

NIGHTWALKERS

In search of a good night's sleep

SUMMER 2023



**STRENGTHENING OUR
COMMUNITY AND
CONNECTIONS**

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RESTLESS LEGS
SYNDROME
FOUNDATION



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Warning and Disclaimer

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

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RLS Awareness Day is September 23.

How do you plan to raise awareness of this disease in the public realm? Follow the Foundation online at www.rls.org or link to our social media outlets to learn more about how you can educate others about RLS.

Our staff is also gearing up for the National RLS Symposium on October 20–22 in Baltimore (www.rls.org/23-symposium-home) at the Maritime Conference Center near the Baltimore/Washington International Airport. Please join us for this two-day event to learn from physician experts, share tips, gain helpful advice from others in the RLS community and participate in the popular "Dine with the Experts" dinner.

This year, we will offer a session led by a panel of RLS patients who will share their insights and stories about living with RLS. We have arranged for an on-site videographer to document the wide range of RLS experiences in our audience to educate others about the impact of RLS on families. If you would like the opportunity to share your RLS journey while at the symposium, please let us know by emailing info@rls.org before the conference. We will give interested participants 15 minutes to describe challenges, coping strategies, and other details that they feel would benefit others. Our goal is to amplify the voices of people living with RLS and in turn educate others about the delays to diagnosis, treatment challenges and other difficulties of living with a chronic medical condition.

On Monday, October 23, the RLS Foundation has a full day of advocacy planned on Capitol Hill in Washington, DC. We invite you to participate in this unique experience. As Americans, we can meet with our legislators to educate them and advocate for public policy that directly affects our health and access to treatment. Your representatives want to hear from you, their constituent, about what is important. Past attendees have remarked that this was an incredible and rewarding experience.

And finally, congratulations to you, RLS Foundation members! I am pleased to announce that Dr. Mark Boulos of Canada has been awarded the Foundation's 50th RLS Research Grant Award, thanks to your generous support. Dr. Boulos will study the safety and efficacy of a Canadian-approved CBD/THC topical oil for treating RLS. See page 7 to learn more.

Mark your calendars and plan to spend time in Baltimore and Washington, DC, with RLS staff and your fellow RLS community members in October. In the words of Mahatma Gandhi, "Be the change you wish to see in the world." We each hold the key to change in the palm of our hands – Grasp it and unlock a new world by becoming an educated consumer and RLS advocate.

Sincerely,



Karla M. Dzienkowski, RN, BSN
Executive Director

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Strengthening Our Community and Connections: During COVID and Beyond

By Adrianna Colucci, RLS Foundation Administrative Assistant

As the lingering shadow of the COVID-19 pandemic begins to dissipate, it is a good time to reflect on the importance of community. In a time of uncertainty, neighbors, local businesses and essential workers stepped up to fill a critical void. We adapted to grocery delivery services, telemedicine practices and work-from-home to prioritize our collective well-being. This common thread allowed us to support each other in unprecedented times.

The pandemic also presented new challenges for the RLS community: *How do you manage your symptoms when you suddenly can't leave your house?* Increased stress, mental health issues and lack of daily physical activity can exacerbate symptoms for some. Despite the restrictions on in-person interactions, the RLS community banded together to form virtual connections and provide support. Whether you offered encouragement to someone during a virtual support group meeting, left a comment on our Discussion Board, or shared your story in *Nightwalkers*, you helped another individual feel understood.

That's why our focus for the upcoming 2023 RLS Patient Symposium in Baltimore is "Making RLS Connections." We want to strengthen the virtual connections you've made by facilitating a two-day, in-person event. Not only will you leave the conference with expanded knowledge from RLS experts, but you'll leave knowing that there is an entire community that understands and empathizes with your experience. The registration form can be found on the back page of this issue, but if you cannot attend our RLS Patient Symposium, there are other ways to strengthen your ties to the community.

ADVOCACY

While the pandemic may have kept us apart physically, it did not stop the community from uniting virtually during important calls to action. You helped shape policy decisions by participating in virtual Hill Days, joining online RLS Awareness Day events and leaving comments on federal agencies' forums.

The RLS Foundation will host its first in-person Hill Day in four years, and you are invited to join us. On Monday, October 23, we will meet in Washington, DC, to educate legislators and their staff on important issues related to RLS research funding, access to treatments and increased awareness. This event is conveniently hosted the day following the RLS Patient Symposium. Register online at www.rls.org/hillday to lend your voice and your story on behalf of those who cannot be there. We need as many participants as possible to amplify our collective RLS voice, but if you cannot attend in-person, you can submit letters or emails to your representatives.

SUPPORT

We have a network of over 70 support groups and support contacts. These dedicated volunteers are there when you need to speak with someone who has had similar experiences and can relate in a way that family and friends without RLS may not be able to. You can expand this network by volunteering to form a support group in your area. If you'd like to make a difference in your community by becoming a support group leader, contact our program coordinator, Clara, at clara@rls.org. Go to page 22 for a complete list of support groups.

Our Discussion Board is a forum where you can connect with members 24/7 by posting a question of your own or by commenting on a previously posted discussion. This is a safe and encouraging space to have conversations on topics both related and unrelated to RLS. You can register at bb.rls.org.

AWARENESS

A former RLS Foundation Board member, Bob Yoakum, coined the phrase that RLS is "the most common disease that you've never heard of." Share our social media posts to help spread awareness of RLS to those closest to you. You might just find that someone you know also has a connection to RLS. Grow your support system by having conversations with your family and friends to help them recognize how your symptoms impact your daily life. We have publications available to help your loved ones understand, and they can even attend a support group meeting alongside you.

These same conversations can also occur with your treating physician. Our Scientific and Medical Advisory Board members have reviewed numerous resource materials designed for medical providers, so you can work with your doctor to find the best treatment plan for you. You can even consider gifting a membership to your physician to keep them up to date! Email info@rls.org if you need to be directed to physician resources.

You may be familiar with "Bedtime Stories," a section in *Nightwalkers* that allows readers to submit their RLS stories. It is a great way to provide hope to your fellow readers and bring awareness to some of your struggles and how you've overcome them.

EDUCATION

Knowledge is power, so stay connected to your community through our monthly webinar series. RLS researchers and specialists volunteer their time to present on important topics related to RLS, giving you access to the most recent research. The live presentations are open to all, so be sure to register under the "Education and Events" tab at www.rls.org.

Dopamine Medications and Impulse Control Disorders

By Stephen Smith, PE

Stephen Smith has been an RLS Foundation Discussion Board moderator and RLS Foundation member since 2013.



Dopaminergic medications (such as carbidopa/levodopa, pramipexole, ropinirole and rotigotine) are frequently prescribed to treat RLS. Doctors often – though not universally – warn patients receiving the drugs that they may cause a dramatic worsening of RLS symptoms over time, an effect known

as augmentation. However, few physicians and patients are aware of another serious side effect of these drugs: impulse control disorders (ICDs). Studies found 6-17% of patients on dopaminergic medications may be affected. Anyone taking these drugs needs to be aware of the potential for such effects and be proactive in educating their providers if side effects develop. As a moderator for the RLS Foundation's Discussion Board forum, I often see this brought up in conversations, and I would like to bring awareness to it here.

ICDs show themselves as behaviors that are disturbing and out of the patient's former patterns. They could emerge as compulsive gambling, compulsive eating, compulsive shopping, hypersexuality or punding (compulsive, repetitive behaviors). Oddly, the patient may not be aware of these new, harmful behaviors. Most ICDs are behaviors that, left unchecked, can destroy financial savings, break up families, cause excessive weight gain or destroy careers. These are serious situations that need to be identified and dealt with promptly. Family members and friends need to be alert and assertive in calling attention to these often destructive behaviors and ensuring that they are taken seriously by both the sufferer and the medical professional.

ICD-induced compulsive gambling doesn't refer to friendly, low-stakes, weekly poker games; light-hearted card games with friends; or occasional trips to a casino, assuming those were activities a person enjoyed before starting on the medication. Instead, it is a powerful need to take excessive and frequent financial risks for a perceived immediate gain, whether at the casino, at the horseracing track, or on day trading stocks.

Compulsive eating is another kind of ICD. Raiding the refrigerator day and night can be an indication of compulsion that may lead to rapid weight gain. To be sure, these medications

can cause weight gain on their own, but compulsion needs to be ruled out if the patient eats compulsively.

Compulsive shopping does not include your daily essential purchases or even the occasional retail therapy. Compulsive shopping is an unrestrained need to buy unnecessary, sometimes unwanted, items. It is shopping purely to satisfy the desire to buy something – anything.

Hypersexuality is not simply defined as an increase in libido. It is an uncontrolled drive to participate in high-risk sexual activities that often do not include one's typical partner. This compulsion presents an obvious risk to familial and friend relationships.

Punding is engaging in a repetitive action, such as compulsively assembling and disassembling something over and over again. Assembling a jigsaw puzzle several times in a row only becomes punding when it becomes an uncontrollable urge to work the puzzle again and again. Punding does not carry some of the dangers of the other ICDs, but it is still cause for concern and a reason to consider another medication to treat your RLS.

The one commonality that ICDs have is that the activity, though it may be of high risk and of high consequence, brings pleasure to the individual when they engage in it. The activity stimulates the dopamine pleasure center of the brain. When the patient becomes addicted to this form of stimulation and needs to fulfill the compulsion repeatedly, there can be serious long-term consequences.

As an additional danger, some studies suggest that patients with ICDs are more likely to develop an additional complication, dopamine agonist withdrawal syndrome (DAWS), a long-term condition that can cause severe depression, anxiety and other psychological symptoms that often do not respond to treatment.

Once an ICD is identified and the offending medication is discontinued or even if the dose is significantly decreased, an individual will cease all compulsive behaviors. There is no other effective treatment for the compulsive behavior. Familial support and perhaps even professional therapy may be required in some cases to repair damage to relationships that ICD-induced behavior may have caused.

