RLS Community Speaks Out

2019 ANNUAL REPORT

RESTLESS LEGS SYNDROME FOUNDATION

RLS

RESTLESS LEGS
SYNDROME
FOUNDATION

Restless Legs Syndrome Foundation, Inc. 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.

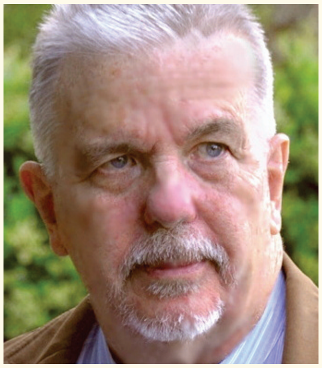
2018 - 2019
Board of Directors

2018 - 2019
RLS Foundation Scientific and Medical Advisory Board

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

12/19/18 Telephonic
2/14/19 Telephonic
4/9/19 Telephonic
7/9/19 Telephonic

2019 Highlights | From the Chairman of the Board



Lewis Phelps
Chair, RLS Foundation
Board of Directors

Like many of you, over the years I have faced ignorance, impatience, and downright hostility from doctors and others as I tried to explain to them the maddening condition we all share: restless legs syndrome. We suffer sleepless nights and pain, knowing something is wrong, yet we were faced with ignorance or (worse) with mis-diagnoses and poor treatments that did nothing or even made life worse.

But because of the work of the Restless Legs Syndrome Foundation, we now live in a world where information is available to patients and doctors alike. The Foundation's webinar series, aimed at health care professionals, offers continuing education on the nature of the disease and medical interventions of value. The Foundation's website offers an informed, science-based repository of information available to patients, their families, and their doctors. Support Groups, with leaders selected and trained by the Foundation, serve the emotional needs of people dealing with the disease. Foundation-certified Quality Care Centers located in the nation's top medical facilities offer state of the art care and management to their patients. A locator service on the Foundation's website directs people to physicians known to be skilled at RLS treatment and sensitive to the toll the disease can take on one's life and work.

We hold national meetings – one in La Jolla, California last year and an upcoming one in Baltimore, Maryland – to provide a forum where leaders in the field can meet with and share knowledge about RLS with our members.

The Foundation also supports the nation's only RLS research grant program, providing startup assistance to researchers looking for underlying causes for the disease. Over the years, we have provided over $1.8 million to 47 grantees, pushing the boundaries of knowledge. Our research funding has also supported data collection efforts, assembling information that can be mined for new treatments and perhaps even a cure.

As noted in last year's Annual Report, the Foundation has been active in Washington DC to share information with Congress and regulators about the disease. The Foundation's presence in DC has been very important in enhancing visibility of the name and the disease. This gives us a fighting chance for competitive grant money when measured up against heart disease, cancer, and neurological conditions like Alzheimer's. This year at least three of our grantees have been awarded additional grants from the National Institute of Health to further their important research. In the midst of panic about wide-spread abuse of opiates, the Foundation has engaged its members and professionals to ensure that federal regulations do not over-burden or prohibit access to medications for those of us with RLS who depend on long-term, smaller-dose prescriptions. With your help, we will continue this work, while simultaneously urging the National Institutes of Health and the Department of Defense to increase funds available for basic and applied research on RLS. The RLS Foundation's presence in Washington, DC, has been very important in enhancing visibility of the name and the disease. This gives us a fighting chance for competitive grant money when measured up against heart disease, cancer, and neurological conditions like Alzheimer's. Further work is needed. Another visit to Washington DC is planned in February to address the possibility of giving RLS higher visibility on grant-supported initiatives

The Foundation is truly lucky to have a deeply engaged set of volunteer leaders – Board of Directors members, Science and Medical Advisory Board members, Support Group leaders, and individuals – who give their time and energy to meet our needs. Our small, hard-working staff in national headquarters oversees the daily work of keeping the Foundation running smoothly. And all of us benefit from the generosity of a committed set of supporters and major donors who provide inspiration and means for everything we do. But it is you, our members, drawn from a pool of quiet, heroic sufferers of an often-discouraging disease, who are our lifeblood and inspiration. Thank you for all you do to support and inspire us.

This is my final year as Chair of the Foundation's Board of Directors. Personal challenges arising from serious injuries I sustained have meant that I have had to lean on others even more heavily than in the past. I have thanked each of them personally, but particularly want to mention with gratitude the way Ron Barrett stepped up to provide leadership when I was unable to do so. As always, Karla Dzienkowski, the Foundation's Executive Director, was ever on the case. As Board leadership shifts to Carla Rahn Phillips – someone I have known and admired for decades – I want to thank every member and supporter of the Foundation for all you have done and will do in the future. Let's keep working until we have this disease licked!

