



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, to improve treatments and, through research, to find a cure for RLS.

## 2022 - 2023

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## 2022 - 2023

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

**2/6/23**  
Telephonic

**6/15/23**  
Telephonic

**9/5/23**  
Telephonic

**9/28/23**  
Telephonic

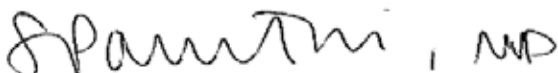
## From the Chairman of the Board

As Chair of the RLS Foundation Board of Directors, I am pleased to report that the fiscal year 2022-23 was an exciting time of growth and opportunity for the RLS Foundation. We experienced growth in membership, programs, social media engagement, and public policy outreach.

The Foundation maintains a healthy financial position that continues its mission to the members who support the work of the Foundation and the greater RLS community. Our financial team informs and advises the Board on matters and conducts an annual audit that confirms our accounting practices' strength to the community that we serve. The Foundation's programs and outreach have tangible costs regarding staff time and resources. To support the Foundation's vital work, generous contributions above and beyond membership dues support critical work essential to the needs of the RLS community. We thank each of our donors for their generous support that allows us to continue our good works.

The Executive Director and staff of the Foundation deserve our sincere thanks and appreciation for their support in serving the needs of the RLS community. With the continued generous support of our community members, the Foundation is well-placed to continue its vital work as we look upward and onward toward the future.

Sweet Dreams!



Shalini Paruthi, MD

Board Chair, Restless Legs Syndrome Foundation



**Shalini Paruthi, MD**

*Chair, RLS Foundation  
Board of Directors*

# RLS Foundation Welcomes New Board Chair, Dr. Shalini Paruthi

By Clara Schlemeyer, RLS Foundation Program Coordinator



*I recently had the pleasure of interviewing Dr. Shalini Paruthi, who joined the Foundation's Board of Directors in 2018 and became Chair this year! Dr. Paruthi also dedicates her time to the AASM (American Academy of Sleep). She is certified in both internal medicine and sleep medicine and has extensive expertise in treating*

*both pediatric and adult patients, but her particular interest is in sleep disorders of childhood – obstructive sleep apnea, insomnia, narcolepsy, and – of course – restless legs syndrome. While treating her patients, she is also educating future doctors at Saint Louis University School of Medicine. Her willingness to teach, treat, and share her knowledge is inspiring.*

**Q.** What was your motivation to get involved with the RLS Foundation, and why did you choose to stay involved?

**A.** My patients are my biggest motivators! I specialize in sleep disorders and have a specific interest in RLS, because I am also an RLS patient. It's something that I see every day that is easily misunderstood, and there is not enough good, reliable, truthful information available for people. I think one of the most important things that physicians can do is to advocate for our patients. When Karla Dzienkowski reached out to me knowing that I had an interest in RLS, and that my primary focus is on pediatric sleep disorders, it was an excellent opportunity for me to bring my advocacy to the Foundation.

**Q.** As a physician who specializes in sleep disorders, what knowledge and skills do you hope to bring to the Board as you step into your role as chair?

**A.** One of the best parts of my day is that I am a teaching physician. I previously taught full-time at Saint Louis University and now am at Saint Luke's Hospital in Saint Louis. In my role at St. Luke's, I continue to teach rotators about sleep disorders. I want to make sure that they have a very strong knowledge of all the different sleep disorders, including RLS, which can be very difficult to recognize and diagnose. Sometimes patients cannot articulate their exact symptoms or the symptoms overlap with other medical disorders. As a teaching physician, in every patient visit, I am not only educating the patient but also educating the learners rotating with me.

Additionally, I chaired the program committee at the American Academy of Sleep Medicine for two years. The program committee plans the annual national SLEEP meeting, during which nearly 5,000 physicians, nurses, sleep technicians and

sleep researchers gather to share knowledge and learn from one another. That experience enabled me to help with the Foundation's educational events, such as our virtual Summits and our in-person Patient Symposium, where I served as moderator and educator.

