, whose circadian rhythm appeared to be within the normal range for age.

**CONCLUSIONS:** An independent circadian factor modulates the intensity of RLS, which seems to peak on the falling phase of the core temperature cycle. Therefore, the diagnostic criteria that RLS occurs with rest and during the night have independent bases. Furthermore, RLS may be partially controlled by some process or substance whose level varies with the normal circadian rhythm.

**Wayne Hening, MD, PhD**  
Department of Neurology  
Professional Center, Second Floor  
97 Patterson Street  
New Brunswick, NJ 08901

*Benes H, Kurella B, Kummer J, Kazenwadel J, Selzer R, Kohnen R. Rapid onset of action of levodopa in restless legs syndrome: a double-blind, randomized, multicenter, crossover trial. Sleep 1999;22:1073-1081*

**OBJECTIVE:** To investigate the efficacy and safety of levodopa plus benserazide in the treatment of restless legs syndrome (RLS), in terms of the frequency of periodic limb movements (PLMs), objective

and subjective criteria of sleep, onset of action, and withdrawal effects.

**DESIGN:** A randomized, double-blind, placebo-controlled, multicenter, crossover trial, with two 4-week treatment periods.

**SETTING:** Outpatient units of three specialist centers in Germany.

**PATIENTS:** Eligible patients had to fulfill the diagnostic criteria of the International RLS Study Group and have sleep disturbances and PLMs during sleep shown on polysomnography at screening. Thirty-five patients were recruited, of whom 32 (13 men, 19 women) completed the study.

**INTERVENTIONS:** Patients received a single dose of standard-release levodopa/benserazide 100/25 mg or placebo at bedtime each night for 4 weeks, before crossing over to receive the alternative treatment for a further 4 weeks; the dose could be doubled if required. The average dosages were 159+/-31 mg of levodopa and 1.56+/-0.29 capsules of placebo.

**RESULTS:** Levodopa/benserazide significantly reduced the number of PLMs per hour ( $p<0.0001$ ), increased the time in bed without limb movements ( $p<0.0001$ ), and improved subjective quality of sleep ( $p=0.0004$ ). The onset of action was rapid after the first dose, and full efficacy was achieved within the first few days of therapy; these improvements disappeared immediately when treatment was discontinued. Levodopa/benserazide treatment was well tolerated and safe.

**CONCLUSIONS:** Levodopa/benserazide is effective and safe in the treatment of RLS. Objective and subjective measures of sleep improved rapidly after the first dose. RLS symptoms recurred immediately after treatment was discontinued.

**Heike Benes, MD**  
Neurology Clinic Schwerin  
Wismarsche Strasse 393  
19017 Schwerin, Germany

*Sorrell J. Taking steps to calm restless legs syndrome. Nursing 1999;29:60-61*

**Jeanne Sorrell, RN, PhD**  
College of Nursing and Health Science  
George Mason University  
MSN:3C4  
4400 University Drive  
Fairfax, VA 22030-4444

*Spiegel K, Leproult R, Van Cauter E. Impact of sleep debt on metabolic and endocrine function. Lancet 1999;354:1435-1439*

**BACKGROUND:** Chronic sleep debt is becoming increasingly common and affects millions of people in more-developed countries. Sleep debt is currently believed to have no adverse effect on health. We investigated the effect of sleep debt on metabolic and endocrine functions.

**METHODS:** We assessed carbohydrate metabolism, thyrotropic function, activity of the hypothalamo-pituitary-adrenal axis, and sympathovagal balance in 11 young men after time in bed had been restricted to 4 h per night for 6 nights. We compared the sleep-debt condition with measurements taken at the end of a sleep-recovery period when participants were allowed 12 h in bed per night for 6 nights.

**FINDINGS:** Glucose tolerance was lower in the sleep-debt condition than in the fully rested condition ( $p<0.02$ ), as were thyrotropin concentrations ( $p<0.01$ ). Evening cortisol concentrations were raised ( $p=0.0001$ ) and activity of the sympathetic nervous system was increased in the sleep-debt condition ( $p<0.02$ ).

**INTERPRETATION:** Sleep debt has a harmful impact on carbohydrate metabolism and endocrine function. The effects are similar to those seen in normal ageing and, therefore, sleep debt may increase the severity of age-related chronic disorders.

*In the news—continued from previous page*

**Karine Spiegel, PhD**  
**Department of Medicine**  
**University of Chicago**  
**5841 South Maryland Avenue**  
**Chicago IL 60637**

*Benz RL, Pressman MR, Hovick ET, Peterson DD. A preliminary study of the effects of correction of anemia with recombinant human erythropoietin therapy on sleep, sleep disorders, and daytime sleepiness in hemodialysis patients (The SLEEPO study). Am J Kidney Dis 1999;34:1089-1095*

End-stage renal disease (ESRD) is commonly associated with complaints of disturbed sleep and sleep disorders, frequently related to periodic limb movements in sleep (PLMS) or sleep apnea that may result in daytime sleepiness and other sequelae. Improvements in quality of life, including subjective sleep quality, have been reported in ESRD patients treated with recombinant human erythropoietin (rHuEPO). We investigated the objective effects of normalizing hematocrit on sleep disorders, sleep patterns, and daytime ability to remain awake in ESRD patients. Ten hemodialysis patients with sleep complaints while on rHuEPO therapy were studied by polysomnography while moderately anemic (mean hematocrit, 32.3%) and again when hematocrit was normalized (mean hematocrit, 42.3%) by increased rHuEPO dosing. Sleep patterns and associated parameters were monitored. Delivered dialysis dose and iron storage factors were monitored. Maintenance of Wakefulness Testing (MWT) was performed to assess daytime alertness/sleepiness. All 10 subjects experienced highly statistically significant reductions in the total number of arousing PLMS ( $p=0.002$ ). Nine of 10 subjects showed reductions in both the Arousing PLMS Index ( $p<0.01$ ) and the PLMS Index ( $p=0.03$ ) when hematocrit was normalized. Measures of sleep quality showed

trends to improved quality of sleep. MWT demonstrated significant improvement in the length of time patients were able to remain awake (9.7 versus 17.1 minutes;  $p=0.04$ ). rHuEPO therapy with full correction of anemia reduces PLMS, arousals from sleep, and sleep fragmentation while allowing for more restorative sleep and improved daytime alertness. These findings may explain one mechanism for the improved quality-of-life parameters reported in ESRD patients treated with rHuEPO.

**Robert L. Benz, MD**  
**Chief, Division of Nephrology**  
**Jefferson Health System—Main Line**  
**Suite 130**  
**Lankenau Medical Bldg, West**  
**Wynnewood PA 19096**

*Glasauer FE, Egnatchick JE. Restless legs syndrome: an unusual cause for a perplexing syndrome. Spinal Cord 1999;37:862-865*

Restless legs syndrome (RLS) is a well-defined symptom complex, occurring either as idiopathic RLS or in association with many other disorders. Although no definite etiology is known for this condition, several pathophysiological mechanisms have been proposed. There is supportive evidence that RLS is a central nervous system (CNS) dysfunction, suggesting involvement of the descending dopaminergic (DA) pathways, but it can also occur with spinal disorders. We present a patient suffering from RLS who eventually was diagnosed with a foramen magnum tumor. Based on the available evidence, we attempt to correlate the location of the tumor with the patient's symptoms of RLS.

