NIGHTWALKERS

In search of a good night's sleep

WINTER 2025

RLS FOUNDATION CERTIFIES NEW QUALITY CARE CENTER

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RESTLESS LEGS SYNDROME FOUNDATION

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RESTLESS LEGS SYNDROME FOUNDATION

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

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KARLA M. DZIENKOWSKI
RN, BSN
Executive Director

Expanding our Reach and Impact

The new year promises growth, transformation and hope. Thanks to the support of members like you, the RLS Foundation is expanding its reach and impact on the community it serves.

We have launched the 2025 RLS Research Grant Program and plan to fund up to three proposals in this cycle. A collaborative partnership with the American Academy of Sleep Medicine Foundation supports two of these awards.

Our new podcast will roll out and the Foundation staff is planning a summit for later this year.

Our advocacy outreach on Capitol Hill will continue to raise awareness of the needs of our community and affect policy change.

As we begin this season of growth and new beginnings, we invite you to stay connected to the Foundation. Your voice, dreams and ideas are an essential part of the Foundation's story.

Thank you for your membership, unwavering support and belief in the power of new beginnings. One day at a time, we will support and transform lives in our RLS community. Working together, all things are possible!

Gratefully,

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 November 1, 2024 through February 28, 2025.

In Honor of:

my amazing sister
RLS husbands
Ginger Blackmon
Dr. Mark Buchfuhrer
Gail S. Buckley
Doug Counsell
Karla Dzienkowski
Christopher J. Earley
Robert Fairly
Dr. Brian Koo
Nancy Lauby
Marty Leonard
Wendy Lindberg
Jonathan Moore
Chris Phillips
Dan Picchietti
Bruce Edward Randall
Alice and Rick Riviere
Dr. John Winkelman

In memory of:

Arthur Alberts
Nancy Crnkovich Ayad
Steve Crnkovich
Gladys Biron
Dr. Dolores Bower
Peter Brooks
Caroline Chamales
Virginia Eisenberger
Barb Farrell
Gordon J. Freeman
James B. Fullerton
Grace L. Healey
Helga J. Heichert
Erik Hinzpeter
Max E. Jester
Dolores Elaine Kemp
Jane Marashian
Joseph R. Mulvey
Helen C. Olson
Jane O. Poole
Ellen Samuels
Joel Schuler
Rosewitha Seltz
Elizabeth L. Tunison
Amy Vrins
Fran Williams
Larry and Frances Williams

Welcoming Your New Board Chair

The RLS Foundation is pleased to announce that Jeffrey Durmer, MD, PhD, has been elected chair of the Foundation's Board of Directors. Dr. Durmer joined the Board in 2019 after serving nearly 10 years on the RLS Foundation Scientific and Medical Advisory Board. Dr. Durmer is a systems neuroscientist, neurologist and sleep medicine physician with expertise in technology-enabled sleep-health delivery systems. He is the chief medical officer of Absolute Rest, where he oversees the development of innovative technology-enabled precision medical and behavioral programs designed to enhance human health, longevity and performance. He is also the telemedicine principal investigator for the Sleep SMART clinical trial, the largest sleep apnea and stroke study funded by the National Institutes of Health (NIH). His past research spans from uncovering the neuroanatomical and neurophysiological substrates of subcortical visual systems involved in blind sight, to developing the first standardized clinical interview tool for pediatric restless legs syndrome.

Q. **Thank you for giving us the opportunity to introduce you as the Board chair of the RLS Foundation! How did you become involved with the Foundation?**

A. I first became involved with the RLS Foundation as a researcher at Emory University. At the time, I was directing the Emory Pediatric Center and the adult sleep laboratory, working to identify various RLS phenotypes with Emory's Clinical Research in Neurology (CRIN) Program and collaborating with the Decode Project in Iceland.

I was working with Dr. David Rye and Dr. Don Bliwise, who introduced me to the RLS Foundation's Research Grant Program, which has funded over $2 million in research to date. I thought it could be a great opportunity to fund research characterizing the phenotypes of children with RLS and further understand the relationship between RLS and ADHD. I submitted an application and became an RLS Foundation Research Grant recipient in 2005. During that period, I had a research poster featured at the annual American Academy of Sleep Medicine meeting, where I met Karla Dzienkowski, who is now the RLS Foundation executive director. Karla's interest in pediatric RLS research led to multiple discussions, and she persuaded me to join the Foundation's Scientific Medical Advisory Board (SMAB). I worked on the SMAB for eight years, helping support the Foundation's work in pediatrics.

Q. **In October 2024, you became the new Board chair. What are some of your responsibilities in this role?**

A. The RLS Foundation is a dynamic and fluid organization, responsive to the needs of people with RLS. We are an advocacy organization, first and foremost, which includes funding pilot projects to advance research into multiple aspects of RLS, providing education and support programs for patients and families, representing the interests of patients, researchers and clinicians, and helping governmental agencies from the NIH to Congress understand the importance of addressing this very common condition and its associated medical comorbidities. As chair, my role is to create clarity and ensure our actions are reflective of our values and mission. My goals for the Foundation are to help it embrace technological and organizational innovation to grow our audiences, refine our financial efficiencies, and improve connectivity between RLS researchers, clinicians, patients and their families.

As someone with extensive experience managing businesses, clinical laboratories and healthcare operations, I look forward to guiding the Board toward a sustainable structure that supports continued growth throughout and after my term.

Q. **Do you believe that your previous work on the SMAB complemented your role on the Board?**

A. Absolutely. In addition to understanding the work of the Board of Directors, I understand the pressures the researchers and clinicians on our SMAB face – both in their practice and on behalf of the organization. I believe there needs to be a transparent and dynamic relationship between the SMAB and Board of Directors to foster collaboration and sustained proactive organizational growth in the future.

I also want to identify how the Board can assist Karla and the Foundation in their work with the SMAB. The more proactive we become, the less reactive we will need to be within the Foundation when issues arise.

Q. **Your professional experience is vast, including work as a neurologist, a systems neuroscientist and a sleep medicine physician. How has each position shaped your clinical expertise?**

A. Neurologists study the brain, the central nervous system, the peripheral nervous system and the relationship of the nervous system to other organ systems and disease states. There are many areas within the broader scope of neurology – stroke, neuroimmunology, cognitive, neuromuscular, movement disorders, etc.

To me, an important aspect of neurology is understanding how to approach the diagnosis and treatment of neurological disorders with specificity (i.e., endotyping/phenotyping) and sensitivity to the individual (i.e., personalized medicine). It's a balance between determining a clinical diagnosis (e.g., RLS) while considering the environment, behaviors, psychology, social stressors and particular therapeutic needs of the individual.

A systems neuroscientist looks at the structures and function of the brain. Today, this type of research has evolved from anatomical and electrophysiological research to cellular and genetic/genomic relationships between brain and body systems underlying epigenetic and disease risk factors. Typically, system neuroscientists think in terms of structure and function and how to associate activities between neurons.

Finally, a sleep medicine physician is a multidisciplinary clinician who applies the neuroscience of sleep and circadian rhythms to different developmental issues and disease-related presentations to find evidence-based ways to improve sleep and wake function, prevent associated diseases, and support the well-being of all individuals through the power of healthy sleep.

As an MD-PhD, I chose sleep medicine because I wanted to translate basic and clinical research findings into scientifically based practices to improve health, performance and well-being in children, adolescents and adults. Over the years, I have focused on how to use healthcare technology to accelerate the accessibility and delivery of sleep healthcare to the millions of underserved people in the US.

Q. **What led to a specific interest in RLS?**

A. I was recruited from the University of Pennsylvania to the Department of Neurology at Emory University. My previous work focused on the consequences of sleep deprivation, the individual variability of the impact of sleep disorders on health and function, and the neuroanatomical structures involved in normal and pathological sleep.