**Q.** What is your favorite part about serving on this Board?

**A.** My fellow Board Members! I have met so many people with such different and diverse talents, backgrounds and perspectives, and every one of them is so dedicated to our mission. They want nothing more than to make sure that we are increasing RLS awareness, improving treatments and looking for the best research opportunities. Each Board member is focused on improving RLS diagnosis opportunities and ensuring wider availability of proper treatment. I just see so much passion, dedication and really great teamwork.

**Q.** How has living with RLS fueled your passion for helping the RLS community?

**A.** Having RLS, and at times suffering terribly from it, has really opened my eyes to the lack of knowledge surrounding RLS. I am very passionate about educating people about RLS and that it is a serious disorder. It can be so disruptive to a person's quality of life or their ability to sleep well at night, which then affects their daytime function. For me, it has increased my compassion and empathy for others who suffer from RLS, and I want to do as much as I can within the RLS Foundation to increase awareness and help others know there is hope in finding a treatment that works for them. In addition, we must remind everyone that RLS is also a pediatric disorder with many young children or teenagers having RLS as their cause of insomnia.

**Q.** What are your future goals and aspirations for the Board?

**A.** The future goals for the Board are very clearly and appropriately tied to our mission. I hope to increase awareness about pediatric RLS. When a child comes to see me in the office, their parents have already tried all sorts of good sleep hygiene and techniques they have found on the internet, or followed suggestions from family and friends. Yet, they can't understand what is being so disruptive to their child's sleep. Often, no one has asked them questions about uncomfortable sensations in the legs or those urges to move in the evenings and the restlessness that comes along with it. Once we diagnose their RLS and begin treatment, they see a huge improvement in their child and the whole family's interactions. As a Board we are making progress in education, and we must recognize that RLS affects the lifespan, from young children all the way up to older adults.

It is incredibly important for us to request proposals for research



projects that can be funded. We have an amazing group of donors who understand just how much RLS affects others, and our best bet is to continue to fund high-quality research that will get us closer to finding better treatments and a cure for RLS. I want to express my deep gratitude for the work of the staff at the RLS Foundation; Karla, Zibby, Clara and Adrianna are an absolutely amazing, hard-working group of dedicated women who really care about people suffering from RLS.

**Q. What is your biggest piece of advice for those struggling with their RLS?**

**A.** People are their own best experts; we can recognize when something is not right within our bodies. When you don't get a satisfactory answer about a problem you are having, it doesn't mean that your doctor does not care or that they are dismissing you. It may just be that they don't know enough about RLS and may not realize what an impact it is having on your quality of life. If at first you see a clinician who does not quite understand what you are saying, it does not mean that all doctors do

not know about it, it just means you need to keep looking until you find the right physician who does know about RLS. Sometimes that means doing a little bit of detective work. Most neurologists should know about RLS, and even if they are not experts, they may be able to refer you either to a movement disorder specialist within neurology or directly to a board-certified sleep physician at an accredited sleep center. Being your own advocate and not settling for the first answer that you get – just being true to your body – is my best piece of advice on RLS.

*To view a list of healthcare providers organized by state who have come forward expressing an interest and knowledge in treating RLS or learn more about RLS Quality Care Centers, visit [www.rls.org](http://www.rls.org).*

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# Welcome New Board Member: Paul Vicary

**T**he RLS Foundation is delighted to announce the appointment of Paul Vicary as the newest member of the Board of Directors. Vicary is a former senior executive in the technology, financial and software services sectors. He worked directly with billion-dollar companies including Digital Equipment Corporation (now Hewlett-Packard), Fiserv Inc., First Merit, Burroughs and Unisys Corporation. In each executive role, he consistently exceeded goals for the company's revenue and growth targets while overseeing multiple divisions.

Vicary was also the founder and CEO of Mr. Golf, Inc., based in Ponte Vedra Beach, Florida. Mr. Golf is a prominent sports-related organization that, among other things, connects golfers to courses across the US and Canada. He developed his business into the second-largest golf travel services provider in North America.

