NIGHTWALKERS

In search of a good night's sleep

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IS THERE STILL A ROLE FOR DOPAMINE AGONISTS?

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Celebrating Our 33rd Anniversary

The RLS Foundation has been a beacon of hope, aid and support for the RLS community since 1992. As we mark our 33rd anniversary in June, we celebrate advances from the last three decades and look to a future with better treatments and a cure. Let's look at some of the progress for RLS:

Genetics. A 2024 study published by Schormair et al. discovered 164 risk genes, with three specifically on the X chromosome. Genome-wide association studies (GWAS) are an important tool in the discovery and confirmation of risk genes for RLS.

Iron Dysregulation and Brain Imaging. Iron dysregulation has been implicated as a cause of RLS. Thank you to the earliest members of the RLS Foundation who made the ultimate gift of brain donation, permitting researchers to unlock the relationship of iron and RLS through the study of these tissues housed at the Harvard Brain and Tissue Resource Center.

Brain imaging holds promise for detecting iron deficiencies to determine which areas of the brain are affected by low brain iron and to evaluate the effects of treatment in follow-up studies.

RLS Foundation Treatment Guidelines. Pharmacologic treatment for RLS has evolved in the last three decades, and treatment guidelines are updated as our understanding of the disease advances. The RLS Foundation published treatment guidelines in Mayo Clinic Proceedings in 2004, 2013 and 2021, and will publish an update later this year. A group of volunteer RLS clinicians and researchers who serve on the Foundation's Scientific and Medical Advisory Board, are currently drafting this supplement.

Advocacy. The RLS Foundation has been advocating for the needs of our community with three overarching legislative priorities: treatment access, research funding at the federal level and awareness and education outreach at the Centers for Disease Control and Prevention.

Progress takes time, talent and an organized effort that supports the voice of our community. Since 1992, the support of RLS Foundation members like you has made this possible. Whether publishing new treatment guidelines, advocating on Capitol Hill, funding promising new research or providing educational resources and expert opinions, your RLS Foundation supports you and the greater RLS community.

When you receive your membership renewal notice this August, know that your support keeps us on the front lines for you, and others like you, who live with the daily challenges of RLS.

Karla M. Dzienkowski

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 March 1 to May 15, 2025.

In Honor of:
All who suffer
Roger Backes
Dr. Richard Bogan
Barbara Farrell
Colette Shoukas
Dr. John Winkelman
Jim Wood

In memory of:
Nancy Crnkovich Ayad
Steve Crnkovich
Helen A. Brown
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Elizabeth "Bill" Tunison
David Van Wassen
My mother and brother with RLS

Is There Still a Role for Dopamine Agonists in RLS?

By Michael Silber, MBChB and John Winkelman, MD, PhD

The American Academy of Sleep Medicine (AASM) recently published a new clinical practice guideline on the management of restless legs syndrome.[1] The guideline has elicited some controversy with respect to the recommendations regarding dopamine agonist medications. This article is co-written by Dr. John Winkelman of Harvard Medical School, who chaired the task force preparing the guideline, and Dr. Michael Silber of Mayo Clinic.

The AASM methodology for clinical practice guidelines allows only two levels of recommendations – strong or conditional – for or against a specific treatment. After careful consideration, the AASM guideline task force decided that dopamine agonists (ropinirole, pramipexole and transdermal rotigotine) should receive a *conditional* recommendation against their standard use for RLS. This recommendation was based on the task force's serious concerns that the combination of the high incidence of augmentation, the lack of augmentation recognition by many practitioners, augmentation's probable irreversibility for many people with RLS, and the difficulties in managing augmentation when it occurs, outweigh the established short-term benefit of these medications.

However, the task force included a statement that each of these drugs "may be used to treat RLS in patients who place a higher value on the reduction of restless legs symptoms with short-term use and a lower value on adverse effects with long-term use (particularly augmentation)." The guideline adds in the discussion section that "dopamine agonists… may be considered in the context of short-term use in circumstances in which movement is restricted (e.g., plane travel), as well as with poor tolerability or lack of efficacy of other RLS therapies."

There is a widespread consensus among RLS experts, reflected in the new guideline, that the alpha-2-delta ligands, also known as gabapentinoids (gabapentin, gabapentin enacarbil and pregabalin), should be the standard first-line agents for treating chronic persistent RLS after other correctable factors, such as relative iron deficiency, are addressed.

SO, IS THERE STILL A ROLE FOR DOPAMINE AGONISTS?

Yes, and there are three circumstances in which they should be considered.

First, patients with RLS and their healthcare providers may have concerns about considering alpha-2-delta ligands because of potential side effects. These include patients concerned about the drugs causing weight gain, patients with active or inactive depression concerned that the drugs could worsen their mood or precipitate a relapse, or patients with neurologic disorders causing unsteadiness concerned that the drugs might increase their risk of falling. If dopamine agonists are considered for these patients instead of alpha-2-delta ligands, the relative risks of the two classes of medications should be carefully balanced in reaching a shared decision by the patient and the provider.

Second, patients who do take alpha-2-delta ligands may develop intolerable side effects from the doses needed to control their RLS. These side effects might include dizziness, unsteadiness, brain fog, weight gain, depression or leg swelling. Third, not all RLS patients obtain relief with alpha-2-delta ligands. For instance, in the large, controlled trial of pregabalin,[2] 29% of patients had little or no response to treatment based on the Clinical Global Impression of Improvement (CGI-I) Scale; this is similar to what is seen in clinical practice.

It is important to understand the risk of augmentation in patients who are started on dopamine agonists. A study from Johns Hopkins University of 164 patients on pramipexole found the rate of augmentation to be 7% per year over 10 years for an average of approximately 70% augmented over the 10 year span.[3] A Mayo Clinic study of 40 patients on pramipexole found that 42% developed augmentation over an average of 8 years of use.[4] A questionnaire-based community study of 266 patients treated with either levodopa or a dopamine agonist for RLS suggested that augmentation occurred at a rate of approximately 8% per year over 8 years of treatment (64%).[5] Therefore, although augmentation is very common, it appears that at least one-third of patients using dopamine agonists for 8–10 years may not experience it and may continue to benefit from the medications. However, as some patients will use RLS medications for over 10 years, and as it is not clear how to identify those who will develop augmentation before starting treatment, caution is warranted.

It is also important to emphasize that unlike side effects from other medications (e.g., alpha-2-delta ligands), augmentation is not immediately apparent. In fact, substantial symptom relief is often present at the outset; this is often called the "honeymoon period." The changes in timing and distribution of RLS symptoms that occur with augmentation usually develop insidiously, often over a period of a few years, leading both patients and providers to believe it is a "natural" worsening of

the RLS, thus delaying awareness of this complication. This delay, and the dosage increases that usually accompany it, make treating augmentation (by taper and discontinuation of the dopamine agonist) much more difficult.

The new guideline emphasizes that when dopamine agonists are offered as treatment choices, important steps should be taken to reduce the risks. First, patients must be educated on the symptoms of augmentation and impulse control disorders. If such changes occur, patients should report them to their healthcare providers. Second, healthcare providers prescribing dopamine agonists must carefully question their patients about symptoms of augmentation and impulse control disorders at every follow-up visit. Third, as the risk and severity of augmentation increases with dose, the most effective way of reducing this risk is to keep the doses of dopamine agonists low. In standard clinical use, the total daily dose of pramipexole should not exceed 0.5 mg, the total daily dose of ropinirole should not exceed 4 mg, and the daily strength of the rotigotine patch should not exceed 3 mg. Doses above these levels represent a high risk of causing augmentation.

Patients and providers should not interpret the new guideline to mean that all patients currently on dopamine agonists should be taken off these drugs. As discussed, there is a significant minority of patients who may not develop augmentation and may safely use the medications long term. If a patient and their provider decide it would be in the patient's best interests to discontinue dopamine agonists, especially if augmentation has already developed, this should be done very slowly, generally over several months, after first correcting any factors that might worsen restless legs, such as low iron values. Abrupt discontinuation of dopamine agonists may cause dopamine agonist withdrawal syndrome, characterized by profound insomnia, marked worsening of restless legs, increased anxiety and occasionally even suicidal depression. In most cases, alternative RLS treatments must be introduced before making any reduction in the dopamine agonists. If patients have not used adequate doses of alpha-2-delta ligands in the past, these drugs should be considered, but in many patients, low-total-daily-dose opioid therapy will be needed.

In summary, the new AASM guideline draws much-needed attention to the risks of augmentation with long-term dopamine agonist therapy. As the guideline recommends against their use only *conditionally*, it should not be interpreted as prohibiting the use of dopamine agonists for RLS in all circumstances. With adequate warnings to patients and careful monitoring, and if doses can be kept low, dopamine agonists can still play a role in the management of RLS in patients for whom iron is not appropriate or effective, for those who do not want to attempt alpha-2-delta ligands, or when alpha-2-delta ligands are ineffective or cause unacceptable side effects. However, it is important to realize that dopamine agonists are not the only or even necessarily the preferred alternative drugs. Other options, including iron therapy, opioids, dipyridamole and peroneal nerve stimulation, are *conditionally* recommended in the recently published AASM guideline. These options will be discussed in the following articles by Dr. Andy Berkowski and Dr. Elias Karroum.