**FE Glasauer, MD**  
**Buffalo General Hospital and**  
**Department of Neurosurgery SUNY**  
**462 Grider Street**  
**Buffalo NY 14215**

*Vitiello MV. Effective treatments for age-related sleep disturbances. Geriatrics 1999;54:47-52, quiz 54*

Fundamental changes in sleep patterns are associated with normal aging, but disturbed sleep with resultant daytime sleepiness and fatigue is an extremely common occurrence among older persons and a frequent catalyst for physician visits. Sleep disorders result from multiple factors—including pharmacologic, physiologic, biologic, and behavioral—and can be mildly debilitating or life-threatening. Diagnosis includes consideration of the presence of physical or mental illness, drug and/or alcohol use or abuse, a primary sleep disorder such as sleep-disordered breathing or periodic limb movements during sleep, changes in circadian rhythms, or poor sleep hygiene. Despite a high rate of use, hypnotics are best suited for periodic rather than chronic sleep disorder symptoms and, in general, should be used only after adjustments in sleep hygiene prove unsuccessful as first-line therapy.

**Michael V. Vitiello, PhD**  
**Department of Psychiatry and**  
**Behavioral Sciences**  
**University of Washington**  
**Seattle WA**

*Rajput V, Bromley SM. Chronic insomnia: a practical review. Am Fam Physician 1999;60:1431-1442*

Insomnia has numerous, often concurrent etiologies, including medical conditions, medications, psychiatric disorders and poor sleep hygiene. In the elderly, insomnia is complex and often difficult to relieve because the physiologic parameters of sleep normally change with age. In most cases, however, a practical management approach is to first consider depression, medications, or both as potential causes. Sleep apnea also should be considered in the differential assessment. Regardless of the cause of insomnia, most patients benefit from behavioral approaches that focus on good sleep habits. Exposure to bright light at appropriate times can help

realign the circadian rhythm in patients whose sleep-wake cycle has shifted to undesirable times. Periodic limb movements during sleep are very common in the elderly and may merit treatment if the movements cause frequent arousals from sleep. When medication is deemed necessary for relief of insomnia, a low-dose sedating antidepressant or a nonbenzodiazepine anxiolytic may offer advantages over traditional sedative-hypnotics. Longterm use of long-acting benzodiazepines should, in particular, be avoided. Melatonin may be helpful when insomnia is related to shift work and jet lag; however, its use remains controversial.

**Vijay Rajput, MD**  
**Robert Wood Johnson Medical School**  
**220 Cooper Plaza**  
**401 Haddon Avenue**  
**Camden, NJ 08103**

*Magnus L. Nonpileptic uses of gabapentin. Epilepsia 1999;40 Suppl 6:S66-S74*

For decades, antiepileptic drugs (AEDs) have been used to treat a variety of nonepileptic conditions such as chronic pain, psychiatric disorders, and movement disorders. As indicated by recent published reports, gabapentin, a relatively new AED, is useful for treating a wide range of neurologic and psychiatric conditions. Although its exact mechanism of action has yet to be determined, gabapentin is likely to have multiple effects. Unlike conventional AEDs used to treat nonepileptic disorders (e.g., carbamazepine, phenytoin, valproate) gabapentin offers the advantages of low toxicity and a favorable side-effect profile. The largest area of nonepileptic use of gabapentin is

neuropathic pain, in which it has demonstrated efficacy in treatment of postherpetic neuralgia, diabetic neuropathy, and trigeminal neuralgia. It has also been reported effective as therapy for several psychiatric disorders, most notably bipolar disorder. In addition, review of the published literature reveals the usefulness of gabapentin in movement disorders, migraine prophylaxis, and cocaine dependence. Future clinical studies will provide further insight into the range of conditions for which gabapentin is effective.

**Dr. Leslie Mangus**  
**Parke-Davis, Division of Warner-**  
**Lambert Company**  
**201 Taber Road**  
**Morris Plains NJ 07950**

## New RLS Foundation Board Member – Peter K. Brooks

After working for nearly thirty years in New York City with J.P. Morgan & Co., Incorporated, in 1995 I elected to take early retirement and relocated to the Monterey Peninsula in Central California. My early retirement decision was heavily influenced by my RLS symptoms, which began in 1992; RLS was dramatically affecting my alertness, as well as making reading and travel extremely difficult. Fortunately, under the supervision of Columbia-Presbyterian Hospital's Dr. Neil Kavey, who formerly served on the RLS Foundation's Medical Advisory Board, I have been able to better cope with my RLS symptoms. Thanks to a medicinal "cocktail" program, which includes Mirapex, Neurontin and Darvon, I can again lead a productive life.

My "second career" in the West is quite different from my New York

banking experience. Largely as a result of first inheriting RLS and secondly being rescued from the hell that is untreated RLS, I find that I have chosen to focus much of my attention on several non-profit volunteer activities. I am actively involved in Development work with the Chartwell School, a local school for Dyslexic children, and I also serve as Financial Advisor to the Carmel Art Association, the nation's second oldest collective gallery, which represents over 120 artists. Additionally, I am pursuing a career as a painter (Abstract Expressionism, not houses) and am very excited by the challenges that painting presents. All this activity hardly leaves any time for occasional necessary rounds of golf in this golfers' paradise. If there's any "silver lining" to my RLS, the stimulation I'm getting from these new activities is most rewarding.

My wife, "Incy" and I have been married 33 years and we have two children Peter, Jr. (27) and his new bride, Jennifer, live in San Francisco and our daughter, Holly (23), lives in Boulder, Colorado.

My education includes St. Paul Academy (1963) and the University of Minnesota (1967). I was born in Minneapolis and lived in Minnesota before relocating to New York in 1967.

I'm looking forward to serving on the RLS Foundation Board, and am particularly interested in helping in the area of Development.



*Peter K. Brooks*

## Word from the Doctors

### RLS at the World Federation of Sleep Research Societies

*Third International Congress  
Dresden, Germany Oct 5-9, 1999*

Richard Allen, PhD  
John Hopkins University Medical Center

This premier world congress for research on sleep and sleep medicine meets every 4 years. At the inaugural meeting in Cannes, France, in 1991, RLS was barely mentioned, but the second meeting in the Bahamas in 1995, included several presentations and a lively focus group on RLS. This year's meeting was the first time a scientific symposium on RLS was held, and another lively focus group and several presentations also took place. Dr. Hening chaired the symposium, entitled "Multiple approaches to the pathogenesis of the restless legs syndrome." The very fact that we now have enough scientific information to have a symposium on the pathology of RLS indicates how much progress has been made in the last 4 years.

Dr. Hening reviewed the data relating RLS symptoms to circadian variation (changes across the day) and in particular noted the relation between symptom severity and body temperature. The regularity of the daily fluctuations in symptoms remains one of the defining characteristics of RLS, but the brain mechanisms producing this variation are essentially unknown.

Genetic studies on RLS have been very limited. Dr. Guy Rouleau presented both an overview of what is known and the plans his group has for conducting linkage analyses on selected families from Quebec where there appears to be a high prevalence of RLS.

