

NIGHTWALKERS

In search of a good night's sleep

Fall 2021

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NightWalkers is the official publication of the Restless Legs Syndrome (RLS) Foundation

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Augmentation is the one word that stops RLS patients in their tracks, and it is the number one reason for calls that we receive at the RLS Foundation. Individuals in the RLS community reach out to the Foundation to receive science-based information and resources, along with contact information for providers who are knowledgeable and experienced in treating RLS augmentation.

The healthcare providers at the RLS Foundation's 11 certified RLS Quality Care Centers report that management of augmentation is the number one reason individuals seek care at these specialty centers.

The Foundation has taken specific steps this year to address this treatment phenomenon. First, in July the Foundation's Scientific and Medical Advisory Board published an updated RLS treatment algorithm in *Mayo Clinic Proceedings* that outlines new first- and second-line therapies to manage RLS. The article is a free, unrestricted journal article made possible by you – the members of the RLS Foundation.

Second, we have revised the *RLS Medical Bulletin* to include the new treatment guidelines for RLS management in adults, children, and special populations, it is included in the middle of this edition of *NightWalkers*.

A Foundation member and donor recently contacted me to discuss ways that her contributions could make the most impact. She is a nurse educator who recognizes and appreciates the importance of science-based information from a trusted resource. I explained our project to update our "RLS Medical Bulletin" to align with the 2021 treatment algorithm. She immediately expressed her delight in supporting those efforts. Although she wishes to remain anonymous, this generous philanthropist asked that her donation be used to underwrite the printing and distribution of the new *RLS Medical Bulletin* to make it available to all members and others who seek RLS treatment and management. Over 10,000 people will receive this quality publication authored by our Scientific and Medical Advisory Board.

Finally, the RLS Virtual Patient Summit held in October gave our members access to experts discussing new RLS research and treatment information. Although we look forward to holding an in-person symposium, any opportunity to have your questions answered by a panel of experts is invaluable, whether in an auditorium or via Zoom.

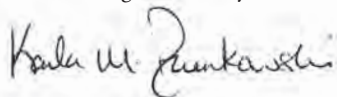
Dopaminergic medications have been the first line of therapy for over three decades, and we now know that these drugs predispose an individual to the development of augmentation. Dr. Berkowski's article in this issue of *NightWalkers* discusses augmentation and treatment strategies that do not include the use of dopaminergic medications.

As we close out 2021, we have much to look forward to in 2022. First of all, the Research Grant Program will request proposals for consideration. To date, we have funded over 48 grant proposals totaling nearly \$2 million. Your return on investment has included discovering the first RLS gene variant – BTBD-9. It has led to the RLS Opioid Registry, discovery of the adenosine relationship to RLS and clinical trial for dipyrindamole. A study of a potential new RLS augmentation treatment using a D-1 receptor-specific antagonist, ecopipam. Another study found that training physicians in medical school to diagnose RLS is cost-effective and improves patient outcomes.

In addition, the brain donations made to the RLS Foundation Brain Bank have led to breakthroughs in our understanding of the relationship between low brain iron and RLS, and the use of iron therapy as a first-line treatment for RLS.

We have learned much, but our work will continue until we have a cure. Future generations of your family and mine are counting on us to make a difference.

We do this together, as always.



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



Karla M. Dzienkowski, RN, BSN
 Executive Director

Honor Roll

The Restless Legs Syndrome Foundation is sincerely grateful for the donations we received in memory and in honor of the following individuals from July 1, 2021 through September 30, 2021

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 Kay Henderson and all RLS Foundation members
 Gail Buckley
 Max Jester

Understanding Augmentation and How to Recover from Dopamine Dependence

by J. Andrew Berkowski, MD, member of the RLS Foundation's Scientific and Medical Advisory Board

Dopaminergic medications had been the mainstay of first-line pharmacological treatment of RLS for many years, but they have significantly fallen out of favor in the past decade due to high rates of augmentation and, secondarily, impulse-control disorders. Clinical consensus guidelines no longer consider these agents to be first-line treatments, despite the abundance of research demonstrating significant efficacy in the short term (months to a few years). The high rates of augmentation, which is thought to be inevitable with long-term use, begs the question: "Should anyone take dopaminergic agents at all for this chronic, lifelong condition?"

Despite relegation of dopaminergics to second-line status in the more updated clinical guidelines since 2015, many RLS experts only use these medications now in rare circumstances. If these therapies are considered, they should be trialed only after the ineffectiveness or intolerable side effects of the other treatments available for RLS. After initiation for daily use, regular monitoring must be performed for early identification of the stages of effects on the dopaminergic system, including dependence, tolerance, mild augmentation and severe augmentation. Dopamine agonists may have initial side effects, including nausea, vomiting, headache, sleepiness and dizziness.

The most commonly used dopamine agonists are the short-acting pramipexole and ropinirole, and the long-acting transdermal rotigotine patch. Levodopa is reserved for intermittent RLS symptoms, due to extremely rapid onset of augmentation (weeks to months) when taken daily. Though no studies have investigated augmentation with intermittent use, three doses or fewer per week has been considered reasonable. Potential uses include evening dosing for occasional RLS symptoms, dosing prior to sedentary situations (e.g., plane flight, theater presentation), and dosing for patients in whom the diagnosis of RLS is in doubt.

Augmentation

Since dopamine agonists became a first-line treatment for RLS in the early 2000s, two decades of experience have demonstrated high rates of (possibly inevitable) augmentation with long-term use. Augmentation is a worsening of RLS with one or more of the following features: an advance of the typical time of day when symptoms begin, two or more hours earlier than before the start of treatment; a spread of restlessness from the legs to the arms or trunk; a shorter interval before symptoms start after inactivity (sitting or lying); progressive dosage escalation to produce the same effect; and even paradoxical triggering of RLS symptoms immediately after taking the medication.

Augmentation has led to the most dramatic paradigm shift in RLS management, as it causes the majority of refractory RLS cases. This phenomenon poses significant philosophical challenges to the clinician, as a potential worsening of the condition long term in most cases should prohibit the use in the short term, regardless of the significant

short-term effectiveness. Because of the increasing prevalence of augmentation, the RLS Foundation's Scientific and Medical Advisory Board published a guideline outlining the identification and treatment of augmentation. The presence of one or more of the following factors is known to increase the likelihood of augmentation: more frequent RLS symptoms before treatment, greater discomfort with RLS symptoms before treatment, co-morbid asthma, older age, longer treatment duration, lower serum ferritin levels, and greater baseline severity of RLS.



J. Andrew Berkowski, MD

Four screening questions are recommended to identify augmentation:

1. Do RLS symptoms appear earlier than when the drug was first started?
2. Are higher doses of the drug now needed, or does the medication need to be taken earlier in the day, to control the RLS symptoms compared to the original effective dose?
3. Has the intensity of symptoms worsened since starting the medication?
4. Have symptoms spread to other parts of the body (e.g., arms, trunk, face) since starting the medication?

Augmentation is considered mild if all of the following are present: symptoms manifest predominantly as a temporal shift of symptoms to earlier in the day compared to before starting treatment; dopaminergic monotherapy is at a total daily dose at or below maximum recommended levels; symptoms cause only mild distress; and there has been no prior increase in total dose above that which was previously therapeutically effective. In cases of mild augmentation, there is more time to make adjustments to treatment regimen, but the symptoms do represent an early stage of dopaminergic system impairment and dependence. This will progress to more severe symptoms and advanced augmentation if no changes are made or dopamine medication dosage is simply increased.

Augmentation is considered severe if it does not fulfill the criteria for mild augmentation (e.g., the total agonist dose exceeds recommended levels or the symptoms cause more than mild distress) or does not respond to treatment of mild augmentation.

Treating Augmentation

Initially, it is important to identify and eliminate or treat factors that exacerbate RLS. These could include poor sleep hygiene or other untreated sleep disorders, ingestion of drugs/foods that worsen RLS symptoms, or low levels of ferritin or percent transferrin saturation. If the iron stores are low, then iron therapy (oral or intravenous) should be considered.