1. Winkelman JW, Berkowski JA, DelRosso LM et al. Treatment of restless legs syndrome and periodic limb movement disorder: An American Academy of Sleep Medicine clinical practice guideline. *J Clin Sleep Med*. 2025; 1;21(1):137-152. doi:10.5664/jcsm.11390.
2. Allen RP, Chen C, Garcia-Borreguero D et al. Comparison of pregabalin with pramipexole for restless legs syndrome. *N Eng J Med*. 2014; 13;370(7):621-31. doi: 10.1056/NEJMoa1303646.
3. Silver N, Allen RP, Senerth J, Earley CJ. A 10-year, longitudinal assessment of dopamine agonists and methadone in the treatment of restless legs syndrome. *Sleep Med*. 2011;12(5):440-4. doi: 10.1016/j.sleep.2010.11.002.
4. Lipford MC, Silber MH. Long-term use of pramipexole in the management of restless legs syndrome. *Sleep Med*. 2012 13(10):1280-5. doi: 10.1016/j.sleep.2012.08.004.
5. Allen RP, Ondo WG Ball E, et al. Restless legs syndrome (RLS) augmentation associated with dopamine agonist and levodopa usage in a community sample. *Sleep Med*. 2011; 12(5):431-9. doi: 10.1016/j.sleep.2011.03.003.

RLS Foundation News!

A taskforce from the RLS Foundation's Scientific and Medical Advisory is updating its guidelines for the treatment of RLS. We hope to have these guidelines published this fall or early next year. The guidelines will include new recommendations for the care and management of RLS, including medication and nonmedication strategies with attention to special populations.

Staying connected with the RLS Foundation ensures you'll be among the first to receive updates and resources as they become available. Follow us on Facebook or Instagram (@RLSFoundation), and be sure to renew your membership for 2026 by September 30 at **rls.org/joinnow**.

AASM Guidelines: Iron and Opioid Recommendations

By Andy J. Berkowski, MD

Andy J. Berkowski, MD, is a member of the Scientific and Medical Advisory Board of the RLS Foundation. This article explores iron therapy and low-total-daily-dose opioids for RLS management based on a recently published American Academy of Sleep Medicine (AASM) guideline for treating RLS and periodic limb movement disorder. Dr. Berkowski served as vice chair of the task force that authored the guideline.

The Role of Iron Therapy Based on the AASM Guideline

The scientific understanding of what causes RLS most significantly points to low iron levels in the brain as an essential factor. However, the mainstream medical system in the US remains largely unaware of research developments in this area over the past two decades. This is seen when third-party payers (i.e., insurance companies) will not cover lab testing and IV iron infusions under the diagnosis of RLS. It extends to primary care clinicians failing to administer iron testing and treatment in the first place, even to patients with very low iron levels who stand to benefit the most.

Iron plays a substantial role in the management of RLS – so much so that our AASM task force added a "Good Practice Statement" at the beginning of the guideline to stress the importance of iron assessment and therapy. The Good Practice Statement is separate from the treatment recommendations and serves as a signal of standard practices that should be reinforced when treating all RLS patients. Good Practice Statements like this one are considered by experts to be almost like a universal principle. In this case, the AASM makes it clear that iron levels in the blood should be checked regularly in those with RLS. Whether this means quarterly or annually, is not important when juxtaposed with the fact that many patients have never had levels checked, much less on a regular basis. The hope is that this gets codified into the everyday practice among doctors and the clinical standards for treating RLS. Additionally, tests for ferritin and iron with total iron binding capacity (TIBC) must be performed together. Both tests may provide different information, and falsely high levels on one test may be disregarded if the other test is low, and thus, more accurate.

Below are some of the suggested parameters for oral iron supplementation (by mouth) and IV iron infusion based on lab results. Unfortunately, the reference ranges in standard lab reports are misleading to both patients and clinicians who may not be familiar with assessing these test results. Reference ranges generally report the average results of the population of people in the geographic region, but not necessarily the range of results that would be considered normal or acceptable medically. Applying reference ranges can thus be misleading. Moreover, those with RLS need much higher blood iron levels than the general population. For example, a lab may list a ferritin range of 10—350 ng/mL, but ferritin < 40 ng/mL is considered low for the general population and < 100 ng/mL for RLS.

In the guideline, we specify that for RLS patients, oral iron or IV iron can be administered when ferritin < 75 ng/mL or transferrin saturation < 20% (abbreviated TSAT%, TSAT = iron/TIBC x 100). Since oral iron cannot be easily absorbed above a ferritin of 75 ng/mL, IV iron is the only recommended option for those with ferritin 75—100 ng/mL. In children, the threshold for administering ferritin is 50 ng/mL for oral iron. We selected these numbers based on the cutoffs used in clinical trials for various types of iron, and there have not been large studies of those with levels above ferritin of 100 ng/mL. Some individuals may benefit from infusion at higher iron levels, but more research is needed on how to identify those individuals other than by doing a one-time trial in each person.

Turning to the treatment recommendations, three forms of IV iron and one form of oral iron are recommended in adults with RLS. Unlike other guidelines, the AASM guideline does not factor in expert opinion but only the data from high-quality published studies, which can limit the number of treatments recommended. Ferric carboxymaltose had the most high-quality research and garnered a *strong* recommendation for RLS treatment while oral ferrous sulfate, IV low molecular weight iron dextran, and IV ferumoxytol are *conditionally* recommended for RLS treatment. This by no means suggests that carboxymaltose is clearly better than, say, dextran. The AASM guideline groups the forms of iron by ratio of benefit to harm, factoring in the level of supporting published research. There are no head-to-head trials of carboxymaltose and dextran, but there are significantly more randomized, controlled trials (RCTs) for carboxymaltose to support its use. It does not mean that dextran would not be strongly recommended if it also had four large RCTs to support it. Other forms of iron, such as oral ferrous bisglycinate and IV ferric derisomaltose, are likely also effective, but they are not mentioned as there are no studies to support a recommendation by the guideline's protocol.

A few other considerations about iron treatment: The guideline neither recommends for nor against the use of IV iron sucrose in adults. The published research could not support a recommendation for this formulation, and the implication is that it should not be used over more proven treatments. IV iron sucrose is one of the most commonly administered and lowest-cost IV iron formulations in the US. However, clinical trials have not shown a benefit in adults with RLS, with the exception of people with end-stage renal disease, or ESRD (i.e., those on hemodialysis), and it was assigned a *conditional* recommendation for use only in people who have RLS and ESRD. Beyond what can be stated in the guideline, it is clear to experts that iron sucrose is not as effective as the three IV formulations recommended, though it may still be better than no treatment. There are chemical differences that support why iron sucrose would be less effective in those with RLS rather than just lacking the research. Conversely, there were no IV formulations recommended for children with RLS. This is clearly because of the lack of published research to date, not because RLS experts do not think IV iron would be effective. These are the limitations of this type of strict, evidence-only guidelines.

The Implications for Opioids Based on the AASM Guidelines

It is well understood that opioids are among the most potent treatments for RLS, with their use dating back to the 17th century. More recent research demonstrates opioid system deficiencies in people with RLS that may help to explain why low doses of these medications provide significant relief of symptoms. However, there has been a tremendous backlash against opioids in the medical field amidst the backdrop of the ongoing opioid epidemic, leading to a great reduction of their use for chronic pain and other conditions. And while opioids may be more effective for reducing RLS symptoms than treatments strongly recommended in the AASM guideline, the potential harms of opioids are also greater, particularly the risks of physical impairment, abuse, chemical dependence, and serious injury or death from the breathing effects of poisoning or overdose. However, the AASM task force felt that the benefits clearly outweigh these risks, particularly as studies suggest the relative safety and stability of these drugs at low doses, specifically in RLS treatment. Moreover, in patients with dopaminergic augmentation, many of the standard recommended treatments for RLS may not be effective, and opioids may be the only treatment strong enough to enable a successful tapering off dopamine agonists. The AASM guideline thus conditionally recommends oxycodone and other opioids for the treatment of RLS.

One may notice in the guideline the interesting wording "oxycodone and other opioids." Why specify oxycodone and why no mention of buprenorphine and methadone, which are used more often than oxycodone? Typically, AASM guidelines evaluate specific drugs, not classes of drugs, and they are based exclusively on high-quality published studies. Sadly, there was only one qualifying study that looked at the benefit to RLS severity for opioids, which happened to be extended-release oxycodone. However, the AASM task force noted a clear class effect for opioids – meaning, not just one drug but the class of drugs is effective. Thus, even though the one quality study was of oxycodone, it is obvious that the same effect would be seen in other opioids, which should be selected based on the person with RLS and their health situation.

A few last notes: Opioids are in the same "*conditionally* recommended for" section with other treatments like ferrous sulfate, peroneal nerve stimulation and dipyridamole; the guideline does not rank treatments in order of use, nor does it imply that these treatments are all equal. They are simply a classification of the differences in benefits over harms and the level of research available. Even strongly recommended agents like IV ferric carboxymaltose or gabapentin may work less frequently than opioids in symptom relief, but the amount of research and the benefit/risk ratios for these exceed that of opioids. This conditional recommendation for opioids is essential to patients with moderate to severe RLS in which first-line interventions have not been successful, particularly those with augmentation. Amidst the difficulties many RLS patients have in accessing opioids appropriately and the hesitation among medical providers to prescribe them, this guideline may help to preserve some of the access to and third-party coverage of opioids as an evidence-based, recommended treatment for the condition. And those suffering with RLS can use all the help they can get.

In the following article, further treatment options including dipyridamole and peroneal nerve stimulation will be discussed.

Dr. Berkowski is a member of the Scientific and Medical Advisory Board of the RLS Foundation. He is the founder of ReLACS Health, a direct specialty care clinic specializing in telemedicine care of RLS and complex sleep disorders, currently serving patients in Arizona, Florida, Michigan, Ohio and soon Minnesota.

AASM Guidelines: Further Recommendations

By Elias Karroum, MD, PhD

Elias Karroum, MD, PhD is a member of the RLS Foundation Scientific and Medical Advisory Board and Director of the RLS Quality Care Center at the University of Virginia. This article explores dipyridamole and tonic motor activation (TOMAC) device for RLS management based on a recently published American Academy of Sleep Medicine (AASM) guideline for treating RLS and periodic limb movement disorder. Dr. Karroum served on the task force that authored the guideline.