The Knowledge and Comfort of Knowing You Are Not Alone = Priceless

By Clara Schlemeyer, RLS Foundation Program Coordinator

For 31 years, the RLS Foundation has been dedicated to improving the lives of the men, women and children who live with RLS by increasing awareness, improving treatments, and funding research to find a cure for this often devastating disease. The RLS Foundation is proud to have the only dedicated RLS Research Grant Program, which funds promising research. We are a patient services organization, committed to ensuring those in the RLS community have access to top-notch resources, support, information and much more. Membership dues from our cherished members are the lifeblood of this organization, and our work can't be done without you, our members.

FIVE REASONS WHY YOUR MEMBERSHIP IS BENEFICIAL

1. ACCESS TO EXPERT RESOURCES

Members can tap into a wealth of knowledge about RLS, including the latest research, treatment options and management techniques. The Foundation offers comprehensive educational materials, such as educational brochures, open-access articles and webinars, which can empower you with a deeper understanding of your disease. All of our publications are available for immediate download through our Member Portal, as well as an archive of webinars on a variety of topics. Our materials are rigorously reviewed and edited by members of our Scientific and Medical Advisory Board. These RLS experts volunteer their time and expertise to ensure all our materials are up to date and scientifically accurate.

2. A CARING AND SUPPORTIVE COMMUNITY

Being an RLS Foundation member means you have access to a support system made up of thousands of individuals living with RLS across the globe who can empathize with what you are going through. You are no longer alone in your RLS journey. An RLS Foundation membership gives you discounted pricing on events such as our upcoming National RLS Patient Symposium, where you will meet individuals from all over the country and foster lifelong connections with those in your same shoes. Sharing personal stories, triumphs and challenges with others who can relate provides a sense of camaraderie and emotional support that can be invaluable for individuals coping with RLS.

3. CREATING YOUR LEGACY THROUGH ADVOCACY

Members of the RLS Foundation have the chance to actively participate in advocacy efforts that aim to raise awareness about RLS and improve the lives of those living with the disease. Through the Foundation's initiatives, you can contribute

to public policy discussions, promote research funding, and collaborate with healthcare professionals to advance the understanding and treatment of RLS. By joining forces with like-minded individuals and making your voice heard, you have the power to affect meaningful change and make a lasting impact on the RLS community for future generations to come.

4. THE ONLY DEDICATED RLS RESEARCH GRANT PROGRAM

As an RLS Foundation member, you contribute to the Foundation's efforts to fund research and drive advancements in the field of RLS. The financial support from membership fees and donations directly fuels research projects such as small clinical trials to investigate new treatment options, with the end goal of finding a cure. By actively supporting these initiatives, you play an instrumental role in accelerating progress, ultimately benefiting not only yourself, but also future generations affected by RLS.

5. EXCLUSIVE MEMBER-ONLY BENEFITS

In addition to the broader benefits of knowledge, community, advocacy and research advancements, RLS Foundation members enjoy exclusive perks. These include discounts on RLS Foundation merchandise in our online store, priority registration for events and conferences, and access to special member-only content in the Member Portal on our website. Four times a year, each member receives our quarterly news magazine, *NightWalkers*, which is meticulously planned, written and edited to deliver news about the latest happenings at the RLS Foundation and in the RLS realm. Our members also receive our Special Accommodations Card for use when traveling, along with our Medical Alert Card, which outlines medications that often trigger RLS and provides safe alternatives.

From gaining access to expert resources and support from a community of peers, to actively participating in advocacy efforts and contributing to research advancements, an RLS Foundation membership offers a comprehensive range of benefits. By joining or renewing, individuals not only empower themselves with knowledge and support but also contribute to the overall mission of improving the understanding and treatment of RLS to improve the quality of life for those living with the disease. The nominal fee to join or renew your membership is \$40, but the benefits that come with it bring peace of mind in knowing that you are a member of an active and supportive community that alone is priceless.

Advisory Board Spotlight: Dr. Stefan Clemens

By Adrianna Colucci, RLS Foundation Administrative Assistant



Stefan Clemens, PhD, HdR, is a full professor in the Department of Physiology at the Brody School of Medicine at East Carolina University. He is a member of the RLS Foundation's Scientific and Medical Advisory Board and the chair of both the Brain Bank and the Research Grant Committees.

Born and raised in a small town in Germany, Clemens spent nearly his entire scientific career in France and the United States. After obtaining his MS in biology from the University of Münster in Germany, he was awarded a PhD in neurosciences and pharmacology from the University of Bordeaux in France. He then moved on to postdoctoral positions at Georgia State University and Emory University School of Medicine before he was recruited to East Carolina University in 2008. His research investigates neural systems in the spinal cord and, more specifically, their role in neurological disorders like RLS and chronic pain. Some of his most recent work focuses on the interactions of the dopamine system with its different receptor subtypes to better understand the mechanisms of augmentation. He holds several patents, including one for the treatment and management of augmentation in RLS.

Q. When and how did you become involved with the RLS Foundation?

A. I have been connected to the subject of RLS since about 2003 through my clinical research, and I even took part in the RLS meeting in 2009 in Baltimore. However, it wasn't until 2015 that Dr. Richard Allen, Dr. Chris Earley and Karla Dzienkowski introduced me to the RLS Foundation. I was invited to become a member of the Scientific and Medical Advisory Board (SMAB) in 2016.

Q. You chair both the Research Grant Committee and the Brain Bank Committee. What are some of your responsibilities in these roles?

A. The Research Grant Committee is responsible for reviewing grant proposals. As chair, I restructured the previous application procedures and the guidelines for grant proposals. Since 1997, the RLS Foundation has supported 50 proposals with nearly \$2 million in funding. After issuing the new call for applications earlier this year, we reviewed 10 pre-applications from researchers in the US, Canada, and Europe. After internal pre-review, six were invited to submit full proposals. All six submitted full proposals, which were then externally peer-reviewed and subsequently discussed within the SMAB. We identified one proposal that will receive funding as a clinical trial this year, to help further the understanding and improved treatments of RLS. This will be the 50th grant funded by the Foundation since the inception of the research grant program.

My introduction to the Brain Bank Committee began in 2017, when Karla invited me to meet with Dr. Berretta, director of the Harvard

Brain Tissue Resource Center (HBTRC), to discuss brain tissue collection under the auspice of the RLS Foundation. As chair, I was tasked to facilitate and oversee the process of documenting collected donated tissue from RLS patients, so it could be accessed by RLS researchers. Over the past few years, we have been working to consolidate the HBTRC database to anonymize, process and store pertinent information that meets both HBTRC and RLS Foundation guidelines. The completed database is now accessible, and researchers can request tissue identified with RLS markers at the HBTRC through the National Institutes of Health NeuroBioBank.

Q. As chair of the Research Grant Committee, you have the opportunity to review grant proposals from researchers internationally. Are you currently working on any research of your own?

A. My lab specializes in studying animal models that mimic the characteristics of RLS, including sensorimotor changes in the spinal cord and changes in sleep onset. We try to understand how and why these behaviors occur, and to explore potential therapeutic options that alleviate symptoms. We have recently published work in *Frontiers of Neurology* in which we show that changes in iron levels in an animal's diet can lead to changes in both sleep onset and spinal cord function that are similar to the symptoms observed in RLS patients. Gaining an understanding of how the spinal cord responds to iron deficits and dopamine function is critical, especially to provide insight into the sensory components of RLS. In animal models, spinal cord function can be readily probed for behavioral responses to experimental drugs and therapies.

Our work in animal models has led to a patent for a new medication that may improve augmentation and relieve RLS symptoms. This work has been followed by a small clinical trial by Dr. William Ondo in Houston to study its safety in RLS patients. An external company has now licensed this patent and is working on testing this drug in a clinical Phase II trial. If successful, this compound could become the first treatment for augmentation in RLS.

Q. The broader focus of your research examines the role of dopamine in the spinal cord and nervous system, but much of your published work also studies dopamine receptors in relation to RLS management. What prompted your specialized interest in RLS?

A. All my work on RLS is essentially a result of my postdoctoral stay at Emory University. There, in the lab of Dr. Shawn Hochman, I morphed from an invertebrate neurobiologist interested in neural networks and their modulation to a vertebrate neuroscientist ready to probe for such changes in clinically relevant models. The Hochman lab had a transgenic mouse model that was deficient in the dopamine D3 receptor and showed some behaviors similar

to those observed in RLS patients. An award from the Christopher Reeve Foundation funded my work in that lab to explore the outcome of this receptor dysfunction in the spinal cord. I have worked on this and other RLS models ever since, and now my research has expanded beyond D3 receptor dysfunction and its role in RLS to explore other concepts.

Q. Throughout your years on the SMAB, what are some of the projects or accomplishments you are most proud to have been a part of?

A. I think it is the fact that working with the HBTRC, we have now successfully consolidated the RLS brain tissue database. This is clinically significant because it will allow researchers to gain access to brain tissue for RLS-specific trials. In addition, I am also proud of the successful restructuring of the grant proposal process, which now reflects the guidelines for evaluations from the National Institutes of Health. This helps grant reviewers assess proposals more effectively and provide better feedback to applicants on potential improvements.

Q. Your experience and educational background is globally diverse, spanning from Germany to France, to the United States. In what ways has this benefited your understanding of healthcare systems, research opportunities and making connections in the medical community?

A. In addition to being a member of the RLS Foundation SMAB, I am also a member of the International and European RLS Study Groups. The European perspective on managing RLS is somewhat different from the perspective in the United States. In Europe, the medical community tends to be more open to prescribing compounds that are not commonly prescribed in the US, including low-dose opioids. Opioid therapy for RLS is typically more accessible in European countries and is an accepted form of treatment*. In light of the US opioid epidemic, I understand the reluctance to prescribe opioids to treat RLS, but their successful use at low doses elsewhere may perhaps open up new collaborative efforts between European and US clinicians.

A global perspective is especially beneficial when reviewing grant applications for the SMAB Research Grant Committee. The European governmental and medical systems are different because the medical lab, medical supplies and researcher positions are typically state funded. In the US, funding needs to be secured for salaries, testing equipment and supplies, and overhead costs. This leads to a different perception of how budgets need to be written for a research proposal, and SMAB reviewers now take this into account when assessing grant applications that come from a different sys-

tem or background.

