CELEBRATING 30 YEARS

2022 - 2021 ANNUAL REPORT

RLS

RESTLESS LEGS
SYNDROME
FOUNDATION

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.

2021 - 2022
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2021 - 2022
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The Restless Legs Syndrome Foundation Board of Directors held meetings on:

10/11-12/21	2/10/22	4/19/22	6/20/22	9/30/22
Telephonic	Telephonic	Telephonic	Telephonic	Telephonic

2021-22 Highlights | From the Chairman of the Board

Carla Rahn Phillips, PhD
Chair, RLS Foundation
Board of Directors

Thankfully, the worst of the Covid-19 pandemic was over by the end of 2022. Nonetheless, the Board of Directors of the RLS Foundation was still unable to return to all of our standard operating procedures. Even before the pandemic, the full Board and various committees were accustomed to meeting remotely several times a year, with individual members participating by Zoom or a telephone connection. Remote meetings work well enough, as Board members can see financial statements, audit reports, and other important information on our computer screens and thus fulfill our responsibilities.

The real change with the pandemic was to hold our annual meeting in the Fall remotely as well, rather than meeting in person, and this continued in 2022. Let's hope an in-person meeting will be possible in 2023. Several new members joined the Board in 2022, and it would be ideal for everyone to interact at an in-person annual meeting.

Despite the lingering effects of the pandemic, the Foundation continued to provide the same high level of support and scientifically-based information about RLS to healthcare professionals and the RLS community in general.

The Foundation continues to be in a healthy financial position, able to fulfill its mission to members and to the broader RLS community. Our financial advisers make sure the Board is fully informed about the Foundation's finances, and our annual audit confirmed the transparency with which we do business.

That said, it would be ideal to increase the number of dues-paying members of the Foundation, given the millions of individuals who suffer from RLS. More memberships would provide the funds to expand and enhance every aspect of the support and services offered by the Foundation. Everything the Foundation provides has a cost in staff time and resources. At present, we rely on generous contributions, beyond membership dues, from members who support various appeals to fund about three-quarters of our crucial work. We thank each of our donors for their generous support.

A focus on increasing membership was one of the key points in the Board's beginning discussions to develop a Strategic Plan for the Foundation in 2022. With clear goals, strategies, and measurement criteria in place, the Board and staff will be able to revisit the plan annually to gauge progress.

As always, the Executive Director and staff of the Foundation deserve sincere thanks and congratulations for ensuring that the Foundation was able to serve the needs of the broader RLS community in 2022. With the generous support of the RLS community the Foundation is well placed to continue its important work into the future.

Best wishes,

Carla Rahn Phillips

Carla Rahn Phillips, PhD
Chair, RLS Foundation Board of Directors

RLS Foundation Celebrates 30 Years

1990

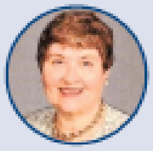
First *NightWalkers* published

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

1995

First RLS support group formed

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



Foundation launches www.rls.org

1996

Scientific Advisory Board established

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

1998

First Ekbom Award presented to Dr. Arthur S. Walters

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

2002

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

2004

Foundation launches online discussion board

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

Medical Advisory Board publishes first RLS treatment algorithm

2007

RLS gene variant discovered

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

2008

Foundation holds RLS scientific conference at Johns Hopkins University

Foundation launches Youth Initiative

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

1992

RLS Foundation achieves nonprofit status

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

Medical Advisory Board established

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

Pickett Guthrie named first executive director

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

Pickett Guthrie (1993–1996)
Carolyn Hiller (1996–1997)
Cate Murray (1997–2000)
Allan O'Bryan (interim 2000–2001)
Georgianna Bell (2002–2013)
Karla Dzienkowski (2014–present)

1997

Foundation moves to Rochester, Minnesota

Foundation launches research grant program

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

Foundation helps fund first RLS research at National Institutes of Health

First *RLS Medical Bulletin* published

This essential reference tool provides RLS diagnosis and treatment recommendations.