In the newly published RLS guidelines by the AASM,[1] two new treatments were considered: dipyridamole and bilateral high-frequency peroneal nerve stimulation (also referred to as tonic motor activation). These two treatments are *conditionally* recommended for adults with RLS.[1] These recommendations are based on an extensive systematic review and pooled data analyses from several studies and subsequent assessment of the evidence quality results using the GRADE process (the Grading of Recommendations Assessment, Development, and Evaluation). The GRADE process consists of four components that shape the direction and strength of a recommendation for a particular treatment. These components include: certainty of evidence, balance of benefits and harms, patient values and preferences, and resource use considerations.[2]

Dipyridamole as a Treatment Option

The rationale to use dipyridamole to treat RLS symptoms was predicted by preclinical studies supporting the existence of a hypo-adenosinergic (low adenosine) state induced by brain iron deficiency in RLS.[3] The molecule adenosine is an organic compound that plays a key role in sleep and wake cycles and the regulation of blood flow to different organs. Adenosine has a suppressive (inhibitory) effect on the nervous system.

In contrast, dipyridamole, used historically for stroke and vascular disease prevention, is a well-known enhancer of adenosine and therefore could contribute to counteracting this predicted decreased adenosine state in the brain of RLS patients.[3] Based on the above rationale, two clinical trials were conducted to test dipyridamole in previously untreated RLS patients.[4,5] The first study was an open-label, non-placebo trial of 15 patients, that examined the efficacy of dipyridamole after eight weeks of treatment.[4] The second study was a randomized, double-blinded, placebo-controlled, crossover trial consisting of 28 participants.[5] This trial tested the efficacy of dipyridamole after two weeks of treatment, and although small, was well-powered and adequate enough to detect significant clinical efficacy between dipyridamole and the placebo. Both of these studies demonstrated clinical efficacy of dipyridamole significantly improving RLS symptoms. The strength of these studies relied not only on subjective rating scales, but also on objective testing for evaluation. Common side effects of dipyridamole were abdominal distension and cramps, dizziness, diarrhea, flushing and fatigue. Symptoms were mild and generally did not lead to discontinuation in the above two studies, except in the open-label study where two patients discontinued dipyridamole after two days due to dizziness.[4]

The task force of the new AASM guideline judged dipyridamole to have an overall low certainty of evidence with a potential benefit that outweighs the potential harms, at a negligeable cost and RLS patients would generally accept that treatment.[1,2] It is important to note, that in both clinical trials, RLS patients were evaluated over a short period of time and were not taking any other medications to manage symptoms. Therefore, although promising, further research is needed to examine the long-term efficacy and side effects of the drug. Furthermore, research is needed to determine the efficacy of dipyridamole in refractory RLS patients or RLS patients taking other medications for RLS management including dopaminergic agents.

Tonic Motor Activation as a New Treatment Option

The bilateral high-frequency peroneal nerve stimulation device, or tonic motor activation (TOMAC) device, is a new wearable, non-invasive, non-pharmacological therapy that recently received clearance and approval by the Food and Drug Administration in 2023 for the treatment of moderate-to-severe and medication-refractory RLS in adults. Developed by Noctrix Health and commercialized under the brand name Nidra, it is available in several US states. The device is worn on the lower legs below the knee over the peroneal nerve, delivering 30-minute sessions that electrically stimulate specific nerve fibers in the peripheral nerve causing a sustained (tonic) activation of the tibialis anterior muscle. Therefore, the mechanism of action of this device is postulated to produce similar effects as the ones voluntarily performed by RLS patients to alleviate RLS symptoms (e.g., walking, standing).[6] Two randomized, sham-controlled, multicenter clinical trials, of moderate-to-severe RLS patients involving the TOMAC device, were available during the review process.[1,2] The first study was a small, mixed, single-blinded, crossover trial tested

over two weeks.[7] The second study, (RESTFUL study), was a larger, double-blinded, parallel trial with efficacy tested after four weeks.[8] It was followed by an open-label second phase, where all participants were switched to active TOMAC therapy for an additional four weeks. Both studies demonstrated clinical efficacy of the TOMAC device with significantly improving RLS symptoms at two weeks[7] and four weeks,[8] respectively.

In addition, the RESTFUL study also demonstrated significant improvement in the sleep quality of participants at four weeks as well as a continued improvement in RLS symptoms and sleep at eight weeks of TOMAC treatment.[8] In both clinical trials, adverse side effects were mostly mild, resolving quickly and decreasing over time.[8] Commonly reported TOMAC device-related side effects included uncomfortable sensations during stimulation and skin irritation at the site of the stimulation. The AASM guideline task force judged the TOMAC device to have an overall moderate certainty of evidence with a potential benefit that outweigh the potential harms, at a high cost and RLS patients would in general accept that treatment. It is important to note that three additional studies have been published related to the treatment of RLS patients with the TOMAC device,[9-11] but were not published yet and therefore were not identified in the guideline. One open-label study was an extension of the TOMAC device RESTFUL trial.[9] Medication-refractory RLS patients were assigned to two separate groups with one receiving TOMAC therapy (44 RLS patients) and the second control group receiving no TOMAC therapy (59 patients). The two groups were followed over 24 weeks and RLS patients using the TOMAC device continued to show improvement in RLS symptoms and sleep quality. They were only mild side effects that resolved without medical intervention which diminished in frequency over longer time of treatment with the TOMAC device and without any discontinuation of therapy.[9]

Another multicenter, mixed, participants-blinded, sham-controlled, randomized, parallel trial was conducted to further evaluate efficacy of TOMAC over a two week period not only in medication-refractory RLS patients, but in patients who have never been treated for RLS.[10] To increase the sample size and power of the study for evaluating efficacy of TOMAC in RLS patients who had never been treated, a subsequent meta-analysis was performed by pooling data from the current trial[10] and a previous trial.[7] The results of this study reconfirmed the clinically significant efficacy and tolerability of TOMAC device as demonstrated in previous studies[7-9] for medication-refractory RLS patients. The meta-analysis of the two clinical trials[7-10] enrolled a total of 33 participants and showed a significant clinical improvement in previously untreated RLS patients on TOMAC therapy.

Finally, a small open-label, non-controlled study of 20 medication-refractory RLS patients on opioid therapy showed that TOMAC therapy could facilitate reduction in opioid dosage without increased RLS symptoms.[11] Taking all above five studies into account, it seems that TOMAC therapy has good evidence in clinical efficacy and safety in RLS patients, particularly for medication-refractory patients. Larger studies are needed to confirm the efficacy of this non-invasive and non-pharmacologic treatment in previously untreated RLS patients as well as its potential capacity to help in reducing dopaminergic agents in RLS patients with augmentation. In addition, we still need further long-term, real-world experience with this new treatment of RLS. Furthermore, the efficacy of this novel therapy should also be investigated, as could also be promising, in special populations with RLS where taking medications could be problematic such as during pregnancy.

REFERENCES

1. Winkelman JW, Berkowski JA, DelRosso LM, Koo BB, Scharf MT, Sharon D, et al. Treatment of restless legs syndrome and periodic limb movement disorder: an American Academy of Sleep Medicine clinical practice guideline. *J Clin Sleep Med*. 2025;21:137-52.

2. Winkelman JW, Berkowski JA, DelRosso LM, Koo BB, Scharf MT, Sharon D, et al. Treatment of restless legs syndrome and periodic limb movement disorder: an American Academy of Sleep Medicine systematic review, meta-analysis, and GRADE assessment. *J Clin Sleep Med*. 2025;21:153-99.

3. Ferre S, Quiroz C, Rea W, Guitart X, Garcia-Borreguero D. Adenosine mechanisms and hypersensitive corticostriatal terminals in restless legs syndrome. Rationale for the use of inhibitors of adenosine transport. *Adv Pharmacol*. 2019;84:3-19.

4. Garcia-Borreguero D, Guitart X, Garcia Malo C, Cano-Pumarega I, Granizo JJ, Ferre S. Treatment of restless legs syndrome/Willis-Ekbom disease with the non-selective ENT1/ENT2 inhibitor dipyridamole: testing the adenosine hypothesis. *Sleep Med*. 2018;45:94-7.

5. Garcia-Borreguero D, Garcia-Malo C, Granizo JJ, Ferre S. A Randomized, Placebo-Controlled Crossover Study with Dipyridamole for Restless Legs Syndrome. *Mov Disord*. 2021;36:2387-92.

6. Charlesworth JD, Adlou B, Singh H, Buchfuhrer MJ. Bilateral high-frequency noninvasive peroneal nerve stimulation evokes tonic leg muscle activation for sleep-compatible reduction of restless legs syndrome symptoms. *J Clin Sleep Med*. 2023;19:1199-209.

7. Buchfuhrer MJ, Baker FC, Singh H, Kolotovska V, Adlou B, Anand H, et al. Noninvasive neuromodulation reduces symptoms of restless legs syndrome. *J Clin Sleep Med*. 2021;17:1685-94.

8. Bogan RK, Roy A, Kram J, Ojile J, Rosenberg R, Hudson JD, et al. Efficacy and safety of tonic motor activation (TOMAC) for medication-refractory restless legs syndrome: a randomized clinical trial. *Sleep*. 2023;46.

9. Roy A, Ojile J, Kram J, Olin J, Rosenberg R, Hudson JD, et al. Long-term efficacy and safety of tonic motor activation for treatment of medication-refractory restless legs syndrome: A 24-Week Open-Label Extension Study. *Sleep*. 2023;46.

