

# NIGHTWALKERS

In search of a good night's sleep

FALL 2023



**MAKE HEALTH  
AND WELLNESS  
YOUR PRIORITY**

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RLS



RESTLESS LEGS  
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As I look back on 2023, there is much to be thankful for. We recently successfully completed our second in-person National RLS Patient Symposium, and I thank everyone who made the trip to Baltimore. A special thank you to Azurity Pharmaceuticals for making this educational opportunity available to the RLS community.

The two-day conference helped establish connections among patients, researchers and healthcare providers. Our conference goals were to:

1. Raise disease awareness through education.
2. Provide information regarding new treatments and management of RLS.
3. Highlight the Foundation's RLS Research Grant Program, designed to discover the causes and a cure for RLS.
4. Energize those living with the disease to ensure awareness of its widespread prevalence and the need for continued research leading to better treatments and a cure.

The pandemic created a unique set of circumstances for group gatherings, and this was the first time our community could gather in person since 2018. The *Dine with the Experts* dinner was a one-of-a-kind experience to connect with RLS experts and strengthen relationships between individuals and the larger RLS community.

The symposium was followed by RLS Advocacy Day on Capitol Hill in Washington. Our community of patients, family members, physicians and researchers joined forces as RLS advocates to meet with and educate key legislative offices about the disease. We impact future public policy by reinforcing federal legislative priorities. The timing of our visit was especially critical as Congress continues to finalize the budget for the next fiscal year. The RLS Foundation Board of Directors took this opportunity to meet in person for the first time

since the Covid pandemic while in Baltimore. Our four days together reinforced the strategic plan for the RLS Foundation going forward. We must continue to raise RLS awareness and fund vital research to improve treatments and discover a cure. These three goals have stood the test of time since the inception of the Foundation in 1992.

This holiday season, we invite you to step forward with us in advancing our goals by doing your part to expand our outreach. Nearly 12 million individuals in the US live with RLS, yet only 6,000 are members of the Foundation. When our collective voice more closely represents the number of individuals living with RLS, this amplifies our efforts.

The Foundation has many vital programs: advocacy outreach in Washington, DC, to ensure continued access to opioid therapy and to seek additional federal funding for RLS research; a monthly webinar series with leading experts to educate individuals about RLS; the only dedicated RLS research grant program to find better treatments and a cure; a network of RLS Quality Care Centers where individuals can receive expert care; support for people with RLS through weekly virtual support groups, local in-person support group meetings, a 24/7 online discussion board, and in 2024, a podcast to further our reach with the public and medical community by featuring important topics.

As we look to the new year, please consider an additional gift to the RLS Foundation in your annual giving plans.

A quote by Mike Ramsdell in the book *A Train to Potevka* is a perfect summation of our journey together:

"We are all on this journey of life together, each given certain gifts to make this world a better place and to help make one another's burdens a little lighter along the way."

We are on this journey together- thank you for joining us!



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# Make Health and Wellness Your Priority

By *Adrianna Colucci, RLS Foundation Administrative Assistant*

**F**all is often marked by back-to-school activities, family gatherings, holiday planning and end-of-the-year deadlines. Amidst the bustle of the season, don't forget to make mental and physical well-being a priority.

Invigorating exercise, a nourishing diet and sound sleep frame health and wellness. These three factors are cyclically connected: a healthy diet supports better sleep and exercise, and vice versa. Make health a top priority now so you can make the most of fall's activities and events.

## PHYSICAL FITNESS

The short-term benefits of exercise are well known – increased energy, a positive impact on mental health and increased muscle mass. But exercise also has significant long-term effects on the body when 150 minutes of weekly activity is achieved.

According to the Centers for Disease Control and Prevention, long-term benefits of exercise include:<sup>1</sup>

- Lowered risk of heart disease
- Maintenance of a healthy body weight
- Improved balance and coordination
- Boosted immune function
- Reduced risk of dementia and Alzheimer's disease
- Reduced risk of certain cancers

The World Health Organization attributes increasing medical challenges to certain chronic, or noncommunicable diseases. The four main types of noncommunicable diseases are:<sup>2</sup>

- Cardiovascular diseases
- Cancers
- Chronic respiratory diseases
- Diabetes

Understanding how outside factors such as fitness impact the development of these conditions is important for establishing long-term prevention guidelines.

An analysis published in July 2023 examined 15 longitudinal studies on the impact of exercise on obesity, cardiovascular heart disease, type 2 diabetes and Alzheimer's disease and dementia.<sup>2</sup> One of these studies, the Aerobics Center Longitudinal Study conducted by the Cooper Clinic in Texas, found that men between ages 22 and 55 who reduced daily physical activity gained a significant amount of weight, while men who maintained their daily exercise did not gain significant weight. The study also determined that 45 to 60 minutes of brisk walking, gardening, cycling or similar activities can support weight loss.<sup>2</sup>

Another longitudinal study, the Harvard Alumni Health Study, surveyed 18,835 men, finding that moderate to vigorous weekly exercise appears to reduce the risk for cardiovascular disease, stroke and hypertension over time. More specifically, the results showed a correlation between increased energy expenditure

and a decrease in the occurrence of cardiovascular heart disease. Similar studies found the same correlation between increased physical activity and lowered risk for type 2 diabetes.<sup>2</sup> Further, according to certain studies, physically active people may have a lower risk of developing cognitive impairments. The results indicate that regular fitness may lead to higher cognitive scores while also preventing dementia and Alzheimer's disease in older adults. The general conclusion is that increased exercise leads to decreased risk of the aforementioned noncommunicable diseases, although noting that more research is needed.<sup>2</sup>

There are small ways to increase your physical activity throughout the day, including taking walks, finding an active hobby such as gardening, opting for stairs, or exercising while performing a typically sedentary task such as watching TV. Effective exercise not only protects your muscles and health, but can also support better sleep and diet habits.

Additionally, ongoing research on RLS and exercise suggests that daytime movement can help to alleviate nighttime symptoms. Mild to moderate exercise typically benefits RLS however, vigorous exercise often triggers RLS symptoms. Vigorous exercise will vary depending upon a person's level of fitness. No matter how you choose to exercise, make sure it is both enjoyable and safe for you by first consulting a healthcare provider.

## BALANCED DIET

A healthy diet supports an active lifestyle by providing the necessary energy to exercise safely. Decades of research also show that diet has a significant impact on shaping gut microbiota, or the microbes harbored by the human body.<sup>3</sup> Microbes are responsible for digestion, absorption, metabolism and the conversion of undigested macronutrients. Diets with high consumption rates of processed, fried or sugar-rich food can lead to reduced microbial diversity and function, resulting in health consequences.

Some nutrients that frame a healthy gut are:<sup>3</sup>

- dietary fiber
- proteins
- vitamins and minerals
- amino acids

Studies also suggest a Mediterranean diet, primarily consisting of fruits, vegetables, legumes, tea, herbs and nuts with moderate to low consumption of fish, dairy and red meat can help maintain health.<sup>4</sup> Specifically, dietary patterns are associated with a decreased risk of obesity, cardiovascular heart disease, diabetes, autoimmune diseases and neurodegeneration, all of which are also associated with regular exercise. The foods promoted in a Mediterranean diet contain biologically active nutrients that have antibacterial or anti-inflammatory properties, to prevent the onset of noncommunicable diseases.<sup>4</sup>

Studies further suggest the consumption of fruits and vegetables leads to the development of beneficial bacteria, supporting better digestion and immunity.<sup>3</sup>

Focus on maintaining a diverse and healthy diet to preserve your energy as the busy holiday season approaches. Take precautions to avoid common RLS triggers, including excess amounts of caffeine, sugar, salt and alcohol. To learn more about common triggers, view the handout on page 11.

### MAINTAINING HEALTHY BODY IRON STORES

For individuals with RLS, brain iron deficiency and dysfunction of the dopaminergic system play a central role in the disease. Dietary iron intake is an essential component in the maintenance of iron stores; only 10%–15% of dietary iron is absorbed by the body. Oral iron intake is not absorbed equally by the body. It is important to be knowledgeable about dietary iron sources to help maintain body iron stores.

Dietary forms of iron are divided into two categories: heme iron and nonheme iron. Heme iron is only found in animal sources such as meat, poultry, fish and shellfish and is easily absorbed in the gut. The body absorbs about 15%–35% of heme iron intake. To enhance the absorption of the iron contained in food sources, pair with vitamin C-rich foods such as orange juice, bell peppers or tomatoes. Conversely, certain substances can impair the absorption of iron in foods. These items include the tannins found in tea and coffee, and calcium in milk products.

Nonheme sources include leafy greens, nuts, seeds, whole grains, legumes and fortified cereals. Although considered a source of iron, these sources are not readily absorbed by the body. The percentage of nonheme iron absorbed by the body is only 5%–12%, as the human gastrointestinal tract does not readily absorb this source of iron.

