

NIGHTWALKERS

In search of a good night's sleep

Summer 2021

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SYNDROME
FOUNDATION

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“To plant a garden is to believe in tomorrow” - Audrey Hepburn

Twenty-nine years ago, the founders of the RLS Foundation believed in tomorrow, and their belief became the cornerstone for change in the field of RLS. Those pioneers put in place three goals to support the Foundation’s mission that have stood the test of time: increase awareness, discover better treatments, and support research leading to a cure.

Education and Awareness

An article by members of the Foundation’s Scientific and Medical Advisory Board (SMAB), “The Management of Restless Legs Syndrome: An Updated Algorithm,” was recently published in the July 2021 edition of *Mayo Clinic Proceedings*. Much has changed in RLS management in the eight years since the publication of the previous algorithm in 2013. The changes to the treatment and management of RLS, based on scientific evidence and the combined clinical experience of our SMAB members, are summarized on page three of this issue. The full article in *Mayo Clinic Proceedings* is open access, available free of charge to patients, physicians and other healthcare providers. Publication of the new algorithm is a testament to the Foundation’s commitment to providing the most up-to-date information to improve the lives of all individuals living with RLS.

Better Treatments

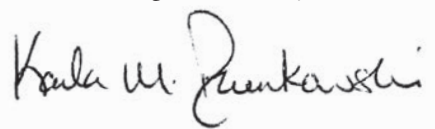
After much positive feedback from the first RLS Virtual Summit held in October of 2020, we will be holding a second RLS Virtual Summit on Saturday, October 9, 2021. This is a members-only, one-day online event that will highlight topics of importance to individuals living with RLS. One of the highlights of this year’s Virtual Summit will be a detailed explanation of the new treatment guidelines outlined in the updated algorithm mentioned above. The effective management of RLS does not benefit from a one-size-fits-all approach. With this in mind, our experts will discuss treatment guidelines for a range of cases, from newly diagnosed patients to those with complex or refractory symptoms

Research for a Cure

RLS research is made possible by members like you. You can take pride in knowing that your generous support has funded nearly \$2 million in grants to RLS researchers. With your help, those researchers have made important strides in understanding the complex relationships involving genetics, brain-iron regulation, dopamine, glutamate, adenosine and treatment strategies.

Future generations rely on us to take action today so that tomorrow will be free from the burden of RLS. As members and supporters of the RLS Foundation, we believe in that tomorrow.

We do this together, as always.



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



Karla M. Dzienkowski, RN, BSN
Executive Director

Honor Roll

The Restless Legs Syndrome Foundation is sincerely grateful for the donations we received in memory and in honor of the following individuals from March 30, 2020 through June 30, 2021

In Memory of:

Gladys Biron
Thelma E. Bradt
Elsie F. Brown
Helen A. Brown
Frank Connolly
Dan Daly
David W. Davis
Alice Ferries
Edward Glass
Dolores E. Kemp
John M. Kikta
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Michael McCormack
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Italo Silvestri
Loretta Louise Vanderhoff
Trevino

In Honor of:

Ginger Blackmon
Dr. Mark Buchfuhrer
Sheila Connolly
Dr. Brian Koo
Jason & Ben Moore
Arthur Walters

The Management of Restless Legs Syndrome: An Updated Algorithm

Restless legs syndrome (RLS) is a common neurological disorder affecting up to 10% of the population in the United States, with nearly 3% experiencing severe symptoms that require daily medical treatment. An article in the *Journal of Neural Transmission* in 2007 reported that it takes nearly 13 years from the onset of symptoms to the initiation of a treatment plan for RLS.

Much has changed in RLS disease management in the last eight years, which has led to the update of the 2013 RLS treatment algorithm by the Scientific and Medical Advisory Board of the RLS Foundation. The updated algorithm was published in the July 2021 edition of *Mayo Clinic Proceedings*, a leading peer-reviewed clinical journal widely read by physicians and often cited in scientific papers. Publication in this journal will ensure the availability of this information to a broad group of clinicians, including primary care providers.

Scientific discoveries since 2013 have led to the better understanding of RLS and new approaches to disease management that include:

Clinical Advancements

- Untoward side effects of dopaminergic therapy; knowledge and understanding of the long-term risks of augmentation, impulse control disorders and rebound
- Consensus guidelines for the iron treatment of RLS
- Consensus guidelines for RLS diagnosis, treatment and management during pregnancy and lactation
- Appropriate use of opioid therapy in low total daily doses for refractory RLS
- Improved RLS diagnosis, treatment and management in children and adolescents

Research Advancements

- Clinical trials for pregabalin and oxycodone
- Adenosine and RLS relationship
- Identification and replication of 13 new RLS risk genes and confirmation of six previously identified RLS risk genes using GWAS (genome-wide association studies)

These advancements relate to ongoing research into the underlying causes of RLS and the search for durable treatments and potential cures for the disease.*

The 2021 RLS treatment algorithm is divided into sections that outline detailed guidance on clinical best practices in RLS disease management, including:

- General treatment considerations
- Alpha-2-delta ligands and iron treatment as first-line therapies
- Iron treatment guidelines for RLS
- Dopamine agonists as a second-line therapy
- Treatment for intermittent, chronic-persistent, and refractory RLS
- Special patient populations and potential future therapies

The new treatment algorithm describes medication selection, use, dose and side effects. Decision trees and tables provide visual guidance for treatment consideration. Nondrug therapies and other approaches are highlighted, which include activities to stimulate the mind and the avoidance of medications and substances known to worsen symptoms. For example, RLS specialists who practice at certified RLS Quality Care Centers report that augmentation from certain medications is the number one reason that patients seek specialized care from a knowledgeable and experienced provider. The 2021 RLS treatment algorithm pays special attention to the use of combination therapies and the appropriate use of opioids in low total daily doses to treat refractory RLS – a common, yet manageable treatment challenge. For the first time, the new treatment algorithm also discusses RLS management in pregnancy, lactation and childhood.

The 2021 RLS treatment algorithm is a comprehensive approach to the management of RLS in the various stages of disease progression and across the life span. Michael Silber, M.B., Ch.B., lead author on the article and director of the Center for Sleep Medicine at Mayo Clinic, says, “This updated algorithm is based on current research, consensus documents and the combined practical experience of a team of practitioners highly experienced in the management of RLS. We hope it will provide practical guidelines for primary care providers and specialists who are needed to treat patients with this common and highly distressing disorder.”

The RLS Foundation has made this an open-access article, available for free download by patients, clinicians and researchers (see below). Executive Director Karla Dzienkowski says, “The publication of the 2021 RLS treatment algorithm is based on the latest scientific knowledge and clinical experience of RLS experts from around the globe who serve on our Scientific and Medical Advisory Board. I thank these members for their service to the Foundation and the RLS community and for their work on this seminal publication that furthers our mission and goals to educate and support RLS research leading to better treatments and a cure.”

*The RLS Foundation funds the only research grant program dedicated to RLS. Member support for the Foundation’s Research Grant Program has funded nearly \$2 million for 47 grants to RLS researchers, whose research forms part of these key advancements. A revised RLS Research Grant Program protocol will be announced later this year to further the quest toward a cure.

Thanks to the support of our members, the Foundation is able to make this important article "open access" – freely accessible to the public at no cost. We encourage you to share the article with your family, friends, healthcare providers and all interested individuals who treat and manage your RLS.



Download at www.rls.org/21Algorithm

The Rise and Fall of Dopamine Agonists

By J. Andrew Berkowski, MD

In the early 2000s, dopamine agonists emerged as a breakthrough treatment group for RLS, as they were very potent yet relatively safe and well tolerated in both short- and long-term studies, though we have come to find out that long-term is a relative concept. The overwhelming number of randomized trials and publications, combined with the clinical success of these agents, turned dopamine agonists into the clear choice for first-line medication of RLS. Dopamine agonists became so engrained into standard of care that the drug names became almost reflexive, as current medical students may attest. If you were to sneak into (or shall we now say “Zoom-bomb”?) a US medical school classroom today and ask for the first thing that comes to mind about restless legs syndrome, the answer would be: ropinirole or pramipexole.

With the publication of the updated 2021 RLS treatment algorithm (see page three), however, that answer is out of date. The RLS Foundation’s Scientific and Medical Advisory Board has relegated the former RLS therapy to the back of the line, because much has changed in the past two decades. Halfway through the first decade of clinical use of dopaminergic drugs, and even more so in the second decade, an insidious side effect called augmentation emerged with a vengeance. Augmentation, from the Latin *augere*, meaning to increase, is aptly named. This phenomenon causes patients not only to experience eventual ineffectiveness of a drug but also to endure a more severe form of the condition, which, in many cases, might not occur naturally. Over time, particularly at higher doses of the medication, augmentation of RLS symptoms frequently occurs.

Now that we have the two decades of experience to look back on, many experts think that augmentation with dopamine agonists is an *inevitable* process if someone is on the medication long enough. Doubling the is the fact that agonists cause a form of brain-dependence, in which patients cannot simply stop the medication and start something else. The withdrawal process can be long and arduous, because symptoms may become more severe as patients begin the process of lowering the dose. To get through the withdrawal process, the other treatment options that clinicians were hoping to avoid by using dopamine agonists then have to be used in most circumstances, and in much higher doses with greater potential for side effects. Fortunately, most patients recover substantially from augmentation once they have been completely off the medication for some time (usually, two to four weeks but up to months for some). But recovery is not always complete, and many are left with more bothersome RLS symptoms than before they started the dopamine medication in the first place.