10. Singh H, Baker FC, Ojile J, Adlou B, Kolotovska V, Rigot SK, et al. Efficacy and safety of TOMAC for treatment of medication-naive and medication-refractory restless legs syndrome: A randomized clinical trial and meta-analysis. *Sleep Med*. 2024;122:141-8.

11. Buchfuhrer MJ, Roy A, Rodriguez S, Charlesworth JD. Adjunctive tonic motor activation enables opioid reduction for refractory restless legs syndrome: a prospective, open-label, single-arm clinical trial. *BMC Neurol*. 2023;23:415.

Moving Beyond Dopamine Agonists: Your Questions Answered

Andrew Spector, MD, is an associate professor of neurology at Duke University with a clinical focus in sleep medicine. He also serves as the sleep medicine fellowship program director and vice chair of professionalism, inclusion, diversity and empowerment in the Duke Department of Neurology. He is the author of the patient guide Navigating Life with Restless Legs Syndrome. *Dr. Spector recently answered questions submitted by participants in an RLS Foundation webinar, available for viewing on www.rls.org.*

The information presented in webinars is offered for informational purposes only and should not be considered a substitute for the advice of a healthcare provider.

Q. **Can dopamine agonists be used as a diagnostic tool? Is there potential to use short-term dopamine agonists for a few days to assess symptoms and determine if it is RLS or a condition that mimics the symptoms?**
A. Yes, dopamine agonists can be used as a diagnostic tool in some cases. Dopamine agonists are strictly used to treat RLS and Parkinson's disease. If symptoms improve in a patient taking dopamine agonists, this provides a clearer indication that they may have RLS, especially if the diagnosis is still undetermined.*

In contrast, gabapentin, which is a typical first-line therapy, is an effective treatment for many disorders and conditions. Therefore, its effectiveness in improving symptoms does not necessarily confirm an RLS diagnosis.

**Medical Editor's Note: RLS symptoms will improve in over 90% of RLS individuals, as long as an adequate dose of the dopamine drug is taken.*

Q. **Is there a risk of overdosing on dopamine agonists?**
A. Dopamine agonists can have unpleasant side effects such as nausea, especially when taken in large doses, but may not pose the same risk as opioids for respiratory depression. Other symptoms of overdose include dizziness, excessive sweating, low blood pressure and hallucinations. Always consult with your healthcare provider before making any changes to your treatment regimen.

Q. **Can augmentation and associated symptoms be reversed?**
A. Generally, symptoms of augmentation improve the longer a patient is off the offending medication.*

**Medical Editor's Note: Symptoms very often do not return to the previous levels before dopamine drugs were started. The RLS symptoms are often harder to control.*

Q. **On average, how long does it take to experience relief from augmentation after getting off dopamine agonists?**
A. It will depend on how long someone has taken a dopamine agonist. Generally, relief is experienced after two weeks, but it may take a few months.

Q. **Can dopamine agonists be taken occasionally or used as a backup without the risk of augmentation?**
A. Yes, short-term use of dopamine agonists can be an effective part of a treatment plan. For long travel, such as plane or train rides, a dopamine agonist such as carbidopa/levodopa (Sinemet) can be particularly helpful in alleviating symptoms.*

Medical Editor's Note: Carbidopa/levodopa should not be a daily treatment due to its high risk of augmentation, so we limit is to no more than three times total per week.

Q. **How do you recommend treating depression or worsening depression during dopamine agonist withdrawal syndrome (DAWS)?**
A. Unfortunately, the only way to control DAWS symptoms is for the patient to go back up on the dose of dopamine agonist for a while. Then, they are slowly tapered off again. DAWS can cause severe anxiety and depression, so it needs to be controlled and monitored closely. Some individuals may feel that they are regressing by going back to a dopamine agonist, even for a short time. But it's a strategy to regroup and safely change medications.

Some individuals can taper off the dopamine agonist entirely, while others might need to continue to take a very low dose to prevent withdrawal symptoms. It is important to remember that everyone's RLS is different and, therefore, medically managed to their specific symptoms.

There are no studies or literature on DAWS in RLS patients but there is some information on patients with Parkinson's disease (which may or may not apply to RLS patents). In the PD patients, DAWS was not associated with how fast or slow the dopamine taper was done.

Q. **During a breakthrough or flare-up, can additional medications or therapies be used on top of a current treatment plan?**
A. It's important to recognize that RLS flare-ups can happen without a clear indicator as to why, and the flare-ups can also pass on their own. If needed, the addition of another medication or an increase in the dose of a current medication is acceptable in the short term. Sinemet (carbidopa/levodopa) or tramadol may be useful in the short term or in more severe cases, a low daily dose of an opioid can be used.

Advisory Board Spotlight: Matthew Viereck, MD

Matthew Viereck, MD, joined the RLS Foundation's Scientific and Medical Advisory Board in 2024. He is an attending physician in the Department of Neurology at Reading Hospital in West Reading, Pennsylvania, and an assistant professor of neurology at Drexel College of Medicine. He graduated from Sidney Kimmel Medical College at Thomas Jefferson University, completed his residency in neurology at New York-Presbyterian Hospital Columbia University Medical Center, and completed a fellowship in sleep medicine at Brigham and Women's Hospital and Massachusetts General Hospital.

Dr. Viereck treats a variety of sleep and neurological disorders and has a special interest in restless legs syndrome, insomnia, hypersomnia, parasomnias and headaches.

Q. **How were you introduced to the RLS Foundation, and what encouraged you to join the Foundation's Scientific and Medical Advisory Board (SMAB)?**
A. I was introduced to the RLS Foundation shortly after my fellowship in sleep medicine. As an attending, I noticed a gap in resources for the RLS patient population, especially in the local area. One of my patients was actively involved with the Foundation, and they encouraged me to explore the opportunity to contribute.

One of the biggest hurdles in RLS care is education – for our patients and for healthcare providers. Many patients go undiagnosed or are mismanaged due to lack of awareness. By joining the SMAB, I have the opportunity to collaborate with experts in the field, provide guidance on the latest research, and ultimately help improve the quality of life for individuals suffering with RLS.

Q. **Throughout your educational and professional achievements, what motivated your interest in RLS and sleep disorders?**
A. During my sleep medicine training at Brigham and Women's Hospital and Massachusetts General Hospital, I had the privilege of working with some of the most distinguished clinicians in the field of sleep medicine. I was particularly drawn to the intersection of neurology and sleep medicine, as sleep disorders frequently overlap with neurological conditions. RLS is a condition that is underrecognized and undertreated despite its significant impact on sleep quality and overall well-being. The challenge of improving diagnostic strategies and treatment options for patients with RLS has continued to fuel my passion for the field.

Q. **You previously served on the American Academy of Sleep Medicine's Emerging Technology Committee. The latest technological RLS therapy is Nidra, a wearable band that uses tonic-motor activation to alleviate symptoms. Considering your experience, how do you envision technologies like Nidra influencing the future of RLS and sleep care?**
A. Technology continues to play an increasingly important role in the management of sleep disorders. The Nidra device represents a promising nonpharmacological option to provide relief to patients who do not tolerate or respond to medication. Wearable devices like Nidra demonstrate a new frontier in personalized sleep care. These technologies have the potential to expand treatment options and improve patient outcomes.

Q. **What are some of the biggest misconceptions about RLS that you encounter in your practice?**
A. There is a misconception that RLS is simply a nighttime discomfort. Unfortunately for many patients, it can significantly impact their quality of life. This misconception causes patients to overlook their symptoms, attributing them instead to restlessness or aging, and therefore they may not seek treatment.

Another misconception exists among providers. RLS is often misdiagnosed or underdiagnosed, without adequate assessment or proper treatment. I am currently developing a program at my clinic to educate healthcare professionals about the latest treatment guidelines for RLS, based on the American Academy of Sleep Medicine's recently published guideline.

Q. **Patient advocacy is a core pillar of the RLS Foundation. What are some challenges related to healthcare access that patients in Pennsylvania might experience? How do you address these issues?**
A. In many areas of my state, there is a lack of not only RLS specialists but sleep specialists. Telemedicine has been instrumental in combatting healthcare inaccessibility in rural and underserved populations. Education for healthcare providers is another way to address healthcare access.

Q. **How can patients reach you if they'd like to seek care?**
A. I am currently seeing new patients at Tower Health Neurology at Reading Hospital in West Reading, Pennsylvania. You can schedule appointments by calling 484-628-4656.

Augmentation: Diagnosis and Treatment

Many individuals who have restless legs syndrome (RLS) experience a downward spiral of symptoms as a side effect of dopaminergic medications. This side effect, called augmentation, is the most common and least understood treatment issue. With appropriate management by a healthcare provider, augmentation can be addressed to alleviate symptoms and allow individuals to return to their normal daily activities.

What is augmentation?
Augmentation is defined as a worsening of RLS symptoms after chronic use of dopaminergic medications. The medication is effective when it is first started, but over time symptoms worsen with continued use. The worsening or change of symptoms needs to be considered in relation to what symptoms were like before starting treatment. Are symptoms getting worse since starting treatment? If the answer is yes, then the treatment may actually be worsening the disease; this is called augmentation.

Symptoms of augmentation include:

- Earlier onset of symptoms in the evening or afternoon
- Increase in symptom intensity
- Symptom spread to other body parts (trunk, arms or face)
- Shorter period of rest or inactivity before symptoms begin
- Loss of effectiveness of the medication dose that previously managed symptoms well
- Paradoxical response in which taking the medication may initially trigger symptoms

Do all RLS medications cause augmentation?
Augmentation is typically a side effect of medications that are designed to increase dopamine in the brain – such as, levodopa – or that mimic dopamine activity – such as, ropinirole, pramipexole and rotigotine, which are approved by the FDA for treating RLS.

