NIGHTWALKERS

In search of a good night's sleep

SUMMER 2025

MAKE THE DAY YOURS
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RLS
RESTLESS LEGS
SYNDROME
FOUNDATION

NightWalkers *is the official publication of the Restless Legs Syndrome Foundation*

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Warning and Disclaimer
Persons suspecting that they may have RLS should consult a qualified healthcare provider. Literature that is distributed by the Restless Legs Syndrome Foundation, including this magazine, is offered for information purposes only and should not be considered a substitute for the advice of a healthcare provider.

The RLS Foundation does not endorse or promote any products or services.

KARLA M. DZIENKOWSKI

RN, BSN
Executive Director

Let 2025 Be the Year You Get Involved

This issue of *NightWalkers* explores the importance of connection by celebrating community engagement, recognizing our dedicated volunteer network, and featuring ways to get involved with RLS Awareness Day on September 23.

As we reflect on our organization's growth, we remember the efforts of the volunteers who established the RLS Foundation 33 years ago. Led by Oran Hawley, these early pioneers began corresponding by letter in 1989 to share news and information. In 1990, Virginia Wilson published the first edition of *NightWalkers*, a quarterly news magazine filled with research updates and insights. *NightWalkers* remains our most popular publication.

In 1994, Juanita Therrell and Thelma Bradt spearheaded the launch of our support group program. These support meetings offered a safe space to share experiences and wisdom. When the COVID-19 pandemic struck in 2020, the RLS Foundation formed virtual support groups to ensure continuous connection. Our support program thrives today, offering both in-person and virtual meetings and 24/7 online support through the online discussion board.

Since 1997, the RLS Foundation has been the driving force behind the only dedicated research program for RLS. We have awarded over $2 million in seed grants to researchers worldwide. Business leader Bob Waterman, who himself had RLS and served many years on our volunteer Board of Directors, established the RLS Foundation Research Grant Program to lead the search for better treatments and a cure. Member contributions to this program have yielded significant discoveries, including:

- The identification of the first RLS gene variant, BTBD-9
- The National RLS Opioid Registry at Harvard
- Research into the adenosine relationship to RLS
- A study on a potential new augmentation treatment using a D-1 receptor-specific antagonist with a clinical trial expected later this year

Our organization was built and remains sustained by volunteers. With RLS Awareness Day approaching on September 23, consider this your sign to get involved! You can contribute by sharing your RLS journey in *NightWalkers*, attending a support meeting or participating in advocacy events, including our annual RLS Hill Day on October 6. If you're looking to use your professional expertise, consider serving on our Board of Directors, whose members strategically guide the Foundation and support its mission. Learn more about board service on page 9.

Let 2025 be the year you step up in service. Your involvement can make a meaningful impact!

And finally, a heartfelt thank you to our volunteers: You are the backbone of this organization, and we are truly grateful.

Karla M. Dzienkowski

Honor Roll

The Restless Legs Syndrome Foundation is sincerely grateful for the donations we received in memory and in honor of the following individuals from May 15 to July 31, 2025.

In Honor of:
Dr. Mark Mauer

In memory of:
Irene Dooley
Valerie MCCarthy
Mary Ellen Strupp
James Willis

Make the Day Yours

By Adrianna Colucci, RLS Foundation Communications Coordinator

Some days with RLS are simply harder than others. A restless night that bleeds into a foggy morning or persistent discomfort can make it feel like the day is slipping away before it begins. But even on the most challenging days, small, intentional actions can help you restore your energy and reclaim control over the day. This article offers strategies to help you navigate overwhelming moments and take back your day.

START WITH COMPASSION

One of the most powerful things you can offer yourself on a tough day is compassion. It's easy to fall into patterns of frustration or self-criticism when symptoms interfere with sleep, focus and productivity. Cognitive restructuring, a technique used in cognitive behavioral therapy, can help you challenge negative thoughts and replace them with more balanced, supportive perspectives.

Cognitive restructuring is a therapeutic approach that helps people identify, challenge and reframe biased or harmful automatic thoughts.[1] Automatic thoughts are the assumptions and feelings that arise instantly in response to a situation. A variety of techniques can be used to challenge them when they're negative.[1]

- **Examine the evidence:** Evaluate the validity of your assumptions by weighing them against evidence such as objective fact or past experiences.
- **Recognize cognitive distortions:** Try to identify any common thoughts you're having that may be irrational or biased such as overgeneralizations, catastrophizing, or all-or-nothing thinking.
- **Consider different perspectives:** Explore other possible interpretations of the situation outside of your own.

Cognitive reframing can instill self-compassion, shifting harmful thoughts into reminders that "It's okay to pause," and "While today may be slower, it is still meaningful."

MOVE WITH INTENTION

There's a well-known correlation between physical activity and mental health. Hormones released during regular exercise can reduce stress, promote relaxation, improve focus and cognition, support immunity and even cause sleepiness.[2] And on difficult days, sometimes it is best to start simple. Even a few minutes of movement can positively affect both mood and body. Here are a few ways to incorporate movement into the day, even when energy is low.

- Get to know your neighborhood. Take short walks to a local coffee shop, find a nearby book-sharing box, discover a new walking path, clean up litter (using caution and protective gear) or observe the local fauna and flora.
- Find an accessible way to add stretching to your routine: dynamic stretching to help you wake up in the morning, mid-afternoon chair yoga (seated yoga) or gentle stretches before bed.
- Break up the workday with desk stretches that release tension in the arms, shoulders, neck and hands.
- Brighten and refresh your space through household chores (e.g., doing the dishes, changing the bedding or gardening).
- Move while you're on the phone or during commercial breaks when watching television.

Use music to inspire movement – queue your favorite songs and put on your most comfortable walking shoes. Remember that movement does not have to be big to be meaningful. And be sure to consult with your physician before making changes to your exercise regimen.

CREATE A RESET RITUAL

Establishing a routine to refocus your mind and body can be helpful during days when you are mentally fatigued. This practice does not need to be elaborate, just consistent. One way to recenter is through breathwork: the intentional control of inhaling and exhaling to invoke calmness. There are many breathwork techniques, such as box breathing, which involves four counts each of breathing in, holding your breath, and exhaling; and four more counts of holding your breath after you exhale.[3]

For some, a short nap can be restorative. Napping for 30 minutes or less will generally offer the most benefits, as it allows your body to rest without entering deeper stages of sleep that can cause grogginess.[4] If you have a traditional sleep-wake schedule, napping during the early afternoon, between 1 and 3 pm, is ideal. This period often coincides with a natural dip in energy, commonly referred to as the "afternoon slump." Resting during this time may improve your energy, alertness and cognition. To avoid interfering with nighttime sleep, limit your naps to at least eight hours before bedtime.[4]

Knowing when to take a short break is an important part of building a sustainable reset ritual. Step away from your screen to write a to-do list by hand, doodle or journal your thoughts. You might also find excitement in discovering a new community event, making plans for an upcoming holiday, or visiting a small business in your area that you haven't visited before.

Everyone's reset ritual will look different, but what matters most is connecting each action to a sense of calm that shifts your mindset and restores energy throughout the day.

STAY CONNECTED

One of the most powerful tools for recharging is human connection. Research increasingly shows that a sense of belonging impacts both physical and mental health, fostering mutual respect, improved self-esteem and reduced stress.[5] For those living with chronic conditions like RLS, it is important to establish a reliable support network that provides encouragement and understanding.

The RLS Foundation offers several resources to help you build your support network. Monthly virtual support groups led by volunteers provide a consistent space for connection. In addition, volunteers lead local support groups that meet in person or virtually, to better serve their local communities. For 24/7 support, the Foundation's discussion board is an online forum where you can read and respond to existing conversations or start your own thread. All support resources are available at www.rls.org/get-support.

It's also important to cultivate a personal support system of friends and family. While not everyone will understand what it's like to live with RLS, many are willing to listen, learn and check in. Nurturing these relationships and offering mutual support can make them even more fulfilling.