Philosophically, this chain of events runs counter to the medical principle of “do no harm.” As RLS is generally a lifelong condition, starting a treatment that may make things worse in a few years, though providing short-term relief, should give any clinician or patient

significant pause. Unfortunately, the message about augmentation remains buried behind the compulsive (pun intended) use of dopamine agonists as standard of care. The medical field is slow to change, particularly with a paradigm shift of such magnitude. In 2015 and 2016, three of the major RLS organizations, including the International RLS Study Group, the European RLS Study Group and the RLS Foundation, began to publish consensus guidelines and recommendations regarding augmentation and began warning the medical community to avoid these treatments as first-line therapies. Nonetheless, around the same time, studies reported, and continue to show to this day, the dominance of dopamine-agonist prescribing, including as first-line treatment. While some RLS specialists are now avoiding the use of dopamine agonists, many providers continue to prescribe them, unaware of the warnings over the past several years.

The reasons for this are many and include everything from the lag of medical education behind rapid advancements, to insurers requiring a trial of dopamine agonists before other treatments are covered. Dopamine agonists constitute three of the only four FDA-approved drugs for RLS, with overwhelming clinical data showing their effectiveness. Yet randomized, placebo-controlled clinical trials – the gold standard for testing drugs – may only go on for a year or two, and what may work for the duration of the study may not work for the years beyond. Additionally, trials of some of the now first-line drugs – gabapentin, for example – are scarce compared to the dopamine-agonist juggernaut. At the same time, there are numerous barriers to the other RLS treatments now favored by the new RLS treatment algorithm: Iron infusions for RLS alone are hardly covered by insurance; alpha-2-delta ligands like pregabalin are defined as controlled substances in most states; and opioids (used to treat RLS since the 17th century) are caught in the crossfire of the war on opioids, making healthcare providers hesitant to prescribe them for cases of RLS for which no other treatments have worked.

Despite the obstacles, education of the medical field on this matter needs to continue. Medical students should reflexively think “check iron levels” when asked about RLS. The new 2021 RLS treatment algorithm is another step in the right direction in our era of rapidly changing science. You can help spread the message by sharing the new treatment algorithm, which is based on decades of scientific and clinical research. Take a copy with you the next time you see your doctor or talk to a friend or relative with RLS. This can speed up the process of change in the post-dopamine era.



J. Andrew Berkowski, MD

Restless Sleep Disorder: A Potential New Sleep Diagnosis

by Karla Dzieńkowski, Executive Director

In the 2013 Patient Odyssey Survey conducted by the RLS Foundation, nearly half (45%) of survey respondents reported the appearance of RLS symptoms before the age of 30. Recognizing sleep issues in childhood is important to prevent development of adverse mood, emotions, social skills, behavior and overall school performance in children and adolescents.

Restless sleep disorder (RSD) is a potential new sleep diagnosis for children and adolescents (ages 6 to 18). RSD represents a constellation of characteristics of disordered and disrupted sleep and often, impaired daytime function (tiredness, behavioral issues, poor school performance, etc.). Pediatric sleep researchers have developed eight criteria for a diagnosis of RSD:

1. Parent, caregiver, bed partner or patient gives accounts of “restless sleep.”
2. Movements of large muscle groups occur throughout the body and can include any combination of head and limb movements.
3. Movements take place during sleep or apparent sleep.
4. Five or more movements are observed during each hour of sleep.
5. Restless sleep is observed three or more times each week.
6. The patient exhibits restless sleep for a minimum of three months.
7. Restless sleep substantially impairs the patient’s life activities, including social, emotional, academic or occupational performance. Other effects include changes in emotional state, short attention span, tiredness, inattentiveness or lack of impulse control.
8. All behavioral, medical or sleep disorders have been eliminated as possible causes of the disrupted sleep, including a review of the patient’s current medications and dietary behaviors to determine whether the disrupted sleep may have another underlying cause.

All eight criteria must be present for a diagnosis of RSD. Restless sleep can co-occur with other disorders such as obstructive sleep apnea, asthma or eczema, so it is important to include screening for those disorders in the consideration of an RSD diagnosis.

Restless legs syndrome (RLS) shares similar features with RSD, such as difficulty falling asleep and staying asleep. Video polysomnography (videorecording of sleep studies) provides a visual picture that helps to differentiate RLS from RSD. In children with RLS, the primary visual feature is an increase in periodic leg movements; whereas in children with RSD, large body movements and repositioning that repeat throughout the night are highlighted on video. More importantly, in RLS, a verbalized “need to move” the legs while awake by the child or adolescent is the key diagnostic feature that is not characteristic of RSD.

In a 2018 study in the scientific journal *Sleep*, children with RSD were found to have low ferritin levels (lower than those found in pediatric RLS patients), and another study in 2021 showed RSD symptoms respond to oral or intravenous iron. Additional studies will further the understanding of this phenomenon and its possible relationship to the development of RLS.

Many adults with RLS report the emergence of RLS symptoms in their youth. RSD may account for some of these early symptoms that were part of their childhood and adolescence. If you suspect a child has a sleep disorder, a comprehensive medical evaluation by a pediatric sleep specialist will help to identify any potential sleep conditions that may be responsible for disrupting a restful night’s sleep.

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Ron Barrett Leaves His Mark on the RLS Community

By Karla Dzienkowski, Executive Director

Serving on the board of a nonprofit organization like the RLS Foundation requires talent, patience and time. Board members keep their eyes on the financial health of the organization, both short and long term; help spot opportunities and provide guidance to management; keep the group focused on achieving the mission; and provide support through personal donations and connecting with donors. Extraordinary board members also bring personal knowledge, experience and expertise to the role.

Ron Barrett, who serves as the Foundation's board treasurer and chair of the Finance Committee, is a case study for the perfect board member. His career is marked by his passion for scientific research and the search for medications to treat specific disease conditions. He has co-authored over 50 peer-reviewed journal articles and holds more than 50 United States patents. Under his leadership as a co-founder of the biopharmaceutical company XenoPort, the first nondopaminergic treatment for RLS — Horizant (gabapentin enacarbil) — was developed and received FDA approval. The drug is the only compound of its type approved for the treatment of moderate to severe RLS. Prior to his time at XenoPort, Ron also worked on new technology that led to drugs for two additional medical conditions.

His interest and expertise in RLS led him to leave retirement and join the Foundation's Board of Directors in 2017. His passion for the cause, combined with his business acumen, have been invaluable in professionalizing our entire financial operation. Preparing a budget, especially during a pandemic, is challenging for a nonprofit that depends entirely on donations. Ron helped reorganize the budget process to better understand exactly what comes in and what goes out. Throughout the budget development, Ron provided valuable feedback and asked the hard questions. He and the Finance Committee continue to provide guidance throughout the year. Ron has helped me grow as the executive director by his patient oversight; he has taught me to see how budget numbers express the work that we do in precise terms.

When individuals join the board, they are asked to think about the legacy they will leave behind for those who follow. Ron's gifts include his passion for the cause, how he models active engagement in governance, the strength of his board participation and the support he provides to other volunteers, board members, staff and me. As he leaves the Foundation's Board of Directors in September, after serving for five years, he leaves with gratitude from us all and with big shoes to fill.

Coffee with Karla

By Clara Schlemeyer, Program Coordinator

Zoom has become the new way for informal gatherings to take place when getting together in person isn't possible. Karla Dzienkowski, executive director of the RLS Foundation, hosted a second "Coffee with Karla" on June 17. Participation was limited in order to have meaningful conversations, but nearly two dozen people joined Karla from across the US and Canada.

Karla started by asking: "What do you want to see from us here at the RLS Foundation?" The responses were varied. We learned that many want more information on new treatments, medical marijuana and strategies for coping with RLS. There is interest in finding new ways to raise awareness. It was suggested that finding a high-profile spokesperson who can "normalize" RLS in the media would help to increase RLS visibility with the general public. Awareness and education among healthcare providers is another area of concern for all. It is critical that we find ways to include RLS education during training for new physicians, physician assistants, registered nurses and others providing patient care. The need for more RLS Quality Care Centers was also discussed. Karla was able to report that we hope to certify additional centers in 2021. Some of the other topics of interest included insomnia, depression, comorbidities and RLS mimics.

We've heard in the past that it would be useful to have a simple, short way to explain RLS to others. Something like an "elevator pitch" would help others to understand that RLS is real, that it is a serious

neurological disease, and that it requires a strong support system to find ways to cope with its symptoms. Then they might better understand those uncomfortable moments when RLS seems to have taken over your life.

Many on the call agreed that it is hard to explain RLS to friends and even family, or for someone without RLS to understand why it is difficult to sit through a whole movie, a road trip or an airplane ride. Put simply, sitting for long periods is impossible, which makes it very difficult to manage a relationship or enjoy a social life when you have RLS. It was suggested that a virtual support group meeting exclusively for family members and partners might be beneficial as an outlet for them to express their frustrations and to share stories about how they cope with the challenges they face, which are different but no less important than those faced by their loved ones who have RLS.

During the hour, Karla gathered a wealth of ideas about how to improve the RLS Foundation's services, what new webinar topics to add in the coming year and so much more. Watch for the next "Coffee with Karla," and be sure to come prepared with questions, comments and helpful suggestions on how the Foundation can better serve the RLS community. Thank you for your continued support. We can't wait to meet you!

Conversations with RLS Physicians: COVID Heroes

By Clara Schlemeyer, Program Coordinator

The COVID-19 pandemic has changed the world of medicine in many different ways. Specialists from four of our RLS Quality Care Centers recently shared their experiences with adapting to the major disruptions caused by the pandemic. While much of the world can work from home, these doctors have faced more complicated challenges to ensure that their patients continued to receive treatment. But how do you evaluate and manage patients while staying safe during a public health crisis? Drs. Mark Buchfuhrer, Christopher Earley, Brian Koo and John Winkelman discussed the ways they have provided care during the COVID-19 pandemic.