The cause of augmentation is unknown, but it is thought that dopamine-related medications may overstimulate the brain and cause a change in dopamine receptors or dopamine levels, leading to an overall decrease in activity in the natural dopamine system. This decrease in natural dopamine function results in an increased need for dopamine-related medications (to replace the underactive dopamine system) and thus an increased dependency on the drug. Studies have shown that all dopamine medications used to treat RLS can cause augmentation. It is unclear which individuals will develop augmentation and how long it will take to develop. Research has shown that the longer a person stays on a dopamine agonist and the higher the dose of the medication, the more likely the medication will augment symptoms.

Augmentation is a side effect of dopaminergic therapy.

Augmentation prevention strategies:

1) Educate healthcare providers to avoid prescribing dopamine medications.
2) Take the lowest effective dose of a dopaminergic drug.
3) Do not exceed maximum FDA-approved dosages for RLS.
4) Avoid carbidopa/levodopa for daily RLS treatment due to rapid augmentation.
5) Keep serum ferritin levels above 100 mcg/L and transferrin saturation > 20%.

RLS
RESTLESS LEGS SYNDROME FOUNDATION

RAISE AWARENESS
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What are predisposing factors for augmentation?
Three factors have been shown to increase the risk of developing augmentation:

- Dopaminergic medication dosages that exceed FDA maximums
- Carbidopa/levodopa taken daily for RLS treatment
- Low body iron stores as measured by a serum ferritin test or percent transferrin saturation (iron/total iron binding capacity).

Serum ferritin, is a lab test that measures the amount of iron storage in the blood. Individuals with serum ferritin levels below the recommended 100 mcg/L or 20% transferrin saturation treatment level are more likely to experience augmentation.

How quickly does augmentation develop?
Augmentation can occur at any time while an individual is taking a dopaminergic medication but typically does not occur until six months after beginning therapy. An estimated 5%–10% of those taking dopaminergic medications experience new onset of augmentation each year. After five years of taking dopaminergic medications 25%–50% of individuals may augment.

Could this just be a worsening of RLS symptoms?
Healthcare providers should conduct a careful medical history and physical exam to rule out other possible causes of worsening symptoms. The diagnosis of augmentation requires that the patient previously demonstrated at least some positive response to the prescribed dopaminergic medication, that other possible causes for a worsening of symptoms have been ruled out, and that there has been a consistent change in symptoms. RLS symptoms can vary in severity from day to day, as well as over time. A few days of symptom worsening is not sufficient for a diagnosis of augmentation.

What conditions are confused with augmentation?
Factors that can temporarily worsen RLS symptoms must be ruled out before confirmation of an augmentation diagnosis. These include:

- Use of medications such as sedating antihistamines (diphenhydramine, doxylamine) or antinausea medications. Examples are cold remedies and sleep aids such as Benadryl, Unisom, or Tylenol PM. Nonsedating antihistamines such as Allegra, Claritin, Clarinex and Zyrtec (usually) are less likely to worsen RLS symptoms.
- Addition of or increased use of antidepressants (exceptions include bupropion and trazodone) or antidopaminergic medications such as haloperidol, risperidone, aripiprazole.
- Use of caffeine, alcohol or nicotine, which can aggravate RLS symptoms
- Low iron stores. A morning, overnight fasting, serum iron panel test that includes serum iron, ferritin, total iron binding capacity (TIBC) and percent iron saturation should be conducted. A test of hemoglobin level or complete blood count (CBC) is not an adequate or sensitive measure of iron status. If an iron panel suggests abnormally low or even low normal iron stores, then iron treatment should be considered.
- Problems with sleep (for example sleep apnea, irregular sleep schedule, chronic sleep loss, or insomnia disorder) that diminish the quality or quantity of sleep. Sleep issues can markedly worsen RLS symptoms.
- Rebound, which may be confused with augmentation. Rebound is a flare-up of RLS symptoms as medication dose is wearing off. "End-of-dose rebound" typically occurs in the early morning. This contrasts with augmentation, where symptoms occur earlier in the evening or afternoon. Rebound in RLS appears to occur most often with shorter-acting medications such as the short-acting form of carbidopa/levodopa (Sinemet), rather than longer-acting dopamine agonists such as pramipexole ER (Mirapex ER) or ropinirole XL (Requip XL). Rebound may disturb sleep at the end of the night and may require medication adjustment.
- Tramadol is a mixed opioid with dopaminergic properties that can cause augmentation. It is the only opioid with these properties, so it is important to monitor for any changes in RLS symptoms and alert your doctor to any worsening of symptoms.

Augmentation indications
It can be challenging to distinguish between augmentation and a worsening of RLS due to natural disease progression. Healthcare providers must be alert to these indications of augmentation:

- Request for a dose increase of a dopaminergic medication prescribed for RLS that previously was effective.
- Reported breakthrough of RLS symptoms with an accompanying increase in symptom intensity and involvement of other body parts.

- 24-hour occurrence of symptoms.
- Request for medication doses earlier in the day. (Symptoms previously appeared solely in the evening or nighttime but now manifest earlier in the day.)

What if augmentation develops?
If an individual suspects augmentation, they should **not** discontinue the use of dopamine medication and should consult their healthcare provider immediately. There is no specific lab test for augmentation, so the provider will need to take a careful history of the RLS symptom progression and review current medications, including over-the-counter therapies. After ruling out other possible causes of the worsening of symptoms, the provider will need to confirm that augmentation is the most likely cause. If symptoms are significant and quality of life is diminished, the healthcare provider may suggest reducing the dosage of the problematic dopaminergic medication or, over time, discontinuing it. The healthcare provider will present available treatment options to help the individual choose the best approach for them in reducing the dopaminergic medication.

How is augmentation addressed?
Once augmentation starts, it will progress even if the dopamine agonist is not increased. Increasing the dose will only lead to more rapid and a more severe worsening of the RLS symptoms. Therefore, increasing the dose should never be considered an option to address augmentation. Ultimately, the dopamine agonist needs to be discontinued, with or without support from alternative medications such as opioids or alpha-2-delta agents like pregabalin, gabapentin or gabapentin enacarbil.

There are several approaches to transition individuals off of dopaminergic medications and methods will vary among RLS experts. The three common treatment approaches include: replacing the dopamine agonist with another drug, "cold turkey" method or the 12-day drug holiday.

The majority of RLS experts transition their patients off dopamine agonists by replacing them with another drug. The gabapentinoid class drugs (gabapentin, gabapentin enacarbil and pregabalin) may be successful for patients on very small doses of dopamine drugs with very mild augmentation symptoms, but they are not very potent and may not be effective in the augmented individual. Gabapentinoids may be more effective when the individual has never taken a dopamine drug.

The majority of individuals will be successful and have the least discomfort transitioning from a dopamine agonist to a low dose opioid. Since the augmentation worsening of RLS by dopamine agonists tends to be permanent, the opioid drug will usually be needed indefinitely. Most opioids can be used but methadone is commonly used as it tends to be very effective, well tolerated and provides sustained relief of symptoms with less frequent dosing.

Alternately, many experts use buprenorphine. It is a partial opioid agonist that activates opioid receptors in the brain to provide long-term relief of RLS symptoms. It is less likely to cause side effects such as euphoria or respiratory depression due to its limited binding capacity to opioid receptors in the brain. Buprenorphine may be easier for patients to access since it is a Schedule III drug and allows for refills, compared to a Schedule II drug like methadone, which cannot include refills and pharmacists are increasingly reluctant to dispense.

During the transition, the opioid is started at a low dose and gradually increased as needed to control RLS symptoms while the dopamine drug is simultaneously weaned off. Some experts will taper the dopamine drugs over weeks or even months, which may be more tolerable and less stressful for some patients. Once the dopamine drugs are stopped, there will be a few weeks of marked worsening of the RLS symptoms requiring higher doses of the opioid. After a few weeks, the RLS symptoms typically improve, and the opioid dose can be reduced to a lower maintenance dose – a low-total-daily-dose of opioid medication.

The second approach is to have the patient go "cold turkey" by immediately stopping the dopamine drug completely. This treatment should be used only for lower doses of the drug (under 4–6 mg for ropinirole and 1–1.5 mg for pramipexole).

If an individual is on higher doses of the dopamine agonists, the drug can be tapered until a lower dose is reached and then the patient can stop the drug "cold turkey." A low to moderate dose of the opioid is then added to relieve the marked worsening of the RLS symptoms. Patients with daytime RLS symptoms may need two or more opioid doses to control their RLS symptoms. If the RLS symptoms are not completely relieved with this low to medium dose, the patient can

add an additional dose of the opioid or take some or the full dose of the dopamine drug previously prescribed to control symptoms. It is often safer to take some or all of the dopamine drug when symptoms are not controlled rather than adding more of the opioid for acute relief as the dopamine drug is more reliable to relieve symptoms. And, if the opioid causes side effects, the symptoms would worsen with an increased dose. It is helpful to first see if the patient can tolerate the opioid by starting at a lower dose.

The next day, the patient should increase the opioid dose. This can be repeated over the next few days if needed until full control of RLS symptoms is achieved. It usually takes 1-4 days to determine the lowest opioid dose that controls the RLS. If the patient has significant adverse reactions to this treatment method (which if done properly should be a minority of patients), a slow taper of the dopamine drug can be instituted as described above. Most patients undergoing this "cold turkey" protocol find it to be a very quick and painless way to discontinue their dopamine drug.

The third approach follows the similar slow taper process as above. However, after the dopamine agonist is tapered off, the individual undergoes 12 drug-free nights (known as a drug holiday) before reassessing further treatment requirements. During the drug holiday, no other RLS medications are used. Individuals should never attempt a drug holiday without consulting a physician to carefully manage the withdrawal. For more information, please refer to the Foundations *Drug Holidays and RLS* handout.