Brain imaging studies reviewed by Dr. Thomas Wetter continue to show some small deficits in the dopamine system and brain

structures controlling integration of movement and sensation.

Dr. Richard Allen presented the data showing reduction in brain iron in RLS patients. He argued these finding could be causing both the dopamine abnormalities and the daily variation in symptoms.

Drs. Allen and Hening chaired a focus-group discussion "The restless legs syndrome: advances and controversies," which was scheduled to meet for two hours from 8 to 10 PM, but this standing-room-only crowd stayed to nearly midnight before exhaustion quelled the lively discussions. This level of participation reflects the intensity of the developing scientific and clinical interest in RLS. In this session, several of the leading experts discussed major issues, including periodic leg movements, occurrence of neuropathy with RLS, treatment options and advances, diagnostic procedures, evaluating severity of symptoms, primary vs. secondary RLS, magnesium, iron and special populations with RLS.

A special guided tour covered most of the poster presentations on RLS, including at least 11 by experts from around the world who have been studying this condition. The topics included periodic movements, brain imaging, family genetic studies, arm restlessness, treatment outcomes, and a good study documenting the marked impact of RLS on quality of life. The decreased quality of life is well known by those who suffer the disorder, but is not generally appreciated by either clinical doctors or government funding agencies.

RLS research continues to grow and attract worldwide attention of clinical and basic scientists.

### The Treatment of Restless Legs Syndrome and Periodic Limb Movement Disorder

*Practical Parameters*

Andrew L. Chesson, Jr. M.D.  
Louisiana State University Medical  
Center, Shreveport

The American Academy of Sleep Medicine (AASM) has a process for developing evidence-based medical guidelines for doctors. When the AASM Board of Directors identifies an area about which it feels guidance is needed for physicians, this is turned over to the AASM Standards of Practice Committee (SOP) for the development of an evidence-based practice parameter. A task force is appointed, generally consisting of experts in the field, as well as members with special expertise that may be needed. This group is commissioned to search out and review the available literature to become familiar with the best peer-reviewed, published evidence available. Dr. Hening's accompanying article describes that process.

The SOP Committee, taking the evidence provided, determines what part of that data is directly applicable for caring of patients and to the practice of sleep medicine. They then formulate recommendations for topics related to diagnosis and/or treatment (in this case for RLS and PLMD [see Figure 1, page 11]), and indicate the level of the evidence establishing how strong the nature of the recommendation should be. With the AASM SOP process the recommendations are usually noted as standards, guidelines or options. A standard indicates that something is a relatively expected level of care. A guideline indicates that the evidence is fairly strong supporting the use of that treatment, with a physician then trying to decide which of the potential recommendations is most

**Figure 1. Practice parameters for the treatment of restless legs syndrome and periodic limb movement disorder. An American Academy of Sleep Medicine Report. Standards of Practice Committee of the American Academy of Sleep Medicine.**

*Chesson AL Jr, Wise M, Davila D, Johnson S, Littner M, Anderson WM, Hartse K, Rafecas J. Sleep 1999;22:961-968*

These are the first clinical guidelines published for the treatment of Restless Legs Syndrome (RLS) and Periodic Limb Movement Disorder (PLMD) providing evidence-based practice parameters. They were developed by the Standards of Practice Committee and reviewed and approved by the Board of Directors of the American Academy of Sleep Medicine. The guidelines provide recommendations for the practice of sleep medicine in North America regarding the treatment of RLS and PLMD. Recommendations are

based on the accompanying comprehensive review of the medical literature regarding treatment of RLS and PLMD which was developed by a task force commissioned by the American Academy of Sleep Medicine. Recommendations are identified as standards, guidelines, or options, based on the strength of evidence from published studies that meet criteria for inclusion. Dopaminergic agents are the best studied and most successful agents for treatment of RLS and PLMD. Specific recommendations are also given for the use of opioid, benzodiazepine, anticonvulsant, and adrenergic medications, and for iron supplementation. In general, pharmacological treatment should be limited to

individuals who meet diagnostic criteria and especially who experience insomnia and/or excessive sleepiness that is thought to occur secondary to RLS or PLMD. Individuals treated with medication should be followed by a physician and monitored for clinical response and adverse effects. It would be desirable for future investigations to employ multicenter clinical trials, with expanded numbers of subjects using double-blind, placebo-controlled designs, and an assessment of long-term response, side effects, and impact of treatment on quality of life. Evaluation of special groups such as children, pregnant women, and the elderly is warranted.

applicable to their specific patient. An option provides a suggestion, which is up to the physician to use or not as he or she feels as most appropriate for an individual patient.

The practice parameters on the treatment of RLS and PLMD also have been formulated into a flow chart to help more easily identify the various levels of recommendations available for the physicians.

The principal benefit of this AASM two-part process is that it allows evidence to be well outlined in the review paper. The review paper data are then formulated into recommendations relevant to patient care and the recommendations are prioritized. Of course, each individual patient is different and has special needs and circumstances, so the ultimate decision needs to be made by a physician who is familiar with not only the medical disorder, but also their own individual patient. The physician, together with the patient, can make the best choice for the optimal balance

between benefits and potential complications or problems.

Lastly, the practice parameter addresses what new research is warranted to be helpful for the group of patients who have the disorder. It is exciting to see that new information about RLS and PLMD is coming out on a regular basis and that some of the recommended research is in fact being proposed for funding already and, hopefully, will have sufficient funding to permit scientists to answer many of the questions about this disorder. That in turn will then be translated into more effective practice parameters for patient care.

#### **A Review**

**Wayne Hening, MD, PhD**  
Robert Wood Johnson School of Medicine

The American Academy of Sleep Medicine's evidence-based review and practice parameters for the treatment of RLS and PLMD mark a milestone in official recognition of the needs and treatment options of patients with these con-

ditions. The evidence-based review is a new tool that allows for an objective, scientific assessment of those treatments that do work (see Figure 2, page 12). It goes beyond mere anecdote and opinion and because it involves a survey of all the accessible literature, it is likely to be free of bias and relatively fair. It makes the reviewing physician think through his or her prejudices and assumptions and actually decide what really matters to patients and how benefit can be fairly assessed. However, it was perhaps no surprise that the RLS review found that the currently favored therapies, especially the dopaminergic agents (levodopa and the dopamine agonists), actually had the greatest basis in the literature. Of course, the task force that worked on this review also realized that the review process had some deficits. First, we had to terminate the review at a fixed date. As a result, we missed many of the more-recent papers, mostly showing

*Continued on next page*

**Figure 2. The treatment of restless legs syndrome and periodic limb movement disorder. An American Academy of Sleep Medicine Review.**

*Hening W, Allen R, Earley C, Kushida C, Picchietti D, Silber M. Sleep 1999;22:970-999*

A task force consisting of six authors reviewed the published literature on the therapy of the restless legs syndrome or periodic limb movements in sleep available in indices through April, 1998. They selected the 45 articles for detailed review which presented original investigations of therapeutic impact on the restless legs syndrome (RLS) or periodic limb movements (PLM)

and which met minimal standards. These articles dealt with a range of pharmacological and other treatment modalities, although most dealt with medications and almost half of those concentrated on dopaminergic agents, especially levodopa in various formulations. Almost half of the articles reviewed used controlled methodologies, most commonly cross-over methodologies with randomized allocation of subjects. Multi-center studies with large numbers of subjects and long-term controlled studies were not found.