2000

Foundation establishes RLS Brain Bank at Harvard Brain Tissue Resource Center

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

Medical Advisory Board publishes first RLS treatment algorithm

2005

National patient meeting held in Orlando, Florida

2006

National patient meeting held in San Antonio, Texas

2012

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

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

# of Service to the RLS Community

2013

Medical Advisory Board publishes revised consensus statement with RLS treatment algorithm

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

2014

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

2015

Foundation relocates to Austin, Texas

***RLS: A Guide for Teens* published**

2016

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

2017

Foundation's Facebook page reaches 10,000 likes

Social media brings increased awareness
The Foundation expands its outreach through Twitter, YouTube, Google+, LinkedIn and Instagram.

RLS Opioid Registry registers over 500 individuals
Surpassing the goal of 200 registrants, participants commit to report on their experience every six months.

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

2018

National RLS Patient Symposium Hosted by Scripps Quality Care Center in La Jolla, CA
Ten RLS experts educate over 180 participants.

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

2019

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

2020

Over 3000 RLS patients and 342 partners respond to RLS Patient Odyssey Survey II
The survey seeks to evaluate the impact of RLS on quality of life for patients and their partners.

RLS Foundation adapts to COVID-19
Establishes weekly Virtual Support Group meetings held on Zoom to connect the worldwide RLS community.

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

2020 RLS VIRTUAL SUMMIT

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

2021

***Mayo Clinic Proceedings* publishes New Algorithm for Treatment of RLS**
Lists alpha-2-delta ligands and iron therapy as first-line RLS treatments; dopamine agonists become second-line treatment.

Second Virtual Hill Day
80 RLS advocates from 30 states contact 101 legislative offices.

2022

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

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

RESTLESS LEGS SYNDROME FOUNDATION
30 YEARS
SERVING THE RLS COMMUNITY
1992–2022

Purity, Knowledge and Wisdom

Celebrating 30 Years

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

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

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

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

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

Today, our growing, sophisticated presence online and in social media is bringing our readers and our community of RLS patients, practitioners, families and friends even closer together. And it has helped to accommodate pandemic realities over the past two years with virtual support group meetings that have further widened our reach and invited once-isolated RLS patients to connect with peers near and far!

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

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

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

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

Iron Treatment Shows Promise in Children with RLS or PLMD

By Karla Dzienkowski, RN, BSN, Executive Director, RLS Foundation

Restless legs syndrome (RLS) and periodic limb movement disorder (PLMD) are two neurological conditions commonly treated with oral iron in children. Some children do not tolerate or respond sufficiently to oral iron, and there is not sufficient data to support the efficacy of intravenous (IV) iron in this patient group. This is an important issue, because RLS that is not well managed can have adverse effects on sleep quality and quantity, emotional health, daytime functioning, and quality of life.

RLS diagnostic criteria for children are:

☐ Urge to move
☐ Rest induced
☐ Gets better with movement
☐ Evening or nighttime worsening
☐ Sensations not caused by another behavioral or medical condition (may or may not be present)

An RLS diagnosis in children is based on the clinical assessment of reported symptoms and does not require documentation of periodic limb movements in sleep (PLMS) however, PLMS (more than 5/hour) do support a diagnosis of RLS and are present in 60% to 70% of children with RLS.

Researchers have hypothesized a relationship between low brain iron stores in both RLS and PLMD. Brain imaging studies have confirmed the presence of low brain iron levels in adults with RLS. In addition, symptom improvement following iron administration in children with RLS and PLMD is reported in medical publications.