*Medical Editor's Note: Opioids are more commonly prescribed in Europe due to a European published study on the drug Targin for treating RLS. Targin (contains oxycodone) is approved for second-line treatment for RLS in Europe.

Q. As a professor at East Carolina University, you play a key role in educating future generations of medical professionals and researchers. What are some of the values you try to instill in your students?

A. When working with students in the lab, I stress the importance of being unbiased toward novel findings. More often than not, experiments yield outcomes that are unexpected or that contradict the underlying experimental hypothesis. In that case, a careful analysis of the data can reveal new scientific concepts. Being ready to accept unexpected findings can be a valuable source for developing novel theories that advance science well beyond the initial hypothesis.

In the classroom, I stress that the nervous system consists of more than only the brain. I have incorporated spinal cord and RLS-specific lectures into the medical curriculum to broaden the medical students' scope. Each year I pose a question to my students: "How many of you are familiar with RLS?" A few years ago, only one or two students out of a class of 80 would raise their hand. These last two years, about a quarter of the class has expressed familiarity with RLS. Expanding the medical curriculum to incorporate RLS and other important but perhaps overlooked medical conditions can increase awareness as students prepare to advance their medical careers.

Q. What are some advancements you hope to witness or participate in within the neuroscience field over the next decade?

A. Within the RLS field, it would be great if the ongoing drug developments lead to treatments that improve the symptoms of RLS, with and without augmentation. In addition, we have started to look at the interaction between the dopamine system and opioids in the treatment of chronic pain. Our data, from both animal models and a small clinical trial, indicate that pairing a low-dose opioid with dopaminergic drugs may ultimately decrease the overall usage of opioids and reduce their addictive properties. If these findings can be repeated in larger studies, this new pain treatment paradigm may also have a significant impact on the management of RLS and lead to treatment options that do not rely strictly on opioids, alpha-2-delta ligands or dopaminergics alone.

RLS Foundation Awards 50th Research Grant

The RLS Foundation congratulates Canadian researcher Mark Boulos, MD, who has been awarded the Foundation's 50th Research Grant Award. The Foundation's Board of Directors approved the \$50,000 award for "Using Cannabis to Treat Restless Legs Syndrome: A Safety and Feasibility Study." The study will use a Canadian-approved cannabidiol/tetrahydrocannabinol (CBD/THC)

topical oil in a double-blind, randomized trial of 30 participants (15 in each study arm) over the course of one year.

Dr. Boulos is an associate professor of neurology at the University of Toronto with extensive experience as a clinician and researcher. He has authored several publications about RLS and other sleep disorders.

Meet the RLS Foundation's Advocacy Partner: Philip Goglas II



By Adrianna Colucci, RLS Foundation Administrative Assistant

Since its establishment in 1992 the RLS Foundation has embedded advocacy into the organization's values. Today, the Foundation continues to strive for its legislative priorities by securing funding for research, protecting access to appropriate treatments, and increasing awareness in the medical and public sectors. For the past six years, the Foundation has contracted with Health and Medicine Counsel (HMC), an organization dedicated to advancing the objectives of nonprofits and the healthcare industry, to guide and focus its advocacy efforts. Located in Washington, DC, HMC represents the RLS Foundation by facilitating relations with government agencies to effectively lead advocacy efforts regarding public policy.

NightWalkers sat down with Philip Goglas, a managing partner at HMC. Under his guidance, the RLS Foundation has successfully organized both virtual and in-person Hill Days and other advocacy events by coordinating congressional meetings and creating training resources. Additionally, his insight into legislation and policy further informs the Foundation's legislative agenda. The Foundation is grateful for his dedication and expertise.

Q. What is the role of HMC, and how does your organization represent the RLS community?

A. We are the eyes and ears for the RLS community here in Washington, DC, guiding the organization through the ever-changing policy and political dynamics. Through our many years of establishing connections with lawmakers, we're able to represent your interests within their offices. We develop relationships with both sides of the aisle to make sure that regardless of who is in charge of the House, who is in charge of the Senate, or who is in the White House, we're able to advance your key priorities.

We also provide strategic guidance to help the RLS Foundation decide which initiatives to push forward or advocate against, and when is the best time to create a call to action. This is how we engage with Congress and federal agencies as well. We met with the Centers for Disease Control and Prevention (CDC) earlier this year to discuss the effect of the updated prescribing guidelines and how we will collaborate to ensure that the community's voice is still being heard.

It's important for us to work closely with advocates so we have access to the legislative offices of each constituent. Every advocate helps us reach another House or Senate office to discuss increased research funding, the inclusion of sleep disorders in budgetary guidelines, and the difference between chronic pain and RLS to maintain access to appropriate opioid therapy. Representatives want to hear **why** these issues impact their constituency, so participation from the community is essential.

Q. What was your biggest motivation for becoming involved with public policy and grassroots mobilization?

A. I've been involved with this type of work my entire career. Before working in the private sector, I worked on Capitol Hill and was involved in grassroots efforts for many years. I've worked in different layers of government – from the local level to the state and then federal levels. In each position, I've engaged with lawmakers and taken part in the legislative process to influence policy. It's been a pleasure to work with the RLS community, and the patient population in general, to provide the human component and the patient perspective when talking about billions of dollars of funding. My undergraduate degree is in government politics, and I have my master's in public administration and public policy, so I use both my work and academic experience to effectively represent your organization.

Q. How do the individual advocacy efforts of our members support your work?

A. Advocacy is not just one day of the year; it is really a year-round process. Advocates make my job much easier. When I enter any of the 535 legislative offices (435 House and 100 Senate), the first question they ask me is, "How does this affect my district or my state, and why is it important that I act?" That's why having large, nationwide grassroots effort is important, since these issues can be addressed as locally as possible. For example, John Cornyn is the senior senator from Texas representing Austin, where the Foundation is headquartered. We've had countless meetings with Cornyn's office, and they've been incredibly helpful because of the importance of helping a constituent. By sharing what struggles you've faced, what has been helpful and how RLS has impacted your life, you can influence the decisions that your representatives make on your behalf.

Q. The RLS Foundation is hosting its first in-person Hill Day since 2019 on October 23. What are some of the most rewarding experiences past participants have conveyed?

A. One of the most important takeaways is that participants feel their voice is being heard and they can feel the difference they are making. Advocates may feel intimidated by all of the legislative jargon, but this is your chance to tell your RLS story, and it is then my job to provide specifics and requests on policy issues that affect the RLS community. I've often heard that it is rewarding to be the voice for the voiceless and to be there for the thousands of people who cannot. There is a feeling of achievement when you know you've helped educate legislators and their staff, many of whom have never heard of RLS.

Q. What are some successes of the RLS Foundation’s past policy initiatives?

A. The Foundation is part of a larger patient organization community that supports robust funding for the National Institutes of Health (NIH), and we have successfully seen continuous increases. The more resources the NIH has, the more that can be allocated to projects that advance the understanding of RLS and other health conditions. To drive these requests, the RLS Foundation and HMC have coordinated meetings with federal agencies such as the NIH and the CDC to elevate the concerns of the RLS community.

We have also successfully advocated for “sleep disorders” to be included in the Department of Defense Peer Reviewed Medical Research Program, which supports medical research in the interests of military personnel, for which sleep disorders are a large issue. The RLS Foundation was also among many instrumental organizations that led to the creation of the Chronic Disease Education and Awareness Program at the CDC, allowing organizations to compete for grant funding for awareness and educational activities for both the larger patient population and for medical providers.

Overall, our continued advocacy efforts have led to a better understanding of RLS for representatives on Capitol Hill and federal agencies. Despite the COVID-19 restrictions, the community has continued to engage through virtual advocacy actions that make our priorities well known to elected officials.

Q. What are three key pieces of advice you would give to someone who is interested in becoming a more involved advocate?

A. Share your story, be yourself, and have fun with it. Rather than being an intimidating experience, advocacy should be an opportunity to connect with your community and take part in democratic processes that allow elected officials to hear from and better represent their constituents. I work with advocates across numerous organizations, and many are shy or intimidated during their first congressional meeting. But with a bit of experience, they become more comfortable and even begin to recruit other members to participate. Most importantly, remember that sharing your story, which only you can tell, can really make a difference in influencing policy decisions.

Join the RLS Foundation Staff in Washington, DC!

On Monday, October 23, the RLS Foundation staff and board members, RLS experts and members of the RLS community will mobilize on Capitol Hill in Washington, DC.

At the RLS Foundation, we are excited to invite you to join us for our first in-person Hill Day in four years! You will spend the full day meeting with congressional representatives to advocate for increased RLS research funding, protected access to appropriate treatments, and expanded awareness in both the medical and public sectors. Most importantly, you will get to share your RLS experience with key legislators who shape public policy.

At our first in-person advocacy event in a few years, we want to make our presence **loud** by including as many voices as possible. You can be part of this remarkable experience. First, reconnect with your community at the 2023 RLS Patient Symposium “Making RLS Connections” on October 21–22 in Baltimore. Then reunite with us on the following Monday for Hill Day. For additional information, advocacy training resources, and a link to register, go to www.rls.org/hillday.

2023 Hill Day

We need you!

Be an **RLS advocate** for your community and join us in Washington, DC!

Register Now at www.rls.org.



You Can Still Go to Harvard: Leaving a Legacy Through Brain Donation

We all leave a legacy by imparting values to our family, friends and everyone we've touched in our communities. But have you considered extending your legacy to future generations through science or scientific research? Your brain is an intricate and complex network, making it an invaluable gift to research. Neuroscience advances our understanding of the nervous system and neurological disorders, including RLS. This insight may ultimately lead to developing more effective treatments and potentially a cure.

The Harvard Brain Tissue Resource Center (HBTRC) facilitates the collection and distribution of brain tissue, which is then made accessible to medical researchers. The HBTRC is one of six centers belonging to the NeuroBioBank (NBB) network, funded by the National Institutes of Health, and houses the Foundation's tissue collection. For the past few years, the RLS Foundation has worked closely with agency leaders, including HBTRC Director Sabina Berretta, MD, to consolidate the process of proper identification of RLS brain donations. Collaboration among these organizations is essential for spreading awareness and making tissue available for distribution to RLS researchers.