Information was extracted from the articles and study design, clinical definition, evaluative measures, side effects, and outcomes were tabulated in 6 evidence tables and summarized in the accompanying text. This literature was evaluated for the nature of the studies performed and its coverage of potential therapies. The review concludes with comments on possible future directions for therapeutic investigation based on the current state of the literature.

*Word from the doctors—continued from previous page*

strong benefits, which concentrated on the dopamine agonists. Second, some treatments in the literature, such as carbamazepine and sclerotherapy, have either fallen out of favor or never been studied independently. As a result, even though the task force was skeptical about their benefits, there were no studies to support that skepticism. Third, it is obvious that the therapeutic studies reported have concentrated on pharmaceutical products. While this may be a fair assessment of what does work, it may merely reflect the fact that there is available funding for studies of medications that may profit sponsoring companies. As a result, behavioral, nutritional, and other alternative therapies are not studied. Also, studies have clearly been largely short-term, single-agent trials, often of small numbers of patients. Long-term studies, comparisons of different agents, and large-scale studies have been missing. It will be a mission for all of us in the future to expand the possible studies into alternative therapies, long-term risks and benefits, comparisons of different agents, and restudy of agents which have been suggested to work, but are currently not used.

The RLS Foundation can help support this process of generating more and different research into treatment of RLS.

### **Polytherapy and Rotating Therapy**

[Editor's Note: In the last issue of *NightWalkers*, we published an article by Christopher Earley, MD, PhD, on this subject. Comments of other members of our Medical Advisory Board follow.]

**Barbara Phillips, MD, MSPH**  
University of Kentucky Medical Center

I also use rotating and polytherapy for patients with RLS. I almost always alternate Sinemet (carbidopa/levodopa) with something else (usually gabapentin) to reduce the chances of the patient developing rebound, augmentation, or both. In this situation, I use a week of one medication, and a week of the other.

Many patients get "some" but not total relief with initial therapy (usually a dopamine agonist). In those patients, I will add another medication, usually from the anti-convulsant group. I do not know if it is important to get to the "maximum" dose of the initial medication or not before adding a second drug. I think that rebound and augmentation are more likely to occur at

higher doses of the dopamine agonists. Adding a second drug early on may have some "dopamine-sparing" effects.

I also have some RLS patients who get relief of RLS symptoms with medication but still find themselves having difficulty falling asleep or staying asleep. I suspect that these individuals have "learned" (or psychophysiologic) insomnia. For all people (not just those with RLS) anything that disturbs sleep (such as pain, loss of a loved one, hospitalization) can lead to distress and anxiety about the ability to sleep. Attention becomes focused on worrying about whether or not they will be able to sleep, and this worry and anxiety can actually prevent sleep. In this situation, short-term use of sleeping pills, excellent sleep hygiene, and perhaps sleep restriction may be of benefit.

Sleep hygiene means going to bed and getting up at the same time; caffeine reduction or (even better) elimination; a quiet, cool, dark sleeping area; no working or worrying in bed; no nicotine or alcohol; no napping; and regular exercise. Restricting the time spent in bed to the time actually spent sleeping is also important. For example, if an individual has learned that he or she

can't fall asleep until 1 AM, it might be helpful to wait to go to bed until that time but to avoid sleeping later and later in the morning or napping. Sometimes rearranging the bedroom or even moving to a different bedroom can get the individual out of the environment where he or she has learned that sleeping is hard.

Benzodiazepines such as clonazepam are acceptable treatment for RLS and are also sleep-promoting. Adding them to the rotation may also help the sleepless RLS sufferer. I think the main thing is to keep trying!

**Claudia Trenkwalder, MD**  
Max-Planck Institute of Psychiatry

The treatment of the RLS seems to be quite difficult in severe

cases. The mild or moderate cases are not as difficult to treat in my opinion. If L-dopa fails, dopamine agonists, opioids or a combination of both can be a reasonable and long-term treatment.

In my experience, primary-care physicians are not able to provide patients with this kind of therapy in most cases, especially when they should combine various agents. Neurologists, too, often refuse to do combination treatment. These patients therefore are mainly restricted to specialized sleep centers or movement disorder centers.

I myself do not have any experience with rotating therapy, but I find the concept itself very difficult to practice, even though I am experi-

enced in treating RLS. It would mean seeing patients very often, almost weekly or twice a week for a long time, until the rotation is established. For primary care physicians or neurologists who are not experienced in treating RLS, I would not recommend this treatment at all.

Furthermore, I think we should first do some studies and see if rotating therapy works or if we get more placebo effects than the real effects of rotating treatment. Having no combination treatment studies, we will get into trouble recommending rotation therapy. In my RLS population there are some severe cases, but it would not justify recommending rotation therapy which I have never tried for RLS in general.

HONOR ROLL

*Sheila Connolly*

- from Juanita Therrell, for a job well done as Chair of the Board of Directors of the RLS Foundation
- from Frank Gillis, June Erickson, Ann Melanson, Harold McConnoughay, Carol Connolly, Linda McKenna, Edna Dodge, Jean Guenthner, Anita Raj, Mary Boulter, Clair Rivoire, Donald Smith, Don Boesen, Bobbie Kittredge, in honor of your work as our support group leader and chair of the RLS Foundation Board
- from Davida Wagner, in honor of your birthday
- from Richard and Barbara Carr, in honor of your birthday

*Dr. Arthur Walters*

- from Olga Morah, for the care given to my husband
- from Juanita Therrell, for service on the MAB

*Dr. Ehrenberg*

- from Juanita Therrell, for service on the MAB

*Dr. Picchiatti*

- from Juanita Therrell, for service on the MAB

*Dr. Chokroverty*

- from Juanita Therrell, for service on the MAB

*Dr. Stuart H. Isaacson*

- from Alice Stillman

*Dr. Richard Sheldon and Dr. Michael Sloan*

- from Mrs. Maurice Talley, in appreciation

*Dr. Frank Elaty*

- from Hazel Borzelleca, in honor of his dedicated service to his patients and the Orlando Florida RLS Support Group

*My friends and family*

- from Pamela Hagler

*Zada Hunter*

- from her daughter, Eilene Toughey

*Carol and Thad Walker*

- from Carol's brother Steve, Merry Christmas
- from Anne and Ken Upchurch, Merry Christmas

*Gretchen Smithey*

- from her husband, Walter, in honor of their 50<sup>th</sup> wedding anniversary

*Fran Greenlaw*

- from Judy Miller, Merry Christmas

*Carol Walker*

- from her husband Thad, Merry Christmas
- from her mother-in-law, Edwina Davis Walker, a small token of love at Christmas

*Edna Dodge*

- from Edith Spicer and Richard and Nancy Fitzgerald

*Bill Tunison*

- from the twins, Christine and Eric, Happy Birthday, Mom

*Dr. Jeffrey Thiele*

- from Barbara Thiele, Happy Birthday

## RLS Around the World

### Report from Switzerland

**Claudio Bassetti, MD, and  
Johannes Mathis, MD**  
University of Bern

The Swiss Restless-Legs Self-Help Association (SRLSA) was founded in 1985 by Mrs. Helga Mühle. At the foundation meeting, 12 members were present. Since 1985 national meetings have been held once a year. In 1993 Mrs. Martha Hofer became the president of the association. She has been assisted since 1986 by the vice-president Mrs. Anni Maurer. The SRLSA now has 120 members divided in regional subgroups (Zurich, Luzern, Aarau, Bern, Wil-St.Gallen and Basel) that organize regional meetings three times a year. The last general assembly of the SRLSA was held in Aarau on October 30, 1999. Since this date, the association is present on the Internet under the address [www.restless-legs.ch](http://www.restless-legs.ch).