When I got to Emory, I found that the team was more focused on movement disorders, so I made a decision to learn more about the basic science and the animal modeling associated with RLS. I found a clinical "missing link" within pediatric RLS. While there were publications and some research being conducted, there was no standardized way to diagnose and treat RLS in pediatric populations. I decided to switch my focus from cognition and the neurocognitive consequences of sleep deprivation and performance to RLS in children.

Q. **You have extensive experience in technology-driven fields. How has technology shifted research and clinical practice within the sleep space?**

A. When my career began to veer out of the academic world, I started a technology-based sleep company called Fusion Sleep and utilized research tools, applying them in a clinical context. This mimicked the phenotype-genotype research work that I was engaged in at Emory. Instead of genotyping, we used technology to improve phenotyping, which subsequently improved the specificity of therapies for specific populations (i.e., truck drivers, pilots and people in other safety-sensitive occupations).

Fusion Sleep grew into a second company called Fusion Health, which later evolved into company called Nox Health, headquartered in Atlanta. Nox Health was a combination of Fusion Health and Nox Medical, an Icelandic sleep health-tech firm that we developed to create the first home sleep testing device for children.

I've used this experience to help other companies expand within the sleep space and develop wearable technologies. Most recently, I helped start a company called Absolute Rest, which uses clinical research tools and technology to evaluate sleep from multiple scientific angles, including circadian rhythm phenotyping to optimize performance, longevity and quality of life in high level athletes, individuals, businesses and health-related organizations.

Q. **What is your advice for those struggling with RLS?**

A. Know that you are not alone. Your symptoms are shared by millions of other people. By joining the RLS Foundation, you will find a community of people going through similar experiences who can provide hope.

Membership to the Foundation not only connects you with a support network, but also keeps you informed on the latest RLS research and news. As we know, being part of a community promotes mental and physical health, and when that community is focused not only on connectivity but also creating solutions to a major health issue, it serves you, your family and the rest of humankind.

Celebrating Over a Decade of Dedication

As a new year begins, the RLS Foundation honors two individuals whose decade-long commitment has shaped its success. Karla Dzienkowski, RN, BSN, became executive director of the Foundation in 2014 after serving on the Board of Directors for six years. Zibby Crawford joined the Foundation alongside Karla as the marketing and membership coordinator.

More than 10 years later, their steadfast commitment continues to inspire and strengthen the organization's mission. Together, they have played a crucial role in shaping the Foundation's growth and ensuring its continued success in providing vital resources, advocacy and research funding. Their dedication has made a lasting difference in the lives of countless patients, and their legacy of service is a testament to their passion and dedication. Congratulations, Karla and Zibby!

A Grateful Farewell: Honoring Our Board Members' Service

The RLS Foundation would like to extend its gratitude to Shalini Paruthi, MD; Jacci Bainbridge, PharmD; Laura Hoffman and Paul Rochester for their leadership during their time on the Board of Directors. Though their formal role as Board members has come to an end, their contributions to the organization will leave a lasting legacy.

Dr. Paruthi served as a Board member since 2018, before becoming Board chair from 2022 to 2024. Her vibrant energy and passion have been a source of inspiration, infusing the organization with renewed purpose. She expertly hosted Foundation summits, presented her knowledge as an RLS provider in webinars, advocated for patients in congressional meetings on Capitol Hill, and chaired countless meetings, all to serve the RLS community. Thank you, Dr. Paruthi, for your leadership!

Dr. Bainbridge previously served as Board chair in addition to eight years as a Board member. Her medical experience has offered a crucial perspective, allowing the Board to make informed decisions that have brought positive change. Beyond her clinical knowledge, her bright personality and sense of humor brought warmth to every meeting. Thank you, Dr. Bainbridge, for your knowledge and expertise!

Laura Hoffman served on the Board for three years and remains a dedicated virtual support group volunteer. Her compassion creates a safe space in support meetings where members of the RLS community build connections. In her role on the Governance and Nomination Committee, she helped lead significant growth of the Board, which welcomed five new members in 2024. Thank you, Laura, for your service as a Board member and continued support!

Paul Rochester's vast business experience enabled him to expertly guide the organization through discussions of future development, strategic planning and financial growth during his eight-year tenure on the Board. His wisdom remains integral to the continued success of the Foundation. Thank you, Paul, for your unwavering dedication!

Rhythms of Restlessness

These poems, contributed by members of our community, reflect the personal journeys and resilience of those living with RLS. If you would like to share your own story, please email info@rls.org.

RLS

Restless and thrashing
all over our bed,
compelled to move,
to turn, to rock,
to wiggle and jiggle
my arms and legs.

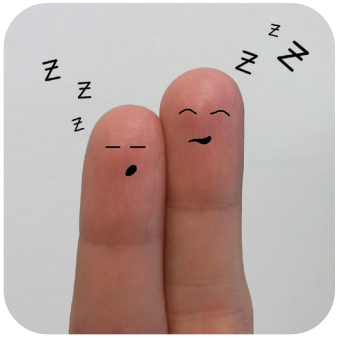
I stretch and flex,
then roll and romp,
a horizontal fast dance
through half the night.
My other half sleeps,
snoring and slurping,
wheezing and waltzing,
through dreams and spells
of abated breath, then
gasps to regain some air.

Then the pain starts,
the aching and burning,
incessant itching, and
creeping, crawling skin.
Sweating, then freezing,
off go the covers.
Now they're back over.
My head, my neck,
my back, both thighs,
all fingers and toes
ache, hurt and burn.

Now hunger hits,
my thirst mounts.
In a swift escape
I'm up and roaming,
snarfing snacks,
guzzling a gallon,
popping pills,
massaging my legs.

My best work I do
between midnight and two,
'til the pills take hold
and I finally fold.
It's a nightly ritual,
sometimes even spiritual.
Then I clear my head
and go back to bed,
like a quiet little mouse,
not to bother my spouse
in his solitary slumber.

Ah, I fondly remember
when we slept together
in peaceful surrender.



Sandra Kanowitz, RLS Foundation member
A humorous but real account of insomnia and restless legs syndrome

Restless Legs Syndrome

Why do you torment me?
What I wouldn't give to
have you finally set me free.

Unwelcome, uninvited,
Into legs and arms you creep.
You take away my sanity.
You rob me of my sleep.

You're the devil in disguise
In the form of a worm.
You creep and crawl inside me,
until I jump and squirm.

If I had a magic wand
And power to cast a spell,
I'd wave it high, say goodbye
And send you back to hell.

Ron Tranmer, RLS Foundation member

Waves of RLS

The urge to move – it comes and goes.
The pains and aches, it forever flows.

But in the night, promise does bloom,
A little pill offering hope, not gloom.
A shake of a bottle, a pill provides,
Helping all sensations to subside.

Back to bed, but not without worry.
Of waking back up from pain and in fury.

What it once was, what it may never be,
Is peaceful slumber, for my partner and me.

Anonymous, RLS Foundation member

Flight RLS

Here I sit upon a plane.
My restless legs drive me insane.
The intercom beeps and the captain announces,
"Stay in your seats through these turbulent bounces."

To stay in my seat will bring me much grief.
These legs want to stretch. They plead for relief.
The guy on my left gave me a weird glance,
And the man on my right thinks there's ants in my pants.

I stare at the seatbelt light overhead.
I've learned to feel trapped when it's glowing red.
My seatbelt now loosened, I slump in my seat,
Rub my poor legs and wiggle my feet.

I look at a book, but just can't relax.
The stewardess walks by passing out snacks.
The intercom beeps and I hear this sweet sound:
"We've found some calm air, you can now move around."

I say "please excuse me" and spring from my seat,
But the guy is asleep so I step on his feet.
I'm out in the aisle, moving and bouncing
When the captain comes on and I hear him announcing,

"Please return to your seats, we're preparing to land."
I take one last stretch and obey his command.
I smile upon landing, "goodbye restless strains."
But then I remember... I'm just changing planes!