RLS Treatment

For mild augmentation, the dopamine agonist medication could be continued and the total dose maintained but given in divided doses, or the medication could be given earlier to precede the onset of RLS symptoms. If symptoms are not managed by splitting the dosage, then the addition of other therapies should be considered, such as iron infusion, alpha-2-delta ligand medications, and possibly opioid medications. Changing to a longer-acting dopaminergic agent such as transdermal rotigotine could be considered, but this will only delay the inevitable augmentation to future months or years. Rotigotine has lower rates of augmentation long term in studies but is thought to mask augmentation due to having a steady level of the drug in the system continuously without time off from the drug. If the second treatment added does not provide symptom relief, then augmentation should be considered severe. Even if augmentation is mild, long-term plans should be discussed for transition to other treatments before more severe augmentation develops. Tapering off the dopamine agonist, with or without a second-line agent added, should be considered long term, to initiate dopaminergic system withdrawal and reconstitution.

For severe augmentation, the goal over several weeks to months is to wean, slowly but completely, off all dopaminergic agents to enable withdrawal, recovery from dopaminergic dependence, and maximal reconstitution of the natural dopaminergic system to as close to previous baseline as possible. One method is to perform a slow wean of the dopaminergic agent, followed by a two-week drug holiday, and then the addition of an alternative agent if still requiring symptomatic treatment. Though this approach is ideal in terms of natural recovery and limiting medication side effects, it is often met with apprehension due to the severity of withdrawal symptoms. The addition of a second medication prior to reduction in the dopaminergic medication is more common. Therapies may include an IV iron infusion (more potent and rapid than oral iron), alpha-2-delta ligands, opioids and, rarely, benzodiazepines. The dopamine agonist weaning process can be highly variable among patients, depending on initial severity of symptoms and strength of dosage. Anecdotal evidence suggests that many patients can go through a mini-withdrawal and recovery process after each dosage decrease in four to seven days, but some may take a few weeks or require increases in the secondary agent if they do not improve. Recovery after complete discontinuation may be the greatest in the first two weeks, though some patients take much longer to recover significantly. Many may have slow improvement beyond the initial few weeks for months or years after discontinuation, though the natural history of dopamine agonist withdrawal and recovery has not been well studied yet.

Dose reduction must be managed by a healthcare provider, and each situation is different; however, there are some management guidelines. Ropinirole may be tapered by 0.25 to 0.5 mg per week as tolerated, pramipexole by 0.125 mg, and rotigotine by 1 mg. However, the initial decreases may be larger, particularly if the patient is on dosages

beyond maximum recommended, with progressively smaller decreases as the patient approaches discontinuation. Symptoms of withdrawal are generally a temporary but possibly severe worsening of restless legs symptoms, including more severe breakthrough symptoms, symptoms during the night leading to insomnia, earlier onset of symptoms during daytime with possible spread to other anatomic regions, and even involuntary limb movements while awake. These symptoms generally improve over several days before the patient can begin the next step in the tapering process. If a second agent is used, it may need to be adjusted to balance effectiveness with side effects, to combat the withdrawal symptoms. Other symptoms during dopaminergic withdrawal may include high levels of anxiety, irritability, insomnia, excessive daytime sleepiness and depressed mood.

After at least two weeks from discontinuation, the patient should be reassessed to see if the new symptomatic agent can be gradually tapered as well, or a second medication added in the case of patients who tapered without additional drug treatment. Several weeks to months after complete withdrawal, recovery is frequently seen and further dosage reduction can be made, as the dosage of a second medication is generally higher in the withdrawal period than weeks to months after recovery, due to progressive reconstitution of the dopaminergic system.

Impulse Control Disorders

Impulse control disorders are another side effect of dopamine agonist therapy. Due to long-term effects on the dopaminergic system and behavioral pathways, dopamine agonists are associated with impulse control disorders (e.g., pathologic gambling, excessive shopping, hypersexuality) within nine months of treatment onset. Symptoms of impulse control disorders (and augmentation) should be screened regularly, regardless of duration of use. The consequences of unrecognized impulse control disorders can be devastating, including substantial financial loss, the threat of criminal prosecutions, substance abuse and social disruption. However, complete resolution of the pathologic tendencies is the general rule with discontinuation or dose decrease of the causative agent.

Education and Awareness

Decades of dopamine agonist use have revealed the risk of augmentation and impulse control disorders. Education of healthcare providers is the first step to raise awareness about RLS treatment guidelines and the adverse side effects of dopaminergic medications. Support for RLS research leading to the identification of new medications that address the chronic progressive nature of RLS and its treatment challenges are priorities for the RLS community.

New Position Statement Declares that Sleep is Essential to Health

A new position statement from the *American Academy of Sleep Medicine* emphasizes that sleep is a biological necessity, and insufficient sleep and untreated sleep disorders are detrimental for health, well-being, and public safety.

Published online in the *Journal of Clinical Sleep Medicine*, the statement notes that sleep is vital for health and well-being in children, adolescents, and adults. While awareness of the value of sleep has risen in the last decade, there is a significant need for greater emphasis on sleep health in education, clinical practice, inpatient and long-term care, public health promotion, and the workplace.

“Healthy sleep is as important as proper nutrition and regular exercise for our health and well-being, and sleep is critical for performance and safety,” said AASM President Dr. Kannan Ramar. “It is the position of the AASM that sleep is essential to health, and we are urging educators, health care professionals, government agencies, and employers to prioritize the promotion of healthy sleep.”

The statement was written by the members of the 2020 – 2021 AASM board of directors, comprising 11 sleep medicine physicians and a clinical psychologist. In recognition of sleep’s significant and multi-faceted connections to health and chronic disease, the authors outlined the following positions:

- Sleep education should have a prominent place in K-12 and college health education, medical school and graduate medical education, and educational programs for other health professionals.
- Clinicians should routinely inquire about sleep habits and symptoms of sleep and circadian rhythm sleep-wake disorders during patient encounters, and hospitals and long-term care facilities should optimize sleep conditions.

- Healthy sleep should be targeted by public health and workplace interventions to improve health-related outcomes, and behaviors that help people attain healthy sleep should be actively promoted.
- More sleep and circadian research is needed to further elucidate the importance of sleep for public health and the contributions of insufficient sleep to health disparities.

“Education about sleep and sleep disorders is lacking in medical school curricula, graduate medical education, and education programs for other health professionals,” said Ramar. “Better sleep health education will enable our health care workforce to provide more patient-centered care for people who have common sleep disorders such as obstructive sleep apnea and insomnia.”

According to the authors, chronic insufficient sleep and untreated sleep disorders are linked to increased health and safety risks such as cardiovascular disease, diabetes, obesity, workplace accidents, and motor vehicle crashes. Data from surveys conducted by the Centers for Disease Control and Prevention and the Maternal and Child Health Bureau show that 34.1% of children, 74.6% of high school students, and 32.5% of adults in the U.S. fail to get a sufficient duration of sleep on a regular basis. Therefore, helping people get enough sleep is one of the goals of Healthy People 2030, which provides 10-year, measurable public health objectives for the U.S.

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Board Spotlight: Linda Secretan

By Clara Schlemeyer, Program Coordinator, RLS Foundation

I recently had the pleasure to sit down and chat with one of the extraordinary members of our Board of Directors, Linda Secretan. Since she became a Foundation member in 1997, she has served the RLS community in so many ways. From starting a support group in Idaho, to serving as the RLS Foundation's representative on the Sleep Disorders Research Advisory Board of the National Institutes of Health, to her leadership roles on the Foundation's Board of Directors, she seems to do it all with compassion and a smile. During her six years of service, Secretan has served as secretary of the Board and chair of the Governance and Nomination Committee, two roles critical to the effective functioning of the Foundation.

Linda's lifelong struggle with RLS and her experience as an educator and life coach make her an invaluable member of the RLS Foundation's Board of Directors.

Q: How did you get involved with the RLS Foundation's Board?

A: I was a long-time member of the RLS Foundation and had just moved to Idaho, transitioned careers and had a lot more free time and flexibility. I spent a long time thinking about just the right volunteer commitment where I could best spend my time and resources. Then I realized that the RLS Foundation had been essential to my well-being for many years. I relied on the Foundation for information, encouragement and general support in dealing with my RLS. I noticed that there wasn't a support group leader in Idaho, so I thought I would apply, and my application was accepted! A generous donor had given the Foundation a grant to create educational materials specifically for kids and adolescents. Since Karla Dzienkowski, executive director at the Foundation, knew of my background in education, she asked me to help out with that project, and I was delighted to volunteer my time and experience with education and RLS. Then I got a call from Karla and Jacci Bainbridge, former chair of the Board, to ask me if I would consider becoming a board member. I was thrilled to be asked. I obviously had to ask questions and think hard about it, but there was no way I could turn them down. It was such an amazing opportunity to grow closer to the organization, learn more and maybe offer more to an organization that had given me so much.