Christopher J. Earley, MBBCh, PhD, FRCPI, from the Johns Hopkins Center for Restless Legs Syndrome, not only has run into technology issues, but also feels that telemedicine doesn't allow the personal interaction that he requires with his patients. "From the patient perspective, the biggest problem was the technology. Young people do fine. The older patients may have a computer but no camera on it. They may have an iPhone, but they didn't know how to connect with it." But more importantly from Dr. Earley's perspective, telemedicine "is just not a good way to see and connect with new patients. Making the diagnosis and knowing what to do is not the problem, but I spend a large part of the visit telling patients what needs to happen. The majority are experiencing augmentation and will have to come off of the medications. I think that takes a real personal connection with the patient to convince them to trust me that things, despite getting worse, will get better. I don't think the virtual world is capable of carrying that message well. I prefer an in-person office visit."

Mark Buchfuhrer, MD, FRCP(C), FCCP, from the Stanford Sleep Medicine Center, said that telemedicine is now a third of his practice. He has quite an international practice, with patients from Canada, Mexico, South America and Europe. Although he can't prescribe medications outside of the US, he can make treatment recommendations for patients' local doctors to follow. "If I have an existing patient, I can follow them indefinitely through telemedicine. If I have a new patient, they have two choices. They can choose to only see me via telemedicine visits, and I can only recommend treatment — they will get prescriptions from their local doctor. Or they can choose to come into my office for an initial exam. Afterwards, I can prescribe and then continue to see them by telemedicine, in addition to making recommendations to their local provider."

John W. Winkelman, MD, PhD, from Massachusetts General Hospital, has found more positives than negatives in treating his patients during the pandemic. He said the transition to telemedicine was almost immediate using Zoom, which his patients have found to be fairly user-friendly. "Most of my

patients are over 70, and many travel quite a distance to see me. An office visit can be a significant burden for them, considering the time and effort to go to the big city, and deal with traffic and parking just to get to Mass General. So, they have almost unanimously said that they prefer to do telemedicine visits. Another positive is that shorter, more frequent check-ins to adjust medications are much easier to schedule. Also, it is nice for me to be able to see and meet my patients' family members, partners or caretakers, to get a number of perspectives on my patients' status. On the negative side, many had some technological challenges with video, but I was allowed to conduct telephone visits in those cases. Finally — again on the positive side — during the public health emergency the hospital allowed us to see patients who were out of state and couldn't travel to Massachusetts."

Brian B. Koo, MD, from the Yale Center for Restless Legs Syndrome, said, "The COVID-19 pandemic has been a challenging time for healthcare and healthcare providers. The practice of sleep medicine and care for restless legs syndrome patients is very amenable to video or telephone care, as the physical examination is often normal, and the communication and receipt of a thorough history is far more important than a physical examination." Dr. Koo has found that telemedicine works very well, and many providers and patients alike enjoy the convenience and are pleasantly surprised with the effectiveness of such visits. "While we have now reverted to in-person visits for about 80% of patient encounters, video and telephone have remained an option in the remaining 20% or so of cases."

One thing that all four physicians have seen in their practices is an increase in RLS symptom severity since the beginning of the pandemic. This is likely due to a number of factors brought on by the pandemic: isolation, stress, anxiety, grief, sleeplessness due to anxiety, or difficulty doing the usual type of moderate exercise that is so helpful for RLS.

The doctors also shared the greatest lessons they have learned from the pandemic: Dr. Buchfuhrer explained, "As a lung specialist, I gained a lot of respect for COVID, which attacks the lungs first. It leaves a lot of people with their lungs destroyed and on oxygen forever. Some have lost their senses of smell and taste and they may never get them back. People are left with headaches and fatigue that can affect RLS, and these symptoms may never go away."

Dr. Winkelman paused and said: "The world is interconnected, and life is fragile. We must be modest about our ability to control things. But science is a wonderful thing and hopefully led us out of this horrible situation that killed so many people."

RLS Treatment

Conversations with RLS Physicians continued from page 7

Dr. Earley remarked: “Wearing the mask can reduce colds and flu; we are all a lot healthier when wearing a mask!”

Overall, the pandemic has shown that telemedicine can be a very good alternative for RLS management for several reasons. Restless legs syndrome does not necessarily require a physical exam or a sleep study to diagnose properly. Instead, diagnosis is based on the patient’s description of symptoms and medical history. In addition, many RLS patients face difficulties traveling to in-person appointments, and some have to travel long distances, given the limited number of experienced RLS providers.

Although this year has been tough on everyone, it is important to remember to thank our medical teams who have stepped up and adapted to the challenges brought on by COVID-19. Besides taking on increased responsibilities overall, they have continued to care for their RLS patients and found ways to accept new patients in desperate need of their expertise. We owe a debt of gratitude to all of the COVID heroes in our RLS community whose dedication has helped to keep their patients safe and healthy in this unprecedented health crisis. Thank you!

Recertification of Three RLS Quality Care Centers

In 2013, the RLS Foundation committed to developing a network of RLS Quality Care Centers to improve diagnosis, treatment and management for individuals living with RLS. Today, the RLS Foundation’s network of Quality Care Centers — nine located in the United States and two in Europe — provides patients with access to care from knowledgeable and experienced healthcare providers specializing in RLS management.

The RLS Foundation is pleased to announce the recertification of three RLS Quality Care Centers: Johns Hopkins University in Baltimore, Maryland; Mayo Clinic in Rochester, Minnesota; and Innsbruck Medical University in Innsbruck, Austria.

To qualify for and maintain status as an RLS Quality Care Center, institutions and their healthcare providers undergo a rigorous review by members of the Foundation’s Scientific and Medical Advisory Board. Recertification requires that healthcare providers demonstrate a high level of expertise and experience in managing a wide range of RLS case complexities, and that they follow current RLS diagnosis and treatment protocols. Healthcare providers must also maintain current licensure and engage in continuing medical education with RLS-specific coursework. Most importantly, they must follow consensus guidelines for RLS treatment.

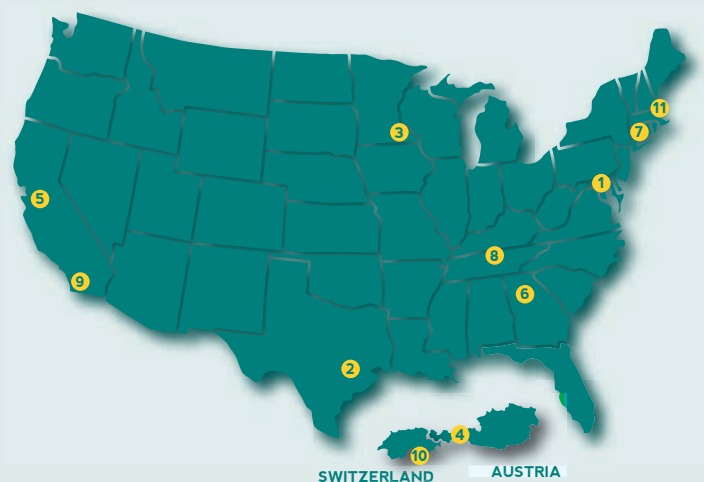
Center recertification requires organizational capabilities for comprehensive diagnostic and therapeutic approaches to manage the healthcare needs of individuals with RLS. Each center must demonstrate the ability to develop a comprehensive treatment plan for each RLS patient that includes access to laboratory facilities, sleep centers, and healthcare providers with specialties in pulmonology, psychiatry and hematology.

Recertification for these three organizations is valid for six years. The remaining eight Quality Care Centers will recertify when their current certification expires.

If your RLS has become unmanageable and you would like to seek expert care at a certified RLS Quality Care Center, visit the Foundation’s website (www.rls.org/qcc) to locate the center nearest you and find contact information to make an appointment.

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



The Buchfuhrers — Celebrating Father's Day as Doctor Team

By Rich Archbold

When Julia Buchfuhrer was growing up, she had a special bond with her father, Mark Buchfuhrer, but, hard as he tried, he could not persuade her to become a doctor like he was.

“No way, no way,” she told her dad. She was interested in other things, like maybe being a marine biologist. But her dad persisted.

He finally got his wish when his daughter decided to go to medical school and become a doctor, but that wasn't the end of the story. Julia Buchfuhrer graduated from med school at Western University of Health Sciences, did her residency at UC Irvine and is finishing her fellowship training at the University of Arizona this month to become a specialist in rheumatology.

She then had to make another big decision: Where to work after finishing her fellowship training? She decided to open up her own practice in Downey next month with — guess who — her father, who has been a doctor for almost 40 years and is nationally known for his work with restless legs syndrome.

Julia Buchfuhrer will open the JB Arthritis and Rheumatology Center at her father's office, 11480 Brookshire Ave., in Downey.

“I am extremely excited to be working side by side with my father,” she said in an interview at his house on the east side of Long Beach last week.

“It's the best Father's Day present I could get,” her father said. “She is going to do great work and help a lot of people.”

Julia Buchfuhrer will be the third doctor in her family. Her mother, Laurie Buchfuhrer, practiced family medicine and was an addiction medicine specialist. She worked at Kaiser Permanente and Long Beach Memorial Medical Center. She got leukemia, though, when her daughter was 6 and retired early. Julia Buchfuhrer said her mom would always tell her to select a career she would enjoy.

“I think she was secretly proud that I followed in her footsteps,” Julia Buchfuhrer said. “When I made the Dean's list in medical school, she told me how proud she was that I was doing medicine and doing it so well.”

Julia Buchfuhrer said she can't wait to start working with her father. “I have so much respect for him and what he has done in his career,” she said. “I will be learning so much from him.”

