

# NIGHTWALKERS

*In search of a good night's sleep*

**Spring 2022**

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SYNDROME  
FOUNDATION

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

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# From the Director

On June 17, 2022 the RLS Foundation celebrates its 30th Anniversary. This marks an important milestone in our mission to improve the lives of the many men, women and children living with RLS, while supporting three goals that have stood the test of time since the organization's inception: raising universal awareness, seeking better treatments and funding research leading to a cure for RLS.

In 1992 a group of dedicated individuals saw the need to raise the profile for RLS in the medical community and in the general public. Thirty years ago, RLS was thought to be a rare medical disorder and was listed as a condition in the National Organization for Rare Disorders (NORD). We now know that it is not rare; it is a common sleep disorder that affects up to 10% of the population. About 1 in 33 Americans (3% of the US population) has RLS that is severe enough to require daily pharmacological treatment.

We would not be where we are today without our organizational volunteers on our Board of Directors, Scientific and Medical Advisory Board, Discussion Board, and our network of Support Group Leaders and Contacts. Thank you to all of our volunteers, past, present and future, for you hold the keys to our success and continued service to the RLS community.

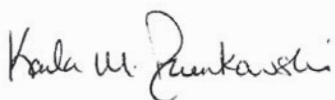
The two-page organizational timeline featured in this issue of *NightWalkers* celebrates our successes over the past three decades and the individuals with next level leadership who made these accomplishments possible. But our work is not done.

As we begin our fourth decade, we must remember that the key to shaping our future is to participate in the present. Each of us needs to do our part to make every year of the next decade count. This includes stepping up to RLS Foundation service just as those early Foundation pioneers did in 1992, with our mission and established goals serving as guidance. Here's how you can help:

- Board of Directors – we are always looking for individuals with a diverse skill set to guide the organization
- Volunteer Network – contact [clara@rls.org](mailto:clara@rls.org) to join our network of Foundation volunteers who support others in need
- Financial Support – advancement of our mission and goals starts with support from every member of this organization
  - Research Grant Program – We need to dig deep, beyond the annual membership dues, to help our RLS researchers to identify new treatments and ultimately a cure for RLS.
  - Public Policy Initiative – Your financial support and your voice is needed to continue educating our legislators and policymakers in Washington about RLS. Our advocacy agenda encompasses three goals: support RLS education and awareness, increase funding for RLS medical research and allow access to treatments including a safe-harbor for RLS patients who require low-total-daily-dose opioids for management of severe RLS when all other treatments are no longer effective. Each day we hear from members about problems finding medical providers willing to treat RLS patients, and barriers to treatment by healthcare providers and pharmacists who are unfamiliar with the appropriate use of opioids in the management of refractory RLS.

To bring about change and to advance the Foundation's mission and goals, we must acknowledge that we, RLS Foundation members, are leading this fight. We must take ownership to make the changes we seek a reality. We will put RLS to rest and spare future generations from this disease. We can do this!

Happy 30th Anniversary!



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



Karla M. Dzienkowski, RN, BSN  
Executive Director

## Honor Roll

*The Restless Legs Syndrome Foundation is sincerely grateful for the donations we received in memory and in honor of the following individuals from January 1, 2022, through April 15, 2022*

#### In Memory of:

my daughter Amy  
my mother and brother  
who had RLS  
Richard P. Allen  
Helen A Brown  
Marguerite Burke  
Steve Crnkovich  
Dan Daly  
Vernon Kowalke  
Herman Peter Lieber  
Dr. Gerald J. Liesen  
Paula Midock  
Joan R. Ralston  
Margaret Robertson  
Phillip Rohler  
Joy Spivey  
Richard Straub  
Uncle Dale  
Mary G. Waier  
Marie Washam  
Robert H. Waterman, Jr.  
Hans Zimmerman

#### In Honor of:

All those who battle RLS daily!  
our son, Bruce  
Sherrill Busboom  
Doylestown Support Group  
Dr. Christopher Earley  
Courtney Griffin  
Robert Kerr  
Anne Marietta  
Mary Ellen Martin  
Adina Turner  
Daniel Vreeland  
John W. Winkelman, MD, PhD  
Richard Watson  
RLS Foundation staff

## Purity, Knowledge and Wisdom Celebrating 30 Years

A pearl – the traditional gift marking a 30th anniversary – is ascribed with the qualities of purity, knowledge and wisdom found in long and deep relationships. At the RLS Foundation, we can think of no more appropriate symbol to mark our 30th year.

The pearl glows with an iridescence that illuminates a disease hidden in the dark for hundreds of years. Its surface is as hard as the toughness and tenacity that we display in our work. And its roundness evokes the wholistic nature of our mission: education, advocacy, diagnosis, care and research – all in the cause of finding a cure.

Just 30 years ago, restless legs syndrome was as misdiagnosed and misunderstood as it had been three centuries earlier. *“Teachers thought I was lazy,”* recalled one Foundation member at the time, while another told her folks she had RLS, only to hear them laugh and say *“it was just in my head.”*

In fact, from the time restless legs syndrome was first identified in medical literature, RLS had remained one of the most widespread yet least understood human diseases, often leading to ridicule and shunning of people who suffered with it. But that began to change in the late 1980s when a group of individuals with RLS contacted NORD (National Organization for Rare Disorders) and began to correspond by handwritten letters. And in 1992, under the leadership of Executive Director Pickett Guthrie, founding members created the Restless Legs Syndrome Foundation.

Thirty years of dedicated, persistent efforts by our board, staff and volunteers have rewarded our community with 12 RLS Quality Care Centers that provide expert, specialized care; and with an extraordinary commitment to medical research that is coming closer every day to finding a cure.

Today, our growing, sophisticated presence online and in social media is bringing our readers and our community of RLS patients, practitioners, families and friends even closer together.

And it has helped to accommodate pandemic realities over the past two years with virtual support group meetings that have further widened our reach and invited once-isolated RLS patients to connect with peers near and far!

Five years ago, on the occasion of another notable anniversary, our 25th, we reported to you on the sea change we were leading in the diagnosis, treatment and research of RLS. We promised you more significant progress by our 30th Anniversary – and we have delivered!

During these most recent five years – the time it can take an oyster to grow a priceless large pearl from a tiny speck of sand – our research has generated a better understanding of augmentation and groundbreaking findings on the efficacy of low-total-daily-dose opioids to manage severe RLS. Meanwhile, advocacy work in Washington has continued to win support for RLS treatment and research among policy makers, helping to prompt recent NIH funding for Dr. Yuqing Li, a 2015 RLS Foundation research grant recipient, to continue his trailblazing research into the role of genetics in RLS development.

We commemorate our 30th anniversary this June and aim to live up to the qualities symbolized by the pearl, with intentions that are pure, undiluted, and wholly dedicated to a singular objective: to gain the knowledge and understanding that will lead us to a cure for restless legs syndrome. And like the pearl, our relationship with you and your fellow supporters grows stronger and more iridescent every year – as we work together toward our common goal.

Meanwhile we continue to be thankful for 30 years of extraordinary progress that we see in things large and small: from the latest research breakthrough to the words of gratitude from one RLS patient that continue to inspire us, day after day: *“It helps to know I am not alone.”*



# RLS Foundation Celebrates 30 Years

**1990**

**First *Night Walkers* published**

Founding member Oron Hawley prints the single-page first issue on his home printer.



**1995**

**First RLS support group formed**

Juanita Therrell leads the first meeting of the group "Sleepless in Seattle."

**Foundation launches [www.rls.org](http://www.rls.org)**



**1996**

**Scientific Advisory Board established**

Robert H. "Bob" Waterman, Jr., chairs this first group of scientific advisors, charged with developing a research grant process.



**1998**

**First Ekblom Award presented to Dr. Arthur S. Walters**

Through this award, the Foundation recognizes service to the RLS community. Future recipients will include Dr. Richard Allen, Cate Murray, Bob Balkam, Sheila Connolly, Bob Waterman, Dr. Wayne Hening, Pickett Guthrie, Dr. Michael Silber, Roberta Kittredge, Dr. Christopher Earley, Lewis Phelps, Dr. John Winkelman, Karla Dzienkowski.



**2002**

**First RLS national patient meeting held in St. Louis, Missouri**

**2004**

**Foundation launches online discussion board**

This new platform offers 24/7 access to support in a private forum.

**Medical Advisory Board publishes first RLS treatment algorithm**

**2007**

**RLS gene variant discovered**

In a groundbreaking study funded in part by the RLS Foundation, researcher Dr. David B. Rye and his team identify a gene variant in RLS, supporting the hypothesis that RLS is hereditary.