Ron Tranmer, RLS Foundation member

5 Ways to Get Involved in 2025

If "get more involved in my community" made it onto your list of New Year's resolutions – we can help you achieve it! There are many opportunities at the RLS Foundation to contribute – big or small. Our amazing network of volunteers help the Foundation's efforts to provide dedicated services and resources to patients and healthcare professionals, and to fund critical research toward a cure. Here are five ways you can get involved.

1. Become an RLS Advocate

Advocacy involves raising awareness, educating others and working to influence policy or public opinion.

How to get involved:

- Participate in Advocacy Action Alerts by emailing your local, state and federal representatives in support of our legislative priorities. Action alerts are found in our monthly newsletter eFriends, email blasts and on our blog (rlsfoundation.blogspot.com).
- Join other RLS advocates on Capitol Hill in the fall for our annual Hill Day event in Washington, DC.
- Use your social platform to increase awareness of RLS and encourage others to take action.

2. Contribute as a Guest Author

If you have a passion for writing or poetry, contributing as a guest author is a fantastic way to get involved. Your story can be shared in Bedtime Stories (see page 22) or on our blog. You are not alone, and our community benefits from shared experiences.

How to get involved:

- Email info@rls.org with your story or to learn more about editorial guidelines.

3. Get Connected on Social Media

Social media is an easy way to connect with the RLS community! By following us on platforms like Facebook, X (formerly Twitter), Instagram and LinkedIn, you can stay up to date on our latest initiatives, events and calls to action.

How to get involved:

- Follow us on all major social media platforms.
- Like, share and comment on our posts to spread the word.
- Use hashtags we create to join the broader conversation.

4. Become A Volunteer

If you're seeking a way to actively serve the RLS community, we encourage you to consider the RLS Foundation Volunteer Program. This program advances the Foundation's goals, with opportunities to engage in our support and educational programs.

How to get involved:

In 2025, we are looking for volunteers who are proactive, dedicated and compassionate for the following positions:

- Become a local support group leader by starting a local RLS Foundation-affiliated support group in your community. Support group leaders organize virtual, in-person or hybrid meetings.
- Become a virtual support group leader and facilitate monthly meetings organized by the Foundation on Zoom!
- To learn more about becoming an RLS Foundation volunteer, visit www.rls.org/get-support. If you have additional questions, contact info@rls.org.

5. Become A Foundation Board Member

The RLS Foundation is fortunate to benefit directly from the knowledge and expertise of members of our Board of Directors – many of whom have RLS themselves or are directly connected through their professional backgrounds.

The Board of Directors play a crucial role in developing and overseeing the organization's goals, monitoring fiscal status and planning for the Foundation's future. The Board guides the organization by making strategic decisions, practicing responsible fiscal oversight and providing organizational management that builds a vision leading to sustainable, long-term growth.

How to get involved:

- If you have experience in nonprofit governance, fundraising, business, patient advocacy, law or education, and would like to learn more about becoming a Board member, reach out to the chair of the Foundation's Governance and Nominating Committee Jim Flaniken, at jsflan@comcast.net.

Planning Ahead: 5 Ideas for 2025

If you've closed the book on your 2024 taxes, it's not too early to turn the page and put your tax plans and strategies in place for 2025. So, here are **five ideas for 2025** that could benefit your personal tax situation or long-term financial plans – and the RLS Foundation, too!

1. Find out if you are "qualified" – that is, eligible to make a qualified charitable donation, or QCD. If you are at least age 70 ½ at the time you intend to donate this year, you can make a tax-free contribution of up to $100,000 from your IRA or an inherited IRA directly to qualified charitable organizations. (Yes, the RLS Foundation qualifies!) And if both members of a married couple qualify by age and have IRAs, they can each make a QCD of up to $100,000. The QCD can lower gross income, be used even if you don't itemize your deductions, and also count toward the required minimum distribution, or RMD, for individuals 73 or older. Which brings us to tip #2:

2. Consider giving your required minimum distribution from your retirement funds directly to charity. If you are at least age 73 and have an IRA or other retirement holdings, the IRS mandates a minimum annual distribution that would normally be taxable income to you, but that you can direct tax-free to a charity of your choice.

3. Give through a donor-advised fund, or DAF, into which you deposit donations with instructions to distribute these funds in your name to charities you designate and on a schedule that you control. This could enable you to take an immediate and significant itemized tax deduction on a large sum of donations to the DAF that will, in turn, be disbursed to charities over a period of future years that you specify.

4. Give appreciated securities from non-retirement assets, such as stock that has gained in value while in your portfolio. While the charity gets the full present value of the stock, you can avoid paying the capital gains tax you would normally be assessed if you were to sell the stock yourself. You may also avoid a Medicare tax surcharge to capital gains. The result: more resources for the charity and lower taxes for you.

5. Make your estate plans with charitable giving in mind. Whether you plan to remember a charitable organization in your will, make a nonprofit group the beneficiary of a paid-up life insurance policy, create life income trusts or annuities – or all of the above – careful financial planning can be a win-win-win for you, your heirs and your favorite charities.

So, with many months ahead in 2025, take time to consider strategies that may be advantageous to you and your family this year and beyond, while doing the most good for causes meaningful to you (which we hope include the RLS Foundation!) But one caveat: While we at the Foundation can suggest ideas like these to consider, we cannot give you financial or legal advice – so you should consult your own accountant, attorney or financial advisor to determine if any of these strategies are right for you.

Boost Your Mood: How Dance Can Improve Mental Health

By Adrianna Colucci, Communications Coordinator

Whether you've danced alone in your car to your favorite songs, swayed with your partner on the dance floor at a wedding or initiated a spontaneous dance party at a family celebration – you've experienced firsthand the positive effects dance can have on mental health.

For individuals with RLS, research suggests that an active lifestyle can be an effective tool for managing symptoms. Finding *enjoyable* and safe activities that also have psychological benefits can further enhance quality of life.

Movement in general has been shown to reduce stress, increase energy and promote a sense of calm. On a biological level, exercise reduces the body's stress hormones, such as adrenaline and cortisol, while also stimulating the production of endorphins.[1] Endorphins are hormones released when the body experiences pain or stress.[2] They act as a neurotransmitter, blocking the nerve cells that receive pain signals. Endorphins also stimulate the release of dopamine, another neurotransmitter that plays a role in mood. An endorphin deficiency may indicate a lack of dopamine and can present as sleep issues, impulsivity and body aches or pains.[2]

Stress can also present as physical symptoms such as tense muscles, headaches, chest tightness or lightheadedness.[1] Bodily movement reduces tension, encouraging relaxation and mental clarity.

Dance is a unique form of physical activity that incorporates choreographed sequences, synchronicity and memorized movements. A systematic review of literature designed to study the cognitive impact of dance found that dance was as effective, if not more effective, than other physical activities at improving psychological outcomes.[3] The studies looked at dance broadly, including traditional dance forms, aerobic dance or theatrical dance across all ages. Preliminary evidence further suggested dance may be superior at improving motivation, distress, depression, memory and emotional well-being.[3]

Formal dance classes are often conducted in social settings, where engagement and a supportive community enhance participant enjoyment.[3] Performing in group settings has been linked to the release of endorphins, inducing relaxation and pleasure. Incorporating exercise with music, which has been shown to have therapeutic effects, can also amplify mental

health benefits. Dance requires multitasking between musicality, artistry, memory and focus, acting as a distraction from mental burdens.[3] While further studies are needed to determine the specific benefits of dance based on genre, frequency and age, its overall health benefits should be recognized.

Fifty percent of people who start an exercise program will cease within six months; therefore, it is important to find an activity that is enjoyable to reap the long-term benefits.[3] Whether it's ballroom or ballet, the samba or swing, dance can have a positive impact on mental health.

