

# NIGHTWALKERS

*In search of a good night's sleep*

**Winter 2023**

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## From the Director

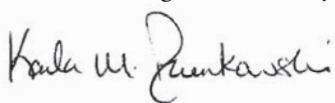
The RLS Foundation is planning for 2023, and we are excited to highlight some of the upcoming activities we have prepared for you. In December, the Foundation announced a new funding opportunity for projects that promote research to further our knowledge and understanding of RLS. The RLS Foundation will fund up to \$50,000 for a well-qualified proposal. Our goal is to fund the Foundation's 50th research grant this summer. A special note of thanks to RLS Foundation members who have supported the RLS Foundation Research Grant Program over the past 25 years in the search for better treatments and a cure. Your gifts have led to advances in our understanding of genetics, iron regulation, neurophysiology, epidemiology, dopamine, treatments, and animal model development. And the Foundation has also funded three unique initiatives: a study identifying the economic burden of RLS, the National RLS Opioid Registry, and the RLS Foundation's Brain Bank at the Harvard Brain and Tissue Resource Center.

Spring will be a season of advocacy for all who live with RLS. The RLS Foundation will be on Capitol Hill to visit with legislators and agency officials about the need for inclusion of RLS in any policy, legislation or regulation to ensure appropriate access to opioid therapy for individuals with severe RLS for whom all other therapies are no longer effective. Please follow the Foundation on social media, in our eFriends monthly e-newsletter and on our blog to receive late-breaking news on how you can help to advocate for RLS. Our work is not yet done, and we need your voice to help propel our advocacy efforts forward.

Mark your calendar and save the date for the RLS Virtual Summit on February 25. This is a members-only, one-day online event that features RLS experts who will highlight topics of importance to individuals living with RLS.

As we prepare for spring, let us think of the words of Margaret Mead: "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever has."

We do this together, as always.



Karla M. Dzienkowski, RN, BSN  
Executive Director  
Restless Legs Syndrome Foundation



Karla M. Dzienkowski, RN, BSN  
Executive Director

## Honor Roll

*The Restless Legs Syndrome Foundation is sincerely grateful for the donations we received in memory and in honor of the following individuals from October 1, 2022, through December 31, 2022*

#### In Memory of:

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## Help! I Think I Have Augmentation and Don't Know What to Do!

Each day at the RLS Foundation we receive calls from individuals seeking support, information and help with augmentation, a distressing challenge to their RLS treatment.

The good news is that, thanks to ongoing research, augmentation is manageable and treatment options are available. This article provides an overview of augmentation that will help you to understand this unfortunate side effect of treatment and the available strategies to manage it.

### What is Augmentation?

Augmentation is a worsening of RLS symptoms that occurs after starting a medication that increases dopamine levels in the brain. These dopaminergic medications include levodopa/carbidopa, ropinirole, pramipexole and the rotigotine patch. At first, medications in this category are very effective, but over time, in a period from six months to several years, RLS symptoms worsen from what they were prior to initiating therapy. The rate of augmentation in people taking dopamine drugs for RLS is 5%-10% per year; in eight years nearly half of individuals taking dopaminergic medication will experience augmentation.

If an individual with RLS notices symptoms progressively worsening after starting treatment with a dopaminergic drug, then augmentation may be occurring. Simply put, the treatment initially prescribed to alleviate symptoms is worsening the disease.

### What are the Symptoms of Augmentation?

Augmentation is an insidious process, and symptoms often go unnoticed. The first indication of an underlying problem is when a patient feels the need to request an increase in medication dose.

All individuals with RLS should recognize the symptoms of augmentation, which include:

- Earlier onset of symptoms, beginning in the afternoon and evening, rather than at bedtime
- Increase in the intensity of symptoms compared to their level prior to starting treatment
- Spread of symptoms to other body parts (trunk, arms or face), rather than being limited solely to the legs
- Shorter period of rest or inactivity before symptoms begin, and treatment medication is not working as long as it did previously
- Loss of effectiveness of the medication at the dose that previously managed symptoms
- Paradoxical response to the medication; in other words, the prescribed medication triggers symptoms rather than alleviating them

Three factors predispose an individual with RLS to developing augmentation:

- Daily administration of carbidopa/levodopa to treat RLS
- Exceeding the maximum dosages approved by the Food and Drug Administration (FDA) for dopaminergic drugs used to treat RLS
- Low body iron stores as measured by a laboratory test of serum ferritin

When someone is experiencing augmentation, aggressive iron supplementation is extremely important. Intravenous formulations effective in raising blood iron storage levels in RLS patients include: Ferumoxytol (Feraheme); low molecular iron dextran (INFeD); ferric derisomaltose (Monoferric) and ferric carboxymaltose (Injectafer). Ferrous sulfate 365 mg pills taken once daily can be used for ferritin levels higher than 75–100 mcg/L or transferrin saturation less than 20%. However, RLS patients with deteriorating symptoms need rapid iron repletion, and oral iron takes months to improve iron status.

If you, as a patient, suspect augmentation, the first course of action is to make an appointment with your healthcare provider; do not stop taking the medications, as prescribed, to manage your RLS.

### How is Augmentation Diagnosed?

Before a diagnosis of augmentation can be made, the first step is to schedule an appointment with your RLS healthcare provider for a thorough medical examination to rule out any underlying medical conditions that can exacerbate RLS symptoms. Two additional aspects of RLS that are often confused with augmentation are night-to-night variability of symptoms and exacerbation of symptoms for several days; neither is indicative of augmentation.

Factors that can worsen RLS include the use of sedating antihistamines; all antidepressants except for bupropion or trazadone; low body iron stores or unexpected blood loss due to surgery or undiagnosed gastrointestinal bleeding (ulcers, polyps); commonly reported triggers of symptoms such as caffeine, alcohol, sugar, salt or nicotine; a secondary undiagnosed sleep disorder such as sleep apnea; or rebound (the prescribed medication is not lasting as long as it did previously and disrupts sleep at the end of the sleep cycle in the early morning hours). Two additional factors that can cause an increase in RLS symptoms are stress and changes in activity level, such as immobility due to surgery or changes in exercise, activity or routines.

# Living with RLS

## Augmentation Diagnosis: What's Next?

RLS is a chronic progressive disease, and it is often difficult to distinguish between disease progression (natural worsening of the disease) and augmentation. Healthcare providers need to be aware of the key indicators of augmentation, which include:

- The patient requests a dose increase of a dopaminergic medication.
- The prescribed dose currently exceeds FDA maximums for the dopaminergic medication.
- The patient reports breakthrough RLS symptoms with an accompanying increase in symptom intensity.
- The RLS involves other body parts (trunk, arms, face).
- Symptoms occur 24/7.
- Symptoms previously appearing only in the evening or nighttime now present earlier in the day, and the patient requests additional medication doses earlier in the day.

There is no test for the diagnosis of RLS augmentation. A thorough medical examination by your healthcare provider who reviews current medications (over-the-counter medications, supplements, prescriptions) to look for drugs that can worsen RLS symptoms, along with a comprehensive history of symptom progression, will help to determine if augmentation is present.

## How is Augmentation Managed?

There are four treatment strategies to manage RLS augmentation. Working with your doctor you can determine the approach that best works for you.

The first approach involves changing the dosing schedule to “split-dose” the dopaminergic medication. Half the dose of the medication is given earlier in the day, and the second half is given at the regularly scheduled time; the total dose is not to exceed FDA maximums. If this approach does not resolve symptoms, a second medication from another medication class is added to the treatment regimen. Alpha-2-delta ligand drugs such as gabapentin, gabapentin enacarbil, and pregabalin are added to the treatment plan while reducing the dose of the dopaminergic agent. This approach may be effective, but the alpha-2-delta ligands may not be sufficient to control RLS symptoms in the absence of the dopaminergic agents.

A second treatment option to manage augmentation is to switch from a short-acting dopamine agonist to a long-acting one, but this approach is not recommended by RLS experts. The FDA approved the Neupro (rotigotine) patch for the treatment of RLS, and the oral medications pramipexole ER and ropinirole XL are also available. There are no studies to determine if the change to a long-acting dopamine agonist will reduce or mask RLS symptoms. RLS experts have found that tapering off long-acting dopamine agonists with preexisting augmentation is considerably more difficult. Although symptoms improve in the short term, the underlying augmentation remains, and in time symptoms will return.

The third approach involves adding an opioid medication such as buprenorphine, suboxone, methadone or oxycodone to the dopamine agonist, then tapering down the dopamine agonist. Once the transition from dopamine agonist to opioids has occurred, the dose of the opioid is reduced. If symptoms persist, an alpha-2-delta ligand can be added to the treatment protocol, or it can be used to decrease the dose of opioid used.

The final approach to address augmentation is to slowly decrease the dose of the dopamine medication, without any other RLS treatment, followed by 12 drug-free nights before reassessing the need for further treatment. The RLS Foundation handout *Drug Holidays and RLS* provides a thorough outline of this approach to the treatment of augmentation. (Request a copy of this handout on page 25.)

For patients with severe augmentation who have taken high dopamine medication doses, it may be difficult to completely eliminate these drugs, due to the worsening of RLS upon withdrawal. A small dose of a dopamine drug in combination with an alpha-2-delta ligand and/or opioid may be necessary to manage symptoms. However, it is important to note that, once a dopamine drug is successfully discontinued, reintroducing any drug in the dopamine class will lead to a rapid reappearance of augmentation. In other words, all drugs in the dopamine class are no longer a treatment option.