**2008**

**Foundation holds RLS scientific conference at Johns Hopkins University**

**Foundation launches Youth Initiative**

Known today as the RLS and Children Program, this initiative focuses on the needs of children and adolescents living with RLS.



**1992**

**RLS Foundation achieves nonprofit status**

The Foundation's headquarters is established in founding member Pickett Guthrie's dining room in Raleigh, North Carolina.

**Medical Advisory Board established**

This panel of RLS experts shares knowledge by serving as speakers and by developing and reviewing educational content published by the Foundation.

**Pickett Guthrie named first executive director**

The Foundation will be led by six directors over the next 30 years:

Pickett Guthrie (1993–1996)

Carolyn Hiller (1996–1997)

Cate Murray (1997–2000)

Allan O'Bryan (interim 2000–2001)

Georgianna Bell (2002–2013)

Karla Dzienkowski (2014–present)



**1997**

**Foundation moves to Rochester, Minnesota**

**Foundation launches research grant program**

Over the next 25 years the Foundation will fund nearly \$2 million in competitive research grants for basic and scientific study of RLS.

**Foundation helps fund first RLS research at National Institutes of Health**

**First *RLS Medical Bulletin* published**

This essential reference tool provides RLS diagnosis and treatment recommendations.

**2000**

**Foundation establishes RLS Brain Bank at Harvard Brain Tissue Resource Center**

The Foundation maintains this collection for tissue distribution to RLS researchers.

**Medical Advisory Board publishes first RLS treatment algorithm**

**2005**

**National patient meeting held in Orlando, Florida**

**2006**

**National patient meeting held in San Antonio, Texas**

**2012**

**Foundation partners with International Restless Legs Syndrome Study Group (IRLSSG) to conduct patient survey**

By gathering information from RLS patients in the US and Canada, this survey reveals the need to better educate healthcare providers, to increase awareness and to continue research toward better treatment options.

# of Service to the RLS Community

**2013**

**Medical Advisory Board publishes revised consensus statement with RLS treatment algorithm**

**Foundation certifies first RLS Quality Care Center**

Staffed by leading RLS experts, these centers provide specialized disease management and today are located at the Johns Hopkins Center for Restless Legs Syndrome; Houston Methodist Neurological Institute; Center for Sleep Medicine at Mayo Clinic; Innsbruck Medical University; Stanford Sleep Medicine Center; Emory Sleep Center; Yale Centers for Restless Legs Syndrome; Vanderbilt University Medical Center; Scripps Clinic Viterbi Family Sleep Center; Neurocenter of Southern Switzerland; Massachusetts General Hospital; and the University of Pittsburgh Medical Center.

**2017**

**Foundation's Facebook page reaches 10,000 likes**

**Social media brings increased awareness**

The Foundation expands its outreach through Twitter, YouTube, Google+, LinkedIn and Instagram.



**RLS Opioid Registry registers over 500 individuals**

Surpassing the goal of 200 registrants, participants commit to report on their experience every six months.

**RLS Foundation launches a public-policy initiative**

Informs federal policy makers about RLS, with three main goals in mind: increasing funding for research, protecting appropriate access to opioid therapy, and expanding physician education and public awareness.

**2020**

**Over 3000 RLS patients and 342 partners respond to RLS Patient Odyssey Survey II**

The survey seeks to evaluate the impact of RLS on quality of life for patients and their partners.

**RLS Foundation adapts to COVID-19**

Establishes weekly Virtual Support Group meetings held on Zoom to connect the worldwide RLS community.

**First Virtual RLS Summit**

12 speakers with a wide range of clinical knowledge as well as respected thought leaders in RLS research educate over 300 participants.



**First RLS Virtual Hill Day**

45 RLS advocates from 18 states contact 105 legislative offices to educate our legislators about RLS and to ask for their support on key legislation important to the RLS community.

**2014**

**Foundation conducts the first RLS Patient Odyssey Survey**

This survey is the first to evaluate the impact of RLS on quality of life from the perspective of individuals with RLS and loved ones who care for them.

**2015**

**Foundation relocates to Austin, Texas**

**RLS: A Guide for Teens published**



**2016**

**YouTube channel established with RLS and Augmentation video and My RLS Journey shorts**

**2018**

**National RLS Patient Symposium Hosted by Scripps Quality Care Center in La Jolla, CA**



Ten RLS experts educate over 180 participants.

**Mayo Clinic Proceedings publishes Guidelines for the Appropriate Use of Opioids in Refractory RLS**

**2019**

**First RLS Patient Hill Day**

30 RLS patients visit 45 congressional offices representing 16 states and including key members of committees that shape health policy.

**2021**

**Mayo Clinic Proceedings publishes New Algorithm for Treatment of RLS**

Lists alpha-2-delta ligands and iron therapy as first-line RLS treatments; dopamine agonists become second-line treatment.

**Second Virtual Hill Day**

80 RLS advocates from 30 states contact 101 legislative offices.

**2022**

**University of Pittsburgh Medical Center (UPMC) certified as the tenth US based RLS Quality Care Center, and expands the network to 12 QCCs**

**RLS Foundation celebrates 30 years of support and service to the RLS community**



## The New NIH Sleep Research Plan

By Linda Secretan, RLS Foundation Board of Directors Member and Support Group Leader

Have you ever waited and waited for a project to come to fruition? Haven't we all? Six years ago, I reported to you about my role as a member of the Sleep Disorders Research Advisory Board (SDRAB). The RLS Foundation has an intimate connection with the birth of this board, which came into being when Congress passed the National Institutes of Health (NIH) Revitalization Act of 1993.

Personally, I prefer the little-known version that says SDRAB owes its birth to the efforts of RLS heroes and former board members Bob Waterman and Bob Balkam.

What we at the RLS Foundation know is that they spent hours, including a famous rainy day in the early 90s with squelching shoes, pounding the halls of the NIH, trying to wake up our nation's health research agency to the urgent realities of RLS, a disease known to a tiny number of the thousands of people who suffer from it and an even tinier number of practitioners who recognize it. That the two Bobs prevailed may be evidenced by the congressional mandate in 1993 that the NIH form the SDRAB to produce a research plan for conducting and supporting sleep disorders research, and to revise it as appropriate.

Congress further mandated that the board of 12 include four people "representing the interests of individuals with or undergoing treatment for sleep disorders."<sup>1</sup> Since that time, the RLS Foundation has had a presence on that board, with a member as a patient advocate! The SDRAB's first Research Plan appeared in 1996. Revisions "as appropriate" appeared in 2003 and 2011. Since there were six to seven years between revised plans, I arrived at my first meeting in December of 2016 with a sense of urgency to get the next revision launched.

We met often in the next four years, sometimes remotely and twice a year in person. From the perspective of the past two years of COVID-19 limitations on travel, I now recall those face-to-face meetings with pleasure, despite the onerous two days of travel forth and back to my home in Idaho. During my term, all four of the patient advocates were women, representing restless legs syndrome, sleep apnea, narcolepsy and circadian rhythm disorders.

We formed a solid bond as "sleep sisters" and have continued to stay in touch. As patient advocates, we fought hard on behalf of patients with all sleep disorders, reminding those members of the board from scientific disciplines about the people behind the diseases, and providing insight from our lived experience.

The project that engaged us at every meeting finally resulted in the release of the new NIH Sleep Research Plan<sup>2</sup> in December 2021. We sleep sisters took pride in our part and felt a good

deal of satisfaction when the entire board from 2016–2020 was recognized at the end of the report.

The time it took to produce the new Research Plan no longer seems excessive in light of the burgeoning research on sleep, including the 2017 Nobel Prize in Physiology or Medicine for circadian rhythm research, links from the human genome project related to sleep disease, and healthful sleep finally being recognized as an essential goal across our lifespan. The plan itself is forward looking, with five Goals and nine Critical Opportunities.

The Research Plan might not replace your favorite bestseller, but it is interesting reading, nonetheless. Give it a read at [www.nhlbi.nih.gov/sleep-research-plan](http://www.nhlbi.nih.gov/sleep-research-plan). The goals have at their heart what the RLS Foundation's Scientific and Medical Advisory Board has long recognized as essential elements in advancing knowledge about RLS: More scientists need to prioritize sleep research, and more young investigators need to become passionate about sleep disorders.

One idea that might especially gratify our RLS community is within Goal 2: research for the treatment of sleep disorders and development of novel therapies. Another idea within Goal 4 mirrors part of our own mission: to increase awareness! Marishka Brown, PhD, the new director of the National Center on Sleep Disorders Research (NCSDR), gave a congressional briefing in January 2022, part of which still has me smiling. Dr. Brown asked the members of Congress to imagine optimal health as a portico upheld by three columns. When I saw Sleep envisioned as one of the columns, I remembered that in my advocate voice, formed and informed by our RLS Foundation's mission, I suggested that we promote sleep awareness by riding on the coattails of the successful campaigns to elevate Nutrition and Physical Activity as essential to good health. Since the scientific members of the SDRAB at the time didn't think much of this homely idea, I was especially happy to see Sleep at last imagined as a foundational part of good health. Have a look for yourself! (See diagram on page 7).