If you're seeking a new physical activity to incorporate into your routine, consult your healthcare provider and investigate concerns such as safety, efficacy and cost before making any changes to your treatment regimen. Exercise should be used in moderation and under the guidance of a professional with extensive fitness, nutritional and healthcare experience.

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Recognizing Possible Mimics of Restless Legs Syndrome

There is no specific diagnostic marker to confirm a diagnosis of restless legs syndrome (RLS); rather, diagnosis is based on an individual's report of symptoms. The quality of sensory symptoms varies from one person to another, so it is important to be aware of RLS mimics that exist. Keep reading for a brief overview of possible RLS impersonators.

Periodic Limb Movement in Sleep (PLMS)

PLMS is a motor phenomenon that occurs during sleep; it is not a diagnosis or a disease. The movement consists of foot flexion with fanning of the toes but can also involve movement of the upper leg. Since the movements occur during sleep, individuals are often unaware that PLMS are occurring, however sleep studies can be used to detect PLMS. PLMS are present in 90% of individuals with RLS, however, the majority of patients who have PLMS do not have RLS. Experts do not recommend treatment when PLMS occur in isolation and without RLS symptoms. Patients with Parkinson's disease, Narcolepsy, Multiple Sclerosis and sleep apnea often experience PLMS, in addition to individuals taking antidepressant and antipsychotic medications.

Nocturnal Leg Cramps

Cramps that awaken people during sleep are common, but they are not a symptom of RLS. The cramps are usually painful and may cause a person to feel the need to get out of bed to stretch the muscle and "break" the cramp. Like RLS, leg cramps may get better by massaging or rubbing the legs. However, one of the key differences between leg cramps and RLS, is that walking can alleviate the symptoms of RLS, while it often exacerbates leg muscle cramps or causes pain. Nocturnal leg cramps usually affect a specific area of the calf or the sole of the foot, but can affect any muscle. Benign nocturnal leg cramps, sometimes known as a "charley horse," are the result of spontaneous chaotic muscle spasms that contract on their own, secondary to abnormal calcium flow in the muscle. After a sudden onset, they typically last from a few seconds to a few minutes and are relieved by stretching the affected muscle. Some people experience them regularly, while others only face isolated occurrences. Muscle cramps can also occur during the day, especially after strenuous muscle activity. Dehydration, uncharacteristic exercise, electrolyte imbalance and cholesterol-lowering medications increase the likelihood of cramping.

Attention Deficit Hyperactivity Disorder (ADHD)

Sleep disorders in children, including RLS, tend to be strongly associated with inattentiveness and hyperactivity. Up to 25% of children diagnosed with ADHD may also have RLS, sleep apnea, circadian disorders and/or periodic limb movements. Any sleep disorder that disrupts or prevents sleep can increase attention problems. Hyperactivity in children is often a response to daytime sleepiness caused by a lack of sleep at night.

RLS and ADHD may also be more directly related. The disorders have much in common, including poor sleep habits, twitching and the need to get up suddenly in the night to walk. Some evidence suggests low brain iron and dopaminergic dysfunction are common factors between RLS, ADHD and PLMS.

Anxiety Disorders/General Discomfort

Anxiety can cause restlessness and agitation at night, making it difficult to fall asleep and resembling RLS. The need to pace or move could be based on internal feelings of anxiety rather than a true underlying urge to move the legs. Movement might help but usually does not resolve anxiety. When it is difficult to find a comfortable sleep position, which results in tossing and turning all night long, consider if anxiety, discomfort or possible insomnia may be the underlying cause of this inability to sleep.

Peripheral Neuropathies and Pinched Nerves

Peripheral neuropathies are nerve disorders that can produce burning, tingling, pain and/or shooting sensations in the limbs. Typically, this feeling is superficial (near the skin), and worse in the soles of the feet. Peripheral neuropathies can also cause an inability to feel sensations in the feet and lower legs and can be accompanied by a similar sensation in the hands (so-called "glove and stocking" distribution). Diabetes is the most common cause of painful peripheral neuropathies. Other causes include alcoholism, rheumatoid

RLS mimics are medical conditions often confused with RLS. Mimics do not include any of the following RLS diagnostic criteria:

- **Urge to move**
- **Induced by rest**
- **Gets better with activity**
- **Evening or night worsening**
- **Sensation not solely accounted for by another behavioral or medical condition**

RLS
RESTLESS LEGS SYNDROME FOUNDATION

RAISE AWARENESS
PROMOTE ADVOCACY
IMPROVE TREATMENTS
SUPPORT RESEARCH
FIND A CURE

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arthritis, systemic lupus erythematosus, amyloidosis, HIV infection, kidney failure, chemotherapy and certain vitamin deficiencies. Individuals with neuropathy often notice symptoms at rest, including at night while in bed. But this is more likely attributed to the distraction walking provides from the symptoms that may more noticeable at rest. The contact of bed sheets on the skin can also accentuate symptoms at night. Unlike RLS, peripheral neuropathies are not associated with a need to move the legs. However, neuropathy may increase the likelihood that a person will have actual RLS symptoms, and this may be the only symptom of the neuropathy. Individuals may experience burning or tingling neuropathy symptoms and RLS symptoms at the same time. Pinched nerves in the lumbar spine (lower back) can also send pain radiating down the leg. Usually lying down helps relieve this pain. Electroneuromyography is the standard diagnostic procedure to confirm a peripheral neuropathy.

Muscle Pain

There are many causes of muscle ache (myalgia) in the legs, and often no specific cause is found. Myalgias may be due to muscle disease (myopathy), excessive exercise, medications (cholesterol-lowering drugs) and rheumatologic diseases. A fairly acute muscle pain that occurs while walking may be a sign of inadequate blood flow to the leg muscles (claudication). Unlike RLS, muscle pain does not cause an urge to move and it does not improve with movement.

Akathisia

The term "akathisia" and its neurological description is attributable to Haskovec (1901, 1903). Akathisia is derived from Greek and means "inability to sit." Since the 1950s, the term has been used to describe restless movements or restless agitation in patients on antipsychotic (dopamine antagonist) agents. However, dopamine antagonists that are used to suppress nausea with chemotherapy or used to improve gastric motility will also cause an akathisia. RLS by definition is a form of akathisia. In contrast to RLS, drug-induced akathisia symptoms may not have a circadian pattern, may involve the whole body, and may not be relieved as effectively by movement. Drug-induced akathisia can have a clinical presentation that exactly mimics RLS; therefore, the clinical distinction is whether the patient is on an antidopaminergic medication.

Meralgia Paresthetica

Meralgia paresthetica is a condition caused by a pinched nerve as it exits the inguinal canal near the groin area. Symptoms include numbness, pain, tingling or burning, typically on an oval area on the front and side of the thigh. It usually occurs on one side of the body and the area usually feels numb to touch. There is absolutely no urge to move with meralgia paresthetica. It typically occurs in people ages 30 to 60, but it can affect people of all ages. Increased weight, hypothyroidism and the chronic use of a high or heavy belt are the greatest risk factors for this condition.

Conclusion

It is important to closely examine your symptoms and work with your healthcare provider to determine if you have RLS or one of its mimics. Consider that all above-mentioned conditions are different from RLS, but they can also coexist with RLS. To learn more about RLS, visit www.rls.org.

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 advance research to 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.

Understanding the Risks of Kratom

In recent years, an increasing number of people have explored kratom, a tropical tree native to Southeast Asia, for medicinal treatment. While kratom has been used as traditional medicine in some countries, recent reports suggest it is being used in the US to self-medicate for pain, anxiety and depression, or to alleviate withdrawal symptoms caused by addiction to opioids and other substances.

The leaf of a kratom tree can be chewed, brewed or crushed into powder for consumption. Products derived from its leaves are marketed as herbal supplements that produce opioid and opioid-stimulant effects. While individuals with RLS may seek alternative treatments to pharmaceuticals, it is important to note that there is no scientific evidence supporting the effectiveness or safety of kratom in treating RLS.