Take a moment to identify your support system and remind yourself that you are not alone. Connect with the broader community by registering for an upcoming support group or re-reading member stories in past editions of *NightWalkers*. And of course, immerse yourself in the experience of being with people you care about – invite your neighbors over to cook dinner, join a club or sports league or call a friend you haven't seen in a while for a heartfelt conversation.

PRACTICE MINDFULNESS

When thoughts become overwhelming, mindfulness can be a helpful tool for regaining focus and grounding yourself in the present. Rooted in ancient Buddhist meditation, this practice trains the mind to observe rather than react.[6] It involves bringing awareness to your thoughts, emotions, sensations and surroundings without judgment. Over time, mindfulness can help reduce emotional reactivity and avoid negative automatic habits such as rumination and overthinking.[6]

Grounding exercises are one way to employ mindfulness. Grounding brings awareness to the body by engaging the senses. This might involve standing in the sun, holding a warm mug, dipping your legs into cool water, or listening to soft music or ambient sounds. Scent can be especially powerful for tuning into the present. You can associate certain candle scents or essential oils with a specific mindset by using the same aroma each time. For example, light a vanilla scented candle when you want to focus, lavender when you're stressed or citrus when you want to feel a bit more energized.

Structured meditation can also positively impact both physical and emotional health.[6] There are many resources available online for guided meditation but for quality and credibility, consider choosing ones offered through universities or medical clinics.

Practicing mindfulness, especially by accepting observations about your own harmful thought patterns, may take time and dedication, but just a few minutes each day will help realign the mind and body. There is no rule book for how each individual should increase their ability to be present and observe and accept their reality, so your mindfulness practice can look however you need it to.

CULTIVATE JOY

Establishing healthy habits and routine can be helpful for structuring the day, but it's important to recognize when your rhythm becomes monotonous and you feel "stuck." While "happiness" and "joy" are often used interchangeably, there are slight differences.[7] Happiness may be fleeting and refers to the pleasurable emotions experienced in reaction to an event, experience or object. Joy is a deeper, more sustained state of mind and comes from within.

Finding and cultivating joy is distinct for everyone, but it can start by remembering the times you felt fulfilled and joyful.[7]

- Find a personal cause you care about and connect with a relevant organization where you can volunteer your time meaningfully.
- Embrace your creative side and find a novel hobby. Practice calligraphy, scrapbook, thrift and restore furniture, learn to play an instrument or sketch for expression, not perfection.
- Discover something new – a genre of music, a style of cuisine or conversational phrases in a new language.
- Foster your curiosity. Choose a topic that fascinates you and become an expert.
- Be mindful of your surroundings. Limit exposure to individuals or environment that consistently generate negativity.
- Some medications can interfere with your natural ability to experience pleasure. Talk to your doctor about your medications, especially if you are taking antidepressants.[7]

Give yourself permission to explore and reconnect with the experiences that bring you joy.

CONCLUSION

Remember that each day belongs to you and integrating small, intentional actions can help you shape the trajectory of your day. RLS is a serious neurological disorder that can significantly impact both physical and mental health. These strategies are intended to support your daily routine, but do not replace clinical treatment. If you are experiencing distressing or severe symptoms, it is essential to seek evaluation and guidance from a qualified healthcare provider or mental health professional. Further mental health resources are available through:

- American Psychiatric Association (www.psychiatry.org)
- National Institute of Mental Health (www.nimh.nih.gov)
- Mental Health America (www.mhanational.org)

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2025 RLS Virtual Summit

Innovations in Patient Care

REGISTER TODAY **SATURDAY, SEPTEMBER 20**
10 - 4 PM CT

This all-day virtual event explores the latest in technology, treatments and RLS clinical approaches. Eight expert speakers will cover key topics, including:

- **Novel sleep devices**
- **Dopamine agonist withdrawal syndrome**
- **Updated strategies for managing augmentation**
- **Comorbid insomnia and sleep apnea**
- **And much more!**

Attendees can submit questions during each session for the live Q&A. Register at www.rls.org/25-summit before September 13 for discounted tickets.

SCAN TO LEARN MORE AND REGISTER

Please note, this is a live event and presentations will **not** be available for viewing at a later time. This event requires a valid email and an electronic device with internet access.

Mindful Moments: Tips from Our Readers

RLS presents both physical and emotional challenges. Finding moments to recenter the mind and renew the body's energy can help protect mental health and overall well-being. We asked members of the RLS community to share techniques they use for practicing mindfulness and restoring balance, especially on days where RLS can feel overwhelming. Please note, everyone's RLS is unique to them, and efficacy will vary among individuals. Thank you to all who submitted responses.

> The one technique that I use almost every day to restore my energy, relax my body and reset my mind is the ancient practice of Yoga Nidra. Yoga Nidra, or non-sleep deep rest (NSDR), is a guided meditation practice to promote a profound state of relaxation. This can be done sitting comfortably or lying down in your bed or on the floor. There are amazing online audio practices that range anywhere from five minutes to over an hour! When I have had an especially difficult night, I sometimes incorporate three to four **Yoga Nidra** sessions during the day. This practice has literally saved my life! I highly recommend it for anyone who needs deep restorative rest. They say that 30 minutes of Yoga Nidra is equivalent to three to four hours of deep sleep.
>
> **Elizabeth**

> The first thing I do when I wake up in the morning, no matter how I slept, is to raise the shade over the window by my bed and just look quietly outside, noticing the weather, the trees, and the light, and listening to the noises. **Then I find two things to be grateful for**, large or small. Then I say, "All right!" and get out of bed.
>
> **Kris**

> What helps me re-center or recharge? **Walks, gardening, leg stretches**, listening to country-gospel hymns on YouTube.
>
> **Tom**

> I walk stairs, do squats or go for a short walk. I remind myself that it could be worse. There are many chronic diseases with fatal prognoses or with more debilitating symptoms. Remember that this too shall pass. **The sun will come up soon** and my symptoms will wane then.
>
> **Kelly**

> I am a 72-year-old male who has had RLS for six years. I dread the evenings because of the discomfort that is sure to follow. I try to use the following techniques to help me relax and fall asleep. Getting a good night's rest is my primary daily goal.
>
> **Take a shower or bath to relax.**
>
> Make sure you are not dehydrated. Drink plenty of water.
>
> Along with my RLS nighttime medication, I take melatonin to help sleep and magnesium tablets to prevent leg cramps. Consult with your doctor prior to incorporating this into your treatment regimen.
>
> Walking during the day is wonderful for helping me relax in the evening. I strive to obtain 6,000 steps each day.
>
> If you start to experience tripping or falling while nightwalking, consult your doctor. Falling can have serious consequences and can contribute to increased anxiety.
>
> If possible, try not to focus on your RLS symptoms, I like to go to my workshop and focus on a project. Engaging in a positive activity and working towards an accomplishment will shorten your evening RLS wrestling match.
>
> No matter how bad your RLS gets, tell yourself that your situation could be worse.
>
> I hope these tips and techniques are helpful for other RLS sufferers.
>
> **Anonymous**

Support Group Leader Spotlight

David Moulton is a longtime Foundation member, and in 2024 he decided to get even more involved with the community by volunteering as a support group leader for the Denver Metro RLS Support Group. His group attracts a large number of people seeking a community of support and understanding. In this Q&A, David shares what led him to volunteer and what inspires him about the RLS community.

Q. Can you tell us a little bit about yourself and your connection to RLS?
A. After a 32-year career working in procurement for the federal government in Washington, DC, I retired in 2004 and moved to Colorado. Here, I have been enjoying skiing, hiking, birding, canoeing, biking and various volunteer activities. One of my favorite volunteer activities for the past 16 years is being a storyteller with a group called Spellbinders. Once a month during the school year, I visit fourth grade classes and tell (not read) stories. This has been the most fun and rewarding job that I have ever had.