## How Do I Find a Provider to Manage RLS Augmentation?

A provider who is knowledgeable and experienced in treating RLS can be found at an RLS Foundation Quality Care Center. The doctors who practice at these centers are certified RLS providers who treat patients with augmentation and are familiar with the available treatment options. There are 10 RLS Foundation Quality Care Centers in the United States and two in Europe; travel to receive expert care is an option available to individuals with RLS, though not all patients can afford to do so. For a list of RLS Foundation Quality Care Centers, visit [www.rls.org/QCC](http://www.rls.org/QCC) or contact the Foundation.

A second option is to work with the healthcare provider managing your RLS treatment. You will want to determine that they have experience in managing augmentation and are willing to work with you through the entire process. Finding a treatment plan to manage your RLS augmentation is not a one-size-fits-all approach, so finding a provider who is willing to work with you is essential.

The RLS Foundation maintains a list of providers who have expressed an interest in treating RLS, and this may be an option for you. To view this list, visit [www.rls.org/Find-a-doc](http://www.rls.org/Find-a-doc) or contact the Foundation. However, these healthcare providers are not certified RLS experts like those practicing at an RLS Quality Care Center.

## I Think I Have Augmentation. What Can I Do to Help Myself?

You can do several things before an appointment with your healthcare provider that will give them insight into the state of your RLS. Below is a helpful checklist of items to prepare you for your appointment:

1. Resist the urge to make any changes to your current treatment plan. Your healthcare provider needs to get a clear picture of your RLS symptoms under your current treatment plan; any changes could make this more difficult.
2. Schedule an appointment with your healthcare provider as soon as possible. Because scheduling delays are common, ask whether your name can be added to a cancellation list when you book your appointment. That way, if there is a cancellation, you may be called to fill the slot in the schedule.
3. Make a list of all medications that you currently take (prescriptions, over-the-counter medications, supplements).
4. Make a chronological list of all medications that you have taken in the past for RLS and note why you stopped taking them.
5. Gather copies of all laboratory test results for iron, and any other recent laboratory test results for your provider to review.
6. Complete an RLS Sleep Diary, included in this issue of *Night Walkers*. The Sleep Diary will provide your healthcare provider with an overview of your sleep patterns and RLS symptoms.
7. Make and bring copies of the following open-access articles from *Mayo Clinic Proceedings*: “The Management of Restless Legs Syndrome: An Updated Algorithm” (2021) and “The Appropriate Use of Opioids in the Treatment of Refractory Restless Legs Syndrome” (2018). For copies of these articles, visit [www.mayoclinicproceedings.org](http://www.mayoclinicproceedings.org) or contact the Foundation.

For more information about augmentation and RLS, visit the RLS Foundation’s Member Portal on [www.rls.org](http://www.rls.org) to find educational resource materials. We invite you to attend the Foundation’s monthly webinar series presented by RLS experts and to watch past webinars online to become more knowledgeable about RLS. The Foundation also sponsors four monthly online Virtual Support Group Meetings, so you can connect with others in the RLS community for support, tips and helpful information.

## HOW TO RECOGNIZE AUGMENTATION

Augmentation is defined as a worsening of RLS symptoms that occurs after starting a dopaminergic medication to treat RLS. The medication is effective when it is first started, but over time symptoms worsen with continued use.

### TIMING

Symptoms appear earlier in the evening or afternoon

Symptom intensity increases

### INTENSITY

### AREA AFFECTED

Symptoms spread to other body parts

Symptoms begin sooner during rest or inactivity

### EARLIER ONSET

### DOSAGE INCREASE

Symptoms are no longer managed by previously effective dosage



## 3rd Annual Sleep Advocacy Forum Connects More than 70 Sleep Disorders

By Karla Dzienkowski, RN, BSN, Executive Director, RLS Foundation

The RLS Foundation participated in the third annual Sleep Advocacy Forum in Washington, DC, on October 24–25, 2022. The forum brings together healthcare leaders and patient advocates to share information and explore opportunities to advocate for people living with sleep disorders. This is the third year of the Foundation's participation in the forum but the first year that participating organizations were able to meet in person, due to pandemic restrictions. Representatives of the RLS Foundation included Kathryn Camp, who is a patient advocate for RLS and Executive Director Karla Dzienkowski. The two-day event featured breakout sessions on the first day and congressional visits on the second day.

### Day 1: Panelists discuss research, health disparities, patient advocacy

The first day of the forum consisted of four separate discussion panels.

The Medical Research Panel featured:

- Dr. Marishka Brown, National Center on Sleep Disorders Research
- Dr. Janet He, National Institute of Neurological Disorders and Stroke
- Dr. Das and Dr. Jones, National Institute on Minority Health and Health Disparities
- Dr. Ruth Denca, Sleep Research Society
- Dr. Louis Ptáček, Society for Research on Biological Rhythms

The panel highlighted programs and opportunities for sleep disorders research. The panelists addressed current issues related to sleep, such as the possible effects of permanent standard time, minorities and health disparities, and sleep requirements in relation to the biological clock.

The Public Health and Patient Care Panel included representatives from:

- Patient-Centered Outcomes Research Institute
- Food and Drug Administration (FDA) Patient Listening Session, with Julie Flygare
- American Thoracic Society, with Gary Ewart
- American Academy of Sleep Medicine, with Dr. Ramon Malhotra
- American Heart Association, with John Laughner



LIBERTY  
IS THE GREAT  
PARENT OF  
SCIENCE AND  
OF VIRTUE;  
A NATION  
WILL BE GREAT  
IN BOTH  
ALWAYS IN  
PROPORTION AS  
IT IS FREE.

THOMAS JEFFERSON  
1743 - 1826

The panel addressed the need for additional research on sleep disorders; the patient listening program at the FDA as a way to add patients' voices to the conversation regarding durable treatments; the need to identify sleep disorders in minorities; and sleep as an essential component of life.

The Patient Advocacy Panel featured participation from:

- American Academy of Sleep Medicine
- American Heart Association
- American Thoracic Society
- Hypersomnia Foundation
- Project Sleep
- Restless Legs Syndrome Foundation
- Sleep Research Society
- Society for Research on Biological Rhythms
- Start School Later
- Wake Up Narcolepsy

The leaders of these organizations outlined their legislative priorities in preparation for the opening of the 118th Congress.

The Patient Panel featured individuals from several of the organizations in the Patient Advocacy Panel. Patients took turns sharing their experiences of living with one or more chronic medical conditions.

### Patients Share Their Common Challenges

Kathryn Camp shared her RLS journey. She described a recent orthopedic surgery and hospitalization, when, during inpatient

rehabilitation, she encountered delays in the delivery of pain medication. She also took notes on the presentations by patients living with other sleep disorders and summarizes them here:

“Despite the range of sleep disorders represented in the Patient Panel, there were striking similarities reported across the group. All the advocates talked about delays in diagnosis. Some reported delays greater than a decade, with potentially life-threatening consequences such as falling asleep while driving. The mother of a young adult with narcolepsy reported that her daughter does not drive at all due to this concern. Prior to diagnosis, panelists didn’t know the cause of their issues with sleep, but they knew something was wrong. Daytime sleepiness was dismissed by school personnel, who simply told a child with undiagnosed narcolepsy to stay off the internet at night! A healthcare provider told a pregnant woman with undiagnosed sleep apnea that of course she was tired – She was pregnant!

Difficulties in finding medical providers with expertise in each disorder was another common thread. Some people had to travel long distances at great personal expense to be properly evaluated and treated. Searching for medications and other therapies that worked was often an exercise in frustration and disappointment. Given the variable nature of sleep disorders, some of us found that medications that might have worked at the time of diagnosis later stopped working, dosages reached toxic levels, or side effects became untenable.

Some patients reported inadequate insurance coverage for sleep studies, medications and specialty care, which became a barrier for diagnosis and optimal treatment.

In looking to the future, all of the panelists sent a clear message that more research is needed into the underlying causes of their disorder,

effective treatment strategies and long-term outcomes. Sleep advocacy was important to all the panelists as a way to share their experiences and to help other patients navigate the complexities of diagnosis, treatment and management of their disorder.”

A question-and-answer session followed each panel presentation and allowed the presenters and attendees to exchange information and learn from others in the sleep realm. The general discussion emphasized the need for greater awareness and education among medical professionals, policymakers and the public regarding issues related to sleep and sleep disorders.

## Day 2: Meetings on the Hill

During the second day of the Sleep Advocacy Forum, attendees visited the offices of a select group of House and Senate members. Dzienkowski notes, “It was a great opportunity for the RLS Foundation to join with the other members of the sleep advocacy community to collaborate and share with legislative staff the challenges faced by individuals living with sleep disorders, including RLS.”

The key issues that emerged from the forum were that it often takes decades to attain proper diagnosis and treatment for individuals living with sleep disorders, there is a need for sleep curriculum in all areas of medical education, and there is need for increased funding for medical research to identify new treatments. In the public sphere, the debate about moving to permanent standard time and safety concerns such as drowsy driving resulting from sleep loss were also key concerns.