### SOUND SLEEP

Quality sleep is essential for the body to function and maintain good physical and mental health. The National Institutes of Health promotes the importance of sleep, noting its relationship with the circulatory system, immunity, metabolism and cognitive function.<sup>5</sup> Lack of sleep may lead to decreased quality of life and daytime productivity, and is also a risk factor for cardiovascular diseases, hypertension and diabetes.<sup>6</sup>

The body's circadian rhythm, or its internal clock, can be dysregulated by external factors. For example, caffeine, which can be a trigger for RLS, is chemically linked to adenosine. Adenosine is a neurotransmitter that induces sleep. It is theorized that caffeine antagonizes the adenosine receptors meant to induce sleep, leading to difficulties falling asleep. Some studies suggest that vitamin D and vitamin C deficiencies may be associated with a higher risk of sleep disorders, short sleep duration and poor quality of sleep. Lastly, diet structure is strongly linked to inflammation in the body, which has an underlying association with chronic insomnia.<sup>6</sup> Insomnia and other sleep disorders can make daily activities, such as driving a vehicle or concentrating



during tedious tasks, not only difficult but dangerous.

Melatonin is another hormone responsible for regulating the circadian rhythm and activating receptors to induce sleep.<sup>6</sup> Since high amounts of melatonin can disrupt sleep, consult with your doctor before taking melatonin supplements. Other over-the-counter sleeping pills containing diphenhydramine or doxylamine can also exacerbate RLS symptoms. For a complete list of medications known to trigger RLS, refer to the RLS Foundation's Medical Alert Card, which is available upon request.

With a sleep disorder like RLS, getting sufficient rest is already difficult. Understanding the importance of sleep and how it impacts the body can lead to more effective conversations with physicians, family members and friends. Strive for healthy bedtime routines to help better manage the disease.

### RELATIONSHIP BETWEEN THE PHYSICAL AND MENTAL

There is a strong link between the physical and mental health of the body.

Benefits of good physical health include improved mood, improved functional capacity and decreased depression and anxiety.<sup>7</sup> A study observing 2,345 healthy adults found that moderate to high rates of exercise were associated with higher life satisfaction across all ages. Though happiness is subjective, it is thought that enhancing physical health helps enhance psychological health. This includes not just decreased stress but also increased self-image.<sup>7</sup> The restorative properties of sleep and the consumption of fruits, decaf green tea and nuts have also been found to have neuroprotective properties, which may lead to improvements in brain health.<sup>4</sup> Exercise, diet and sleep are factors that combat not only physical diseases but mental health disorders as well.

Increased stress and anxiety may exacerbate RLS symptoms, so be sure to prioritize self-care during the busy fall season by finding a new hobby or setting aside time to relax.

## CONCLUSION

Exercise, proper diet and quality sleep remain significant in the maintenance of physical and mental health. Make small changes by integrating some of these elements into your daily routine to positively influence your mind and body. Before making any changes to your RLS management plan, be sure to consult with your treating physician.

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# RLS Foundations Awards 50th Research Grant

By Dr. Mark Boulos, MD, FRCPC, MSc

The RLS Foundation has awarded a research grant to Dr. Mark Boulos, MD, FRCPC, MSc, to study the use of cannabis to treat RLS. With this award, the RLS Foundation Research Grant Program has funded 50 grants to date, totaling nearly \$2 million. Dr. Boulos is an Associate Professor of Neurology at the University of Toronto who has extensive experience as a clinician and researcher in sleep disorders.

I am very grateful to be a recipient of the 2023 Restless Legs Syndrome Foundation Research Grant. My study, "Using Cannabis to Treat Restless Legs Syndrome: A Safety and Feasibility Trial" will help establish the feasibility and safety of using cannabis to manage treatment-resistant restless legs syndrome (RLS). Unfortunately, there has been very limited research in this area to date, so we believe this study will be an important first step in the evaluation of cannabis as a treatment for RLS. The results of this study may help inform larger clinical trials that will investigate the efficacy of cannabis as an RLS treatment.

As a sleep medicine physician, I often see patients with RLS who are suffering, and none of the therapies they have tried have adequately addressed their discomfort. Since cannabis has been legalized for recreational use in Canada, a few of my patients have independently tried cannabis for treating their RLS,

reporting that it provided them the relief that they had been unable to find through other treatments. However, much of the evidence for cannabis in RLS has been anecdotal, and there haven't yet been clinical trials conducted to evaluate the safety and efficacy of this approach.



The study we plan to conduct at Sunnybrook Health Sciences Centre in Toronto, Canada, will be a randomized, controlled trial where participants with refractory RLS will receive either medical cannabis or a placebo. The study will be double-blinded, meaning that both the study staff and participants will not know whether they are receiving cannabis or the placebo. Participants will be given the study drug for eight weeks and will be closely monitored for any adverse effects.

Our study aims to measure several key aspects of RLS, including symptom severity, quality of life, subjective and objective measures of sleep quality, and leg movements. We will perform assessments at baseline and during an eight-week follow-up to see how the study drug may change these important outcomes.

Ultimately, our goal is to improve the lives of individuals affected by RLS by providing new avenues of hope and relief. We are excited to begin this research study, and we are very thankful to the RLS Foundation for their support. If you live in Ontario and might be interested in participating in this study, please contact our team at [mark.boulos@sunnybrook.ca](mailto:mark.boulos@sunnybrook.ca).

# Advisory Board Spotlight: Jacquelyn L. Bainbridge

**BSP Pharm, PharmD, FCCP, MSCS, FAES**



By Adrianna Colucci, RLS Foundation Administrative Assistant

Jacquelyn L. Bainbridge, BSP Pharm, PharmD, FCCP, MSCS, FAES, is a Professor at the University of Colorado Anschutz Medical Campus, where she holds joint appointments in the Skaggs School of Pharmacy and Pharmaceutical Sciences, Department of Clinical Pharmacy, and the Department of Neurology in the School of Medicine. Dr. Bainbridge received her doctorate in pharmacy from the University of Colorado in Denver, where she subsequently completed a specialty residency in neurology. With her extensive background in pharmacy and a passion for improving the lives of individuals affected by restless legs syndrome (RLS), Jacqui brings a wealth of knowledge and compassion to the RLS Foundation's mission. Her expertise and commitment to the cause make her an invaluable asset, driving the Foundation's efforts to advance research, raise awareness, and support those living with RLS.

**Q:** What drew you to the RLS Foundation originally and how has the foundation changed since you started?

**A:** I was drawn to the RLS Foundation through Marge and Doug Fuhrer and Dr. Maureen Leahy. I gave a lecture to one of the patient groups at National Jewish for Dr. Leahy because she couldn't attend, and I fell in love with the people. All attendees asked good, thoughtful questions, and I felt my answers could contribute to their quality of life.

The Foundation has changed substantially — we're under new leadership and we have a new Executive Director, whose heart is in the right place.

**Q:** How has your background as a clinical pharmacist and professor helped you in your position as a board member at the RLS Foundation?

**A:** My experience as a clinical pharmacist means I understand drug-to-drug interactions and can identify the best medication options for specific patients, specifically the selection of medications through comorbid conditions. My background has made me very empathetic to the condition.

**Q:** What about the RLS Foundation's mission excites you the most?

**A:** The work we do for awareness and advocacy excites me the most. We've also brought back some of the essential patient education programs to the Foundation.

**Q:** In your opinion, what is this board's biggest challenge currently?

**A:** The biggest challenge is getting more board members in different leadership areas. Having a more diverse leadership representing many different backgrounds to round out the Board can be a challenge.

**Q:** You have been involved with the Foundation in many ways since 2007; what accomplishments are you most proud of?

**A:** The things that I'm most proud of, in no specific order, are helping with the patient education programs, working closely with Bob Waterman, and walking the halls of the National Institutes of Health to find out where research is needed most.

**Q:** What are your future goals and aspirations for the RLS Foundation as a whole?

**A:** To continue our patient education conferences, bring in more board members with diverse backgrounds, and align our strategic plan with our mission.

**Q:** What memory are you most fond of when you reflect on your time serving the board?

**A:** Years ago we had a program held at the Drier's home. I was able to meet many previous board members who were considered "legends" - people like Peter Brooks. The program brought many people together and allowed me the opportunity to meet them.

**Q:** In your opinion, what is the key to a successful board?

**A:** Working together and uniting as a team to advance the mission of this organization.

**Q:** What research are you currently working on? Anything RLS-related that you can tell us about?

**A:** I did get my last grant funded through BioPharmaceutical Research Company (BRC). It will be a clinical trial, looking at CBD and CBG versus placebo. We will then crossover patients with RLS. The National Institute on Drug Abuse (NIDA) will distribute the medication. It is currently only open to Colorado residents at this time.

# Varicose Veins Treatment Improves RLS: Fact or Fiction?



By Mark Buchfuhrer, MD

*Dr. Mark Buchfuhrer is a pulmonologist and sleep specialist in Downey, California, and is affiliated with multiple hospitals in the area, including PIH Health Hospital-Downey and Stanford Health Care-Stanford Hospital. He received his medical degree from the University of Ottawa Faculty of Medicine and has been in practice for more than 40 years. Dr. Buchfuhrer serves on the Foundation's Scientific and Medical Advisory Board and is the medical editor of NightWalkers.*

**V**aricose veins have been implicated as a possible cause of RLS, and treating this condition has been touted as a valid treatment for RLS. Is this real or complete fantasy? Let's look at all the studies on this topic.

The first mention of any association of possible vascular cause (blood vessels refers to arteries and veins) of RLS was by Karl Ekbom (who named the disorder RLS) in 1944, when he speculated that this association may exist. He based this upon observations that some of the RLS patients complained of cold feet, that a few patients worsened when exposed to protracted cold and that vasodilator medications (drugs that relax arteries) helped RLS symptoms. However, all these vascular effects are due to arteries and not veins. In a 1960 article, Ekbom made no mention of the theory that there was a vascular cause of RLS.