In 2005, I started noticing symptoms that turned out to be RLS. My primary care physician prescribed Requip (ropinirole), which initially worked very well. I eventually developed augmentation and made a lengthy and difficult transition from ropinirole to gabapentin. As I researched this strange disease, I discovered the RLS Foundation and immediately became a member. Through the Foundation, I learned a lot about RLS and discovered a support group that I found to be quite helpful.

Q. What encouraged you to become an RLS Foundation support group volunteer?
A. I wanted to learn more about RLS and possible treatments and share that information with other members, so I became active in discussions in the existing Colorado support group. On several occasions, I read about interesting developments in *NightWalkers*, and I arranged to have the authors speak during our meetings. When the Colorado group leader decided to resign, he asked me to take over his role. I wanted the group to continue so I accepted the challenge and, with the support of the RLS Foundation, I took on the leadership role.

Q. How do you create a safe, welcoming space for people who may be nervous about attending their first meeting?
A. I encourage people to just sit in and listen for a while until they feel comfortable asking questions or sharing their experiences.

Q. Are there any memorable moments or conversations from the group that have stuck with you?
A. Hearing the frustration and depth of despair expressed by some of our members sticks with me. But their thanks to the group members for simply being there motivates me to keep the group going.

Q. What areas of growth in the RLS community are you most excited for?
A. Advocacy, research and education are areas that excite me. We need advocacy to convince our legislators to provide more funding for research. From articles in *NightWalkers*, I have learned that there are several promising avenues of research that might advance the understanding of RLS and the development of more effective treatments. It takes a lot of money to do this research. We need to educate our legislators that RLS is a serious problem for many of their constituents and that they should provide funding for research to alleviate the scourge of RLS.

Many in the public and the medical community are quite ignorant about RLS and the current treatment recommendations – including some who still believe that RLS is something made up by the drug companies. We need to bring awareness to the medical field that RLS is real and that it is serious.

Q. What brings you joy or helps you recharge outside of volunteering?
A. Being active outside and enjoying the wonders of nature recharges my personal batteries. I love the freedom of movement in my canoe, on my bicycle and on foot. I also particularly enjoy observing and learning about birds and their habitats in many places around the world.

David Moulton enjoying the Colorado outdoors in a handcrafted canoe he built himself.

RLS Awareness Day

RLS Awareness Day is September 23, but we're dedicating the entire month to raising awareness! Join us by taking part in our weekly activities. Be sure to follow us on social media for updates on our events and ways to get involved.

Instagram: RLSFoundation **X: @RLSFoundation** **Facebook: RLS Foundation**

Week 1: September 1-6

Awareness

September 1: Bring RLS awareness to your neighborhood! Email info@rls.org to request an extra copy of *NightWalkers* to share with a friend, local medical clinic, community center or long-term care facility. Email subject line: *Share RLS NW*

And don't miss RLS Hill Day, our annual advocacy event on Monday, October 6! Visit www.rls.org/advocate for more.

Week 2: September 7-13

Creative Expression

September 8: Are you an artist, photographer, graphic designer or simply artistic? Submit a design for our Spring Fundraiser campaign!

Selected artwork will be featured on the greeting cards mailed to RLS Foundation members during our fundraising campaign. For further information and deadlines, visit www.rls.org/getinvolved.

Week 3: September 14-20

Community Support

September 18: Join us for a special monthly virtual support meeting! This meeting will provide a safe and supportive space for RLS community members to invite friends, family, caregivers, or loved ones to learn about RLS and its impact on health and wellbeing.

Register at www.rls.org/get-support.

Week 4: September 21-27

RLS Advancements

September 23: We kick off RLS Awareness Day by announcing the winners of our giveaway! To enter, visit our Instagram and Facebook.

We are also excited to highlight the four studies awarded funding through our 2025 Research Grant Program! Learn more about these researchers at www.rls.org/funded-research.

September 20: Register for our 2025 RLS Virtual Summit: *Innovations In Patient Care*!
Eight experts will provide the latest on technology and treatments. More info on page 5.

Curious about Board Service? Hear from Our Governance Chair

Jim Flaniken is a retired senior executive who joined the RLS Foundation Board of Directors in 2023. He recently became chair of the Governance and Nominating Committee and is using his previous leadership experience to strategically expand the board, recruiting diverse and qualified individuals. Jim shares his insights into what makes a good board member and how to learn more about board service.

Q. Why is board recruitment and development so important for the Foundation?

A. Recruiting and developing board members is critical to the long-term health and impact of the RLS Foundation. It is paramount that we are building a board that is not only capable today but also positioned to guide the Foundation well into the future. Thoughtful recruitment ensures we bring in people who not only care deeply about those living with RLS, but also bring energy, ideas and expertise to move our mission forward. Our board sets the strategic direction of the organization, ensures strong governance and upholds our mission to improve the lives of those affected by RLS. To do this effectively, we need a diverse and engaged group of leaders who bring fresh perspectives, expertise and commitment.

Q. What qualities and skills are valuable for board service?

A. First and foremost, we are looking for individuals who are passionate about making a difference in the lives of those suffering from RLS. We value individuals who are passionate about the Foundation's mission and committed to actively contributing their time, talent and resources. Given the role of the board, key qualities of its members include integrity, strategic thinking and collaboration. We are especially interested in candidates with experience and skills in nonprofit leadership, healthcare, finance, law, marketing, advocacy or fundraising. We welcome individuals who bring lived experience with RLS, as their insight is vital to ensure our work remains relevant and impactful. Some of our most impactful board members are those with personal or family experience with RLS, as they bring a level of insight and urgency that strengthens everything we do.

Q. What is the Board of Directors responsible for?

A. The Board of Directors is responsible for overseeing the overall direction and fiscal health of the RLS Foundation. It is an opportunity to help shape the future of the organization. This includes setting strategic priorities, ensuring financial stewardship, supporting fundraising efforts, helping build strong relationships with donors, maintaining high ethical standards and evaluating the performance of the organization and its leadership. Board members also serve as ambassadors for the Foundation, helping to broaden awareness and strengthen partnerships in their communities and professional networks. Board service is about being a voice for those living with RLS – and helping accelerate progress toward better treatments, increased awareness and ultimately a cure.

Q. How can interested applicants learn more?

A. We love connecting with individuals who want to contribute to our mission in a meaningful way. If you are curious about board service, we encourage you to start by visiting our website at www.rls.org to learn more about who we are and what we do.

Those who are ready to explore board opportunities more seriously can reach out to me as chair of the Governance and Nominating Committee at jsflan@comcast.net. I would be happy to provide additional details about expectations, time commitments and the nominating process. There is real purpose in this work – and we would be honored to explore such an opportunity with you.

Join the RLS Foundation Board of Directors

Shape the future of RLS research, outreach and advocacy.

We are seeking passionate and committed individuals to join our Board of Directors. Board members guide the direction of the organization to advance our mission and goals. We welcome applicants who bring:

- clinical expertise
- lived experience with RLS
- nonprofit leadership
- a background in business, law, finance, communications or education

Learn more about Board Service by using your mobile device to scan the QR code! If you are ready to explore board opportunities, please reach out to the chair of our Governance Committee, Jim Flaniken at jsflan@comcast.net.

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[1] Bogan RK, et al. Sleep. July 2023;46(10).

INDICATION

The Nidra Tonic Motor Activation (TOMAC) System is intended to reduce symptoms of primary moderate-severe Restless Legs Syndrome and to improve sleep quality in adults refractory to medications.
Rx Only. Caution: Federal law restricts this device to sale by or on the order of a medical professional.

Please visit www.nidraRLS.com/isi for complete Safety information including all contraindications and potential complications.

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MKT-01043 v01

Q&A: How to Increase Happiness and Well-Being

Gary Bradt, PsyD is a speaker, author and clinical psychologist who earned his doctorate from Hahnemann University Hospital. His passion lies in helping individuals adapt to change and enhance their happiness and well-being and he has given over 350 keynotes for high-level companies. Dr. Bradt is uniquely connected to the RLS Foundation as the son of Thelma Bradt, a founding member.