Lew Phelps
Chairman of the Board

Researchers Develop Self-Assessment Tool for RLS Severity

A new tool to evaluate RLS symptom severity has been developed that may improve the ability of clinicians to provide high-quality care to patients, and expand opportunities for researchers to conduct large studies.

An international team of researchers has developed a self-administered version of the International Restless Legs Syndrome Severity Scale, or IRLS, which has been used by clinicians and researchers worldwide since 2013. In the IRLS, an individual's RLS severity is rated on a scale from "very severe" to "none" based on a patient questionnaire.

This scale helps clinicians monitor a patient's symptoms, plan treatment and measure outcomes; and is used widely in research. Its use is limited, however, by the need for a clinician familiar with the scale to administer it to the patient.

To overcome this limitation, the International Restless Legs Syndrome Study Group (IRLSSG) has developed a self-administered version, called the sIRLS. In a recent study published in *Sleep Medicine*, a team of IRLSSG researchers validated its effectiveness and reliability.

"Overall, we showed that the self-administered scale – the sIRLS – is a reliable, valid and precise instrument, as good as the clinician-administered scale," says Denise Sharon, MD, PhD, of Tulane University School of Medicine, who led the study. "The sIRLS can be successfully and effectively used for research and in the clinical practice to evaluate RLS symptom severity and the quality of care of RLS patients."

Since patients can take the sIRLS without assistance – in the clinic, by mail or online – it offers an economical option that can be used by clinicians who are not familiar with administering the IRLS. It can also be used by researchers who are conducting large, epidemiological studies when the cost of a reliable, clinician-administered scale would be prohibitive. Both versions are designed for patients who have already been diagnosed with RLS.

The sIRLS has the same structure and questions as the IRLS, but the wording is tailored for use by patients rather than clinicians. The researchers consulted with members and staff of the RLS Foundation to develop this more consumer-friendly language.

"Many RLS Foundation members helped us with this task," says Dr. Sharon. "We circulated versions of these instructions, and RLS Foundation members took the time to review the wording, complete the test and give us very important feedback."

In both tests, patients complete a questionnaire in which they rate 11 aspects of their RLS symptoms over the past week, using a five-point scale. For example, questions ask how often they have symptoms, and how RLS affects their ability to carry out their daily affairs.

To determine if the sIRLS could successfully be taken without a healthcare professional present, the researchers recruited 173 RLS patients from eight research centers in four countries, who took both versions of the test.

In their findings, the researchers note that while both scales are effective and reliable, one version should be used consistently when comparing assessments taken at different times. The sIRLS currently is available only in English.

The 21 co-authors of the study included several members of the RLS Foundation Scientific and Medical Advisory Board: Arthur S. Walters, MD; Lynn Marie Trotti, MD, MSc; and Jennifer G. Hensley, EdD, CNM, WHNP; as well as former Medical Advisory Board chair Richard P. Allen, PhD.

"I would like to express my gratitude to RLS Foundation members who helped us in developing and studying the sIRLS," Dr. Sharon says. "To all who participated, thank you!"

New Study on How Opioids Work for RLS

The RLS Foundation has awarded a grant of $36,398 to Sergi Ferré, MD, PhD, of the National Institute on Drug Abuse, for a study to explore how opioid medications work in the brain to relieve RLS symptoms. This research builds on several Foundation-funded studies previously conducted by Dr. Ferré, who is a member of the RLS Foundation Scientific and Medical Advisory Board.

“Dopamine agonists, alpha-2 delta agents and opioids are highly effective in treating RLS,” says Christopher J. Earley, MB, ChB, PhD, FRCPI, chair of the Scientific and Medical Advisory Board. “Dr. Ferré’s grant is the first to try and understand the biologic elements that may be common to these three classes of drugs that makes them so effective in treating RLS, thus opening the door for future drug development.”

Opioid medications act on three types of opioid receptors in the brain. One of these – the mu opioid receptor – is the target of the opioid medications, such as methadone, that are a very effective treatment for severe RLS when used in low total daily doses. RLS is a neurological disease that has a distinctly different underlying neuropathology than that associated with typical pain syndromes. Clinical experience among experts who use opioids to treat severe RLS has not shown the degree of drug misuse, dependency or addiction that is commonly associated with opioid use to treat chronic pain.*

In the current study, “Elucidating the mechanisms of the therapeutic effects of opioids in RLS,” Dr. Ferré’s team aims to identify the locations of mu opioid receptors involved in improving RLS symptoms with opioids. With this information, they hope to determine if specific opioid medications could selectively act on these mu opioid receptors, reducing the risk of unwanted side effects.