Vicary is a highly sought motivational speaker and senior management consultant. He has contributed to numerous for-profit and nonprofit organizations as an independent director. As an alumnus of the University of Western Ontario, he holds an economics and business degree. Vicary is an avid golfer, club fitter and instructor in The Villages, Florida, where he and his wife Susan, currently reside. As someone who lives with RLS, he understands the importance of maintaining and strengthening an organization that provides essential resources to the RLS community.



Vicary says, "As many can attest, for years I felt I was walking alone with this disease. Countless sleepless nights with excruciating pain, uncontrollable movement and discomfort. I was driving myself crazy trying to identify and resolve the problem. Through the efforts of the University of Florida's neurological team, I was properly diagnosed and treated for this disease. I was also directed toward the RLS Foundation and the research it has been doing to identify

better treatments and find a cure for this debilitating disease affecting millions. I am thrilled to be able to play a small part in this fight and to help others understand that they are not walking alone."

"Paul Vicary's considerable business experience, leadership skills and board expertise will undoubtedly prove invaluable to the RLS Foundation," says Shalini Paruthi, M.D., chair of the RLS Foundation Board of Directors. "We welcome Vicary to the Board of Directors and look forward to working together."

# Interview with a Legend: Pickett Guthrie

By Clara Schlemeyer, program coordinator, RLS Foundation

*Pickett Guthrie was asked to share with our members some of her memories about starting the Foundation and her thoughts on where we are now and where we are headed. Guthrie was the Foundation's first executive director and continues to be one of our biggest supporters. She received the Ekblom Award, with deep appreciation of meritorious service, in 2008.*

## **Q: How did you first get involved with the RLS Foundation?**

**A:** I am the middle cog among three generations who suffered with RLS; my father had RLS (but, of course, back then no one knew what it was), and my daughters also have it. I was stubborn. I had a very demanding job, but I couldn't sleep. As I tried to get help from my general practitioner, he finally remembered that my father had complained about the same condition. My internist sent me to the medical school at Duke University because he didn't know what to do for me. Eventually, someone in the Neurology Department at Duke admitted that he did know what it was, but he did not have a clue about how to treat it. Eventually, I went to the National Organization for Rare Disorders in Washington, D.C., where they had received other inquiries about RLS.

About that time, Oron Hawley and Virginia Wilson were also looking for answers about their own suffering and started exchanging letters to share information. That is when Oron, at age 90-plus, started a very simple newsletter about RLS and wanted to start a support group for sufferers as well.

Oron really does deserve most of the credit. Although he did not have a severe case of RLS, it made him mad that it was so difficult to find treatment. So, he and Virginia decided to have a small support group, just the two of them! Virginia was really a go-getter type of person, so I started chatting on the phone with Virginia. It is hard to imagine now, but this was a time before computers and the internet enabled people to make connections.

I joined the small support group, but really, a support group in and of itself does not have much credibility. I was working for a very large law firm, and I was told that in order to have any credibility we needed to form a significant organization. Since I had the knowledge and the ability to deal with the legal requirements, I filed for incorporation, formed a board of directors, filed for 501(c)(3) status and created the Restless Legs Syndrome Foundation. We were up and running all at once!

It was a unique group of people who decided that we were going to try to do something, not just sit and let life happen. Those were very exciting years, because initially we were told that there weren't many people with this obscure disease – that RLS is a rare disorder. I attended the national meeting of the Council on Rare Disorders in Washington, D.C., and discovered that RLS is *not* a rare disorder.

**Q:** What were some of the guiding principles that helped you as the first executive director of the RLS Foundation?

**A:** The most important function of the Foundation, ironically, was to listen to our members. People with RLS just needed to be heard, and they needed to know that RLS is a real, not so rare, disease. They needed to be directed to legitimate medical information. I think the Foundation has always stood for that, for providing information that you could trust. Over the years, the Foundation has built that reputation for truth and transparency, sharing confirmed medical information from RLS experts. We were trying not to frighten people but to reassure them and give them hope.