Dr. Bradt answered questions in an RLS Foundation webinar, "How to Improve Happiness and Well-Being," available on www.rls.org. The information presented in webinars is offered for informational purposes only and should not be considered a substitute for the advice of a healthcare provider.

Q: How does someone maintain happiness when their world seems to be coming down around them?
A: When you feel overwhelmed, don't hesitate to ask for help. Reach out to those who love and care for you. Consider seeking a professional counselor. Physicians, family, friends, pastors and rabbis may be able to refer you to the right counselor. Finally, don't forget to notice and practice gratitude for life's small, daily pleasures, which remain even during the most difficult times.

Q: How do you find happiness when pain and other disabilities render you not only useless but a burden to others?
A: This question makes two assumptions that you may want to challenge: that you are a burden to others and that you are useless.

Give yourself some perspective by questioning: When the people you love most are struggling, do you consider them a burden? Or do you wonder how you can help them?

Pain and disabilities do not render you useless. We see this in stories from inspiring people such as Dick Woodward, a pastor who developed a neurodegenerative disease leaving him paralyzed from the neck down. In this state, Dick made his most dramatic impact on the world. Only able to move his head and confined to his bed, Dick dictated teachings that were eventually distributed around the world. Over time, hundreds of churches were founded due to this work. In short, when Dick could no longer do anything, he accomplished more than he ever dared dream. Never give up hope.

Q: When you are overwhelmed due to medications or breakthrough symptoms, how do you do joyful things?
A: I can integrate a personal experience to answer this question. My first child had severe medical problems. When he was four months old, he had to have open heart surgery. I'll always remember watching him on the gurney on the way to the surgery, thinking I might never see him again as the elevator doors shut. At that moment, I had a choice. I could have stayed in the hospital room and let my emotions overwhelm me. Instead, I opted to take a walk outside with my wife. It was a beautiful day, and we leaned on each other for support. In those moments, I began the lifelong journey of learning to let go of what I cannot control and focus instead on what I can control.

Therefore, instead of fixating on what makes you overwhelmed, find a bit of happiness wherever you can to help you cope. Having and keeping that hope allows us to continue each day. We can't control what happens to us, but we can always choose how we respond.

Q: How do I keep from feeling angry when I am awakened multiple times a night?
A: You can't keep from feeling your emotions, but you have control over how you respond to them. I have found that mindfulness meditation can be a useful tool for managing troubling thoughts and emotions. For example, when we learn to meditate, we notice when we are angry. We can then determine how best to respond to it.

In addition, recent research suggests that we don't have to sit on a cushion for hours daily to benefit from meditating. You can meditate washing the dishes, taking a walk, or as you lie awake at night. Even a few minutes a day of regular practice may have a beneficial impact.

Q: How do you maintain happiness in the evening when your legs are feeling so restless?
A: Remember that you have a choice. You can either be constantly focused on and consumed by what is happening with your legs, or you can see what you can do to maximize your chance of finding some peace and calm.

For example, instead of focusing solely on your legs and the negative commentary your mind might produce, you might pick up the phone and talk to a friend or loved one, read a book, take a walk, do a crossword puzzle, or engage in any other activity you find enjoyable. In short, choose activities that you know will support your happiness. Every little bit helps.

Understanding Epidemiology Studies: Clinical Insights

By Dr. William Ondo, RLS Quality Care Center Director at Houston Methodist Neurological Institute

Medical epidemiological studies, also called observational studies, assess information from existing data sources. These studies often make news headlines, reporting "associations" between some factor (e.g., medicine, food, activity) and some outcome (typically a feared medical condition). No epidemiology/observational study can ever deduce that one factor "caused" the other, a distinction that is often blurred by media sources. A classic example: there is an extremely high association between ice cream consumption and deaths by drowning. However, it is unlikely that ice cream consumption causes death by drowning and unlikely that death by drowning causes more ice cream consumption. It is much more likely that both occur more in summer, which explains the association. Although a useful, fast, and inexpensive mode of study that has heralded many medical advances, in isolation, retrospective epidemiology studies are among the least scientific and potentially misleading forms of analysis.

One recent observational study correlated the use of gabapentin with developing dementia.[1] This study incorporated many of the statistical strategies used to improve the accuracy of observational studies. However, even the most strenuous and well-meaning analysis can't overcome the potential for bias in any retrospective (analyzing previously collected data) study. This specific study compared 26,416 patients who used gabapentin for low back pain against 1,103,678 patients who did not take gabapentin for low back pain. All diagnoses were based on recorded standardized electrical diagnosis codes. The researchers from this study then used a complex process to make the larger non-gabapentin group more similar to the gabapentin group by specifically selecting a subset of 26,000 individuals from the non-gabapentin group to use in the direct comparison. By doing this, the researchers can "correct" for some intrinsic differences to make the comparison relatively more fair. Patients with other established risk factors for dementia that might bias the group (independent of gabapentin use) were excluded. At the end of this correction, the two groups were similar for age, sex, race, hypertension, diabetes, heart disease and some other disorders that have been associated with developing dementia, based on electronic medical record data.[1]

However, researchers can't correct for every factor. Fortunately, the authors of this study included the baseline characteristics of the 26,000 gabapentin group vs. the 1.1 million non-gabapentin group. Overall, the gabapentin group was much "sicker," older, and had many additional factors that would otherwise increase their risk for dementia. Although the researchers corrected for some of these, they could not correct for many other potential dementia risk factors, such as hearing loss, social isolation, obesity, physical activity/exercise, and general attitudes toward health/healthy lifestyles. The published results do not allow us to determine whether the gabapentin group had more of the unmeasured dementia risk factors. However, because they had higher risks across almost every other reported baseline characteristic, it is reasonable to infer that they likely had more of these unmeasured risk factors as well. It was also indicated that the gabapentin baseline group were prescribed a greater number of opioids and other pain treatments. Based on this information, the gabapentin baseline group likely had more severe pain issues, which would at least suggest less exercise and more social isolation.

Potentially the biggest uncorrected risk factor for these types of observational studies is the frequency of health care visits. The more a person seeks medical assistance, the more likely they are to receive treatment and obtain a diagnosis for medical conditions. No individual who has not seen a physician is diagnosed with dementia and patients who visit a physician less often are also less likely to receive a subsequent diagnosis of dementia. This is a major, although underrecognized, intrinsic bias with all observational studies.

Other issues that may account for bias include the accuracy of the medical records, since no patient was interviewed or completed any type of questionnaire for this study. Further, generalizations to one disease (back pain) cannot always be attributed to another (RLS). For example, alpha-2-delta ligand medications (gabapentin, gabapentin enacarbil and pregabalin) improve sleep in RLS, which is known to lessen dementia risk in general. Specifically, they increase deep (delta) sleep, which is also hypothesized to reduce dementia.

Unfortunately, proper scientific studies to prove causality require prospective (collecting data moving forward in time) trials, which are lengthy, expensive and very challenging. With respect to this study, proving an association between gabapentin and dementia would require randomizing thousands of similar people to take either gabapentin or a placebo, with no chance of taking similar medicines. Participants are followed regularly for 10-15 years, examining how many in each group develop dementia. That idealized version of the study is essentially impossible on practical, financial and ethical grounds. There are high quality, but short (12-48 week) randomized prospective trials demonstrating the benefit of gabapentin enacarbil and pregabalin for RLS, however these can't definitively eliminate the possibility of side effects that occur only after many years. Interestingly, there have been only a few small studies of gabapentin for RLS, but because of its low cost, long-established safety profile, and similarity to gabapentin enacarbil and pregabalin, it is commonly used.

At this point, I do not feel this association study of gabapentin with dementia should deter people from using gabapentin for RLS. We consider this medicine to be among the safest overall options for RLS.

[1] Eghrari NB, Yazji IH, Yavari B, Van Acker GM, Kim CH. Risk of dementia following gabapentin prescription in chronic low back pain patients. *Reg Anesth Pain Med.* Published online July 10, 2025. doi:10.1136/rapm-2025-106577.