Overall, the Sleep Advocacy Forum helped to foster cooperation among organizations representing more than 70 known sleep disorders. The RLS Foundation looks forward to another productive forum in 2023.

## 2023 Research Grant Opportunity

The RLS Foundation announced a new funding opportunity for projects that promote research to understand RLS. For this new round of funding, the primary research priorities are:

- **Brain iron homeostasis:** Elucidate the genetic/epigenetic, developmental, and biological factors that contribute to RLS-relevant alterations in brain iron homeostasis.
- **Comorbidities:** Elucidate the interactions between RLS and comorbid disorders, such as cardiovascular disease and sleep apnea.
- **Non-pharmacologic treatments:** Elucidate benefits of non-pharmacological treatments of RLS. Examples include, but are not limited to, transcranial or spinal magnetic stimulation, transcranial direct current stimulation, cognitive behavioral therapy, intermittent compression of the leg.
- **Other topics:** Other research areas accepted for funding consideration.

Additional information about the grant process and its past awardees is available at: [www.rls.org/research-grants](http://www.rls.org/research-grants).

The Foundation began accepting letters of intent (LOI) for each of these research directions and as outlined in the guidelines on December 9, 2022.

The Research Grant Committee will review all submissions and extend invitations for full proposals in late February. The link to submit full proposals will be included in the letter of invitation, and the deadline for the full proposal submission is April 5, 2023.



# National Academies Workshop: Exploring Sleep Disturbance in Central Nervous System Disorders

On November 2–3, 2022, the RLS Foundation attended the Sleep Disturbance in Central Nervous Systems Workshop held at the National Academies in Washington, DC. More than a thousand people attended the two-day workshop virtually or in person.

This important event, open to the public, brought together key opinion leaders in government, academia, industry, philanthropic organizations and the nonprofit sector to examine the role of sleep in central nervous system (CNS) disorders and seek collaboration in the identification of new strategies to hinder the development of sleep disorders commonly associated with these conditions.

Six meeting sessions across the two-day format focused on CNS sleep disturbances and were each followed by a moderated panel discussion and a question-and-answer session for participants. Workshop presenters chose discussion topics that included:

- Sleep disorder prevalence, and factors contributing to the development of sleep disorders.
- Current knowledge in the field of sleep, and an overview of physiological changes that occur in humans across the life cycle.
- Research encouraging collaboration among the various disciplines:
  - to accelerate breakthroughs in the understanding of sleep disorders and prevention strategies,
  - stressing the importance of public-private partnerships to advance the understanding of brain function and the relationship between genetics and CNS sleep disorders.
- Changes in human circadian rhythm resulting from societal factors with nightly impacts, such as lighting and shift work, on how well (sleep quality) and how long (sleep quantity) people sleep.
- Sleep as a new vital sign – a measurable element that evaluates CNS function and its response to therapeutic interventions to alleviate untoward effects of sleep disturbance.

Executive Director Karla Dzienkowski gave a presentation on the importance of screening for sleep disorders at the primary care level. Dzienkowski noted, “The RLS Foundation’s ODYSSEY II study found a decade-long gap between the onset of bothersome symptoms of RLS and proper diagnosis of the disease. A similar delay in diagnosis has long been documented in other sleep disorders. Annual screening of patients for sleep disorders by medical providers will shorten delays to diagnosis and the initiation of treatment, leading to better management of sleep disorders and better patient outcomes. A short sleep questionnaire at the primary care level would not overly burden the practitioner or the patient. Moreover, if the questionnaire indicated a potential sleep disorder, it would provide valuable information for follow-up treatment.”

A 2016 RLS Foundation-funded study found that training primary care providers to diagnose RLS correctly would be cost-effective. The study, “The Economic Evaluation of RLS,” was conducted by William Padula, PhD, of Johns Hopkins Bloomberg School of Public Health,

in collaboration with Christopher J. Earley, MD, MB, BCh, PhD, FRCPI, at Johns Hopkins Medicine; and Charles E. Phelps, PhD, MBA, at the University of Rochester (retired).

The study found that in 65% of cases, the costs of training healthcare providers in the US to recognize and treat RLS are expected to be lower than costs related to patient medical care, as well as costs related to lost work and time. Training primary care providers may also eliminate the time gap between correctly diagnosing troublesome symptoms and initiating treatment, leading to better patient outcomes.

The key themes emerging from this conference were:

- The recognition of sleep as an essential life function – a pillar of health.
- The importance of sleep education starting in the K-12 curriculum. This would reinforce the importance of sleep throughout the human life span for optimal health and the prevention of sleep comorbidities such as depression, cardiovascular disease, diabetes and obesity.
- Social and environmental factors account for disparities in sleep quality, quantity, regularity and duration. These disparities could be alleviated through proper planning by public officials and urban designers.

Sleep is an evolving field in medicine. In the future, it may achieve consideration as a new vital sign – a metric that provides valuable insights into the health and well-being of humans. Collaborative research among all sectors in the healthcare realm will help to further the understanding of sleep and biological rhythms and to advance the science of sleep and interventional medicine, leading to an improved health-related quality of life for everyone.



*Dr. Louis Ptáček and Karla Dzienkowski*



# The 'Opioid Issue' Still Needs Your Attention

*By Lewis Phelps, Former Chair, RLS Foundation Board of Directors*

Five years ago, we wrote in *NightWalkers* about the challenges that people with RLS and their doctors face in getting opioid prescriptions filled. In recognition of the seriousness of the problem experienced by many of our members, we retained the services of a public affairs firm in Washington that specializes in healthcare issues to help us alert policymakers about the problem and to craft sensible federal policies that recognize the unique role these medications play in providing relief for many among us.

In response to concerns about opioid addiction, the Foundation has funded groundbreaking research that documents the long-term safety and efficacy of opioids as a treatment for severe RLS.

Over the intervening years, we have deployed Foundation staff, members of our Scientific and Medical Advisory Board, and individual Foundation members to visit members of Congress, federal agencies, and others making or influencing policy, legislation or regulation on this topic.

Nevertheless, those who write the guidelines and rules about dispensing opioids continue to get it wrong: They craft guidelines appropriate for treatment of chronic pain that lack recognition of the unique neuropathology of RLS and the specialized consideration required in treating RLS, but rather include RLS in the category of generalized pain issues.

Documentation can be found in medical literature as far back as four centuries ago about the safety and efficacy of low total daily doses of opioids to treat people with severe RLS that has failed to respond to other treatments. This so-called "off-label" use is relatively common when physicians discover that drugs can alleviate conditions beyond those specifically approved by the government. (For example, a medication approved for high blood pressure is frequently prescribed to musicians to prevent performance anxiety.) To obtain approval "on label," the government requires extensive, costly years of testing. Pharmaceutical companies are unwilling to invest in such lengthy trials, particularly in the case of drugs like common opioids that cannot be patented. With no hope of recapturing the costs of testing a drug, no company will undertake the licensing process.

To be sure, there are approved drugs that are useful in treating RLS symptoms. These include alpha-2-delta ligands (gabapentin-type drugs, originally developed to treat seizure disorders and nerve pain), iron infusion, and dopaminergic drugs such as pramipexole, ropinirole, rotigotine and levodopa/carbidopa.

Unfortunately, experience has shown that while dopamine agents improve symptoms over the short term, over time, they can make RLS worse. This is an untoward effect of dopamine therapy known as augmentation, in which the medication prescribed to treat RLS symptoms actually makes the disease worse over months or years. Thus, dopamine drugs are no longer favored for long-term use.

When all other options have failed, as they do for many people with RLS, there is only one remaining treatment available: opioids.

The Centers for Disease Control and Prevention (CDC) has recently published a revised guideline for the use of opioids to treat chronic pain. The new rules are similar in many respects to prior versions, except that they reduce the maximum recommended daily dose of opioids to an even lower level than before.

Available information indicates that three-fourths of RLS patients using opioids are prescribed doses below these new CDC guidance levels. Alarming, this means that about one-fourth of patients receiving opioids are at risk of losing access to the only effective treatment for their disease.

It appears that the new guidelines ignore well-established scientific evidence that RLS is different from chronic pain and needs to be treated differently. Consider the following facts:

- In contrast to chronic pain, where opioids lose their effectiveness over time, when used to treat RLS, the drugs continue to provide relief from RLS symptoms for years, even decades.
- When prescribed for chronic pain, patients must increase doses over time to achieve relief. In contrast, The RLS Opioid Registry, a longitudinal study conducted at Massachusetts General Hospital, has found RLS patients remain at low total daily doses for decades; no increases are required to sustain relief.
- RLS patients typically do not develop opioid use disorder or develop issues of tolerance or dependence. Research and expert opinion have found that the low total daily doses used to manage severe RLS do not lead to tolerance or dependency issues, which are hallmarks of opioid use disorder.

To be fair, the revised CDC guideline recognizes that it is only advisory, not mandatory. "This clinical practice guideline provides recommendations but does not replace clinical judgment and individualized, patient-centered decision-making."