An article in the November 2021 issue of *Sleep Medicine* titled "Clinical efficacy and safety of intravenous ferric carboxymaltose treatment of pediatric restless legs syndrome and periodic limb movement disorder" evaluates the single administration of IV iron in 39 children with a diagnosis of RLS or PLMD confirmed by two pediatric sleep specialists. The participants in the study included 29 children with RLS (14 boys, 15 girls) and 10 with PLMD (all boys), ages 2–17 years. Children in this cohort were selected using a retrospective chart review; they were referred for iron treatment from June 2019 to December 2020. All children selected to participate in the study had previously been prescribed oral iron but were categorized as "treatment failures" due to untoward side effects (e.g., constipation, vomiting, tooth discoloration) or failure to increase serum ferritin by at least 4 mcg/L after three months of taking an oral iron supplement, in conjunction with a lack of symptom improvement. It is important to note that none of the children in the study had another sleep disorder or a known problem absorbing nutrients from food (malabsorption syndrome).

Seattle Children's Hospital was the only site selected for this study. The hospital has a dedicated iron infusion clinic for children supervised by a pediatric sleep specialist. The children were carefully monitored throughout the IV iron infusion process, including monitoring for the occurrence of any adverse reactions. All 39 children received a complete medical evaluation. A full iron panel (serum ferritin, serum iron, total iron-binding capacity, transferrin) and Clinical Global Impression (CGI) Scale score was obtained at baseline and eight weeks post-infusion with ferric carboxymaltose.

PLMS: Periodic limb movements in sleep; repetitive jerking movements involving the lower leg and foot, with flexion of the big toe, that occur during sleep.

PLMD: Periodic limb movement disorder; requires a sleep study to confirm diagnosis (PLMS more than 5/hour) and the PLMS must be linked to causing clinically significant sleep disturbance or impaired daytime function. In addition, the PLMS cannot be due to drugs that cause PLMS or RLS.

Treatment failure: Unsuccessful medical management to treat a diagnosed medical condition.

Clinical Global Impression (CGI) Scale: Seven-point scale for the physician to rate disease severity and improvement in the patient.

The study found:

- Pre-infusion CGI symptom severity for the group showed moderate illness. Post-infusion reports revealed "much improved" to "very much improved" CGI scores following one-time administration of IV ferric carboxymaltose.
- Mean ferritin levels for the group rose from 14.6 mcg/L to 112.4 mcg/L.
- Children with PLMD, compared to those with RLS, had similar improvements in symptoms and iron tests.
- Seven study participants experienced mild side effects to IV iron treatment.

In summary, in children with RLS and PLMD, iron is a common treatment consideration. For children who experience a poor response or adverse effects to oral iron therapy, IV iron is a promising new treatment alternative. Future research using randomized, controlled trials is needed to evaluate further the benefits of IV iron therapy in children.

DelRosso LM, Ferri R, Chen ML, Kapoor V, Allen RP, Mogavero MP, et al. Clinical efficacy and safety of intravenous ferric carboxymaltose treatment of pediatric restless legs syndrome and periodic limb movement disorder. *Sleep Medicine*. 2021;87:114-8.

Understanding Augmentation and How to Recover from Dopamine Dependence

by J. Andrew Berkowski, MD, member of the RLS Foundation's Scientific and Medical Advisory Board

Dopaminergic medications had been the mainstay of first-line pharmacological treatment of RLS for many years, but they have significantly fallen out of favor in the past decade due to high rates of augmentation and, secondarily, impulse-control disorders. Clinical consensus guidelines no longer consider these agents to be first-line treatments, despite the abundance of research demonstrating significant efficacy in the short term (months to a few years). The high rates of augmentation, which is thought to be inevitable with long-term use, begs the question: "Should anyone take dopaminergic agents at all for this chronic, lifelong condition?"

Despite relegation of dopaminergics to second-line status in the more updated clinical guidelines since 2015, many RLS experts only use these medications now in rare circumstances. If these therapies are considered, they should be trialed only after the ineffectiveness or intolerable side effects of the other treatments available for RLS. After initiation for daily use, regular monitoring must be performed for early identification of the stages of effects on the dopaminergic system, including dependence, tolerance, mild augmentation and severe augmentation. Dopamine agonists may have initial side effects, including nausea, vomiting, headache, sleepiness and dizziness.