Dr. Ondo serves as director of the Movement Disorder Clinic at the Houston Methodist Neurological Institute, a certified RLS Quality Care Center. He is board certified in adult neurology and sleep medicine and is an active member of the RLS Foundation Scientific and Medical Advisory Board.

RLS Researcher Honored with Citation Milestone Award

Congratulations to James R. Connor, PhD, MS, for receiving the 2025 Career Citation Milestone Award, a Research and Innovation award from Penn State College of Medicine! This honor recognizes one of Dr. Connor's early and influential publications: a 2003 study titled "Neuropathological examination suggests impaired brain iron acquisition in restless legs syndrome," published in *Neurology*.[1] The article has since been cited over 700 times, continuing to advance neuroscience and inform future research on RLS.

Dr. Connor is a distinguished professor of neurosurgery, neural and behavioral sciences and pediatrics at The Pennsylvania State University College of Medicine. He also serves as the university's vice chair of neurosurgery, as well as director for its Center for Aging and Neurodegenerative Diseases. His primary areas of research focus on understanding the cellular and molecular mechanisms by which cells regulate their iron status. Dr. Connor has served the RLS Foundation Scientific and Medical Advisory Board for over 10 years and resides on the research grant committee.

We are proud to join in the celebration of Dr. Connor's enduring commitment to research and discovery.

Personal Note from Dr. Christopher Earley, MB, BCh, PhD: Chair of the RLS Foundation's Scientific and Medical Advisory Board

One of the greatest fortunes of both my personal life and my professional career was meeting Jim and having the opportunity to work so closely with him for over 30 years. In the mid-90s, my colleague Dr. Richard Allen and I had postulated that altered brain iron might play a role in the pathology of RLS. I perused the scientific literature and found that Dr. James Connor dominated the scientific literature on the subject of brain iron. And as it transpired, he was working just an hour and half away from Baltimore. Dr. Allen contacted him and explained what we were looking for in terms of assessing brain iron. We scheduled an appointment, drove to his lab and the rest is history. Jim has been, and remains, one of the world's foremost experts in brain iron homeostasis. It is true to say that without his collaboration, much of the work I've done over the past 30 years on understanding the role of iron homeostasis in the pathology of RLS would likely not have happened. Jim is highly deserving of the 2025 Career Milestone Award – not only for his decades of work on brain iron homeostasis, but also for his translational research on iron homeostasis and its role in RLS. It was through that work that we established the importance of low brain iron in RLS, which subsequently led to clinical trials demonstrating the value of intravenous iron therapy in RLS. Truly an example of bench-to-bedside translational research – made possible, in no small part, by Jim.

[1] Connor JR, Boyer PJ, Menzies SL, et al. Neuropathological examination suggests impaired brain iron acquisition in restless legs syndrome. *Neurology*. 2003;61(3):304-309. doi:10.1212/01.wnl.0000078887.16593.12.

Bill Tunison: Leader, Educator, Community Builder

By Karla Dzienkowski, RLS Foundation Executive Director

As the RLS Foundation continues to grow, we take this moment to pause and reflect on those whose early vision and dedication laid the groundwork for everything we do today. The resources and advocacy we offer today are rooted in the efforts of those who came before us – founding members who recognized the urgent needs within the RLS community.

In this issue of *NightWalkers*, we honor one of our earliest members: Elizabeth "Bill" Tunison. From the very beginning, RLS was a constant part of her life. She battled its symptoms through childhood but over time, the severity of her symptoms only deepened. Driven by a longing for guidance and hope, she reached out to Pickett Guthrie, one of the founders of the RLS Foundation. It was here that Bill found a community that not only understood the impact of RLS but was committed to advancing the future of improved treatments through advocacy and research. Inspired by the example set forth by Pickett Guthrie and other devoted founders, Bill established the first Southern California RLS support group. She generously volunteered her wisdom, warmth and unwavering commitment to a community often searching for answers and connections. Her work has been carried on by a series of dedicated volunteers, and over time the Southern California support group has become the largest in the RLS Foundation's network. The group continues to serve the community today.

In 1997, Bill was elected to the RLS Foundation Board of Directors, where she played a vital role in advancing the Foundation's mission to increase education and awareness. We will always be deeply grateful to her for introducing renowned sleep physician Dr. Mark Buchfuhrer to the RLS Foundation in 1996. Dr. Buchfuhrer remains a source of expert care for RLS patients across the nation. He is actively involved with the Foundation today as a certified RLS Quality Care Center expert, a member of the Scientific and Medical Advisory Board, and medical editor of *NightWalkers*.

Beyond her work with the Foundation, Bill was a principal and district administrator and a professor at Whittier College. She was an innovator in the education field, writing and hosting two educational television shows: *Living in the West* and *Storytime*. Her background in teaching helped shape the compassionate, community-centered approach that remains at the heart of the Foundation.

Christine Wait (above) with her mother Elizabeth "Bill" Tunison (below).

We are reminded of Bill's remarkable life and enduring impact through her daughter, Christine. Christine carries forward her mother's dedication to the RLS community by making regular gifts to the RLS Foundation in her memory. This tribute is deeply personal for Christine, who like her mother, experienced RLS in her childhood. Christine's support honors her mother's legacy, ensuring that the mission to improve lives continues for future generations.

Bill Tunison's legacy is a cornerstone of the RLS Foundation's history, rooted in compassion and service. If you would like to honor someone special with a gift in their memory, you can do so by donating online at www.rls.org/donatetoday. Your support carries forward the legacy of those who made this community what it is today.

Personal Note from Dr. Mark Buchfuhrer, MD: RLS Foundation Scientific and Medical Advisory Board Member

I first met Bill in 1991 when she came to see me due to severe augmentation from a high dose of Sinemet (carbidopa/levodopa). At that time, I did not know much about RLS. However, she presented me with a plan to get off the Sinemet using Permax, which has since been withdrawn from the market due to other side effects. This worked very well and Bill was so relieved that she decided to start a support group. She asked me to volunteer as the medical advisor to the support

Continued on next page

group which I was not initially keen to do but her persuasive personality talked me into doing it. Once I started attending the meetings, I was shocked as to how many patients showed up and how many patients were suffering from restless legs. She also strongly encouraged me to work with the RLS Foundation and over time, because of her continued encouragement, I was able to develop one of the largest RLS practices and gain my current expertise with treating RLS. This has been one of the most rewarding parts of my professional and life career and I have to give my heartfelt thanks to Bill for gently but persistently persuading me to get involved in treating restless legs patients.

Lean on Me

In Bill Withers' 1972 global hit record, "Lean on Me," he sang about the essence of community. Withers wrote that we must support one another and that everyone at some point has a moment of need that others will rally to answer with their help:

> **"Lean on me when you're not strong, and I'll be your friend, I'll help you carry on.**
> **For it won't be long 'til I'm gonna need somebody to lean on."**

But when Withers released this song, a community for people with restless legs syndrome simply did not exist. They were scattered, living in the shadows. RLS was not taken seriously, people who suffered from it were ridiculed, and its symptoms were dismissed.

This began to change 20 years later when the RLS Foundation came into being. A community of doctors and nurses, patients and caregivers, researchers and clinicians, members and supporters was established – all of the people needed to unite and move toward improved understanding, diagnosis, treatment and, ultimately, a cure for RLS.

You are a vital part of this community through your membership in the RLS Foundation. Your annual support and your involvement keep you connected with the latest developments – through our online resources, our webinars, virtual and in-person events, and the pages of this magazine you are holding.

Moreover, your active membership makes it possible for us to engage an even wider community – through our tireless advocacy for RLS patients, our 15 Quality Care Centers, a growing physician network, and nationwide volunteer support network who bring to life our credo "You are not alone."

So when your 2026 Membership Card and early invitation to renew arrive in your mailbox this season, please reply at once to reaffirm your commitment to our remarkable membership community. Even if you have made a recent special gift to one of our fundraising appeals, your annual dues – just $40 – are crucial to keep the lifeblood of our organization flowing.