Her father, though, sees it as a two-way street.

“We will be learning from each other,” he said, sitting next to her in his home.

Mark Buchfuhrer was born on July 11, 1952, in Montreal, Canada. His parents were survivors of the Holocaust. His father, Norbert Buchfuhrer, was born in Poland and was a teenager when the Nazis



Following in her father's footsteps, Dr. Julia Buchfuhrer will be joining her father at his private practice in Downey, CA. (Photo by Tracey Roman)

sent him to a concentration camp in Warsaw. He escaped when he was 22 when he got on Oskar Schindler's now-famed list. Schindler was a German businessman who saved more than a thousand Polish-Jewish refugees from the Holocaust by employing them in his factories during World War II.

Mark Buchfuhrer's mother, Rose Katz, meanwhile, spent a year in a concentration camp in Hungary at the end of World War II and was saved. She met Norbert Buchfuhrer, her husband-to-be, on a boat going to Canada. She was a cashier in a hat design company in Hungary, but when she was asked her job skill in Canada, she said she was a hat designer — even though she had never actually designed hats, her son said. “But it turned out she had a skill in hat design and became very well known for her hat designs,” he said. She and her husband married in 1948 and had two children, Mark and his sister, Stephanie, who lives in Montreal.

Norbert Buchfuhrer died when he was 73, his wife died when she was 93.

“My mother used to tell me, ‘I'm going to live a long life to show you that you can, too,’” her son said. In high school, Mark Buchfuhrer said he wanted to be a scientist. “But my mother kept telling me to be a doctor, a doctor, a doctor. She said I could be successful as a doctor and take that skill anywhere and not be restricted to one place. She told me that 10,000 times.”

He finally listened and went to medical school at the University of Ottawa, graduating in 1977 and becoming the first in his family to

RLS Foundation News

The Buchfuhrers continued from page 9

become a doctor. He became a specialist in pulmonary medicine, treating diseases of the respiratory system. “My mom was overjoyed,” he said. He did his residency in Toronto where he met his wife-to-be, who was in her fourth year at medical school. They got married on June 22, 1980. They spent their honeymoon on an eight-day drive from Toronto to the Harbor-UCLA Medical Center in Torrance, where Mark had a fellowship in pulmonary medicine.

The couple spent a weekend in Seal Beach and liked the area so much they decided to live in Long Beach; they bought a condo in Marina Pacifica in Long Beach before buying a house on the east side near Long Beach State University, where they have lived for 37 years.

They have three children: David Buchfuhrer, 37, a software engineer; Michael Buchfuhrer, 35, a business owner; and Julia Buchfuhrer, 32. Mark Buchfuhrer was on the attending staff at various places, including Stanford University Medical Center, Harbor City; Downey Community Hospital (now PIH Health, Downey); USC Medical Center, Long Beach Community Hospital, and Good Samaritan Hospital, Los Angeles. He opened up his private practice in Downey in 2001 with his office now at 11480 Brookshire Ave. He became an expert, one of the few in the United States, in treating restless legs syndrome, which is a disorder causing pain and sleepless nights. The primary symptom of RLS, he said, is an urge to move one’s legs when trying to rest or relax. “This urge is often so compelling that RLS sufferers may have to walk, shake their legs, ride a bicycle, massage their legs, or stretch to alleviate their discomfort,” he wrote in a clinician’s manual on RLS. He has become beloved by his patients. “There isn’t a week that goes by without a patient telling me how my treatment has saved or changed their life,” he said.

Meanwhile, his sons and daughter were growing up. Julia Buchfuhrer graduated from Hill Middle School, which has since been converted to the Sato Academy of Math and Science, before attending Poly High School where she became an outstanding student. In eighth grade, she won first place in the Press-Telegram Halloween Scary Story Contest.

She also became an excellent soccer player and was a member of the Belmont Shore Women’s Rugby team. “I got injured a lot playing rugby, but that’s where I saw how doctors could help people get better,” she said. “I liked the idea of helping people medically.”

She also became a huge fan of bike riding, which her father also liked. “We cycled together all the time,” she said. “We rode with a group in Irvine called the Orange County Rebel Riders.

“We went on mountain rides and on past Father’s Days, we would go cycling for miles and come home for a family get-together.”

Julia Buchfuhrer had a scare one time when her bike hit a rock on an 8-mile trail in Rock Creek, 30 miles south of Mammoth Lakes. “I got thrown off my bike and suffered a nasty gash in my forehead,” she said. “Blood was gushing all over. Vultures were even circling in the sky. My dad bandaged me up, and hikers came by who helped us.” She still has a visible scar above her left eye.

And when she was 30, she got breast cancer, and she had a double mastectomy and reconstructive surgery. But she is a fighter.

“The hardest part was enduring three-to-four months of chemotherapy, but I missed only two-to-three days of training,” she said.

Julia Buchfuhrer said she loves doing things with her father and listening to him tell stories. “He is a great storyteller. We have become great friends.”

“She’s my buddy,” her father said, putting his arm around her. “I’m so happy she’s here for Father’s Day.”

Julia Buchfuhrer said she will fly back to Arizona this afternoon, Sunday, June 20, to finish her medical training and won’t have time to do her traditional Father’s Day bike ride with her dad. But she will celebrate Father’s Day at a family get-together.

She is also already planning a few weekend trips to Mammoth Lakes in August to hike and make up for some lost bike rides.

“Since we are both our own bosses, we can schedule as many of these trips together as we like,” she said with a grin.

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<https://www.presstelegram.com/2021/06/20/rich-archbold-the-buchfuhrers-celebrating-fathers-day-as-doctor-team/>

Wanted: Experienced RLS Healthcare Providers

One of the most daunting challenges faced by many patients with RLS is finding healthcare providers they can trust: nurse practitioner, physician assistant or other healthcare specialists who understand the complexities of RLS, who can make an accurate diagnosis, and who can manage a patient's symptoms and develop a treatment plan with understanding and compassion.

If you're reading this article, it's likely that you or a loved one has RLS and, hopefully, you also have an RLS healthcare provider whom you trust with your treatment. If so, you are among the lucky ones.

But some individuals with RLS are entering a confusing, even frightening, period in their lives. Maybe their RLS journeys have just begun or their trusted providers have retired or moved away, or maybe they live far from one of the RLS Foundation's certified RLS Quality Care Centers.

If you are among the lucky ones with a great RLS healthcare provider, you can take one simple action today that will make a world of difference for a fellow patient in the RLS community: **Simply nominate your RLS provider to join the RLS Foundation's Health Care Provider Network.**

It will take just a minute or two to fill out and send in this form with your provider's basic contact information, or you can submit the information online at www.rls.org/RLSdoc. The Foundation will take care of the rest. After receiving your nomination,

Foundation staff will review your provider's credentials, and, upon approval, reach out with an invitation to be listed in the FREE online RLS Healthcare Provider (HCP) Network. The Foundation will also send your provider printed materials that are designed to educate and inform both providers and their patients.

The RLS HCP Network serves a crucial need in the national RLS community. While it's easy these days to go online and find crowdsourced reviews on any service imaginable, there is a woeful shortage of information available online about RLS providers and the care they offer. That's why your nomination is so important.

If you already have a great RLS doctor, nurse practitioner, physician's assistant or other medical professional, please share the wealth with a recommendation to the RLS HCP Network at www.rls.org/RLSdoc, so that the Foundation can pass along the information to others in need. And if you're looking for a great provider, please check out the network at www.rls.org/Find-a-doc and let the Foundation help you find one!

As a special thank you for participating in this healthcare provider call to action, the RLS Foundation will enter your name into a weekly Find-a-Doc drawing to win an RLS T-shirt. At the end of the summer one lucky winner will receive a free registration to the Foundation's RLS Virtual Summit on Saturday, October 9. Best of all, you'll feel great knowing that you did your part to help a fellow RLS patient!



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

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

Name _____

Address _____

City _____

State _____ Zip _____

Phone _____

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

RLS Volunteers Are Making a Difference

National Volunteer Week occurs every year in April. It is an opportunity to shine a light on all the volunteers who lend their time, talent and voice to make a difference in the RLS community. As a small, but rapidly growing nonprofit organization, at the RLS Foundation we rely on the time and dedication of many volunteers to carry out our mission to increase awareness, improve treatments and, through research, find a cure for RLS!

One of the major changes resulting from COVID-19 was the switch to virtual support group meetings. Social-distancing requirements led us to temporarily stop in-person meetings; your health and safety is our number one priority. However, we were determined to keep the RLS community connected, and we did so by hosting online meetings on Zoom. Since the onset of the pandemic, more than 16 support group leaders have stepped up and agreed to run the virtual meetings. This was in addition to the more than 70 support group leaders and contacts across the country who stuck by us during these difficult times – ready and eager to help those looking for support. Thanks to our volunteers, support groups have become more accessible to many more people, including those who live outside the US.

Virtual support group meetings aren't the only online resource providing support to RLS community members. With COVID-19 preventing people from leaving the house, many who may not have been very comfortable with using a computer before have turned to technology as a useful resource. More people than ever are logging in to our online discussion board, which is available 24/7 with no geographic limitations. The discussion board is an excellent tool for people who are seeking answers, looking for strategies to cope with their RLS and just wanting to connect with others in the RLS community. Our discussion board moderators volunteer their time and experience, and we really appreciate all they do for the RLS community.

Meanwhile, members of the Foundation's Board of Directors, volunteers responsible for setting organizational goals and priorities and monitoring the Foundation's fiscal status and future plans, were tasked with making major decisions under uncertain circumstances to keep the RLS Foundation moving forward. Members of the Board helped

to ensure the continuation of all Foundation-driven initiatives, including our advocacy efforts in Washington, DC. Because of their hard work, we did not have to compromise on services provided to our community.