The first study reported in medical literature was published in 1995 by Kanter (University of California, Irvine Medical Center), who observed that many of the patients he treated for varicose veins noted a marked improvement in their RLS symptoms. Kanter screened 1,379 patients who presented at a vein treatment center for RLS and found that 22% had RLS. One hundred and thirteen of these patients with RLS (36%) agreed to have sclerotherapy. Of the 113 patients, 111 (98%) reported relief from their RLS symptoms. Relief was defined as either complete resolution or sustained marked improvement of symptoms. Forty percent responded to one treatment and 78% to two treatments. At two years, 28% (12 out of 43) who were available for follow-up had recurrences of their RLS symptoms. At the end of his article, Kanter indicated that a multicenter study using the IRLS rating scale and sleep studies before and after sclerotherapy was in progress. Still, no further studies have been published replicating his results, which is essential to validate research findings.

In 2007, McDonagh (Venous Research Foundation, Schaumburg, Illinois) reported that 174 consecutive patients presenting to the clinic for varicose vein issues were evaluated, and it was found that 36% of these patients had RLS (diagnosed using the

RLS diagnostic criteria). Ninety-eight percent had chronic venous disease compared to only 19% of a control group comprised of 174 age- and sex-matched healthy subjects. However, 93% of the control group patients who were subsequently diagnosed with RLS had chronic venous disease, which was similar to the study group patients who originally presented to the clinic. Chronic venous disease was found in only 9% of the healthy control group without RLS. The researchers concluded that RLS and chronic venous disease were related.

In 2007, Hayes (Alabama Vascular and Vein Center) performed endovenous laser ablation with chemical sclerotherapy on 35 patients with ultrasound-verified superficial varicose veins and RLS (diagnosed using the RLS diagnostic criteria). Eighty-nine percent of these patients had a decrease in their IRLS scores (average before treatment was 21) of 15 points or more (on the 40-point scale), 53% had scores of 5 or less (minimal RLS) and 31% had no symptoms at all six weeks after their procedures. No long-term follow-up was performed.

In 2017, Fronck evaluated 371 patients who had ultrasound-proven varicose veins at the La Jolla Vein Center in California and found that 16% had RLS and 32% had leg cramps. The researchers could not find a specific anatomic pattern of vein involvement in either of these symptomatic groups.

In 2019, Sundaresan (University of Texas Medical Branch) performed endovenous radiofrequency ablation and chemical sclerotherapy on 35 patients (out of 134 patients screened for RLS) who had RLS (average IRLS score of 19.8) and ultrasound-proven varicose vein disease. Twenty-nine percent had a follow-up IRLS score of 0 (no RLS at all), 57% had a decrease of 10 points or more and 17% had no improvement. Long-term follow-up was not done on these patients.

A 2020 study by Yolgosteren (Bursa University, Bursa, Turkey) found that half of 40 patients diagnosed with RLS in a sleep center had ultrasound-proven varicose veins. The characteristics of the patients with or without varicose veins were similar otherwise.

A 2021 study by Dezube (Saint Elizabeth Medical Center, Boston) analyzed 207 patients presenting to the vein center and found that 137 had superficial varicose veins by ultrasound and 70 did not. Of the 137 patients with varicose veins, 79% reported RLS symptoms (which they defined as the presence of nocturnal or recumbent leg pain or cramping at rest – clearly not accepted RLS diagnostic criteria) and 46% of those with-

out confirmed varicose veins had RLS symptoms. Ninety-nine patients were treated with surgery followed by radiofrequency or chemical ablation and 86% reported resolution of their RLS symptoms. No scale was used to document the improvement, and no long-term documentation was done.

The most recent study, done in 2022, was performed by Pyne (Rochester Regional Health, Rochester, New York). The researchers examined patients with varicose veins in the lateral subdermal venous plexus (spider veins in the side of the thighs that normally are only treated for cosmetic reasons) as they thought there might be a correlation, although all the other investigations focused on the lower leg varicose veins. They chose patients who presented at their vein clinic with thigh spider veins and RLS (no criteria given for the diagnosis), nocturnal leg cramping or both. When treated with chemical sclerotherapy, 93% of these patients had relief at 30 days and one year. Improvement in RLS symptoms was not defined by the accepted IRLS scale, but rather symptomatic relief was defined by the patient indicating significant relief or complete relief.

So, after reading the conclusions of the above studies, most readers might be convinced that treating varicose veins can be beneficial for improving or resolving RLS symptoms. However, many issues first need to be discussed. All the studies linking varicose veins with RLS and successful treatment were performed by physicians at vein treatment centers. Patients seek treatment at these clinics with symptoms. The question remains whether there is a difference in the percentage of RLS between patients without varicose veins and those with varicose veins, and if varicose veins actually cause or worsen RLS symptoms. A study done in 1999 (“What are the symptoms of varicose veins? Edinburgh vein study cross sectional population survey”) gathered 1,566 people from the general population and found no difference in leg symptoms (RLS, heaviness in the legs, aching, cramps, itching or tingling) in patients with or without varicose veins. It is likely that since varicose veins are so common – present in 15% of men and 25% of women, with some studies finding rates of up to 60% for both sexes – it is not surprising that there will be coincidental overlap between RLS (10% of the adult population) and varicose veins.

The other issue is that in all the studies performed by vein clinics and no RLS experts were involved, making the diagnosis of RLS somewhat questionable. Although a few studies used the RLS criteria and even the IRLS rating scale, others just used clinical descriptions, leaving it up to non-RLS physicians to deter-

mine the validity of the diagnosis. (Some studies even lumped cramps and RLS together.)

What about the high success rates of varicose vein treatment for improving RLS? There is a very significant placebo (sugar pill) response in individuals with RLS. All the studies were done as open-label, unblinded studies (meaning the doctors and the patients knew what treatment was performed), which brings very strong bias into these studies due to the placebo effect. The only way to be sure that any treatment is effective is to perform a double-blinded (patients and doctors do not know which treatment was administered), controlled study (one group gets the treatment and the other gets a placebo or sham treatment). No such study has ever been done, although several of the studies suggested that they should be done or were about to do them.

Despite the high rates of success of the published studies for varicose vein treatment, I have never seen a patient who had prolonged RLS benefit from such treatment. I cannot say definitively that varicose vein treatment does not help RLS, since no scientifically proper studies have ever been done, but I would not recommend that any of my patients undergo such treatment in hopes of improving their RLS.

#### DEFINITIONS:

IRLS (International Restless Legs Syndrome Scale): This is based on 10 questions about RLS symptoms with each question rated from 0-4. Therefore, the highest score is 40. Rating severity is detailed below:

- 0 No RLS symptoms
- 1-10 Mild RLS
- 11-20 Moderate RLS
- 21-30 Severe RLS
- 31-40 Very severe RLS

Sclerotherapy: The process of injecting a chemical solution directly into the varicose or spider vein to make the vein stick together and prevent blood flow into the vein.

Radiofrequency vein ablation: A procedure that uses radiofrequency energy to heat and damage a vein’s wall, thus closing off the vein to blood circulation.

Endovenous laser ablation: A procedure that uses heat from a laser to reduce or collapse varicose veins.



# National RLS Opioid Registry: 3-Year Research Update

By John Winkelman MD, PhD

About 3% of the US population has RLS severe enough to require daily medical treatment. Food and Drug Administration (FDA) approved treatments, including iron therapy, alpha-2-delta ligands and dopamine agonists, are initially effective for most patients. However, for some these therapies prove ineffective with time or cause adverse reactions. As many as 50%–70% of patients using dopamine agonists develop augmentation, a worsening of RLS symptoms due to these medications.<sup>1</sup>

When symptoms are unresponsive to first-line therapies, the disease is known as refractory RLS. For people who have refractory RLS, low-total-daily-dose opioids can be an appropriate treatment option. However, concerns regarding opioids in both the medical and public sectors create barriers for RLS patients who require access to such medication.

Prompted by the lack of long-term research surrounding opioids and RLS, John Winkelman, MD, PhD, director of the Massachusetts General Hospital RLS Quality Care Center and a member of the RLS Foundation’s Scientific and Medical Advisory Board, is conducting a study to observe the safety and efficacy of long-term opioids in RLS management. The National RLS Opioid Registry is intended to provide clinical evidence to help physicians manage patients with refractory RLS more effectively. Dr. Winkelman has received three grants from the RLS Foundation’s Research Grant Program to support this work.

In the study, participants are treated by their local providers and fill out extensive surveys online every six months. The researchers previously reported that at enrollment, participants had been taking opioids for refractory RLS for a median duration of one to three years. Now five years since the first participants were enrolled, the researchers have analyzed the three-year follow-up data and presented their findings at the World Sleep Society meeting in October in Rio de Janeiro.

## PARTICIPANT RETENTION AT 3 YEARS

The retention rate of year three participants is very high at 94.4%. Of the 500 original participants, 438 remain involved in the study.