Q: How has joining the Board affected your RLS journey?

A: First of all, it is very exciting to be on the Board, because you tend to hear about things first. You understand what is happening with the Scientific and Medical Advisory Board; when any research reports are published, we are the first to know. The Board is kept updated on all of the advocacy efforts, and that gives me a lot of insight and hope. Being on the

Board reminds me that no matter how my own symptoms wax and wane – as they do, no matter how many regimens that I try – there is always a group that has my back. The Board is not just a bunch of names on a piece of paper, but people who are really interested in investing in and improving the lives of people with RLS. Serving on the Board makes my RLS more bearable, brings me hope and keeps the mission front and center in my mind.



Linda Secretan

Q: How has your service as a support group leader helped you during your time on the Board?

A: I consider myself a patient advocate serving on the Board. My time as a support group leader is so beneficial to my board service, because I have the opportunity to talk to many RLS patients to understand their concerns and their difficulties. I am able to be their advocate in board discussions and decisions that affect the people we serve, our members.

Q: How has your experience as a life coach helped you on the Board?

A: Any good coach begins with the premise that clients are creative, resourceful and whole – always approaching things from an awareness of great humility and curiosity. I think that also makes a good board member. We must be curious and assume the people that we deal with are creative, resourceful and whole, except that they have this interesting but limiting disease. Knowing that we are all sound people, we can make a difference, we can change, and we can learn. Always be curious, because when you are curious you keep your mind open.

Q: You chair the Governance and Nomination Committee. What does that involve?

A: As the Governance Committee, we are guardians of the bylaws. We are charged with making sure that, as a Board, we are doing right by ourselves and adhering to our own principles and standards. The other part of this committee involves nomination. As the Nomination Committee, we are always looking for people who are interested in board service. It is our job to seek out members of the community, Foundation members or individuals with leadership qualities. It takes passionate people to do the work. We have the best executive director in the world, but ultimately the Board is responsible for making some important decisions. We must make decisions about how to spend and allocate the resources available.

continued on page 7

Nighttime Agitation – Is It RLS?

By Kathy Richards, PhD, RN, FAAN; member of the RLS Foundation's Scientific and Medical Advisory Board

For people in the dementia stage of Alzheimer's disease (AD-D), the problem of nighttime agitation, defined as the presence or worsening of behaviors such as aggression or wandering in the afternoon or evening, is a management challenge for their caregivers. This problem often leads to more and more restrictive living environments for persons with AD-D, including placement in nursing homes. In addition to AD-D, nighttime agitation might be a manifestation of a common neurologic condition: restless legs syndrome (RLS). Symptoms of RLS match those of nighttime agitation – that is, not being able to remain still, and experiencing symptoms in the evening.

In a recent study published in the *Journal of Post-Acute and Long-Term Care Medicine*, the characteristics and behaviors of 76 older adults with AD-D, nighttime agitation, and newly diagnosed RLS were measured. RLS was diagnosed using the Behavioral Indicators Test – Restless Legs, a validated tool for diagnosis of RLS in persons with AD-D. The individuals in the study were unable to cognitively and verbally report their RLS symptoms. The older adults with AD-D were also observed for nighttime agitation behaviors. Assessment of iron status and sleep quality (using motion sensors) was conducted for these patients as well. The researchers found that fewer minutes of documented sleep and lower transferrin (iron) saturation were associated with more frequent behaviors of nighttime agitation. Over three-quarters of the patients with RLS and nighttime agitation had been prescribed medications that

worsen RLS, such as antihistamines and serotonin reuptake inhibitors (antidepressant medications).

These findings support clinical consideration of nighttime agitation as a sign of RLS and highlight the need for further research to identify new management strategies. The findings also suggest that medical providers should take steps to identify and diagnose RLS; treat iron deficiency anemia if indicated by low transferrin saturation; and deprescribe medications that worsen RLS. The combination of these strategies will lead to a reduction in any RLS component of nighttime agitation in patients with AD-D. In addition, it is recommended that nursing homes change common practices that are likely to worsen RLS discomfort and nighttime agitation, such as restricting residents from evening walking and putting them to bed early.

Kathy Richards, PhD, RN, FAAN, is a research professor at The University of Texas at Austin, School of Nursing. As a UT Austin PhD graduate, Kathy has conducted sleep research in Alzheimer's disease for 20 years, and received over \$25 million in NIH funding to support her research endeavors.



*Kathy Richards,
PhD, RN, FAAN*

Q & A Secretan continued from page 6

Q: What do you look for in a board member?

A: People are surprised to know that not all of our board members actually have RLS. It is not required that you have RLS, but you must have knowledge about the disease and what it means to live with RLS. You need to be willing to commit your time and resources to this important cause. This is a working board. All board members are expected to attend each meeting. In ordinary times, we hold one face-to-face meeting a year and three to four meetings by phone or Zoom. Your financial commitment to the Foundation should be equal to or greater than any of your other charitable giving commitments. One of the key responsibilities for each board member is to thank our major donors, by either phone or letter. When a donor gives a substantial gift to the Foundation, it is important that they get recognition and sincere thanks from a board member. Often, we learn more about the concerns and interests of donors through thank-you calls. This knowledge helps us keep in touch with members and helps inform future board decisions.

Q: Are you currently looking for new board members? How do you find them?

A: We are always looking for new board members; our terms don't last forever — which is a good thing. We want new people who have new ideas. Several of our current members attended the RLS Symposium held in La Jolla a couple of years ago. It was a great

opportunity to meet new people in person with an interest in board service. Sometimes we look at people who have come to us for help, or who have become interested enough to become a donor, and we reach out to see if they may be interested in further service.

When I was considering what to spend my volunteer energy on, I realized that there are many causes that are dear to my heart. Racial justice and climate change are both important issues. I wanted to make a difference in the world, and not just for RLS. I was torn. But, here is the thing: If my RLS isn't somewhat manageable, then I'm not able to do anything. My RLS wouldn't be manageable without the support I receive from the Foundation. I wouldn't know what to do, where to go, how to find information, how to manage my RLS. Once I put that into perspective, there was only one answer. I am only able to volunteer because of the support of this Foundation — the support of this Board — so I darn well better serve this Board and the Foundation, and that's what made my decision.

Q: Do you have any advice for those who are considering the decision to join the Board?

A: Talk to us! Find out how we operate, find out how you might fit, ask questions. We are open to speaking with you. If we can provide the information that would tip the balance toward your becoming more involved, give us a call.

The Signs of Augmentation Q&A with Dr. Mark Buchfuhrer

Mark Buchfuhrer, MD, FRCP(C), FCCP is a pulmonologist and sleep specialist in Downey, California, and is affiliated with multiple hospitals, including PIH Health Hospital-Downey and the RLS Quality Care Center, Stanford Sleep Medicine Center, at Stanford Hospital in Palo Alto, California. Dr. Buchfuhrer serves on the Foundation's Scientific and Medical Advisory Board. In a recent webinar, "The Signs of Augmentation," Dr. Buchfuhrer answered some questions posed by the audience. The webinar recording is available in the Member Portal on www.rls.org.

Q: After a person has experienced augmentation, is it true that the effects may not go away even months later. What can be done?

A: In general, augmentation symptoms resolve within two weeks to several weeks upon discontinuing a dopamine agonist medication. Unfortunately, symptoms may never go away in some patients, or there may have been an additional natural worsening of the RLS which is likely in patients who have been on dopamine agonists for many years (the baseline may have shifted over the years). However, most patients get marked improvement once dopamine medications are stopped and are better in two weeks to a few months.

Q: Are there any alternatives to medications that can cause augmentation?

A: Augmentation is a unique treatment phenomenon associated with dopaminergic therapy in individuals with RLS. The dopamine agonists (ropinirole, pramipexole, rotigotine) and Tramadol (a mixed opioid with dopaminergic properties) are known to cause augmentation. All other medications used to treat RLS, such as the alpha-2-delta ligands, do not cause augmentation. A careful review of the patient's history to rule out mimics of augmentation – including new life stressors, antidepressant and other medication use, lifestyle changes, and low iron stores as measured by a serum ferritin lab test – must be conducted to reach an accurate diagnosis of RLS augmentation.

Q: Can augmentation happen when you have barely been experiencing RLS symptoms for years? My disease just went from 1 to 10.