In previous studies funded by the RLS Foundation, Dr. Ferré’s laboratory developed an animal model for RLS using a brain iron-deficient rodent that models the brain iron deficiency that is characteristic of RLS in humans. Their model combines two techniques, optogenetics and microdialysis, to trigger and measure the release of glutamate from brain cells in live animals. The researchers used this model to confirm that brain iron deficiency increases the release of glutamate in the brain area known as striatum; other studies have reported increased glutamate in the RLS brain.

Dr. Ferré’s team also validated that several RLS drugs – the dopaminergic drugs pramipexole and ropinirole, and the alpha-2-delta ligand gabapentin – work by counteracting this high release of glutamate. In addition, the researchers pinpointed a subtype of receptor in the brain – the dopamine D4 receptor – as a main target for the effects of the dopaminergic drugs in the striatum, and therefore, as a new target for drug development. In a more recent study, Dr. Ferré’s laboratory reported that low levels of receptors of the neurochemical adenosine are responsible for the high levels of glutamate released in the striatum. This finding has led to exploration of drugs that increase adenosine levels in the brain – for example, dipyridamole – as a new treatment approach for RLS. According to Dr. Ferré, the reduced levels of adenosine receptors (specifically, the adenosine A1 receptors) may be the underlying cause of not only restless legs, but also the state of enhanced wakefulness (hyperarousal) experienced by people who have RLS.

In the current study, the researchers will focus on a specific neuron in the striatum, the cholinergic interneuron, which releases the neurotransmitter acetylcholine and has a high number of both adenosine A1 receptors and mu opioid receptors. The researchers hypothesize that in RLS, there are fewer adenosine A1 receptors in these cholinergic interneurons, which therefore become overactive and release more acetylcholine. The researchers also hypothesize that opioids should be able to counteract this by activating mu opioid receptors in the cholinergic interneurons. Dr, Ferré’s team will use its animal model to explore these questions.

“If the results of the study confirm our hypotheses, we will have probably found the main mechanism of the therapeutic effect of opioids in RLS,” says Dr. Ferré. “Those results would then stimulate the search for opioids with a preferential efficacy for the mu opioid receptors localized in the striatum, in the cholinergic interneurons, which should be absent of unwanted side effects.”

The RLS Foundation is grateful for the generosity of individuals whose financial gifts make this work possible, says Executive Director, Karla Dzienkowski. “The Foundation’s research grant program is dedicated to find better treatments and, ultimately, a cure for RLS. This study will help us to understand why opioid medications are effective at relieving severe, unrelenting symptoms of restless legs syndrome, which will lead to an improved quality of life for people with RLS,” Dzienkowski says.

**If opioid therapy is a treatment option to manage your RLS symptoms, your healthcare provider will work closely with you to find the dose that manages your symptoms while minimizing side effects of therapy.*

Study Finds Augmentation Drug a Good Candidate for Research

A research study funded by the RLS Foundation suggests that the drug ecopipam may be a potential candidate for treating augmentation in RLS patients.

In a small, exploratory study, some patients who took ecopipam for five weeks experienced relief from augmentation symptoms, and the drug showed minimal side effects. Ecopipam is an investigational drug currently being studied to treat Tourette's syndrome and other conditions.

"Overall, the results are encouraging," says William Ondo, MD, who conducted the study at Houston Methodist Neurological Institute. "While this study was too small and too short in duration to evaluate whether ecopipam is effective in reversing augmentation, it shows that it is a good candidate to explore in larger studies." Dr. Ondo is director of the RLS Quality Care Center at Houston Methodist, and a member of the RLS Foundation Scientific and Medical Advisory Board.

Augmentation is a common and serious side effect of RLS treatment with dopaminergic drugs, including carbidopa/levodopa (Sinemet), pramipexole (Mirapex), ropinirole (Requip) and rotigotine (Neupro).

At first, these drugs may be highly effective at controlling RLS symptoms, but over time they can make RLS worse for many patients. Symptoms typically start appearing earlier in the day, increase in intensity, or start affecting the arms and trunk in addition to the legs. An estimated 50–70 percent of people who take dopaminergic drugs for RLS develop augmentation within 10 years.

The current treatment for augmentation is to reduce the dosage of the dopaminergic medication or to stop taking it. Withdrawal can be intense and difficult, and alternate treatment options are limited. "Our hope is that if we can find an effective treatment for augmentation, then some RLS patients may be able to continue taking the dopaminergic drugs, which are highly effective for many patients," says Dr. Ondo. "Our goal is to find a long-term, effective treatment so that RLS patients can enjoy a better quality of life."

Baseline Data on Opioids Sets the Stage for Long-Term Study

A study on the long-term safety and effectiveness of opioids to treat RLS has gathered baseline data from more than 400 participants. In work funded by the RLS Foundation, a team led by John Winkelman, MD, PhD, has created a national registry of patients who take opioids to manage their RLS, and will follow these patients for at least the next five years.