So, the new Research Plan is a satisfying document – mostly. While Goal 2 mentions circadian rhythm disorders, narcolepsy, sleep apnea and insomnia, there is no mention of RLS except where it appears after my name as representing the RLS Foundation. This omission illustrates the real need for continued advocacy work.



Linda Secretan

*continued on page 7*



There is such good up-to-date information to be had at NINDS, one might ask why restless legs syndrome research, and even all sleep research, isn't located there. That may go back to the mysteries still swirling around our RLS heroes' long journey to seek recognition for RLS. As Bob Balkam told me a few years ago, when he and Bob Waterman went to NINDS as a logical place to talk about a neurological disorder, they were told to go away; no one wanted to hear about this thing called restless legs syndrome!

Where they finally landed isn't as important as that they did find a place for us, along with other sleep disorders, at the NIH. We have been treated with respect there, and our voice is heard, and will continue to be heard, from the newest RLS presence on the SDRAB: RLS Foundation Board member Jeffrey S. Durmer, MD, PhD.

As the new Research Plan rolls out, we might exercise some activism at the NIH. Let Dr. Brown and the NCSDR know that you want better links and more prominent recognition of restless legs syndrome. Narcolepsy affects an estimated 1 in 2,000 people in the U.S. Sleep apnea is serious and needs to be treated for the 25% of men and 10% of women who have it, but at least it can be readily diagnosed and treated. Up to 3% of adults suffer from a circadian rhythm sleep disorder (CRSD) and may account for 10%–16% of people who have a sleep disorder. Restless legs syndrome? You know the numbers. It is a disease that affects 7%–8% of the population, with 2–3% requiring daily pharmaceutical treatment to manage unrelenting



symptoms. Yet, many individuals experience delays – nearly 13 years of needless suffering – to obtaining a correct diagnosis and subsequent treatment. This includes children, too.

Let's get busy! Celebrate our contributions to sleep awareness and support for research as we continue to advocate for RLS awareness, better treatments and ultimately a cure!

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<sup>1</sup> Congressional language establishing the National Center on sleep Disorders. <https://www.ncbi.nlm.nih.gov/books/NBK19959/>

<sup>2</sup> National Institutes of Health Sleep Research Plan <https://www.nhlbi.nih.gov/sleep-research-plan>

## RLS Research Grant Program Committee to Review Proposals

In January, the RLS Foundation's Research Grant Program announced the opening of the 2022 funding cycle for the program. Researchers from around the globe submitted letters of intent, and five primary investigators were invited to submit a full proposal for funding consideration.

The Foundation's Research Grant Committee will conduct a rigorous review of the proposals, and the Foundation will announce any grant awards in July.

Since the program's inception in 1997 the RLS Foundation has funded 49 grant proposals totaling nearly \$2 million in funding. "As we celebrate the Research Grant Program's 25th Anniversary, we thank our members for supporting RLS research by our committed RLS researchers," says Karla Dzienkowski, executive director.

These gifts, above and beyond member dues, have led to the discovery of the first RLS gene variant (BTBD-9); the establishment of the RLS

Opioid Registry; better understanding of the RLS and adenosine relationship; and a study using the D1 receptor-specific antagonist in the brain as a potential medication treatment for augmentation. They also supported an economic evaluation of RLS that found physician training in medical school to diagnose RLS is cost-effective and improves patient outcomes.

In addition, the brain donations made by individuals with RLS to the RLS Foundation's Brain Bank (before the National Institutes of Health revised the US Brain Bank System) have led to breakthroughs in the relationship between low brain iron and RLS, and the emergence of iron therapy as a first-line treatment for RLS. If you would like to make a tax-deductible contribution to support the RLS Foundation's Research Grant Program, please visit [www.rls.org](http://www.rls.org), or contact the Foundation at [info@rls.org](mailto:info@rls.org).

## RLS Augmentation: Potential New Therapy

The drug ecopipam shows promise for bringing relief to RLS patients who develop augmentation, a common side effect of dopamine medications.

Stefan Clemens, PhD, HdR, a professor of physiology at East Carolina University, is a member of the RLS Foundation's Scientific and Medical Advisory Board, and chair of the Foundation's Research Grant Committee. Regarding the worsening of RLS symptoms known as augmentation, Clemens developed the hypothesis, "Augmentation may be a consequence of increased D1-receptor activation in the nervous system" and that "identifying a new pharmacological target that specifically tackles the long-term side effects of standard dopaminergic treatments in RLS may keep the treatments effective for a longer time or avoid augmentation altogether."

In other words, a dopamine-1 (D1)-receptor antagonist medication might be a new way to treat RLS and the symptoms of augmentation.

This new concept was first presented by Clemens and his group at the 2015 meeting of the International Restless Legs Syndrome Study Group. In 2016, a small pilot study funded by the RLS Foundation and performed by William Ondo, MD, suggested a positive clinical outcome when patients with RLS augmentation took ecopipam, a D1-receptor antagonist drug.

Clemens obtained a US patent for ecopipam to treat RLS augmentation, and East Carolina University has entered into a licensing agreement with Emalex Biosciences to study this first-in-class medication.

Many regular readers of *NightWalkers* know the basic facts about RLS treatments and the risks of augmentation, but a bit of history is useful to understand the importance of the new approach.

For the 7% to 8% of the adult US population affected by RLS, some 3% need regular daily medication to control their symptoms. The Food and Drug Administration (FDA) has approved three dopaminergic drugs (pramipexole, ropinirole and rotigotine patch) for the treatment of RLS, and for decades these medications were considered first-line therapies for RLS.

Unfortunately, recent research has shown that of the patients on dopaminergic drugs, 7-8% per year develop augmentation so that by 10 years, almost 80% will be augmented and will experience a worsening of their symptoms caused by the drugs themselves. Augmentation typically includes an earlier onset of symptoms, an increase in intensity, a shorter period of rest or inactivity before symptoms start, and the involvement of other body parts (arms, torso or face). There are no FDA-approved medications for the treatment of RLS augmentation.

New clinical guidelines published in 2021 in the *Mayo Clinic Proceedings* no longer recommend dopaminergic drugs, but rather

name iron and alpha-2 delta-ligands, such as gabapentin, first-line treatments for RLS. When a patient's RLS becomes unresponsive to first- or second-line therapies due to augmentation or other side effects, it is considered refractory (resistant to treatment), and a low-total-daily-dose opioid therapy is the only option currently available. That is why new approaches and new drug therapies are urgently needed.



Stefan Clemens, PhD, HdR

According to Clemens, ecopipam works by selectively blocking the dopamine D1-receptor subtype, whereas other dopaminergic medications that are used to treat RLS activate other dopamine receptor classes, in particular D3 and D2 subtypes. D3 and D2 receptors mediate inhibitory actions in the nervous system, meaning that they reduce excitability and thus reduce RLS symptoms. Over time, however, those effects wane and the nervous system responds with an upregulation of the D1-receptor subtype, the target of this new drug. In contrast to D3 and D2 receptor-mediated actions, the D1-receptor subtype mediates excitatory action in the nervous system, thus increasing its excitability and increasing the severity of the symptoms. The new drug, ecopipam, is thought to reduce the activation of the D1 receptor and in turn decrease the severity of augmentation symptoms.

The RLS Foundation's executive director, Karla Dzienkowski says, "RLS augmentation is an untoward side effect of dopaminergic therapy. The potential for a new treatment for this side effect gives hope for the future for those living with the daily impacts of RLS augmentation. It could be a game changer."



## Board Spotlight: Paul Rochester

By Clara Schlemeyer, RLS Foundation Program Coordinator

*Paul Rochester is an angel investor, public and private board member, and mentor to CEOs from high-tech companies and founders at all stages seeking growth and significance. He is a trusted business advisor to numerous companies and active board member to another half dozen. Rochester brings to the board his business experience, mentorship and leadership skills, which are all invaluable to the RLS Foundation. We recently spoke about his experience on the RLS Foundation Board of Directors.*

**Q: How and why did you get involved with the RLS Foundation?**

**A:** A friend named Bob Waterman introduced me to the Foundation. You know Bob as a former chair of the board and founder of the RLS Foundation Research Grant Program. Bob and I were discussing different things when I mentioned that I had restless legs syndrome. He kind of perked up and said, “Oh, I have that, too!” So, we talked about our experiences for a while, and then he said, “I know an organization that could really use you on their board,” and that was the RLS Foundation. Bob invited me and my wife to visit with members of the board. I was very interested in the work they were doing, and Bob convinced me that my business experience would be a great addition. That was about five years ago.