At lower doses, kratom is reported to cause stimulating effects such as increased alertness and energy, excessive talking and rapid heart rate.[1] At higher doses, it may have sedative effects such as relaxation, pain relief and confusion. Kratom leaves contain various chemical substances, including mitragynine which, when digested, breaks down into 7-hydroxymitragynine. Both compounds interact with opioid receptors in the brain, which may explain why some individuals experience lessened pain or heightened pleasure.[1] According to the Drug Enforcement Administration (DEA), side effects may include nausea, itching, dry mouth, drowsiness, loss of appetite and tachycardia.[2] Instances of hallucinations, insomnia, liver toxicity and seizures have also been reported.[2]

While kratom is currently legal in the US, it remains unregulated and is not approved for any purposes by the Food and Drug Administration (FDA). A lack of regulation can lead to lack of uniformity in the product. Different sources may contain vastly different amounts of the active drug, making it difficult to determine the precise dose someone is actually taking. Kratom products have also been found to contain harmful contaminants, including heavy metals and bacteria.[1]

Kratom is not legally marketed in the US as a drug or a supplement. The FDA warns the public to refrain from using kratom, and the DEA has listed kratom as a Drug and Chemical of Concern.[2] Further research is needed to confirm kratom as a safe and effective treatment for any medical purpose. If you are considering pursuing a new form of treatment, it is important to consult with your healthcare provider and investigate concerns such as safety, efficacy and cost before making any changes to your treatment regimen.

Medical Editor's Note: Testing for mitragynine is typically included on an opioid screen. It is often picked up by physicians prescribing controlled substances like opioids on a urine screen test.

This publication has been reviewed and approved by the RLS Foundation Scientific and Medical Advisory Board. Literature distributed by the RLS Foundation, including this publication, is offered for informational purposes only and should not be considered a substitute for the advice of a healthcare provider. The RLS Foundation does not endorse or sponsor any products or services.

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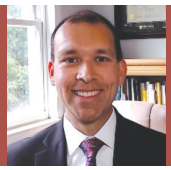


BY J. ANDREW BERKOWSKI
MD

How can variations in ferritin testing affect the decision to use iron supplementation for RLS treatment?

SILBER MH, BLOCK DR, LOUIS EKS. SERUM FERRITIN MEASUREMENTS DIFFER ACCORDING TO ASSAY USED: IMPLICATIONS FOR IRON THERAPY IN RESTLESS LEGS SYNDROME. J CLIN SLEEP MED. PUBLISHED ONLINE 2024. DOI:10.5664/JCSM.11332

THE BACKGROUND

RLS is most strongly linked to low brain-iron levels. Iron supplementation – either by an oral tablet or intravenous (IV) infusion – has been one of the best treatments for RLS for many years. The decision to use iron supplementation depends on blood testing for iron, and one of the two essential tests is ferritin, which is a protein that stores iron and often reflects the amount of iron present in one's body, particularly when ferritin is low. Many publications such as the 2024 American Academy of Sleep Medicine (AASM) Clinical Practice Guidelines recommend supplementation for ferritin < 100 mcg/L. Different companies make lab tests for ferritin called immunoassays, and these tests are supposed to be calibrated to a gold standard set by the World Health Organization (WHO) to maintain accuracy. However, in other conditions related to iron, there have been discrepancies reported among lab testing methods that show variation in ferritin results. This study aims to look at two immunoassays and their accuracy in those with RLS.

THE RESEARCH

Researchers from Mayo Clinic in Rochester, Minnesota, obtained 116 blood samples from patients with RLS and used the Beckman and Roche immunoassays to determine ferritin levels. Though both brands of assays were extremely well correlated with each other (i.e., precise), their absolute levels differed widely (i.e., were inaccurate). For example, a Beckman ferritin of 50 mcg/L led to a Roche level of 83 mcg/L. A Beckman level of 75 ng/mL produced a Roche level of 121 mcg/L.

THE BOTTOM LINE

This study raises concerns about the accuracy of different brands of ferritin lab tests. Those that consistently generate higher values than the standard may lead to undertreatment with iron supplementation if applied with reference to ferritin thresholds based on the lower or more accurate values.

FURTHER QUESTIONS

What does the WHO use as the gold standard for ferritin measurement, and why are some manufacturers of testing assays differing so widely? Should clinicians and those with RLS routinely be investigating which brand their lab is using for the test? Because of the good consistency and correlation, can those companies start recalibrating their assay results to solve this problem? Could variation of testing have contributed to the variability in response to IV iron in some of the research studies in the past if different lab assays were used? Aside from relying equally on a morning, fasting transferrin saturation (TSAT%) to assess iron, should we be more inclined to raise our threshold for ferritin when it comes to considering IV iron as a treatment?

Does blood donation increase the risk of RLS?

NGOMA AM, MUTOMBO PB, MOSLI M, OMOKOKO MD, NOLLET KE, OHTO H. RESTLESS LEGS SYNDROME AMONG BLOOD DONORS: A SYSTEMATIC REVIEW AND META-ANALYSIS. VOX SANG. PUBLISHED ONLINE 2024. DOI:10.1111/VOX.13780

THE BACKGROUND

RLS is heavily linked to iron levels in the brain. In turn, low iron levels in the body generally mean even lower iron levels in the brain. Blood donation immediately reduces a large source of iron contained in the blood, leading to lower iron levels or even iron deficiency after donation. The increasing demand for donor blood worldwide may be in conflict with the risk of iron loss leading to or exacerbating RLS as a potential adverse effect of blood donation. This study examines research studies of blood donation to investigate the prevalence of RLS in blood donors, identify contributing factors and examine the impact on donor health and global blood supply.

THE RESEARCH

The authors performed a type of research study called a systematic review and meta-analysis. They created predefined criteria centered around RLS and blood donors and scanned large databases to screen for all research studies that met their protocol. Eleven studies from eight countries, including Europe, India and the US, involving 20,255 blood donors were included in the analysis. When the data were combined, the prevalence of RLS was 10.3% higher than in many of the studies of the general adult population that may be around 3%–5%. RLS was more common in women and older individuals. There was very good consistency of results among the 11 studies, but authors note that the majority (97%) of the results were from North America and Europe and question the generalizability globally. There was a trend showing an increase in RLS in those with iron deficiency, seen most commonly in frequent blood donors.

THE BOTTOM LINE

This study suggests that blood donation is associated with an increased risk of RLS.

FURTHER QUESTIONS

Should those with RLS donate blood? Can some with higher iron levels or those who have never responded to IV iron donate blood as long their iron levels remain above minimum thresholds? Is it possible that blood donation can cause RLS to develop in some individuals who would ordinarily not experience symptoms, due to the voluntary reduction in iron levels from blood donation? Should organizations such as the American Red Cross be screening for RLS as part of the intake process for blood donation and counsel those with RLS symptoms on the risks? It is possible that these studies may have over-detected borderline RLS by repetitively screening for RLS, when the subjects would have otherwise never mentioned it. How can we create a prospective study in which those with RLS willing to donate blood are randomized to blood donation or no donation so we can compare the effects of donation?

Can compression stockings help with symptoms of RLS in pregnant women?

KAPLAN Ö, BAŞER M, ÖZGÜN MT. THE EFFECT OF COMPRESSION STOCKINGS ON THE COMPLAINTS, WELL-BEING AND SLEEP QUALITY OF PREGNANT WOMEN WITH RESTLESS LEGS SYNDROME: A RANDOMIZED CONTROLLED STUDY. REV DA ASSOC MÉDICA BRAS. 2024;70(7):E20240145. DOI:10.1590/1806-9282.20240145

THE BACKGROUND

RLS occurs more frequently in pregnancy, at a rate of 15%–30% in Turkey (Türkiye), from where this study originates. In pregnant women, nonmedication approaches are even more highly sought after due to the largely uncertain risks of toxic effects of medications to the unborn child. Device approaches using compression, vibration and stimulation have all been tried in the treatment of RLS; however, very little research on treatment of RLS in pregnancy currently exists, even for medications. The AASM in its most recent guidelines specifically cites pregnancy as a special population for which more research is needed. This study investigates the use of compression stockings and their impact on RLS, sleep and overall well-being.