Regardless of approach, withdrawal from a dopamine drug may be very difficult and should not be attempted without medical supervision. Working together with your healthcare provider, you can determine the best approach for augmentation management.

Conclusion

The overall goal of RLS treatment is symptom management during times of inactivity rather than a total elimination of symptoms. If augmentation develops, treatment strategies are available.

Augmentation prevention strategies are important to reduce risk and include:

- Educate healthcare providers to avoid prescribing dopamine medications in the first place, with rare exception.
- Take the lowest effective dose of a dopaminergic drug.
- Do not exceed maximum FDA-approved dosages for RLS, and do not increase a previously stable dose of a dopamine agent.
- Avoid carbidopa/levodopa for daily RLS treatment due to rapid augmentation.
- Keep serum ferritin levels above 75-100 mcg/L and transferrin saturation above 20%.

RLS patients who take dopaminergic medications should be alert to signs and symptoms of augmentation and be advised to contact their healthcare providers immediately if symptoms develop. Individuals should not make any changes to their treatment without first consulting their providers.

This publication has been reviewed and approved by reviewers from the RLS Foundation Scientific and Medical Advisory Board.

It Takes a Hero

What does it take to push for a cure for RLS day in and day out, month after month, forging ahead with the determined, steady pace of a marathon runner, and keeping the finish line in the mind's eye?

It takes an RLS Hero ... and you can be one, too.

RLS Heroes – the RLS stands for Recurring Leadership Support – are members who sustain our work at the RLS Foundation around the clock with gifts that are charged automatically to their credit cards each month. It's easy to become an RLS Hero: just visit our website at **rls.org/give** and hit the button to donate. It's that simple, and it's profoundly important to us!

RLS Heroes provide a steady and reliable stream of revenue – literally the lifeblood of our operations. As an RLS Hero, you will make sure that our progress continues uninterrupted. You will enable us to jump into the fray at critical moments and take advantage of emerging new opportunities.

In this issue of *NightWalkers*, you'll find some of the advances that our RLS Heroes are making possible. You'll hear how we're updating treatment recommendations to reflect new management strategies. You'll read about the emergence of new therapies to calm RLS symptoms during sleep. And you'll learn about our latest advocacy trip to Washington and plans for our next Hill Day. As an RLS Hero, you can have a hand in advances like these.

Monthly giving is easy – just authorize the Foundation to make a safe and secure monthly charge to your credit card, confident that you can change or cancel your pledge at any time. And it's a win-win for you and for us. As long as you stay enrolled, your membership will renew automatically and remain in force. You will also receive less mail from us, putting more of your contributions to work.

RLS Heroes aren't hard to find. Just look within our membership to see deeply devoted supporters who are leading the charge toward a cure. You can join this impactful group of Foundation members who sustain our progress all year long by scanning the QR code or visiting **rls.org/give**. Be sure to select "Recurring" gift type to become an RLS Hero today.

Thank You for Two Decades of Exceptional Service

By Karla Dzienkowski and the RLS Foundation staff

On behalf of the RLS Foundation, we would like to sincerely thank Lew Phelps for his outstanding service and commitment to the organization. For nearly two decades, he answered the call to service on the RLS Foundation Board of Directors, serving as board chair, Finance and Audit Committee chair, Governance and Nomination chair, Corporate Relations chair and chair emeritus.

In every role, Lew was pivotal in providing guidance and insight that helped shape the organization's direction, growth and success. His leadership and corporate expertise helped the board to navigate many organizational challenges and unlock new opportunities, leading to positive change and the Foundation's growth.

Lew, as you step away from the Board, please know that we cherish your time, effort and service to the Foundation. Your dedication to the cause has made a lasting impact, and your legacy will inspire future organizational leadership.

Thank you for your unwavering commitment to service and contributions to the RLS Foundation.

The Night Sky Surrounds Me: My Journey with RLS

By Margaret O'Donnell

Margaret O'Donnell is a Seattle playwright, poet and retired immigration attorney active in pro bono asylum cases. She writes about the migration of people, the effects of climate change on all of Earth's creatures, the intricacies of human relationships, and the workings of US law and government. You can find more of her work at www.odonnellplaywright.com.

I watch the night sky. On clear nights, when Orion moves slowly from east to west, his archer belt pointing directly to Sirius, I feel myself moving with the Earth's turning as I keep company with the moon, new to crescent to half to gibbous to full, cycling, ever cycling. Once in my nighttime wanderings, I saw an atmospheric river rushing directly over my head, exactly as if I were standing in a transparent bubble on a river bottom, looking upwards.

The night sky and keeping up with the weekly *New Yorker* were the best and the only good things about the four years I spent nightwalking during the COVID-19 pandemic. No matter how exhausted I was from lack of sleep, I had to keep moving.

Gabapentin, my RLS medication of 18 years, stopped working suddenly in December 2019. For two years, I saw three well-meaning but underinformed sleep physicians, who tried and failed to treat my refractory RLS. These doctors advertised themselves as experts in RLS; I believe they sincerely thought they were. They prescribed medications that had no effect, medications that worked for a few months and then augmented my symptoms beyond bearing, and medications that made me so sick I thought I was overdosing. My husband called 911 then – the result of one misguided prescription.

It's difficult to describe the despair that RLS evoked in me, because the disease robs me of both reason and creativity, of both hope and perspective. I was ashamed to tell even my close friends and family about my agony. When I tried, I saw the incomprehension in their eyes. After all, everyone knew someone with mild RLS symptoms. They could sleep. Why was it so hard on me? I didn't know either.

I lived with this despair for the last two years of my RLS excursion to hell before I found the RLS Foundation in late 2023. I had no RLS medication during those terrible two years. I thought I was condemned, that nothing could help me. I was in a black hole, which swallowed up my ability to connect with my friends and family, scrubbed beauty out of every day, made my nights a torture chamber, and destroyed my ability to write.

I am a writer. Writing is my passion and my joy. When I retired in 2019 from the practice of law, I was free at last to devote myself full time to writing the plays and poetry that give my life expression and fully engage every part of my brain and body.

Writing connects me with the world around me – the trees, the air, the soil, the Earth's creatures. My life lost meaning a few months after I retired, in the years before I found the RLS Foundation. Does that sound overly dramatic? I assure you; it is not. The disease consumed me, body and mind and soul. My joy and my creativity died.

Scrolling for any information that could help, one day in August 2023, I found the RLS Foundation website. I called. Staffer Adrianna Colucci immediately sent me a packet of information – brochures, back issues of *NightWalkers* magazine, reports of RLS studies, and a list of RLS Quality Care Centers. The nearest expert was a thousand miles away, in southern California. I called Dr. Mark Buchfuhrer's office at once and made an appointment to see him – a pulmonologist and sleep specialist with extensive RLS management experience and a leading RLS researcher – in September.

Then I had second thoughts. I couldn't bear the thought of sitting in a car on the way to an airport, getting through a security line, sitting for three hours on the plane, and sitting in a car to get to his office. I couldn't sit still for more than an hour. And what if the visit was useless? So, I canceled the appointment. I made another appointment for November. I canceled that appointment, too. Finally, I made an appointment and kept it in March 2024.

March 2024 saw the worst flooding in a century in Los Angeles. The Los Angeles River raged far over its banks, fed by torrents of rain and whipped by wind. On the train platform at the airport, people dressed for spring wrapped their arms around themselves and cowered. At the hotel, there was no central heat; my husband and I huddled together over a space heater throughout our stay. We walked the half-mile to the doctor's office the next morning along a street as wide and busy as a highway, as I castigated myself for coming to southern California and dragging my husband along.

When Dr. Buchfuhrer walked into the examination room, I was stiff with armor against inevitable disappointment. Why should this be different from my past experiences? Slowly, as he asked me about my long history with the disease, I saw that this time, this doctor would be different. It was the way he spent at least half an hour on my history, asking questions, that gave me new insight into my own journey. He wasn't fidgety or bored. He seemed genuinely interested in me as a patient. It was when he said, "I know I can help you," that I began to let my armor go. No other doctor had ever said that.

Dr. Buchfuhrer worked closely with me over the course of the year, tweaking the medication that has given me sleep again. Within three months of my first visit to his office, I slept three or four hours at a time. Within six months, I was sleeping through the night on most nights, with few daytime RLS episodes. In July 2024, Dr. Buchfuhrer enrolled me in an RLS research study for the new Nidra leg bands, a nonpharmacological device that uses tonic motor activation to alleviate RLS symptoms quickly, before they take over the body and mind. I didn't need to use the bands until the beginning of this year, when, inexplicably, my symptoms began to recur every two to three hours during the night and sometimes during the day.

I didn't want to increase the dosage of my medications, since I'm already somewhat drowsy and unsteady in the evenings under their influence. Now I use the bands most nights once and sometimes twice or three times a night. But instead of staying up for an hour, walking until the symptoms subside and I can sleep, I now get up, turn on the bands, and get back in bed within 10 minutes.

It's been expensive, tiring and time-consuming to travel to California for doctor visits and the Nidra band fitting, but what is it worth to have your life back? Dr. Buchfuhrer listens carefully to me and takes what I say seriously. I am the best source of information about my experience of the disease, and he honors that. He carefully calibrates my medication and dosing regimen and isn't put out when it doesn't work as well as he wants it to. I no longer blame myself for the disease.

RLS is a chronic condition. I know I'm not going to be cured, but now I am sleeping. I have my brain back. My doctor's attention to and belief in me, the carefully calibrated medication, and the Nidra bands brought me back to life. I'm writing. I travel again. I connect with friends and family. I'm walking in the woods. I no longer blame myself. I am at peace.