It was important that we build credibility among medical professionals. We went to our first meetings at SLEEP and the American Academy of Neurology to show that we were a professional organization, and that restless legs syndrome was not a joke but a legitimate, common disease that needed attention and required medical treatment.

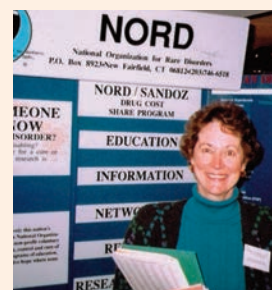
**Q:** What is your best memory with the RLS Foundation?

**A:** That very first SLEEP meeting, it was heady stuff. Here we were, three determined people trying to get the word out about RLS, and the Foundation was still operating out of my dining room with material spread out on the dining room table. Nobody knew that we didn't have an actual office and that I wasn't even receiving a salary. So, we had to fake it. We just had to take a deep breath and act as though we were just as legitimate as anybody else there. That was exciting!

**Q:** What do you want your legacy to be?

**A:** From the beginning, we formed the Foundation to help other people with RLS. And, as the Foundation has grown, that is still the focus: to help those with RLS through education, resources and research to find a cure. Initially, when we got calls from people suffering from RLS, about all we could do was to hold their hands and offer a compassionate ear. But now there is significant help available in terms of resources, webinars, support groups and advocacy opportunities, and it's very satisfying.

I am proud to have been the first executive director, but I never





could have done it without so many people who rolled up their sleeves to help, whether they had any previous professional experience or not. Most of our first board members had no experience serving on a board of directors, but they were willing to serve on the RLS Foundation's board because that's what was needed to form a Foundation.

**Q:** Where do you hope to see the Foundation in the next 30 years?

**A:** Of course, we would all like to unlock the mystery of RLS and find a cure. I am so proud to see that the RLS Foundation is now a major player in the world of sleep professionals, so the success of this organization is significant. Even though we don't yet have a cure for RLS, I would love to see RLS have less impact on the quality of life of people who suffer from it. That means finding better treatments that will allow those with RLS to live full and happy lives. Tragically, suicide is a real issue for some people with RLS.

We know now that RLS can be diagnosed and treated effectively. Although the Foundation has made great progress in educating

the public about RLS, there are still people who have trouble finding a healthcare provider who can help them manage their disease. There will always be a need for the Foundation. Better education and information, and not just fewer desperate people, would be a simple way to put our goals. I would like to see the primary care doctors and specialists treating patients with RLS send them to the RLS Foundation for reliable information and compassionate support.

In my day, people wound up at the Foundation in desperation, when their healthcare providers had no answers for them. It is my hope that in the next 30 years we can provide hope and education to RLS patients by connecting them with an RLS specialist who can help them manage their disease, so that it doesn't destroy their lives. The general public must understand that RLS affects every aspect of a person's life in such a profound way, because it robs them of the ability to sleep or even to rest. Members of the RLS Foundation understand the devastating impact that RLS has on quality of life and can support each other to minimize that impact.



# National RLS Opioid Registry Reaches 4th Anniversary

*By John W. Winkelman, MD, PhD, and Jordana Zackon, BA*

The National RLS Opioid Registry is a longitudinal observational study funded by the RLS Foundation to assess the efficacy, dose escalation and complications in patients using prescribed opioids for RLS. Many people, including healthcare providers, are surprised that this class of medication is used for RLS. How did we get to the point where opioids are the treatment of choice for people with treatment-resistant RLS?

There are four classes of medications for RLS: dopaminergic agents (also known as dopamine agonists), alpha-2-delta ligands (gabapentin, pregabalin, gabapentin enacarbil), iron and opioids. Dopamine agonists have been the mainstay of medical treatment for most people with RLS, accounting for over 60% of prescriptions for RLS in the US. Initially available in the US for Parkinson's disease in 1974 and approved by the Food and Drug Administration for RLS in 2005, they became extremely popular for RLS due to their prompt suppression of RLS symptoms with relatively few side effects. Unfortunately, only a minority of patients continue to benefit from dopaminergic agents beyond 10 years. More concerning, these treatments can lead to worsening of RLS with prolonged use, a side effect known as augmentation, in at least 30% to 50% of people who take them.

