FORWARD TOGETHER

2024-2023 ANNUAL REPORT



The Restless Legs Syndrome Foundation is dedicated to improving the lives of the men, women and children who live with this often devastating disease. The organization's goals are to increase awareness, improve treatments and advance research to find a cure for RLS.

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2023-2024

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The Restless Legs Syndrome Foundation Board of Directors held meetings on:

10/19/2023 In-person

1/5/2024 Telephonic

3/5/2024 Telephonic 3/8/2024 Telephonic **6/11/24** Telephonic

9/16/2024 Telephonic

From the Chairman of the Board

As Chair of the RLS Foundation Board of Directors for the 2023-24 calendar year, I am pleased to report that this was an exciting time of progress and development for the RLS Foundation. We experienced growth in membership, educational programs, support events, social media engagement and public policy outreach. At the top of the fiscal year, we successfully hosted an in-person National RLS Patient Symposium in Baltimore, MD, bringing together over 120 active RLS community members. This conference provided attendees with the latest insights and research on RLS, while strengthening the development of relationships and support networks.

The Foundation maintains a healthy financial position, reflecting our commitment to honor the members who champion our mission and for the greater RLS community. Our financial team informs and advises the Board and conducts annual audits, reinforcing the integrity of our accounting practices to the communities we serve. Recognizing that our programs and outreach incur significant costs in staff time and resources, we are deeply grateful for the generous contributions beyond membership dues that make this essential work possible. We extend our heartfelt thanks to each donor for their unwavering support, which empowers us to continue our mission. Sincere thanks and appreciation to the Executive Director and staff of the Foundation, in serving the needs of the RLS community. With the continued generous support of our community members, the Foundation is well positioned to continue its vital work as we look upward and onward toward the future.



Shalini Paruthi, MD *Chair, RLS Foundation Board of Directors*

Sweet Dreams!

Spanntn, mp

Shalini Paruthi, MD

Board Chair, Restless Legs Syndrome Foundation

Celebrating Excellence: RLS Foundation Recognized Among Top Non-Profits

onprofits across the United States are evaluated annually by charity "watchdog" groups whose ratings are based on leadership, adaptability, impact and results, community, and financial transparency, helping to assure donors that their contributions are put to sound use.

RLS Foundation is pleased and honored to have received top ratings in 2024 from three such organizations:

- Charity Navigator 4/4 stars
- Candid Platinum transparency
- Great Non-Profits 2023 top rated

Recognition enhances the visibility of the growing RLS community and provides confidence that the Foundation is driving forward its mission to increase awareness, improve treatments and fund research leading to a cure. Support from members like you allows the RLS Foundation to strive for and achieve these lofty goals. Thank you for your support!



'Making RLS Connections': 2023 National RLS Patient Symposium

n important part of the RLS Foundation's mission is to increase awareness of the disease through education, for the general public and for healthcare providers. In pursuit of this mission, the RLS Foundation hosted a two-day, in-person RLS Patient Symposium in Baltimore on October 21–22, 2023. The symposium hosted leading RLS experts who presented topics relating to iron, alternative therapies, diet, co-occurring conditions and brain donation. Each day ended with an opportunity for the audience to pose questions to a panel of RLS experts in a live Q&A. This unique opportunity further allowed attendees to establish and strengthen connections with each other, RLS expert physicians and RLS Foundation staff.

SYMPOSIUM SPEAKERS

The RLS Foundation would like to thank all of the experts who volunteered their time to present on essential RLS subjects. This year's speakers included:

- Shalini Paruthi, MD
- Gary Bradt, PsyD
- J. Andrew Berkowski, MD
- Christopher Earley, MB, BCh, PhD, FRCPI
- Jacquelyn Bainbridge, PharmD
- Avinash Aggarwal, MD
- Mark Buchfuhrer, MD, FRCP(C), FCCP
- Sabina Berretta, MD