Our sleep center is committed to the management of patients with RLS. Over the last few years we also performed a few research projects on RLS and PLMS.

This year we completed a prospective analysis of clinical features in 55 patients with RLS (Bassetti et al., submitted for publication). We found that the mean age at symptom onset was  $41 \pm 21$  years, and that in 27% of patients, RLS started before the age of 20. Sensory disturbances were described as *painful* in 56% of patients and localized in legs (98%), arms (35%), and internally (45%). Insomnia (58%) was more common than hypersomnia (24%). In 67% of patients, no etiology of RLS was found. These patients were significantly younger, more often had a positive family history for RLS, and complained less frequently of insomnia than did patients with a known cause of their RLS.

In a study of 19 patients with obstructive sleep apnea (OSA), we found two types of periodic limb activities according to their inter-movement interval (IMI) (Briellmann et al., Eur Neurol 1997). A longer IMI of about 54 seconds was noted in limb movements associated with respiratory events. In these patients, treatment with nasal CPAP (continuous positive airway pressure) typically reduced periodic limb activity. Conversely, a shorter IMI of about 38 seconds was recorded in limb movements independent of apneas and hypopneas that persisted under nCPAP. Based on these observations, we suggested that the persistence of PLMS under CPAP may be due to 1) residual upper-airway obstruction when the IMI of limb movements is long, or 2) non-respiratory facilitation of PLMs when the IMI of limb movements is short.

In a video-polysomnographic study of 20 patients with RLS we identified different presentations of PLMS (Mathis et al., Clin Neurophysiol, in press). In most patients, movements corresponded to a Babinski-like extension of the great toe. Occasionally, movements of the whole leg resembling a triple flexion response were observed. Less commonly, we observed a third pattern with combined leg-arm movements resembling a locomotion pattern. In patients with RLS, we have recently reported the high frequency also of periodic stereotyped flexion-extension tremor-like activities of the foot (Bassetti et al., Clin Neurophysiol, in press).

In the near future, we are planning research on the pathophysiology of RLS (with Professor Anna Wirz-Justice, Basel, Switzerland) and on the treatment of RLS with non-dopaminergic drugs (with Dr. Matthias Gugger, Bern, Switzerland).

land). During the coming year we are also scheduling a workshop on RLS at the national level to increase awareness and knowledge in our country of RLS among non-sleep specialists.

### International RLS Groups

The following independent groups, located outside of the US, work in cooperation with the RLS Foundation.

#### AUSTRALIA

Warriewood  
Sleep Disorders Australia  
Beverley Yakich  
02-9415-6300

#### CANADA

Sleep/Wake Disorders Canada  
1-800-387-9253 (in Canada)  
416-483-9654

#### ENGLAND

Thorpe Bay, Essex  
Ekbom Support Group  
Eileen Gill  
01-702-582-002

#### GERMANY

Munich  
Deutsche Restless Legs Vereinigung  
Max-Planck Institute  
Claudia Trenkwalder, MD  
089-30-62-2585  
Hans Wienecke  
089-55-02-8880

#### HOLLAND

Amsterdam  
Dutch RLS Foundation  
Marleen Schipper  
(0)299-435194  
M.F.Schipper@flash.A2000.nl

#### NEW ZEALAND

Nelson  
Convenor of Richmond  
RLS Support Group  
Moira Robinson  
64-3-544-6312

#### SWITZERLAND

Zurich, Wil, Aarau  
Support Group Switzerland  
Anni Maurer  
056-2825403  
Marta Hofer  
01-9233709

## Book Review

Reviewed by: Michael Polydefkis, MD, Johns Hopkins University School of Medicine

**John A. Senneff**

MedPress, PO Box 691546,  
San Antonio, TX 78269

**N**umb Toes and Aching Soles: Coping with Peripheral Neuropathy is written by a peripheral neuropathy patient for other peripheral neuropathy patients. As the title suggests, the book focuses on peripheral neuropathy (PN) and mentions RLS only in passing. It is divided into sections that center on diagnosis, conventional treatments, and alternative treatments. The author, John Senneff, does an excellent job of explaining in layman's terms the vocabulary of peripheral nerve disease, diagnostic tests, and the rationale behind the tests. This in itself makes the book valuable reading for people with PN. Peripheral nerve disease is a specialized field, with a terminology that can be daunting for patients. Mr. Senneff's explanations are straightforward and accurate.

Treatment options for PN and PN pain are the focus of most of the book. The evidence behind the most commonly used PN medications is systematically reviewed. In addition, numerous patient testimonials from Internet bulletin boards, forums and newsletters are included. Mr. Senneff again does an excellent job explaining the treatment options, their rationale and side effects. Taken together, the patient testimonials make it clear that not all medications work for all patients and it often takes time and patience to arrive at the correct dosage and dosing schedule. It is often a matter of trial and error, and the author correctly stresses that effective doctor-patient communication is essential. Although the author repeatedly gives the disclaimer that testimonials should not be taken as evidence of proof, I fear patients who read the book may be tempted

to give up on a medication or treatment too quickly, hoping for a "silver bullet" with another medication. Another minor criticism is that in summarizing scientific evidence behind a given medication, the author assigns equal importance to a well-controlled study (double-blind placebo) and a series of case reports. The chapter on alternative treatments is useful as a source of information; however I agree with Dr. Wolfe's comments in the foreword where he cautions patients about alternative therapies that are exorbitant in cost or claims of effectiveness. I personally feel there is no role for such alternative treatments as chelation therapy or hyper-

baric oxygen in treatment of PN, but for those patients that have questions about these or other treatments, they are presented objectively. With these small caveats, I believe the treatment sections of the book are a valuable and accurate reference for neuropathy patients.

In summary, I find Mr. Senneff's book an excellent source of information for people with PN. It is easy to read, up to date, and accurate. There is not much mention of RLS other than to say many RLS patients have PN. However, I would enthusiastically recommend it to PN patients as well as those RLS patients with PN.

## Memorials

The RLS Foundation is sincerely grateful for the donations that we have received in memory of the following people.

<i>Margaret Baeremwald</i>	<i>John Lingl</i>
<i>Raymond T Bitley</i>	<i>Isolia Marty</i>
<i>Phillip N. Brownstein</i>	<i>Harold McGuigan</i>
<i>Arthur J. Bearss</i>	<i>Harold Meerdink</i>
<i>William Buckham</i>	<i>Al Merkel</i>
<i>Laura Buswell</i>	<i>Leona Meyer</i>
<i>Rhoda Cochran</i>	<i>John Morah</i>
<i>Charles Donachie</i>	<i>H. O'Reilly</i>
<i>Dr. James Byron Dumm</i>	<i>Lila Sales</i>
<i>Eleanor Derbyshire</i>	<i>Jeanne Schell</i>
<i>Helen Foreman</i>	<i>Harold Shapiro</i>
<i>Phyllis Frum</i>	<i>Frances Shields</i>
<i>Lucille Stidham Hooker</i>	<i>Gertrude Simpson</i>
<i>Richard E. Kaufmann</i>	<i>Florence Wray</i>
<i>Thelma Leffler</i>	<i>W. Kurt Wohlert</i>
<i>Estelle Levin</i>	

We extend our sympathy to the families and friends of those who have passed away and wish them comfort in their loss.