Of participants who discontinued the study:

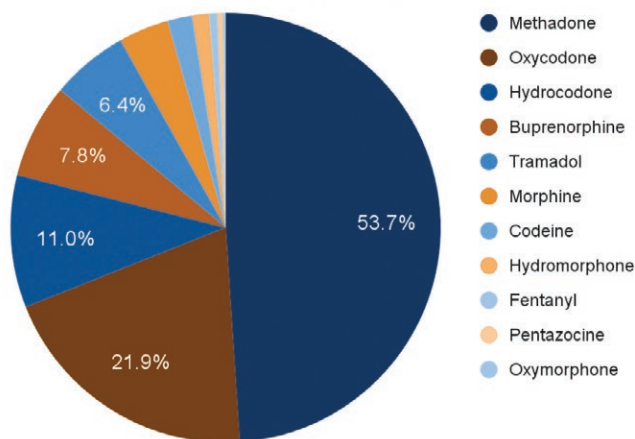
- Twenty-eight discontinued opioid treatment of RLS.
- Twenty lost contact with the research team.
- Fourteen are no longer in the study for another reason.

## MEDICATION CHANGES AT 3 YEARS

About half (53.7%) of registry participants used low-dose methadone to treat RLS symptoms. Other opioids used by partic-

ipants included oxycodone (21.9%), hydrocodone (11.0%) and tramadol (6.4%). Of 438 participants, 9.6% use a combination of two opioid medications to treat their RLS.

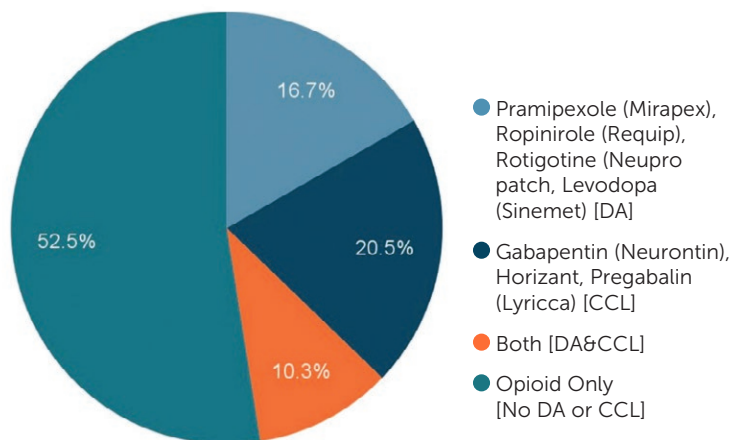
Percent of Patients on Opioid Types



Research indicates methadone has a reduced abuse potential compared to other opioids and therefore can be an effective option for long-term treatment.<sup>1</sup>

Nearly half of the participants used a second or occasionally a third medication to supplement the opioid.

Other RLS Medications



## DOSE CHANGES AT 3 YEARS

After three years, 34.9% of participants maintained the same dose of their medication, 19.2% decreased their dose and 45.9% increased their dose.

Three primary factors increased the likelihood that participants would increase their dose by any amount:

- Notable anxiety at the time of enrollment
- Switching opioid medications between the time of enrollment and the three-year survey
- Less than one year of existing treatment on an opioid at the time of enrollment

The following additional factors increased the likelihood that participants would increase their dose by high amounts:

- Opioids being prescribed for another condition in addition to RLS (such as comorbid pain)
- Adding a dopamine agonist between the time of enrollment and the three-year survey
- A diagnosis of depression at the time of enrollment
- At least mild insomnia at the time of enrollment

### SYMPTOM SEVERITY AT 3 YEARS

A majority of participants at the time of enrollment experienced moderate persistent RLS symptoms. At year three, there has been little change in RLS severity. Most participants did not

have clinically significant insomnia at the time of enrollment, which continues to be true at year three.

### CONCLUSION

Longitudinal research such as The National RLS Opioid Registry is significant for RLS patients, allowing physicians, federal regulatory agencies and legislators to better understand the medical role of low-total-daily dose opioid in RLS management. The Registry will continue to observe participants for as long as they are willing to participate so that we can continue to gain insight into the long-term safety, efficacy, and stability of low-total-daily dose opioid medications for severe cases of RLS. The RLS Foundation continues to provide funding to the National RLS Opioid Registry thanks to contributions from dedicated members.

<sup>1</sup> Silber M et al. "The appropriate use of opioids in the treatment of refractory restless legs syndrome." *Mayo Clinic Proceedings*, vol. 93, no. 1, 2018, pp. 59–67, <https://doi.org/10.1016/j.mayocp.2017.11.007>.

## RLS and the Holidays: Time to Get Creative

For all the joy and excitement that the holidays can bring – from Thanksgiving Eve to New Year's Day – this season also greets people who have RLS with an uptick of symptoms. The reason is simple: So many activities and practices associated with the holidays can trigger RLS symptoms.

From attending office holiday parties to hosting large family dinners. Staying up late or rising early to grab the 4 AM Black Friday deals. Traveling to reunite with friends and family or simply to escape on vacation. Most folks can tolerate and adjust, but sleep disruption and travel are both difficult when combined with RLS.

Fending off the holiday stress can exacerbate your RLS. Certain coping methods, such as consuming too much coffee or alcohol, can also lead to disrupted sleep and restless legs. And at the RLS Foundation, don't get us started on air travel – we could write a whole chapter on flying with RLS alone!

So, with the holidays upon us, it's time to get creative. Commit yourself to a better sleep routine. Sleep specialist and RLS Foundation Scientific and Medical Advisory Board member Mark Buchfuhrer, MD, who co-authored the book *Restless Legs Syndrome: Coping with Your Sleepless Nights*, cautions RLS patients to avoid all known triggers and medications shown to aggravate RLS and to watch their intake of caffeine and alcohol. When taken close to bedtime, these may aggravate RLS by interfering with normal sleep patterns. But you may not need to abstain from the holiday punch bowl or cappuccino machine! Just be judicious about when and how much you drink alcohol or coffee.

The RLS Foundation also recommends scheduling travel in the

morning or afternoon to avoid flights at night and to opt for seat selection. (An aisle seat makes it easier to stretch your legs or get up to walk around.) The special accommodations card found on the back of your Foundation Membership Card (available from the Foundation upon request) will assist you in securing aisle seating. Work with your RLS provider to find treatment strategies that will mitigate the effects of travel on RLS.

Moreover, try to avoid stressful situations whenever possible. Don't deny yourself holiday fun, but be willing to decline an invitation or opportunity that you feel might be too much to handle. Practice yoga, meditation or relaxation techniques, and find time to get outside and soak in some sun on a walk. You can even shop early or online to reduce the stress of gift giving.

Speaking of gift giving, if the RLS Foundation is on your list, you can also get creative in the many options you have to support us. You can make a gift of appreciated securities or a qualified charitable distribution (QCD) from your IRA account (either of which could give you a tax benefit), use an online payment service like PayPal, direct a contribution from your donor-advised fund, go online at [www.rls.org](http://www.rls.org) to make a credit card gift – or simply send an old-fashioned check by December 31!

We hope our work continues to earn your generosity, no matter which way you choose to give. But most importantly, we want you to give yourself the gift of joy (and stress relief) during this busiest time of year that is now upon us. Here's wishing you a happy, safe, restful, relaxing and fun holiday season as 2023 draws to a close – and please know we'll do our best to work toward a cure for RLS in the new year ahead!

# Triggers for Restless Legs Syndrome

Restless legs syndrome (RLS) is a sensorimotor condition that can interfere with sleep as well as rest-related waking activities. Various treatments can help control RLS symptoms, but there is no cure.

The exact cause of RLS is not known but three main areas of study have emerged that involve the relationship between dopamine, iron and genetics. RLS runs in families and researchers have found a strong family basis for early-onset RLS.

Dopamine is a chemical neurotransmitter in the brain and nervous system. With decreased brain iron which is common in RLS patients, dopamine may not function properly. This dopamine dysfunction combined with other chemical systems in the brain that may also be iron dependent can result in RLS symptoms. More research is needed to fully understand the role of dopamine and the other brain chemicals involved in causing RLS symptoms.

Before considering drug therapy, people with RLS can try managing symptoms through nondrug strategies. One of these strategies is to identify and avoid factors that may trigger or exacerbate RLS symptoms.

## Common RLS Triggers

- Caffeine has been linked to an increase in RLS symptoms. Caffeine is present in coffee, tea, chocolate, soda and many other common food and beverages.
- Nicotine in any form has been anecdotally linked to an increase in RLS symptoms.
- While studies have not been conducted on alcohol consumption and RLS, many people find that consuming alcohol, especially in the evening hours, leads to an increase in RLS symptoms.
- While mild to moderate exercise may help relieve RLS, vigorous exercise can trigger symptoms for some people.
- Many people have identified stress and anxiety as triggers for RLS symptoms.
- Some individuals find that limiting their refined sugar intake during the day helps to reduce evening bouts of RLS.
- Many prescription and over-the-counter medications tend to increase RLS symptoms.
- Antihistamines (used to treat colds, allergies and insomnia) block dopamine receptors in the brain and may trigger RLS symptoms. Actifed, Benadryl, Robitussin, and Sudafed (unless labeled nondrowsy) are commonly used and sometimes culprits of RLS symptoms. Several second-generation antihistamines are less likely to affect RLS than first generation antihistamines but still may be associated with RLS worsening; these include Allegra, Clarinex, Claritin/Alavert, Xyzal, and Zyrtec (usually).
- Antinausea drugs, like antihistamines, block the brain's dopamine receptors, increasing RLS symptoms. These drugs include Compazine, Dramamine, Phenergan and Reglan. Alternative drugs that are less apt to worsen RLS symptoms include Zofran, Vistaril and Kytril for nausea; and Transderm Scop for motion sickness.
- Many antidepressants such as selective serotonin reuptake inhibitors (SSRIs, like Cymbalta, Effexor, Paxil, Prozac, Serzone and Zoloft) and tricyclic medications (Elavil, Tofranil and others) have been linked to a worsening of RLS. Alternatives include Wellbutrin, Norpramin (desipramine) and Desyrel (trazodone). Response to any of these medications may vary from one person to another. It is important to consult with a physician on how they may impact RLS symptoms.