**Q: How has joining the board impacted your RLS journey?**

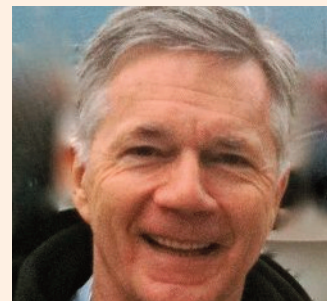
**A:** You certainly know that you're not alone! I have learned so much about the disease, the different treatments and the promising research being conducted. I finally switched medications to a therapy that involves opioids. I was very nervous about doing so, especially with the stigma surrounding opioid use. I learned that many others were taking opioids for their RLS, including other board members, which made me feel more comfortable. I have met a lot of amazing physicians as part of the board process, Dr. Chris Earley included. In addition, I have had the opportunity to speak with some of our very generous donors to thank them for their support. I always enjoy having a conversation with them about their experience to understand how the Foundation can help in their particular situation.

I don't think the world understands RLS. When I tell someone that I have RLS, they often don't know what it is. When I talk to someone who has RLS, especially a donor, they will tell me how miserable they've been and what they have been through to find a treatment plan that works for them. Serving on the board and speaking to others with RLS, you certainly appreciate that this is a very distressing disease, and the ramifications affecting daily life are often misunderstood.

**Q: What do you enjoy the most about working with this board?**

**A:** It is so great to be around smart people who are passionate and share a common cause. That's the way I see it. Carla Rahn Phillips, our current chair, and Karla Dzienkowski, our executive director,

are both incredible and very driven. It is nice to be around people who are working hard to change the public perception of RLS, to educate the medical community; and are committed to empowering those with RLS with the information they need to advocate for themselves.



Paul Rochester

**Q: How has your experience with managing high-tech companies helped you on this board?**

**A:** Well, it's different in many ways, but we have a lot of the same challenges. At the Foundation, we have a very different product; information is our product. As for my high-tech management experience, I hope I have contributed to the Foundation's vision, mission and process of setting lofty goals.

**Q: Where do you see the board in 2022 and beyond?**

**A:** I expect some new members to join. We lost two great board members last year who passed away: Bob Waterman, former chair emeritus; and Ron Anderson, who was new to the board but brought enthusiasm and fresh ideas. In addition, Ron Barrett rotated off the board after serving two terms as treasurer. While some people may drop off after multiple terms, new folks will join and bring a whole new perspective. We have all missed holding meetings in person. I am hoping to attend an in-person meeting, maybe this year, and looking forward to it!

## My RLS Experience: Quite a Spectacle

By Randy Vermillion, RLS Foundation Member since 2015

The torture I endure in the evening can be quite a spectacle.

When my RLS symptoms are mild – understand, my symptoms are never far from me – they are just a dull nuisance. People seated next to me will not know I am suffering.

However, if the symptoms are not mild, it's not just a "have-to-move-my-leg" sensation or a trivial movement that occurs. There is a pain that drives my leg to be moved. When my symptoms are bad, an involuntary call is made for an RLS leg jerk. I'm sure my body doesn't request permission from my brain. About every 20 seconds, I am totally immersed in a complete limb movement that comes with both a dull ache and a sharp painful sensation. At the tail end of that building sensation, I am consumed with the pain. Every 20 seconds the sensations build until my leg jerks in a painful, sometimes dramatic fashion.

After the release of that pain (the leg jerk) I am back to normal! For about a second. The sensations return and begin building all over again. Standing helps. Standing changes the dynamic and my situation is frequently better, but only by a little bit. But still, it is better. And I am usually standing at social events: parties, family get-togethers, etc.

About that leg movement: Spectacle is a good descriptive word, because the movement itself is no small action. Sometimes I feel as if I could take out Bruce Lee!

The medications I am prescribed help. They help me survive. I can't imagine my life without them. But there is a cost – I don't mean monetarily; I mean in side effects. In reality, I would take the relief regardless of the side effects. Luckily there are different medications to work with.

Understand first that everybody is different. Different meds and med combinations work differently for each person. It can take a frustratingly long time to arrive at an optimal dose or combination of doses that are effective. Be sure to work with a healthcare provider who doesn't move too slowly – or too quickly, as many of the drugs aren't at peak efficiency when they are started.

I unfortunately have been on nearly every medication and every medication combination. I remember when I was given my first med years ago. Decades ago, actually. Every evening I would stand behind the couch while my wife and I spent time together, watching TV or talking about the day's events. Every night for about three hours I would stand, rocking back and forth to alleviate the symptoms, and she would sit on the couch. She is a beautiful, caring person and an RN.

One day after some successful research, she came home with a Neupro patch. We were just beginning to learn about RLS, and she tied my behavior to a possible resolution. After I put on the patch, maybe 20 minutes later, I didn't need to rock back and forth. I didn't have symptoms! I gave sitting down a try. My symptoms were gone, and I was sitting down!

Fast forward to about a year ago. The Neupro patch no longer worked for me. Over time, as the disease aged with me, I had tried most of the meds used for combating RLS. I had been on pramipexole, gotten away from it and was back on it. Pramipexole is a dopamine agonist, and my symptoms got really bad. I had never augmented so I didn't know what was occurring.\* The very meds that were controlling my symptoms began to make them worse. Pramipexole was the cause, in this case, and I learned removing it in "cold turkey" fashion was the best path for me.

The plan was to make pregabalin my medication. First, though, we needed to get the pramipexole out of my system. I cannot describe accurately the pain and fatigue I experienced in the next seven days. It would be three nights before I slept. All pain, no sleep – not even a wink. And, I mostly stood through the night. Right? I had to stand for most of the overnight! That, and sometimes I lay on the floor and writhed in pain, just to mix it up. Sleep eventually overcame pain on the fourth day, and I fell asleep for six hours! It would be two more days until I slept again. It was about then that pregabalin was introduced and started being effective.

Soon, though, I wanted an alternative because the side effects were taking a toll. During an RLS support group meeting, I learned methadone could be effective. My healthcare provider prescribed it for me. It was introduced slowly, and the combination is proving effective. Not long after that I began getting woken up by symptoms. So, we introduced a small amount of pramipexole.

Being woken up in the middle of the night with symptoms had not occurred before, until very recently. And, unfortunately, I've also begun experiencing symptoms in my arms and core occasionally. Overnight, usually after 1 am, I wake to the symptoms. Right now, for example, I am editing this draft because I had to get out of bed. It's a reminder that I do not think I have ever been 100% symptom free except for short amounts of time.

Previous to my current provider, I was being seen in the neurology department of a major medical facility. I started asking questions when we failed to successfully address my changing symptoms. I did learn they had other RLS patients, but that I was their most challenging case! That news, plus their slow decision process and their policy prohibiting prescribing methadone, made me want to get some new eyes on my condition. I understand a cautious approach but not at the expense of living with symptoms for longer than necessary. I decided to look for a care provider that might be a better fit. The torture I endure in the evening can be quite a spectacle.



Randy Vermillion

*continued on page 11*

The provider I selected does prescribe methadone, an opioid. This class is often the last line of defense for someone experiencing severe symptoms who has worked through the other RLS medications.

Where am I going from here? Continuous monitoring of my condition, and hopefully a close match between treatment and relief! My current provider and the RLS Foundation community are on top of things. They are fighting the right wars, I think: getting the information out there, and pushing for and funding new and better treatments. I am thrilled to be with my current nurse practitioner. She is sharp and has a solid background in the field. She has lots of patients who are also seeking guidance and relief. She listens and attends to my changing symptoms. And, I'm not her worst patient!

I have learned of a study, written about in *NightWalkers*, that was conducted in Spain using dipyridamole, an anti-platelet drug. The study shows dramatic, positive results for participants with RLS symptoms. I am making the rounds with my cardiologist, my electrophysiologist, my coumadin clinic pharmacist and my RLS care provider to assess the risks and rewards of taking this drug in an off-label use. Cross your fingers. Mine are.