We also thank the hundreds of people in the RLS community who responded to our calls to action, volunteering their time to contact their legislators asking for support on the issues crucial to everyone affected by RLS. Every voice makes a difference and amplifies our efforts in Washington. We look forward to 2022, when we can plan to join together, in person, for another "Day on the Hill" to meet with lawmakers face-to-face and request their support.

Finally, we would like to give special thanks to our volunteers on the Scientific and Medical Advisory Board (SMAB), who provided extraordinary service to the Foundation and the RLS community in addition to their professional responsibilities during the pandemic. Several SMAB members served on the front lines of their hospitals, clinics and labs to treat patients and conduct vital research, despite the risk of contracting COVID-19. They also found the time and energy to revise the protocols for the Foundation's RLS Research Grant Program, which will increase the depth and breadth of RLS-related research. To increase patient accessibility to expert care, the SMAB approved adding physician assistants and advanced practice registered nurses to the list of certified providers in our network of RLS Quality Care Centers. Finally, a committee of SMAB members revised important treatment guidelines and educational materials regarding RLS for patients and healthcare providers alike (see page 3).

The contributions of our volunteers go on and on, but one thing is certain: no matter how big or small, your contribution matters. From support group leaders to Discussion Board moderators, from members of the Board of Directors to members of the Scientific and Medical Advisory Board, our volunteers have worked hard during this past year to face the unique challenges brought on by the COVID-19 pandemic. All of our volunteers adapted to the circumstances and stood with the RLS Foundation to support and further our mission. Without you, our members, our work would not be possible. Thank you!



2021 RLS VIRTUAL SUMMIT:

Please join us on Saturday, October 9th for a member-only online event to hear more about the all-new treatment algorithm and tips to deal with your RLS from experts practicing at many of the Foundation's certified RLS Quality Care Centers. Members may register to attend at www.rls.org/summit.

Understanding the Relationship Between Iron and Restless Legs Syndrome

Brain Iron Plays a Role

Research conducted over the past two decades has deepened our understanding of the relationship between iron and restless legs syndrome (RLS). Scientists have found that brain iron deficiency plays a role in the development of RLS. Consensus-based clinical treatment guidelines, published in 2018, provide direction for appropriate clinical management of RLS.¹ These guidelines recommend iron treatment when serum ferritin, the primary storage unit for iron, is found to be in the low normal range (≤ 100 mcg/L). Serum ferritin is a peripheral measure of iron that has been found to correlate inversely with RLS symptom severity.^{2,3} When serum ferritin level is low, it is postulated that iron levels in the brain will also be low and this may cause or worsen RLS symptoms.

The Role of Iron in the Body

Iron is essential to all living cells in the body. Different proteins regulate the distribution of iron throughout the body. Transferrin is responsible for transporting iron to the different organs whereas ferritin, in large part, is responsible for storage of iron within each cell.

When dietary or supplemental iron enters the bloodstream, about 80-85% will go to bone marrow, where it will be used to make red blood cells. The next largest proportion of iron is distributed to the liver. A small percentage – less than 5% – is distributed to other organs, including the muscles, kidneys, heart and brain. The brain gets less than 0.1% of the newly-absorbed iron.

As the iron-rich red blood cells die, they are broken down by specialized cells called macrophages. The iron from broken-down red blood cells is redistributed throughout the body, with most going back to the bone marrow and liver. It is this source of iron that is mainly utilized by the body to supply iron to other organs in the body. Again, a small percentage of that iron goes to the brain.

Understanding Low Iron Levels

When iron stores are low, the body's first response is to increase the percentage of iron going to bone marrow. Under severe iron-deficient conditions, as much as 99% of the body's iron will go to the bone marrow. This protective mechanism permits the body to continue making red blood cells by sacrificing iron distribution to other organs, including the brain.

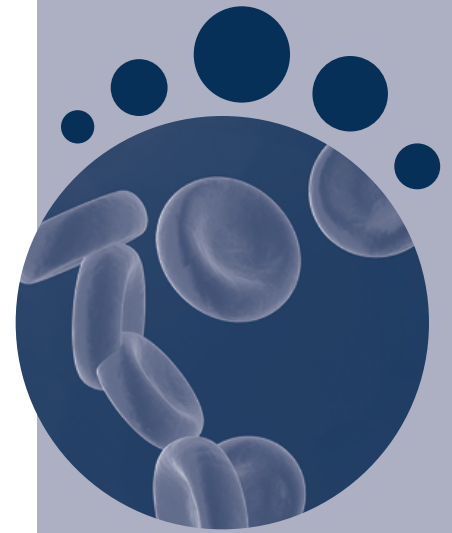
Animal studies have shown that low brain iron will directly or indirectly impact several systems in the brain, including the dopaminergic system. At baseline, dopamine levels vary significantly throughout the day, following the circadian rhythm, when dopamine levels are already lower at night and during sleep. Under low brain iron conditions, there is an additional decrease in the dopaminergic signal. A relative overall decrease in dopamine activity will have the greatest impact. Because of the circadian nature of RLS (worse at night and least likely to occur in the morning), a decrease in dopamine signaling as a result of low brain iron can exacerbate RLS.

Specific blood tests are used to determine body iron stores. Hemoglobin/hematocrit tests are the most commonly-requested measures, primarily to detect anemia (low red blood cell count). However, even in those RLS patients with severe iron deficiency, anemia is uncommon. Therefore, more direct measures of the body iron status is essential in evaluating any patient with RLS.

Complete Iron Measures

Serum ferritin level has been the standard measure for assessing the iron status of the body. However, it only directly reflects the iron stores in the bone marrow and the blood. The iron status of other organs (e.g., muscle, heart or brain) cannot be assumed to be the same as serum ferritin levels. Because infection and inflammatory processes can falsely elevate the serum ferritin level (i.e., the ferritin is no longer a reflection of the iron stores), it is necessary to wait at least six weeks after illness subsides before scheduling a ferritin test to get the true measure of body iron stores. Age is also a factor, since serum ferritin levels will increase with age and with declining kidney function. So, a fasting ferritin of 50 mcg/L in a 20-year-old woman is normal but should be considered abnormal in a 70-year-old woman.

A complete iron panel should include serum iron and ferritin level, total iron binding capacity and percent iron saturation. The complete iron panel will provide a broader understanding of the patient's iron status. Total iron binding capacity (TIBC) will also be affected by infection and inflammatory processes; so, like



Oral iron supplements are recommended when ferritin levels are less than 75 mcg/L.

Consider intravenous (IV) iron if 100 mcg/L level isn't reached.

Iron tests include:

- serum iron and ferritin level
- total iron binding capacity (TIBC)
- percent iron saturation



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ferritin, it is not a reliable marker for iron status under these conditions. Furthermore, serum iron levels increase significantly within 15 minutes of eating food and can vary by nearly 50% from morning to night. A dinner low in meat content the evening prior, followed by an early-morning blood test (i.e., before 9 AM) after fasting for at least 8 hours is recommended to provide a true picture of iron status. Also, if you are taking an iron supplement, as an iron pill or in combination with a vitamin pill, that should be stopped at least two days prior to the blood collection.

Dietary Sources of Iron

About 10% of the average daily dietary intake of iron (10-20 mg) is absorbed in the gastrointestinal (GI) tract. The same amount of iron in plant-based foods does not provide the same amount or type of iron found in animal proteins. Animal protein sources of heme iron, such as meat, fish and liver provide the most absorbable form of iron in the gut. Non-heme iron contained in beans, grains, fruits, vegetables and nuts are not as readily absorbed by the human GI tract.

Oral Iron

Based on current consensus reports, it is recommended to treat RLS patients whose ferritin levels are less than 75 mcg/L with iron supplements, with the goal of getting the ferritin above 100 mcg/L. Oral iron supplements with at least 60-65 mg of elemental iron should be used. To achieve maximum absorption, take the iron supplements on an empty stomach. To enhance iron absorption, take with 200 mg of vitamin C or with a beverage high in vitamin C such as orange juice; this is especially important if you are taking antacids or medications to treat acid reflux. It is essential to avoid calcium (dairy products, supplements, antacids), tea and coffee within two hours of taking iron supplements, as this will reduce iron absorption. To maintain the effectiveness of thyroid medications, avoid taking iron pills within four hours of thyroid medications.

Oral iron supplementation takes between three and nine months before many individuals obtain adequate stores. Recent research indicates that taking iron once per day is as effective as dosing twice daily, with marginal loss of therapeutic effect. An additional benefit of once-daily dosing is fewer adverse GI effects. Studies have shown that serum iron is redistributed to the brain to a much greater extent at night. Therefore, it has been recommended that the iron pill be taken in the evening as opposed to the morning.

An iron panel (serum iron, ferritin, TIBC and percent iron saturation) should be checked after

three months. Remember to stop the iron pill two days before the blood is drawn. If the goals were not reached after three months, then consider an iron infusion. Once ferritin goals have been reached, further need for the iron supplementation will vary from individual to individual.

To determine the next step, stop the iron supplements and check a serum ferritin level in three and in six months to see if there is any indication that the ferritin level is dropping again. If the ferritin level is dropping after discontinuing the iron supplements, then some level of daily supplementation may be required in order to maintain iron levels within a clinically optimal range. If GI bleeding or menstrual issues are causing blood loss, then some level of iron supplementation should probably be continued.

Oral iron therapy should only be instituted under the care and supervision of a physician. Serial lab tests are required to determine therapy effectiveness and to monitor for iron overload.