**Before considering drug therapy, people with RLS can try managing symptoms through nondrug strategies. One of these strategies is to identify and avoid factors that may trigger or exacerbate RLS symptoms.**



**RAISE AWARENESS**  
**PROMOTE ADVOCACY**  
**IMPROVE TREATMENTS**  
**SUPPORT RESEARCH**  
**FIND A CURE**

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# Identifying Your RLS Triggers

Knowing what factors worsen your RLS is key to managing symptoms so RLS doesn't impede your daily activities.

The RLS Foundation has developed a symptom diary to keep a daily record of symptoms, activities (exercise, gardening, household tasks), stress level and intake of exacerbating substances (alcohol, nicotine, caffeine, salt, sugar). Keeping the diary for five to seven days can help you identify triggers for your RLS symptoms. With guidance from your healthcare provider, you can then eliminate or change these factors and monitor how this affects your symptoms.

It is important to share with your healthcare provider a list of all prescriptions, supplements and over-the-counter medications that you take, and any concerns you may have about them. Some of your medications may be triggers for your RLS. If you experience an increase in RLS while on any medication, contact your provider to discuss a change in your treatment plan. Do not discontinue any long-term prescription medication without first consulting your physician.

For a copy of the symptom diary, visit [www.rls.org](http://www.rls.org) or contact the RLS Foundation at [info@rls.org](mailto:info@rls.org) or 512-366-9109.

*The RLS Foundation is dedicated to improving the lives of the men, women and children who live with this often devastating disease. Our mission is to increase awareness, improve treatments and, through research, find a cure for restless legs syndrome.*

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

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## 10 Tips for Traveling with RLS




**1** Make a list of strategies that help you cope with your RLS symptoms.



**zzz** **2** Get a good nights sleep prior to travel.


**3** Bring mental alerting activities with you (sudoku, crosswords, video games).



 **4** Practice mild to moderate physical activity before boarding, and between connections.


**5** Book travel during the morning hours when RLS symptoms are generally least troublesome.



 **6** Request an aisle seat, seat selection is important.


**7** Download the RLS Foundation Special Accommodations Card at [www.rls.org](http://www.rls.org) or email [info@rls.org](mailto:info@rls.org).



 **8** Know and avoid your triggers especially when traveling.

**9** Research alternative approaches to manage symptoms (massage, compression socks, stretching).



 **10** Discuss medication options with your doctor (Sinemet or opioids like Tramadol for short-term relief).



Get more information:  
<https://bit.ly/3yK9zcY>

# By Kids, for Kids: Advocating for a Good Night's Sleep

By Adrianna Colucci, RLS Foundation Administrative Assistant

**S**leep sets the foundation for health and well-being at every age but is especially significant during adolescence. Sleep fuels cognitive changes during the transition to adulthood, playing a central role in emotional regulation, academic performance and overall mental health.<sup>1</sup>

Still, many children and teenagers have persistent issues falling asleep or receiving sufficient rest. Motivated by the lack of sleep education in their age group, two young advocates, Yash and Sanjay Malhotra, founded Kids Talk Sleep, a 501(c)(3) nonprofit focused on increasing awareness about the benefits of sleep with content created for kids, by kids!

## MISSION

Yash and Sanjay were both diagnosed with RLS as young children, so they have firsthand experience understanding the role of sleep in physical and mental health. Kids Talk Sleep promotes sleep education by creating informative videos and sharing academic resources on their website: [www.kidstalksleep.org](http://www.kidstalksleep.org). Their content covers healthy bedtime habits and the role of sleep in physical and mental well-being, with more videos to come!

Giving back to the community is another pillar of the organization. The nonprofit accepts donations and collects new sleep-related items such as pillows, pillowcases, blankets, sheets and sleeping bags, all of which are donated to Epworth, an organization that provides support to foster youth and children in need. Yash and Sanjay recently completed their first neighborhood drive (pictured below) and made their first contribution!

## AWARENESS AND SUPPORT

Kids Talk Sleep specifically highlights the benefits of a later start time for schools, which allows students to get sufficient sleep to perform their best. Various environmental factors alter sleep architecture, but circadian rhythms naturally shift later during teenage years due to the delayed timing of melatonin and thus

lead to later sleep onset. This means most adolescents have difficulties falling asleep before 11:00 PM.<sup>1</sup>

Studies show that poor sleep has short and long-term impacts on memory, hormones, mood and susceptibility to illness. The American Academy of Pediatrics and the American Academy of Sleep Medicine recommend that middle and high schools start no earlier than 8:30 AM.<sup>1</sup>

## INSPIRATION

Yash and Sanjay spent long hours submitting legal paperwork, creating a website, establishing donation avenues, researching content and organizing events to launch Kids Talk Sleep. They continue their work, knowing that donations directly impact kids' lives by improving sleep conditions. They are currently planning another donation drive to expand their outreach and help even more children!

When asked what advice they would give to other kids who would like to become more involved in the community, they said:

"If you are passionate about something, embrace it. Think about what you can do to help others in your community, then make it a reality, and inspire others to do the same. Whether you want to establish your own organization or join an existing one, there are many nonprofits in your community that welcome volunteer hours or monetary donations."

To check out Kids Talk Sleep, visit their website at [www.kidstalksleep.org](http://www.kidstalksleep.org). Thank you to Yash and Sanjay for all you do on behalf of the sleep community!

<sup>1</sup> Au R, et al. "School start times for adolescents." *Pediatrics*, vol. 134, no. 3, 2014, pp. 642–649, <https://doi.org/10.1542/peds.2014-1697>.



# 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; 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](mailto:info@rls.org) with "Ask the Doctor" in the subject line. Select questions in areas of common interest are published in NightWalkers. Questions are edited as needed and published anonymously.*

**Q. Is there any other treatment for severe RLS besides opioids?**

**A.** Yes, alpha-2-delta ligands can be used to treat severe RLS; however, it is not uncommon for those with severe RLS to have significant residual symptoms on these medicines. A combination of an alpha-2-delta ligand and a hypnotic agent – alongside the proper treatment of sleep apnea, iron deficiency, and any other factors associated with RLS – is important in treating severe RLS. Unfortunately, optimal treatment of all these factors in some persons with severe RLS still can be insufficient to best treat RLS, and in these circumstances, an opioid medication may be the only agent to provide complete relief.

**Brian Koo, MD**

**Q. A medication pump that pumps morphine directly into the spinal column has decreased my RLS symptoms. Over the course of 3.5 years, the dosage has increased but I'm pretty much RLS free. Why isn't this procedure more well-known?**

**A.** In most patients with RLS, oral opioid medication is sufficient to treat RLS, and thus an opioid pump is not necessary.

**Brian Koo, MD**

**Q. My RLS caused significant issues during a milder form of surgery where I was under anesthesia. Is there an underlying reason my legs moved so much? If not, what are the recommendations if you need surgery that requires you to remain still?**

**A.** RLS can often be triggered during medical procedures for a variety of reasons, some of which are not clear. The immobilization of lying for long periods on a table, and medications used to prevent nausea and allergic reactions, for example, can contribute to exacerbated RLS symptoms. An increase in RLS sensations can lead to periodic limb movements (PLMs) or semi-conscious movements by the individual under anesthesia. For those on preventive medications for RLS, coordinating with the clinician to take an additional dose of the medication prior to the procedure could be an option. Opioids are often used during procedures as part of sedation or anesthesia, so the anesthesia team can be made aware that small amounts of fentanyl or morphine can be given through the IV, which may significantly relieve the RLS symptoms and movements during the procedure. It is also important to visit

with the surgical team and share the RLS and Surgery handout and the RLS Medical Alert Card so that everyone on the team is aware of medications to avoid and substitutions that are available to prevent exacerbation of RLS symptoms. These materials are available upon request from the RLS Foundation.

**J. Andrew Berkowski, MD**

**Q. There is a recent article in National Geographic about monoclonal antibodies as a potential solution for chronic pain and the opioid crisis. Could this be an answer for RLS?**

**A.** Monoclonal antibodies target specific proteins in the body to effectively neutralize them. Many of these are used to mediate the immune response (as advertised in any TV commercial where the drug name ends in -mab). More recently, calcitonin gene-related peptide (CGRP) antibodies have become very popular for treating migraine headaches. Currently, there is no specific target in RLS to even consider constructing a monoclonal antibody, so there is no clear use of this technology for RLS.

**William Ondo, MD**

**Q. What is the latest research on neuromodulating therapy?**

**A.** Neuromodulation can be a very broad term that essentially means a treatment that impacts the underlying disease process rather than just treating symptoms. In RLS the only treatment that might be considered neuromodulation in this context is intravenous iron, if one believes that reduced brain iron is the underlying key to RLS. Any other treatment for RLS that claims to be neuromodulating is simply a marketing ploy.