Preregistration for brain donation is also available through The Brain Donor Project, a nonprofit dedicated to increasing awareness and simplifying the donation process. Tish Hevel, CEO of The Brain Donor Project, partnered with the NBB to help potential donors get connected to one of the brain banks in their network.

Though these conversations can be difficult, now may be the time to introduce the topic of brain donation to your family. Your family or next of kin will play a large part in honoring your

wishes for donation, so preparation is important. Though pre-registration is not required for brain donation, it can be helpful for potential donors and their families. Below are some quick talking points to help with the conversation.

- Brain donation is open to everyone, regardless of whether or not they are affected by a nervous system disorder. In fact, it is equally important for researchers to have access to brains that are not affected by a nervous system disorder. The "control" brain allows for comparison and furthers knowledge of the brain in general.
- Being an organ donor does not automatically make you a brain donor. There is a separate consent process specific to brain donation.
- Just one brain can have a massive impact, potentially providing data for hundreds of studies.
- Due to support from the federal government and foundations, there is no financial obligation to your family for the recovery, shipment, processing or distribution of a donated brain.
- Whether you register through The Brain Donor Project or HBTRC, you can still go to Harvard. Let your next of kin know that you want your tissue to go to the HBTRC as part of your end-of-life planning and provide them with the phone number to HBTRC: 1-800-BRAIN BANK (1-800-272-4622).

There is much to learn about how you can further your legacy through brain donation. If you have additional questions, be sure to visit the FAQ page on the HBTRC website at hbtrc.mclean.harvard.edu or The Brain Donor Project at braindonor-project.org. All registration forms are available on the website. Thank you for your consideration of leaving a gift that will have a lasting impact on the RLS and medical community.



In Memory of John B. Williams 1936–2023

The RLS Foundation mourns the death of a former Board member, John B. Williams of Baton Rouge, Louisiana. John served as an RLS Foundation support group leader from 1995 to 2007 and as a dedicated member of the Board of Directors from 1995 to 2001. The Foundation is thankful for John's leadership, service, friendship and commitment to the RLS Foundation and its members. John was a valued member of the RLS community and will be greatly missed.

RLS Foundation Research Grant Program: 1997-2023

The RLS Foundation Research Grant Program supports basic and clinical research on restless legs syndrome (RLS).

In 1997, the RLS Foundation established the Research Grant Program to fund small research grants (\$25,000–\$35,000) to stimulate and provide data for larger grants at federal agencies such as the National Institutes of Health, Department of Defense, biotechnology and medical technology companies. Funding priorities include basic and clinical research to promote a better understanding, advance new treatments and find a cure for RLS. The Research Grant Program invites innovative approaches, interdisciplinary studies and support of promising postdoctoral candidates.

The primary areas of funding have been genetics, epidemiology, iron regulation, neurophysiology and animal models/treatment. The Foundation's Scientific and Medical Advisory Board reviews grant applications and selects studies for funding based on scientific merit and alignment with funding priorities.

Since the grant program began, the Foundation has funded 49 research grants totaling nearly \$1.9 million. Eighty-five percent of the grant recipients reside in the United States and the remaining 15% of grant recipients are international. The average grant amount is \$38,569.

Ten of the recipients secured additional funding for their studies from government agencies, for total grant award dollars of over \$10 million. Recipients have published findings in over 25 papers and several book chapters.

Research Grant Program Makes Headway

In 2007, Dr. David Rye, funded in part by the RLS Foundation, discovered the first gene variant (BTBD9) that contributes substantially to the risk for RLS. In 2017 Dr. Sergi Ferré, with research grants from the RLS Foundation, hypothesized that the reason for increased glutamate and dopamine transmission in RLS is due to a decrease in adenosine transmission; increased dopamine and glutamate transmission leads to PLMS and hyperarousal in RLS. Dr. Ferré's team have also pinpointed a subtype of receptor in the brain – the dopamine D4 receptor – as a new target for dopamine drug development.

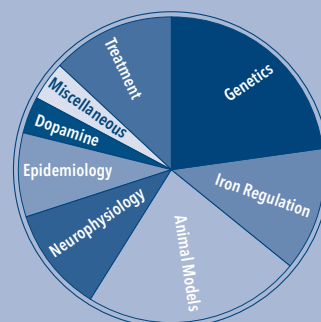
Dr. John Winkelman was awarded a grant in 2017 to develop the RLS Opioid Registry to evaluate the longterm safety and effectiveness of opioids for treatment of refractory RLS. This study will yield important data that will help to establish treatment parameters and future research.

These studies advance our knowledge and understanding of the causes of RLS and paves the way to improved diagnostic methods and more effective treatments.

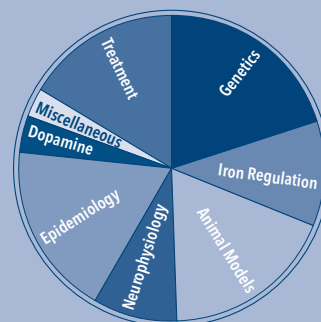
To keep our researcher's work moving forward toward a cure, please make your tax deductible contribution to the RLS Foundation at www.rls.org or call 512-366-9109.



% Studies



% Funds



Grants by Priority Area, 1997-2023

Priority Area	No.	% of Studies	Award	% of Funds
■ Genetics	11	22%	\$368,954	19%
■ Iron Regulation	6	12%	\$206,311	11%
■ Animal Models	11	22%	\$364,450	19%
■ Neurophysiology	5	10%	\$157,500	8%
■ Epidemiology	4	8%	\$326,356	17%
■ Dopamine	2	4%	\$69,600	4%
■ Treatment	9	18%	\$376,749	20%
■ Miscellaneous	2	4%	\$49,250	3%
TOTAL	50	100%	\$1,919,170	100%



RAISE AWARENESS

PROMOTE ADVOCACY

IMPROVE TREATMENTS

SUPPORT RESEARCH

FIND A CURE

Restless Legs Syndrome Foundation
 3006 Bee Caves Road, Suite D206
 Austin, Texas 78746
 (512) 366-9109
www.rls.org
rlsfoundation.blogspot.com
bb.rls.org



Grant Award Recipients

Genetics

Lan Xiong, MD, PhD (2009)

Genome wide gene expression profile & iron regulation in RLS patients carrying the MEIS1 genetic risk variant

McGill University, Montreal, Canada

Guy Rouleau, MD, PhD (2008)

Defining the risk variants within the MEIS1, BTBD9, MAP2K5/LBXCOR1 genomic regions in RLS patients

Human Research Centre, Notre Dame Hospital, Montreal, Canada

Juliane Winkelmann, MD (2008)

Worldwide genome-wide association study for RLS: WW-GWA-RLS

Institute of Human Genetics
GSF National Research Center, Munich, Germany

David B. Rye, MD, PhD (2006, 2007, 2008)

RLS genome study - USA/ICELAND

Emory University School of Medicine, Atlanta, GA

Juliane Winkelmann, MD (2005)

EU-RLS-GENE – Three loci for RLS on chromosome 12q (RLS-1); 14q (RLS-2); and 9p (RLS-3) mapping study

Institute of Human Genetics
GSF National Research Center, Munich, Germany

Lan Xiong (2003)

Dissecting Genes Involved in Restless Legs Syndrome in French-Canadian Population with Elevated Prevalence

McGill University, Montreal, Canada

David B. Rye, MD, PhD (2002, 2004)

Genetic linkage analysis of RLS in Iceland

Emory University School of Medicine, Atlanta, GA

Guy Rouleau, MD, PhD (1999)

Searching for genes predisposing to restless leg syndrome in the French-Canadian population

Montreal General Hospital Research Institute, Montreal, Canada

Iron Regulation

Padmavathi Ponnuru, PhD (2011)

A role for MEIS1 in brain iron deficiency in Restless Legs Syndrome

Drexel University College of Medicine, Philadelphia, PA

Stephanie Miller Patton, PhD (2006)

The contributory role that iron-sulfur cluster proteins play in RLS

Pennsylvania State University College of Medicine, Hershey, PA

Stephanie Miller Patton, PhD (2005)

The contribution of iron regulatory proteins (IRPs) to the dysregulation of iron homeostasis in RLS

Pennsylvania State University Milton S. Hershey Medical Center, Hershey, PA

James R Connor, PhD (2003)

Is Defective Transferrin Receptor Expression in the brain the underlying cause of RLS?

Pennsylvania State University Milton S. Hershey Medical Center, Hershey, PA

James R. Connor, PhD (2001)

Elucidating mechanisms for regulation of iron acquisition by the brain

Pennsylvania State University, University Park, PA

Judith Owens, MD, MPH (1999–2000)

Restless leg and periodic limb movements in children with iron deficiency anemia and elevated lead

Brown University School of Medicine, Providence, RI

Animal Models

Yuqing Li, PhD (2015)

Characterization of Meis1 heterozygous knockout mice as a model of Willis-Ekbom Disease

University of Florida, Gainesville, FL

Sergi Ferré, MD, PhD (2014, 2015)

Measuring corticostriatal neurotransmission in iron-deficient rats as a model for screening of drugs potentially useful in WED-RLS

National Institute on Drug Abuse, Baltimore, MD

Yuan-Yang Lai, PhD (2012)

Effect of histamine H3 receptor antagonism on PLM in iron-deficient rats: an animal model of RLS and its treatment

University of California Los Angeles and Sepulveda Research Corporation, Los Angeles, CA

Subhabrata Sanyal, PhD (2011)

Genetic modeling of Restless Legs Syndrome in Drosophila

Emory University School of Medicine, Atlanta, GA

Seiji Nishino MD, PhD (2004)

PLMS in hypocretin-deficient narcoleptic dogs

Stanford Center for Narcolepsy Research, Palo Alto, CA

Byron C. Jones, PhD (2004)

Proposal to create mouse colony to identify candidate genes related to RLS

Pennsylvania State University, University Park, PA

Yuan-Yang Lai, PhD (2002)

Ventral mesopontine junction mediated muscle activity during sleep

University of California, Los Angeles, North Hills, CA

Felipe Espinosa, DVM, PhD (2001–2002)