KEYNOTE SPEAKER

Gary Bradt delivered an inspiring keynote presentation on how to increase happiness and well-being that was the catalyst for an incredible weekend! A professional motivational speaker, last year Bradt approached the Foundation, offering to give back to the organization that his mother, Thelma Bradt, had helped start over 30 years ago. Through his engaging narrative and insight-

ful anecdotes, Bradt illuminated the path to amplifying happiness in life with a blend of humor and wisdom; he emphasized the significance of embracing gratitude, investing in meaningful connections and nurturing a resilient mindset. Bradt's compelling talk offered actionable strategies to navigate life's challenges and left the audience equipped with a newfound perspective on increasing happiness amidst life's hurdles.



DINE WITH THE EXPERTS

The RLS Foundation hosted *Dine with the Experts*, an event that allowed participants to attend a seated dinner to converse with an RLS expert and other symposium attendees. The conversations sparked connections, from swapping personal stories to sharing tips. *Dine with the Experts* was a reminder that those living with RLS are *not alone* and there is an entire community to provide support.

MAKING CONNECTIONS

The theme for this event was "Making RLS Connections." Going far beyond an educational seminar, the experience forged new relationships among fellow attendees. It was heartening to witness how the two-hour "Meet and Greet" was extended beyond the scheduled hours as individuals conversed and shared stories until late. Some participants had never spoken to another individual with RLS, and discovered a new sense of belonging among the group. Participants who brought family and friends grew closer as their partners learned more about the disease and how other family members cope with its effects on daily life.

The RLS Foundation thanks Azurity Pharmaceuticals for its support of this educational event. The Foundation invites you to join in future educational events, including its monthly webinar series and the upcoming Virtual Summit on April 6. To learn more about the Virtual Summit visit www.rls.org/summit.

National RLS Opioid Registry: 3-Year Research Update

By John Winkelman MD, PhD

bout 3% of the US population has RLS severe enough to require daily medical treatment. Food and Drug Administration (FDA) approved treatments, including iron therapy, alpha-2-delta ligands and dopamine agonists, are initially effective for most patients. However, for some these therapies prove ineffective with time or cause adverse reactions. As many as 50%-70% of patients using dopamine agonists develop augmentation, a worsening of RLS symptoms due to these medications.1

When symptoms are unresponsive to first-line therapies, the disease is known as refractory RLS. For people who have refractory RLS, low-total-daily-dose opioids can be an appropriate treatment option. However, concerns regarding opioids in both the medical and public sectors create barriers for RLS patients who require access to such medication.

Prompted by the lack of long-term research surrounding opioids and RLS, John Winkelman, MD, PhD, director of the Massachusetts General Hospital RLS Quality Care Center and a member of the RLS Foundation's Scientific and Medical Advisory Board, is conducting a study to observe the safety and efficacy of long-term opioids in RLS management. The National RLS Opioid Registry is intended to provide clinical evidence to help physicians manage patients with refractory RLS more effectively. Dr. Winkelman has received three grants from the RLS Foundation's Research Grant Program to support this work.

In the study, participants are treated by their local providers and fill out extensive surveys online every six months. The researchers previously reported that at enrollment, participants had been taking opioids for refractory RLS for a median duration of one to three years. Now five years since the first participants were enrolled, the researchers have analyzed the three-year follow-up data and presented their findings at the World Sleep Society meeting in October in Rio de Janeiro.

PARTICIPANT RETENTION AT 3 YEARS

The retention rate of year three participants is very high at 94.4%. Of the 500 original participants, 438 remain involved in the study.

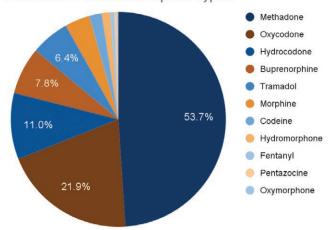
Of participants who discontinued the study:

- Twenty-eight discontinued opioid treatment of RLS.
- Twenty lost contact with the research team.
- Fourteen are no longer in the study for another reason.