Neuromodulation also more specifically often means electro-magnetic stimulation treatments. Examples that have been rarely used in RLS include deep brain electrical stimulation, spinal cord electrical stimulation and transcranial magnetic (superficial brain) stimulation. These are aggressive treatments without definitive studies proving their effectiveness. More recently, a peripheral nerve stimulator of the peroneal nerve in the leg was approved for RLS and should be available soon. The concept involves mildly contracting muscles in the leg, possibly mimicking volitional movement.

**William Ondo, MD**

**Q. Are there any scientific or medical studies that link long-term RLS with the development of neuropathy?**

**A.** Neuropathy is an extremely common condition where the function of the peripheral nerves, usually in the legs, declines, resulting in a lack of sensation, often worsening balance, and sometimes pain. Up to one-third of people over 75 have neuropathy; there are many different causes, and often no clearly defined cause. There is mixed evidence that neuropathy is a risk factor for RLS but no evidence that RLS causes neuropathy. Although some medicines are associated

with causing neuropathy, none of the RLS treatments, including ropinirole, have ever been so associated.

**William Ondo, MD**

**Q.** Does transcranial magnetic stimulation help RLS?

**A.** Transcranial magnetic stimulation (TMS) creates a magnetic field around a probe that is placed over the head and, like any magnetic field, could affect electrical signaling in the brain. In the United States, TMS has been approved for depression and obsessive-compulsive disorder. There are at least two small studies that show some benefits of TMS for restless legs, but it has never been demonstrated in a large study. Although an intriguing treatment option, due to its perceived safety, it is not a very practical treatment as it requires many sessions and is almost never covered by insurance.

**William Ondo, MD**

**Q.** Can RLS present as muscle spasms? If not, what are some potential diagnoses or triggers?

**A.** The two disorders are completely unrelated, so RLS does not present as muscle spasms or leg cramps. Muscle spasms and leg cramps are often confused with RLS since they both occur in the legs, are associated with an urge to move and most often occur at nighttime. Due to this confusion, RLS has been treated with medications that may help leg cramps but do not help RLS.

Muscle spasms and leg cramps are very common, occurring in 50% of people over age 50, so there will be significant overlap with RLS patients. Most leg cramps are idiopathic (occurring for no known reason) but can be caused by neurologic disorders; metabolic disorders, including extracellular fluid volume depletion and electrolyte disturbances; and medications. However, the most common triggers or causes are prolonged sitting without

changing position and vigorous exercise.

**Mark J. Buchfuhrer, MD, FRCP(C), FCCP**

**Q.** I am experiencing ice-cold sensations in my lower legs and toes requiring a heating pad in bed. Is this associated with RLS?

**A.** It is not uncommon for RLS patients to experience temperature sensations (hot or cold) in their legs, with or without their RLS symptoms being active. It is likely that these symptoms may be due to neuropathy, which is very common (affecting over 20 million Americans), is more common in older people and may be even more common in RLS patients.

**Mark J. Buchfuhrer, MD, FRCP(C), FCCP**

**Q.** I had a flare-up of osteoarthritis, and at the same time, RLS flared up in the same leg, both lasting for two weeks. Could RLS be connected to the arthritic flare-up?

**A.** It is quite common for any type of pain to trigger a flare-up of RLS. This phenomenon is not well understood. I also see many patients who have RLS symptoms flaring up only in the leg with the pain, and we also cannot explain this.

**Mark J. Buchfuhrer, MD, FRCP(C), FCCP**

**Q.** Over the years, I've noticed my legs will get worse in the evenings or when I have a full bladder. Do you have any ideas as to why?

**A.** RLS is known to follow the circadian (24-hour body clock) rhythm, worsening in the evening and at bedtime. The reason for this is not fully understood and was previously thought to be fluctuating dopamine levels, which are lower later in the day. It is quite common for any discomfort (like a full bladder) to trigger RLS symptoms.

**Mark J. Buchfuhrer, MD, FRCP(C), FCCP**

## Celebrating Excellence: RLS Foundation Recognized Among Top Non-Profits

**N**onprofits across the United States are evaluated annually by charity "watchdog" groups whose ratings are based on leadership, adaptability, impact and results, community, and financial transparency, helping to assure donors that their contributions are put to sound use.

RLS Foundation is pleased and honored to have received top ratings this year from three such organizations:

- Charity Navigator - 4/4 stars
- Candid - Platinum transparency
- Great Non-Profits - 2023 top rated

Recognition enhances the visibility of the growing RLS community and provides confidence that the Foundation is driving forward its mission to increase awareness, improve treatments and fund research leading to a cure. Support from members like you allows the RLS Foundation to strive for and achieve these lofty goals. Thank you for your support!





**BY J. ANDREW BERKOWSKI**  
MD

## Examining Brain Regions After Treatment with Intravenous Iron

**KIM TJ, KIM MH, KIM JH ET AL. "CHANGE OF IRON CONTENT IN BRAIN REGIONS AFTER INTRAVENOUS IRON THERAPY IN RESTLESS LEGS SYNDROME: QUANTITATIVE SUSCEPTIBILITY MAPPING STUDY." SLEEP. 2023;46(8). DOI:10.1093/SLEEP/ZSAD154.**

### THE BACKGROUND

Though not fully understood, brain iron deficiency plays a significant role in the biological development of restless legs syndrome (RLS). Lesser known are the specific brain regions that have poor iron metabolism and contribute to the condition. Intravenous (IV) iron is a first-line treatment for RLS, but the exact way in which it works and why the effects are varied across a spectrum of those with RLS are yet to be determined. This study looks at the effects of IV iron in specific brain regions using magnetic resonance imaging (MRI) techniques.

### THE RESEARCH

The researchers enrolled 40 adults with RLS and 20 age- and sex-matched control subjects in this study, with 31 RLS participants completing the full study. RLS volunteers could not have anemia or severe iron deficiency, determined by ferritin < 15 ng/mL. The baseline International RLS Study Group Score (IRLS) was 29.7. (On the scale, 21–30 is severe; 31-plus is very severe.) The study participants had a baseline MRI, blood tests, and measurements of sleep and RLS symptoms. Researchers then administered an infusion of ferric carboxymaltose 1,000 mg and reassessed the participants at six weeks (t1) and 24 weeks (t2). An MRI processing technique called quantitative susceptibility mapping (QSM) was used to determine changes in iron in specific brain regions for this study.

Surprisingly, there were no significant MRI differences between healthy controls and RLS subjects at baseline, even in regions of interest that showed differences in previous studies using a variety of imaging techniques. In RLS subjects compared to baseline, after IV iron their QSM values differed significantly in the regions of the brain called the caudate nucleus, putamen (both of the basal ganglia), and pulvinar of the thalamus. Three of the regions of interest showed no significant changes: the substantia nigra, red nucleus and cerebellum.

From t0 to t1, an increase in QSM in the pulvinar positively correlated with improvement in RLS severity using the IRLS scale. This fits with previous research showing the pulvinar/thalamus may not work properly in RLS and the pulvinar helps to prevent symptoms of RLS. Conversely, a decrease in the QSM of the caudate correlated with improvement in RLS symptoms. Based on this, the authors suggest that combined with previous research, the caudate may not have a direct relationship with iron for RLS, or that an improperly functioning caudate as a cause of RLS may be insensitive to the effects of IV iron. QSM differences did not correlate with changes in blood tests of iron and blood counts, again supporting the notion that testing blood levels of iron may not be a reliable correlate to brain levels in those with RLS, particularly when it comes to the effectiveness of the iron infusion.

### THE BOTTOM LINE

This study with MRI using QSM before and after IV iron infusion found some clinical correlations to RLS symptoms, particularly in the areas of the pulvinar of the thalamus and the caudate nucleus of the basal ganglia, which may help our understanding of the complex role of brain iron in RLS.

### FURTHER QUESTIONS

The controls did not receive IV iron and follow-up MRIs, so how would their brain regions have changed as a result of the IV iron infusion compared to those with RLS? Could the changes be due to IV iron itself and not related to RLS at all? How would the results differ for a group with similar iron levels but without RLS?

Sixty-one percent of RLS subjects were on dopamine agonists in the study, so would there be any difference for those on dopamine agonists or with augmentation compared to others who were taking other treatments or no medications at all? Do long-term changes to the dopamine system in the brain from dopamine agonists change or reduce the effectiveness of IV iron?

We continue to get varying and often contradictory results when it comes to changes in brain iron in specific regions. Is this due to inconsistency among different techniques or differences in how the same techniques are used by different centers or researchers? Does selection of a patient group by demographics, RLS severity or iron status contribute to the inconsistencies too? What methods can researchers develop that can lead to readily reproducible and consistent results for potential use in clinical practice? Or, are we quite far from understanding the role of iron in areas of the brain in order to inform clinicians about treatment decisions with IV iron?