Your Voice Matters

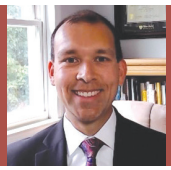
Have you used mindfulness, self-care or mental health practices to navigate a difficult time? We invite you to share your experience with the RLS community by submitting to our quarterly magazine, *NightWalkers.* By sharing your personal experiences, you can inspire and uplift others in your community.

We welcome poems, short stories, personal essays and other written works.

Guidelines:

- **300-600 word limit**
- **Use inclusive and respectful language**
- **Share the wisdom or hope you have gained**
- **We are unable to promote or endorse products or**
- **services**

Please email adrianna@rls.org with additional questions or to submit your piece.



BY J. ANDREW BERKOWSKI
MD

Can magnesium supplementation improve symptoms of restless legs syndrome?

GORANTLA S, RAVISANKAR A, TROTTI LM. MAGNESIUM CITRATE MONOTHERAPY IMPROVES RESTLESS LEGS SYNDROME SYMPTOMS AND MULTIPLE SUGGESTED IMMOBILIZATION TEST SCORES IN AN OPEN-LABEL PILOT STUDY. J CLIN SLEEP MED. 2024;20(8):1357-1361.
DOI:10.5664/JCSM.11206

THE BACKGROUND

Magnesium is a controversial dietary supplement for RLS treatment. It is often used and recommended within the medical field and among patients, but in stark contrast to iron supplementation, to date magnesium has not been shown to be efficacious in high-quality studies, nor has any biological evidence pointed to a link between magnesium and RLS. One unvetted theory is that magnesium enhances the effect of the opioid receptors in the brain and may influence RLS symptoms through this pathway. Due to its widespread availability and very low risk of adverse effects, the authors of this pilot study aimed to investigate magnesium citrate and whether it can be helpful in the treatment of RLS.

Of note, the authors employed a test called the multiple suggested immobilization test (m-SIT) as both a subjective and an objective measurement of RLS. This is used primarily in research studies but not in doctors' offices and sleep centers. The m-SIT monitors individuals in a reclined position for a series of three one-hour intervals that are each one hour apart during the evening. These circumstances would be likely to induce the peak RLS symptoms for most individuals. A muscle sensor is placed on the sides of the lower legs to measure periodic limb movements during wakefulness (PLMW). Subjects also report a discomfort score on a 0–10 scale every 10 minutes.

THE RESEARCH

The study enrolled 12 adults diagnosed with primary RLS who had not previously been treated for the condition. Over eight weeks, participants took 200 mg of magnesium citrate daily. There was no placebo arm of this study. To measure the effects of the supplementation, the researchers administered the IRLS score, the Kohnen RLS Quality of Life scale, and m-SIT. The participants had a median IRLS score of 18 (upper end of moderate range) and a baseline magnesium level of 1.85 mg/dL (reference range 1.7–2.2 mg/dL).

The results showed a statistically significant reduction in IRLS scores (-6.7) and improvements in quality of life among participants, using the Kohnen scale. Additionally, the m-SIT revealed a decrease in PLMW from a median of 30.4 limb movements per hour, averaged over the three hours of the test, to 8.6 per hour after eight weeks of magnesium supplementation. The discomfort score also decreased for all three trials from a median of 19 to 6, which was also statistically significant in the eight subjects who completed the m-SIT. Blood magnesium levels did not show significant changes, and levels did not correlate with improvement of symptoms. The supplement was well tolerated without major adverse effects or withdrawal of participants from the study.

THE BOTTOM LINE

This small, prospective, open-label pilot study of magnesium citrate suggests a possible benefit of magnesium citrate given over eight weeks using subjective and objective RLS symptom measurements, thus supporting the need for further research into this dietary supplement.

FURTHER QUESTIONS

Without a randomized, double-blinded placebo arm, what portion of the measured improvement to RLS was truly due to the magnesium compared to the placebo effect? If magnesium is shown in randomized trials to demonstrate efficacy, what is the mechanism by which it may improve RLS? Considering there was no significant change in blood magnesium levels, would the effect be related to an impact of the magnesium supplement from a direct chemical standpoint compared to inducing an improvement to the condition by increasing the body's iron levels? The authors suggest that because most magnesium is stored in tissues of the body, including bone and muscle, the blood magnesium level may not show an overall improvement in the body's magnesium levels, which are impractical to measure reliably.

Magnesium is thought to reduce the excitability of the brain from an electrochemical standpoint, such as in the case of the use of magnesium sulfate in seizure prevention in pregnant women with preeclampsia. Could this direct reduction in excitability have an impact on the brain's ability to generate the abnormal signal for RLS in a similar fashion?

Dr. Berkowski is a member of the Scientific and Medical Advisory Board of the RLS Foundation and the In the News columnist. He is the founder of ReLACS Health, a direct specialty care clinic specializing in telemedicine care of RLS and complex sleep disorders, currently serving patients in Arizona, Florida, Michigan, Ohio and soon Minnesota.

Gaining Perspective: Living with a Lifelong Condition

By Stephen Smith, PE

Stephen Smith is an RLS Foundation member and RLS advocate. He is a dedicated volunteer who provides support to the RLS community through the online RLS discussion board. To register for the discussion board, visit bb.rls.org.

I have been a moderator of the Foundation's online discussion board for over a decade. I also participate in several RLS social media groups. In these groups, I try to provide reliable information about the diagnosis and effective treatments for RLS, and I help individuals find ways to cope. Some important strategies I have developed for living with the disease are to learn as much as I can about it, keep perspective on my symptoms, and connect with others in the RLS community for support.

Each person's RLS undoubtedly impacts them in different ways and can be perceived as severe without a clinical frame of reference. When I think back to my original RLS diagnosis, I recall that my RLS had been an annoyance during travel for many years, but it wasn't bad enough to request help until it suddenly took a dramatic turn for the worse. I sought out a sleep specialist and at my first appointment, the physician gave me several sleep medicine questionnaires to complete, one of which was the International Restless Legs Syndrome (IRLS) Rating Scale.[1] This test assesses the severity of RLS symptoms through 10 questions that ask the respondent to rate their experiences. Total scores can range from 0 to 40. Generally, scores between 1 and 10 correspond to mild RLS, 11 to 20 to moderate, 21 to 30 to severe, and 31 to 40 to very severe.

After I completed the IRLS Rating Scale, the doctor determined my score to be 29, which put me at the top of the severe category. Because my RLS had been milder in the past, I tried answering the questions to evaluate my earlier status and found my score would have been about 19, which would have been classified as moderate. I realized that mild, undiagnosed RLS had been part of my life for several decades.

Reviewing my history got me interested in the questionnaires used to evaluate RLS. Most everyone has seen the four or five questions used for diagnosis, but there are also questionnaires that score RLS severity. A common use of these questionnaires is during clinical trials to evaluate potential new treatments. Often, a patient is first given a questionnaire to evaluate their suitability for the study. If accepted, they get a set of questions (possibly different ones) that are used to evaluate how severe their RLS is before, during and after the study. This allows the researchers to see how well the treatment worked. These questions may be the same as the IRLS Rating Scale questions but can also be adapted to the special needs of the study.

As I have grown older, my RLS has slowly become a bit worse. Without treatment, I estimate my score would be 31 or 32. With my current treatment, my score is around 18 or 19, similar to my baseline RLS symptoms before they suddenly became worse.

All this makes me wonder what my future might hold. I have been reading the medical literature to learn about higher scores for extremely severe RLS. I have found that there are people whose scores can be as high as 39 out of 40, which makes my 32 seem rather mild. To reach these upper levels, an individual must have symptoms for more than eight hours a day and seven days a week. They also must find that walking provides little or no relief to their need to move, that RLS severely disrupts their daily life, and that their sleep deprivation causes very severe problems with anger, depression and/or anxiety.

Although I realize that the chances my RLS will approach those levels is almost nonexistent, this knowledge has helped me keep my own RLS in perspective during the really bad nights we all experience. My score at the low end of very severe also allows me to understand and sympathize with what life must be like for those whose scores are higher than mine.

Understanding the way that the questionnaires work allows me to approach my RLS objectively. And knowing what life might be like if my RLS gets much worse helps keep things in perspective.

This provides an incentive to do everything that I can to stay on top of my treatment, to support RLS Foundation research efforts any way that I can, to stay apprised of any new RLS treatments that could be helpful for those of us with very severe RLS. And most importantly, remember to try to enjoy life today.

1. Walters AS, LeBrocq C, Dhar A, et al. Validation of the International Restless Legs Syndrome Study Group rating scale for restless legs syndrome. *Sleep Med*. 2003;4(2):121-132. doi:10.1016/s1389-9457(02)00258-7.

Find Support

If you or a loved one is affected by restless legs syndrome and are seeking a safe space to connect with others facing similar challenges, we invite you to explore our support programs available within our RLS Support Network. Active programs include outreach through our Virtual Support Program, local meetings organized by Support Group Leaders, Support Contacts and our RLS Discussion Board. To learn more about support options visit rls.org/support.

Local RLS Support Groups

Led by Foundation volunteers, these RLSF-affiliated groups hold meetings virtually and/or in-person to provide support on a local level within their community. To learn more about a particular group in or near your community, contact the Support Group Leader listed.