*\*Editor's Note: Augmentation is a serious side effect of dopamine medications. Symptoms occur earlier in the day, intensify, cause a shorter period of rest/inactivity before symptoms start and spread to other body parts. If you think you have augmentation, contact your RLS provider and do not make any changes to your current treatment plan until you have consulted your provider.*

One way that Vermillion takes his mind off his RLS is through photography. Our cover this month is one of his photos, and here are a few more. You can see more at [randy-v.com](http://randy-v.com)



**WANTED:**



**Great RLS Healthcare Providers**

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

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

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Address

City

State  Zip

Phone

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



## We Have to be Diligent

By Stephen Smith, PE, RLS Foundation Discussion Board Moderator and RLS Foundation member since 2013

Like many with RLS, it took a number of years for me to be diagnosed and start getting treatment. And like many, my first medication was a dopamine agonist, which caused me to augment a year later. While I was augmenting, I was honored to be asked to participate in the Foundation's project to create a film on augmentation. Near the end of the project, those of us who were interviewed found out that a short video was also created about each of us, titled "My RLS Journey." These videos can be found at <https://www.rls.org/get-involved/share-your-story>.

Years later, the severity of my RLS increased, so that I was having problems falling asleep. My RLS had also spread from my legs to my arms and abdominal muscles. I was seeing a neurologist at that time who was treating my migraine headaches, so I mentioned these new issues to her. Like everyone else, I didn't have words to describe the sensations, and, because my complaints involved my arms and abs and not just my legs, she performed an EEG to make sure that I wasn't experiencing seizures and then started me on a series of different prescription sleep aids, which were all ineffective.

My sleep was so bad that I was becoming very sleep deprived. My doctor ran out of sleep meds to try, so I decided to see a sleep doctor, where I was immediately diagnosed with RLS and periodic leg movements in sleep (PLMS) and was prescribed pramipexole. One year later, the pramipexole stopped working, so my sleep doctor switched me to the rotigotine patch. That worked for 15 months, after which I returned to pramipexole.

Life circumstances changed, and I met with a neurologist who specializes in treating RLS; I was prescribed methadone and started tapering off pramipexole. After about six months, I developed depression that was so severe that I was constantly thinking about suicide. My doctor and I decided that the depression was a side effect of the methadone, so I was switched to tramadol ER (extended release). After about six months on tramadol, I started experiencing different side effects and switched back to methadone. For the next few years, I alternated between methadone and tramadol to minimize the side effects but wondered whether there was an alternative that would avoid all this switching and the side effects.

I kept asking my different doctors (general practitioner (GP), neurologist and sleep therapist) what I could do to improve my sleep. Sleep studies showed that it was taking me hours to fall asleep and that once I did get to sleep, I was only asleep for about half the time.

Since my doctors all seemed to be out of ideas, I started doing my own research and found that poor sleep, depression, anxiety, low energy, poor appetite and nonexistent libido were all consistent with low

testosterone levels. My GP had checked these at the end of one of my tramadol cycles, but I was just barely within the normal range so they concluded I was okay. I wasn't convinced, and so I went to a clinic that specializes in men's health. I was now nearing the end of a methadone cycle, and they found that my free testosterone was well below normal and started me on a testosterone supplement. Within days, my depression had disappeared and I could feel happiness for the first time in years. My appetite and energy levels came back, as did my libido. I do not know if the symptoms were due to a sensitivity to methadone, but for now I am going to assume that they were.

So, the moral of this story is that I not only had to advocate for my own health, but I also had to research my own health challenges and then visit the appropriate specialists to confirm my suspicions – or not.

The most important lesson I have learned is that we all have to be diligent in our search for the best ways to manage our health. My RLS journey was only getting started with my first pramipexole pill. Augmentation and now my low testosterone levels have required all of my doctors and me to pay careful attention to the details of my RLS treatment.



Stephen Smith, PE

### MY RLS JOURNEY: STEPHEN'S STORY



Stephen discusses his passion for running while coping with RLS.

# Suggested Coping Methods for Restless Legs Syndrome

Restless legs syndrome (RLS) is a sensorimotor condition that can interfere with sleep and with periods of inactivity such as sitting. Treatments are available to control symptoms, but there is no cure. Finding methods to cope with your RLS symptoms can provide relief and significantly improve your quality of life.

Each individual's RLS is different, and the effectiveness of a coping strategy will vary among individuals. It may take several attempts, but it's important to find one or more strategies that work to manage your symptoms.

## General Coping Strategies

**Bedtime routine.** Find a nighttime routine that provides the most symptom relief and stick with that routine. A consistent bedtime routine is extremely important for managing RLS.

**Mind-engaging activities.** Mind-stimulating activities such as word puzzles, reading, knitting, playing an instrument, writing, playing video games or engaging in stimulating conversation are all effective coping measures. If symptoms persist, try doing these while standing or walking if they can be done safely.

**Warm or cold temperature.** Some people find temporary relief from a warm or cold bath or shower. Alternating warm and cold therapies is a strategy you can try to reduce problematic RLS symptoms.

**Exercise.** Temporary relief of symptoms can occur from light to moderate forms of exercise such as walking, stretching, yoga, leg lifts, romantic intimacy or biking. Moderation is key; vigorous exercise can exacerbate RLS symptoms. It is important to find the amount of exercise that works best for you.

**Over-the-counter creams.** There is no specific item that works best. Finding a product that relieves RLS symptoms is a trial-and-error process where the outcome is unique to each person.

**Massage.** Massage is a coping method that brings temporary relief from aggravating RLS symptoms. Your partner can learn what type and amount of massage is best for you and may enjoy being an active participant in your healthcare.

**Pressure application.** Some people with RLS report symptom relief from using products that apply pressure to their legs. These include compression support stockings, weighted blankets, alternating leg compression devices and elastic bandage wraps.

**Activity.** Moving your body while engaging in sedentary activities such as watching television may lessen your RLS symptoms. Try sitting on a rocking chair or yoga ball, walking, pacing or jogging in place.

**Trigger avoidance.** Avoid food, beverages (such as those containing caffeine or alcohol), nicotine and medications that can cause your RLS symptoms to worsen. See the RLS Foundation Medical Alert Card for medications to avoid and safe alternatives.

**Education of others.** One way to cope with RLS is to educate those around you about the disease. Explain your symptoms to your spouse, boss, friends, service personnel or co-workers. By learning about RLS, they will be more understanding and able to help you to engage in productive coping methods.

## Coping Methods for Travel

Travel is often hard for people with RLS. Schedule flights for midmorning or early afternoon before symptom onset. Maintain a consistent bedtime and waking routine. Discuss medication strategies with your healthcare provider before starting lengthy flights or traveling through time zones.

**Pre-travel practices.** Try stretching, walking or standing before you begin your travels. Be sure to avoid all RLS triggers. When packing, include plenty of activities to keep your mind engaged and any other items you use as coping strategies.

**Room to move.** When traveling on a plane, train or bus, make arrangements for special seating if available (such as an emergency exit, bulkhead or aisle seat). Take your RLS Foundation Special Accommodations Card to present to staff and attendants, and explain your need to get up and move from time to time during the trip. When driving, plan ahead to make stops every few hours.



## Find your individual coping strategies

### Common strategies:

- Establish a bedtime routine
- Keep your mind engaged
- Practice moderate exercise
- Massage affected areas
- Avoid known triggers



RAISE AWARENESS

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[bb.rls.org](http://bb.rls.org)



**Snacks.** Raisins, cereal and popcorn eaten one at a time and chewed slowly can help keep your mind engaged while you travel.

## Coping while at Work

To promote an RLS-friendly work environment, discuss your RLS and things that are helpful to manage symptoms with your managers and co-workers. A note from your doctor or an RLS Foundation Special Accommodations Card can help you explain your RLS to others in the workplace.

**Request a sit/stand workstation.** A variety of desks are available. Consider asking for a standing or flexible workstation to reduce the number of hours you spend sitting. If this is unavailable, try changing your seat height often to keep your legs from remaining in one position for too long, or get up and move around often.

**Work the night shift.** Most people's lives do not allow for a complete schedule upheaval, but some individuals with RLS find that working during the night is a good strategy. By keeping active all night, they find relief from RLS symptoms during the day. Night work can have unintended consequences; be sure to talk with your healthcare provider before changing to the night shift.

**Stay on your feet.** Find opportunities during working hours to stand on your feet. Standing during phone calls and meetings, using a standing desk and walking during breaks are coping strategies to try.

## What works for you?

Share your RLS coping methods with others by posting on the Discussion Board at [bb.rls.org](http://bb.rls.org) or by submitting your story to [info@rls.org](mailto:info@rls.org) to share in the Bedtime stories section of the RLS Foundation's acclaimed quarterly magazine, *NightWalkers*.

## Summary

Each person experiences RLS differently, and it may take several trials to find one or more coping strategies that work for you. Educate yourself and help others learn about RLS and what you do to manage your disease.