Although alpha-2-delta ligands are often effective for RLS, they do not work for everybody, and their side effects sometimes interfere with their use. Similarly, iron is helpful for some, particularly those with low or low-normal iron levels, but not all. Opioids have been known to be effective treatments for RLS for hundreds of years and are the final option for some patients with severe, treatment-resistant or augmented RLS who do not tolerate or respond to the three other categories of medication. Generally prescribed at low doses, they are often dramatically effective for RLS. In contrast to dopamine agonists, small uncontrolled studies suggest that low-dose opioids continue to control symptoms over at least a decade, with minimal dose escalation and no evidence of augmentation.

More widespread acceptance of opioids as an RLS treatment has been hampered by legitimate concerns regarding the risks of tolerance, withdrawal, side effects and misuse/abuse. Such concerns have become amplified due to the current opioid crisis, in which opioid treatment of chronic pain has led to terrible consequences. In the absence of large-scale studies addressing these concerns, opioids remain too scary for most healthcare providers to prescribe and for patients, even those with severe RLS, to take.

Funded by the RLS Foundation in 2017, the National RLS Opioid Registry is an attempt to partially bridge the knowledge gap for these medications. Five hundred adults (24-90 years old) from 44 states and six countries were recruited over a period of 18 months to participate in this observational study, located at Massachusetts General Hospital in Boston, under the direction of Dr. John Winkelman. Participants who were taking a prescribed opioid daily for diagnosed RLS and had a

previous therapeutic response to dopamine agonists were eligible for enrollment.

At enrollment, each participant's diagnosis of RLS was confirmed via phone interview. Additionally, information was collected on demographics, duration and initial and current opioid dosages, side effects, concomitant RLS medications and dosages, past RLS treatments, augmentation history, other current central-nervous-system medications, RLS severity, psychiatric history, suicidal ideation and opioid-abuse risk factors. Participants then completed a baseline online survey that collected information on health, medications, family history of RLS, impact of RLS on quality of life, lifestyle habits, insomnia severity, daytime sleepiness, and depression and anxiety symptoms.

All current participants have completed online surveys every six months since their enrollment, consisting of the same questionnaires administered during the initial interview and survey. They have reported any changes in medications, health, and opioid side effects.

Registry participants are predominantly female (57%), and most (72%) are age 60 or older. Participants had been taking opioids for a median of 1–3 years upon entry into the registry. Half of participants were taking only an opioid for treatment of their RLS. Approximately half of all registry participants use methadone, almost a quarter use oxycodone, and about a tenth use hydrocodone. The two most commonly used opioids (and mean doses) were methadone (10 mg) and oxycodone (15 mg). Overall, the severity of RLS symptoms experienced at baseline was in the mild range, though 17% of participants reported symptoms in the severe or very severe ranges. The most common side effects at registry entry were constipation (52% of subjects), drowsiness (24%) and itching (19%).

By November 2021, all participants had reached their two-year anniversary of registry entry, nearly 60% had reached their three-year anniversary, and the first enrolled participants were completing their four-year surveys. At the two-year follow-up, there was no significant change in average RLS or depression symptoms experienced by participants; however, there was a slight increase in anxiety symptoms. Over this period, 13.6% of participants added a dopamine agonist and/or an alpha-2-delta ligand, whereas 10.0% removed such a medication. Individuals taking these medications in addition to an opioid reported worse RLS symptoms compared to those on opioid monotherapy, as the other medications were often added to address persistent symptoms.