The most commonly used dopamine agonists are the short-acting pramipexole and ropinirole, and the long-acting transdermal rotigotine patch. Levodopa is reserved for intermittent RLS symptoms, due to extremely rapid onset of augmentation (weeks to months) when taken daily. Though no studies have investigated augmentation with intermittent use, three doses or fewer per week has been considered reasonable. Potential uses include evening dosing for occasional RLS symptoms, dosing prior to sedentary situations (e.g., plane flight, theater presentation), and dosing for patients in whom the diagnosis of RLS is in doubt.

Augmentation

Since dopamine agonists became a first-line treatment for RLS in the early 2000s, two decades of experience have demonstrated high rates of (possibly inevitable) augmentation with long-term use. Augmentation is a worsening of RLS with one or more of the following features: an advance of the typical time of day when symptoms begin, two or more hours earlier than before the start of treatment; a spread of restlessness from the legs to the arms or trunk; a shorter interval before symptoms start after inactivity (sitting or lying); progressive dosage escalation to produce the same effect; and even paradoxical triggering of RLS symptoms immediately after taking the medication.

Augmentation has led to the most dramatic paradigm shift in RLS management, as it causes the majority of refractory RLS cases. This phenomenon poses significant philosophical challenges to the clinician, as a potential worsening of the condition long term in most cases should prohibit the use in the short term, regardless of the significant short-term effectiveness. Because of the increasing prevalence of augmentation, the RLS Foundation's Scientific and Medical Advisory Board published a guideline outlining the identification and treatment of augmentation. The presence of one or more of the following factors is known to increase the likelihood of augmentation: more frequent RLS symptoms before treatment, greater discomfort with RLS symptoms before treatment, co-morbid asthma, older age, longer treatment duration, lower serum ferritin levels, and greater baseline severity of RLS.

J. Andrew Berkowski, MD

Four screening questions are recommended to identify augmentation:

1. Do RLS symptoms appear earlier than when the drug was first started?
2. Are higher doses of the drug now needed, or does the medication need to be taken earlier in the day, to control the RLS symptoms compared to the original effective dose?
3. Has the intensity of symptoms worsened since starting the medication?
4. Have symptoms spread to other parts of the body (e.g., arms, trunk, face) since starting the medication?

Augmentation is considered mild if all of the following are present: symptoms manifest predominantly as a temporal shift of symptoms to earlier in the day compared to before starting treatment; dopaminergic monotherapy is at a total daily dose at or below maximum recommended levels; symptoms cause only mild distress; and there has been no prior increase in total dose above that which was previously therapeutically effective. In cases of mild augmentation, there is more time to make adjustments to treatment regimen, but the symptoms do represent an early stage of dopaminergic system impairment and dependence. This will progress to more severe symptoms and advanced augmentation if no changes are made or dopamine medication dosage is simply increased.

Augmentation is considered severe if it does not fulfill the criteria for mild augmentation (e.g., the total agonist dose exceeds recommended levels or the symptoms cause more than mild distress) or does not respond to treatment of mild augmentation.

Treating Augmentation

Initially, it is important to identify and eliminate or treat factors that exacerbate RLS. These could include poor sleep hygiene or other untreated sleep disorders, ingestion of drugs/foods that worsen RLS symptoms, or low levels of ferritin or percent transferrin saturation. If the iron stores are low, then iron therapy (oral or intravenous) should be considered.