"The goal is to assess the long-term safety and efficacy of opioids in RLS, which will help patients and their physicians make more informed decisions about their RLS treatment," says Dr. Winkelman, director of the RLS Quality Care Center at Massachusetts General Hospital.

Participants in the study have completed phone interviews and an initial online survey about their RLS symptoms, treatment, medical history, habits and behaviors. Most have now completed six-month follow-up surveys online.

"Our data shows that people who are taking opioids for RLS are similar to the RLS population in general," says Dr. Winkelman. "They are women, are older, and often are able to get good control of their RLS with low total daily doses of opioids. This is not surprising, given what we generally see in our patients."

Here are some highlights of the data:

- Participants are mostly women (60 percent), and their average age is 65.
- About one-third experienced their first RLS symptoms before age 20.
- Over 50% are taking only an opioid medication to manage their RLS.
- Almost half of participants are taking methadone, at an average total daily dose of 10 mg. The next most common opioid medication is oxycodone, at an average total daily dose of 20 mg.
- 40 percent of those taking an opioid report having no RLS or mild RLS symptoms in the previous week; 25 percent still report severe or very severe symptoms.
- Almost half of participants report a lifetime history of depression; many report a lifetime history of anxiety.
- Over three-fourths of participants (77 percent) are considered low risk for opioid abuse, based on a standardized clinical questionnaire.

"It's exciting that we have been able to recruit this many people who are interested in contributing to answering these questions about opioids in RLS," says Dr. Winkelman.

The RLS Foundation is grateful to all who have participated in this study so far. The RLS community has really stepped up to help each other and future generations that will benefit from these findings.

Methadone May be Less Addictive Than Other Opioids, Study Finds

Scientists at the National Institute on Drug Abuse (NIDA) and their collaborators report that methadone may produce less euphoria than other opioids, suggesting it may hold less risk for abuse or misuse.

In a study led by Sergi Ferré, MD, PhD, and Annabelle Belcher, PhD, published in the *Journal of Clinical Investigation*, researchers conducted experiments using cells in culture, as well as an animal model, to assess the effects of different opioids on the brain. They found that methadone was much less potent than morphine and fentanyl in activating receptors that drive feelings of euphoria.

In the experiments, the scientists examined the response of opioid receptors in cells in the ventral tegmental area (VTA) of the brain. The VTA is a key area involved in the brain's "reward circuit." The researchers found that opioid receptors located in the VTA link with receptors for another neurotransmitter called galanin to form complexes; and that these complexes are less responsive to methadone than to the other opioids.

The researchers also looked at patient data from the RLS Opioid Registry and from a clinical trial for opioid use disorder (opioid addiction). In both studies, significantly fewer patients said they experienced a "high" from taking methadone compared with the other opioids – confirming results of the lab experiments.

"Our work provides very important support for the use of methadone in RLS. These results provide a substantial basis for arguments for its continued availability and use as an opioid treatment with little addictive potential," says Dr. Ferré, who is a member of the RLS Foundation Scientific and Medical Advisory Board.

"The results also open a new path to address the discovery of opioids with lower risk of addiction, which already include methadone. Our ongoing studies will identify the mechanism by which methadone does not activate the opioid-galanin receptor complexes, which light up the reward circuitry, to use this as the basis for future drug development. This is the Holy Grail in the search for effective opioids for the treatment of pain and RLS – we want to emulate that," Dr. Ferré says.

Opioid therapy is used to treat RLS when all other options have failed. At low total daily doses, opioids are effective for controlling RLS symptoms in most patients. Methadone and oxycontin are specifically used for RLS because they are longer-acting, so a single dose can control symptoms across a span of many hours.

The NIDA findings present a new way for clinicians to distinguish among opioids, according to co-author John Winkelman, MD, PhD. "This study suggests that methadone may be distinctive in that it doesn't activate the euphoric, or rewarding, centers in the brain, and therefore lessens the risk of misuse or abuse. From this perspective, methadone in low doses is not as worrisome as other opioids. However, it is still an opioid and needs to be used only in select patients and carefully in those individuals," says Dr. Winkelman.

RLS patients who may feel stigmatized for taking methadone can find reassurance in these new findings, according to RLS Foundation Executive Director Karla Dzienkowski, "This gives the RLS patient community validation for this treatment, and hope for the future."

Medical Cannabis and RLS

Jacquelyn Bainbridge, PharmD, FCCP, MSCS; and Mark Buchfuhrer, MD, FRCP(C), FCCP, FAASM

The medical use of cannabis (marijuana) is increasing in the United States. The drug remains illegal under federal law, even though it is legal in 33 states and the District of Columbia. However, a federal spending bill passed in 2014 prohibits the Justice Department from using federal funds to enforce this ban in states with medical marijuana laws.