Unfortunately, experience demonstrates that such language is widely ignored. Suggestions are transmuted into hard and fast rules. The Foundation receives reports from members and physicians that state regulators have converted this guideline into rigid regulations, insurance companies have refused to provide coverage for opioids even when within the recommended limits, pharmacies have refused to fill legal and proper prescriptions for opioids for RLS, hospital emergency rooms have treated patients using opioids for RLS control as if they were addicts and criminal drug dealers, and some doctors, clinical practices and medical centers have stopped prescribing opioids at all to

*Continued on page 10*

## Thanks to Two Brilliant Leaders

The RLS Foundation is grateful for the contributions of two exceptional leaders who have given of their time and talents to serve the organization as chair of the Board of Directors.

### Thank you to Carla Rahn Phillips

The RLS Foundation thanks Carla Rahn Phillips, PhD, for her leadership as chair of the Board of Directors of the Restless Legs Syndrome Foundation. Her dedication, skill, perseverance and devotion to duty throughout her two-year term of office have not only led the Board through all its meetings, but also contributed immensely to the Foundation's mission through many hours in meetings with federal agencies, consultants, accountants, auditors and non-profit organizations; all while she has continued her output of gracious and thoughtful thank you notes to donors.

Dr. Phillips has provided leadership during one of the most challenging times in the history of the RLS Foundation due to the COVID-19 pandemic, resulting in substantial strengthening of the Foundation's financial position during her term in office. The Foundation's Board of Directors, Scientific and Medical Advisory Board, volunteers and staff sincerely thank Dr. Phillips for her service, and salute her for her dedication to the duties of the job, perseverance, attention to detail, wit and leadership.

*Continued from page 9*

treat RLS. Even worse is the letter patients receive that their physician no longer treats RLS and they will need to find a new provider. These reactions are driven by fear, not science.

It is notable that the new guideline acknowledges that the general advice the CDC provides on opioids specifically does not apply to three situations: patients with sickle cell anemia, cancer patients with pain, and palliative care (end-of-life) treatments. We believe that the CDC needs to add RLS to the list of medical conditions that lie outside of its recommendations for the treatment of chronic pain.

How is the Foundation responding to this challenge facing its members? We have already held conversations with the leadership at the CDC. We note that:

- RLS is a distinct neurological condition that responds differently to opioids than chronic pain.
- RLS is a very significant disorder with a greater disruption in health-related quality of life than many other recognized medical conditions.
- There is a four times greater risk of suicide among those with severe RLS than in the general population, and twice the risk than that of people with severe chronic pain.
- There is strong evidence that using opioids to treat RLS does not lead to tolerance or dependence on opioids.
- Most of the drugs approved by the Food and Drug Administration to treat RLS (Requip, Mirapex and Neupro) actually make the condition worse over time, and the

### Welcome to Dr. Paruthi as Board Chair

Shalini Paruthi, MD, serves as the Foundation's new chair of the Board of Directors. Dr. Paruthi joined the board in 2017 and adds her perspective and expertise as not only a physician who treats adults and children with RLS, but also a patient and caregiver, since she and her children are living with RLS.

Dr. Paruthi is board-certified in sleep medicine and internal medicine, and received her medical degree from the University of Missouri-Kansas City School of Medicine. She went on to complete her internal medicine residency and sleep fellowship at the University of Michigan.

Dr. Paruthi's interest and energy extend to research pursuits as well, to expanding the understanding of sleep and its many disruptions and diseases. She is co-director of the Sleep Medicine and Research Center at St. Luke's Hospital in St. Louis. She has contributed widely to activities of the American Academy of Sleep Medicine, chairing sleep-focused conferences, participating in task forces, and serving on committees, including the Education Committee and the national SLEEP Meeting Program Committee. Currently she is on the editorial advisory board for Sleep Review, a journal for sleep specialists.

remaining approved drug (Horizant) is either not tolerated or is not fully effective in a large percentage of people with severe RLS.

- The CDC should specifically exempt RLS from the guideline for opioid prescribing in the same way that it has exempted sickle cell disease. Like sickle cell disease, RLS is a disease with a genetic predisposition.

The RLS Foundation hopes that the CDC will respond to these arguments. If it does not, we expect that we will need to carry the same discussion to other venues that are involved in the process, up to and including the United States Congress.

We will keep members of the RLS Foundation advised of our progress. It is possible that we will ask members to add their voices to the more than 500 members of the Foundation who have already submitted comments to the CDC during the public comment period preceding the issuance of the new opioid guideline (more than 10% of all comments listed). Although we did not achieve the hoped-for goal in that process, it is clear that there is more work to be done. Please be alert to calls for action.

Our efforts to fight for the rights of those with RLS to obtain the medical treatment they need and deserve, without undue restrictions, are ongoing. The RLS Foundation is a volunteer-driven organization, and we appreciate your continued financial support to increase our advocacy efforts. For more information on how you can get involved, go to [www.rls.org/advocacy](http://www.rls.org/advocacy).





# RLS Symptom Diary

The RLS Symptom Diary is a tool to track your daily activities, RLS symptoms and sleep patterns.

- Use the table on the back of this page to keep a diary for two weeks.
- Once you have completed the diary, then complete this page, which summarizes the information you've collected.
- After completing both pages, review them with your healthcare provider to help identify patterns or triggers that may contribute to sleepless nights and RLS symptoms.

Name: \_\_\_\_\_

Today's Date: \_\_\_\_\_

**1) Number of days I completed my RLS Symptom Diary:**

☐ 1 day ☐ 2-3 days ☐ 4-7 days ☐ 1-2 weeks ☐ 2+ weeks

**2) The RLS symptoms I recorded most frequently can best be described as (check all that apply):**

☐ painful ☐ creeping ☐ crawling ☐ aching ☐ pulling ☐ tugging ☐ pins & needles ☐ other \_\_\_\_\_

**3) On average, I experienced my symptoms at what time(s) each day:**

☐ early morning ☐ midmorning ☐ midday ☐ afternoon ☐ evening ☐ night ☐ late night

**4) On average, I slept how many hours each night:**

☐ less than 2 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8+

**5) On average, I exercised how long each day:**

☐ 0-15 mins ☐ 15-30 mins ☐ 30-60 mins ☐ 60+ mins

**6) When I exercised (versus when I didn't exercise) my symptoms were:**

☐ better ☐ worse

**7) When I moved around (versus when I didn't move around) my symptoms were:**

☐ better ☐ worse

**8) I consumed the following substances while keeping my RLS Symptom Diary:**

☐ caffeine ☐ alcohol ☐ tobacco products ☐ over-the-counter medication ☐ prescription medication

List all medications: \_\_\_\_\_

**9) On average, on a scale from 1-5 (with 5 being the worst) my symptoms were how severe:**

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

**Questions for my healthcare provider:**

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# RESTLESS LEGS SYNDROME FOUNDATION PATIENT SYMPTOM DIARY

To be completed after waking up for the day:							
	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7
Date:							
I woke up today at what time?							
I went to bed last night at what time?							
I woke up how many times during the night, if any?							
I slept how many hours last night?							
To be completed just before your bedtime:							
Today I experienced my RLS symptoms at what time(s)?	<input type="radio"/> early morning <input type="radio"/> midmorning <input type="radio"/> midday <input type="radio"/> afternoon <input type="radio"/> evening <input type="radio"/> night <input type="radio"/> late night	<input type="radio"/> early morning <input type="radio"/> midmorning <input type="radio"/> midday <input type="radio"/> afternoon <input type="radio"/> evening <input type="radio"/> night <input type="radio"/> late night	<input type="radio"/> early morning <input type="radio"/> midmorning <input type="radio"/> midday <input type="radio"/> afternoon <input type="radio"/> evening <input type="radio"/> night <input type="radio"/> late night	<input type="radio"/> early morning <input type="radio"/> midmorning <input type="radio"/> midday <input type="radio"/> afternoon <input type="radio"/> evening <input type="radio"/> night <input type="radio"/> late night	<input type="radio"/> early morning <input type="radio"/> midmorning <input type="radio"/> midday <input type="radio"/> afternoon <input type="radio"/> evening <input type="radio"/> night <input type="radio"/> late night	<input type="radio"/> early morning <input type="radio"/> midmorning <input type="radio"/> midday <input type="radio"/> afternoon <input type="radio"/> evening <input type="radio"/> night <input type="radio"/> late night	<input type="radio"/> early morning <input type="radio"/> midmorning <input type="radio"/> midday <input type="radio"/> afternoon <input type="radio"/> evening <input type="radio"/> night <input type="radio"/> late night
From 1 to 5 (5 being the worst), my symptoms were how severe?							
My major stresses today were:							
I consumed any of these substances during the day: (include the time that you consumed each item)	<input type="radio"/> Caffeine <input type="radio"/> Alcohol <input type="radio"/> Tobacco products <input type="radio"/> Over-the-counter medications <input type="radio"/> Other (please list)	<input type="radio"/> Caffeine <input type="radio"/> Alcohol <input type="radio"/> Tobacco products <input type="radio"/> Over-the-counter medications <input type="radio"/> Other (please list)	<input type="radio"/> Caffeine <input type="radio"/> Alcohol <input type="radio"/> Tobacco products <input type="radio"/> Over-the-counter medications <input type="radio"/> Other (please list)	<input type="radio"/> Caffeine <input type="radio"/> Alcohol <input type="radio"/> Tobacco products <input type="radio"/> Over-the-counter medications <input type="radio"/> Other (please list)	<input type="radio"/> Caffeine <input type="radio"/> Alcohol <input type="radio"/> Tobacco products <input type="radio"/> Over-the-counter medications <input type="radio"/> Other (please list)	<input type="radio"/> Caffeine <input type="radio"/> Alcohol <input type="radio"/> Tobacco products <input type="radio"/> Over-the-counter medications <input type="radio"/> Other (please list)	<input type="radio"/> Caffeine <input type="radio"/> Alcohol <input type="radio"/> Tobacco products <input type="radio"/> Over-the-counter medications <input type="radio"/> Other (please list)
I exercised for how many minutes today?	Times:	Times:	Times:	Times:	Times:	Times:	Times:
Additional comments:							



# RLS Advocacy: 3 Steps You Can Take To Make An Impact

*by Adrianna Colucci, RLS Foundation*

RLS patients are familiar with self-advocacy, often having to play the dual role of patient and educator. Even within the medical community, a lack of understanding of RLS results in delays in proper diagnosis and treatment. Advocacy is a primary activity of the RLS Foundation, focusing on allocating funds to RLS research, increasing physician and public education, and protecting access to effective treatments.