For mild augmentation, the dopamine agonist medication could be continued and the total dose maintained but given in divided doses, or the medication could be given earlier to precede the onset of RLS symptoms. If symptoms are not managed by splitting the dosage, then the addition of other therapies should be considered, such as iron infusion, alpha-2-delta ligand medications, and possibly opioid medications. Changing to a longer-acting dopaminergic agent such as transdermal rotigotine could be considered, but this will only delay the inevitable augmentation to future months or years. Rotigotine has lower rates of augmentation long term in studies but is thought to mask augmentation due to having a steady level of the drug in the system continuously without time off from the drug. If the second treatment added does not provide symptom relief, then augmentation should be considered severe. Even if augmentation is mild, long-term plans should be discussed for transition to other treatments before more severe augmentation develops. Tapering off the dopamine agonist, with or without a second-line agent added, should be considered long term, to initiate dopaminergic system withdrawal and reconstitution.

For severe augmentation, the goal over several weeks to months is to wean, slowly but completely, off all dopaminergic agents to enable withdrawal, recovery from dopaminergic dependence, and maximal reconstitution of the natural dopaminergic system to as close to previous baseline as possible. One method is to perform a slow wean of the dopaminergic agent, followed by a two-week drug holiday, and then the addition of an alternative agent if still requiring symptomatic treatment. Though this approach is ideal in terms of natural recovery and limiting medication side effects, it is often met with apprehension due to the severity of withdrawal symptoms. The addition of a second medication prior to reduction in the dopaminergic medication is more common. Therapies may include an IV iron infusion (more potent and rapid than oral iron), alpha-2-delta ligands, opioids and, rarely, benzodiazepines. The dopamine agonist weaning process can be highly variable among patients, depending on initial severity of symptoms and strength of dosage. Anecdotal evidence suggests that many patients can go through a mini-withdrawal and recovery process after each dosage decrease in four to seven days, but some may take a few weeks or require increases in the secondary agent if they do not improve. Recovery after complete discontinuation may be the greatest in the first two weeks, though some patients take much longer to recover significantly. Many may have slow improvement beyond the initial few weeks for months or years after discontinuation, though the natural history of dopamine agonist withdrawal and recovery has not been well studied yet.

Dose reduction must be managed by a healthcare provider, and each situation is different; however, there are some management guidelines. Ropinirole may be tapered by 0.25 to 0.5 mg per week as tolerated, pramipexole by 0.125 mg, and rotigotine by 1 mg. However, the initial decreases may be larger, particularly if the patient is on dosages beyond maximum recommended, with progressively smaller decreases as the patient approaches discontinuation. Symptoms of withdrawal are generally a temporary but possibly severe worsening of restless legs symptoms, including more severe breakthrough symptoms, symptoms during the night leading to insomnia, earlier onset of symptoms during daytime with possible spread to other anatomic regions, and even involuntary limb movements while awake. These symptoms generally improve over several days before the patient can begin the next step in the tapering process. If a second agent is used, it may need to be adjusted to balance effectiveness with side effects, to combat the withdrawal symptoms. Other symptoms during dopaminergic withdrawal may include high levels of anxiety, irritability, insomnia, excessive daytime sleepiness and depressed mood.

After at least two weeks from discontinuation, the patient should be reassessed to see if the new symptomatic agent can be gradually tapered as well, or a second medication added in the case of patients who tapered without additional drug treatment. Several weeks to months after complete withdrawal, recovery is frequently seen and further dosage reduction can be made, as the dosage of a second medication is generally higher in the withdrawal period than weeks to months after recovery, due to progressive reconstitution of the dopaminergic system.

Impulse Control Disorders

Impulse control disorders are another side effect of dopamine agonist therapy. Due to long-term effects on the dopaminergic system and behavioral pathways, dopamine agonists are associated with impulse control disorders (e.g., pathologic gambling, excessive shopping, hypersexuality) within nine months of treatment onset. Symptoms of impulse control disorders (and augmentation) should be screened regularly, regardless of duration of use. The consequences of unrecognized impulse control disorders can be devastating, including substantial financial loss, the threat of criminal prosecutions, substance abuse and social disruption. However, complete resolution of the pathologic tendencies is the general rule with discontinuation or dose decrease of the causative agent.