Medical cannabis is recognized as a legitimate medical application for many conditions. A position statement from the American Academy of Neurology, "Use of Marijuana for Neurological Disorders," outlines the benefits of some form of medical cannabis for conditions such as multiple sclerosis, epilepsy, and others. While RLS is not included in this position paper, many patients with RLS are looking to experiment with medical cannabis to relieve their symptoms when other treatments are unsuccessful, too expensive or cause unwanted side effects.

Current treatment for RLS

Current medications that are approved by the US Food and Drug Administration (FDA) for treating RLS include dopaminergic agents and an alpha-2-delta ligand drug. These drugs work by enhancing dopamine activity in the brain (ropinirole (Requip), pramipexole (Mirapex), rotigotine (Neupro patch)); or by modifying calcium channels on nerves (gabapentin enacarbil (Horizant)), which changes the excitability of nerves that carry RLS sensations or pain.

In addition, several drugs approved for treatment of other medical conditions have undergone clinical studies in RLS patients and provide symptom relief when consistently used "off-label." Off-label use is when a medication is used for a disease or medical condition that it is not approved to treat, according to FDA regulations.

Medical cannabis in RLS

We are not sure how cannabis works. It may act on cannabinoid receptors in the brain that affect areas involving motor activity, coordination and pain relief by blocking pain receptor pathways.

There are no current studies or clinical trials on the use of medical cannabis in RLS. Though cannabis is not FDA approved to treat RLS, anecdotal evidence from some patients' experiences has shown that it may improve some of the symptoms commonly associated with RLS.

Typically, ingested cannabis (through brownies or cookies, for example) does not seem to benefit RLS very much, while inhaled cannabis (through a cannabis cigarette or vaporizer) works very quickly and effectively. Most people with RLS report that after only a few puffs of a cannabis cigarette or a few inhalations of vaporized medical cannabis, even very severe symptoms are relieved within minutes. The relief does not last long, wearing off after one or two hours, so inhaled cannabis works best for RLS symptoms that occur mainly at bedtime. (Note that smoking cannabis allows for combustibles to be released into the air and may pose a health risk to the patient and bystanders.) Patients have reported that a one-month supply of medical cannabis may last three to four months when used to treat bedtime RLS symptoms.

Cannabis is a complex plant. Of its 489 chemical constituents, 70 are known to be cannabinoids, and the rest are potentially unwanted neuroactive substances that cross the blood-brain barrier. Cannabinoids may cause drug interactions, so patients who take cannabis should consult with their physician or pharmacist to avoid any unwanted interactions with their other medications.

Within cannabis products, tetrahydrocannabinol (THC) is the major psychoactive ingredient (that is, it affects mental processes) that causes individuals to experience a "high." Cannabidiol (CBD) is the major nonpsychoactive component. From a medical standpoint, products high in CBD and low in THC are believed to produce desired effects in the brain, with little or no side effects on mental processes.

Some of the cannabinoids widely consumed are:

- Cannabinoid-rich preparations of cannabis in the herb (plant) or resin form
- Cannabinoid-containing pharmaceutical products containing natural cannabis extracts (Sativex, a GW Pharmaceuticals/ Greenwich Biosciences drug in clinical trials in the United States and approved for use in Canada and other countries)
- Synthetic cannabinoid (dronabinol (Marinol)), tetrahydrocannabinol (THC) or nabilone (Cesamet)

Studies have shown that medical cannabis may reduce pain and muscle spasticity symptoms. These studies found patients were able to tolerate cannabis well without significant side effects. The most common reported side effects of cannabis are dizziness, fatigue, dry mouth and nausea.

Many factors limit the use of medical cannabis to treat RLS. First, no clinical trials have documented its benefits for treating RLS. Second, studies of medical cannabis to treat pain and muscle spasticity were relatively small and conducted over a short period of time, and therefore do not provide information on how a patient would respond to long-term use. Moreover, the long-term side effects or complications of medical cannabis itself are unknown.

Finally, since cannabis is still considered illegal under federal law in the US, it is very difficult for researchers to study its medical use. Very few well-controlled trials of cannabis have been designed because institutions will not allow human consumption due to its federal legal status.

In summary, in addition to federal acceptance of the legality of cannabis, more clinical trials are needed to validate whether medical cannabis would be an effective treatment for RLS.

Raising Our Voice to Congress: RLS Advocacy Day on Capitol Hill

Thirty members of the RLS community from across the US gathered in Washington, DC, on May 3 for the first RLS Advocacy Day on Capitol Hill.