Intravenous Iron

Intravenous (IV) iron should be considered if adequate ferritin levels are not achieved after 3 months on appropriate daily oral iron supplements. In two randomized, double-blind, placebo-control studies, patients with normal hemoglobin, ferritin less than 300 mcg/L and transferrin saturation of less than 45%, showed significant improvement in RLS symptoms after being administered 1,000 mg of iron intravenously. Therefore, treating RLS patients whose ferritin level is 100 mcg/L or less with intravenous iron may provide an alternative option to oral iron supplementation.

The consensus-based iron treatment guidelines for RLS include two first-line IV iron formulations: ferric carboxymaltose (Injectafer) and low molecular weight (LMW) iron dextran (INFeD). Both formulations pose a low risk for allergic reaction. Alternative IV iron formulations such as iron sucrose (Venofer), sodium ferric gluconate (Ferrelecit) and ferumoxytol (Feraheme) lack adequate clinical trials to verify their efficacy in treating RLS.

An important note: premedication with diphenhydramine prior to IV iron infusion should be avoided in RLS patients, as it known to aggravate or trigger RLS symptoms.

The iron infusion itself will cause an acute reactive increase in ferritin that is independent of the iron load. It may take up to six weeks for the

ferritin to equilibrate. Furthermore, the iron infusion may take up to six to eight weeks to provide full benefits on the RLS symptoms. Therefore, an iron panel and clinic evaluation should be done about six to eight weeks post-infusion to establish the current iron status, to assess for any improvement in RLS and adjust medications as indicated. There is limited data on the value of repeated IV iron treatment in those who benefited from the initial treatment and who later present with worsening of RLS symptoms and a drop in iron levels. Further iron assessments and treatment decisions should be driven by the return or worsening of RLS symptoms.

Conclusion

Keeping the body's iron stores at an optimal level is a complex process involving blood tests and periodic re-evaluation of the RLS treatment plan. For individuals with RLS, it is important to work with a healthcare provider who understands the delicate relationship between iron and RLS in order to properly manage the disease.

¹Allen RP, Picchetti, D, Auerbach M, et al. Evidence-based and consensus clinical practice guidelines for the treatment of restless legs syndrome/Willis-Ekbom disease in adults and children: an IRLSSG task force report. *Sleep Medicine*. 2018;41: 27-44. Open Access Article.

²O'Keefe ST, Gavin K, Lavan JN. Iron status and restless legs syndrome in the elderly. *Age Ageing*. 1994.23(3):200-203.

³Sun ER, Chen CA, Ho G, et al. Iron and the restless legs syndrome. *Sleep Medicine*. 1998. 21(4):371-377

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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By Elias Karroum

More Evidence Showing Direct Damage to the Small Vessels of the Brain in RLS

“Restless legs syndrome shows increased silent postmortem cerebral microvascular disease with gliosis.” Walters AS, et al. *J Am Heart Assoc.* June 2021.

The Background

Recent studies have suggested an association between restless legs syndrome (RLS) and high blood pressure, stroke and heart disease (increased cardiovascular risk). In addition, imaging studies using MRI, have demonstrated a possible greater level of “silent” (without the patient’s having symptoms) small-vessel disease of the brain in patients with RLS. Moreover, RLS has been associated with many inflammatory and immunologic diseases such as multiple sclerosis, Celiac disease, rheumatoid arthritis, Crohn’s disease and inflammatory bowel disease, where specialized cells of the body’s immune system are involved.

These specialized cells play important roles. T cells coordinate cellular immunity by helping to regulate the defense of other cells of the immune system and can attack cells directly infected by microbes or cancer cells. B cells are responsible for humoral immunity, as they produce antibodies against antigens. Macrophage cells are the first line of defense of the immune system. And mast cells play multiple roles, such as in allergic reactions, wound healing, vessel development and more. The aim of the current study was to investigate the degree of “silent” small-vessel disease and the degree of inflammation and immune system abnormalities involving the above-described cells in RLS patients by analyzing postmortem samples of the brain tissue.

The Research

To study the brain directly, tissue samples extracted from a brain region called the motor cortex (involved in the execution of voluntary movements) were obtained from the Arizona Study of Aging and Neurodegenerative Disorders and the Banner Sun Health Research Institute Brain and Body Donation Program. The study involved five patients with RLS and nine patients without RLS who were rigorously selected based on documented history or proven diagnosis of any stroke or neurological diseases through examination of brain tissue samples. Analysis performed on the brain tissue specimens of the subjects selected included looking under the microscope at the degree of injury to the small vessels and the surrounding brain tissue. In addition, the researchers looked at signs of inflammation and immune system abnormalities by targeting markers that can identify specifically the T cells, B cells, macrophage cells and mast cells in the brain tissue. There was no difference between RLS patients and non-RLS subjects based on age and gender. There was a significant increase in the extent of small vessel and tissue injuries in the brain samples from the RLS patients compared to the non-RLS subjects. Additionally, the T cells markers were increased in brain tissue samples from RLS patients compared to the non-RLS subjects – but not B cells, macrophage cells or mast cells. The T cells that increased in activity were small vessel and brain tissue injuries.

The Bottom Line

By looking at actual brain samples, this study appears to confirm directly the increase in “silent” small vessels damage and tissue injuries of the brain in RLS that was indirectly noted in MRI studies. This result is convergent with the mounting evidence linking RLS with an increased cardiovascular risk. This study also shows an invasion of T cells in the same damaged regions of the brain in RLS which also could support the previous evidence for a link between RLS and inflammatory and immune system diseases.

Further Questions

Are the above findings solid enough from a scientific standpoint, given the very small sample size of the RLS patients and the non-RLS subjects? This is a major limitation that was raised by the authors of this paper, who pointed out the pertinent fact that the subjects and patients in this study were highly selected to have no other neurological problems and therefore this limited the sample size. What is the contribution of the T cells to the small vessel and tissue injuries found in the brain samples of RLS patients? Future studies should look in more detail at any difference in T cell subtypes and functioning between RLS and non-RLS subjects.

RLS Is More Prevalent in People Who Have Postural Orthostatic Tachycardia Syndrome

Caroline Dodson et al. “Restless legs syndrome is increased in postural orthostatic tachycardia syndrome.” *J Clin Sleep Med.* April 2021.

The Background

Postural orthostatic tachycardia syndrome (POTS) is a common condition that affects up to 3 million people in the United States, usually affecting adolescents and younger adults, particularly women. POTS is associated with symptoms such as lightheadedness, fatigue, brain fog, palpitation (heart beating fast), trouble with concentration, problems with exercising and headaches. Symptoms occur frequently when the patients are standing upright (orthostatic) and there is a significant increase in the heart rate without a significant drop in the blood pressure noted. Both POTS and RLS have been associated with sleep disruption, autonomic abnormalities (related to the “autonomic nervous system,” which works largely without our awareness or consciousness), and inflammatory and immune system abnormalities (the body systems that normally protect us against infections among other functions). Therefore, the aim of this study was to investigate how commonly RLS occurs in POTS patients.

The Research

The researchers recruited 96 patients with POTS and 130 subjects without POTS from a national patient meeting as well as from a group of Vanderbilt employees. The diagnosis of POTS was considered positive by the investigators when the participants were diagnosed by a physician. For the diagnosis of RLS, the researchers used a validated, self-administered diagnostic tool, the Cambridge-Hopkins questionnaire (CH-RLSq). The CH-RLSq incorporates all four standard criteria for the diagnosis of RLS. Researchers also asked

questions related to excluding conditions that can mimic RLS, including muscle cramps and positional discomfort. When the participants were diagnosed by the CH-RLSq as having definite or probable RLS (these two categories are both taken together as a positive diagnosis of RLS), they were further contacted by phone to evaluate for RLS severity with the international RLS severity scale (IRLS). Patients with POTS were more likely to have RLS (14.6%) compared to the participants without POTS (4.6%). Because of difference in age and gender between the POTS group and the non-POTS group, the researchers conducted a more restricted analysis and looked at the 96 participants without POTS who were the closest in age and gender to the 96 patients with POTS. The results were still the same with significantly more RLS in the POTS group. Results were also similar when only women were compared between the two groups. Subsequently, the researchers were able to contact by phone only 13 participants (10 patients with POTS and three without POTS) out of the 20 subjects who had a positive RLS diagnosis. The severity of RLS based on the IRLS was in the moderate range for these 13 participants.

The Bottom Line

This is the first study to look at how common RLS is in POTS patients. It showed a three-fold increase in the rate of RLS for patients with POTS compared with subjects without POTS. The new information provided by this study has clear implications from a clinical standpoint, given that POTS is common and can cause significant suffering for patients. The addition of RLS may increase their sleep disturbances and further reduce their quality of life.

Further Questions

What is the true impact of RLS in patients with POTS? This study showed that the severity of RLS was in the moderate range in POTS and non-POTS participants. However, the number of subjects evaluated with the IRLS was small, particularly in the non-POTS group. Therefore, future studies should analyze the severity of RLS and its association with sleep disturbances and quality of life in a larger sample of patients with POTS compared to healthy participants. What are potential causal links between RLS and POTS given the common association of both disorders with autonomic and immune abnormalities? In that context, it would be interesting, for example, to investigate the implication of small fiber neuropathy (damage of small fiber nerves) in patients with both POTS and RLS.

By Daniel L. Picchiatti, MD

Does Treating RLS Decrease Your Risk of Cardiovascular Disease?

“Treating restless legs syndrome was associated with low risk of cardiovascular disease: A cohort study with 3.4 years of follow-up.” Gao X, et al. *Journal of the American Heart Association*. February 2021.

The Background

Many, but not all epidemiology studies have shown cardiovascular disease (CVD) to occur more frequently in people with RLS compared to those without RLS. However, these prevalence studies primarily

show a higher-than-expected association of RLS with CVD and do not prove causation or address whether treatment for RLS can make a difference in CVD.