Considering all registry participants, there was no change in median opioid dose from baseline to two years. Roughly two-fifths of all participants increased their opioid dose from baseline to two years. Approximately half of those increased their dose by a small amount (at most 2.5 mg methadone, 6.7 mg oxycodone), and only 8% increased by more than 6.25 mg methadone or 16.7 mg oxycodone. While roughly one-third of participants increased their daily opioid dose from baseline



to one year, only about one-fourth reported dose increases from one year to two years, and 17% reported dose decreases. Compared to baseline, after two years 42% of participants still on opioid medications were on the same opioid medication and dose. Roughly 15% had switched to a new opioid medication. Those who switched to methadone during the two-year period reported significantly lower RLS symptoms than at baseline. However, this group also saw increases in daily opioid dose equivalent with the switch. Participants who switched to opioids other than methadone reported slightly worse RLS severity than at baseline.

Of particular interest to both clinicians and patients is the ability to predict who might need to increase opioid dose, especially in large amounts. The registry allows us to determine such predictors based on participants' prescription patterns. Moreover, we may be able to anticipate such large increases and suggest alternatives or be more vigilant about dose increases. Less than 5% of participants saw large increases (of more than 12.5 mg methadone or 33.3 mg oxycodone) from baseline to two years. The strongest predictors of these large dose increases were when opioid medications were prescribed for other pain conditions in addition to RLS; when non-opioid RLS medications (dopaminergic agents, alpha-2-delta ligands) were discontinued since baseline; and being

under age 45. Other strong predictors included switching opioid medications, male sex, history of depression, and having more severe insomnia symptoms at baseline.

Participants in the National RLS Opioid Registry generally continue to use opioids at low doses with good efficacy. At the two-year follow-up, the majority of participants had not increased their opioid dose. Moreover, most of those who did increase their dose did so by a small amount. We hope that the registry will continue to collect information for many years to educate people with RLS, healthcare providers, and regulators about the safety and tolerability of opioids for RLS.

*John W. Winkelman, MD, PhD, is a professor of psychiatry at Harvard Medical School and chief of the Sleep Disorders Clinical Research Program in the Department of Psychiatry at Massachusetts General Hospital. Dr. Winkelman serves as director of the RLS Quality Care Center at Massachusetts General Hospital. Jordana Zackon, BA, is a research coordinator on Dr. Winkelman's research team. Dr. Winkelman received funding from the RLS Foundation Research Grant Program to further his research on RLS.*

## In Memoriam: Robert H. Waterman, Jr., RLS Foundation Leader

The RLS community has lost a giant with the recent passing of Robert H. (Bob) Waterman, Jr. His career as a management consultant and senior partner with McKinsey & Company culminated with the publication of the first "blockbuster" book on sound management practices. *In Search of Excellence*, co-authored by Waterman and his McKinsey partner, Tom Peters, rose to the top of the New York Times Best Sellers list, and changed the way business leaders around the globe thought about their roles as heads of successful companies.

Like many individuals who have served on the Board of Directors of the RLS Foundation, Waterman was afflicted with the disease – so much so that it disrupted his career as a senior partner at McKinsey and led him to a path as an independent management consultant with The Waterman Group. It also led him to more than two decades of leadership at the RLS Foundation.

Waterman served as chair of the Board of Directors for six years (1999–2005) and later as chair emeritus (2010–2019).

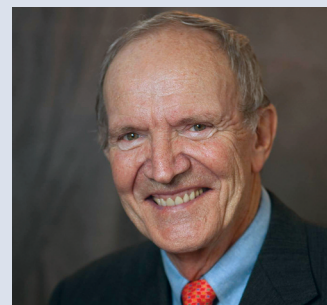
Bob brought his insights, along with his passion for excellence, to the RLS Foundation community. He was a strong proponent of strategic planning and led the strategic planning initiatives for the RLS Foundation Board for many years. He believed in setting BHAGs – Big Hairy Audacious Goals – and in that vein articulated basic strategic goals that remain at the core of the Foundation's work today: Improve Awareness; Develop Better Treatments; Find a Cure.

As a member of the Board during the organization's early years, he took it upon himself to establish the Research Grant Program. The program's purpose was to attract leading researchers from around the globe to apply for seed grants to further develop a hypothesis for external funding at the National Institutes of Health or other organizations in the hopes of identifying durable treatments and a cure for RLS.