# How Can an Iron-deficient Diet Affect Sleep and Spinal Cord Reflexes?

**WOODS S, BASCO J, CLEMENS S. "EFFECTS OF IRON-DEFICIENT DIET ON SLEEP ONSET AND SPINAL REFLEXES IN A RODENT MODEL OF RESTLESS LEGS SYNDROME." FRONT NEUROL. 2023;14:1160028. DOI:10.3389/FNEUR.2023.1160028.**

## THE BACKGROUND

As noted in the previous study, a primary cause of RLS is low levels or defective iron metabolism in specific brain areas. Animal models that have been developed for low iron have demonstrated behavioral changes in these animals that correlate with human symptoms of RLS, including increased limb movements. This study aims to examine the effect of an iron-deficient diet on spinal cord reflexes and sleep quality that have not been previously examined.

## THE RESEARCH

A set of mice were divided into three groups that included a diet containing normal levels of iron (control) and a second with a diet reduced in iron (ID) but not enough to cause anemia (low blood counts). These two groups of mice were observed and tested for up to 10 weeks. A subset of the ID mice was returned to a normal iron-containing diet (Ex-ID) to investigate the reversibility of the changes from the diet over an additional seven weeks.

In analyzing the spinal cord postmortem, the ID mice had an increase in the transferrin receptor compared to controls, similar to the increase in this receptor in various areas of the brain shown in previous studies. The increase in the transferrin receptor is thought to be an attempt to obtain more iron in that region but may also lead to changes in how the area functions.

For sleep testing, researchers used a combination of video and electric field sensors to detect movement. ID mice had less

sleep, fewer sleep episodes, and more limb and body movement in the first two hours of the resting period but similar sleep behavior to the control and Ex-ID groups for the remainder of the sleep period. This may be analogous to the beginning of the night sleep disruption, which follows a circadian pattern (biological clock) seen in humans with typical RLS.

In spinal cord reflex testing using pain and temperature stimuli, the ID group had a shorter reaction time, which was more pronounced in ID females than males, and this reflex reverted to control speeds in the Ex-ID group. This indicated that the iron deficiency may have led to abnormal hyper-excitability in the spinal cord but was reversible with recovery of iron levels.

## THE BOTTOM LINE

An iron-deficient diet in mice leads to increased movement, reduced sleep, and abnormal spinal cord responses that are generally reversible with improvement in iron levels, suggesting that RLS may involve iron deficiency beyond just the brain, including the spinal cord.

## FURTHER QUESTIONS

Can the increase in transferrin receptor protein in the spinal cord along with exaggerated reflexes help to explain further the physiological connection of periodic limb movements in sleep (PLMS) and RLS? How does this observation expand on other studies showing increased pain sensitivity in iron-deficient humans with RLS? RLS affects a greater percentage of women than men, but can the greater abnormality of reflexes in female rodents compared to males help in our understanding of sex differences? In which subsets of humans can similar iron deficiency cause changes in the spinal cord or sleep – just the ones with genetic predispositions to RLS linked with iron deficiency, or a more general population?

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

## 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, 2023 through September 30, 2023*

### In Honor of:

All of those suffering  
from the pain of RLS  
Theresa Cullen  
Susan Greaker  
Stephanie Rodriguez  
Dr. Kenneth Sassower  
Jill Scehovic

### In Memory of:

My brother  
My mother and brother  
with RLS  
Nancy Crnkovich Ayad  
Hollis Ballard  
Dick Bennett  
Thelma E Bradt  
Peter Brooks

Elsie F Brown  
Helen A Brown  
Margaret Collins  
Lorraine F Coughlan  
Steve Crnkovich  
Butch Elmore  
George Engel  
Walter H Funke DDS

Grace Healey  
Helga Heichert  
Paula Midock  
Helen Ragsdale  
James Davidson Reighard  
Mrs. Dorothy Roberts  
Dr. Roland E Roberts  
Ellen Samuels

Helen M. Shedenhelm  
Linda R Smalley  
Susanne Tershak  
Mary Waier  
John Ray White

# Exercise and RLS: Your Questions Answered

By Katie Cederberg, PhD

Katie Cederberg, PhD received her doctorate in rehabilitation science from the University of Alabama at Birmingham and is currently a postdoctoral scholar at Stanford University, where she conducts research on the efficacy and effectiveness of exercise for managing symptoms of RLS and co-occurring conditions. She recently answered questions related to RLS and exercise in an RLS Foundation webinar available on [www.rls.org](http://www.rls.org).

**Q. Is exercising the brain more important than exercising muscles before bedtime to stop RLS symptoms?**

**A.** Exercising the brain has been anecdotally helpful in relieving some symptoms, primarily described as a distraction for your brain. Physical exercise is shown to have benefits for RLS, as well as maintaining general health and wellness. There is no study that compares the effectiveness of physical versus mental exercises, but both can be utilized to manage symptoms.\*

**\*Medical Editor's Note:** Mental activities such as doing a crossword puzzle, playing solitaire, playing a video game or chess will typically relieve RLS symptoms. However, watching a very interesting and engaging movie tends to worsen RLS.

**Q. The more I keep moving in the day the less I notice the symptoms. Is this masking symptoms instead of curing them?**

**A.** Research has yet to determine whether there is a physiological change in the body when exercising that leads to a relief in RLS symptoms. Any movement, especially walking relieves RLS.\*

**\*Medical Editor's Note:** A short amount of walking may only relieve RLS temporarily (it will quickly return when back at rest) but more prolonged walking may relieve the RLS for hours.

**Q. Can stretching or doing specific exercises stop an ongoing episode of RLS symptoms?**

**A.** For some people, exercise can relieve the symptoms of an ongoing episode of RLS. Based on the questionnaire, some people experienced relief through movement while symptomatic, halting RLS symptoms and allowing them to fall asleep. Others experienced only temporary relief, and symptoms returned when they stopped their movements. The duration of exercise or movement may determine whether temporary or prolonged relief will occur.

**Q. Does taking an opioid to reduce symptoms of RLS pose any issues with exercise?**

**A.** Consult your physician to determine if there are any contraindications to engaging in exercise based on your personal medical history and health.\*

**\*Medical Editor's Note:** There should be no issue with exercising while taking opioids unless the opioids are causing side effects of

sedation which may impair coordination.

**Q. The idea of "exercise snacks" is becoming popular. Is there any suggestion that this will benefit people with RLS?**

**A.** "Exercise snacks" refers to breaking up your daily exercise goal into smaller portions throughout the day. For example, instead of one 30-minute session, exercise is completed in three 10-minute sessions. While there are no studies that pertain specifically to RLS, this may be beneficial based on studies for cardiovascular health. w

**Q. When exercising, does it matter what modality is used? Walking versus a treadmill, or exercise bike versus a street bike?**

**A.** There are physiological differences in how you exercise. How your body moves and what muscles are utilized will be different on a treadmill versus walking on the street. Every patient tends to have a preferred mode of exercise so trial and error can determine which is best. There is no current research studying how modality interacts with RLS symptom effect.

**Q. What are some options for individuals who are mobility impaired and have RLS?**

**A.** There are adaptive exercise options for those who are mobility impaired. Consider consulting an exercise professional to find exercises that best fit abilities and needs. NCHPAD (the National Center for Health, Physical Activity and Disability) has exercise resources, including a YouTube channel for those with mobility impairments.

**Q. Does aerobic swimming help RLS under some circumstances, or worsen RLS?**

**A.** It depends on one's circumstances and previous experience with exercise and workout routines. Starting an activity at a higher intensity than normal or introducing new workouts that your body is not used to may aggravate symptoms. When starting a new activity, it is a good idea to start small with lesser intensity and work slowly up the intensity scale.

**Q. Are some exercises better than others to reduce the severity of RLS or to keep it from getting worse?**

**A.** It will depend on the type of exercise your body is familiar with. If you are looking to try a new activity, monitor your intensity level and start small.

**Q. Will exercise help mitigate the progression of RLS, from mild symptoms as a child to increasing severity throughout the decades?**

**A.** Exercise can become more difficult with age, and studies have shown that exercise can help mitigate some aging factors. There is no research that studies the role this can play in RLS.

**Q.** Is it possible there are different types of RLS with similar symptoms but different outcomes for exercise?

**A.** Exercise heterogeneity/response heterogeneity refers to the different outcomes experienced by each individual based on similar practices. Further research needs to address this question: Will exercise be as beneficial to an individual with severe RLS compared to an individual with moderate RLS?

**Q.** Are there exercises that can help with RLS felt specifically in the legs, arms or other parts of the body?

**A.** There is no research that studies this specifically for RLS, but physiological research shows there are different benefits compared to completing an entire body workout versus focusing on one part of the body. There are additional cardiovascular benefits when the entire body engages in exercise. Make sure that your physician and exercise specialist are aware that intense activity can exacerbate symptoms so they can tailor the program to you.

**Q.** In your studies, have you seen people report lower usage of their medications when they instituted an exercise program?

**A.** Very few of the studies included individuals who were using medications. Another study may need to be completed to determine how exercise affects medication dosages.

**Q.** Are there benefits to incorporating electrolytes, water, protein or energy bars into an exercise program?

**A.** It is advisable to consult with your doctor or dietician to ensure that your health and nutritional needs are being considered in an exercise program.

**Q.** In your studies, what tool do you use to measure RLS severity?

**A.** The International Restless Legs Syndrome Study Group Questionnaire is utilized to determine severity. It is comprised of a 10-item questionnaire, using a scale measuring from 0 (no RLS symptoms) to 40 (very severe symptoms).