A: Augmentation is an insidious process; it occurs slowly over time without notice. The gradual increase in medication doses over time that exceed FDA maximums contributes to the development of augmentation. In addition, the presence of low iron stores (ferritin < 75–100 mcg/L) is another contributing factor in the development of augmentation. However, sometimes augmentation may appear very quickly and be triggered by other factors.

Q: Are there any new treatments for RLS augmentation?

A: There are no new treatments, but researchers are looking at the D1 receptor subtype in the brain. Current dopamine agonists target the

D2 and D3 receptors and may cause hyperactivity in the D1 subreceptors which cause RLS symptoms to increase. The RLS Foundation funded a study by Dr. William Ondo, and he plans to conduct a larger study of a medication that blocks the hyperactivity of the D1 receptor.

Q: How is augmentation managed in individuals using the rotigotine patch (Neupro)?

A: The first step is to switch to an opioid medication by tapering or just stopping the Neupro patch. Once off the Neupro patch for about two weeks, the opioid dose can usually be decreased significantly, similar to treating augmentation due to short-acting dopamine agonists.

Q: Are there any other negative physical impacts of augmentation besides a worsening of RLS symptoms?

A: Sleep disruption, anxiety, depression and/or suicidal ideation can develop as a result of the sleep loss associated with augmentation. Augmented individuals often have to change their daily routines to accommodate the earlier appearance of symptoms.

Q: Is it possible to take "drug holidays" from dopamine drugs to make augmentation less stressful/painful?

A: Drug holidays are not an appropriate treatment strategy for augmentation. A true drug holiday involves stopping a medication for a period of time that is longer than the time period that withdrawal symptoms lasted. Augmentation requires the development of a new treatment plan to manage symptoms during periods of inactivity. Taking a drug holiday will only temporarily reestablish the effectiveness of the dopamine agonist drug before augmentation quickly returns.

Q: Which medication classes do not cause augmentation?

A: Alpha-2-delta ligands and opioids do not cause augmentation. These two medication classes can be used as a monotherapy or in combination to manage augmentation. One exception is Tramadol, a mixed opioid with dopaminergic properties that raises the risk for augmentation.

Q: Is it possible to take RLS medication intermittently, and can this approach expand the time before the occurrence of augmentation?

A: For intermittent RLS, it is possible to take a dopamine agonist medication up to three times a week without the development of augmentation. It is the daily use of dopamine agonists that raises the risk for the development of augmentation. Sinemet can be used for patients with daily RLS as a rescue medication (for breakthrough RLS symptoms) up to three days per week; exceeding this maximum raises the risk for augmentation

Raising Awareness With Pen and Paper

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

RLS awareness and education are two recurring themes for individuals living with RLS. Unfortunately, healthcare providers often lack awareness of the disease and/or the clinical knowledge to manage patients according to consensus treatment guidelines.ⁱ

Three women based in the UK, Ireland and the Netherlands joined forces to do something about it. Julie Gould, Charlotte Deerenberg and Rachel Andrews met online and decided to address the lack of RLS training offered during medical school.

In the UK, the undergraduate and postgraduate training curriculum for physicians does not include a study component dedicated to RLS that introduces the diagnostic criteria, treatment considerations and long-term management of the disease. In the US as well, medical students lack training in diagnosing neurological sleep disorders like RLS.

Lack of knowledge can have a negative impact on patients. Clinically significant RLS has an estimated prevalence of 2.7%, yet this common neurological sleep disorder is often misdiagnosed and undertreated.ⁱⁱ

In 2017, an RLS Foundation-funded study published in *Sleep Medicine* found that training physicians in medical school to accurately diagnose RLS leads to lower overall healthcare costs and better health outcomes for patients.ⁱⁱⁱ

Deerenberg says, “Most individuals wait to see a physician until symptoms are more severe, affect daytime functioning, and simple remedies (stretching, physical activity, massage) are no longer effective.”

A 2007 article in the *Journal of Neural Transmission* reported that it takes on average 12.7 years from the onset of symptoms for an RLS diagnosis to be made and treatment to begin – resulting in nearly 13 years of needless suffering.

When Gould, Deerenberg and Andrews recognized the absence of RLS in the curriculum to train physicians, they took a proactive



Julie Gould



Charlotte Deerenberg



Rachel Andrews

approach to address this educational gap. Working together, they decided to raise awareness by creating a letter-writing campaign to educate key individuals (legislators, persons in the medical community, and leaders of organizations) about the disease.

In August 2021, *The Lancet*, a leading peer-reviewed medical journal, accepted and published their article, “A call for better training in restless legs syndrome.”

Andrews observes, “RLS evokes severe resistance in the medical community; individuals with RLS understand that resistance, and *The Lancet* overcame the resistance to RLS.”

Gould says, “We seek more correspondence from *The Lancet* article and plan to continue our outreach to raise awareness of RLS and inclusion of restless legs syndrome in the medical school curriculum.”

Whether it is a group of concerned individuals meeting around a dining room table in Raleigh, North Carolina, to establish the RLS Foundation in 1992, or a small team collaborating online in 2021 to publish an article in *The Lancet*, one thing is clear to the RLS community: Our work is not yet done. Each of us needs to do our part.

What will you do to raise awareness and the need for medical education about RLS?

ⁱ Silber M, Buchfuhrer M, Earley CJ, Koo BB, Manconi M, Winkelman JW, for the Scientific and Medical Advisory Board of the Restless Legs Syndrome Foundation. The Management of Restless Legs Syndrome: An Updated Algorithm. *Mayo Clin Proc.* July 2021;97(7):1921-1937. doi: 10.1016/j.mayocp.2020.12.026. Open Access Journal Article.

ⁱⁱ Allen RP, Arthur S, Walters AS, Montplaisir J, Hening W, Myers A, Bell TJ, Ferini-Strambi L. Restless legs syndrome prevalence and impact: REST general population study. *Arch Intern Med.* 2005 Jun 13;165(11):1286-92. doi: 10.1001/archinte.165.11.1286.

ⁱⁱⁱ Padula W, Phelps CE, Moran D, Earley CJ. Allocating provider resources to diagnose and treat restless legs syndrome: a cost-utility analysis. *Sleep Med.* 2017 Oct;38:44-49. doi: 10.1016/j.sleep.2017.06.034. Epub 2017 Jul

10 Steps Closer

The race to find a cure for restless legs syndrome isn't a sprint – it's a marathon. It takes patience, pacing and perseverance. And this race requires a combination of awareness, advocacy and analysis. At the RLS Foundation, we are confident that, with the help of our loyal and dedicated members, we will reach the goal.

As we approach the end of another promising year of progress, here are 10 steps that you can take to bring us closer to a cure.

Renew your membership for 2021: Even if you missed the call for an “early bird” renewal, it's not too late to renew for another year and secure the benefits of being a dues-paying member. And remember that we count on every dollar of membership dues to run the everyday operation of our organization – costs that we can't get from grant funding.

Respond to a special appeal: On the other hand, your dues may be all paid, but we still count on contributions to our special appeals and fundraisers to ensure that we can respond to emerging needs and take advantage of newfound opportunities. Dues and appeal gifts work hand in hand to bring us closer to a cure!

Pay it forward: Even if your dues are all paid up, some of your fellow members are on fixed incomes or going through hard times. When you provide someone in need with a “scholarship membership,” your kindness will keep that member active in our support network and convey a message of hope and caring.

Remember the RLS Foundation in your will: By including the Foundation in your estate planning, you can make an ultimate gift in a way that could improve tax consequences for your heirs while establishing a legacy of support that will last beyond your lifetime.

Give from your assets: You may also have creative ways at hand to give during your lifetime while improving your own tax status through a gift of appreciated securities or the mandatory distribution from your

retirement account. Since everyone's situation is unique, we encourage anyone contemplating such a gift to consult with a financial advisor.

Make your voice count: You can help secure two key ingredients in our quest for a cure – nationwide awareness and federal funding – when you become an RLS Foundation advocate. Contact your legislators, share your experience with RLS and how it affects your everyday life, and let them know how they can support the RLS community.

Tell a friend: Advocacy can take a personal turn when you tell friends or loved ones about us and encourage them to support us through their own memberships. After all, they have a great role model: You!

Get a company matching gift: Did you realize that many companies match employee donations to non-profit organizations as a way to demonstrate corporate social responsibility? Just ask your human resources department if your company matches employees' charitable contributions, to obtain and submit the matching gift form that most require for participation.