## Why I Started A Support Group

By Connie Clark, Southeast Nebraska Support Group Leader

I started a support group because RLS is the most disappointing, bewildering, lonely, and stubborn malady I've ever experienced.

Disappointing—because just when I'd think my workday had ended and it was my time to rest, RLS would sneak up like a thief after the family silver, and poof, no more rest. (Disappointing, also, because the prescription I spent so much on only worked for a few nights.)

Bewildering—because until recently, RLS was not just misunderstood, but in the minds of many, it didn't exist at all! Yet, there I was, stumbling around the house in my half-sleep, sedated and tranquilized because the doctor could only guess I had "stress" (he was right about that), knowing I had a job to go to and a family to care for, and feeling every sleepless hour eat into tomorrow's energy.

Lonely—because between 1961 and some time in the 1970s, I never heard of anyone else experiencing the symptoms I lived with night after night. It was only after reading a magazine article that I discovered my misery had a name, although no treatment or cure was then known. Lonely, also, simply because of the

experience of wandering around the house awake night after night while my family slumbered peacefully away. Lonely, too, because it's so hard to describe to the unafflicted, it's often easier to simply suffer in silence.

Stubborn—because it's often so hard to treat. Yes, we do have medications today that help, but they're not consistently reliable or effective for all, and for many the side effects are worse than the syndrome. Most of the time Mirapex, and the occasional Sinemet, works fine for me, but I can count on several nights a month just like the "old days" to keep me humble.

Further, since I began to learn about RLS, thanks to the Foundation, my husband, Bob, has been successfully treated for PLMD, which began in 1996, and was rapidly destroying his health. We've also realized that several other family members (two daughters and Bob's mother) have experienced RLS, PLMD, or both. How many of our grandchildren will be victims? I wonder.

Well, I'm stubborn, too. And I refuse to be a lonely martyr, suffering my disappointments in silence.

Support groups for other problems have changed and improved my life beyond all expectations, why wouldn't a support group for RLS do the same thing? I believe that "what goes around comes around" and that if I share my experience, strength, and hope with others with RLS, those positives will come back to me many times over. That's already proven to be true, just from the few months I have spent organizing and holding SE Nebraska's first support group meeting. The people who have called, written, and attended the meeting have given me far more than I can ever give them.

Besides those benefits, I believe it will take all of us together to promote and find a cure for RLS and PLMD. I know a little about it from my own experience; you know more about it from yours. Alone, a cure is impossible. However, when we cooperate by combining the RLS and PLMD experiences of every Jane and John with the discoveries of our physicians and researchers, a cure is inevitable. For the sake of our grandchildren, let's work together to make it soon.

### RLS Support Group Network

#### ALABAMA

*Shoals Area Support Group*  
Coretha Downs  
256-247-3171  
Maxine Crouch  
256-446-5317

#### ARIZONA

*Scottsdale Support Group*  
Lynne Gessner  
480-947-0009  
lgess@doitnow.com  
Joan Schebler  
480-949-9918

#### *NW Valley Support Group*

Loretta DeSandro  
602-584-5608  
lordes@inficad.com  
Bette Silcott  
602-546-1973  
elad@aol.com

#### ARKANSAS

*Hot Springs Village Support Group*  
Enid Scripture  
501-922-0049  
escriptu@msn.com

#### CALIFORNIA

*San Diego Support Group*  
Sharon Burley  
858-558-7681  
sburley@webtv.net

#### *Oceanside Support Group*

Jeanette Speake  
760-940-0487  
Lou Engel  
760-439-4093

#### *San Francisco Peninsula Support Group*

Gretchen Smithey  
650-401-8026

Joanne Bellan  
415-664-2366  
*RLS Support Group (East Bay) San Francisco*  
Dori Davi  
925-837-7711

*Orange County Support Group*  
Hetty Olwin  
714-962-0578

#### *California Central Coast Support Group*

Sue Arzouman  
805-534-0734  
jimsuearzouman@email.msn.com

#### *Inland Empire Support Group*

Grace Ruggles  
909-887-3732  
Mary Petri  
909-792-1794

#### *Southern California Support Group*

Elizabeth L. Tunison  
562-699-4917  
tuni22@aol.com

#### COLORADO

*Denver Support Group*  
June Sheridan  
303-344-4964  
Marge Fuhr  
303-494-4913  
DDFuhr@aol.com

#### CONNECTICUT

*Southern Connecticut Support Group*  
Patty Yurkas  
203-327-5729  
yurkas@ibm.net  
Reggie Springer  
203-324-5733  
rcs4pas@aol.com

**CYBERSPACE**

Jodi Judson  
jmjudson@bellsouth.net

**DELAWARE**

*Eastern Shores Support Group*  
Bonnie Wise  
410-208-2810  
Micki Buck  
410-749-5911

**FLORIDA**

*Broward County Support Group*  
Lillian Kaufman  
954-724-0438  
lillian00@webtv.net

*Lower Pinellas Co. Support Group*  
Virginia G. England  
813-518-6200  
v.g.english@juno.com  
*Palm Coast Support Group*  
Charlotte M. Schultze  
904-445-7158  
schatzie@pcf.net

*Central Florida Support Group*  
Barbara Stock  
407-629-8791  
brstock@aol.com

*Sarasota/Manatee Support Group*  
Thelma Bradt  
941-359-6398  
tbradt@mindspring.com

*South Florida Support Group*  
Jeanne Kalish  
561-495-1555  
Joy Kahn  
561-488-4557  
JoyB222@aol.com

**GEORGIA**

*Atlanta Support Group*  
Dick Hawkins  
770-938-4709  
klichawk@mindspring.com

**ILLINOIS**

*Northern Illinois Support Group*  
Nancy Yang  
847-244-0180  
nancy2@aol.com

**IOWA**

*Central Iowa Support Group*  
Delila Roberts  
515-597-2782  
Elaine Tucker  
515-388-4736

**KANSAS**

*Eastern Kansas Support Group*  
Barbara Wacker  
913-682-4537  
bwcol@1vnworth.com

**LOUISIANA**

*Capital Area Support Group*  
John B. Williams  
504-344-3767  
jbeardenw@juno.com

**MAINE**

*Restless in Maine*  
Karlene Fenderson  
207-777-8580  
karlene@exploremaine.com  
Theodore Beaudoin  
207-783-3151

**MARYLAND**

*Baltimore Area Support Group*  
Patricia Sarratt  
410-879-6943  
psarratt@earthlink.net  
Beatrice Weitzel  
410-254-4456

**MASSACHUSETTS**

*RLS Support Group of Massachusetts*  
Carol Connolly  
781-641-1104  
carol.connolly@simmons.edu  
Sheila Connolly  
508-790-7640  
sfconnolly@capecod.net