The Research

The researchers used a large commercial health insurance database in the United States to look for new cases (incidence) of CVD in individuals with RLS over a time span of five years. They looked for new cases of heart attack (myocardial infarction), chest pain (angina), atrial fibrillation, heart failure and stroke. At baseline, none of the cases had heart disease, cancer or kidney disease. They compared more than 24,000 people diagnosed with RLS, ages 20 to 64, to more than 145,000 people without RLS. In addition, they compared treated to untreated cases of RLS to assess whether treatment influenced CVD outcomes. Approximately two-thirds with RLS were prescribed a medication appropriate to RLS, which included dopamine agonists, alpha-2-delta ligands, other antiseizure medications, benzodiazepines, and opioids used in low total daily doses. Adjustments were made for confounding factors.

Results: People with RLS were more likely to develop CVD than people without RLS – a 53% higher risk in the untreated group and a 26% higher risk in the treated group. Looked at in another way, the risk of CVD was 13% lower for people who were prescribed RLS treatment than for people who were not prescribed RLS treatment. The risk was lower for all different RLS treatments – dopaminergics, anticonvulsants, benzodiazepines and opioids. However, RLS treatments reduced risk only for those on combinations of different medications, not for those receiving just a single medication. Importantly, the study did not look at treatment with iron, which was an uncommon treatment for RLS during the time span of this study but has now become a first-line therapy.

The Bottom Line

This large epidemiology study found an increased risk of developing CVD (incidence) over five years in individuals with RLS. This expands on the results of many other prevalence studies. In addition, this was the first epidemiology study to assess whether treatment of RLS decreases the risk of CVD, showing a 13% lower risk with treatment. While these findings do not prove causation, they are a very important contribution to the increasing evidence that there might be a causal relationship between RLS and CVD.

Further Questions

What are the underlying mechanisms by which RLS and CVD might be related: sleep disturbance, effect on blood pressure, or some other common factor between RLS and CVD? Why did a combination of RLS medications show decreased CVD risk but single medication use did not? Does iron therapy for RLS result in decreased CVD risk, too?

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

Q: My family physician is very adamant that I taper down and eventually stop taking generic Klonopin. I know that opinions are shifting now as to its being addictive. I have tapered to one-fourth of my prescribed dose. This medication helps me; why should I accept advice from a GP regarding discontinuing use of it? The previous attitude of my neurologist, which I have not seen in a while, was to "not upset the apple cart." I suffer from RLS, Celiac disease, anxiety and depression, which adds to my resistance to the GP's advice. She manages the medication that was originally prescribed by my neurologist and I don't think she is qualified to address these other issues. Can you discuss this in broad terms?

A: Your family doctor has your best interests in mind. Klonopin (clonazepam) has a very long half-life (over 40 hours) and therefore causes daytime sedation/drowsiness in many patients who take it on a daily basis. This sedation is often not apparent to the patient, as it may occur in a gradual fashion. There are much shorter-acting benzodiazepines that may provide the same benefit for helping sleep promotion and maintenance (benzodiazepines do not reduce RLS symptoms) and would be a better choice.

Benzodiazepines like Klonopin do cause tolerance and dependence quite commonly, and stopping them can cause significant distress. Your family doctor has the correct idea about directing you to try to decrease your Klonopin dose, and you may find that you do just as well on a lower dose (possibly even on your current one-half dose) which then brings the risk of side effects, tolerance and dependence way down. You may not be able to get completely off the Klonopin, but you might still do well on a lower dose. Even though your previous neurologist may have more expertise for prescribing Klonopin, your family doctor should have sufficient expertise with this drug to manage changes, and of course, your medical status changes over time and should be reassessed.

Mark Buchfuhrer, MD, FRCP(C), FCCP

Q: Can brain iron levels be increased by doing an iron infusion directly into the cerebrospinal fluid for people with severe RLS?

A: An infusion of iron directly into cerebrospinal fluid (CSF) might avoid gastrointestinal side effects and improve brain iron absorption, but this procedure is not an option at the moment for safety reasons. There is evidence from animal experiments that injecting certain amounts of iron into the brain might cause neuronal atrophy and cell death. A similar iron-related neuronal toxicity in humans occurs where iron accumulates from erythrocytes (red blood cells) and causes hemorrhagic stroke.

Mauro Manconi, MD, PhD

A: Iron infusion directly into the CSF or brain could be extremely dangerous. Iron, although essential for all life, can facilitate potentially dangerous biological reactions if not extensively

regulated by the body. Putting iron directly into the CSF would bypass those regulatory mechanisms.

William Ondo, MD

Q: I am an 87-year-old female. I've had RLS for about 45 years. I am currently taking methadone, pramipexole and Lyrica. Approximately 20 years ago, I developed left-sided temporal arteritis, for which I was taking 70 mg of prednisone for over a year. After that, my RLS appeared only in the left leg and never in the right. Recently, I had surgery on my right knee. Within a week of the surgery, the RLS started occurring in both legs (but never both at the same time) and also in my arms and upper torso. My medicines were not as effective as in the past, so my neurologist increased the dosage of methadone. While this helped some, I was still getting very little sleep. Six weeks after the surgery, my RLS seems to be back in the left leg only, and the symptoms in the arms and upper torso have disappeared. Does surgery affect RLS and the effectiveness of medications?

A: I'm glad to hear that the worsening of RLS symptoms that you experienced after surgery was transient and did not require a change in your medications. In any case, before considering any changes, I would recommend a full iron panel, including a full blood count, ferritin, transferrin and serum iron levels. Surgery can cause significant blood loss, requiring transfusion in some cases; in one report, total knee arthroplasty was associated with 38% hidden blood loss. Blood loss can trigger or worsen symptoms of RLS. Some of the medications that are used throughout the perioperative period may also trigger or worsen symptoms of RLS. Before surgery, during surgery and immediately after surgery, oral medications, including RLS medications, are discontinued and not always replaced with a different mode of administration (intravenous, intramuscular or transcutaneous). It is important to educate the surgical team about RLS, medications to avoid and acceptable substitutes, along with plans to manage RLS symptoms in the postoperative period. The RLS Foundation medical alert card, hospitalization checklist and surgical handout should be shared with the surgical team and individual accompanying you on the day of surgery before your procedure.

Denise Sharon, MD, PhD, FAASM

A: I have seen many patients with worsening RLS after major surgery or other types of trauma without any significant blood loss or change in iron/ferritin levels. We really do not have an explanation for why this occurs. Some patients get only temporary worsening of symptoms, in which case it will seem that their current medications are not potent enough. However, others get more permanent increases in RLS symptoms.

Mark Buchfuhrer, MD

Bedtime Stories

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

I have had RLS from about the age of 8. With age it has become worse. I am now almost 66. In 2003 I crashed a plane and received third-degree burns over 80% of my body, but I lived. I then had what I thought was a weird form of hyperactivity that affected all of my body. I would walk every night from about 10 pm to 3 am. Finally, it was diagnosed in about 2011 as severe RLS. I now take pramipexole and carbidopa/levodopa. Recently I added an opioid because I have been losing control of the RLS. In an effort to control a mild digestion problem, I had found what I thought was an intolerance to gluten. In the process of eliminating gluten, I started to notice occasional, not-so-bad nights of RLS. As I tightened the gluten regime, I was finding a link between very small amounts of gluten and really bad RLS. A few days ago, I did a complete gluten cleanse of my home. I am now getting no RLS symptoms in the evenings. I still take a half dose of medications before sleep just in case. I am amazed at not being awakened by RLS or needing to get up in the morning because of RLS. I'm curious to know if this is an isolated case and to hear if there are Celiac disease sufferers who have RLS. I am curious to see the longer-term effects. — *David*

Medical Editor's Note: Other patients have reported improvement with eliminating gluten foods but there are no formal studies confirming this treatment. It should be noted that both pramipexole (Mirapex) and especially carbidopa/levodopa (Sinemet) tend to cause RLS augmentation when taken on a daily basis. Combining both of them together on a daily basis markedly increases the risk of worsening RLS due to augmentation.

I have had RLS for 40 years and have been taking pramipexole (Mirapex) for most of that time. It has gotten worse over time; I have had symptoms every night, even with the medication. A few weeks ago, I noticed that for the prior three nights in a row I had no symptoms whatsoever. And this has continued. I wondered what had changed; I was not doing anything different. Then I read about a woman in Seattle, where I live, who had no RLS symptoms after receiving her second Moderna vaccine dose. And that was true for me too. I'm going to let my doctors know. This is an amazing development for me after all these years. — *Lisa*

Note: For more information on COVID-19 vaccines go to www.cdc.gov.

Sixty years of RLS! The 11 tips stated recently in *NightWalkers* are things I learned long before RLS was medically recognized as a legitimate health concern. A few other things that I would add to those tips:

1. Caffeine is a no-no for most sufferers, particularly after lunch. Examples are coffee and sodas with caffeine; pain medications that contain caffeine and too much chocolate (read labels).