MEDICATION CHANGES AT 3 YEARS

About half (53.7%) of registry participants used low-dose methadone to treat RLS symptoms. Other opioids used by participants included oxycodone (21.9%), hydrocodone (11.0%) and tramadol (6.4%). Of 438 participants, 9.6% use a combination of two opioid medications to treat their RLS.

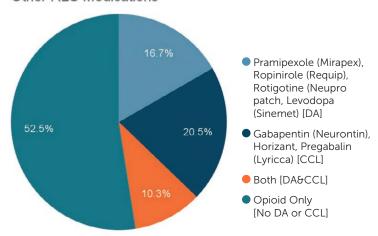
Percent of Patients on Opioid Types



Research indicates methadone has a reduced abuse potential compared to other opioids and therefore can be an effective option for long-term treatment.1

Nearly half of the participants used a second or occasionally a third medication to supplement the opioid.

Other RLS Medications



DOSE CHANGES AT 3 YEARS

After three years, 34.9% of participants maintained the same dose of their medication, 19.2% decreased their dose and 45.9% increased their dose

Three primary factors increased the likelihood that participants would increase their dose by any amount:

- Notable anxiety at the time of enrollment
- Switching opioid medications between the time of enrollment and the three-year survey
- Less than one year of existing treatment on an opioid at the time of enrollment

The following additional factors increased the likelihood that participants would increase their dose by high amounts:

- Opioids being prescribed for another condition in addition to RLS (such as comorbid pain)
- Adding a dopamine agonist between the time of enrollment and the three-year survey
- A diagnosis of depression at the time of enrollment
- At least mild insomnia at the time of enrollment

SYMPTOM SEVERITY AT 3 YEARS

A majority of participants at the time of enrollment experienced moderate persistent RLS symptoms. At year three, there has been little change in RLS severity. Most participants did not have clinically significant insomnia at the time of enrollment, which continues to be true at year three.

CONCLUSION

Longitudinal research such as The National RLS Opioid Registry is significant for RLS patients, allowing physicians, federal regulatory agencies and legislators to better understand the medical role of low-total-daily dose opioid in RLS management. The Registry will continue to observe participants for as long as they are willing to participate so that we can continue to gain insight into the long-term safety, efficacy, and stability of low-total-daily dose opioid medications for severe cases of RLS. The RLS Foundation continues to provide funding to the National RLS Opioid Registry thanks to contributions from dedicated members.

¹ Silber M et al. "The appropriate use of opioids in the treatment of refractory restless legs syndrome." Mayo Clinic Proceedings, vol. 93, no. 1, 2018, pp. 59–67, https://doi.org/10.1016/j. mayocp.2017.11.007.

RLS Foundations Awards 50th Research Grant

By Dr. Mark Boulos, MD, FRCPC, MSc

The RLS Foundation has awarded a research grant to Dr. Mark Boulos, MD, FRCPC, MSc, to study the use of cannabis to treat RLS. With this award, the RLS Foundation Research Grant Program has funded 50 grants to date, totaling nearly nearly \$2 million. Dr. Boulos is an Associate Professor of Neurology at the University of Toronto who has extensive experience as a clinician and researcher in sleep disorders.

am very grateful to be a recipient of the 2023 Restless Legs Syndrome Foundation Research Grant. My study, "Using Cannabis to Treat Restless Legs Syndrome: A Safety and Feasibility Trial" will help establish the feasibility and safety of using cannabis to manage treatment-resistant restless legs syndrome (RLS). Unfortunately, there has been very limited research in this area to date, so we believe this study will be an important first step in the evaluation of cannabis as a treatment for RLS. The results of this study may help inform larger clinical trials that will investigate the efficacy of cannabis as an RLS treatment.