RLS patients and Foundation staff were joined by Jeffrey Durmer, MD, PhD, a member of the Foundation's Scientific and Medical Advisory Board; and Sandra Katanick, a member of the Board of Directors; for a whirlwind day of meetings with congressional offices. An RLS Foundation delegation also attended meetings on May 2. Over the two days, the Foundation met with staff members of 45 Congressional representatives representing 16 states, including key members of committees that shape health policy.

"Our first advocacy day exceeded everyone's expectations," says Karla Dzienkowski, Executive Director of the RLS Foundation. "This was an exciting opportunity for staff and RLS community members to join forces to advance our goals. We made headway in educating key offices that can champion our legislative agenda."

RLS Advocacy Day took place at the heart of the federal appropriations process, when Congress designates dollars to fund specific areas of the government – and at a time when Congress is engaging in oversight activities to implement key legislation that addresses the opioid epidemic: the Comprehensive Addiction and Recovery Act (CARA), and the SUPPORT for Patients and Communities Act.

The day began with a prep session led by the Health and Medical Counsel of Washington (HMCW). "Most folks don't know what restless legs syndrome is, including people who make decisions at the highest level of government," said Peter Herzog, a legislative associate at HMCW. "That's where decision-makers rely on their staff who focus on these issues, on expert opinion, and on their constituents. RLS patients are both experts and constituents, and their input matters to legislators."

Participants formed five teams, each with an agenda of back-to-back meetings with senators and representatives.

In the meetings, they shared their stories and challenges of living with RLS. They advocated for support on three key issues: increasing research funding for RLS, protecting appropriate access to opioid therapy for patients with severe RLS, and expanding RLS physician education and public awareness.

Donna Rivers and her husband, Martin, traveled from Oregon to participate. "It amazed me how little most people know about RLS. I was happy to be a part of that education process," says Rivers, who volunteers as an RLS support group leader. "The experience was empowering in that I felt our plight as RLS sufferers was recognized. I believe the education provided to legislative staffers will be heard by our representatives."

Rosemary Stader, an RLS support group leader who traveled from Ohio with her husband, Gregory, says that most of the congressional staff appreciated the meetings. "I think we made a difference! The people we saw were interested; they were engaged, wrote down notes, and I think they will support our cause."

"It was win, win, win," says Julie Herbert, from Missouri. "I got to advocate for the needs for those of us with RLS, to exercise my rights as a citizen, and to spend time with some wonderfully interesting people, many of whom also have RLS, reinforcing my awareness that I am not alone. One more win: I became increasingly aware of the great work that the folks at the RLS Foundation are doing on our behalf."

"I feel like anything we do to take action with regard to our RLS gives us more strength to deal with a disorder that so often leaves us feeling frustrated and helpless," Herbert adds. "I'm so glad I went."

The RLS Foundation would like to thank all who participated in the first RLS Advocacy Day on Capitol Hill, all who joined in spirit, those who submitted letters or videos, or responded to calls to action, and those who continue to generously provide financial support for RLS advocacy efforts.

To learn more about RLS advocacy, visit www.rls.org.

We're Making Progress: Let's Keep Going

RLS Community,

Thank you for your continued advocacy and support. In May, a delegation of RLS Foundation staff, board members and over 20 patients attended the first **RLS Advocacy Day on Capitol Hill** in Washington, DC. Our team of advocates sat down with staff of more than 45 legislative offices to educate them about RLS, share the personal stories and struggles of many of their constituents, and outline our community's unique policy considerations. This was our fourth round of meetings in DC since we launched our advocacy initiative in October 2017.

As a direct result of our advocates' hard work educating their federal representatives, Congress continues to highlight **RLS medical research** at the **National Institutes of Health** through report language in annual appropriations bills. Emphasizing the importance of funding in this area will help to move research forward, create new treatment options for patients, and bring us closer to a cure. The **Department of Defense** also continues to pursue important research activities on sleep disorders. Thanks to our community and others, Congress continued to include sleep disorders as a category eligible for funding in fiscal year (FY) 2019, and we are working to ensure the category is included for FY 2020.

We are also happy to report the impact our advocacy campaign made on the **Pain Management Best Practices Inter-Agency Task Force Report**. Over 350 RLS patients and advocates submitted comments on the report, and the RLS community's voice has been heard! Many of our concerns are reflected in the report, including an emphasis on the importance of clinical guidelines that are supported by evidence and created by organizations like the RLS Foundation that are experts in the treatment of certain conditions.

These recommendations underscore the importance of resources such as guidelines on the appropriate use of opioids for treating RLS*, published by members of the RLS Foundation Scientific and Medical Advisory Board. We encourage you to share these guidelines with your healthcare providers to educate them on appropriate treatment practices.