Education and Awareness

Decades of dopamine agonist use have revealed the risk of augmentation and impulse control disorders. Education of healthcare providers is the first step to raise awareness about RLS treatment guidelines and the adverse side effects of dopaminergic medications. Support for RLS research leading to the identification of new medications that address the chronic progressive nature of RLS and its treatment challenges are priorities for the RLS community.

2021 - 2022 Webinars

October 2021
SIBO, Diet and RLS
Dr. Leonard Weinstock

January 2022
Cannabis and RLS
Jacquelyn Bainbridge, PharmD

February 2022
The Ins and Outs of RLS: From an RLS Expert
Denise Sharon, MD, FAASM

March 2022
RLS and Heart Disease
Lynn Marie Trottie, MD, MSc

April 2022
Drug Holidays: What to Expect
Christopher Earley, MB, BCh, PhD, FRCPI

April 2022
Clinical Trials: What to Expect
Jordana Zackon

May 2022
RLS Opioid Registry Update
John W. Winkelman, MD, PhD

June 2022
Iron Infusion 101
Michael Auerbach, MD

July 2022
Surgery and Hospitalization with RLS
Andrew Berkowski, MD

August 2022
Hormones, Sleep and RLS in Women
Dr. Jennifer G. Hensley

September 2022
The RLS Experience: Patient Odyssey II Findings
Speaker: Charles E. Phelps, PhD

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

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!*

Leaders	**$10,000 and above**
Benefactors	**$5,000 to $9,999**
Patrons	**$2,500 to $4,999**
Sponsors	**$1,000 to $2,499**
Sustainers	**$250 to $999**
Supporters	**$100 to $249**
Friends	**$75 to $99**
Contributors	**$1 to $74**

Leaders ($10,000 or more)

Jim and Sandra Aberer
Charles & Ellen Brown
Mrs. Joanne Correll
Mr. Steven Denning
The Dzienkowski Family
Mrs. Rhondda L. Grant
Pickett M. Guthrie
Mrs. Jill Mitchell
Greg and Rhonda Oberland
Lewis M. Phelps
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Lisa and. Kenneth Wahl

Benefactors ($5,000 to $9,999)

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Dr. Kristi Totten
Ms. Patty Trail
Mr. Eugene Trantham
Mr. Wayne Tripp
Mr. Jonathan Troccoli
Ms. Valerie Troiano
Mr. Tom Truex
Mrs. Janet Tschantz
Ms. Pat Turcotte
Ms. Carol Turkaly
Mrs. Leona Urban
Gary Van Liew
Ms. Marne Vangemert
Ms. Pamela Vaughn
Mr. Randall Vermillion
Mr. Richard Vezza
Ms. Joan Voigtlander
Mrs. Nicole Vos
Mr. Alex Vuksanovic
Kate Wagner
Gordon Waldron
Mrs. Gail Waldron
Ms. Chris Walford
Mr. Kevin Walsh
Nora L. Walter
Nora Walter
Mrs. Charlotte M. Walters
Neva M. Warsen
Dr. Barbara Wauchope
Mr. Burton A. Weichenthal
Mrs. Janet Weiden
Kit Weinschenk
Mrs. Christine E. Weinstein
Ron Weisberg
Mr. Scott Weitzman
Ms. Elizabeth Welch
Mr. Bill Wendt
Ms. Sheila Wengert
Robert J. Werra MD
Ms. Helen Wheeler
Mr. David Whelpton
John and Jeanne White
Ms. Tamra White
Leah R. Wickham
Ms. Deborah Wilcox
Mr. Robert H. Wiliams
Dr. Keith D. Wilkinson
Mr. David Williams
Mrs. Kathleen Willis
Ms. Elizabeth Wilson
Mr. Bob Wise
Jerome P. Witek
Mr. Edward Wojczynski
Marcia C. Wolf
Ms. Barbara A. Wolf
Ms. Emily Wong
Ms. Melanie Wood
Mrs. Lillian M. Worthan
Mr. Cody Wray
Gail Wright
Mrs. Anita Wright
Ms. Lois Yarbor
Ms. Ellen Yezzi
Mr. William Young
Ms. and Mr. Kathleen Zaback
Ms. Ann L. Zimmerman
Irene Zion
Beverly Zoschke
Mrs. Elizabeth zu Hone
Mrs. Joy D. Zumbrunn