*Cederburg and her team are planning further studies to explore questions about RLS and exercise. Opportunities to participate may be announced in future editions of Nightwalkers.*

## Your Generosity Can Change Lives: The Power of Giving Tuesday for a Small Nonprofit

It's heartening to see a day dedicated to giving back in a world often filled with hustle and bustle. Giving Tuesday, which is celebrated on the Tuesday following Thanksgiving, is a global movement that encourages people to contribute to their favorite charitable organizations. One organization that deserves our attention is the Restless Legs Syndrome (RLS) Foundation. Participating in Giving Tuesday at the RLS Foundation is an opportunity to make a difference and support those suffering from this often-misunderstood condition.

### THE IMPACT OF GIVING TUESDAY

Your participation in Giving Tuesday at the RLS Foundation is essential for several reasons. First and foremost, it provides the means to fund critical research to better understand RLS, improve diagnosis methods, and develop more effective treatments. You become a part of the solution to this complex medical challenge through generosity. Moreover, Giving Tuesday offers a unique opportunity to connect with the RLS community. It's a day when people from all walks of life come together with a shared purpose – to support those living with RLS. By participating, you contribute financially and become part of a supportive network that can provide comfort and encouragement to individuals and families affected.

### EDUCATION AND AWARENESS

Another crucial aspect of the RLS Foundation's mission is education and awareness. Through Giving Tuesday donations, the

Foundation can create and distribute valuable resources, organize awareness campaigns, and promote a better understanding of RLS among healthcare professionals and the public. By participating in this annual event, you help dispel misconceptions and stigmas associated with the condition, ultimately improving the lives of those affected.

### THE JOY OF GIVING

Your participation in Giving Tuesday at the RLS Foundation isn't just about supporting a cause; it's also about experiencing the joy of giving. The act of contributing to something greater than oneself can be immensely fulfilling. Knowing that your donation, no matter how small, can make a difference in someone's life is a powerful motivator and a source of personal satisfaction.

Giving Tuesday at the RLS Foundation reminds us of the impact we can have when we come together to support a worthy cause. By participating in this annual event, you contribute to research, advocacy and education outreach related to RLS and become a part of a compassionate community. Your generosity can change lives, foster understanding and bring hope to those affected by this disease. So, mark your calendar for Tuesday, November 28, open your heart, and make a meaningful contribution this Giving Tuesday to help the RLS Foundation in its mission to improve the lives of countless individuals living with RLS.

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

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

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\*Member of RLS Foundation Board of Directors

## Register for a Virtual Support Meeting

Each month we host meetings at these times:

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

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

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

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**2024 RLS VIRTUAL SUMMIT**

**SAVE THE DATE: APRIL 6**

## BEDTIME STORIES

### MY SPIN BIKE HAS GIVEN ME RELIEF!

I, too, have suffered the slings and arrows of having restless legs. Inherited from my mother, who inherited it from her mother, I have dealt with this frustrating condition since I was in my early thirties. When my children were small, we would visit friends for an evening of dinner and movies or sports on television. Instead of lounging and relaxing like everyone else, I was walking around in the back of the living room. Forty years later, I still stand up most of the time to watch television. When I told my doctor this, she said "I don't think I would tell anyone that!"

I want everyone in the RLS community to know that when I read your stories, I totally get it. I have had all the feelings that you have described and have felt your pain through your stories to the point of bringing me to tears.

Living in this time of such advanced medicine, I felt very fortunate to tell my mother how much relief I was getting when I started taking the RLS medications. I thought I had found the answer, and my life would be "normal." But you know what happened – augmentation. I won't describe it because you have all suffered it, and your own story is probably very much like mine.

I want to concentrate on what I have discovered that has given me relief. We bought a spin bike and put it in an extra bedroom with a television. I get on the bike and put it on a very high resistance. I started at about 70 resistance and am now up to 83.\* I ride the bike in the standing position, or what they call "out of the saddle," and watch television. You cannot imagine the relief it gives me to get that much pressure on my legs while being distracted by an interesting television program. It is a total indulgence for me, and I use this technique almost every afternoon. It is also a tool I can use if I can't sleep at night. I can turn on the television, get on the bike and after about 20 minutes, I am almost always ready to get off and go to sleep.

I have also gotten back on a low dose of pramipexole. My doctor has led me to try the lowest dose of lorazepam along with it, and this gets me a good night's sleep almost

every night. I'm determined to use the spin bike to avoid another case of augmentation. I may have to ride harder or longer than I do now, but I'm also getting the health benefits of the bike, so it will be worth it. I currently spend 30 minutes to an hour on the bike daily, and some days I may get on the bike to read or listen to music.

A good spin bike that you can ride in a standing position isn't cheap, but if your experience is like mine, it will be worth every cent. I've been doing this now for about a year and believe me, if my bike breaks down, I will replace it the very next day!  
-Nita

**\*Medical Editor's Note:** It is possible that using a higher resistance might decrease the time needed to provide more prolonged relief for RLS symptoms, but from what I hear from my patients, any exercise even with little resistance or slow walking should have comparable benefits. However, a small percentage of patients may need a particular exercise or higher exercise level to get adequate and prolonged relief, 20-30 minutes seems to be a fairly common duration of exercise needed for sustained relief.

### THE CAUSE OF MY RLS

After three decades, I may have found the cause of my RLS: blood donations. I used to give blood every eight weeks for years. I've even got a 16-gallon donation pin to prove it. There were times when my iron level was marginal, but I never gave it much thought. Due to other medical issues as I approach 70, I can no longer donate. During the last year, I've been able to cut my ropinirole dosage, and last week I stopped it completely. Augmentation was never a major issue, although I was taking 3 mg of ropinirole. However, I was generally judicious in my dosage, taking a portion of a pill and then waiting to see if it was enough to prevent or stop the devils in my legs. Anyway, if you donate blood, you might want to reconsider.\*

-Marty J.

**\*Medical editor's note:** The relationship between RLS and blood donation is well documented in the medical literature.

## Publications

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

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 of

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

### DONATION APPLIED TO

Research

Where it is needed most

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

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

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

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

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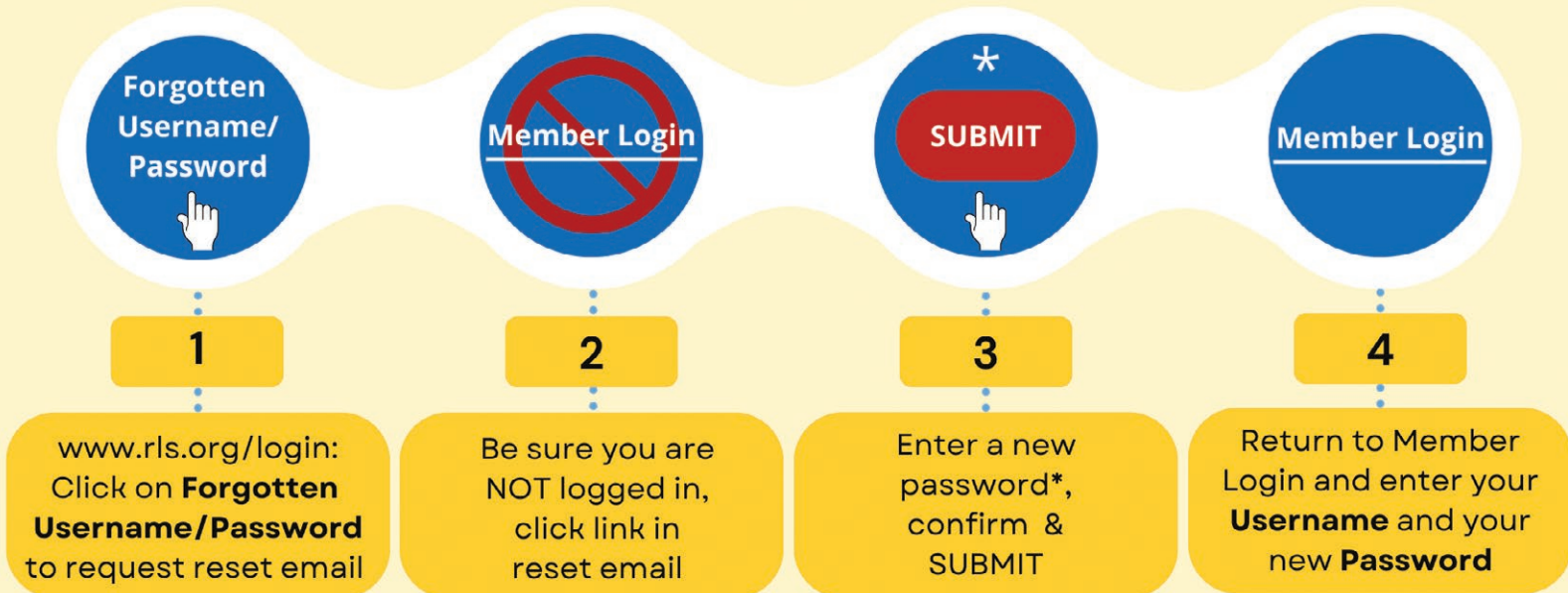
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## HOW TO CHANGE YOUR RLS.ORG PASSWORD



**\* YOUR NEW  
PASSWORD  
MUST  
CONTAIN:**

Minimum of 12 characters  
One Upper Case Letter  
One Lower Case Letter  
One Number  
One Special Character (@,#,\$, or !)

Note: Password cannot include your Username or "RLS"