In conjunction with the Task Force's report, the **Centers for Disease Control and Prevention** (CDC) has also acknowledged that its 2016 Guideline for Prescribing Opioids for Chronic Pain has been broadly misapplied, which has resulted in a loss of appropriate patient access and significant disruptions of care. The guideline is intended for primary care doctors managing individuals with chronic pain. While RLS is not a chronic pain condition, it's important to note that the guideline has contributed to a loss of access for many RLS patients who take low total daily doses of opioids to appropriately manage their RLS.

In April, the CDC published a commentary in the New England Journal of Medicine outlining ways in which the guideline has been misapplied. For example, the guideline has been misapplied to unintended groups (such as RLS patients), as well as resulted in sudden discontinuation of opioid therapy – a practice that would be potentially devastating for someone with RLS. The CDC is also working to address these misapplications through improved educational resources for patients and providers. Please visit www.cdc.gov/drugoverdose/resources for more information on these efforts.

These outcomes from the Task Force and the CDC are great steps in the right direction, but we need to keep pushing these issues forward. RLS patients across the country are still losing access to opioid therapy as a result of stigma, fear and miseducation.

Thank you again for your tireless advocacy on these issues, and your continued financial support. We will continue to update you on our progress to increase medical research, maintain patient access, and improve education and awareness.

We do this together, as always.

Sincerely,

Karla Dzienkowski, RN, BSN Executive Director, RLS Foundation	Christopher J. Earley, MB, BCh, PhD, FRCPI Chair, RLS Foundation Scientific and Medical Advisory Board

*To view the article "The Appropriate Use of Opioids in the Treatment of Refractory Restless Legs Syndrome" and an explanatory video, visit www.mayoclinicproceedings.org.

Webinars 2019

RLS and Depression
December 9, 2019

Speaker: Brian Koo, MD

SIBO and Gut Connection to RLS
November 6, 2019

Speaker: Leonard Weinstock, MD

Animal Models in RLS Research
October 15, 2019

Speaker: Byron Jones, PhD

What's New in RLS Research
September 5, 2019

Speaker: Mauro Manconi, MD, PhD

RLS Coping Strategies
August 12, 2019

Speaker: Norma Cuellar, PhD, RN, FAAN

Congressional Visits in Your Hometown
July 30, 2019

Speaker: Peter Herzog

Basic RLS Pathophysiology
July 15, 2019

Speaker: James R. Conner, PhD, MS

Medications for RLS
June 20, 2019

Speaker: Michael H. Silber, MBChB

Comorbidities and RLS
April 12, 2019

Speaker: William Ondo, MD

Managing RLS with Opioids
March 8, 2019

Speaker: John W. Winkelman, MD, PhD

Augmentation and RLS
January 24, 2019

Speaker: Mark J. Buchfuhrer, MD, FRCP(C), FCCP

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.

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Ms. Alejandrina Torrens
Mrs. Ruby Townsend
Mr. Melvin G. Trammell
Ms. Janet L. Trent
Ms. Carol Turkaly
Mr. James Turner
T. Michael Ulwelling
Dr. Gary Utz
Ms. Mary Valiant
Mr. and Mrs. Robert Van Etten
Ms. Elizabeth VanderBurg
Patricia Vavrick
Ms. Shirley Veach
Mr. Richard Vezza
Mr. Robert Visser
Mr. Steven Vogel and Ms. Jane Henderson
John M. Wadahara
Kate Wagner
Ms. Judy Wagnitz
Ms. Stephanie Waldhart
Gordon Waldron
Mr. Gary Walker
Mrs. Shirley M. Ware
Mrs. Mary Ann Watrous
Mr. and Mrs. Lawrence P. Watson
Mr. Rupert Watson
Kit Weinschenk
Ms. Nanci Weissgold
Ms. Victoria Welch
Mr. Bill Wendt
Mrs. Mary Wendt
Sheila C. Wheatley
Mr. Stephen White
Ms. Carolyn Wilcox
Ms. Deborah Wilcox
Mrs. Diane R. Wilds
Dr. Keith D. Wilkinson
Mr. Kent Williams
Larry and Fran Williams
Ms. Laurena Williams
Ms. Donna Willis
Ms. Caroline R. Willms
Judy Willoughby
Ms. Naomi Wilson
Mrs. Ruth Wixted
Mary Lou Wohlhieter
Mr. Eduard Wojczynski
Mrs. Lucy H. Wong
Ms. Barbara Wood
Mr. Gerald Wood
Mr. Gordon Woodard
Mrs. Julia Woodward
Mr. Cody Wray
Mrs. Anita Wright
Mr. Des Wytmans
Ms. Lois Yarbor
Mr. Ted Yednock
Mrs. Alice B. Yoakum
Mr. Sheridan Young
Mr. William Young
Mr. Joseph Zabreznik
Ms. Ann L. Zimmerman
Barbara Zizka
Mr. Mel Zoerb

Treasurer Report

Ron Barrett, PhD
Treasurer

I would like to thank the members of the RLS Foundation for their continued support and commitment to the RLS Foundation during our 2019 fiscal year. Individual donations comprise most of the financial support for Foundation programs and activities, representing 77% of total revenue to the organization.