As the RLS Foundation approaches its 30th anniversary in 2022, the RLS community is thankful for Waterman spearheading the Research Grant Program at this pivotal point in the organization's early years. Member support of this initiative has led to 48 grants totaling nearly \$2 million in funding. In 2022, the Research Grant Program will celebrate its 25th anniversary. Bob's leadership and vision for the program has led to breakthrough discoveries in genetics, iron regulation, neurophysiology and treatment.

Waterman received the prestigious Ekblom Award in 2008 in recognition of his meritorious service to the RLS Foundation.

Memorial donations in his honor can be made to the Waterman Research Fund to support RLS research at [www.rls.org/waterman](http://www.rls.org/waterman).



*Robert H. Waterman, Jr.*

## 2022 - 2023 Webinars

### January 2023

RLS and Exercise

Katie Cederberg, PhD, CPT

### March 2023

Dopamine Agonists vs Alpha-2-Delta Ligands

Michael H. Silber, MBChB

### April 2023

Aging with RLS

Kathy Richards, PhD, RN, FAAN

### May 2023

Causes of RLS

Philip Becker, MD

### July 2023

RLS and Comorbidities

Kunal Agarwal, MD, FAAFP, FAASM, DipABOM

### September 2023

How to Educate your Healthcare Provider

Speaker: Karla Dzienkowski, RN, BSN

## 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 Ekbohm 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](mailto:info@rls.org).

### Levels

We value all of our supporters at every level. Each of you makes an important impact on the programs that help so many living with restless legs syndrome.

*Thank you!*

<b>Leaders</b>	<b>\$10,000 and above</b>
<b>Benefactors</b>	<b>\$5,000 to \$9,999</b>
<b>Patrons</b>	<b>\$2,500 to \$4,999</b>
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Mr. David A. Ward	
Ms. Jill Washer	
Mr. Roger Wasserman	
Mr. Randall Waters	
Mr. Gregory Weber	
Ron Weisberg	
Mr. Michael Weiskirch	
Mr. Scott Weitzman	
Mr. and Mrs. Eugene Wendt	
Ms. Sheila Wengert	
George & Willi Wheeler	
Ms. Helen Wheeler	
Mr. David Whelpton	
Mrs. Carol White	
Mr. Stephen White	
Elise & Woody Widlund	
Ms. Deborah Wilcox	
Mrs. Diane R. Wilds	
Mrs. Kathleen Willis	
Mr. Roy Willman	
Ms. Elizabeth Wilson	
Mr. Thomas P. Windmiller	
Ms. Lynsey Winner	
Dr. Elva Winter	
Jerome P. Witek	
Mr. Marvin Withers	
Ms. Lila Witt	
Ms. Kristen Wolden	
Marcia C. Wolf	
Ms. Yvonne M. Wollemann	
Diane W. Wood	
Mrs. Linda R. Wood	
Melanie Wood	
Mrs. Lori J. Wood	
Ms. Elizabeth Woods	
Mr. Cody Wray	
Gail Wright	
Mr. James Wright	
Mrs. Lynn Wyvill	
Dr. Bonnie Yankaskas	
Ms. Lois Yarbor	
Ms. Ellen Yezzi	

# Treasurer Report



**Greg Oberland**

*Treasurer, RLS Foundation  
Board of Directors*

Thank you for your continued financial support and unwavering commitment to the RLS Foundation during our 2022 fiscal year. Individual donors provided the majority of support for Foundation programs and activities, representing 81% of donations collected. In 2022, we funded two grants through the RLS Foundation Research Grant: one for a longitudinal study on the use of opioids to treat RLS and the other for a cannabis safety and feasibility study. Together, these two grants fulfill our Foundation's goals of finding 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 in 2023!

Sincerely

A handwritten signature in black ink that reads "Greg Oberland". The signature is fluid and cursive, with the first letters of the first and last names being capitalized and prominent.