An updated clinical guideline issued by the Centers for Disease Control and Prevention (CDC) in November failed to identify a medical exception for RLS regarding access to opioid therapy, despite exceptions being made for other medical conditions. It is important to recognize the role that low total daily doses of opioids have in providing relief for those with RLS when other treatments are not effective in controlling symptoms.

The RLS Foundation encourages everyone in the RLS community to use their advocacy voices to reach the legislative sector by participating in some of the activities suggested below!

## 1. Connect with Your Community

We have a network of support groups and contacts across North America that allow you to connect to the entire RLS community. (See page 23.) Host a virtual or in-person meeting to write letters and share your RLS story with your congressional representatives. There is power in numbers. Emphasize that, without the explicit mention of RLS in CDC guidelines, state and federal agencies have the potential to deny effective treatment to the RLS community. You can visit [www.congress.gov/members/find-your-member](http://www.congress.gov/members/find-your-member) to search for your state representative's contact information.

## 2. Spread Awareness

Speak to your friends, family, neighbors and healthcare providers about your experience. Educating those around you introduces them to an unfamiliar topic while encouraging them to participate in bringing about change. Social media is a great resource for sharing your message and connecting with people or groups who understand your RLS.

## 3. Participate in Hill Day

The Foundation hopes to host a 2023 Hill Day – a day dedicated to educating congressional representatives about the impact RLS has on physical and mental health, as well as the barriers to effective treatment. The last in-person RLS Hill Day was in 2019, when 25 members of the Foundation traveled to Washington, DC, for two days of meetings with their legislators.

You can participate in Hill Day by writing letters, submitting videos or joining the RLS Foundation team in Washington to tell your RLS story. Look for our call to action for participants in future emails, blog posts and eFriends newsletter! Learn more about making your voice heard and view the many advocacy resources at <https://www.rls.org/get-involved/advocacy-resources>.



## Evaluating IV Iron Side Effects, Including Hypophosphatemia

Boots JMM, Quax RAM. "High-Dose Intravenous Iron with Either Ferric Carboxymaltose or Ferric Derisomaltose: A Benefit-Risk Assessment." *Drug Saf.* 2022;45(10):1019-1036. doi:10.1007/s40264-022-01216-w

### The Background

Intravenous (IV) iron has emerged as a first-line treatment for RLS because low iron levels in the brain have been established as a central cause of the condition. Research and experience using IV iron have shown improvement in the condition. The newer formulations of IV iron allow larger doses to be administered over shorter periods of time, allow fewer trips to the infusion center and reduce time sitting in the infusion chair. Recently, concerns have arisen over hypophosphatemia, or low phosphorus levels, as a possible side effect commonly associated with ferric carboxymaltose, or FCM (Injectafer), which is the most studied formulation for RLS. This article is a review looking primarily at ferric carboxymaltose and ferric derisomaltose, or FD (Monoferric). It provides a risk-benefit analysis based on the review of published literature on side effects from IV iron.

### The Research

The authors identified studies illustrating that low phosphorus levels after IV iron are more common than previously thought. The research points to a hormone called fibroblast growth factor-23 (FGF-23) as the main cause of this phenomenon. FGF-23 is increased in the body due to iron deficiency anemia and, for unclear reasons, is not broken down or deactivated after infusion with FCM as in normal circumstances. The high levels of FGF-23 then cause the kidneys to filter out more phosphate into the urine, leading to low levels in the bloodstream.

The authors found numerous clinical trials of FCM with hypophosphatemia (inorganic phosphorus level less than 2 mg/dL) in the range of 45%–75%, and more severe hypophosphatemia (less than 1 mg/dL) in up to 11% of patients in one study. These low levels peaked at two weeks but continued for over two months in some patients. For the other formulations, hypophosphatemia was less common: FD 4%–8%, ferumoxytol (Feraheme) 0.9%, iron sucrose (Venofer) 0–1.5%, and no hypophosphatemia was found in two studies of low molecular weight iron dextran (INFeD). The authors also noted several case series showing FCM could result in osteomalacia, or a thinning of bone that could lead to pain and small bone breaks, likely due to FCM lowering activity of vitamin D, which maintains healthy bones. The authors suggest if FCM is chosen for infusion, patients should have a baseline phosphorus level over 3.1 mg/dL to avoid severe hypophosphatemia. If they have lower levels or other risks for hypophosphatemia or osteomalacia, using a different choice for iron infusion is recommended.

The authors then looked at hypersensitivity reactions from iron

infusions. These are generally no worse than moderate in severity and occur in 11%–22% of infusions. The most common reaction is called a Fishbane reaction, in which iron is released into the bloodstream freely and can cause flushing, muscle aches or tightness in the torso, and joint pains, which immediately resolve when the infusion is stopped and then restarted at a lower rate.

Some hypersensitivity symptoms are thought to be related to complement activation-related pseudo-allergy (CARPA). This mild, non-allergic immune reaction to the infusion can lead to isolated symptoms of shortness of breath, racing heart, low blood pressure, nausea or abdominal pain. The symptoms typically resolve with a lower infusion rate but occasionally require a patient to receive a newer-generation antihistamine or steroids; future reactions can be prevented with a lower infusion rate or by receiving steroids prior to infusion. Serious adverse events of any type are thought to occur in only 0.2%–1.7% of all infusions, regardless of formulation. Anaphylaxis, or a severe, life-threatening allergic reaction, is extremely rare and thought to occur in fewer than 1 in 250,000 infusions.

### The Bottom Line

Overall, even mild infusion reactions are uncommon with IV iron. Those receiving FCM for RLS should be monitored for low phosphorus levels, and those at higher risk for hypophosphatemia should seek an alternative IV iron formulation.

### Further Questions

FCM is the most well-studied formulation for RLS, but are the other strong formulations (dextran, derisomaltose and ferumoxytol) equally effective at equivalent doses? Many patients with RLS receiving FCM do not have iron-deficiency anemia or levels of iron as low as patients in these studies. Could the risk of hypophosphatemia be lower or less severe in RLS patients for this reason?

An older type of IV iron did cause rare but serious infusion reactions, but it was taken off the market years ago. Serious infusion reactions from current formulations are quite rare, but the fear of reactions persists among medical providers and remains a significant barrier to RLS patients obtaining infusions. What is the best way to disseminate knowledge of this invaluable first-line treatment and allay concerns about risks?

Cost and payment coverage play a significant role in the choice of infusion, more than effectiveness or side effects; often only a few types of iron are covered by third-party payers or available at a given infusion center. Moreover, most insurers do not cover iron infusions for RLS alone, but only if the infusions are associated with more severe iron deficiency. If and when iron infusion becomes routinely covered for RLS, what should be the guidelines for iron infusion types specifically for RLS?



J. Andrew Berkowski, MD



This is a very good article and discussion as it introduces Monoferic as a good and possibly safer choice than Injectafer. However, what is left out is the results of the study showing the differences between Monoferic and Injectafer and the results of the risk-benefit analysis.

## Can Noninvasive Vagus Nerve Stimulation Help RLS?

Hartley S, Bao G, Zagdoun M, et al. “Noninvasive Vagus Nerve Stimulation: A New Therapeutic Approach for Pharmacoresistant Restless Legs Syndrome” [published online ahead of print, 2022 Nov 15]. *Neuromodulation*. 2022;S1094-7159(22)01335-6. doi:10.1016/j.neurom.2022.10.046

### The Background

The vagus (cranial nerve 10, from the Latin meaning “wandering”) is an important nerve coming out of the brainstem that helps the brain control a wide variety of functions such as heart rate, breathing, digestive system activities, and even muscles in the throat. It also transmits feedback to many areas of the brain. This nerve travels through the neck and can be accessed easily by nerve stimulation techniques. Vagus nerve stimulators (VNS) have been used in many areas of medicine to help treat seizure disorders, chronic pain and depression. There may be many areas of overlap of aspects of RLS in the brain and nervous system with that of the vagus nerve. This study looked at the feasibility of VNS, and its effect on the symptoms of RLS.

### The Research

This was a non-randomized, open-label study of 15 patients (eight male, seven female; average age 62.7 years) with severe RLS who received VNS for treatment. (All subjects got the treatment and were aware of it, without a group for comparison.) Each individual had a transauricular VNS, a noninvasive stimulator outside the skin going across parts of the ear, for one hour per week for eight consecutive weeks. The study tracked RLS severity, quality of life, and measures of anxiety and depression. Actigraphy, which is a device that tracks body movement (similar to a fitness tracker but with more sophisticated sensors), was also used at night on the ankles and wrists to measure sleep and limb movements.