Potential mouse model for human-RLS (hRLS)

University of Texas Southwestern Medical Center, Dallas, TX

David B. Rye, MD, PhD (2001)

Neural substrates of and pharmacologic interventions for restless legs syndrome and paroxysmal limb movements during sleep

Emory University School of Medicine, Atlanta, GA

David B. Rye, MD, PhD (2000)

Fellowship for Drs. Amanda Freeman and Glenda Keating - Non-human primate model of PLMS

Emory University School of Medicine, Atlanta, GA

Neurophysiology

Stephanie Miller Patton, PhD (2012)

The role that the nitric oxide pathway plays in regulating vasodilation of the legs in Restless Legs Syndrome

Pennsylvania State University College of Medicine, Hershey, PA

Stephanie Miller Patton, PhD (2009)

The role that the hypoxia response pathway & neuronal nitric oxide synthase (nNOS) plays in the mechanism of RLS

Pennsylvania State University College of Medicine, Hershey, PA

Douglas E. Wright, PhD (2006)

Contributions of Abnormal Sensory Input from Muscle in RLS

University of Kansas Medical Center, Kansas City, KS

Karin Stiasny-Kolster, MD (2004)

Quantitative sensory testing (QST) in RLS

Department of Neurology, Marburg, Germany

William Bara-Jimenez, MD (1997–1999)

Restless Legs Syndrome Foundation Fellowship

National Institute of Neurological Disorders and Stroke, Bethesda, MD

Epidemiology

Hochang Benjamin Lee, MD (2013)

Subcortical white matter hyperintensities on brain magnetic resonance imaging: a comparison between early-onset and late-onset RLS subjects

Yale University, New Haven, CT

Jeffrey Durmer, MD, PhD (2005)

Identification of restless legs syndrome in children

Emory University School of Medicine, Atlanta, GA

Lorene M. Nelson, PhD, and Stephen V. Van Den Eeden, PhD (2004)

Pilot study of restless legs syndrome in Kaiser Permanente

Stanford University School of Medicine, Stanford, CA

Kaiser Permanente Division of Research, Oakland, CA

Christopher J. Earley, MD, PhD (2001)

Epidemiological study of an elderly twin cohort

Johns Hopkins University Bayview Medical Center, Baltimore, MD

Dopamine

Shawn Hochman, PhD (2003)

Spinal Dopamine Dysfunction and Restless Legs Syndrome

Emory University School of Medicine, Atlanta, GA

David Eidelberg, MD (2002)

A quantitative whole-brain imaging study of the dopamine transporter in the RLS using FP-beta.CIT PET Scanning

North Shore University Hospital, Manhasset, NY

Treatment

Mark Boulos, MD (2023)

Using Cannabis to Treat Restless Legs Syndrome: A Safety and Feasibility Study

University of Toronto, Toronto, Canada

Sergi Ferré, MD, PhD (2019)

Elucidating the mechanisms of the therapeutic effects of opioids in RLS

National Institute on Drug Abuse, Baltimore, MD

John Winkelmann, MD, PhD

(2017–2019, 2019, 2020, 2021, 2022)

Multicenter Longitudinal Pilot Observational Study of Efficacy and Tolerability of Long-term Treatment of Restless Legs Syndrome Using Opioids (RLS Opioid Registry)

Harvard Medical School/Massachusetts General Hospital, Boston, MA

William Ondo, MD (2016)

Treatment of RLS augmentation with Ecopipam, A D1 Specific Antagonist

Houston Methodist Neurological Institute, Houston, TX

Michael Polydefkis, MD (2000)

A Trial of gabapentin in RLS stratifying patients by presence/absence of small fiber neuropathy

Johns Hopkins University School of Medicine, Baltimore, MD

William G. Ondo, MD (2000)

Assistance with the Harvard Brain Tissue Resource Center

Baylor College of Medicine, Houston, TX

Miscellaneous

William Padula, PhD, MS, Msc (2016)

Economic Evaluation of Restless Legs Syndrome (RLS)

Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

William G. Ondo, MD (2000)

Assistance with the Harvard Brain Tissue Resource Center

Baylor College of Medicine, Houston, TX

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.

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All rights reserved.

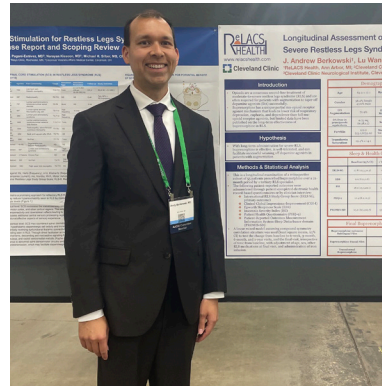
SLEEP 2023: An Awareness and Education Opportunity

The RLS Foundation staff represented the RLS community at the annual 2023 SLEEP Conference in Indianapolis on June 3-7. This five-day conference is a collaborative effort of the American Academy of Sleep Medicine and The Sleep Research Society. Their goal is to unite healthcare professionals and researchers to discuss the latest advancements in sleep medicine through presentations hosted by experts, poster sessions, patient advocacy forums, and booths for advocacy groups and sleep-related organizations. Among the presenters were members of the RLS Foundation's Scientific and Medical Advisory Board, including Dr. John Winkelman, Dr. Elias Karroum and Dr. Andy Berkowski; and Dr. Katie Cederberg, who hosted the Foundation's January 2023 webinar.

Participation at SLEEP allows the Foundation's staff to network with sleep specialists from across the world who are conducting RLS research, including meeting with the International RLS Study Group. These connections help the Foundation diversify its monthly webinar series, topics in *NightWalkers*, and speakers at patient meetings.

Staff members spoke to physicians, researchers and PhD students to expand awareness of this disease in the medical community and to emphasize the importance of furthering RLS research. They distributed educational materials, including the *Physician Medical Bulletin*; the *Causes, Diagnosis and Treatment of RLS* brochure, pediatric publications and other patient resources. This outreach expands the Foundation's reach to the RLS patient community – *your* community. At the meeting, physicians consistently remarked on the increasing number of RLS patients they see, from children to older adults, and the importance of having a patient services organization to recommend. The conversations at SLEEP also helped the Foundation grow its recommended healthcare provider directory, which helps patients across the United States find a physician with experience managing RLS. Additionally, Foundation staff members gained insight into technological advancements for different sleep disorders and promoted the Foundation's Research Grant Program, which recently funded its 50th research study. (See page 7.)

Stephen Smith, moderator of the Foundation's Discussion Board, joined the conference to participate in the Patient Advocacy Forum. This unique session educates medical professionals about the patient experience so they can understand how to better support their patients. Smith discussed his difficulties with finding a provider who was knowledgeable about RLS treatment. His experience, largely undermined by those from whom he sought help, led to extreme delays in his diag-



Dr. Andy Berkowski answering questions at his poster.



Adrianna Colucci, Clara Schlemeyer, Zibby Crawford and Karla Dzienkowski representing the RLS Foundation.

SLEEP 2023
JUNE 3-7 | INDIANAPOLIS, IN

A JOINT MEETING
AASM American Academy of Sleep Medicine | SRS Sleep Research Society

DELAY IN DIAGNOSIS
Chair: **Raman Malhotra, MD**

- Amy Clifton, BSN, RN (Patient)
- Allison Puglisi (Patient)
- Stephen Smith (Patient)**
- Alexandra Wharton (Patient)
- John Ensminger (Parent)
- Gilles Frydman (Advocate)
- Amy Kant (Advocate)
- Rebecca King (Advocate)
- Monica Mallampalli, PhD (Advocate)

nosis and proper treatment. Many people with RLS can relate to Smith's story, and the Foundation thanks him for sharing his story on behalf of the RLS community.

Your support allows us to have a presence in influential spaces such as SLEEP to represent the interests of your community. Thank you to all who support us through membership and generous donations!



BY J. ANDREW BERKOWSKI
MD

RLS Poster Abstracts Displayed at SLEEP 2023

An important part of SLEEP 2023 is the Poster Hall, where researchers discuss their latest research. This year, there were 15 posters describing RLS research. The following are some of the poster abstracts.

“LONG-TERM RESPONSE TO TONIC MOTOR ACTIVATION (TOMAC) THERAPY FOR REFRACTORY RESTLESS LEGS SYNDROME”

Roy A, Ojile J, Kram J, et al. 0713. SLEEP. 2023;46(Supplement_1):A313-A313. doi:10.1093/sleep/zsad077.0713

THE BACKGROUND

Nonmedication options for RLS are highly sought, and a new peroneal nerve stimulator device has been developed. With a removable cuff worn around the legs under both knees, this device sends an electrical signal through the peroneal nerve, stimulating the nerve and muscles, and theoretically sending feedback to the brain, relieving symptoms of RLS, similar to the effect of walking. An initial randomized, controlled trial (the RESTFUL study) showed very good short-term relief of RLS symptoms and device tolerability. This study extended observation of the device's effect for more than 24 weeks.

THE RESEARCH

Fifty participants from the RESTFUL study were extended on the device after week 8 for an additional 24 weeks. Subjects did one 30-minute session of stimulation per night if they had RLS symptoms. The clinician-determined responder rate improved from 64% at week 8 to 76% at week 32. The IRLS Score, determined by

a questionnaire to measure the severity of RLS, continued to improve from week 8 to week 32, with an average reduction of 11.6 points from baseline.

THE BOTTOM LINE

The peroneal nerve stimulation device using tonic motor activation showed continued improvement in moderate to severe RLS for over 24 weeks of treatment.

FURTHER QUESTIONS

How will the device fare with real-world use compared to these trials? How will this treatment compare to current standard treatments? Can the device improve RLS as whole with decreasing need to be used over time, as shown in these studies?

“CONTRASTING PAINFUL AND PAINLESS RESTLESS LEGS PHENOTYPES: AN ADULT TWIN FAMILY STUDY”

Champion D, Bui M, Aouad P, et al. 0698. SLEEP. 2023;46(Supplement_1):A307-A307. doi:10.1093/sleep/zsad077.0698

THE BACKGROUND

Recent research has shown key differences between the more typical (painless) forms of RLS and the painful variants. This study looks to the Twins Research Australia database to find differences and similarities between these groups.