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

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

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# National RLS Opioid Registry: A Four-Year Window into RLS

By John W. Winkelman, MD, PhD

The National RLS Opioid Registry is collecting much-needed data on the efficacy and safety of long-term opioid treatment for RLS. Opioids have been shown to successfully treat the symptoms in patients with severe RLS, even when current approved treatments have lost effectiveness; however, there is a lack of substantial data to support opioids as a long-term treatment option. Given the current overdose crisis, data on the efficacy and safety of opioids for the treatment of RLS is needed so that providers and patients can make informed treatment decisions, especially in the face of increasingly strict opioid regulations.

## Research Goals and Methodology

By asking questions about specific opioid dosages over time (including the first stable dose) and validated questions about RLS severity (IRLS, RLS-QLI), we aimed to assess the efficacy of opioid medications in the treatment of RLS. By asking questions about specific side effects over time, we aimed to assess the tolerability and safety of opioid medications. By obtaining a medical and psychiatric history, a list of concomitant medications, and information on habits, behaviors, and mood, we aimed to further understand how these factors may influence the efficacy and safety of opioid medications in this population.

We originally set a goal to enroll 200 subjects within two years. To our surprise, there was enormous interest in this study and were able to enroll 500 participants in 18 months. Enrollment was closed in September 2019. Upon enrollment, participants completed a phone interview lasting approximately 45 minutes. Information about RLS symptoms, past and current medications, specific dosages, and opioid side effects was collected during this interview; in addition to more sensitive information related to psychiatric conditions and opioid risk factors.

Within seven days after the phone interview, participants completed a 30-minute online survey. This survey collected information on medical history, sleep behavior, habits, recreational drug use and mood. All information is kept on a secure server at Massachusetts General Hospital and the data and the digital key connecting the data with individuals' names is further secured. Only the principal investigator (JWW) and his employed research coordinator have access to identified data.

Every six months following the initial enrollment interview, participants are sent a follow-up survey that takes approximately 20 minutes to complete. The follow-up survey consists of a combination of questions from the baseline phone interview and baseline survey. The links to access both the baseline and follow-up online surveys are sent to personal email addresses.

## Enrollment

Enrollment was limited to individuals with a diagnosis of RLS, confirmed by the Hopkins-Hening Telephone Interview performed at

the start of the baseline phone interview; those taking an opioid, which may be confirmed by state prescription drug monitoring programs; and a past medication history that includes a positive response to dopamine agonists for RLS treatment, as confirmed by questions about past RLS treatments. The participant population is 57% female with the mean age being 65.1 years old (range 24–90 years). This population is primarily white and well-educated. Participants in the registry represent 44 different U.S. states and six countries.



John W. Winkelman, MD, PhD

## Longitudinal Follow-Up

Over the past four and a half years we have continued to send follow-up surveys every six-months to all remaining participants (excluding those who have discontinued opioids and those who are deceased). A total of 467 participants completed the 1-year follow-up survey (97.7% retention of eligible participants), 458 completed the 2-year follow-up survey (95.2% retention of eligible participants). Not all of the participants have reached their 3-year and 4-year anniversary but 358 of the former and 107 of the latter have completed surveys. Overall, 18 participants are considered lost to follow-up, 4 participants withdrew, 8 participants passed away, and 26 subjects have discontinued their opioid treatment. Retention is high as a result of participant commitment and our continuing efforts to encourage continued participation through vigilant follow-up with participants (emails, phone calls) as well as emailing of quarterly data updates. We play no role in the medical care of Registry participants, whose RLS treatment is provided by their local prescribers.

## Published Insights

Baseline, 1-year and 2-year longitudinal data have been analyzed from the RLS Opioid Registry. Nearly half of all participants are taking methadone and roughly one-quarter taking oxycodone formulations. Prescribed opioids are generally used at low doses (eg median methadone dose = 10 mg, oxycodone dose = 15 mg) with good efficacy.

Longitudinally from baseline to two years, the severity of RLS symptoms has remained stable in participants. Roughly 40% of participants increased their prescribed opioid dose during this time, though generally by small amounts. Larger dose increases (methadone dose increases of more than 7 mg or oxycodone dose increases of more than 17 mg) occurred in 8% of participants. These larger dose increases were present in those with one of the five following features: switching specific opioid medication from baseline to 2-years, stopping a dopamine agonist or gabapentin/pregabalin/ gabapentin enacarbil, having significant baseline insomnia, reporting a history of

*continued on page 16*

Major Depressive Disorder at baseline, and use of their opioid(s) for non-RLS pain. Our 1-year data was published in *Sleep* and the 2-year data was presented at the annual Associated Professional Sleep Societies (APSS) meeting in June 2021 (and has been submitted for publication). We have also analyzed data relating to the effects of COVID-19 on the severity of RLS symptoms just prior to, and following, the national pandemic restrictions in March 2020.

The strengths of the registry are clearly evident in the capacity of the dataset to assess a large population of RLS patients taking opioids for RLS. The Registry remains open to collaborators who desire to examine specific questions relating to RLS that can be addressed through its database. One such collaborator, Dr. Elias Karroum, will assess the effects of painful RLS on outcomes collected through the Registry.

## Conclusion

At this time, we are very pleased that the RLS Opioids Registry is obtaining the data we had hoped, and participant commitment is high, as demonstrated by low rates of attrition. We aim to accurately answer questions about the efficacy and safety of opioid medications for the treatment of RLS, and in doing so, we are keeping with the Foundation's mission to improve the lives of those living with RLS. I thank the RLS Foundation and its members for their continued support of the RLS Opioid Registry.

The RLS Foundation and member donations have supported the RLS Opioid Registry and Dr. Winkelman's work. Winkelman has been a member of the RLS Foundation Scientific and Medical Advisory Board for over 20 years and is director of the RLS Quality Care Center at Massachusetts General in Boston, MA.

## University of Pittsburgh Medical Center Becomes Quality Care Center No. 12

The RLS Foundation has certified the University of Pittsburgh Medical Center (UPMC) as the 12th center in its network of RLS Quality Care Centers.

UPMC joins 11 institutions in the US and Europe that are certified by the RLS Foundation as RLS Quality Care Centers. Through this program, the Foundation aims to improve diagnosis and treatment of the disease worldwide.

### RLS Quality Care Centers:

- Provide expert care to RLS patients
- Serve as information and referral resources for regional support groups and for healthcare providers who treat patients with RLS
- Support patients and families through educational offerings and literature
- Share information with other centers to improve clinical best practices
- Partner with the RLS Foundation on quality improvement projects to raise the standard of care for RLS patients everywhere

"We are pleased to welcome UPMC into the RLS Foundation Quality Care Center network," says Executive Director Karla

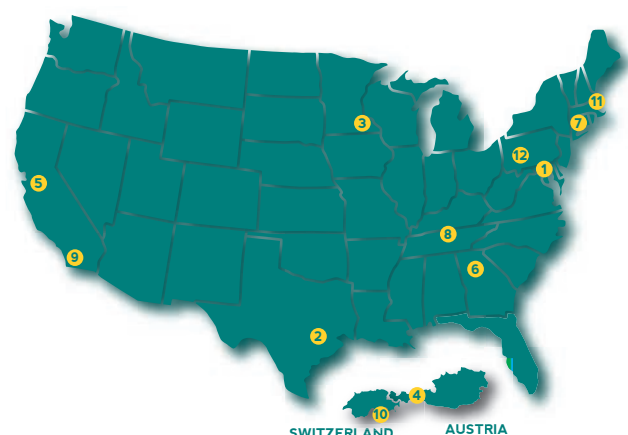
Dzienkowski. "People with moderate to severe RLS face many challenges in managing their symptoms. Having access to healthcare providers who are highly skilled and experienced in treating RLS is essential for patients to get adequate treatment and improve their quality of life."

An estimated 2% to 3% of adults need daily clinical treatment for RLS. As an RLS Quality Care Center, UPMC will serve as a destination for RLS patients who need expert medical care. "We are honored to receive this designation," says Avinash Aggarwal, MD, director of the Quality Care Center at UPMC. "Our goal is to provide the best and most comprehensive care for patients who have RLS. Designation as an RLS Quality Care Center certifies that we adhere to the highest standards of care and will identify us as having expertise to treat RLS at all levels of severity. We are particularly proud to be the first in our region to receive this designation." Dzienkowski adds, "Our goal is to help RLS patients find healthcare providers with expertise in disease management at an RLS Quality Care Center. We look forward to our work in partnership with UPMC to advance the quality of care for RLS patients."

To learn more about the RLS Quality Care Center Program, visit [www.rls.org/qcc](http://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



## Effects of the COVID-19 Pandemic on RLS

“Restless Legs Syndrome Severity in the National RLS Opioid Registry During the COVID-19 Pandemic.” Benjamin Wipper, Christopher Romero-Gutierrez, John W. Winkelman. *Sleep Medicine* 2021;12:786408. November 2021.