2. As soon as it is feasible after supper, remove all clothing that could be restrictive in any way, especially things that have elastic. Even socks! Note that some RLS sufferers prefer tight-fitting clothes/socks so this may vary considerably.
3. Be careful about sugar consumption in the late evening, especially artificial sweeteners. These are triggers for many RLSers.
4. If you take medication, be sure to take them at the same time every day. RLS legs need medications before symptoms appear, and for some of us, taking medication even 15 minutes late brings on the worst symptoms imaginable, and the medicine takes much longer to work. Better to take it a few minutes early than a few minutes late!
5. Family members and friends who have never experienced an episode of severe RLS don't have a clue about how it has an impact on your daily life. Have a serious discussion with those close to you about RLS, and have them research it if they are skeptical. They will be less likely to urge you to do things, or not do things, that you know are bad for you.
6. Don't needlessly suffer from all the life disturbances that RLS can bring about. If you have severe symptoms but hate the idea of taking medications, talk with a knowledgeable doctor about the pros and cons of not doing so. Lack of quality sleep could have much more serious consequences than taking some of the medications available now. However, be cautious. Start out with the lowest dose possible of any medication, and give it a chance to see if it brings relief. Taking more than necessary brings on a different set of problems. Learn all you can about each type of medication before you take the first dose! — *glfngrl*

I have a large flat rice bag that I heat in the microwave oven every night. I find that both the weight and the heat provide counterstimulation to help calm my legs so I can get to sleep faster. Unlike a heating pad, which has to be turned off eventually, my rice bag simply cools down by itself. A good-sized rice bag made of 100% heavy cotton denim is 12 inches by 18 inches with rows of 2-inch compartments filled three-fourths full with uncooked white rice. I heat it for one and a half minutes. — *Jeanne*

Sugar is a major trigger for my RLS. Changes to my diet include: 1) I've cut out all sugary foods, including fruit juices. I have replaced them with fresh fruit. 2) I substitute regular pasta with vegetable pasta. 3) I buy ketchup with no sugar added. 4) No wines or cocktails (ugh). My favorite dessert now is an apple and dried cherry cobbler (Pink Lady apples and no sugar added). I can eat that with no RLS. Also, I walk at least a mile a day. Exercise seems to also help with my RLS. — *Chuck P.*

Make Something to Heal Something

By Brian Schrag, PhD, RLS Foundation Member

“Always just beyond the edge of consciousness . . . like electricity. Toes. Ankles. Calves that have to move. RLS, a tailgater crowding my rearview mirror, a bully breathing down my neck, a whiff of something rotting just behind the wall. Always there. Always ready to twist a moment of peace and relaxation into a kicking, screaming fight to make the feeling leave.”

I teach people how to make artistic things that help them flourish. My own struggles with RLS have convinced me that communities affected by RLS could also benefit from developing habits of life-giving creativity.

My journey, resulting in this conviction, began in a village in the Democratic Republic of Congo. My wife and I helped start a project to translate the Bible into a language called Mono, encouraging speakers to integrate the new Scripture into their lives through their own types of singing, dancing, poetry, proverbs, storytelling, carving and so on. I eventually earned a PhD in ethnomusicology at UCLA and founded the Center for Excellence in World Arts (CEWA) at Dallas International University.

Along the way, I became more and more aware of the infinite range of suffering in the world, and saw how arts have often brought relief, soothing people's anguish. So, I started studying music, dance, visual and other arts therapies, integrating their insights into our training, inviting experts to teach at the CEWA. Our students now spark healing creativity in communities in the US and around the world, to increase others' well-being.

Two diseases forced me to take my own medicine. First, I learned that I have Huntington's Disease (HD) — neurodegenerative, incurable — and started making songs, T-shirts, jokes, schticks and a snarky virtual alter ego to express and undermine my despair and fear. Everyone with HD eventually loses control of their movements in a way that makes them look drunk. (I'm not there yet.) Police kept accusing a woman in our HD support group of public inebriation, so I wrote the song, “HD Blues,” and made a T-shirt with “No sir, officer, I am not drunk. . .” on the front and a description of HD on the back. Protection and education neatly nestled on a bed of 100% cotton.

Then came RLS — in my humble opinion, Ridiculously Labeled Sickness. I was often awake all night. Exhaustion and hopelessness led to the excerpt from a longer lament at the beginning of this column. And its neurological roots and medications made me unable to take most of the antidepressants I need for HD's emotional symptoms. RLS forced me to choose between sleep or sadness, rest or rage. You who have it bad can relate to this sampling of pleas from an RLS discussion

board post: “Scared, appreciate any help;” “a living nightmare;” “suicidal now;” “am I in hell?” and “HELP!”

Despite these diseases — sometimes *because* of them — I found that it's possible to craft a new normal life, one that even includes moments of purpose, joy and satisfaction. Along with care from medical personnel and support groups, the arts can play a pivotal role. Expressive arts therapy experts Stephen Levine, PhD, DSSc, and Ellen Levine, PhD, MSW, write that “the therapeutic power of art rests not in its elimination of suffering but rather in its capacity to hold us in the midst of that suffering so that we can bear the chaos without denial or flight.”

That's deep and mostly true. But I've seen things that arts *can* cure. They can spark hope out of despair. Nurture community where there was loneliness. Replace ignorance with knowledge. Swap pacing or crumpled exhaustion on the floor with dancing. Exchange emotional and physical trauma with contentment.

Making, giving and experiencing artistry at any skill level can increase well-being. Your legs may still disobey, but with hope, pleasure, catharsis, understanding and community, it's possible not just to endure, but to thrive.

Two possible action points: First, make something for yourself or someone else that feels good — some of you already do this. Everyone has a creative spark, and what you make doesn't have to be seen or heard by anyone else. Try something. Embrace imperfection. Second, you can help build a virtual collection of arts produced by people affected by RLS, gathering songs, poems, stories, dances, paintings, jewelry, quilts, films, video games and many other forms. Email info@rls.org if you'd like to be part of getting this collection off the ground.

Let's start an RLS Arts-Making Movement.

‘Cause sometimes pacing turns to dancing
Sometimes lonely points to loved
And sometimes endless dark night brightens into hope

Brian Schrag is a senior arts consultant with SIL International. For more, explore www.BrianAtPlay.com/restless-legs-syndrome.



Brian Schrag, PhD

RLS Support Network

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

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

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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.

Introducing Our New Virtual Support Leaders:

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Clinical Trials

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

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

New Study of Abnormal Sensations and Movements

A new study lead by Dr. Elias Karroum at George Washington University School of Medicine and Health Sciences, and Dr. Arthur Walters at Vanderbilt University Medical Center, will be available to RLS Foundation members and their partners starting in early summer.

Participants will complete a survey designed to understand the prevalence of specific abnormal sensations and movements in the restless legs syndrome (RLS) patient. The study will also evaluate the impact of these features on the quality of life, quality of sleep, and severity of RLS, and provide a greater understanding of RLS in the public realm.

An email will be sent to all RLS Foundation members inviting both the RLS patient and their partner to participate in early summer.

Understanding the Role of Epigenetics in RLS

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

Contact: Jessica at 410-550-1046

Intravenous Iron Therapy in Patients with Anemia and RLS

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

Contact: Jessica at 410-550-1046

Hormones and Their Role in Restless Legs Syndrome

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

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

Contact: Abdalla Albanna, abdalla.albanna@yale.edu or 203-785-7393

Investigational Nerve Stimulation Device

Researchers at SRI International (funded by Noctrix Health) are looking for people with RLS to test an investigational nerve stimulation device designed to reduce RLS symptoms. The study involves the evening use of small nerve stimulation devices attached to both legs, an actigraphy sleep assessment (a noninvasive method of monitoring rest and activity cycles), and daily electronic surveys for up to five weeks at home. There will be three, two-hour in-lab visits at the Human Sleep Research Laboratory in Menlo Park, California, scheduled in the evening at your convenience. You may qualify if you are 18 to 75 years old, have RLS, and live in the San Francisco Bay area. If you qualify to participate, you will be compensated up to \$400 for your participation.

Contact: 650-859-4532 or sleep@sri.com

Wearable Compression Vibratory Device

Are you experiencing bothersome RLS symptoms at least five days a week? Have you been experiencing these bothersome symptoms for at least three months? Have you been taking the same dosage of medication for RLS or no medication for at least two months?

If so, you may qualify to participate in a two-month investigational study to test a wearable compression vibratory device for patients (age 18 and older) with RLS who live in the San Francisco Bay area.

Qualifying participants will receive all study related materials at no cost and be paid for their time upon completion of the study requirements.

Contact: Ryan McCormick, CA Center for Sleep Disorders, rmccormick@sleepdx.com or 510-263-3331

Is RLS Affecting Your Child?

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

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

Visit: www.science37.net/rls-teens

Publications

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

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

MEMBERSHIP

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

DONATION

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

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

DONATION APPLIED TO

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

PAYMENT METHOD

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

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

Card number _____ Expiration date _____

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

Name _____ Address _____

City _____ State _____ Zip _____

Email address _____ Phone number _____

Restless Legs Syndrome Foundation | 3006 Bee Caves Road | Suite D206 | Austin, TX 78746



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Foundation Frequently Asked Questions: Membership Renewal

When does my membership renew?

All annual memberships renew on September 30, according to our fiscal year. However, regardless of your join date, you will receive four issues of *NightWalkers* (equivalent to one year's worth of membership) for the calendar year in which you join.

How can I tell if my membership has expired?

There are several ways to check the current status of your RLS Foundation membership:

- 1) View the back of your most recent copy of *NightWalkers* to locate the expiration date of your membership, printed above your name and address.
- 2) Go online to our website (www.rls.org), click "Member Login," enter your username and password and click "Renew Your Membership Here." You will be routed to a page that lists your membership details, including status.
- 3) Give us a call at (512) 366-9109 or email us at info@rls.org. We're happy to check your record in our system!

How do I renew my membership?

Go online to our website (www.rls.org); click "Member Login," enter your username and password, then click "Renew Your Membership Here." You can also renew over the phone by calling (512) 366-9109 or by sending a US check payable to the RLS Foundation. Please be sure to specify "Membership" in the memo section of your check.

I accidentally renewed my membership twice. Can you help?

A second transaction through the renewal page will be applied as an additional year of membership. If you prefer to apply this as a donation or to request a refund, please contact us right away at (512) 366-9109.