THE RESEARCH

The randomized, sham (i.e., placebo)-controlled study involved 63 pregnant women diagnosed with RLS who were in the third trimester at a mean of 30 weeks gestation. Participants were divided into two groups: one using therapeutic compression stockings and the other sham stockings. Both sets followed a three-week regimen, putting on the stockings when waking up and removing them at bedtime. Measurements included the International RLS Study Group Score (IRLS), Pittsburgh Sleep Quality Index (PSQI) and WHO-5 Well-Being Index before the study and after three weeks.

Findings indicated statistically significant improvement in RLS severity in those using compression stockings, and though there was more improvement in sleep quality and well-being in the treatment group, they did not meet statistical significance compared to the sham stocking group. The IRLS score improved by 12.2 points in the treatment group versus 8.9 points in the sham group. The mean IRLS score in the therapeutic group went from 21.2 (severe) to 8.9 (mild to moderate) on this 0–40 scale.

On average, relief from symptoms began in approximately four days for the experimental group compared to five days for the sham group. Participants expressed satisfaction in both arms of the study, along with the additional benefit of pain relief in both. Subjects noted more discomfort from the compression stockings, such as tightness and difficulty putting on the stockings, compared to the sham group.

THE BOTTOM LINE

This study suggests that compression stockings may be well tolerated and beneficial to RLS symptoms during pregnancy.

FURTHER QUESTIONS

What is the mechanism by which wearing compression stockings improves RLS symptoms? Is it by the compression providing stimulation to legs, or is it due to a change in the blood flow from compression? Would there have been more of an effect if participants had been allowed to wear the stocking during the night? Or, only in the evening and night but not during the day? As in many RLS studies there was a large placebo effect in which the non-treatment group also showed significant improvement. In this study, could the sham stockings themselves actually provide some degree of therapeutic effect, aside from a placebo effect, due to the wearing of stockings and contact with the skin over most of the legs? Are this and other small studies enough to recommend routinely that pregnant women with RLS try compression stockings, given that this is a low-cost, low-risk intervention?

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

Speaking Up for RLS: A Day of Advocacy on the Hill

Annually, the RLS Foundation hosts Hill Day in Washington, DC – an opportunity for members of the RLS community to unite and educate legislators on the RLS Foundation's key congressional priorities. Twenty RLS community members, physicians, Foundation board members and staff met on September 9, 2024, to participate in this event. They split into four groups and visited over 25 offices, advocating for increased research funding, education, and access to treatments, including low-total-daily-dose opioids.

In this article, you will follow one group's day including Avinash Aggarwal, MD (director of the RLS Quality Care Center at University of Pittsburgh Medical Center), Adrianna Colucci (RLS Foundation staff member) and Foundation members Donna Anastasi, Jane Gorski and Marydale Stevens.

8:30 am

Hill Day participants met at the Health and Medicine Counsel (HMC), an organization that coordinates and guides the RLS Foundation's advocacy program. The HMC staff reviewed the Foundation's legislative agenda and answered questions. Advocates were given time to connect with other members of their groups and bond by sharing personal stories.

The groups departed, walking first to the Capitol for a group photo and then parting for their assigned meetings.

10:30 am

The group met with representatives from Senate offices. With only 20 minute meetings, it was important be concise to provide clinical context while also conveying the emotional aspects.

It was Dr. Aggarwal's second time participating in Hill Day. "As a physician, I witness how public policy impacts patients every day," she says. "From restrictions on prescribing certain evidence-based medications for RLS patients to the insurance denials, certain pervasive issues in our healthcare system require public advocacy. Hill Day is an important opportunity to discuss the impact of these issues on patients' health with our representatives."

A prominent theme in these meetings was the emotional toll of RLS, in addition to the physical. Jane Gorski emphasized, "RLS is beyond a sleep disorder – it impacts relationships, social activities, mood and more. This is what I wanted to convey to the legislators – that RLS is life altering and destabilizing." Stories such as Gorski's explain the urgent need for increased research funding.

1 pm

Breaking for lunch, groups were able to reflect on their morning meetings and converse on topics beyond RLS.

This was Marydale Stevens' first time participating in RLS advocacy. "I enjoyed the opportunity to learn from RLS physicians and connect with my community" she reflects. "Most of the legislative staffers were unfamiliar with RLS, and in our brief time, we effectively advocated for further research funding and increased awareness."

2 pm

The day continued with back-to-back meetings with House representatives. Emerging topics included opioid access, telehealth limitations, lack of educational resources and difficulties finding a provider.

"When I am symptomatic and unable to get up and move, that sense of urgency can cause a panic response," explained Donna Anastasi to legislative representatives. "With refractory RLS, none of the typical medications relieve the symptoms. Some of them even make the symptoms worse. For me, being on a low total daily dose of opioids has been life-altering. My hope is that our stories will be powerful enough to convey the depth of our experiences to those who do not have RLS."

4:30 pm

Participants debriefed at the HMC headquarters. After thanks and farewells, participants dispersed to their homes – having traveled from Oregon, Arizona, Indiana, Missouri and other states.

"Attending Hill Day was the best thing I have ever done for my restless legs, both by advocating for all who suffer from the disease as well as learning from all those who attended the event with me," says Gorski.

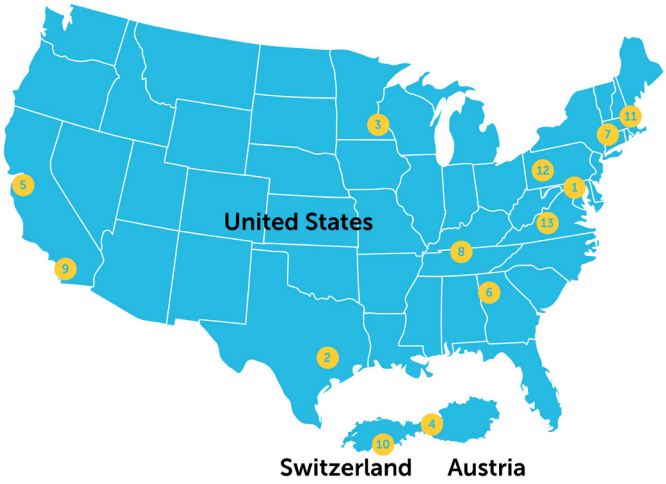
The Foundation is so thankful to all who attended Hill Day in 2024! Hill Day is an annual event, so stay tuned to RLS Foundation news if you'd like to participate in this year's advocacy efforts. To learn more about upcoming advocacy events, visit www.rls.org/advocate.

UVA Certified as a New Quality Care Center

The RLS Foundation is excited to announce the University of Virginia at Charlottesville (UVA) as a certified RLS Quality Care Center. UVA joins a network of 12 other institutions in the US and Europe that are certified by the RLS Foundation as Quality Care Centers. UVA will serve as a destination for RLS patients who need expert RLS care.

"We are extremely honored to be recognized as an RLS Foundation Quality Care Center," says Elias Karroum, MD, PhD, director of the Quality Care Center at UVA. "This designation reflects our commitment to provide exceptional care and advance innovation to make a meaningful difference in the lives of the patients that we serve. We are proud to lead the way in ensuring our commitment to the highest standard of care to successfully manage all forms of RLS severity."

To learn more about the RLS Foundation's Quality Care Center program and to find a center near you, visit www.rls.org/QCC.