**MICHIGAN**

*Oakland County Support Group*  
Shelly Skelton  
248-682-7228  
shelskel@juno.com

*Greater SE Michigan Support Group*  
Jan Prentice  
734-453-4847  
ackiepen@aol.com

*Western Michigan Support Group*  
Neva Warsen  
616-532-1698  
nmwarsen@aol.com

**MINNESOTA**

*SW Minnesota Walkers*  
Rosewitha Seltz  
320-587-7047  
scountry@hutchtel.net

**MISSOURI**

*St. Louis Support Group*  
Hanne Spence  
314-487-0370  
hmspence@artsci.wustl.edu

**NEBRASKA**

*Greater Omaha Support Group*  
Linda Sieh  
402-832-5321  
lorensieh@hotmail.com  
Joan Sulentic  
712-566-2668

*Southeast Nebraska RLS Support Group*  
Connie Clark  
402-474-5632  
cow\_boy@inebraska.com

**NEVADA**

*Southern Nevada Support Group*  
Leeann & John Felbaum  
702-294-0540  
SouthernNevadaRLS@hotmail.com

**NEW HAMPSHIRE**

*Granite State RLS Support Group*  
Fran Blakeney  
603-225-2103  
GraniteStateRLS@aol.com  
*Nightwalkers of Kendal*  
Madith Hamilton  
603-643-2135

**NEW MEXICO**

*Albuquerque Support Group*  
Don Tryk  
505-856-6690  
Dtryk@msn.com  
John Isaminger  
505-293-6723

**NEW YORK**

*Manhattan Support Group*  
Marilyn Sachs  
212-684-0565  
marilynosp@aol.com  
*Central New York RLS Support Group*  
Vincent Lucid  
315-668-8620  
DrSpeedbump@email.msn.com  
*RLS/PLMD of Long Island Support Group*  
Carol & Bob Germann  
516-735-2295  
PLMSRLOfLI@aol.com

**NORTH CAROLINA**

*Greater Western North Carolina Support Group*  
Doris Walston  
828-668-7180  
dww@icu2.net  
*Restless in Raleigh*  
Amelia Lewellen  
919-847-7506  
rlwellen@mindspring.com

**OHIO**

*Southwestern Ohio Support Group*  
Jan Schneider  
937-429-0620  
Janmsch@aol.com

**OREGON**

*Portland Support Group*  
Cynthia Edwards  
503-297-1932  
*Salem Hospital Support Group*  
Delores Johnson  
503-370-5170

**PENNSYLVANIA**

*Greater Philadelphia Support Group*  
Edwin & Kathryn Overman  
610-688-5540  
*Lancaster Support Group*  
Sally Bair  
717-397-2618  
*SOUTH CAROLINA*  
*Midlands Support Group*  
Joan Waln  
803-356-3444

**TEXAS**

*Greater Houston Support Group*  
Carolyn Achee  
281-361-7366  
Helen Simons  
713-468-4192  
hmsimons@aol.com

**VERMONT**

*Southern Vermont Support Group*  
Eleanor Powers  
802-824-5093  
Patty Arthur  
804-384-9013  
pararthur@aol.com

**VIRGINIA**

*Central Virginia Support Group*  
Pamela Hamilton-Stubbs, MD  
804-273-9900  
phstubbs@hsc.vcu.edu  
*Lynchburg Area Support Group*  
Pollyanna B. Middleton  
804-384-3216  
ARTANdPB@aol.com

**WASHINGTON**

*Olympia Night Walkers*  
Kim Chase  
360-493-7436  
*Spokane Area Support Group*  
Gene Sivertson  
509-448-8424  
Eleanor Jones  
509-326-1816  
*Tacoma Area Support Group*  
Marian Cooter  
253-582-1069  
rlstacwa@yahoo.com

*Central Washington Support Group*  
Ray Gilbert  
509-662-0156  
rmg31118@aol.com

**RLS Support Group of Seattle & Vicinity**

Juanita W. Therrell  
425-746-6295  
Becky Christie  
206-525-8655  
Beckyc@u.washington.edu  
Susan Bean  
425-885-2604  
suzybean@msn.com

**WISCONSIN**

*Fox Cities Support Group*  
Maxine Welhouse  
920-733-4579  
*Madison Support Group*  
Roger Backes  
608-276-4002  
roger.backes@mh.cdc.org  
Jim Albertson  
608-251-6347

## Bedtime Stories

**B**edtime Stories are the opinions of the authors only and not of the RLS Foundation, its employees, or the Board of Directors. Publication in the *NightWalkers* does not imply endorsement by the RLS Foundation. Stories may be altered for length or clarity.

**I** am joining the ranks of the sufferers of RLS who consider pramipexole (Mirapex) a miracle. I read about it in the August 1998 *NightWalkers* newsletter and later letters from individuals who had luck with it.

I asked my primary care doctor for Mirapex and he prescribed 1 mg. once a day for me. I found that a tablet one hour before bed time was enough. I haven't had any more RLS at all.

I had been taking 3 doses of Sinemet and permax a day without much relief. I was only getting 4 or 5 hours of sleep a night. I would walk the floor at night or go in the kitchen and make a batch of yeast rolls or some cookie dough to put in the fridge to be baked later. I have had a severe case of RLS for the last 7 years and a mild case for 40 years. I am 83 years old.

I really appreciate the *NightWalkers* newsletter for keeping us informed.

*Grace Allbright  
Orange, Texas*

**I**n response to Barbara Phillips, M.D. MSPH on the use of opiates: I am a 72-year-old male, a retired dentist. I have had RLS (not leg cramps) for thirty years. I do not smoke, drink, am not overweight and exercise moderately. Also, I believe I have tried every medication I have seen in print.

Because I'm a dentist, I would never try a narcotic because of my experience with addicts that asked me for prescriptions.

About twenty years ago my physician arranged for me to spend a night at the Stanford Sleep Clinic. I was a pincushion with probes and instruments all night.

The following morning, the neurologist, after going through all the paper tracings, pronounced he knew what my problem was, but didn't know how to treat it.

The neurologist gave me a prescription for Klonopin and something else. The Klonopin worked great for maybe five months, and then nothing. Later, I journeyed to Vancouver, British Columbia, and obtained a prescription for a drug similar to Sinemet. That helped for a while. Again I called upon Stanford for help. They suggested Percodan. This was very effective for six months, then tapered off. The next ten years I suffered through with Percodan and Sinemet with limited success. In 1994 I had back surgery. While in the hospital, I had access to a morphine drip and to my delight, no RLS problem. Upon release from the hospital, I consulted with my internist about the continuation of the morphine. Naturally, he was hesitant but agreed to let me try M.S. Contin, 15 mg. twice a day. He made it clear that he would not agree to increasing the dosage. I am pleased to report that as long as I don't forget my medication, I can stay in bed all night. It has changed my life. Morphine is known to be addictive, but I have taken Percodan for fifteen years (one a day) and now morphine for four and one half years and exhibit absolutely no signs of addiction. I receive no more euphoria from either than a plain aspirin. No side effects. If I mistakenly take a second Percodan after 5 p.m. I will be awake all

night. At age 72, I would not go back to what I used to go through. At least for older people, opiates may have a great place in their lives. Unless one experiences a bad case of RLS, no one can appreciate how desperate a person can get. I can handle my back pain, but not RLS.