Greg Oberland  
Treasurer, RLS Foundation Board of Directors



# 2022 - 2023 Highlights | Financials

## Revenues and Support

Contributions	\$764,362
Membership Dues	\$143,150
Other	\$36,547
<b>Total revenues and support</b>	<b>944,059</b>

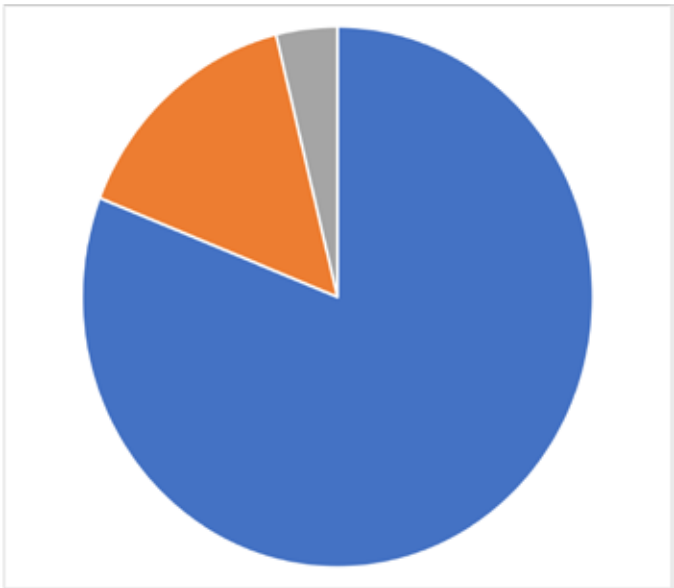
## Expenses

Program Services	
Education	\$430,527
Membership	\$172,507
Research	\$83,313
Support Groups	\$30,891
<b>Total program services</b>	<b>\$717,238</b>
Fundraising	\$74,538
Management and general	\$82,179
<b>Total expenses</b>	<b>\$873,955</b>

Statements of Activities For the Fiscal Year Ended September 30, 2023

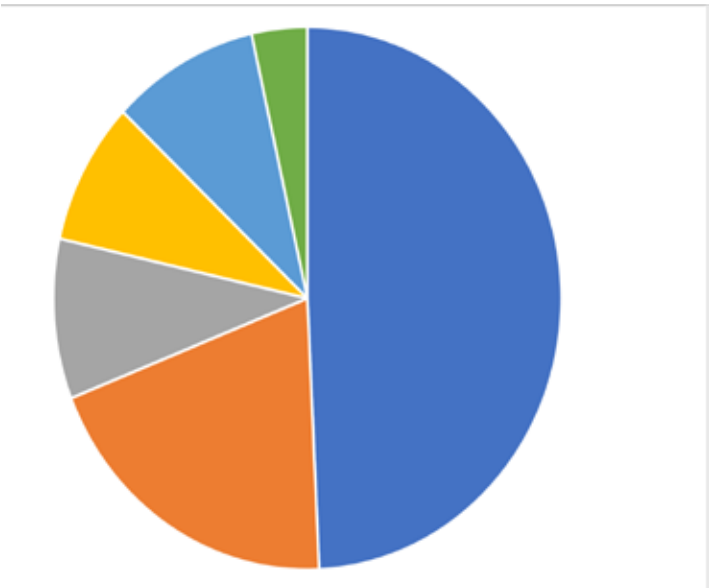
The RLS Foundation’s full financial statements, the complete audit opinion of Montemayor Britton Bender PC, and all accompanying notes are available online at: [www.rls.org](http://www.rls.org)

## 2023 Where Our Funds Come From



- Contributions 81%
- Membership Dues 15%
- Other 4%

## 2023 Where We Use Our Funds



- Education and awareness 49%
- Membership 20%
- Research 10%
- Support Groups 4%
- Fundraising 9%
- General and Administrative 9%



RESTLESS LEGS  
SYNDROME  
FOUNDATION

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Austin, TX 78746**

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info@rls.org**

**www.rls.org  
rlsfoundation.blogspot.com  
Discussion Board: bb.rls.org**