Our QCCs are located in the following regions:

1. Johns Hopkins, Baltimore, MD
2. Houston Methodist Neurological Institute, Houston, TX
3. Mayo Clinic, Rochester, MN
4. Innsbruck Medical University, Austria
5. Stanford, Palo Alto, CA
6. Emory, Atlanta, GA
7. Yale, New Haven, CT
8. Vanderbilt, Nashville, TN
9. Scripps, San Diego, CA
10. Neurocenter of Southern Switzerland, Switzerland
11. Massachusetts General, Boston, MA
12. University of Pittsburgh Medical Center, Pittsburgh, PA
13. University of Virginia, Charlottesville, VA

Become an RLS Foundation Support Group Leader!

The RLS Foundation is excited to announce that our 2025 volunteer application for support group leaders is open! We are looking for proactive and compassionate individuals who would like to establish a support group in their community.

As a local RLS support group leader, your primary responsibilities are to:

- Hold at least one meeting annually (in-person, virtually or hybrid)
- Form a meeting structure and organize a meeting space
- Foster new connections in your area to grow your group over time
- Collaborate with a medical advisor and work with Foundation staff to promote Foundation resources

If you would like to learn more about becoming an RLS Foundation volunteer visit www.rls.org/get-support. To complete an application, scan the QR code.

RLS Research Virtual Summit Q&A

On November 13, 2024, an audience of nearly 150 participants attended the RLS Research Summit on Zoom. The event included a full day of presentations, as well as an audience Q&A with a panel of RLS experts. The event was moderated by Shalini Paruthi, MD, and panelists were J. Andrew Berkowski, MD; Mark Boulos, MD, FRCPC, CSCN(EEG), MSc; Katie Cederberg, PhD, CPT; James Connor, PhD, MS; Karla Dzienkowski, RN, BSN; Christopher J. Earley, MB, BCh, PhD, FRCPI; Brian Koo, MD; William Ondo, MD; and John Winkelman, MD, PhD. This Q&A includes excerpts from the session.

The RLS Foundation is unable to respond to individual medical or treatment-based questions due to liability issues. Individuals with RLS should consult a qualified healthcare provider before making any changes to their treatment plan.

Augmentation

Q: Why are alpha-2-delta ligands not as effective after someone develops augmentation from dopamine agonists?

Dr. Ondo: There are many theories surrounding augmentation and the interaction between medications and different dopamine receptors. After someone has augmented, an alpha-2-delta ligand may not offer the necessary relief, based on the severity of symptoms.

Dr. Koo: I agree. The RLS symptoms are most severe during the period where an individual is tapering off of a dopamine agonist. The next step may be to use opioids. Based on the efficacy of opioids, it may be difficult to replace opioids with a medication that works just as well.

Dr. Earley: I also agree. Opioids tend to work better at managing RLS symptoms during the withdrawal period of augmentation as someone tapers off of dopamine agonists. If someone is willing to forego all RLS medications for three to four weeks (also known as a drug holiday), alpha-2-delta ligands may be more effective after that time.

Q. Has there been a reanalysis of the augmentation rates for rotigotine (Neupro patch) compared to other dopamine agonists? Some research suggests there is a lower chance of augmentation with rotigotine.

Dr. Berkowski: Rotigotine is a 24-hour drug. The hallmark symptom of augmentation is the progressively earlier development of symptoms during the evening or afternoon. Since rotigotine is long-acting, we think it may mask the augmentation for a longer period of time rather than reduce the risk. Thus, any studies showing lower numbers than other dopamine agonists are likely a significant underestimation of the augmentation simmering underneath but with delayed appearance.

Dr. Earley: In the long-term clinical trial with rotigotine, the rates of augmentation were low for the reason that Dr. Berkowski just gave. However, the biggest issue for patients was the development of a rash and therefore discontinuation of the patch altogether. This discontinuation rate was equal to the annual rate of seeking alternatives to dopamine agonists. Therefore, it is still difficult to determine whether rotigotine has a lesser risk of augmentation.

Dr. Winkelman: I would also point out that there were methodological problems with the study referenced by Dr. Earley. First, the researchers used doses that are not recommended for RLS in the United States. Second, some of the people deciding whether the patient was experiencing clinically significant augmentation had some credibility issues, as representatives from the pharmaceutical company were involved in this decision-making, raising concerns about the reliability of their results.

Opioids

Q: What are the side effects of methadone?

Dr. Winkelman: Constipation is the most common side effect but can be managed by diet and hydration or with stool softeners and bowel stimulants. The second most common is daytime sleepiness. Even if methadone is taken at night, it is a long-acting medication and can cause drowsiness during the day. It is also important to look for signs of central sleep apnea, a sleep disorder that disrupts breathing during sleep. A sleep study in a sleep laboratory may be necessary to diagnose central sleep apnea.

Other side effects may include itching, nausea and sweating. Nausea is often most common when first starting the medication, although this usually improves over time or with antinausea medications. Sweating may also occur because opioids interfere with the production of reproductive hormones. For men, this includes testosterone. Regular testosterone tests are important, and if the testosterone level is low, testosterone cream or gel can be used.

Lastly, everyone who takes methadone should get an electrocardiogram (EKG). The EKG can determine if the heart rate-corrected QT interval (QTc), or the heart's electrical activity, is within normal limits. Though rare, methadone can produce an irritability or change in heart rate.*

**Medical Editor's Note: In addition, a side effect somewhat unique to methadone is symptoms of air hunger/shortness of breath which may or may not be associated with anxiety. Many of us have had patients with this side effect and often we have to stop the methadone and change to a different opioid which typically does not have this side effect.*

Q. Can tramadol cause augmentation?

Dr. Berkowski: Tramadol is often referred to as a "dirty" opioid. It has features of true opioids (like methadone or

buprenorphine) but also has serotonergic and norepinephrine properties. These are the antidepressant chemicals that are used in most antidepressants. As we know, most antidepressants exacerbate RLS symptoms, which may be why some physicians see a phenomenon of RLS symptoms worsening in patients on tramadol. When the patient is taken off of tramadol and it is replaced with a standard opioid, the RLS symptoms get better. Whether this is true augmentation is difficult to say. Typically, tramadol is not recommended for daily long-term use when there are so many true opioids available without the additional chemical effects.

Dr. Earley: Though tramadol is formally registered with the FDA as an opioid, when compared to other opioids, tramadol is insensitive to morphine receptors.* It acts similarly to antidepressants, primarily the reuptake of noradrenaline and serotonin.

We published a series of cases where tramadol appeared to progressively increase the onset of RLS symptoms, mimicking what is typically seen in augmentation. The dose that was once effective was no longer. When taking individuals off of tramadol, some displayed withdrawal symptoms often seen in dopamine agonist withdrawal.

**Medical Editor's Note: Tramadol binds to the opioid receptor with 6000-fold less affinity than morphine to which all opioids are compared (called morphine mg equivalent dose or MMED).*

Q. If someone has a history of drug abuse, can they still take buprenorphine? If someone develops augmentation from a dopamine agonist, is there a better alternative?

Dr. Berkowski: Developing an RLS management plan is a balance of risk and benefit. Buprenorphine is an opioid and theoretically can be abused, but far less so than other opioids. In someone with a history of drug abuse, opioids are of significant concern. Opioids are considered in more severe cases of RLS if alpha-2-delta ligands (gabapentinoids) and iron therapy are not fully effective, and for those who have experienced augmentation.

It is important to properly manage RLS to prevent disruptions in quality of life, sleep and cardiovascular health. Research from Dr. John Winkelman's National RLS Opioid Registry shows that individuals can maintain small total daily doses of opioids long term. Buprenorphine specifically may be less abused as it tends not to cause any euphoric effect, or "high." It also does not cause the withdrawal symptoms most often felt in other opioids when one goes too long without the opioid (dysphoria), which often makes one seek the relief from the drug. If taking opioids is a risk, a physician should carefully monitor one's use through strategies including urine drug screens, a pharmacy database review and an opioid agreement.