### The Background

The societal changes and effects of the COVID-19 pandemic have led to increased psychological distress, including anxiety and depression. As RLS symptoms are directly correlated with a person's degree of anxiety and depression, this study looks at the effects of the pandemic on RLS. The National RLS Opioid Registry follows 500 participants (98% based in the United States) who enrolled from 2017 to 2019 and who have used opiates for treatment of RLS. The registry administers surveys every six months, which track RLS severity, insomnia and mental health and provide a window on changes in RLS patients.

### The Research

The authors evaluated the survey results from the registry immediately before and during the pandemic using the International RLS Study Group scale (IRLS), the Insomnia Severity Index (ISI), the General Anxiety Disorder-7 (GAD-7) scale, and the Patient Health Questionnaire-9 (PHQ-9) – a commonly used scale that measures levels of depression.

In the first comparison, called the “between-subjects analysis,” 153 subjects who filled out a six-month interval survey pre-COVID (January–February 2020) were compared to 155 subjects who happened to fill out their interval survey in the early COVID period (March–April 2020). The IRLS scores were significantly higher for the early COVID surveys compared to the pre-COVID surveys. The ISI and GAD-7 scales also showed a trend toward worsening of these conditions in the early COVID group, but the difference was not statistically significant.

Second, the authors did a “within-subjects analysis,” which compared participants to themselves but at different time points before and throughout the pandemic. IRLS scores were higher than baseline in the spring and fall of 2020 but returned to baseline by spring 2021. The GAD-7 and PHQ-9 scores, however, showed higher levels of anxiety and depression in early COVID compared to baseline, and participants did not return to baseline by spring 2021. Overall, though, there were no increases in ISI scores; the authors found that those with worsened RLS symptoms also had higher scores on the ISI, suggesting the interplay of insomnia and RLS symptoms.

### The Bottom Line

In this study, RLS subjects experienced a worsening of RLS symptoms for at least the first six months of the pandemic but eventually returned to baseline by spring 2021. However, anxiety and depression worsened and had not improved more than a year after the pandemic began.

### Further Questions

What aspects of increased isolation early in the pandemic led to a worsening of RLS? Could it have been lifestyle effects, including inactivity, poor diet and increased alcohol consumption? Or was it the complex interaction of personal and societal stressors, anxiety, depression and disruption to sleep? Further examination of the effects on RLS of this seismic disruption to society may lead to a better understanding of the provoking factors for RLS and ways to mitigate them. Also, those in the opioid registry often have a history of augmentation from dopamine agonists or of more severe RLS in general. What was the effect of the pandemic on those with mild to moderate RLS?



J. Andrew Berkowski, MD

## Is Augmentation Associated with Smoking, Depression or Other Traits?

“Factors Associated with Augmentation in Patients with Restless Legs Syndrome.” Beatrice Heim et al. *European Journal of Neurology*. Online December 2021 ahead of print.

### The Background

Augmentation may be the most significant issue affecting patients with RLS over the past two decades. It is a phenomenon caused by long-term use of dopamine agonists leading to inevitable worsening of the condition, with a constellation of features including progressively increased severity, symptoms coming faster with rest or earlier in the night, and the spread of symptoms to other areas of the body. Augmentation may be accompanied by symptoms of impulse control disorder (ICD), another harmful side effect of dopamine agonists. This study investigates the demographics and neuropsychological traits in a group of patients who have developed augmentation versus those who have not yet developed augmentation.

### The Research

The study looked at 122 people on dopamine medications, exactly half with and half without augmentation. The authors examined demographics, neuropsychological questionnaires and behaviors like smoking. There was no difference between groups in onset age of RLS symptoms, alcohol use and illicit substance use. Two questionnaires, the BIS-11 and HADS, which reflect depression-impulsivity and depression-anxiety, respectively, showed no differences between groups. However, the group with augmentation had RLS for a longer time; higher scores on the IRLS (more severe); higher doses of the dopamine medication (roughly 3 times the dose of the non-augmented group); and a greater percentage who smoked cigarettes, with more years and quantity of smoking. The Toronto Alexithymia Scale (TAS-20) demonstrated that subjects with augmentation had more difficulty describing and identifying emotions and tended to focus emotions externally, compared to those without augmentation.



# In the News

By J. Andrew Berkowski, MD

## The Bottom Line

This study supports other research showing that augmentation becomes more likely the longer a person has taken a dopamine medication and the higher the dose. This study also highlights smoking as an impulse control behavior that is more common with augmentation.

## Further Questions

It is the old chicken-and-egg quandary: Does the type of individual who would smoke more heavily have the biopsychological predisposition to develop augmentation, or does augmentation cause individuals to smoke more? Given the findings about smoking, why wasn't alcohol or illicit drug use more common in the augmentation group? Is this related to the age of the individuals or

their European region? What explains why the lack of ability to recognize and deal internally with emotions was associated with augmentation, whereas anxiety and depression were not? It is essential to continue research aimed at understanding augmentation, including brain biology as well as behavioral and psychological changes during, and in recovery from, augmentation.

*Dr. Berkowski is a member of the Scientific and Medical Advisory Board of the RLS Foundation and is the new In The News columnist. He is a sleep specialist at ReLACS Health, a direct specialty care clinic specializing in the virtual care of RLS and complex sleep disorders, and currently serving patients in Michigan and Ohio. Follow his blog at [relacshealth.com](http://relacshealth.com).*

## Together We Are Strong

The RLS community really showed up for Virtual RLS Advocacy Week on April 4–8. With help from the Health and Medicine Counsel (HMC) in Washington, D.C., the Foundation was able to virtually meet with nine U.S. congressional offices! In states from California to Florida, nine passionate advocates from the RLS community stepped up to tell their story to the appropriate staff member for their representative.

Linda Secretan, RLS Foundation board member, met with Janessa Tolman and Jocelyn Francis from the office of Sen. Jim Risch of Idaho. She says that both were very engaged and interested to learn more about restless legs syndrome. Since sharing her compelling RLS story, Secretan encourages all in the RLS community to participate, saying, “A sure cure for that ‘all alone’ feeling is sharing your story. As constituents we have power. Our legislators are truly interested in and responsive to our personal story of RLS. Join us in Advocacy Week. Tell your own unique RLS story. Together we are not alone. Together we are strong!”

RLS Foundation Board Chair Carla Rahn Phillips joined each meeting to provide background information about the Foundation while adding her inspiring 40-year journey living with RLS. “Phillips added valuable information about the Foundation and allowed the staffers to hear first-hand the very real and negative impact of untreated RLS,” says Clara Schlemeyer, RLS Foundation program coordinator.

Phil Goglas of HMC concluded each meeting with great urgency and clarity. He succinctly articulated the Foundation's legislative priorities and made sure the staffers had all the follow-up information that they needed.

*“Advocacy for the RLS community means to educate ourselves, families, and friends about this disease that robs us of a normal life. However, this Advocacy Week at the Foundation has offered an opportunity to virtually inform our congressional members around the country in a personal explanation of this debilitating disease and how it affects our entire lives. Thank you for giving me the voice to represent those who desperately seek help in coping with RLS.”*

— Roberta Kittredge

Although Virtual RLS Advocacy Week is over, the work continues. The Foundation works hard year-round as Goglas and his team at HMC attend meetings on Capitol Hill and keep the Foundation informed of any upcoming policy or legislation affecting the RLS community. You can be an advocate today by writing a letter, making a phone call or visiting your representative's local office.

Advocacy is a key component in letting others know about issues that are of importance to you and your healthcare. “We each need to do our part and let our representative know what they can do for us, their constituents!” says Schlemeyer. “Thank you to the nine amazing advocates who stepped up and shared their RLS story.”

The very first RLS Advocacy Day on Capitol Hill took place in 2019. Over two days, 30 members of the RLS community met with a total of 45 congressional offices representing 16 states from across the country and including key members of committees that shape health policy. The Foundation looks forward to the next Hill Day to make even more connections with lawmakers.

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

I am 81 years old and have suffered with restless legs for over 50 years. The symptoms were classic, and I spent many nights walking or standing. Some nights I could not lie down or sit most of the night. For the last 10 years, the attacks came almost every night; three hours of interrupted sleep was the best I could hope for. I tried every medication available, like pramipexole, Requip, muscle relaxants and others. I was really getting quite desperate.

On the internet, I found that some people had done well using oxycodone. Reluctantly, my doctor prescribed oxycodone, 20 mg a day, which worked very well for a few months. The biggest drawback was extreme constipation. Then I started to require more and ended up taking 40 mg\* a day for about six months. The drug kept the restless legs attacks down in number and severity, but after almost a year of taking the oxycodone, I started to get serious side effects. I would be burning up one minute and have to stand outside in the snow, and the next minute I would be chilled to the bone and wrapped in a blanket with the furnace on high.