As a sleep medicine physician, I often see patients with RLS who are suffering, and none of the therapies they have tried have adequately addressed their discomfort. Since cannabis has been legalized for recreational use in Canada, a few of my patients have independently tried cannabis for treating their RLS,

reporting that it provided them the relief that they had been unable to find through other treatments. However, much of the evidence for cannabis in RLS has been anecdotal, and there haven't yet been clinical trials conducted to evaluate the safety and efficacy of this approach.



The study we plan to conduct at Sunnybrook Health Sciences Centre in Toronto, Canada, will be a randomized, controlled trial where participants with refractory RLS will receive either medical cannabis or a placebo. The study will be double-blinded, meaning that both the study staff and participants will not know whether they are receiving cannabis or the placebo. Participants will be given the study drug for eight weeks and will be closely monitored for any adverse effects.

Our study aims to measure several key aspects of RLS, including symptom severity, quality of life, subjective and objective measures of sleep quality, and leg movements. We will perform assessments at baseline and during an eight-week follow-up to see how the study drug may change these important outcomes.

Ultimately, our goal is to improve the lives of individuals affected by RLS by providing new avenues of hope and relief. We are excited to begin this research study, and we are very thankful to the RLS Foundation for their support. If you live in Ontario and might be interested in participating in this study, please contact our team at mark.boulos@sunnybrook.ca.

RLS Advocacy Day: Empowering Change on Capitol Hill

By Kris Schanilec

he RLS community was back in Washington on Oct. 23, 2023, for the fourth annual RLS Hill Day on Capitol Hill. Thirty people gathered for the all-day event, traveling from as far as California to as close as DC to bring the needs of RLS patients to the attention of members of Congress.

Participants advocated on behalf of the RLS community for three priorities:

- Sleep disorder research funding
- Access to opioids as an appropriate RLS treatment
- Funding for awareness and education programming

"The impact of our advocacy day cannot be overstated. It's through these conversations with legislators that we pave the way for improved education, access to treatments, and the groundbreaking research needed to find better therapies and a cure for RLS," says Karla Dzienkowski, executive director of the RLS Foundation.

The day started with a meeting at the offices of Health and Medicine Counsel (HMC), an organization that coordinates the Foundation's advocacy activities. HMC managing partner Phil Goglas and RLS Foundation board chair Shalini Paruthi, MD, reviewed the day's agenda and what to expect in the meetings with legislative staff.

The advocates then set off for Capitol Hill, where they broke into four teams to meet with the staff of senators who represent their home states. At noon, the teams came together briefly for lunch in the Senate cafeteria, then tackled the House side in the afternoon.

In the meetings, the advocates shared their personal stories about the challenges of living with RLS and asked their legislators to support specific priorities. (See "Legislative and Policy Priorities" below.)

"Lawmakers want to hear from their constituents, and meeting with their staff is a very effective way of raising their awareness about the issues affecting the RLS community," Dr. Paruthi says. "Every conversation we have is a step forward in building a network of informed legislators who can take actions that are in the best interests of their constituents who suffer from RLS."

Dr. Paruthi, Dzienkowski and Goglas formed a fifth team that crisscrossed the Senate and House office buildings throughout the day to meet with legislators who sit on key that shape health policy.



RLS Foundation staff member Adrianna Colucci coordinated Hill day. "By far, one of the largest accomplishments of the day was how receptive legislative staff were to the stories people shared, showing that the most influential information comes from those who live with the disorder," she says. "The connections made between representatives and constituents in those meetings are vital to recruiting support and elevating the Foundation's legislative priorities."

The Foundation's contingent visited the offices of 10 states: Arizona, California, Colorado, Indiana, Iowa, Maryland, Michigan, Missouri, Pennsylvania and Texas. The staff was joined by medical experts Avinash Aggarwal, MD; Jacquelyn Bainbridge, PharmD; J. Andrew Berkowski, MD; and Shalini Paruthi, MD; by board members Marcia Ball, Dave Loskutoff and Lewis Phelps; and by 16 advocates from the RLS community. Thank you to all who participated!