CALIFORNIA

Bay Area CA RLS Support Group (NEW)
CJ Liang
BayAreaCA_SupportGroup@rlsfvolunteer.org

San Diego, CA RLS Support Group
Lindy Munoz
SanDiegoCA_SupportGroup@rlsfvolunteer.org
(619) 851-5602

Southern California RLS Support Group
Mary Cuseo
SouthernCalifornia_SupportGroup@rlsfvolunteer.org
(562) 810-3157

COLORADO

Denver Metro CO RLS Support Group
David Moulton
DenverMetroCO_SupportGroup@rlsfvolunteer.org
(970) 819-0498

CONNECTICUT

Cheshire, CT RLS Support Group
Malcolm Ferguson
CheshireCT_SupportGroup@rlsfvolunteer.org

GEORGIA

Georgia RLS Support Group (NEW)
Sandra Norman
Georgia_SupportGroup@rlsfvolunteer.org
(847) 863-9564

IDAHO

Boise, ID RLS Support Group
Linda R. Secretan
BoiseID_SupportGroup@rlsfvolunteer.org
(661) 341-0530

North Idaho RLS Support Group
Matthew Hill
NorthID_SupportGroup@rlsfvolunteer.org
(208) 762-1400

ILLINOIS

Illinois RLS Support Group (NEW)
Connie Jeschke
Illinois_SupportGroup@rlsfvolunteer.org
(618) 559-5520

MASSACHUSETTS

North Shore MA RLS Support Group (NEW)
Kelly Ebert
NorthShoreMA_SupportGroup@rlsfvolunteer.org
(630) 203-7216

Plymouth, MA RLS Support Group
Diane M. Morrell
PlymouthMA_SupportGroup@rlsfvolunteer.org
(603) 642-6059

MICHIGAN

Oakland County MI RLS Support Group
Linda L. Tuomaala
OaklandCountyMI_SupportGroup@rlsfvolunteer.org
(248) 435-4024

MINNESOTA

Twin Cities MN RLS Support Group
David Gagne
TwinCitiesMN_SupportGroup@rlsfvolunteer.org
(612) 325-8860

NEW HAMPSHIRE

Seacoast NH RLS Support Group
Roberta J. Kittredge
SeacoastNH_SupportGroup@rlsfvolunteer.org
(603) 957-1059

NORTH CAROLINA

Asheville, NC RLS Support Group
Michael Small
AshevilleNC_SupportGroup@rlsfvolunteer.org
(518) 624-3346

OHIO

Columbus, OH RLS Support Group
Rosemary Stader
ColumbusOH_SupportGroup@rlsfvolunteer.org
(614) 940-7142

SOUTH DAKOTA

Sioux Falls, SD RLS Support Group
Kris Wathier
SiouxFallsSD_SupportGroup@rlsfvolunteer.org
(605) 929-8288

Yankton, SD RLS Support Group
Phyllis Hunhoff
YanktonSD_SupportGroup@rlsfvolunteer.org
(605) 668-6257

If you would like to start a Local RLS Support Group in your area to host in-person or virtual meetings, contact zibby@rls.org.

RLSF Support Contacts

Additional support is available through volunteer Support Contacts who are available to answer questions or provide personal support through conversation rather than group meetings. Support Contacts are listed by state below and available at the number provided.

CALIFORNIA
Bill Becker
Bill_Contact@rlsfvolunteer.org
(530) 232-0343

Carol Galloway
Carol_Contact@rlsfvolunteer.org
(415) 459-1609

Susan Schlichting
Susan_Contact@rlsfvolunteer.org
(310) 792-2952

FLORIDA
Neil R. Greenwood
Neil_Contact@rlsfvolunteer.org
(863) 644-2649

ILLINOIS
Bob Hartnett
Bob_Contact@rlsfvolunteer.org
(872) 243-1298

MAINE
Regis P. Langelier
Regis_Contact@rlsfvolunteer.org
(207) 351-5352

MARYLAND
Louis Siegel
Louis_Contact@rlsfvolunteer.org
(585) 703-6585

MISSOURI
Kathy Page
Kathy_Contact@rlsfvolunteer.org
(660) 368-2382

NEW HAMPSHIRE
Sheila C. Connolly
Sheila_Contact@rlsfvolunteer.org
(508) 783-5747

PENNSYLVANIA
John Alexanderson
John_Contact@rlsfvolunteer.org
(908) 797-1587

Alice J. Maxin
Alice_Contact@rlsfvolunteer.org
(724) 664-1895

TEXAS
Lisa Marie Smith
Lisa_Contact@rlsfvolunteer.org
(979) 900-8033

WASHINGTON
Charlotte E. Spada
Charlotte_Contact@rlsfvolunteer.org
(360) 293-7328

CANADA
Beth Fischer
Beth_Contact@rlsfvolunteer.org
(867) 765-8062

RLSF Virtual Support Groups

This Foundation-hosted RLS support program provides an accessible opportunity for community support, regardless of your location. Meetings are held monthly and are free and accessible to the public to attend using your personal device. To view the complete list of upcoming meetings and register for a specific date, visit rls.org/support.

Virtual Support Group (VSG) meetings are scheduled each month at the following times:

First Tuesday VSG
12pm PT, 1pm MT, 2pm CT, 3pm ET

Second Wednesday VSG
5pm PT, 6pm MT, 7pm CT, 8pm ET

Third Thursday VSG
12pm PT, 1pm MT, 2pm CT, 3pm ET

Fourth Saturday VSG
10am PT, 11am MT, 12pm CT, 1pm ET

Note: VSG meeting dates are subject to change. Visit our website for the most up-to-date schedule.

RLSF VIRTUAL SUPPORT GROUP LEADERS:

Laura Hoffman
Laura_VSG@rlsfvolunteer.org

Bill Wendt*
Bill_VSG@rlsfvolunteer.org

Judy Amateis
Judy_VSG@rlsfvolunteer.org

*Member of RLS Foundation Board of Directors

RLS Online Discussion Board

Accessible online 24/7, this public forum provides a virtual space for support and an opportunity to seek insight from fellow RLS community members.

Ann Battenfield
ann.rlsfmod@gmail.com

Beth Fischer
beth.rlsfmod@gmail.com

Betty Rankin
bett.rlsfmod@gmail.com

Stephen Smith
Stephen.rlsfmod@gmail.com

Visit bb.rls.org to read previous discussion topics or to submit your own question.

RLS Foundation Leads Push for Research Funding

On February 20, a team from the RLS Foundation, including Board Chair Dr. Jeffrey Durmer, Executive Director Karla Dzienkowski, and Communications Coordinator Adrianna Colucci, went to Capitol Hill to address concerns about National Institutes of Health (NIH) funding cuts and the impact on sleep-related research projects. They were joined by the Health and Medicine Counsel (HMC), an organization that guides and coordinates the Foundation's advocacy efforts in Washington, DC.

Recent cuts to NIH funding and layoffs put research progress in jeopardy. The Foundation is in a unique position to advocate for the research community, urging legislators to restore funding to ensure labs remain open and operational. NIH funding is critical to supporting key personnel, maintaining essential equipment and retaining young investigators who work alongside senior researchers.

The RLS Foundation met with eight congressional offices. The House and Senate representatives resided on key committees, such as Appropriations, Health, Education, Labor and Pensions (HELP), and Ways and Means.

The RLS Foundation is asking Congress to provide sustained funding to the NIH and expand support for programs such as the Chronic Diseases Education and Awareness Program at the Centers for Disease Control and Prevention. These programs provide researchers with avenues to seek support at increased funding levels.

The Foundation is also asking Congress to include sleep disorders on the list of conditions eligible for funding through the Department of Defense Peer Reviewed Medical Research Program (PRMRP). Brian Koo, MD, a member of the RLS Foundation Scientific and Medical Advisory Board, is a PRMRP grant recipient. As medical director of the Sleep Laboratory at the Veterans Affairs Connecticut Healthcare System, Dr. Koo is conducting research to examine melanocortin biology among RLS patients.

Decreased funding for essential federal programs will halt progress for ongoing and future RLS and sleep research projects The RLS community has always been a strong advocate for RLS research, and now, more than ever, your voices are needed. To stay informed, follow the RLS Foundation on social media, read the Foundation's blog, and sign up for its monthly e-newsletter. Visit **www.rls.org** to learn more.

All are welcome to join the RLS Foundation on Monday, October 6, in Washington, DC, for an in-person Hill Day. As a community, RLS advocates will meet with legislators to advocate for medical research funding, education and awareness programming and patients' access to RLS treatments. Learn more and register at **rls.org/HillDay**.

LEGISLATIVE & POLICY PRIORITIES

FOR FY 2026

MEDICAL RESEARCH

Please provide the NIH with sustained funding.
Please include "sleep disorders" in the Department of Defense PRMRP and restore funding to $370 million.

PATIENT ACCESS TO APPROPRIATE TREATMENT

Please accommodate the needs of patients who rely on the regular use of low-total-daily doses of opioids to manage their RLS.

EDUCATION AND AWARENESS

Please provide $5 million for the NNCSS.
Please provide at least $6 million for the Chronic Diseases Education and Awareness Program at the CDC.

Publications

The following publications are available for Foundation members to view and download at 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.

Qty	Patient Handouts	Qty	Patient Handouts	Qty	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		

Qty	Patient Brochures	Qty	Patient Brochures
	Causes, Diagnosis and Treatment for the RLS Patient		RLS Guide for Children
	Giving Avenues		RLS Guide for Teens
Qty	**Healthcare Provider Brochures**	Qty	**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 by credit card of:

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DONATION APPLIED TO

☐ Research

☐ 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 *(Per RLS Foundation policy, we do not rent, sell or share our mailing list.)*

Name _____ Address _____

City _____ State _____ Zip _____

Email address _____ Phone number _____

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2025 HILL DAY

MONDAY, OCTOBER 6

JOIN THE RLS FOUNDATION IN WASHINGTON, DC TO ADVOCATE FOR KEY ISSUES AND SHAPE PUBLIC POLICY BY SHARING YOUR STORY WITH LEGISLATORS.

YOUR VOICE MATTERS

VISIT RLS.ORG/HILLDAY OR EMAIL ADRIANNA@RLS.ORG FOR MORE INFORMATION