In fiscal year 2019, the Foundation continued to support the mission and organizational goals of awareness, education, and research to find a cure. Members of our Scientific and Medical Advisory Board reviewed and updated our library of educational materials to educate the general public and medical community about RLS. These volunteers served as presenters in our monthly webinar series and the healthcare provider only webinar series aimed at educating the medical community about the diagnosis and management of patients with RLS. Our educational outreach continues through information posted to the Foundation's website and social media channels including Facebook, Twitter, Instagram, YouTube, and LinkedIn to reach RLS sufferers and their healthcare providers. Volunteers that lead our support groups and discussion board provide individuals with RLS the opportunity to exchange information and coping strategies with others who live with the daily challenges of RLS. The RLS Foundation's acclaimed quarterly magazine, *NightWalkers*, provides members with in-depth stories about RLS Foundation funded research, and information regarding promising research and treatments available today. These diverse channels provide the Foundation access to a broad audience of individuals with the disease, fulfilling our mission to provide knowledge and raise awareness of RLS.

The second and third components of our mission are to support the development of improved treatments and a cure for RLS. The Foundation has provided an additional year of funding for a multi-center longitudinal pilot observational study of the efficacy and tolerability of long-term use of opioids as a treatment for RLS. Information from this study has enhanced the Foundation's advocacy efforts to assure that any legislative and policy regulations to address the opioid epidemic do not negatively impact the medically necessary use of opioids by individuals with refractory RLS. A second grant was funded to study how opioid medications work in the brain to relieve RLS. The aim of this study is to discover why this class of medication is effective in treatment of RLS and could lead to new non-opioid drug development.

The RLS Foundation advocacy program helped to raise the profile for RLS in Washington DC. In 2019, the Foundation conducted the first RLS Advocacy Day on Capitol Hill. The RLS Foundation delegation met with key legislative offices to seek additional research funding for RLS, seek a safe harbor for RLS in any policy or legislation and expand awareness and physician education. Members, like you, make these advocacy efforts possible through your generous support.

The RLS Foundation's Finance and Audit Committee reviews and recommends for Board approval the budget for the upcoming fiscal year. Throughout the year, the Committee monitors revenue and expenditures of the Foundation and then oversees the annual audit performed by an independent accounting firm. This financial oversight ensures donations and other foundation income are spent on programs beneficial to the members of the RLS community.

It has been my pleasure to serve you as Treasurer during the 2019 fiscal year. I look forward to our continued work together and the future success of the Foundation in 2020!

Sincerely

Ronald W. Barrett, PhD

2018 Highlights | Financials

Revenues and Support

Contributions	$612,710
Membership Dues	$163,562
Other	$15,509
Total revenues and support	**791,781**

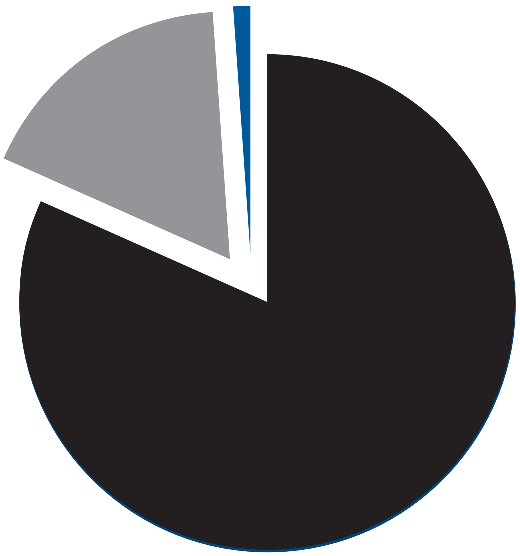
Expenses

Program Services	
Education	$370,836
Membership	$206,650
Research	$83,266
Support Groups	$28,119
Total program services	$688,871
Fundraising	$83,597
Management and general	$69,889
Total expenses	**$842,357**

Statements of Activities For the Fiscal Year Ended September 30, 2019

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

2019 Where Our Funds Come From



●	Contributions	77%
●	Membership Dues	21%
●	Other	2%

2019 Where We Use Our Funds

●	Education and awareness	44%
●	Membership	25%
●	Research	10%
●	Fundraising	10%
●	General and administrative	8%
●	Support Groups	3%

RLS Community Speaks Out

RESTLESS LEGS
SYNDROME
FOUNDATION

3006 Bee Caves Road
Suite D206
Austin, TX 78746

512-366-9109
info@rls.org

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