Support RLS Foundation fundraisers: You can become part of our fundraising team! Ask friends and family to support the RLS Foundation on Giving Tuesday (Nov. 30), or select the RLS Foundation to receive donations on all smile.amazon.com purchases.

Become a monthly sustaining member: Sustaining members are our supermembers! They ensure that the lifeblood of our operation will continue to flow uninterrupted month after month. And automatic giving means that we're saving on printing and postage, too, putting more of every gift to work toward a cure.

Remember: We're running a marathon, so pace yourself. But keep this list of steps in mind and do what you can, when you can. Above all, plan to celebrate with us when we cross the finish line together!

Give Back on Giving Tuesday this November

By Karla Dzienkowski, Executive Director, RLS Foundation

As we head into the holiday season, we look back on the gifts we were given in 2021, as well as the losses we've endured, and hope to hold on to the memories we've made. On Thanksgiving in the US, families and friends gather to appreciate time together in person, or perhaps on Zoom. On the Tuesday following Thanksgiving, non-profit organizations like the RLS Foundation celebrate Giving Tuesday. It is a one-day event set aside to give back to organizations that make a difference in our lives and our communities.

Giving Tuesday began in 2012 as a day to encourage individual acts of kindness and generosity to organizations that are meaningful to us and make an impact on our lives. The power of the internet and social media connects individuals worldwide for a day that focuses on giving back, and doing good in the process.



All gifts to the RLS Foundation on Giving Tuesday are tax deductible to the full extent permissible by law, and all contributions go directly to the Foundation. Giving Tuesday does not charge any fees to participating organizations. If you would like to support the good works of the RLS Foundation on Giving Tuesday, November 30, go to www.rls.org/GT. Or, you can mail a check to the Foundation with “Giving Tuesday” in the memo line. However you choose to support our common goals on Giving Tuesday, we are grateful!

New Administration Presents New Opportunities

By Philip Goglas II, Managing Partner, Health and Medicine Counsel

The Restless Legs Syndrome Foundation continues to advance critical priorities of the RLS community despite the uncertainty created by the COVID-19 pandemic. The Foundation successfully hosted another Virtual Capitol Hill Advocacy Day this spring, as well as key awareness activities during the month of September and the Virtual Summit in October. We will also again be participating in the virtual Sleep Advocacy Forum, which continues our collaboration with other sleep organizations to advance our shared priorities.

With support from the RLS community, we celebrate the creation of the Chronic Disease Education and Awareness (CDEA) Program at the Centers for Disease Control and Prevention (CDC). This competitive grant program aims to advance work with stakeholders on education, outreach and public awareness activities for chronic diseases such as RLS. There is a clear disparity in public and professional awareness of chronic diseases that are not funded through a direct CDC appropriations line in the federal budget. This new program will strengthen the scientific base for these activities, leading to positive and meaningful patient outcomes. We will continue to advocate for increased funding for the CDEA that will result in more grants being awarded.

The RLS Foundation continues to work with the leadership of the National Institutes of Health NeuroBioBank and the Brain Donor Project, both to strengthen this critical collaboration and to ensure the proper identification of RLS brains by including the Johns Hopkins Questionnaire (tool to validate RLS diagnosis) in the packet of intake forms.

The Foundation also continues to advocate for appropriate access to low-total-daily-dose opioid therapy for RLS patients through targeted outreach with federal agencies and key congressional committees. We have begun to meet with members of congressional committees with oversight on opioid policy. As a new Congress started this year, we have a unique opportunity to educate members about the needs of our patient community and the direct effect that policies have on our community.

At the end of May, the White House released its comprehensive Fiscal Year 2022 (FY 2022) Budget Request to Congress. The first budget request of the Biden-Harris Administration called for significant investment in a variety of federal programs and included many elements from the infrastructure enhancement proposals. The budget request also called on Congress to provide meaningful funding increases for medical research, public health and higher education programs. Congress has already been advancing the FY 2022 funding process on Capitol

Hill, with the House passing a majority of the appropriations bills for FY 2022 and the Senate taking action this fall.

Some highlights from the recommendations of the Appropriations Committee as of September show the success of the Foundation's advocacy on several key initiatives, including opioid policy.

Centers for Disease Control and Prevention: Includes \$5 million (an increase of \$3.5 million) for the CDEA Program. Also included is \$5 million for the National Neurological Conditions Surveillance System, the same level that was funded in FY 2021.

National Institutes of Health: Includes \$2.79 billion for the National Institute of Neurological Disorders and Stroke (NINDS), an increase of \$286.12 million over FY 2021. In regard to sleep disorders, the Appropriations Committee notes the leadership of NINDS in advancing research into underrepresented sleep disorders, including narcolepsy, restless legs syndrome, and Kleine Levin syndrome. The committee encourages NINDS to bolster this research and review the state of the science around sleep disorders to better support initiatives that advance scientific understanding of specific sleep disorders affecting patients.

The Appropriations Committee also notes continued support from the National Institute on Drug Abuse (NIDA) for research to better understand opioid use disorder and urges engagement with stakeholders to examine contributing factors to drug abuse, including sleep and circadian-dependent mechanisms.

Although the pandemic has created roadblocks to meeting in person with congressional representatives, our partnership with the Health and Medicine Counsel has enabled us to collaborate with other advocates in the sleep community to enhance our voice. As the importance of sleep on health grows as a public health issue, we continue to urge the inclusion of RLS in those discussions and advocate for more public awareness and education.

In the News

By Elias G. Karroum, MD, PhD

A promising peripheral nerve stimulation as a noninvasive treatment for RLS

“Noninvasive neuromodulation reduces symptoms of restless legs syndrome.” Mark J Buchfuhrer et al. *Journal of Clinical Sleep Medicine* 2021;17(8):1685–1694. August 2021.

The Background

Currently the treatment of moderate to severe RLS relies significantly on medications including alpha2-delta drugs (like gabapentin, gabapentin enacarbil and pregabalin), dopaminergic agents (like pramipexole, ropinirole, rotigotine patch), as well as opioids (mostly in refractory patients). All these pharmacological treatments can have significant side effects; as a result, patients can be resistant to treatment, and some patients can be unwilling or unable to take any pharmacological treatments. For those reasons, searching for alternative noninvasive and nonpharmacological treatments for RLS is warranted. Therefore, the authors of this paper studied the efficacy of a novel, noninvasive peripheral nerve stimulation technique in alleviating the symptoms of RLS.

The Research

The new noninvasive, transdermal (delivering electrical stimulation through the skin) peripheral nerve stimulator approach tested by the researchers consisted of a wearable device positioned at the upper part of each leg where the common peroneal nerve can be stimulated. This nerve is responsible for the movement of the foot and toes upward and the sensation over the external region of the leg and the upper region of the foot. The device was activated each night by the patient to deliver an electrical stimulation for 30 minutes at bedtime. To test the efficacy of this device for reducing RLS symptoms, the researchers performed a multisite clinical trial that was randomized (patients assigned at random to a certain predefined treatment group), was single blinded (patients did not know exactly which of several treatments they were given) and had a crossover design. In other words, subjects received, consecutively, both the actual effective nerve-stimulation treatment and a placebo treatment (a treatment initially similar to the actual nerve stimulation but omitting the final step of programmed effective stimulation). Each patient with moderate to severe RLS enrolled in this study (35 completed all the steps of the study and 37 total patients' data were analyzed) performed two weeks of actual nerve stimulation and two weeks of placebo treatment in a random order every night for 30 minutes around bedtime.

Efficacy of the stimulation device was primarily analyzed based on four patient-reported measures. These were: the International Restless Legs Syndrome Study Group Rating Scale (IRLS) at baseline before any intervention and after the two weeks of each intervention (actual stimulation and placebo stimulation); the Clinical Global Impressions-Improvement (CGI-I) scale after the two weeks of each intervention; and a numerical rating scale (NRS) for RLS symptom severity, evaluated before, during and after the nightly use of the device. The major results of this study showed a significant improvement in RLS symptoms, with a reduction in the severity of symptoms on the IRLS

from baseline entry in the study by 6.8 points for the actual stimulation, and by 3.4 points for the placebo stimulation; a high positive response on the CGI-I for the actual stimulation (66%) compared to the placebo stimulation (17%) and, a decrease in the NRS rating for severity of RLS symptoms during and after the actual stimulation, compared to the placebo stimulation. In addition, the positive response to the actual stimulation was demonstrated both for patients that were not taking any medication for RLS and for those who had medication-resistant RLS. There were no significant device-associated side effects.