THE RESEARCH

Adult twins and family members were screened for RLS and placed into “painful” and “painless” groups for comparison of characteristics. Of 1,327 subjects who responded, researchers found that the classic painless RLS was associated with iron deficiency, but painful RLS was not. Conversely, painful RLS was associated with other pain conditions such as migraines and abdominal pain, whereas painless RLS was not associated with pain disorders.

THE BOTTOM LINE

This study further demonstrates that there may be a variety of distinct conditions or variations that we call RLS.

FURTHER QUESTIONS

Do those with painful RLS have more problems in the pain pathways of the brain or nervous system? Are these variants more responsive to opioids, or alpha-2-delta ligand medications like gabapentin? What is the role of IV iron for those with painful RLS compared to those with painless RLS?

“PERCEPTIONS OF PEOPLE WITH RESTLESS LEGS SYNDROME ON THE EFFECT OF EXERCISE ON SYMPTOMS: RESULTS OF A NATIONWIDE SURVEY”

Cederberg K, Sikes EM, Mignot E. 0701. SLEEP. 2023;46(Supplement_1):A308-A308. doi:10.1093/sleep/zsad077.0701

THE BACKGROUND

The effects of exercise on RLS symptoms have always been controversial. This study evaluates patient perspectives on exercise and its effect on their RLS.

THE RESEARCH

A nationwide survey of 528 participants with RLS was administered, looking into the effects of exercise. About 72% of respondents reported that exercise generally improved RLS symptoms. A sudden change in exercise on one day or exercise progressively later into the evening was more likely to cause a worsening of RLS.

THE BOTTOM LINE

This study supports the idea that exercise is generally beneficial to symptoms of RLS, but some aspects of exercise may be counterproductive. The first publication from this survey collaboration was published in the Journal of Sleep Research, see link: <https://onlinelibrary.wiley.com/share/r/9YERFSMBCCFVASA>

DAGXH?target=10.1111/jsr.13980

FURTHER QUESTIONS

What is the biological way that exercise at one time of day can affect RLS symptoms at another? Are there certain types of exercise that are more beneficial than others? Why would late night exercise or suddenly more strenuous exercise have the opposite effect on symptoms?

“SUICIDALITY IN PATIENTS USING OPIOID MEDICATIONS TO TREAT SEVERE, REFRACTORY RESTLESS LEGS SYNDROME: PREVALENCE AND ASSOCIATIONS”

Zackon J, Winkelman J. 0702. SLEEP. 2023;46(Supplement_1):A308-A309. doi:10.1093/sleep/zsad077.0702

THE BACKGROUND

Previous research has shown high levels of suicidal thoughts, particularly in those with depression and severe RLS. This study investigates suicidal thoughts through participants of the National RLS Opioid Registry.

THE RESEARCH

Researchers looked at survey questions of active and passive suicidal thoughts prior to and during opioid treatment. Active and passive suicidal ideation decreased from 22.0% to 7.0% and 36.7% to 13.4%, respectively, after treatment with opioids, but 7.8% of respondents still had suicidal thoughts within two weeks before they took the survey. Passive suicidal ideation was less common on methadone, which was linked to lower depression and RLS severity.

THE BOTTOM LINE

This study highlights the importance of monitoring and addressing mental health in people with severe RLS, including those on opioids for treatment.

FURTHER QUESTIONS

Despite improvements to suicidal ideation, what is the reason for high residual rates of depression and suicidal thoughts, even with opioid therapy? Why was methadone linked to lower rates of suicidal thoughts: better control of RLS, or anti-NMDA properties? What impact does dopamine agonist augmentation and long-term withdrawal

effects have on depression and suicidal thinking, and are these independent of RLS severity or opioid use?

“SPINAL CORD STIMULATION FOR RESTLESS LEGS SYNDROME: CASE REPORT AND SCOPING REVIEW”

Carvalho D, Pagani-Estévez G, Kisson N, Silber M, Tippmann-Peikert M. 0707. SLEEP. 2023;46(Supplement_1):A310-A311. doi:10.1093/sleep/zsad077.0707

THE BACKGROUND

Due to the potential side effects of several classes of RLS medications, many desire a procedural treatment for RLS, and this abstract looks into spinal cord stimulators.

THE RESEARCH

The clinicians report a case of a 77-year-old woman with severe RLS and other pain conditions who had a spinal cord stimulator inserted, which led to a 50% reduction in RLS symptoms after seven days and a 75% reduction after six months. The daily opioid dose was reduced by about 25% and pain levels improved by 50% with improvement in sleep quality. The group reviewed published literature and found reports of 16 other patients who had improved RLS symptoms from spinal cord stimulation.

THE BOTTOM LINE

Spinal cord stimulation may have a positive effect on RLS and may warrant further study specifically for RLS.

FURTHER QUESTIONS

What is the mechanism by which a spinal cord stimulator can improve RLS? Does it improve RLS directly, or does RLS improve secondary to leg or back pain getting better? Would it work only in patients with pain, or could it also be effective for RLS without other conditions?

“LONGITUDINAL ASSESSMENT OF BUPRENORPHINE EFFECTIVENESS FOR SEVERE RESTLESS LEGS SYNDROME AND DOPAMINERGIC AUGMENTATION”

Berkowski JA, Wang L, Mehra R. 0699. Sleep. 2023;46(Supplement_1):A307-A308. doi:10.1093/sleep/zsad077.0699

THE BACKGROUND

Buprenorphine is a unique opioid medication that has a very low risk of respiratory depression (slowed breathing) or euphoria (getting “high”), reducing safety risks such as fatal poisoning or abuse, in comparison to typical opioids. This is the largest long-term study to date of buprenorphine treatment for patients treated with severe RLS and augmentation.

THE RESEARCH

Fifty-five patients with severe RLS and/or augmentation were treated with buprenorphine and followed for up to 21 months. Of the 76% who stayed on the medication through the final visit, RLS severity significantly improved, along with all measures of sleep quality, mental health and daytime sleepiness. Of those who were on a dopamine agonist at baseline, 82.1% were able to discontinue their medication and 12.8% were on a reduced dose at the final visit.

THE BOTTOM LINE

This study demonstrates buprenorphine’s long-term effectiveness in assisting with severe RLS and augmentation.

FURTHER QUESTIONS

What is the relative effectiveness and tolerability of buprenorphine compared to classic RLS opioids like methadone? With lower overall safety risks and regulation by the DEA, should forms of buprenorphine become the go-to opioid for moderate to severe RLS over others?

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

RLS Treatment Questions Answered

Michael H. Silber, MB, ChB, is a board-certified neurologist and sleep specialist who serves as a member of the RLS Foundation Scientific and Medical Advisory Board, and as director of the RLS Quality Care Center at Mayo Clinic. Dr. Silber shared his RLS treatment knowledge in a recent webinar by answering audience questions.

Q. What are the effects of gabapentin and pregabalin on memory and brain function?

A. For most patients, gabapentin and pregabalin do not impact their memory or brain function. There is no evidence that alpha-2-delta ligands cause dementia. Some patients, typically older in age, report "mental fogging," or difficulties with concentration and memory with the drugs. In this case, the dose should be decreased or the drug should be stopped.

Q. Is it safe to take both dopamine agonists and gabapentin at the same time?

A. Yes, it is safe. They have different mechanisms, and some patients may require lower doses of multiple medications. It is important to be aware of the different side effects that may develop.

Q. Once augmentation occurs with one dopamine agonist, should you try other drugs in the dopamine agonist class?

A. It is not generally recommended. Switching to another dopamine agonist after developing augmentation may help temporarily, but eventually augmentation will occur again. The rotigotine patch may be associated with a lower risk or milder augmentation, so with careful monitoring, it may be an option for some patients who have developed augmentation on pramipexole or ropinirole.

Q. What impact does age have on medication effectiveness?

A. All side effects of medications can worsen with age. The effectiveness of medication is impacted more by the duration of use than age.

Q. Can I switch between ropinirole and pregabalin every 6, 12 or 18 months to prevent augmentation?

A. There is limited research that studies the effectiveness of a drug holiday or switching between classes of medications to reduce augmentation. It is a difficult treatment plan to maintain and may lead to loss of control of the restless legs each time a change is made.

Q. Does the ability of these medications to treat symptoms of RLS tell us about the root cause of the disease?

A. It is known that the dopamine system is clearly involved in causing RLS and is theorized that sufficient iron levels in the brain are important for maintaining dopamine function. The function of alpha-2-delta ligands in treating RLS is less understood.

Q. Is augmentation inevitable?

A. No, it is not inevitable. A Johns Hopkins study found a 70% risk of augmentation over 10 years on pramipexole. Some patients are well managed on low doses of dopamine agonists for long periods of time without augmentation.

Q. What medications should be considered if you are augmenting on dopamine agonists but are allergic to gabapentin and related drugs?

A. First, consider iron status in the body through a complete iron panel and replenish if necessary. Opioids can also be considered.

Q. What is the best method for going from a dopamine agonist to an alpha-2-delta ligand?

A. Titrate the alpha-2-delta ligand medication while maintaining the same dose of the dopamine agonist. Once the alpha-2-delta ligand dose is sustained for a week, slowly reduce the dopamine agonist over the course of months, depending on the initial dose.

Q. Are long-acting dopamine agonists (extended-release) better for preventing augmentation?

A. The rotigotine patch may be associated with a milder form or a slightly reduced risk of augmentation. There are some extended-release forms of pramipexole, and while one study in Europe suggests it may reduce the risk of augmentation, physicians in the United States have little experience prescribing it.

Q. Can the augmentation caused by dopamine agonists be reduced by decreasing the dose of the dopamine agonist?

A. Yes, the dopamine agonist can be tapered slowly and for some, the effects of augmentation disappear without introducing another medication. With severe augmentation, sometimes the individual cannot completely taper off the dopamine agonist and needs to remain on a lower dose.