Bill Withers sang of a universal truth in the song's refrain:

> **"You just call on me, brother, when you need a hand. We all need somebody to lean on.**
> **I just might have a problem that you'll understand. We all need somebody to lean on."**

Thank you for being that "somebody" through your generous and loyal support of our membership community.

Renew online today at www.rls.org/renew.

BY J. ANDREW BERKOWSKI
MD

In the News: RLS Poster Abstracts from SLEEP 2025

This edition of In the News highlights some of the most relevant RLS poster abstracts from SLEEP 2025 – the annual meeting of the Associated Professional Sleep Societies. This national conference brings together physicians, researchers, professionals and organizations to share the latest in sleep and circadian science. This year's conference took place in June in Seattle.

5-Year Data from the National RLS Opioid Registry

WINKELMAN J, KILTY A, WIPPER B, ZACKON J, ADAMS S. 0904 FIVE-YEAR OUTCOMES FROM THE NATIONAL RLS OPIOID REGISTRY: EFFICACY, STABILITY, AND TOLERABILITY. *SLEEP*. 2025;48(SUPPLEMENT_1):A392-A393. DOI:10.1093/SLEEP/ZSAF090.0904.

THE BACKGROUND

Opioid medications are a longstanding treatment for moderate to severe RLS, conditionally recommended in the 2025 American Academy of Sleep Medicine's clinical practice guideline. The National RLS Opioid Registry has tracked 500 individuals with RLS who have been on opioid treatment for five years. This abstract looks at the stability of the opioid dose, effectiveness for treatment, and level of adverse effects in this group.

THE RESEARCH

At the five-year mark, 410 of 500 participants remained on opioids and continued in this study. Forty-nine percent remained on the same or lower opioid dose than at baseline for the study. Among those that had an increase in opioid dose, 62% increased by 25 MME (daily mg morphine equivalents) or less. The median International Restless Legs Scale (IRLS) score remained stable from baseline to five years at 13.3 to 13.1, respectively (low moderate range of severity on this 0–40 scale). The most common adverse effects reported were constipation (48.3%), drowsiness or fatigue (20.7%), and itching (17.6%). Twenty-one percent of subjects switched opioid medication types, and the vast majority of them converted to methadone or buprenorphine from other opioids. Most individuals switching to methadone and buprenorphine had an increase in their daily MME and accounted for the majority of subjects who had large increases in their MME. The biggest risk factors for a large opioid dose increase were a switch to buprenorphine, an IRLS score in the severe range or worse, a family history of substance abuse, elevated anxiety levels, and having been on opioids for less than a year at baseline of the study.

THE BOTTOM LINE

The National RLS Opioid Registry reveals that opioid therapy is largely stable after five years of treatment, with most individuals seeing either a reduction or no more than a modest increase in opioid treatment strength.

FURTHER QUESTIONS

Why were those who switched from one opioid to buprenorphine or methadone the ones most likely to see an increase in MME? Could this be accounted for by the fact that those with more severe RLS and dopaminergic augmentation need long-acting opioids more frequently and thus higher treatment doses? Or is it simply a lack of consistency of the MME calculation? Methadone historically has been difficult for calculation of equivalencies due to relative increased strength at higher doses. Buprenorphine is so difficult to predict that the Centers for Disease Control and Prevention removed the MME equivalencies for buprenorphine from its data tables.

For those who discontinued opioids or had large dose increases, how often was this due to opioid use disorder (i.e., addiction)? For those who were off dopamine agonists (i.e., no longer experiencing active augmentation) and on opioids for more than a year, to what degree did they increase the dose of their opioid treatment?

How much more research is needed to convince the medical field at large that opioids are a necessary part of RLS treatment and the outcomes are generally very good?

Can Peroneal Nerve Stimulation Lead to Real-World Improvement in RLS Symptoms?

BUCHFUHRER M, SINGH H, ROY A, ET AL. 0911 REAL-WORLD OUTCOMES OF TONIC MOTOR ACTIVATION (TOMAC) FOR REFRACTORY RESTLESS LEGS SYNDROME (RLS). *SLEEP*. 2025;48(SUPPLEMENT_1):A396-A396. DOI:10.1093/SLEEP/ZSAF090.0911.

THE BACKGROUND

Peroneal nerve stimulation is the only nonmedication treatment for RLS recommended in the American Academy of Sleep Medicine's 2025 clinical practice guideline. The nerve stimulator, worn as a cuff just below both knees, induces tonic motor activation (TOMAC) of the leg muscles, essentially mimicking the effects of walking to relieve symptoms of RLS. Shorter randomized, controlled trials have demonstrated the safety and efficacy of TOMAC in the treatment of RLS, and this project reports on real-world use of the device.

THE RESEARCH

The study followed patients prospectively for 90 days who were prescribed the TOMAC device by a clinician. By March 18, 2025 (after the date of abstract submission above), 120 subjects were past 90 days since obtaining the device and were analyzed. Their mean IRLS score improved by 7.3, and 59% were much improved or very much improved according to the Clinical Global Impressions (CGI) scale. There were no serious adverse effects, and only nine individuals had adverse effects which mostly involved problems at the area where the TOMAC cuffs were applied. Participants in this study were 2.7 times more likely to decrease their RLS medication dose than increase it, and the mean decrease in dosage for the three common treatment groups was 0.36 mg pramipexole equivalents, 7.2 MME of opioids, and 218 mg gabapentin equivalents. Even with the medication dose decreases, there was improvement to the IRLS score, the CGI scale and the Medical Outcomes Study-Sleep Scale II (MOS-II).

THE BOTTOM LINE

In a real-world group of RLS patients treated with TOMAC, the device was well tolerated and was associated with RLS symptom improvement and medication dose reduction.

FURTHER QUESTIONS

Because TOMAC is used as an additional treatment (adjunct) to medication in most of these cases, what proportion of the improvement is due to the device versus adjustment to other areas of the treatment process (e.g., IV iron infusion therapy or increases in other medication dosages)? Would the proportion of the effect due to TOMAC be maintained after, say, one year compared to 90 days out? How would a group of similar patients see a reduction in their symptoms or medication dose if not treated with TOMAC simultaneously? (This may require a randomized trial to answer.)

How Common is RLS During Pregnancy?

MANCONI M, ESTEVENS AM, HACKETHAL S, ET AL. 0909 RESTLESS LEGS SYNDROME DURING PREGNANCY AND PUERPERIUM: DATA FROM THE LIFE-ON COHORT. *SLEEP*. 2025;48(SUPPLEMENT_1):A395-A395. DOI:10.1093/SLEEP/ZSAF090.0909.

THE BACKGROUND

Previous research has shown that a significant number of women develop RLS during pregnancy. This study gathers details on factors associated with RLS during pregnancy.

THE RESEARCH

The study followed 439 women from 10–15 weeks' gestation through 12 months after delivery. Those who met criteria based on the International RLS Study Group criteria were tracked using the IRLS Scale and had an overnight sleep study done. About 26% of the women met criteria for RLS though only about half of this group previously has RLS, outside of the current pregnancy. Depression, family members with RLS, and previous symptoms of RLS were the three largest risk factors for developing RLS during this study. About 20% of the subjects had an IRLS score > 20 (severe or very severe RLS) and about 26% of women had a periodic limb movement index (PLMI) on their sleep study of > 15/hr. There was a higher proportion of moderate or severe RLS during the third trimester of pregnancy than the other two periods.

THE BOTTOM LINE

This study reinforces the fact that RLS occurs frequently during pregnancy, even in those who have not had RLS in the past.

FURTHER QUESTIONS

Was there a correlation with iron levels (i.e., ferritin and percent transferrin saturation/TSAT) and likelihood to develop RLS during pregnancy? What percentage of pregnant women with RLS will have RLS again in a subsequent pregnancy? Should obstetricians routinely screen for RLS, along with other pregnancy-related conditions?

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

Meet the RLS Foundation's Newest Team Member!