The cold sweats and icy chills became intolerable. I just had to get off the oxycodone, which I did. That took two months of misery, but the payoff was worth it. My doctor found a short study of restless legs patients who found that taking a drug to lessen the oxycodone withdrawal symptoms also helped stop the restless leg attacks. I started taking one pill a day about one year ago, and I have had no more restless leg attacks. The drug that was prescribed was buprenorphine-naloxone, 2–0.5 mg. It comes in a tiny film or pill you dissolve under the tongue. The film made me a bit nauseous, but I had no problem with the pill. I found it worked best for me to split the pill and take half every 12 hours. The drug is very constipating, but polyethylene glycol 3350 every three days and one Movantik pill, plus five glasses of water a day solve that problem. I want to stress that my restless legs were very severe. I consider it a medical miracle there was a drug that gave me relief from a miserable disease. I hope this helps someone out there. – Ron

**\*Medical Editor's Note:** Opioids are quite safe and effective at low doses, generally no higher than 30 mg, but some patients will get side effects especially at higher doses. The constipation can typically be managed with over-the-counter treatment.

Several years ago, I started developing RLS. I am 68 now. I sat twitching in front of the TV near bedtime, but, lucky for me, when I went to bed it subsided. (Dad had it pretty bad and thought it could be my turn, genetically speaking). I mentioned it to my general practitioner (GP), and he prescribed pramipexole. Within a week, I was regretting the decision, and I quit the pill. My legs started to itch constantly; weakness set in, making me feel like not getting out of bed; and RLS didn't go away at bedtime anymore. My GP didn't

think it was the pill and started testing nerve conductivity, and then an MRI found some stenosis, indications of peripheral neuropathy, yadda yadda.... Meanwhile, my RLS progressed. Exercise helped some, and I found that extremely hot showers were comforting. This went on for two or three years while my RLS was getting progressively worse. About four months ago, I had a thought: The hot showers might be too hot. I had been doing the same thing in the shower for decades. So, after three weeks of warm showers, I started to feel a bit of a change. After three months, I was having RLS-free evenings and nights. It's been four months now, and my RLS is really down to almost nothing. I could say more, but if you are taking near-scalding hot showers, STOP and switch to just warm, and give it a few months. It is working for me. Good luck. – Bob

**\*Medical Editor's Note:** The temperature of the showers or baths that help RLS patients vary considerably. While most like relatively hot water, some like cool, some like ice cold and some even alternate hot and cold water.

My RLS was getting so bad it was really depressing me, as it completely destroyed trying to have a relaxed evening. I researched the pharmacology and found that it was associated with low levels of magnesium, iron and dopamine. I didn't find taking magnesium supplements did much. Adding an iron supplement was a minor help, but the real breakthrough was improving my dopamine levels. I had read that some dopamine-boosting drugs lead to an unwanted rebound increase in RLS over time, but I have found one that doesn't seem to have that effect – at least not for me after two months. The drug is bupropion\*\*, which is approved as an antidepressant in the US but only as an anti-smoking aid in Australia, where I live. However, I found a psychiatrist willing to prescribe it for me, and to my delight it fixed my RLS within 24 hours. And my RLS has stayed fixed, except for occasional, very mild symptoms if I don't also keep up my iron supplements. And after two months, no rebound. As an added bonus, it also improves general mood and motivation levels. Worth a try. – Tom

**\*Medical Editor's Note:** Bupropion (brand name Wellbutrin) does have some dopamine agonist properties and often provides a mild (occasionally modest) improvement in RLS symptoms. It is one of the only anti-depressants that helps RLS.



# Ask the Doctor

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

**Q: Do you have any advice for getting rid of RLS during the daytime while I'm awake and trying to concentrate at school?**

**A:** RLS symptoms typically emerge at rest and in the evening. Since your concern is related to daytime symptoms, I assume that evening symptoms are controlled, suggesting a worsening during daytime. This may require a reassessment of your iron stores, including blood work for ferritin, transferrin saturation and iron-binding capacity, and a revision of your treatment plan to address daytime symptoms. More specific to daytime symptoms at school, you can increase your active participation in classroom assignments and engage in mental-alerting activities such as controlled breathing; in slow and controlled drinking of water through a straw; and in light-to-moderate physical activity in place, combined with movement during breaks.

*Dr. Denise Sharon*

**Q: What do you think about topical CBD (cannabidiol) for treatment of RLS symptoms?**

**A:** CBD is the nonpsychoactive chemical component of the cannabis plant. It is found in edibles and in oil formulation. CBD promotes relaxation and sleep but is not a treatment for RLS. A product with a combination of CBD and low-dose THC (tetrahydrocannabinol, the main psychoactive component of cannabis) is helpful in alleviating RLS symptoms when inhaled. In the US, the 2018 Farm Bill removed legal restrictions from hemp-derived CBD, but the use and possession of cannabis is defined as illegal by the federal government.

*Dr. Mark Buchfuhrer*

**Q: I am pregnant and have been suffering from RLS severely since the first week of the 2nd trimester. Is there anything I can do/take? Please help. I'm getting about two or three hours of sleep on a good night.**

**A:** RLS typically emerges or worsens during pregnancy due to fluctuations in iron levels. Pregnant women should obtain morning, fasting blood tests for ferritin and transferrin saturation (iron + total iron binding capacity). If the ferritin is < 75 ng/mL or transferrin saturation < 20%, pregnant women should consider an IV infusion of a strong formulation of iron that can be given as 1,000 mg in one or two infusions. This can be ordered by a primary care physician or obstetrician if they have access to an infusion center, or with a referral to a hematologist who can order this procedure. Iron supplements taken orally can be helpful but may take too long to help during the pregnancy.

*Dr. Andy Berkowski*

**Q: If you have poor circulation, can blood thinners have a positive impact on RLS symptoms?**

**A:** Blood thinners do not have an impact on RLS. Dr. Ferré's adenosine study and the more recent Dr. Garcia Borreguero study both evaluated dipyridamole as a potential RLS therapy, but the

effect on RLS likely is not through making platelets less active (thinning the blood) but rather through affecting the adenosine system. Further studies are needed to replicate study findings on larger groups of patients.

*Dr. Mark Buchfuhrer*

**Q: Would a procedure to reduce varicose veins help to reduce RLS symptoms?**

**A:** There are no surgical procedures to reduce or eliminate RLS symptoms. A British study found that painful legs attributed to varicose veins did not improve with surgery. Cosmetic appearance was the only benefit from the surgical procedure.

*Dr. Mark Buchfuhrer*

**Q: I sometimes feel the same symptoms in my arms and shoulders as I do in my legs. Does anyone else have this too?**

**A:** Arm symptoms are not uncommon in RLS. One study reported arm symptoms in about 30% of patients, although these tended to occur with more severe RLS. Arm symptoms are sometimes described as identical to leg symptoms but are often described a little differently, though they still qualify as RLS. Isolated arm symptoms, without any leg symptoms, have been reported but are extremely rare. Arm symptoms after years of leg symptoms may occur as a natural progression of disease or as a feature of augmentation, usually associated with dopaminergic drugs. Treatment of arm symptoms has never been formally studied but appears similar to treatment of leg symptoms.

*Dr. William Ondo*

**Q: Is the treatment of RLS with methadone safe and effective? Also, is it mostly considered a drug of last resort?**

**A:** Methadone is a safe and effective treatment for refractory RLS when opioid guidelines are followed. A 2018 *Mayo Clinic Proceedings* article, "The Appropriate Use of Opioids in the Treatment of Refractory Restless Legs Syndrome," provides guidelines for physicians and patients to follow to minimize risk associated with this treatment. When RLS becomes unresponsive to first- or second-line therapies, a thorough assessment should be conducted by you and your healthcare provider to rule out any factors that may be contributing to a worsening of your RLS. Then, opioid therapy should be considered as an effective and safe therapy for treating your RLS.

*Dr. Mark Buchfuhrer*

**Q: What are your thoughts about the use of magnesium to reduce nightly RLS symptoms?**

**A:** There are no credible studies that support the use of magnesium to alleviate RLS symptoms. However, there are lots of anecdotal reports from patients claiming benefit from this treatment, but it is not clear whether this is just due to a "placebo effect."

*Dr. Mark Buchfuhrer*



# RLS Support Network

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

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

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\*Member of RLS Foundation Board of Directors

## Register for a Virtual Support Meeting

Each month we host meetings at these times:

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

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

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## Publications

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

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

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

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