The average International RLS Study Group Rating Scale (IRLSSG) score was 31.9 (in the very severe range of this 0–40 scale), and anxiety and depression measures were also high at baseline. Ten of the 15 patients were taking medications that can cause augmentation of RLS, including dopamine agonists and/or tramadol, but according to the authors, none met the Max Planck Institute criteria for augmentation. Those who were on high doses of dopamine agonists or had ferritin levels less than 50 mg/L were excluded from the study.

After the eighth week, the IRLS Score improved to 24.6 (severe range). Four of the 15 were considered full responders with an IRLS Score below 20, six showed partial improvement, and five were nonresponders. There was statistically significant improvement in scores for RLS quality of life, depression and

anxiety. Actigraphy showed a statistical trend toward improved ability to fall asleep but no difference in sleep quality or leg movements before and after eight weeks of treatment. No side effects were reported from patients.

### The Bottom Line

In a study of 15 patients with severe RLS, transauricular VNS was shown to improve quality of life, depression and anxiety, though the effect on RLS severity was modest and varied among subjects.

### Further Questions

As an open-label study with no control/comparison group, it is hard to assess how much of the 7.3-point improvement to the IRLS Score was due to placebo effect (the positive effect of knowing one is receiving treatment). Assuming a large component is indeed due to the treatment itself, is the effect directly on RLS, or is VNS positively impacting anxiety and depression, with improvement to RLS being a secondary effect from the mood benefits? Given the complexities and overlap of both RLS and the vagus network in the brain, by which pathways is VNS working to reduce RLS symptoms (e.g., pain/opioid system, seizure/reduced excitability, dopamine)? What should be the frequency and timing of treatment; would nightly VNS be more effective than weekly? As seen in other treatments like IV iron, some patients had no response to treatment. So, what are the underlying differences that can predict who will respond to this treatment?

In the current and challenging era of RLS treatments – with IV iron hard to obtain, dopamine agonists rightly excommunicated, and alpha-2-delta medications (like gabapentin) and opioid controlled substances – there continues to be burgeoning interest in nonmedication treatments using external devices (e.g., pressure, nerve stimulation). This study is a nice first step, and a randomized, controlled trial of VNS would be most welcome.

*Dr. Berkowski is a member of the Scientific and Medical Advisory Board of the RLS Foundation and the “In the News” columnist. He is a sleep specialist at ReLACS Health, a direct specialty care clinic specializing in telemedicine care of RLS and complex sleep disorders, currently serving patients in Michigan and Ohio.*

# Bedtime Stories

*Bedtime Stories are the opinions of the authors only and not of the RLS Foundation, its employees or its Board of Directors. Publication in NightWalkers does not imply endorsement by the RLS Foundation. Therapies and results described in Bedtime Stories reflect the experiences of individuals and cannot be generalized to everyone with RLS. It is important to talk to your healthcare provider and investigate concerns such as safety, efficacy and cost before making any changes to your treatment regimen. Stories may be edited for length or clarity.*

I have had RLS since I was a teenager. I was prescribed dopamine drugs for over 10 years. I went from one dopamine agonist to another; the last one prescribed was called pergolide. I'd been on pergolide for a couple of years when, like the other drugs, it stopped working. I went to my general practitioner (GP) and assumed that I would be prescribed another dopamine drug. But this time my GP said there was nothing else she could prescribe. She said I needed to see a specialist, and she cut me from the drug abruptly.

I could never explain in words the pain I suffered for the next six months while waiting to see a specialist. The burning, stabbing the restlessness were completely out of control. Eventually, I was sent to an amazing specialist in Guys Hospital London. He wouldn't let me leave the hospital without taking oxycodone, and without it, I definitely wouldn't be here now.

I took oxycodone for nine years, and six months ago my specialist suggested that I try buprenorphine. It's been a difficult six months, and I'm not at the end of this yet, but I'm not going to give in. I need to know what life is going to be like when I am completely off oxycodone and only on buprenorphine. At present, the side effects are horrible and I'm not functioning that well, but the RLS in my legs is definitely better. I hardly get it in my arms at all now, and the pain has also been reduced.

I can't believe what I'm reading about the CDC opioid prescribing guideline. Without the opioid I wouldn't have survived. I'm sure there are many people out there like me, suffering like me. If only someone could come up with a device that creates or mimics the sensation and pain we suffer. The CDC must understand what we deal with night and day, and how it impacts our lives and mental health. Opioids saved my life! – *Deborah from the UK*

**Medical Editor's note:** I recommend returning to oxycodone to avoid the horrible buprenorphine side effects.

I am an 80-year-old lady who has had RLS for 40 years. For the first 30 years, Mirapex worked beautifully, but then augmentation happened and I had to stop using dopamine agonists. My doctor then prescribed Neurontin, then Lyrica, but neither had any effect. By this time, my RLS had become very severe and unresponsive to standard pharmacologic agents. I knew the only medications that would provide any measure of relief were opioids. But my primary care provider said she would never under any circumstances prescribe opioids for RLS. I saw a neurologist who would prescribe one 50 mg tablet of tramadol taken every other day. He then referred me to a pain clinic. The doctor at the pain clinic was wonderful and prescribed hydrocodone four times a day as needed. I want to share my experience so you and your doctor can consider another avenue to obtain critically needed opioids. – *Dorothy C.*

I began having symptoms of RLS at around age 4 or 5. My mother also suffered from RLS, and back then she was told it was all in her head. She recognized what was happening to me and would put me in a warm bath, massage my legs and sing songs or tell me stories until I would fall asleep. Of course, she tried taking me to doctors who always said the same thing – it's growing pains.

For many years, I fought it like so many others, getting very little quality sleep. I finally saw a neurologist who put me on Requip. Within a short time, I began experiencing symptoms earlier in the day, so he switched me to Mirapex. I took that for a long time and once again started having earlier and more intense symptoms. In those days, they believed the disease was progressing so they increased the dosage. At that time I had not heard about augmentation or refractory RLS. Many of you know this story. I know because I read your stories and I understand all too well.

Fast forward, I am now 65, and it is a daily struggle. I'm one of the unfortunate RLS sufferers who didn't respond to many of the prescribed medications currently recommended for treatment. Fortunately, I was directed by one of the members of the Portland OR Support Group to a specialist at Kaiser Permanente, and she started me on a low-dose opioid along with 0.125 mg of Mirapex, which I am still taking four years later. But it hasn't been easy convincing new doctors and new insurance providers to continue prescribing these medications that make my life livable. It seems I'm always being questioned by pharmacists, insurance companies, and doctors unfamiliar with RLS. I have taken the exact same low dose since I started. I've never asked for it to be increased and I take it exactly as prescribed. I get so frustrated at the sideways looks, having to explain myself and being treated as if I'm a criminal just for trying to get a little sleep.

As I age, not getting quality sleep becomes more concerning, as sleep is so crucial to healthy living. So, I continue to advocate for RLS by taking literature to my care providers, writing to lawmakers explaining what I live with on a daily basis, and taking every opportunity to talk to people about this dreadful disease. I am so grateful to the RLS Foundation for providing me with important information to give to my doctors' offices and for all the hard work they do each day in the fight for better understanding and education of a disease that affects so many people. Thank you! – *Elizabeth*



*In a recent RLS Foundation webinar, Mark Buchfuhrer, MD, FRCP(C), FCCP answered questions posed by the audience. The recording, Ask the Doctor with Dr. Buchfuhrer, will be made available soon as a podcast in the Member Portal on [www.rls.org](http://www.rls.org).*

## Treatment

### **Q: Are RLS movements voluntary or involuntary?**

**A:** Movements with RLS are both voluntary and involuntary. When your body reacts to RLS symptoms by responding to the urge to move, such movements are considered voluntary. However, 85%–90% of RLS patients experience periodic limb movements in sleep (PLMS), which are involuntary leg movements that occur during sleep and sometimes also occur in RLS patients while they are awake and at rest.

### **Q: How common is RLS in the upper body, and why is it so much more severe than RLS in the legs?**

**A:** RLS always first occurs in the legs, and then it can spread to other areas of the body, typically the arms. It is more severe because it occurs concurrently with the progression or worsening of RLS, which most commonly develops as a side effect of augmentation.

### **Q: I've had RLS for many years. I'm on three meds, and at I am on a hydrocodone regimen, allowing me to sleep at night. However, my RLS is becoming worse in the daytime. What do I do?**

**A:** Hydrocodone is an opioid that is not associated with augmentation and therefore would not be the cause of worsening RLS symptoms. It is recommended that you look at other factors that may be triggering daytime symptoms. For example, increased stress, changes in activity, decreased iron levels, a change in lifestyle, or additional medications like antihistamines or antidepressants can cause RLS symptoms to worsen.

### **Q: I'm trying to get pregnant and for a decade have been on Mirapex, which is possibly not safe for use during pregnancy. What do I do?**

**A:** Mirapex is not approved for use during pregnancy. It is important to monitor iron status throughout your pregnancy, as the fetal needs for iron and increasing blood volume can lower iron levels in pregnant women. Avoid any factors that can exacerbate RLS, such as various medications and triggers. It is also important to include mild-to-moderate, low-intensity physical activity (approved by your OB-GYN) to minimize RLS symptoms.