The Bottom Line

The importance of the above study is that it demonstrated with significant evidence that a noninvasive and non-medication-based treatment – electrical stimulation of the common peroneal nerve supplying the legs and feet – can be a safe and effective short-term method to manage troublesome symptoms of RLS.

Further Questions

Is this method of peripheral nerve stimulation truly effective and safe in RLS patients in the long term? Larger clinical trials and analysis of real-world usage are needed to consider the therapeutic value, as well as potential adverse effects, of this type of peripheral nerve stimulation. In addition, is the common peroneal nerve the only possible nerve to target with this device, or is it the best way to bring about a significant reduction in RLS symptoms? The tibial nerve is another important peripheral nerve in the legs and feet that supplies the muscles of the calves, the gastrocnemius, and the soleus muscles. The calf region is the most frequently reported area of unpleasant sensations by RLS patients.

A promising new medication (dipyridamole) for the treatment of RLS

“A randomized, placebo-controlled crossover study with dipyridamole for restless legs syndrome.” Diego Garcia-Borreguero et al. *Movement Disorders*. August 2021. Online July 2021 ahead of print.

The Background

Dopaminergic agents, the first-line medical treatment prescribed for treatment of RLS, are very effective at alleviating RLS symptoms but have a major long-term complication known as augmentation. In addition, only two other medication classes have been shown to be effective in RLS: alpha2-delta drugs (gabapentin, gabapentin enacarbil, pregabalin) and opioids (methadone, buprenorphine, oxycodone). Therefore, there is a clinical need for other medical treatments for RLS. The authors of this paper, based on an RLS animal model with brain iron deficiency and low adenosine state, hypothesized and included some preliminary limited clinical evidence about the role of dipyridamole in alleviating RLS symptoms. Adenosine is an organic compound that plays an important role in many biological functions, including having a depressing effect on the central nervous system.



By Elias G. Karroum
MD, PhD

Dipyridamole is a medication that can increase the availability of adenosine outside the cells.

The Research

To test the efficacy of dipyridamole at reducing RLS symptoms in a more robust way, the researchers performed a randomized, double-blinded and placebo-controlled study with a crossover design. That is, patients were assigned at random to a certain predefined treatment group and received, consecutively, both the actual dipyridamole treatment and a placebo (a treatment similar to the dipyridamole treatment but without the active properties of dipyridamole). Each of the 28 patients with severe RLS enrolled in the study initially received, at random, either the dipyridamole treatment or the placebo treatment for two weeks. This was followed by one week of no treatment, and then finally by two weeks with the treatment not given initially. Neither patients nor researchers knew which treatment was being administered when and to whom.

The primary measure of the efficacy of dipyridamole in this study was the IRLS, completed at baseline before any treatment was given and then after each two-week period of alternative medication (dipyridamole or placebo). The researchers also had secondary measures of efficacy, reported by the patients, including the Clinical Global Impressions (CGI) Scale and the Medical Outcomes Study (MOS) Sleep Scale. In addition, after each two weeks of either treatment, the researchers performed a multiple suggested immobilization test (mSIT), followed by a sleep study (diagnostic polysomnogram). The mSIT is a test developed specifically for studying the severity of unpleasant RLS sensations at different times of the evening and night by using a numerical severity scale and the frequency of leg movements while the patient is awake and not moving for one hour.

The major study finding was a significant improvement in RLS symptoms, along with a reduction in RLS severity on the IRLS from baseline (before treatment) by an average of 13 points for the dipyridamole treatment, compared to 5 points for the placebo treatment. With dipyridamole (compared to placebo) treatment, patients also significantly improved their RLS symptoms and sleep characteristics, based on the secondary patient-reported measures (CGI, MOS, and numerical severity scale for the mSIT) and secondary objective measures (reduction in leg movements on the mSIT and the sleep study, as well as better sleep efficiency, deeper sleep and a shorter time to fall asleep). There were only mild side effects with dipyridamole treatment, including mainly abdominal distension, dizziness, diarrhea and fatigue.

The Bottom Line

The importance of the above clinical study is that it confirmed with significant evidence from both subjective and objective measures that dipyridamole, a drug with a different mechanism of action from other established RLS medications, can be a safe and effective treatment of patients with severe RLS, at least over a trial period of two weeks.

Further Questions

Is dipyridamole truly effective and safe for RLS patients in the long term? Larger clinical trials and real-world usage are needed to consider the therapeutic effects, as well as potential adverse effects, of this type of medication. In addition, can the beneficial effect of dipyridamole on sleep (related most likely to the increase of adenosine outside the cells), with a shorter time before the onset of sleep and during sleep, be exploited in future as a potential treatment of sleep disorders other than RLS, such as insomnia? Finally, it is still to be determined if dipyridamole can be effective in patients with refractory symptoms on dopaminergic medications or who have dopaminergic augmentation, given that all enrolled patients in this study had never received previous treatment with dopaminergic agents.



Here's an easy way to provide hope and access to knowledgeable and experienced RLS healthcare providers to others who struggle with RLS in your community:

Nominate your healthcare provider and send the RLS Foundation their contact information so we may invite them to join our FREE RLS Healthcare Provider Network.

Name _____

Address _____

City _____

State _____ Zip _____

Phone _____

Approved HCPs will be invited into our online provider network and sent RLS Foundation materials to educate and share with their patients.

Ask the Doctor

The RLS Foundation is unable to respond to individual medical or treatment-based questions due to liability issues. Your personal healthcare provider knows you best, so please contact your provider with specific questions related to the ongoing management of your RLS. We welcome your general-interest medical questions, which may be submitted to info@rls.org with "Ask the Doctor" in the subject line. Select questions on areas of common interest will be published in a future issue of *NightWalkers*. Questions will be edited as needed and published anonymously. The following questions were answered by Dr. Mark Buchfuhrer during a recent "Ask Dr. B." webinar.

Q: Do you have any suggestions for homeopathic or natural ways to deal with RLS other than a TENS (transcutaneous electrical nerve stimulation) unit?

A: Helpful strategies to avoid worsening RLS symptoms include avoiding triggers such as alcohol, a very common RLS trigger. Sugar, salt and gluten are less likely to be reported as RLS triggers. Moderate forms of exercise are beneficial in managing RLS symptoms, whereas excessive exercise can lead to an increase in symptoms. Hot or cold showers are helpful for some individuals. Devices that vibrate or wrap around the leg and foot may alleviate aggravating symptoms. The key is to determine your personal RLS triggers and to avoid them. It is also important to identify alternative treatments to cope with troubling symptoms. Hot or cold showers, massage, exercise and mentally engaging activities such as crossword puzzles or video games are examples of coping methods to manage symptoms.

Q: Are there any new promising treatments for RLS?

A: There are no new game-changing treatments on the horizon. It is important to remember that it takes time from research and development of a drug until it is approved for medical use. Support for the RLS Foundation's Research Grant Program and its advocacy program in Washington help to raise awareness of RLS and the need for additional research funding for RLS researchers.

Q: At what level of ferritin do you recommend iron infusions for RLS?

A: Ferritin level of 100 mcg/L or less is the new recommended parameter for iron infusion. However, there are circumstances where we will do iron infusions on patients with ferritin levels higher than 200 mcg/L. It is important to avoid ferritin testing when ill; ferritin is an acute phase reactant that is elevated during an infection or inflammation process. If you are ill, wait at least six to eight weeks to test your ferritin level.

Q: Do people with RLS get addicted to opioids? If so, what is the percentage?

A: Addiction is a psycho-social term. The correct terms to evaluate the potential for problems with opioid use are dependence and tolerance. Dependence is the body's adaption to the use of a drug to function and the occurrence of withdrawal symptoms when the drug is stopped. Tolerance is the diminished response to a drug that requires a dosage increase to achieve the same response that occurred at the lower dose.

When opioids are prescribed appropriately, the risk for development of opioid use disorder is minimal. The low total daily doses prescribed for management of RLS symptoms lessen the likelihood for the development of dependence and tolerance. A 2018 Mayo Clinic Proceedings article, "The Appropriate Use of Opioids in the

Treatment of Refractory Restless Legs Syndrome," provides guidelines for physicians and patients to follow to minimize risk associated with treatment.

Q: Do you think that dopamine agonists permanently damage the dopamine receptors for many individuals with RLS?