Treasurer Report

Greg Oberland

Treasurer, RLS Foundation Board of Directors

I want to thank the members of the RLS Foundation for your continued financial support and unwavering commitment during our 2021 fiscal year. In 2021, individual donors provided the majority of support for Foundation programs and activities, representing 76% of gifts to the organization.

The mission and organizational goals of awareness, education and research leading to better treatments and a cure served as our guideposts in the fiscal year 2021. Members of the Scientific and Medical Advisory Board served as presenters for our popular free monthly webinar series. Volunteers that lead our support groups, virtual support groups, and discussion board provide individuals with RLS the opportunity to connect, exchange information, and share coping strategies with others in the RLS community who share the daily challenges of RLS. Our education outreach is expanded through the broad power of the Foundation's website and social media channels, including Facebook, Twitter, Instagram, YouTube and LinkedIn, to reach the RLS and healthcare communities. The RLS Foundation's acclaimed quarterly magazine, *NightWalkers*, continues to delight our members with in-depth stories about the most promising research and treatments available today. Communicating through these many channels, we reach a more extensive and younger audience, fulfilling our mission to raise awareness and education about RLS.

Finding better treatments and a cure are the two goals that support our mission. Therefore, the Foundation has provided an additional year of study to the Opioid Registry, a multi-center longitudinal pilot observational study of the efficacy and tolerability of long-term treatment of RLS using opioids. The study has enhanced our advocacy efforts to ensure that any legislative and policy regulations address the appropriate use of opioids, including individuals with refractory RLS. Further research will help us determine why this medication class has been effective for over 300 years, leading to potential new drug development.

The RLS Foundation continues to work with key legislative offices to discuss the need for additional research funding, seek a safe harbor for RLS in any policy or legislation, and expand RLS awareness and education for healthcare providers. Generous support by RLS Foundation members makes our Public Policy Initiative possible.

The RLS Foundation's Finance and Audit Committee monitors revenue and expenditures to ensure they are in balance, and review forecasts for the upcoming fiscal year. Meanwhile, the Board of Directors provides financial oversight for the organization by ensuring monies are spent in programs beneficial to the members of the RLS community.

Each gift received, regardless of size, allows us to fulfill our mission and goals while ultimately bringing us one step closer to a cure.

I am pleased to serve on the RLS Foundation's Board of Directors and as the organization's treasurer. I hope that my experience as a corporate executive with more than 30 years experience will be a great asset to the organization. I look forward to the Foundation's continued success in 2022 and our continued work together!

Sincerely

Greg Oberland

Greg Oberland
Treasurer, RLS Foundation Board of Directors

2021 - 2022 Highlights | Financials

Revenues and Support

Contributions	$714,129
Membership Dues	$158,833
Other	$64,463
Total revenues and support	**937,425**