Elyse Hopfe is a recent graduate of the University of Texas at Austin (UT), where she earned her degree from the Stan Richards School of Advertising & Public Relations. During her academic years, Elyse developed a strong foundation in communication and outreach, with extensive experience facilitating both group and individual peer support meetings.

Elyse joined the RLS Foundation as program manager in May. She will oversee several key initiatives, including the Foundation's volunteer support network, social media, webinar series and other outreach programs supporting people affected by RLS. Her passion for advocacy and support will be instrumental in expanding the Foundation's reach and strengthening its connection to the RLS community.

Q. How were you introduced to the RLS Foundation, and what sparked your interest in pursuing a position here?

A. I was introduced to the RLS Foundation through a job listing forwarded to me by a UT professor. I applied as quickly as I could when I found out that I could make a difference for RLS patients using health communication. I know from experience the difficulty of living with a chronic condition, and I know that feeling less alone is a tether of support. Once I met and shared stories with the kind and passionate RLS Foundation staff, I knew that the position was meant for me.

Q. Based on what you've learned about RLS during your time here, why do you feel it is important to increase awareness?

A. I am still discovering more and more about RLS every day, but I know that increasing awareness is essential because of how much life-changing progress is yet to be made. By hearing the stories of people with RLS and watching doctors recount their extensive research and experience in treating RLS patients, I learned the absolute necessity of making things better for those with RLS, which starts with making the rest of the world listen. The RLS Foundation has such an impactful history surrounding its growing community, and increasing awareness about the disease will lead to more discoveries and discussions for everyone who becomes involved.

Q. What influenced your passion for mental health and wellness advocacy? What practices or philosophies do you want to integrate into the support meetings hosted by the Foundation?

A. My passion derives from my volunteer experience leading both group and individual support sessions. Having a therapist can be amazing, but there is a different, beautiful and powerful connection to be gained from fellow community members who have shared your experiences in a nonclinical environment. Talking circles are an ancient practice from Indigenous cultures, including those in Canada and US, and I want the restorative effects of support groups to be recognized as a gift from that learned practice. We work to ensure support spaces are nonhierarchical, safe and inclusive.

Q. What aspects of the RLS Foundation's mission resonate most with you?

A. I really resonate with the action-oriented idea behind our mission. The Foundation is not passively existing to host the connections within the RLS community, but it is alive and working to make change for people who have the disease through advocacy, research and overall education and awareness. I want to be the change, not just someone witnessing it.

Q. What would you like volunteers and community members to know about you as you get started?

A. While I do not experience RLS myself, I am devoted to amplifying the voices of the people who do. I will surely make mistakes as I acclimate to my role, but I'm committed to this challenging work and to providing the best experience for all volunteers and community members. Please reach out to me at elyse@rls.org if you want resources or if you feel inclined to get to know me a bit better. I am very grateful to be part of this very personal mission.

Q. Outside of work, how do you like to spend your time?

A. I absolutely love the Texas heat, and I very often swim or walk outdoors. I am an avid reader, thrifter and video editor when I'm not spending time with my friends. My nightly routine often includes cooking something nostalgic with my television playing in the living room. Recently, I've been teaching myself how to play bass guitar, but I've never played for an audience!

Q. Do you have a favorite quote or motto that inspires your work?

A. A motto that I have internalized from yoga class is "kind mind, kind body, kind spirit." Whenever I feel lost, or purposeless, or not good enough, I remind myself that acting through kindness will result in work that is honest and true.

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 physician with specific questions related to the ongoing management of your RLS. It is important to talk to your healthcare provider to investigate concerns such as safety, efficacy and cost before making any changes to your treatment regimen.

Q. What are the differences between tramadol and buprenorphine?

A. Buprenorphine is a true opioid, meaning it has a more powerful effect on the opioid system compared to tramadol. Buprenorphine also has unique properties compared to standard opioids. Standard opioids fully stimulate the opioid receptor, while buprenorphine only partially stimulates the reaction at the opioid receptor. For this reason, it is less likely than other opioids to cause breathing problems, constipation, chemical dependence and other adverse effects.

Tramadol has more of the norepinephrine and serotonin chemical effects, which are good for certain pain conditions and mood but unfavorable for RLS. Tramadol is not safer than standard opioids despite a lower level of regulation by the Drug Enforcement Agency (Schedule IV). Some believe it should be Schedule II like most opioids.* Buprenorphine is Schedule III.

Andy J. Berkowski, MD

**Medical editor's note: Drugs, substances and certain chemicals used to make drugs are classified into five schedules. The schedule depends on the drug's acceptable medical use and its abuse or dependency potential. Schedule I drugs have a high potential for abuse and the potential to create severe psychological or physical dependence. Schedule V drugs represent the least potential for abuse. Schedule II drugs cannot contain refills and need a new prescription every month.*

Q. The Food and Drug Administration recently approved Journavx (suzetrigine), a non-opioid medication treatment for moderate to severe acute pain. Is there any interest in this drug to manage RLS?

A. Suzetrigine works by selectively blocking the sodium channel, which is primarily expressed in peripheral pain-sensing neurons, effectively inhibiting the transmission of pain signals to the spinal cord and brain. This mechanism provides pain relief without affecting the central nervous system like opioids do. It targets a specific sodium channel on peripheral nerves to prevent pain signals from reaching the brain.

Our theory for RLS symptoms is that the discomfort sensations and urge to move are generated by areas in the brain and sent to the affected areas of the body. Therefore, suzetrigine, which blocks transmission of pain sensations from the peripheral nerves to the brain, likely will not be effective in relieving RLS symptoms since it is blocking nerve impulses in the opposite direction of what should provide relief.

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

Q. What blood pressure medications worsen RLS?

A. Medicines that worsen RLS are usually central acting-antihistamines, possibly anticholinergic medicines, dopamine-blocking medications, and to a lesser extent serotonin reuptake inhibitors (SSRIs), although SSRI medicines typically only worsen the leg kicking component of RLS rather than the urge to move. Some very old hypertension medicines such as methyldopa and reserpine could potentially worsen RLS by blocking dopamine, but none of the currently used antihypertensive medicines fall into any of those categories, so they would not be expected to worsen RLS.

William Ondo, MD

Q. When is it appropriate for a provider to prescribe a fentanyl patch for RLS management?

A. There are very few situations in which fentanyl would be appropriate to treat RLS. Most RLS patients have symptoms limited to the evening or starting in the early morning through the evening and sleep time. Fentanyl lasts for three days, and therefore we may be giving medication for a significant amount of time when the patient does not have symptoms.

It is much better to target the RLS symptoms with treatment that coincides with the duration of the symptoms, which is why drugs like methadone and buprenorphine, which have a fairly long durations of action lasting between eight and 12 hours or longer, are preferred.

It is possible that fentanyl may work well in a patient who has symptoms around-the-clock and for whom giving a fentanyl patch every three days may be more convenient. However, the concern is that fentanyl is such a potent drug that if there were an issue with mis-dosing, serious side effects would be more likely to occur.

The only time that I have patients on fentanyl is when they are getting the drug for another pain condition, and the fentanyl can play a dual role treating the RLS and the pain. However, I am not usually the one prescribing it but just helping the pain management prescribing doctor in adjusting the dose for both pain and RLS.