A: There is no definitive answer to this question. In the Garcia-Borreguero study, RLS patients with augmentation who stopped taking dopamine agonists and were then prescribed an alpha-2-delta ligand were compared to RLS patients who only took an alpha-2-delta ligand to manage RLS symptoms. The RLS patients who previously took dopamine agonists did not respond as well to alpha-2-delta drugs (gabapentin, gabapentin enacarbil, pregabalin) as patients who never took dopamine agonist drugs. It has been hypothesized that the dopamine agonists left permanent damage, preventing them from getting to their baseline symptoms prior to dopamine agonist administration.

Q: Does RLS always progress as a disease? Can it be stabilized with the correct medication?

A: RLS does not always progress as a disease. Some individuals may experience a spontaneous remission that lasts for months, years or forever. RLS symptoms can wax and wane over time. In my practice, the majority of patients not on dopamine agonists are extremely stable over the years. Patients prescribed opioid therapy to manage refractory RLS are on low total daily doses that remain unchanged or only minimally increased over a time span of two to three decades.

Q: Has a definitive link been established between intestinal disease and RLS?

A: Dr. Weinstock has studied the relationship between SIBO (small intestinal bacterial overgrowth) and RLS. It may be that a gut issue leading to a malabsorption of iron causes the occurrence of RLS symptoms. Anecdotally, patients have reported a benefit to treatment of SIBO, but over time results are diminished. More research into the gut-RLS relationship is needed.

Q: How can I compensate for methadone's negative impact on testosterone levels and all sexual functions?

A: Side effects of methadone treatment include diminished libido and erectile dysfunction in men. If this side effect occurs, the physician needs to consider another treatment option to manage RLS symptoms. The RLS Foundation's new consensus treatment guidelines discuss alternative therapies such as buprenorphine (Belbuca, Suboxone, Subutex). Research by Dr. Rye has found these alternative therapies successful in managing RLS. Problems such as decreased libido are much less commonly experienced on buprenorphine.

Bedtime Stories

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

My doctor recommended a vibrating pad for 30 minutes of counterstimulation (vibrations). It works very well, although occasionally there are those nights when nothing works and you think you are going to lose your mind. I've also found that lying on my stomach and letting the lower part of my legs and my feet dangle will sometimes work. I have a weighted heating pad that sometimes works, or a teaspoon of prescription cough medicine with codeine. (A pill with codeine does not work.) I have a list of things I try when it gets really bad. – *MJamick*

Avoid sugar and alcohol, as they seem to be immediate triggers to bring on symptoms. Stretching and five minutes of walking on my treadmill help with exacerbations of both leg and arm restless symptoms. – *JoAnne*

A warm shower before bed and an electric blanket or throw at night helps my RLS. Jiggling my legs in a constant motion when seated for few minutes can relieve PLMs (periodic limb movements) and RLS. Also, try a stomping motion with the bothersome leg for a few minutes to relieve symptoms. – *KH*

I have had RLS for over 50 years; I am now 73. It has plagued many family members – one uncle found relief with opioid medications into his 90s. Nights were difficult with the crawling sensation in my legs and feet. I'd often have to pace for 20 minutes before I could get any relief. Nothing helped. Car, plane and train rides were miserable, as I couldn't keep my feet still! Somehow, I discovered a simple solution 10 years ago that has given me my sleep back! An RLS Leg Cream is a homeopathic remedy. I only use a small amount on my calves and thighs every night at bedtime. It has definitely changed my life! – *Patty*

I have had RLS since before it was recognized ... for some 45 years. Recently I tried a once-daily, sublingual dose of tincture of CBD oil. Although a short trial period of 10 days, it has been effective in mitigating symptoms so far. – *Dana L*

I downloaded and read the updated algorithm for managing RLS, and there was a brief mention of the use of cannabis and also of magnesium supplements, concluding that neither was very effective, but it was only referring to the ingestion of those substances. I know it is only anecdotal, but I have often gotten relief from a CBD ointment obtained from a very reputable grower, as well as from a magnesium gel rub. Granted, my RLS only involves my toes and sometimes my ankles, so it is easy to treat with ointments and rubs, though a little messy in the bedsheets. But it is worth it for me to be able to get to sleep. Just wanted to share this as something RLS sufferers might want to give a try before starting on medication, and it seems like there would be no harm from either substance. Hope this tip helps some of you fellow "Nightwalkers"! – *Kate S.*

My RLS journey is a long one, but I am better now than I have been in a long time. I began having RLS in 2000 at the same time that I was diagnosed with erythromelalgia. I took Sinemet at first, but it required increasing doses to get good results, so my doctor switched me to Mirapex in 2004. It worked very well until 2015, when I developed symptoms of augmentation. My symptoms got so bad that I could not keep my body still, not just my legs. I had symptoms all day and night and only fell asleep for an hour or two at night. It was the worst experience I have had in my entire life. I switched to the Neupro patch and that helped for almost a year, but then the symptoms of augmentation began again. I live in a state where marijuana is legal. One evening when I was particularly desperate after not sleeping for many days, a friend brought over some marijuana and suggested that I try it. I did and finally slept for a few hours. I used marijuana for about a year, until I discovered two other things that helped me. During this period, I started having pain in the sciatic nerve. A physical therapist prescribed exercises that involved lying on my stomach and pushing my head and upper body up like the upward-facing-dog yoga pose. I noticed that the frequency of RLS decreased after addressing my sciatica issues. One night when I was having an episode of RLS, it occurred to me to try lying on my stomach in bed. I don't find this position very comfortable, but it does cause a slight bending of the back in the direction of the upward-facing-dog yoga pose. Much to my surprise, the RLS symptoms stopped immediately. I continue to use this technique when I have RLS. The good news is that I only have RLS a few times per month. Sometimes I need to get up and "dance a jig," but then I can go back to bed. Sweet dreams! – *Ann*

One of my earliest memories: I was 4 years old and my older sister was 16. She complained constantly about how much I kicked at night and how horrible it was, because she had to remake my bed every day because I pulled the sheets off while I slept. I'm 55 now. Several years ago, I did a sleep study, and I had a limb movements every two seconds. Not only do I have severe RLS; I also have periodic limb movements. I've learned that at least two aunts have RLS. I have reason to believe there are dopamine-related issues on my mom's side. I've also been diagnosed with Ehlers-Danlos syndrome (EDS). I found success with clonazepam, but my doctor wants me to stop it. I tried a taper. I found I relied more on caffeine and sugar, which ruins the healthy diet. Clonazepam puts me into a healthy sleep and provides me with the energy I need to live the active life I enjoy. Staying active – that means a daily walk with my dogs, swimming several days a week, along with riding my stationary bike – takes me to my "Zen." I stretch but am cautious because of the EDS; hypermobility is part of it, and it can lead to dislocation. Most important is staying educated and being my own advocate. I have regular doctor and physical therapy visits and make sure I know how to speak the language. – *Cindy*

RLS Support Network

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

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

United States Support Groups

ARIZONA

Bonny Lepore
Prescott Valley, AZ
928-899-4845
rlshopeprescott@rlsgroups.org

CALIFORNIA

Caroline Chamales
San Diego, CA
917-526-1339
caroline@rlsgroups.org

Sheila Richards
Westlake Village, CA
818-577-0237
srichards@rlsgroups.org

Susan Schlichting
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*Member of RLS Foundation Board of Directors

Register for a Virtual Support Meeting

Each month we host meetings at these times:

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

To register for a Virtual Support Group meeting go to www.rls.org/vsg.

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Clinical Trials

A clinical trial is a research study that uses volunteers to investigate specific health questions. The RLS Foundation does not conduct clinical trials; however, as a service to our members, we list clinical trial opportunities on www.rls.org and in NightWalkers. Below is a partial list of RLS clinical trials currently seeking volunteers. Please contact the institution directly if you are interested in participating. All studies listed have received Institutional Review Board approval, which allows us to ensure that they follow established protocols. Please note: This is not a comprehensive list. To search for clinical trials in your area, visit www.searchclinicaltrials.org or www.clinicaltrials.gov.

To learn more about clinical trials, members can download the handout Clinical Trials and Research from www.rls.org or request a paper copy from the Foundation.

Do You Continue to Have Insomnia Even Though Your RLS is Well Controlled?