Dr. Koo: In severe cases of RLS, it may be difficult to effectively manage symptoms without an opioid. While it is tricky, longer-acting opioids like buprenorphine or methadone may lessen the risk of abuse compared to shorter-acting opioids like oxycodone.

Alpha-2-delta Ligands and Dopamine Agonists

Q. Do you think that the FDA will change its guidance about dopamine agonists given the latest published guidelines, which recommend caution due to augmentation?

Dr. Ondo: Currently, the FDA does not recognize the entity of augmentation. Though researchers have submitted studies showing evidence of augmentation, the FDA has yet to take an official position. It is unlikely that the FDA will change its guidance, which is why awareness in the medical and public sectors is important. If dopamine agonists are to be used, patients should be aware of the risk.

Q. If alpha-2-delta ligands work moderately, can dopamine agonists be prescribed to be used as needed?

Dr. Koo: This requires caution. Using a dopamine agonist may significantly improve RLS symptoms in the short term as the medication is used. Patients may be tempted to use the medications more than occasionally, and it is possible to augment quickly. Speak with your healthcare provider to determine if other factors such as ferritin levels or sleep apnea can be addressed first.

Dr. Winkelman: It may be reasonable to use a dopamine agonist as a rescue; it can be used on occasion during a long plane ride, car ride or other instances of immobility. Still, it should be used with caution.

Q. Can gabapentin safely be used alongside opioids?

Dr. Earley: Mechanistically, gabapentin and opioids are different. Therefore, they can supplement each other pharmacologically. If someone is experiencing side effects from an opioid, they may be able to decrease the dose by adding gabapentin. Some patients have a reasonable response when gabapentin is used alongside opioids, even if the gabapentin was ineffective on its own.

Dr. Koo: While gabapentin and opioids can be used in combination to treat RLS safely, the prescribing physician should carefully monitor. There is a warning on both packages that they are respiratory suppressants. Due to the low dose of the opioid though, many patients can use both to effectively treat their symptoms.

Find Support

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

Local RLS Support Groups

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

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(603) 642-6059

MICHIGAN

Oakland County, MI RLS Support Group
Linda L. Tuomaala
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(248) 435-4024

MINNESOTA

Twin Cities MN RLS Support Group
David Gagne
TwinCitiesMN_SupportGroup@rlsfvolunteer.org
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NEW HAMPSHIRE

Seacoast NH RLS Support Group
Roberta J. Kittredge
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NORTH CAROLINA

Asheville NC RLS Support Group
Michael Small
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(518) 624-3346

OHIO

Columbus OH RLS Support Group
Rosemary Stader
ColumbusOH_SupportGroup@rlsfvolunteer.org
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SOUTH DAKOTA

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

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

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

RLSF Support Contacts

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

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

Carol Galloway
Carol_Contact@rlsfvolunteer.org
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Susan Schlichting
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(310) 792-2952

FLORIDA
Neil R. Greenwood
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ILLINOIS
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MARYLAND
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Louis_Contact@rlsfvolunteer.org
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MISSOURI
Kathy Page
Kathy_Contact@rlsfvolunteer.org
(660) 368-2382

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

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

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

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

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

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

RLSF Virtual Support Groups

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

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

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

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

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

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

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

RLSF VIRTUAL SUPPORT GROUP LEADERS:

Laura Hoffman
Laura_VSG@rlsfvolunteer.org

Bill Wendt*
Bill_VSG@rlsfvolunteer.org

Judy Amateis
Judy_VSG@rlsfvolunteer.org

*Member of RLS Foundation Board of Directors

RLS Online Discussion Board

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

Ann Battenfield
ann.rlsfmod@gmail.com

Beth Fischer
beth.rlsfmod@gmail.com

Betty Rankin
bett.rlsfmod@gmail.com

Stephen Smith
Stephen.rlsfmod@gmail.com

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

BEDTIME STORIES

SHARING MY RLS SOLUTION

A few months ago, I started using a vitamin C firming body butter purchased from a US-based chain store recognized for its curated selection of organic, health-conscious items. I initially bought it because it smells so good. A few weeks ago, my best friend, who also suffers with RLS, commented on the smell, so I gave her my bottle to take home to try. She called me last week to tell me that she hasn't had any RLS symptoms since she started using it. As soon as she said that, I connected the dots and realized that my symptoms had also decreased to maybe once a week, and the intensity was far less. I don't know if there's a connection, but I thought I'd share the information just in case it can offer relief to fellow RLS sufferers. Good luck!

Pam

INFUSED LOTIONS FOR RELIEF

I have RLS and have found a cream that helps with the urges in my leg. It is a lotion infused with hemp seed oil and is easily found in many stores. When I feel the RLS sensation starting, I get a small amount of cream and rub it in the part of the leg that is affected, and it really works to make the sensation go away. Hope it works for you as well as it has worked for me!

Elizabeth

LEARNING RLS TRIGGERS

I've suffered from RLS since high school. I'm now 70. Many of my family members suffer from RLS, including my mother, siblings and daughters. For years, doctors dismissed my symptoms or outright ignored what I was telling them. Finally, in my 20s, a neurologist told me I had RLS and gave me medication. This particular drug worked wonders for years then just stopped working. I started another drug that helped for a number of years, but it started to cause augmentation. Then I had knee replacement surgery, and the leg operated on went wild. It jumped around nonstop for days. I couldn't sleep – I was desperate! My primary care provider had just left the practice, and I hadn't yet seen my new one. After a series of calls between offices and a lot of frustration, another medication was added and I finally slept.

For me, a change in activity levels sets it off. For example, if I haven't done much walking for a while, after I go on a walk the legs start when I try to relax. If I have been consistently walking but then stop, the sensations in my legs start again. Some types of alcohol set off my symptoms. Even some of the medications recommended have made the symptoms worse. My symptoms are somewhat controlled at the moment, but I notice the meds aren't working as well as before. I have an appointment with a nurse practitioner in a neurology practice soon to discuss my next move.

Estelle

RLS IN THE REARVIEW MIRROR

I have had nightly bouts with RLS for about 30 years, often getting out of bed at night and walking around the bedroom for seven or eight minutes. My all-time record for RLS attacks in one night is eight!

I have stumbled on a simple procedure that has changed all that. I now take a magnesium supplement after dinner and, not long before I head for the bedroom, I take a trazodone tablet.* I have had only one occurrence of RLS in almost two months, and that was about two weeks ago. I have not changed my diet, nor have I exercised more or less.

Frankly, I am a changed person, now feeling rested and not having to stay in bed later in the morning than I would like. I am not a doctor, but I do feel very lucky to have found something that has RLS in the rearview mirror.

H. Carmichael

**Medical Editor's Note: All antidepressants can worsen RLS. Trazadone, like other antidepressant drugs, can increase suicidal thoughts in children, teens and young adults within the first few months of taking it.*

CURIOUS SOLUTIONS LEADING TO RESEARCH QUESTIONS

I believe I am an occasional RLS sufferer addressing RLS one to three times per week. I am 75 years old and have been dealing consciously with RLS for about 25 years. I feel there is a good probability I've had issues prior but had no explanations about occurrences.

I have noticed a few things over time. First, prior to the onset of RLS, I experienced sensations between sharp itching (think bug bite) or average itching. These are mild and relieved by scratching the affected area. This is generally followed within a few minutes by the subtle "movement" of muscle into the RLS condition. The RLS may continue between 15 minutes to an hour after. Curiously during that time, I often have the urge to slip my legs over the side of the bed, where they will dangle comfortably for a minute or so (gravity or change of blood flow?) before I pull them back on the bed.

A "remedy" I discovered a couple of years ago is to drink pickle juice. Some people have indicated immediate relief, but I find it takes my RLS about 10 minutes to subside. During that recovery time I can again feel muscle movement that stops short of my RLS condition. I hope my observations aren't unique and there will be others who can provide more information to help science discover a reason and cure for RLS.

Roberta

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		

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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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