"We are grateful to everyone who participated," says Dzienkowski. "We hope others will consider joining us in the future to advocate in Washington and in our home states, and by joining our letter-writing campaigns and other calls to action throughout the year."

See page 11 to hear first-hand from Foundation members who participated in RLS Advocacy Day on Capitol Hill.

Join the cause: Become an RLS advocate!

To learn more about the RLS Foundation's Advocacy Program, visit www.rls.rg/advocacy. You can also sign up to receive Foundation updates by sending a request to info@rls.org.

A Letter to Our Legislators



BY TONI TROST

Toni Trost lives in a small town near Portland, Oregon. She experienced RLS as a child and was finally diagnosed in her 30s. Trost traveled across the country to join the RLS Foundation and 30 other advocates in Washington, DC last October to share her RLS story with legislative representatives at RLS Advocacy Day on Capitol Hill. Outside of advocacy, her hobbies include sewing, knitting and hiking.

have had a difficult time writing this. I have difficulty describing the symptoms. I also have difficulty describing their effects on my life. I have lived with this disorder for so long that I'm unable to tell you what life would be like without it. I don't know what it's like to sleep through the night every night. I have no idea what it would feel like to have rested like that. When friends hear about how little I sleep, they say they couldn't survive on so little sleep. They couldn't be up and about for so many hours at a time. But some of us have no choice,

RLS has financial, physical and emotional repercussions for me. I live in Portland, Oregon, but I see an RLS specialist who practices near Los Angeles. I travel there twice a year for follow-up appointments, prescription renewals, medication changes and advice. I was there last week. Each trip costs me close to \$1,500. I was also just at the pharmacy. I take four medications to control my symptoms. Two are not generic and are not covered by my insurance. The four medications together cost me \$1,000 a month. In total, RLS costs me \$15,000 a year – the same as my take-home pay.

Physically, I deal with arthritis and muscle strain due to overuse injuries. My arthritic feet ache from the pacing and standing that occurred before I received effective treatment for my RLS. I was frequently on my feet 18 to 20 hours a day, something that still occurs from time to time. I also have arthritis in my wrists and hands. But I sew, embroider, knit and crochet, often for hours, to distract myself from the sensations in my legs.

Emotionally, this disorder has tested my resilience. When I have breakthrough symptoms that I can't find a way to relieve, I have a hard time finding hope. I have had reactions to medications that left me suicidal and depressed. I struggle with low-grade depression and anxiety. One of the curses of insomnia is that you have too much time for self-reflection. I think about my

future with this disorder. It has worsened as I've aged. The sensations and insomnia are worse, and symptoms break through more frequently. I worry that my RLS will become resistant to treatment or that I will run out of treatment options. I worry about what the lack of sleep has done and is doing to my health. I worry about losing access to my medications due to legislative changes or drug shortages. I worry that my doctor will retire and that I won't be able to find another one. I worry that a time will come when I can no longer afford my medications. My mind is full of "what ifs." The thought of living life like I did before treatment knocks me flat. Nights without my insomnia medication are the worst. It's difficult to be awake when the rest of the world is asleep. When I'm not sewing or doing some sort of needlecraft, I'm often crying with frustration and exhaustion. My mind and body are sore and exhausted by this disorder.

RLS affects my daily routine and the routines of those around me. I take medication for RLS three times a day. I try to plan activities around these times. Road trips, flights, movies, concerts, meetings, even the drive home from work – all can be impacted by RLS. I dread traveling by air. I'm not afraid of flying – I'm just afraid of being stuck in my seat due to delays or turbulence. Aisle seats are a must in case I need to pace. I paid for extra legroom and an aisle seat to fly out here.