Q. When should you consider split dosing?

A. If someone is on a low-dose dopamine agonist but begins to display early signs of augmentation, the dose may be increased but should not surpass the recommended maximum daily dose. When someone's dose is closer to the maximum daily dose, the dose can be split to be partially taken earlier in the day, and then later at night. However, careful monitoring is needed to be certain that augmentation does not progress with this approach. Every management plan should be based on the individual and should be monitored closely by a healthcare professional.

Q. Where do you find an RLS expert to manage a severe case of RLS?

A. Refer to the RLS Foundation website (www.rls.org) for a complete list of Quality Care Centers or the Healthcare Provider Directory, which lists recommended physicians who have experience managing RLS.

Q. Are dopamine agonists appropriate for RLS in any situation?

A. While dopamine agonists are not considered the first line of defense for RLS, they may be considered when individuals cannot take alpha-2-delta ligands due to contraindications, if alpha-2-delta ligands have been ineffective or have caused side effects.

Q. Should I increase my dose of pramipexole if my symptoms are worsening or just “tough it out”?

A. Consult with a physician who can complete a thorough evaluation to determine if iron levels are insufficient, if there are triggers such as medication worsening RLS symptoms, or if augmentation is occurring. If there are no signs of augmentation and the dose is below the recommended maximum dose, sometimes an increase is an option.

Q. How hard is it to go from a dopamine agonist to an alpha-2-delta ligand?

A. It may be a lengthy process to taper off the dopamine agonist and then titrate the alpha-2-delta medication to a dose that works best. There is some data that suggests an alpha-2-delta ligand is not as effective for those who have been on a dopamine agonist. For those with severe augmentation, tapering off a dopamine agonist may be more difficult.

Medical Editor’s Note: Getting off a dopamine agonist is much

easier when transitioning to an opioid.

Q. What is the difference between gabapentin and gabapentin enacarbil? Can they be used simultaneously?

A. The two are not used together. Gabapentin enacarbil is an extended-release form of gabapentin, released slowly over 24 hours. Though more expensive, it may be helpful for those who have RLS symptoms throughout the day and not solely at night.

Medical Editor’s Note: The effective release time is actually closer to 12 hours. Sometimes, an additional dose of regular gabapentin may be added near bedtime to increase the effect of gabapentin enacarbil.

Q. What is the National Opioid Registry?

A. The National Opioid Registry is a longitudinal study funded by the RLS Foundation and conducted by Dr. John Winkelman at Harvard Medical School. It is a voluntary study to observe the effectiveness of opioids spanning years in being used to treat RLS. The study is no longer enrolling new participants.

Q. Can augmentation occur with an alpha-2-delta ligand?

A. There is no evidence that augmentation occurs with alpha-2-delta ligands. Besides dopamine agonists, only tramadol has been associated with augmentation.

Be Your Best RLS Advocate

By Clara Schlemeyer, RLS Foundation Program Coordinator

September 23 is RLS Awareness Day, and the RLS Foundation invites you to spread the word and connect virtually with the RLS community. Throughout September, we will be sharing the most effective ways to be your best RLS advocate. We have weekly planned activities, and we hope you will participate to help us increase recognition of this often misdiagnosed and overlooked sleep disorder. Follow us on social media all month long to learn new ways to educate yourself and others about this common condition – which many people have never heard of – and spread the word about available treatment options.

Ways to Participate:

1. September Webinar

Our September webinar is titled “How to Educate Your Physician” featuring RLS Foundation Executive Director Karla Dzienkowski, RN, BSN. Many individuals with RLS are first diagnosed and treated by their primary care physicians. However, we know that training on RLS is minimal in some medical schools, and many patients, due to their location, are unable to seek treatment at one of our RLS Quality Care Centers or from an RLS-experienced neurologist. This one-hour presentation is designed to empower you with the tools to present information and have productive conversations with your treating physician. You will learn tactics to approach your physician in the most

effective way, so you receive the best care possible.

2. Unleash Your Creativity!

Use your frontal cortex (also known as the hub of creativity in your brain) to design the RLS Foundation’s next magnet and/or sticker. Use the templates found on page 23 and mail your design back to us, and we will ask the members of the RLS community to vote for their favorite design. Be as creative as you want –and most importantly, have fun! We encourage you to share your creation on social media and use the hashtag #2023RLSAwarenessDay to spread the word about RLS.

3. Help Us Update Our Word Cloud

Everyone describes their RLS differently; if there was one word to describe your experience with RLS, what would it be? Please submit your “word” through this simple link at www.survey-monkey.com/r/23wordle.

It is estimated that 7%–8% of the US population lives with RLS. Our goals for RLS Awareness Day are to help you educate your physician, raise awareness and get others involved. You are not alone on your journey. You have the support of the RLS Foundation staff, Board and volunteers, and many others who understand the struggles of RLS. We can’t wait to share your creativity with the RLS community!

BEDTIME STORIES

DIARY OF A NIGHT WITH RESTLESS LEGS SYNDROME

I wear a patch all day and take my meds at dinner. No alcohol or caffeine, not even chocolate in my diet anymore. I take iron and magnesium with orange juice before bedtime.

10:30 pm. It's time for bed. We chat for a bit until our hearts slow and our eyes close. I don my mask and turn on the CPAP machine.

11:30 pm. I am awakened by the jerking of my legs. Crawling on my skin commences and I need to move. Time to get up. I'll take a walk around the kitchen. Walking doesn't stop the movement. I try to rock back and forth, dance, stretch on my feet. Maybe I can rock in the recliner for a bit. Relaxation sets in, maybe sleep. No such luck, the movement begins again. Make it stop! I'll try this cream, a gift from my hubby's colleague. Still moving. Let me try a spray of magnesium on my legs. Still moving, aching. Time to ride the recumbent bike. Still moving, aching. What time is it anyway? 1:00 am. Still no sleep, still no relief. So tired. Time for a hot bath with Epsom salts and melatonin. My bed is comfortable. I don my mask. Try to sleep.

3:00 am. It begins again. Here I am on my feet, at my computer, writing this diary. Not sure when I will sleep. My husband is always willing to massage my legs, but I don't want to wake him now. Maybe I'll find something to sort or organize. I need a distraction.

The routine will most likely repeat itself tomorrow or several times this week. Please don't tell me to try soap under my sheet. It's been at least 14 years since my "official" diagnosis—we've tried it all. Some meds worked only temporarily. I know augmentation. I know people's doubt and disdain. Don't tell me it's in my head. You have no idea. There is no pattern or rhyme or reason. It's genetic. My cousin lives just like me. There is no cure. They cannot explain it. Plenty of theories. Iron deficiency is one. I take iron supplements every day and eat more greens than anyone I know. I've tried all the things, even the sleep study. I am a regular walker. I've tried yoga, stretching and chiropractic medicine. Sure, sleep apnea is related, but treating sleep apnea for three years has not solved the issue. I saw a neurologist again today. He's taking it seriously. Wants to help me. He said living with RLS can be very dark sometimes. Maybe he gets it.

-Michelle

Medical Editor's Note: With proper treatment, there is an excellent chance that her RLS can be adequately controlled and she will not have to suffer almost nightly.

To find an RLS Quality Care Center go to <https://www.rls.org/treatment/quality-care-centers> or

contact us at info@rls.org for assistance in finding an RLS provider.

POSITIONED FOR BETTER SLEEP

RLS has plagued me for most of my life. My first memory of my legs jumping and jerking was in elementary school while seated at my desk. My legs did not bother me at night, so I slept well. At age 40, I was rear-ended by a high-speed driver, causing severe whiplash, traumatic brain injury, and damaged discs in my neck and spine. It was not until about age 60 (I'm currently 66) that the symptoms became totally disruptive to my sleep. This led to severe brain fog, which significantly affected my job performance at the time.

After trying virtually every nighttime, sleep-inducing and relaxation medication, it was time to see a doctor. My general practitioner prescribed Sonata (zaleplon), which worked great for a year or two. My doctor then referred me to a neurologist who prescribed gabapentin to replace Sonata. This also worked well, and I continue to take only 100–200 mg per night, down from the original dose of 600–1,200 mg. After 12 months of experimenting with medical marijuana in conjunction with gabapentin, this combination enables me to get more restful sleep – most of the time. There are nights when RLS rears its ugly leg and begins twitching one or the other of my legs just as I am dozing off. How timely!

After experimenting with every conceivable position of my legs to see if there was an impact on the twitching, I discovered one that actually works for me 95% of the time. At the very first sign of symptoms in bed, I will curl into a fetal position with my face on my hands so I can breathe easily. To be clear, my body is facing the mattress with my knees folded under me coming to rest on my lower ribcage. My arms are at my sides with bent elbows, so that my hands are positioned under my head. Sometimes it takes a couple of minutes for my legs to calm, while other times I will drift into slumber in that position. It seems like only a few minutes have elapsed when I wake up realizing that I have fallen asleep in that position. At that point, I will simply roll onto my side and fall back asleep almost immediately – it seems my RLS has also fallen asleep. For me, this position has been my *deus ex machina*, my savior. This position may not work for everyone, but if it performs well for merely a few people, then it will have been worth sharing. Give it a try! I wish you the very best of results.

In addition, during the past year, I have experienced fewer poor sleep nights than ever. I attribute this to my introduction to the benefits of various nutraceuticals. My brain is functioning better than it has in years, along with my slumber.

2023 National RLS Patient Symposium

RLS patients, caregivers, partners, and loved ones will all come together in October at the Maritime Conference Center to learn from top RLS experts. We have carefully curated a day and a half of the latest RLS information, everything you need to know to effectively manage your RLS. Join us and others in your community for a weekend of education, connection, and hope. Find details at www.RLS.org.

GENERAL SESSIONS

How to Increase Happiness and Well-Being: Gary Bradt, PsyD

Our keynote speaker is the son of an RLS Foundation founder, Thelma Bradt. A world renowned motivational speaker, Bradt will present evidence-based strategies to enhance happiness and overall well-being with practical tips and techniques for cultivating positive emotions and improving quality of life. Like his mother, Bradt has RLS and will be emphasizing the connection between emotional well-being and managing RLS symptoms effectively.