There are several medication alternatives to Mirapex (pramipexole) that you can ask your doctor about: Clonazepam (benzodiazepine); Sinemet, a dopamine agonist not typically taken daily for non-pregnant women, but okay on a daily basis for a few months; and methadone or other opioids such as oxycodone, used in very low doses. However, there are some potential risks of opioids, which include neonatal withdrawal syndrome or respiratory depression, which is why opioids should only be used in the most severe cases.

### **Q: Is RLS a disease that will progressively get worse as I age, and if so, is there any way to stop the progression?**

**A:** RLS is a disease that progresses slowly over decades. There are a few things you can do to stop progression, such as checking and replacing iron if needed to achieve adequate iron levels, maintaining moderate physical activity, and avoiding medications and foods that may trigger or make RLS symptoms worse.

### **Q: What is the first-line treatment for RLS in children?**

**A:** The first line of treatment for RLS in children is iron therapy. While oral iron can be used, the most effective treatment is intravenous iron therapy. Gabapentin can also be used to help alleviate both RLS and insomnia in children.

## Medications

### **Q: Are any studies being done on the use of buprenorphine in the treatment of RLS?**

**A:** My team was the first to use Belbuca (which is pure buprenorphine, a partial opioid) in low doses for RLS. While there are no published studies, over 100 of my patients use it and report few side effects. It is, however, often an expensive medication. Dr. Christopher Earley was the first to use generic Suboxone (which contains buprenorphine and naloxone) to treat RLS, which gave me the idea to use the newer (and more expensive) Belbuca.

### **Q: Can clonazepam cause secondary RLS, as other medications do?**

**A:** All cases of RLS should be considered primary rather than secondary, though people with a genetic predisposition to RLS may need a trigger or secondary event/condition that initiates symptoms. While there are certain medications that can trigger RLS, clonazepam can be used as a treatment to help RLS patients go to sleep. However, it has a long half-life, often resulting in daytime drowsiness.

### **Q: Does the long-term use of gabapentin cause neurological problems?**

**A:** No, the long-term use of gabapentin is not likely to cause neurological problems. The medication can cause short-term problems such as memory loss, drowsiness or depression due to depressing brain function, but consistent use is unlikely to cause long-term damage.

### **Q: I am taking 0.5 mg of Mirapex daily. I want to try the 10-day drug holiday. Can an opioid help with the holiday?**

**A:** An opioid can help with a 10-day drug holiday and is often used to wean patients off of dopamine agonists. Possible side effects may include constipation and depression. However, once you restart the Mirapex, it will work better for only a few days or weeks, and then you will regress back to where you were before the drug holiday.



**Q: Is dipyridamole a reasonable treatment for RLS?**

**A:** Dipyridamole is a medication that increases adenosine in the brain. RLS patients have low adenosine levels, and taking dipyridamole will help to increase those levels. A study by Dr. Sergi Ferré, funded by the RLS Foundation, found dipyridamole to be effective in raising brain levels of adenosine. Another study by Dr. García-Borreguero found that RLS patients without augmentation who took dipyridamole experienced improvements in their RLS symptoms.

**Q: What's next if opioids stop working?**

**A:** The first step is to determine if there are any new medications that have been added to your treatment that may worsen your RLS. Second is to look for iron loss due to surgery or unexplained bleeding disorders, as these can lower iron levels and worsen RLS symptoms. Third, consider: Has there been a change in your activity level due to recent surgery, or a new job that has made you more sedentary?

You can then examine the dosage of your medication. It is unlikely that opioids would stop working entirely, and only a small percentage of patients are on very high doses. There are likely other factors worsening your RLS, but the next step regarding medications would be to try combination therapy. The Neupro patch, gabapentin, dipyridamole or an iron infusion can be used in addition to the prescribed opioids to get better control of RLS symptoms.

**Q: I am going in for surgery soon and I am wondering how I can best prepare myself regarding my medications.**

**A:** Make sure all doctors, surgeons and other medical professionals are aware of your RLS. Bring the Medical Alert Card provided by the RLS Foundation, which lists medications to avoid because they can worsen RLS, as well as acceptable substitutes. Contact the RLS Foundation for the handouts titled *Surgery and RLS for the Patient* and *Hospitalization Checklist for the Patient with RLS*. Consult your doctor, but continue to take your medications regularly up to the day of surgery.

## Augmentation

**Q: How do you deal with the risk of RLS augmentation when you have a patient who is taking levodopa to treat Parkinson's disease?**

**A:** RLS patients have sufficient dopamine but low iron levels, while Parkinson's patients have low dopamine but sufficient iron levels. For unknown reasons, patients with RLS and Parkinson's do not typically get augmentation on daily levodopa. However, other options may include non-dopamine drugs or the Neupro patch, which has a lower risk for augmentation.

**Q: I have been off dopamine agonists for three months but still have augmented symptoms. Can augmentation be permanent?**

**A:** The symptoms you are experiencing after a three-month period free of dopamine agonists should be considered your new baseline. These symptoms could be due to a natural progression of RLS, but they may have been permanently worsened due to the augmentation. After three months off dopamine agonists, further improvement is unlikely.

**Q: Is there any research involving repairing receptors damaged by long-term use of dopamine agonists?**

**A:** Dopamine agonist medications stimulate dopamine sub-receptors D2 and D3, but neglect D1 and D5. This may be the cause of augmentation, as the D1 receptors become hyperactive and worsen RLS symptoms. Dr. William Ondo received funding from the RLS Foundation to conduct a small clinical trial of Ecopipam, a drug that blocks D1 and D5 receptors. It was found to be a safe drug, but larger studies need to be done to determine its effectiveness for RLS.

**Q: Is it ever okay to occasionally use dopamine agonists after augmentation and recovery?**

**A:** The occasional or intermittent use of dopamine agonists is okay, but for short-term use only.

## Iron Therapy

**Q: Could RLS symptoms be iron related even if iron/ferritin levels test within the normal range?**

**A:** Yes. Iron and ferritin levels are evaluated by blood tests, which give iron levels in the blood but often do not reflect iron levels in the brain. However, the lower the level of iron in the body, the higher the possibility that the brain is not getting enough iron. Patients with ferritin levels less than 100 mcg/L and iron saturation levels less than 20% should be considered for aggressive iron replacement to achieve adequate iron levels in the brain.

**Q: If I get an iron infusion, what changes might I expect?**

**A:** After an iron infusion, approximately 60%–70% of patients experience an improvement of symptoms, sometimes enough to lower or eliminate medication, or at least to significantly relieve symptoms. Recommended iron infusion products include Injectafer, Feraheme, and INFeD.

**Q: Why is taking iron with vitamin C on an empty stomach more effective in raising your ferritin level?**

**A:** Vitamin C creates an acidic environment in the stomach, which promotes better iron absorption, as does taking the iron on an empty stomach. Intravenous iron is much better at increasing iron levels and decreasing RLS symptoms, since only a small percentage of patients can adequately increase iron levels in the brain with oral iron.

**Q: Are there any promising developments on the horizon?**

**A:** Dr. William Ondo is conducting research on the drug Ecopipam, which blocks D1 and D5 sub-receptors and may help to reduce or eliminate augmentation. There are studies being done on animals to determine the mechanism of RLS and possible treatments. My team is involved with neurostimulation research for treating RLS symptoms.

**Q: Can you discuss hereditary evidence for RLS? I am concerned for my children.**

**A:** RLS is likely caused by hereditary genes, believed to be related to genes passed on by the Vikings many centuries ago. There is also an environmental component, demonstrated by the 15% of cases where one twin develops RLS and the other does not.

## Comorbidities & Other Conditions

**Q: Can RLS be triggered by anxiety?**

**A:** Yes. All forms of stress – physical, mental and emotional – can trigger RLS.

**Q: Do you know of any correlation between RLS and autism spectrum disorder?**

**A:** It is often difficult to diagnose RLS in people with autism. While the correlation is unsure, studies have shown that intravenous iron given to children who have autism with likely RLS has a profound clinical effect.

**Q: Do you see a relationship between RLS and neuropathy of the feet?**

**A:** Yes, there is a relationship, as neuropathy is more common in RLS patients. Neuropathy can cause discomfort and distress, which may trigger RLS. However, in patients with neuropathy, it can be difficult to diagnose RLS, since many of the symptoms are similar.

**Q: Has there been any research done that might link RLS and Turner syndrome?**

**A:** There is no research on this topic.

**Q: Have there been any studies regarding menopause and the onset or exacerbation of RLS symptoms, and whether hormone replacement therapy may relieve symptoms?**

**A:** No studies have been done, but changes in hormones can affect RLS. In women who menstruate, it is very common for RLS symptoms to worsen during the PMS part of the cycle. Hormone replacement therapy and hormonal birth control pills can make symptoms better or worse, depending on the individual. Some female patients get better or worse with menopause, while others experience no change.

**Q: Is RLS linked to ADHD (attention-deficit/hyperactivity disorder)?**

**A:** There is a link, though it is not well understood. In a research study of children with ADHD, 25%–40% were diagnosed with

RLS. In children with RLS, over 25% were diagnosed with ADHD.