I made this trip across the country because it is important for you, our representatives, to understand that the harmless-sounding name of this condition belies a disorder with serious difficulties for those who suffer from it regularly. I think a lot about those who are struggling with the condition who haven't been diagnosed or treated because they don't have access to knowledgeable medical professionals or because they can't afford to spend \$1,000 a month on medication. Please consider their needs and the needs of the rest of the RLS community as you create policies and build budgets. Fund research into the causes of the disorder. Fund educational programs for professionals and the public. Fund research into affordable, effective treatment. Consider the needs of the RLS community when policies surrounding opioids appear. For many of us, low doses of opioids are the only treatment that alleviates our symptoms, allowing us to lead our lives without the limits this disorder can impose. Speak up for us. Please.

Creating Connections on Capitol Hill

By Adrianna Colucci, RLS Foundation Communications Coordinator

n February 4, RLS Foundation Executive Director Karla Dzienkowski, Board Chair Dr. Shalini Paruthi and staff member Adrianna Colucci traveled from their Southern states to Washington, DC. Over the course of two days, they met with 10 legislative offices, educating representatives about RLS and its impact on the patient community. These meetings emphasized the need for increased research funding, enhanced education and awareness, and protected access to critical therapies including low-total-daily-dose opioids. This visit came at a pivotal time when committees were making key decisions on policy issues within federal agencies.

Advocacy efforts specifically targeted the United States Senate Committee on Appropriations. This committee has jurisdiction over all discretionary spending in the Senate. Its responsibility is to write legislation allocating funds to federal agencies and departments each year.1 The RLS Foundation met with the offices of Senators Jon Tester (MT), Jack Reed (RI) and John Boozman (AR), who serve on the Appropriations Committee.

Philip Goglas, a managing partner at the Health and Medicine Counsel (HMC), and Matt Duquette, an HMC representative, coordinated the Capitol Hill meetings on behalf of the RLS Foundation. Goglas explains, "We meet with appropriators because they decide how much funding the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC) receive, and further, what conditions are eligible for study."

The Foundation asked that the NIH be provided with sustained funding for fiscal year 2024 of at least \$50.924 billion. Researchers can apply for grants to conduct crucial RLS research through funding across relevant NIH centers.

The Foundation also requested at least \$6 million in funding for the Chronic Diseases Education and Awareness Program (CDEA) at the CDC. The CDC has an active public health campaign dedicated to sleep disorders, slated to end in 2024.2 Funding for the CDEA would allow this valuable public health education effort to continue.

The Foundation's advocacy team met with members of the Defense Committee and subcommittees from both the Senate and House, including the offices of Senator John Tester (MT), who is chair of the Defense Subcommittee; Senator Jack Reed (RI) and Congressman Steve Womack (AR). The Senate Armed Services Committee oversees the nation's military, including the Department of Defense (DoD). The DoD Peer-Reviewed Medical Research Program (PRMRP) supports research to enhance the health and well-being of military service members, veterans, retirees and their family members. RLS is a major sleep disorder that affects an estimated 40,000 active-duty military personnel. The Foundation advocated for continuing to include "sleep disorders" in the PRMRP, which allows researchers to apply



RLS Foundation Executive Director Karla Dzienkowski, Board Chair Shalini Paruthi, MD, and Communications Coordinator Adrianna Colucci

for grants related to RLS. A member of the RLS Foundation's Scientific and Medical Advisory Board, Brian Koo, MD, of Yale University, was awarded a research grant under the PRMRP.

The Foundation also met with members of the House Energy and Commerce Committee and the Ways and Means Committee, as well as the Labor Health and Human Services Education subcommittees. These groups oversee policy affecting healthcare, specifically for opioid-related legislation. The Foundation asked for accommodations for patients who rely on the regular use of lowtotal-daily doses of opioids to manage their RLS. When legislation addressing the opioid epidemic is introduced, it is important to consider the needs of the RLS community by carving out the same accommodations for the use of opioids that is given to disorders such as sickle cell anemia, cancer and palliative to those with RLS. The Foundation stressed the need for physicians to prescribe opioids appropriately and without arbitrary barriers.

Representing the RLS community as both a patient and a sleep physician, Dr. Paruthi emphasized that the RLS community needs additional research to better understand the pathophysiology of RLS and to improve treatments. "We work with legislative staff to shed light on what RLS individuals suffer from and how it disrupts daily life," she says.