*Wil Bline, DDS  
Anchorage, AK*

**T**he November newsletter came just in time to help me. My RLS symptoms always increase with the change of seasons. I spend almost a week with little sleep and spend most of the nights walking the floor.

When reading about the two new medicines, I asked my doctor if one of them might work for me, as my old medicine was not doing the job. I got started taking 0.25 mg of Requip three times a day. The first night I had taken two pills and had no leg pains. It has been that way for over two months. This is the longest relief for me in over 50 years. I am only getting 3 to 4 hours of sleep at night, but it is much better than the one-half hour to 1 hour I had been getting for a long time. I will soon take a long trip by car and will see if I have any problems. I will take each day as it comes and hope that this medicine will work for a long time.

*Beverly Kelling  
Hayward, WI*

*Continued on next page*



I wanted to share with your readers something that has helped me combat PLMD.

First let me say that I am a physician, retired, 67 years old. I had RLS for many years but that seems to have improved markedly with age. The PLMD however has not, and in fact seems to be getting worse. When I was in medical school, we never heard RLS mentioned. In fact I had been in practice several years when I heard it discussed at a medical meeting. What a revelation it was! So that's what I have had all these years!

My nights were really making my life miserable because of the PLMD until I hit upon the idea that I will describe. The first time I am aroused by the leg sensations, which is generally around 1 a.m., I make myself get up, go to an open doorway, stand about three feet away from it, place a hand on each side of the door frame about shoulder high, and lean forward, keeping my feet flat on the floor and my legs and body straight. I maintain this position as long as possible, maybe even back up a little more or bend my elbows some. The keys are to keep the feet flat on the floor, hold the position long enough (or repeat it several times), and feel an intense stretching of the calf muscles.

This works great for me (except on the rare occasion when the sensation is in the thigh muscles instead of the calves). Before I hit upon this maneuver, I used to endure those crawly feelings half the night, but this seems to stop it, although occasionally I have to repeat the process later. I have never talked to anyone else about doing this, so I don't know what kind of success rate it would have. Try it.

John Wanamaker, MD  
Hamburg, Iowa

# RLS Foundation Publications

## MEMBERSHIP

In addition to knowing that their membership contributions help to support the research and education efforts of the RLS Foundation, members also receive *NightWalkers*, the Foundation's quarterly newsletter; enrollment of their healthcare providers in the Foundation's education program; and free shipping and handling on all books, brochures, articles, and videos. (\$25, US; \$30, Canada; \$40, other international)

TOTAL

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## BROCHURES

**Living with Restless Legs:** This booklet—written for those with RLS, family members, and others in search of more information about RLS—highlights the symptoms and treatments and identifies secondary causes of RLS. (©2000) [Single copy free to members.]

\$ \_\_\_\_\_

**Medical Bulletin and Bibliography:** This material is intended for professionals and is mailed free of charge upon request to members' healthcare providers. (©1999) [Single copy free to members.]

\$ \_\_\_\_\_

**WeTalk: The We Move Web-chat Newsletter:** This material contains a transcript of an on-line session from November 1998, when Drs. Richard Allen and William Ondo answered questions about RLS. (©1999) [Single copy free to members.]

\$ \_\_\_\_\_

## ARTICLES

**NightWalkers: Victims of a Hidden Epidemic** by Robert H. Yoakum: Written by an RLS Foundation Board member, this article was published in the November/December 1998 issue of the *Saturday Evening Post* and is a satirical and informative look at living with RLS. (©1998) **\$5.00 each**

\$ \_\_\_\_\_

**Restless Legs Syndrome: A Disease in Search of an Identity** by Sudhansu Chokroverty, MD, and Joseph Jankovic, MD: This article, from the March 1999 issue of *Neurology*, presents an overview of the malady. (©1998) **\$9.00 each**

\$ \_\_\_\_\_

## VIDEOS

**Medical Answers** This PBS special's featured guest, RLS specialist Dr. Richard Allen, answered questions from callers in the Baltimore area during the hour-long program. (©1998) **\$27.95 each**

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**Meet the RLS Foundation:** This 45-minute panel discussion, led by Elizabeth Tunison of the Southern California Support Group, focuses on the roles of the Foundation's staff members, the future of the Foundation, and the direction of RLS research. (©1999) **\$9.00 each**

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## BOOKS

**The Promise of Sleep** by William C. Dement, MD, PhD, & Christopher Vaughan: According to RLS Foundation Board member Karen Lazarus, "This scientific book, with various stories of sleep studies done over the past 40 years, reads like a novel." (©1999) **\$24.95 each**

\$ \_\_\_\_\_

**Sleep Thief—Restless Legs Syndrome** by Virginia N. Wilson, with Arthur S. Walters, MD, ed: Written by one of the founders of the RLS Foundation, this book contains both a lay perspective of living with RLS, as well as professional essays from a variety of medical experts. (©1996) **\$16.95 each**

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## Everything You Want to Know About RLS . . . But Don't Know Whom to Ask

Join us to listen to the RLS experts discuss their most recent research findings. Several members of the RLS Foundation's Medical Advisory Board will be attending the 52<sup>nd</sup> Annual Meeting of the American Academy of Neurology in San Diego this spring, and at the invitation of the RLS Foundation, have agreed to present an RLS education program just for you.

This world-renown group will convene on Sunday, April 30 from 1:00 - 5:00 p.m. at the San Diego Concourse and will include Richard P. Allen, PhD, Johns Hopkins University School of Medicine; Charles Adler, MD, PhD, Mayo Medical Center - Scottsdale; Wayne A. Hening, MD, PhD, UMDNJ-Robert Wood Johnson Medical School; William Ondo, MD, Baylor College of Medicine; Michael Silber, MB, ChB, Mayo Medical Center - Rochester; and Arthur S. Walters, MD, UMDNJ-Robert

Wood Johnson Medical School. J. Steven Poceta, MD, Scripps Clinic and Research Foundation, will serve as our moderator.

Following the meeting will be a question-and-answer session. We won't be able to take questions from the floor, but you are invited to submit your question at the time of registration or in writing at the meeting. We are able to bring this meeting to you at no charge, but we need to know if you are coming so that we can reserve a spot for you. Brochures containing registration information will be available from your nearest support group leader or from the Foundation office in mid February. Please contact Cindy Stier to reserve your spot (507-287-6465 or e-mail at [stier@rls.org](mailto:stier@rls.org)). A block of hotel rooms has been reserved and will be available on a first-come, first-served basis.

## Dinner With the Doctors

Following the education meeting, you will have a unique opportunity to continue the discussion with these RLS experts in a small-group setting. Each physician will host a table of 8 to 10 people for dinner at Rainwaters at 6:00 p.m. Cost of the meal is \$50 and seating is limited. RSVP by **April 21, 2000**, to Cindy Stier at the RLS Foundation.



Restless Legs Syndrome Foundation  
819 Second Street SW  
Rochester MN 55902-2985  
Address Service Requested

Nonprofit  
U. S.  
Postage Paid  
Permit #287  
Rochester, MN