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

Find Support

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

Local RLS Support Groups

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

CALIFORNIA

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

MINNESOTA

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

NEW HAMPSHIRE

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

NORTH CAROLINA

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

OHIO

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

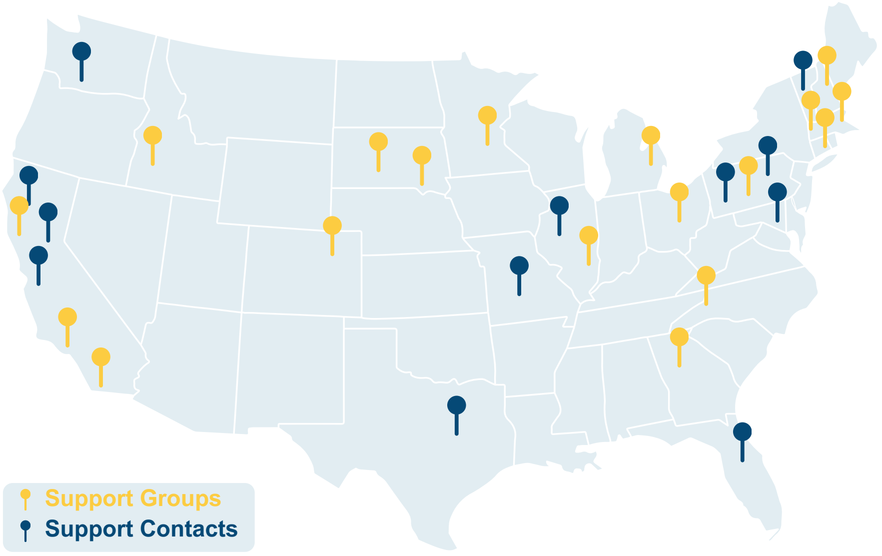
PENNSYLVANIA

Pennsylvania RLS Support Group
Kevin Knabe
pennsylvania@rlsfvolunteer.org
(215) 530-4682

SOUTH DAKOTA

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

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



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

RLSF Support Contacts

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

CALIFORNIA

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

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

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

FLORIDA

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

ILLINOIS

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

MAINE

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

MARYLAND

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

MISSOURI

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

NEW HAMPSHIRE

Sheila C. Connolly
sheilac_contact@rlsfvolunteer.org
(508) 783-5747

PENNSYLVANIA

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

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

TEXAS

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

WASHINGTON

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

CANADA

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

RLSF Virtual Support Groups

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

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

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

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

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

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

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

RLSF VIRTUAL SUPPORT GROUP LEADERS:

Laura Hoffman
Laura_VSG@rlsfvolunteer.org

Bill Wendt*
Bill_VSG@rlsfvolunteer.org

Judy Amateis
Judy_VSG@rlsfvolunteer.org

*Member of RLS Foundation Board of Directors

RLS Online Discussion Board

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

Ann Battenfield
ann.rlsfmod@rlsfvolunteer.org

Beth Fischer
beth_contact@rlsfvolunteer.org

Betty Rankin
bett.rlsfmod@rlsfvolunteer.org

Stephen Smith
stephen.rlsfmod@rlsfvolunteer.org

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

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. Therapies and results described in Bedtime Stories reflect the anecdotal 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 PURPOSEFUL PROCRASTINATION

I find when my RLS symptoms become demanding, some attention becomes necessary. Lots of typical exercise is difficult. What helps me in the kitchen after preparing my food is to leave the dishes for later. I wash my dishes by hand for later busy work. I do not use the dishwasher. With my hands in the warm water and the easy movement of my body as I'm gently rubbing, rinsing, drying and putting away, it gives me much relief.

Pam

ANTIDEPRESSANTS AND RLS: MY REVELATION

My story is for anyone who is currently being prescribed the antidepressant Aropax (paroxetine, also known as the brand name Paxil). For at least 20 years, I had been prescribed 20 mg a day. I regularly suffered from RLS and attributed it to being hereditary. However, since stopping the tablet around six months ago, I no longer suffer from RLS. Unfortunately, one major side effect of Aropax is twitching. So, for anyone out there suffering the same issue, Aropax may be contributing.

Perry

Medical Editor's Note: Antidepressants such as selective serotonin reuptake inhibitors (SSRIs) like paroxetine or selective serotonin reuptake inhibitors (SNRIs) like Celexa or Effexor very commonly worsen RLS.

THEN VS NOW: REFLECTING ON GROWTH

I suffer from restless legs every day and have since I was a little girl. "Growing pains," "too much exercise," or "too little exercise" were all reasons given to me to explain why I felt the way I did. That creepy-crawly, can't-keep-your-legs-still feeling has been a part of my life for over 50 years. When I was a child, RLS was not a condition that was given as a diagnosis. It was not part of a doctor's vocabulary. It wasn't until much later, almost 30 years later, that I finally found relief. Trial and error with various medications has given me my life back. Almost at age 70, I can now live with RLS. Thank you for all the awareness, effort, and research being conducted. I am forever grateful!

Luanne

RECLAIMING LIFE AFTER AUGMENTATION

I was first prescribed ropinirole in 2007. It was miraculous. I could sleep through the night without being woken up several times with unbearable RLS symptoms. After about six years, it stopped being so effective. I started experiencing daytime symptoms, but I was still sleeping well. I realize now that I was experiencing augmentation but had been in denial.

By 2016, my RLS was so severe in the daytime that I couldn't sit through a car journey or watch a film. The RLS spread to my face, back and hands. Luckily, I joined an online forum. I learned about augmentation. When titrating off ropinirole, the withdrawal nearly killed me. My physician here in the UK had minimal knowledge and refused to prescribe anything to help me get off of ropinirole. I contacted my multiple sclerosis neurologist and while she admitted that she knew little about RLS, she prescribed OxyContin (oxycodone) and pregabalin.

I was on this combination for five years, but my RLS was still very severe. According to the International RLS Rating Scale, my symptoms were 38/40. I researched and read every article and book on RLS and heard about buprenorphine from another forum member who had been prescribed buprenorphine. It stopped all her RLS symptoms overnight. I pushed my doctors to allow me to try buprenorphine, which I was prescribed in 2021. Overnight, my RLS symptoms were nearly eliminated. It was absolutely miraculous. Several other patients here in the UK have had similar results. The initial side effects of nausea, anxiety, sweating and constipation do settle or can be resolved. If anyone has refractory RLS, I suggest you ask your doctor to consider prescribing low-dose buprenorphine. It has made my life 'livable.'

Estelle

Publications

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

Qty	Patient Handouts	Qty	Patient Handouts	Qty	Patient Handouts
	Augmentation: Diagnosis & Treatment		Hospitalization Checklist		RLS Research Opportunities
	Can an Active Lifestyle Prevent or Improve RLS Symptoms?		Iron and RLS		Surgery and RLS
	Complementary/Alternative Medicine and RLS		Medication Withdrawal after Augmentation		Symptom Diary for RLS
	Coping Methods		Medications and RLS: Patient Guide		Triggers for RLS
	Depression and RLS		Pain and RLS		Recognizing Possible Mimics of RLS
	Drug Holidays and RLS		Periodic Limb Movements During Sleep		Your First Doctor Visit for RLS
	Guide to Living with RLS		Research Grant Program		
	Healthcare and Your Child with RLS		RLS and Aging		

Qty	Patient Brochures	Qty	Patient Brochures
	Causes, Diagnosis and Treatment for the RLS Patient		RLS Guide for Children
	Giving Avenues		RLS Guide for Teens
Qty	**Healthcare Provider Brochures**	**Qty**	**Healthcare Provider Brochures**
	Pregnancy and RLS: A Guide for Healthcare Providers		RLS and PLMD in Children and Adolescents
	2021 RLS Medical Bulletin: RLS Diagnosis and Treatment		

MEMBERSHIP

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

DONATION

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

☐ I would like to make a recurring monthly gift by credit card of:

$_________ Start date: _________

DONATION APPLIED TO

☐ Research

☐ Where it is needed most

PAYMENT METHOD

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

☐ Please charge $__________ to my ☐ American Express ☐ Discover ☐ MasterCard ☐ VISA

Card number____ Expiration date ____________

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

Name ______________________________ Address ______________________________________

City _________________________________ State ______________ Zip ___________________

Email address _____________________________ Phone number ________________________

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Discussion Board: bb.rls.org

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linked.com/restless-legs-syndrome-foundation
@RLSFoundation_Est1992

2025 HILL DAY

MONDAY, OCTOBER 6

Join the RLS Foundation for our annual advocacy event in Washington, DC! Together, we will advocate for key issues by educating legislators on the impact and severity of RLS.

YOUR STORY MATTERS

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