Advocacy plays a pivotal role in shaping public policy, bridging the gap between the community and lawmakers. The Foundation thanks Matt Duquette and Phil Goglas from the HMC for coordinating these meetings and leading our advocacy efforts. If you would like to learn more about how to become involved in RLS advocacy, go to www.rls.org/getinvolved/advocacy.

- ¹ "Committee Jurisdiction: United States Senate Committee on Appropriations." United States Senate Committee on Appropriations. www.appropriations.senate.gov/about/ jurisdiction.
- ² "National Healthy Sleep Awareness Project." Centers for Disease Control and Prevention. www.cdc.gov/sleep/projects_ partners.html.

Unique RLS Coping Strategies

he treatments available to manage RLS are limited, and there is no cure. Therefore, various nonmedicinal coping methods may provide relief when managing this disease. The RLS Foundation asked members of the RLS community to share the tips and tricks that help them cope!

Everyone's RLS is unique to them, and efficacy will vary among individuals. It is important to talk to your healthcare provider and investigate concerns such as safety, effectiveness and cost before making any changes to your treatment regimen. Thank you to all who submitted responses.

"I do about 15 minutes of yoga in the middle of the night, including stretching and breathing." – *Elizabeth*

"Putting together puzzles helps me through evening hours of RLS." – *Nancy R*.

"I drink a magnesium supplement before bed, put magnesium oil spray on my legs, and immerse my legs and feet in cold water." – *Lluvia V*.

"Pushups from the knees with in-and-out breaths anytime when I can't sleep. You can also go up and down carpeted stairs 10 times to get sleep." – *Sharon C.*

"One of my biggest coping strategies is acceptance. For the past 15 years or so I have practiced acceptance of RLS to the best of my ability. Sometimes that can be near impossible. But when I can be 'one with my RLS,' my mental health is grateful." – *Jennifer C.*

"Depending on the time of day, I stand up in the kitchen and walk around gathering ingredients to cook or bake to do something that takes my mind off my legs!" – *Karen H.*

"I change the shower pressure to a hard flow, turn up the temperature to as high as I can stand it, and shoot the water on the back of my knees." – *Paula B*. "I choose my seat in meetings, performances and movies where I can inconspicuously get up to stand in the back or 'escape.' At night, I listen to a YouTube recording of a Rife frequency for RLS and do not share a bed." – Lynette C.

"I add 4–6 cups of magnesium chloride flakes – not Epsom salts – to a warm bath. Epsom salts, which are magnesium sulfate, are not nearly as effective. Travel tip: Contact your hotel to request a room with a tub, briefly explaining that a soak helps you sleep better." – *Nick C.*

"Keeping my calves cool helps reduce symptoms. I purchased a cooling pad for my bed to help maintain a level of coolness. I also recently was prescribed a wrap that has electrodes attached to it. It provides electrical stimulation to the peroneal nerve, and the stimulation mimics movement and sensation to the lower legs and feet." – Beth

"I distract myself as much as possible. Once, on a flight, I had a severe RLS episode. Strangely enough, I played the Angry Birds game on my phone for hours. It helped." – *Deborah M.**

*Medical Editor's Note: Mental activities such as video games, chess, crossword puzzles, solitaire, etc. can relieve RLS symptoms. Simple distractions such as watching a movie may not help.

2023-2024 WEBINARS

January 2024

When Should I Visit an RLS Quality Care Center? Avinash Aggarwal, MD

February 2024

Navigating RLS in Different Life Stages: Children, Teens, Adults and Seniors Shalini Paruthi, MD

March 2024

How to Increase Happiness and Well Being Gary Bradt, PsyD

May 2024

Understanding Augmentation: Causes, Symptoms and Treatment Strategies
Mark Buchfuhrer, MD, FRCP(C), FCCP

August 2024

RLS Advocacy: Preparing for Hill Day 2024 Phil Goglas, II

October 2024

RLS and Pregnancy Jennifer Hensley, EdD, MSN, RN, CNM, WHNP-BC, LCCE

RLS Foundation Virtual Summits

April 2024

RLS Research Virtual Summit

RLS Foundation Levels of Giving

At the RLS Foundation, we rely on private donations to make our work possible. While we do receive some industry grants, our lifeblood is you and your commitment to our mission. We cannot thank you enough for the support you give every year.