Many people continue to experience insomnia even though their RLS is under good control. Such sleeplessness is often distressing and can produce negative daytime consequences. John W. Winkelman, MD, PhD, with the Sleep Disorders Clinical Research Program, Massachusetts General Hospital, is conducting a research study, performed virtually by video and/or phone, investigating the efficacy of a Food and Drug Administration-approved sleep medication, suvorexant (Belsomra), for the treatment of this condition.

Participants will attend six virtual meetings and two brief phone visits with Dr. Winkelman. The study will take approximately 10 weeks to complete. Participants will be compensated up to \$250 for completion of the study. To qualify, participants must be:

- 25–85 years old
- Experiencing RLS that is well controlled
- Treating their RLS with a non-opioid medication
- Living in the New England area or California

Participation voluntary and will not change the RLS care that you currently receive. All information learned from the study will be kept confidential. Names and other personal information will not be attached to the study data.

Contact: For more information, please contact research coordinator Jordana Zackon at 617-643-6026 or jzackon@mgh.harvard.edu. Please also share this information with family members or friends who may be interested in this study.

Investigational Wearable Device to Treat RLS

You may be able to help advance RLS research by enrolling in the RESTFUL study. This eight-week clinical trial evaluates an investigational treatment option for managing RLS based on a wearable device instead of a medication. You may be eligible for the RESTFUL study if you've had an insufficient response to one or more RLS medications and your current RLS symptoms are moderate or severe. If you're currently taking an RLS medication, you will be able to continue taking it during the study while using the study device. The trial requires four in-person clinic visits. You will be compensated for your time and travel.

The RESTFUL study is currently enrolling at IRB-approved sites in California, South Carolina, Colorado, Missouri, Texas, Ohio, and Georgia.

Contact: For more information and to apply, visit <https://www.patientwing.com/RESTFUL-FB>.

Understanding the Role of Epigenetics in RLS

Researchers at Johns Hopkins School of Medicine, led by Christopher J. Earley, MB, BCh, PhD, are conducting a study designed to address the question of why RLS has such a high inheritance risk. If you are a woman who currently has iron deficiency anemia then you may be eligible for this study. We are looking for women who do and do not (control group) have RLS symptoms.

Contact: Jessica at 410-550-1046

Intravenous Iron Therapy in Patients with Anemia and RLS

Researchers at Johns Hopkins School of Medicine, led by Christopher J. Earley MB, BCh, PhD, are conducting a clinical trial to establish the effectiveness of intravenous iron in treating patients who have an anemia and who also have RLS symptoms. If you currently have an iron deficiency anemia and have frequent RLS symptoms then you may be eligible for this clinical trial.

Contact: Jessica at 410-550-1046

Hormones and Their Role in Restless Legs Syndrome

RLS community: Brian Koo, MD, and his team of researchers at Yale have received funding from the Department of Defense to continue their study of hormones in RLS and are looking for RLS study participants. The research aims to uncover the underlying biological mechanisms of RLS – an essential step to develop new, more effective treatments for RLS and to discover a cure.

Dr. Koo's team is conducting the study to determine whether levels of specific hormones are increased in the blood and spinal fluid of persons with RLS. The researchers are able to reimburse you for the cost of your travel (up to \$600) for a one-time visit to New Haven, Connecticut. The research requires that participants undergo blood draws and a spinal tap. The researchers are looking for individuals with moderate to severe primary idiopathic RLS who do not have other disorders such as kidney disease, multiple sclerosis, Parkinson's disease or severe neuropathy and who are not currently taking medicine for RLS. If you are taking medicine for RLS, you can discuss with Dr. Koo the possibility of temporarily coming off of your medicine. If you believe you are eligible or have any questions about the research, please contact the study team.

Contact: Brian Koo, MD at brian.koo@yale.edu or call (203) 785-4261

Is RLS Affecting Your Child?

Science 37 has a six-month research study for youth ages 13 to 17 affected by restless legs syndrome (RLS). The study explores whether a medication that is already approved for RLS in adults is also effective in adolescents with RLS. If it's a condition your child is struggling with, consider joining this research study. This study is open to those ages 13-17 with RLS who are living in CA, CO, CT, DC, DE, FL, GA, IA, ID, IL, IN, MD, ME, MI, MN, MO, MT, NC, NH, NJ, NY, OH, OK, PA, RI, SD, TN, TX, UT, VA, WI, WV. You can participate through an app from the comfort of your own home, and compensation is available.

Contact: 310-464-2190, RLSstudy@science37.com

Visit: www.science37.net/rls-teens

Publications

Most of 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.

Quantity	Patient Handouts	Quantity	Patient Handouts	Quantity	Patient Handouts
	Augmentation: Diagnosis & Treatment		Drug Holidays and RLS		Periodic Limb Movements During Sleep
	Augmentation: A Quick Guide		Guide to Living with RLS		Research Grant Program
	Augmentation FAQ		Healthcare and Your Child with RLS		Surgery and RLS
	Can an Active Lifestyle Prevent or Improve RLS Symptoms?		Hospitalization Checklist		Symptom Diary for RLS
	Clinical Trials and Research		Iron and RLS		Triggers for RLS
	Complementary/Alternative Medicine and RLS		Medication Withdrawal after Augmentation		Understanding Possible Mimics of RLS
	Coping Methods		Medications for RLS		Your First Doctor Visit for RLS
	Depression and RLS		Pain and RLS		
Quantity	Patient Brochures	Quantity	Patient Brochures	Quantity	Patient Brochures
	Causes, Diagnosis and Treatment for the RLS Patient		RLS Guide for Children (nonmembers \$5)		
	Giving Avenues		RLS Guide for Teens (nonmembers \$5)		
Quantity	Healthcare Provider Brochures	Quantity	Healthcare Provider Brochures	Quantity	Healthcare Provider Brochures
	Pregnancy and RLS: A Guide for Healthcare Providers		RLS and PLMD in Children and Adolescents		
	2021 RLS Medical Bulletin: RLS Diagnosis and Treatment (nonmembers \$10)				

MEMBERSHIP

Yes, I want to join the Restless Legs Syndrome Foundation or renew my membership. (\$35* US • \$45* International)
*Amounts in US dollars

DONATION

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

I would like to make a recurring monthly gift of \$_____ Start date: _____

DONATION APPLIED TO

- Research
 Richard P. Allen Memorial Research Fund
 Where it is needed most

PAYMENT METHOD

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

Please charge \$_____ to my American Express Discover MasterCard VISA

Card number _____ Expiration date _____

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

Name _____ Address _____

City _____ State _____ Zip _____

Email address _____ Phone number _____

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In the Summer 2021 *NightWalkers* article Make Something to Heal Something, Brian Schrag, PhD challenged readers to help build a virtual collection of arts produced by people affected by RLS. Schrag wrote: "Let's start an RLS Arts-Making Movement" by gathering songs, poems, stories, dances, paintings, jewelry, quilts, films, video games and more!

It is in response to this article that I submit this RLS Word Search. Just a sampling of what I've "created" (besides knitting and poetry) to deal with my RLS.

– Isabella Horsky

WORD SEARCH

- | | | |
|--------------|---------------|-------------|
| Activity | Frustration | Research |
| Anemia | Health | Severity |
| Augmentation | Insurance | Sleep |
| Brain | Jerking | Stimulants |
| Caffeine | Legs | Suffering |
| Cerebral | Movement | Sugar |
| Challenge | Muscles | Supplements |
| Cope | Spasms | Syndrome |
| Diagnosis | Opioids | Therapy |
| Dietary | Pacing | Tingling |
| Disease | Patience | Trials |
| Dopamine | Possibility | Triggers |
| Endure | Prescriptions | |
| Ferritin | Remedy | |

S I S N O I T P I R C S E R P J F D
L E C N E I T A P S O R S V E P I P
A M U S C L E C G N I T I R R E F A
I O N S D I O I P O I S K W T B M T
R R F O B P H N D M U I O A I J R U
T D M V I G T G U P N Q R N N I C B
E N O F T T L L P G M Y P P G Y R G
P Y V P C H A L L E N G E G L A A S
O S E H A N E T V E S A E S I D I H
S M M L T M H R N J E R L N N S M D
S S E S E H I P A E S N S P G D E Y
I A N N O R C N G P M C I E L U N T
B P T U B D H R E P Y G L E P Q A I
I S Y V N O I T A R T S U R F O J V
L A R B E R E C W E U Q L A Y F C I
I S U F F E R I N G S D U F O G A T
T L C I N S U R A N C E N C I H P C
Y B Y D E M E R L Y T I R E V E S A