**Q: Is there a correlation linking RLS, sleep apnea and insomnia? If so, should one be tested for sleep apnea?**

**A:** There is a slight correlation. An inadequate quality of sleep due to sleep apnea and/or insomnia can cause an increase in RLS symptoms and a quicker onset of symptoms

## Alternative Therapies & Nonprescription Options

**Q: Has hypnotherapy ever been tried or been successful in decreasing RLS symptoms?**

**A:** There is no evidence that hypnotherapy relieves RLS.

**Q: Are there any lifestyle treatments that are being studied to improve symptoms? For example, lowering sodium or caffeine, or increasing exercise?**

**A:** Mild-to-moderate exercise can improve RLS, while vigorous exercise can worsen symptoms. Avoiding alcohol and drugs that worsen RLS, as well as food triggers, will help to reduce symptoms as well.

**Q: Are there any studies on successful nonprescription treatment options?**

**A:** Anecdotal evidence suggests that vibration devices or sequential compression devices can relieve symptoms when used at night. There is ongoing research to determine whether neurostimulation is a treatment option.

**Q: Are zinc and thiamine beneficial for RLS?**

**A:** There is no evidence that they are beneficial.

**Q: Can elevating the legs while sleeping help with RLS? I have an adjustable bed.**

**A:** Anecdotal evidence suggests that it may help some RLS patients.

**Q: Can treating varicose veins help lessen symptoms of RLS?**

**A:** There is no credible evidence that treating varicose veins will relieve symptoms.

## General Questions

**Q: I am traveling overseas soon. Other than walking around the airplane as much as possible, do you have any suggestions for relieving RLS?**

**A:** For shorter flights (up to four hours), Sinemet can help alleviate symptoms. For moderate flights (up to six hours), Tramadol is recommended. Patients who are already taking opioid prescriptions can take an additional dose, which can last from six hours to 12 hours, depending upon the opioid. Walk or move whenever you can, when the fasten seat belt sign is off. Contact the RLS Foundation for additional resources on traveling with RLS.

# RLS Support Network

RLS **support group leaders** bring people together to share their experiences, gain coping strategies, learn from medical experts, and build a community of care. For a list of international support groups, visit [rls.org/internationalsupport](http://rls.org/internationalsupport). The Foundation also has a network of volunteer RLS **support contacts** who provide help by phone or email.

You can find support at any time, day or night, on the RLS Foundation's **discussion board**. Visit [bb.rls.org](http://bb.rls.org) or email [rlsmods@rlsgroups.org](mailto:rlsmods@rlsgroups.org) for more information on how to get started.

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\*Member of RLS Foundation Board of Directors

## Register for a Virtual Support Meeting

Each month we host meetings at these times:

- First Tuesday at 3 pm ET
- Second Wednesday at 8 pm ET
- Third Thursday at 3 pm ET
- Fourth Saturday at 1 pm ET

To register for a Virtual Support Group meeting go to [www.rls.org/vsg](http://www.rls.org/vsg).

**Note:** VSG meeting dates are subject to change due to US national holidays. Check our website for the most up-to-date listing.

## Virtual Support Leaders:

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## Resolving to Be Extraordinary

Making resolutions is a New Year tradition. How to be better, happier, healthier, more effective, more caring, more aware and more fit in the 12 months ahead – that's what we all aspire to and, with luck and hard work, what we will succeed at.

We at the RLS Foundation have made a New Year's resolution to be more extraordinary in 2023. That's a tall order, but we're up to it. It means building on three decades of scientific leadership in the quest to cure RLS. Adding to 30 years of excellence in RLS diagnosis and care. And ensuring unabated advocacy to make our voices heard in the halls of power.

One way that our members are helping us become even more extraordinary this year is by chipping in less than 2 extra cents every day – the cost of increasing our annual dues from \$35 to \$40. This additional measure of support will really add up and allow us to serve our community even better than before.

But there is another step that you can take, as an RLS Foundation member, to turn ordinary into extraordinary. You can become a recurring supporter by authorizing a routine monthly donation to be charged to your credit card.

Regular monthly support is the lifeblood of the Foundation, ensuring that we can support our ordinary, routine budgetary

requirements. But recurring support also guarantees that we will be ready to react to the extraordinary, whether it's a critical need or a stellar new opportunity that emerges.

Your recurring gift might help us formulate and coordinate a response to newly found symptom concerns brought to our attention through our patient community. Your monthly support could give us the opportunity to grow awareness of new treatment methods among our healthcare provider network – or to build on the latest scientific findings with a new research initiative or clinical trial.

Recurring support is the key to meeting both ordinary and extraordinary needs with ample, ready resources. It's a safe and secure way for you to give, which you can change or cancel at any time. It means less printing and postage so that more of your gift goes into our program work.

But best of all, it allows us to be extraordinary whenever that moment calls. And it all becomes possible when you take your own extraordinary step and become an RLS (Recurring Leadership Support) Hero for the Foundation. Go to [www.rls.org/hero](http://www.rls.org/hero) for more information.

### Our QCCs are located in the following regions:

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**3.** Center for Sleep Medicine  
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**4.** Innsbruck Medical University, Department of Neurology, Sleep Lab and Sleep Disorders Outpatient Clinic  
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**5.** Stanford Sleep Medicine Center  
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**6.** Emory Sleep Center  
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## Publications

Most of the following publications are available for Foundation members to view and download at [www.rls.org](http://www.rls.org). Please note that all publications are copyrighted and may not be altered, used in whole or in part without prior permission from the RLS Foundation. Members that are unable to print from the website may order publications below.

Quantity	Patient Handouts	Quantity	Patient Handouts	Quantity	Patient Handouts
	Augmentation: Diagnosis & Treatment		Hospitalization Checklist		RLS Research Opportunities
	Can an Active Lifestyle Prevent or Improve RLS Symptoms?		Iron and RLS		Surgery and RLS
	Complementary/Alternative Medicine and RLS		Medication Withdrawal after Augmentation		Symptom Diary for RLS
	Coping Methods		Medications and RLS: Patient Guide		Triggers for RLS
	Depression and RLS		Pain and RLS		Recognizing Possible Mimics of RLS
	Drug Holidays and RLS		Periodic Limb Movements During Sleep		Your First Doctor Visit for RLS
	Guide to Living with RLS		Research Grant Program		
	Healthcare and Your Child with RLS		RLS and Aging		
Quantity	Patient Brochures	Quantity	Patient Brochures		
	Causes, Diagnosis and Treatment for the RLS Patient		RLS Guide for Children		
	Giving Avenues		RLS Guide for Teens		
Quantity	Healthcare Provider Brochures	Quantity	Healthcare Provider Brochures		
	Pregnancy and RLS: A Guide for Healthcare Providers		RLS and PLMD in Children and Adolescents		
	2021 RLS Medical Bulletin: RLS Diagnosis and Treatment				

## MEMBERSHIP

☐ Yes, I want to join the Restless Legs Syndrome Foundation or renew my annual membership for \$40 paid in US dollars.

## DONATION

☐ I would like to make an additional tax-deductible donation of \$\_\_\_\_\_.

☐ I would like to make a recurring monthly gift of

\$\_\_\_\_\_ Start date: \_\_\_\_\_

## DONATION APPLIED TO

- ☐ Research  
☐ Richard P. Allen Memorial Research Fund  
☐ Robert H. Waterman Memorial Research Fund  
☐ Where it is needed most

## PAYMENT METHOD

☐ I have enclosed a check in the amount of \$\_\_\_\_\_ in US dollars, drawn on a US bank, payable to the RLS Foundation.

☐ Please charge \$\_\_\_\_\_ to my ☐ American Express ☐ Discover ☐ MasterCard ☐ VISA

Card number \_\_\_\_\_ Expiration date \_\_\_\_\_

## CONTACT INFORMATION (Please make any changes to address on reverse side. We do not rent, sell or share our mailing list.)

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## Common Medications That May Trigger RLS Symptoms

### Antihistamines

All sedating antihistamines containing diphenhydramine; Benadryl, Robitussin, Dimetapp, cold & flu products

Alternatives: Allegra, Clarinex, Claritin, Xyzal, Zyrtec (usually)

### Antidepressants

SSRIs like Cymbalta, Effexor, Paxil, Prozac, Serzone, Zoloft; Tricyclics like Elavil, Tofranil

Alternatives: Wellbutrin, Norpramin (desipramine), Desyrel (trazodone), Depakote

### Atypical Neuroleptics

Clozaril, Risperdal, Seroquel, Zyprexa

Alternative: Abilify (possibly)

### Note:

Response to any of these medications may vary; consult with your physician on how they may impact your RLS symptoms.

### Antinauseates

Compazine, Dramamine, Phenergan, Reglan, Vistaril

Alternatives: Zofran, Kytril (nausea); Transderm Scop (motion sickness)

### Sleep Aids

All containing diphenhydramine or doxylamine, Advil PM, Bayer PM, Excedrin PM, Silenor, Sominex, Tylenol PM, Unisom

Alternatives: Ambien, Lunesta, Sonata, Suvorexant

### Antipsychotics

Haldol, Loxitane, Mellaril, Moban, Navane, Prolixin, Serentil, Seroquel, Stelazine, Thorazine, Vesperin