Unrestricted gifts give the Foundation the flexibility to target funds for programs and projects that are in the most need of financial support.

Restricted gifts may be designated to three areas: Quality Care Centers, education and research. Donations to these funds are earmarked for special projects that may complement your intentions more closely.

Monthly giving allows you to spread your donation out over the year and enables us to count on a more even stream of gifts. You can also choose to restrict your gifts with this option. Monthly giving can be done by setting up a recurring credit card gift.

Tax-deductible donations are the quickest and easiest way to give to the RLS Foundation. Checks payable to the RLS Foundation or credit card donations completed online are fully tax deductible and provide an immediate source of income for programs.

Appreciated securities are gifts that may allow you to eliminate capital gains taxes. In nearly all cases, you are able to claim a charitable income tax deduction equal to the fair-market value of the securities, check with your tax advisor.

Bequests given through your estate at the time of your death are an attractive way to make sure that your interests are preserved. When you let us know about your plans to give a gift in your estate, you become a member of our Ekbom Heritage Society, an elite group at the Foundation committed to our mission and vision for the future.

If you would like to learn more about planned giving, please contact us at 512-366-9109 or info@rls.org.

Levels

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Thank you for your continued financial support and unwavering commitment to the RLS Foundation during our 2023-24 fiscal year. Individual donors provided the majority of support for Foundation programs and activities, representing 80% of donations collected.

This year, the RLS Foundation Research Grant Program reached an important milestone by funding four research studies – two in the U.S. and two in Europe. This historic funding level is made possible through member support and a collaboration with the American Academy of Sleep Medicine Foundation (AASMF), which cofunded one grant award. These grants fulfill our mission of advancing research to find better treatments and, ultimately, a cure for RLS.

The RLS Foundation's Finance and Audit Committee monitors revenue and expenditures to ensure they are balanced and reviews forecasts for the upcoming fiscal year. Meanwhile, the Board of Directors provides financial oversight for the organization by ensuring monies are spent on programs beneficial to the members of the RLS community. Each gift received, regardless of size, allows us to fulfill our mission and, ultimately, brings us one step closer to a cure.

It is my pleasure to serve on the RLS Foundation's Board of Directors and as Treasurer. I look forward to the Foundation's continued success!

Sincerely

Jug Oberland

2023 - 2024 Highlights | Financials

Revenues and support

Contributions	\$907,285
Membership Dues	\$134,567
Other	\$92,461
Total revenues and support	\$1,134,313

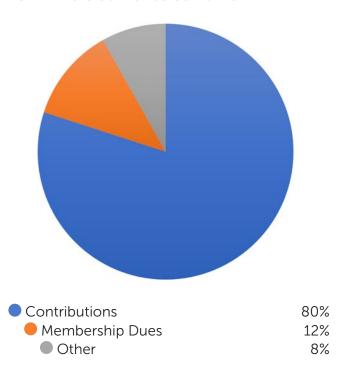
Expenses

Program services	
Education	\$515,631
Membership	\$194,938
Research	\$241,860
Support Groups	\$47,136
Total program services	\$999,565
Fundraising	\$74,017
Management and general	\$94,035
Total expenses	\$1,167,617

Statements of Activities For the Fiscal Year Ended September 30, 2024

The RLS Foundation's full financial statements, the complete audit opinion of Montemayor Britton Bender PC, and all accompanying notes are available online at: www.rls.org

2024 Where Our Funds Come From



2023 Where We Use Our Funds