The Basics of RLS - What You Need to Know:

J. Andrew Berkowski, MD

This is more than just the surface-level basics of RLS. In this presentation attendees will understand the fundamental aspects of RLS, including symptoms, prevalence, and underlying mechanisms. The importance of early detection, accurate diagnosis, and appropriate management strategies will be emphasized.

Common Co-Occurring Disorders with RLS:

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

Expert discussion on the frequently encountered co-occurring disorders in individuals with RLS. We will discover the relationship between RLS and conditions such as insomnia, anxiety, depression, pregnancy, Parkinson's, and multiple sclerosis and strategies for integrated care and comprehensive treatment approaches.

Breaking Down Iron and RLS:

Christopher J. Earley, MB, BCh, PhD, FRCPI

An in-depth exploration of the role of iron deficiency in Restless Legs Syndrome (RLS) complimented by RLS expert lead case studies highlighting the significance of iron supplementation and its impact on RLS symptomatology. Discussion on iron metabolism, absorption, and recommendations for patients with RLS will give insight into the major role that iron plays in the brain and body of individuals with RLS.

RLS Research: Sergi Ferré, MD, PhD, HdR

Hear from a leading RLS researcher on the latest research findings using rodent models to study RLS, and understand the neural mechanisms, genetic factors, and potential therapeutic targets. Find out the translational implications and future directions for RLS research.

Complementary and Alternative Therapies for Managing RLS: Jacquelyn (Jacci) Bainbridge, PharmD

Take a deep dive into various complementary and alternative therapies for RLS management. Explore the effectiveness of non-pharmacological interventions such as acupuncture, yoga, mindfulness, and much more. Discover new strategies for integrating these therapies into comprehensive treatment plans for those in every walk of their RLS journey.

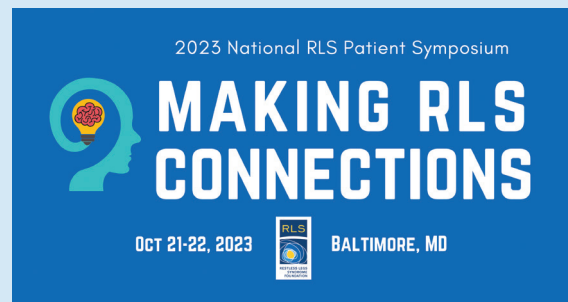
Gut Connection: Diet, SIBO & RLS: Avinash Aggarwal, MD

Discover the emerging understanding of the gut-brain connection and its relevance to RLS. Understand the potential role of diet, gut microbiota, and small intestinal bacterial overgrowth (SIBO) in RLS pathophysiology. Gather practical recommendations for dietary modifications and gut health optimization in the management of your RLS symptoms.

Leaving a Legacy: 5 Reasons to Consider Registering as a Brain Donor: Sabina Berretta, MD

Uncover the importance of brain donation for RLS research. Discuss the impact of brain tissue studies in advancing our understanding of RLS and potential treatment breakthroughs while addressing common misconceptions and ethical considerations surrounding brain donation.

SCHEDULE



FRIDAY, OCTOBER 20

3:00-4:00 PM: Check-in,
4:00-6:00 PM: Meet & Greet

SATURDAY, OCTOBER 21

6:30-8:30 AM: Breakfast Buffet (included for all overnight guests)
8:30 AM-3:30 PM: General Session
5:30-7:30 PM: *Dine with the Experts*

SUNDAY, OCTOBER 22

6:30-8:30 AM: Breakfast Buffet (included for all overnight guests)
8:30 AM-12:00 PM: General Session

Donations That Also Save You Money

At the RLS Foundation, we are truly grateful for every donation that we receive, and we are sometimes surprised at the creative ways there are to give. Whether you send a dollar bill, a valuable gold coin or a good old-fashioned check, your gifts are always put to good use. Some of our retired members have asked about giving through an IRA, so we thought a short explanation might be helpful. If you or retired friends and family members are looking for a smart way to give from the heart, a qualified charitable distribution – or QCD for short – might be the answer!

A QCD is a benefit that the IRS established to allow individuals who are at least 70½ years old to transfer up to \$100,000 from their IRAs to qualifying charities tax-free each year. For a married couple, if both spouses are age 70½ or over and both have IRAs, each spouse can exclude up to \$100,000 for a total of up to \$200,000 per year.

These distributions must be authorized by your IRA trustee to be sent directly from the IRA to a qualified charity. And – good news – the RLS Foundation is qualified to receive QCDs. What we are not qualified to do is to give you financial or tax advice. We're just providing general information here, and we encourage you to investigate the QCD option with your accountant or tax advisor. That said, here are some ways that a QCD could benefit both the donor and the charity.

Normally an IRA distribution is considered taxable income in the year it is received. But a QCD transmitted directly to a charity does not count as income and is not subject to federal

income tax. These savings could be significantly greater than the tax savings you would get if you itemized your charitable deductions. Moreover, you can make all your charitable giving through QCDs and still take the standard deduction.

Furthermore, individuals aged 73 or over also face a required minimum distribution, or RMD, from their retirement accounts – a payment that is typically taxable. The QCD can help satisfy this minimum distribution requirement and save further taxes or penalties for failing to take the RMD. State and local tax rules vary widely, so we can't comment on those, except to say that you might discover further tax benefits beyond your federal tax obligations by giving to charity through a QCD.

The types of accounts eligible may include traditional and Roth IRAs (though Roth IRA distributions are already tax-free), as well as active Simplified Employee Pension Plan (SEP) IRAs and Savings Incentive Match Plan for Employees (SIMPLE) IRAs that meet specific conditions. Again, your tax advisor should know for sure. A final note to donors who use donor-advised funds – another savvy way some supporters are managing their charitable giving. You cannot deposit QCDs directly into donor-advised fund accounts, but that method of giving comes with its own tax advantages.

As you make your charitable giving plans for the rest of this year, consider some of the ideas we've shared here and, to paraphrase the drug ad disclaimers we're so used to hearing on TV: "Ask your tax advisor if QCDs are right for you!"

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 April 1, 2023 through June 30, 2023

In Honor of:

Amy and Tina
Raquel Arber
Dr. Mark Buchfuhrer
Sheila Connolly
Tom Gonyer
Dr. Courtney Griffin

Norman Perry
Jack and Ralph Policar
Richard Watson
Theron Wilkes
Fran Williams
Travis Wood

In Memory of:

Carole Adams
Nancy Crnkovich Ayad
Gerald D. Bardeson
Josie Barrett
Peter Brooks
Helen A. Brown

Dr. Christopher Earley
George Engel
Janet G Gorecki
Arlene Grinnell
Grace Healey
Catherine Keizer

Paula Midock
Jason R Moore and
Ben Moore
Joan Ralston
Lawrence "Rocky"
Rockwood

Elizabeth "Bill" Tunison
George Wheeler
Diane Woudstra
Wayne L. Miller

Publications

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

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

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

MEMBERSHIP

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

DONATION

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

I would like to make a recurring monthly gift of

\$_____ Start date: _____

DONATION APPLIED TO

Research

Where it is needed most

PAYMENT METHOD

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

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

Card number _____ Expiration date _____

CONTACT INFORMATION (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

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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*Member of RLS Foundation Board of Directors

Register for a Virtual Support Meeting

Each month we host meetings at these times:

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

To register for a Virtual Support Group meeting go to www.rls.org/vsg.

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

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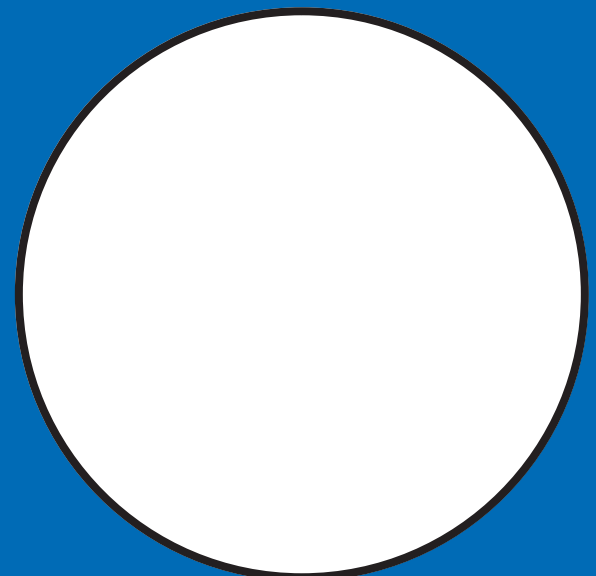
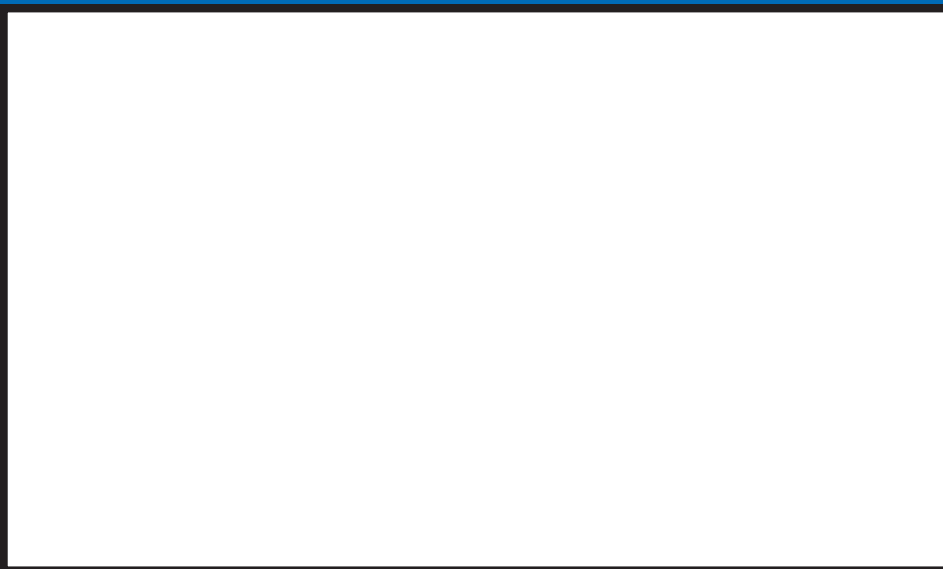
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