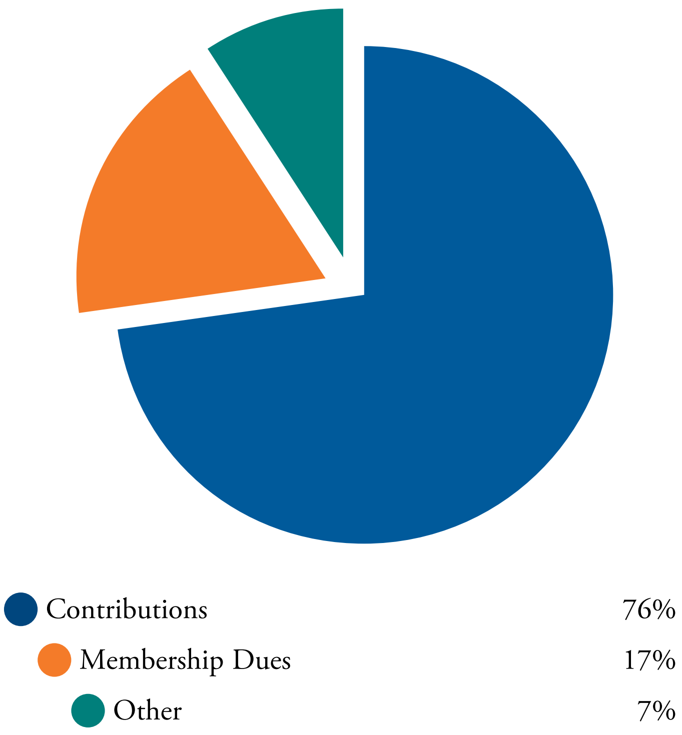
Expenses

Program Services	
Education	$417,539
Membership	$161,536
Research	$35,971
Support Groups	$26,675
Total program services	$641,721
Fundraising	$70,285
Management and general	$65,185
Total expenses	**$777,191**

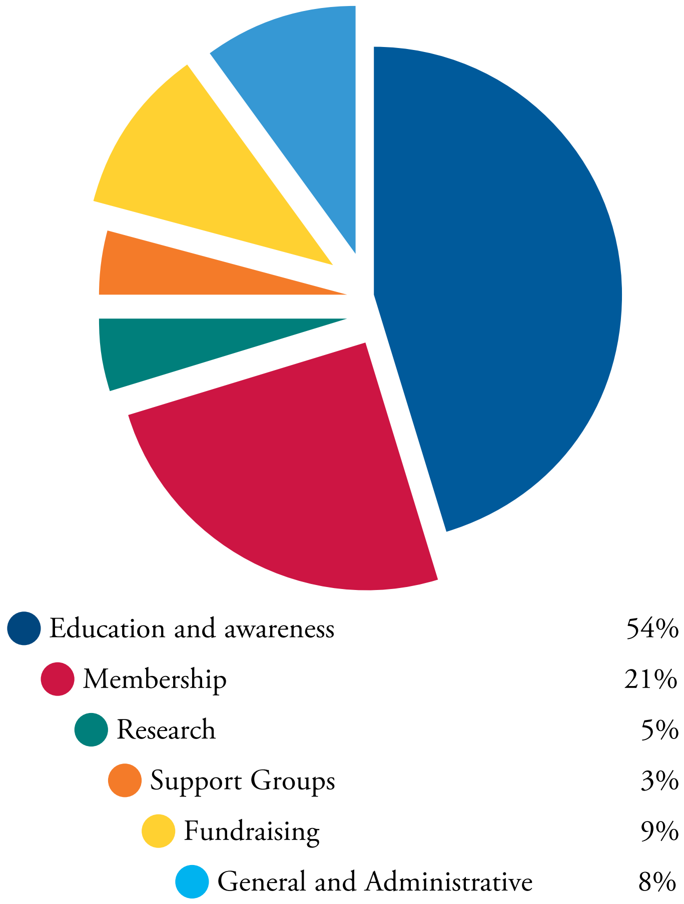
Statements of Activities For the Fiscal Year Ended September 30, 2022

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

2022 Where Our Funds Come From



2022 Where We Use Our Funds



RESTLESS LEGS SYNDROME FOUNDATION

30

YEARS

SERVING THE RLS COMMUNITY

1992–2022

RLS

RESTLESS LEGS
SYNDROME
FOUNDATION

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