RLS Foundation
1992–2017

2017>

RESTLESS LEGS
SYNDROME
FOUNDATION
25 YEARS
OF PROGRESS
1992-2017

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.

2017 - 2018
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The Restless Legs Syndrome Foundation Board of Directors held meetings on:

December 15, 2016
Telephonic Meeting

February 7, 2017
Telephonic Meeting

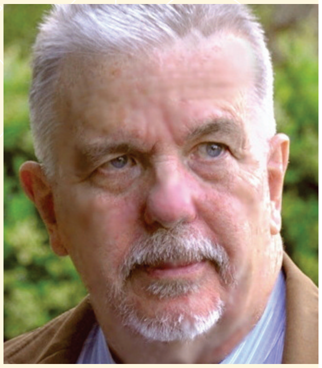
April 7, 2017
Telephonic Meeting

May 17, 2017
Telephonic Meeting

July 11, 2017
Telephonic Meeting

September 29, 2017– October 1, 2017
Annual Meeting

2017 Highlights | From the Chairman of the Board



Lewis Phelps
Chair, RLS Foundation Board of Directors

From the time restless legs syndrome was first identified in medical literature three centuries ago, RLS has remained one of the most widespread yet least understood human diseases, often leading to shame and ridicule. But, the medical landscape began to change in the late 1980s when a group of researchers led by Dr. Arthur S. Walters, founder and first chair of RLS Foundation's Medical Advisory Board, rekindled the attention of the medical community toward RLS. Then, in June 1992, Pickett Guthrie, Dr. Walters and other forward-thinking individuals got together to take charge of their own health issues when their doctors were ignoring them; they founded the Restless Legs Syndrome Foundation. In 25 fast-paced years, we have moved from a small group gathering around a kitchen table to an established foundation that has transformed medical opinions, increased awareness both in the medical community and in society, and funded research that is creating new and better treatment options.

This year we celebrate 25 years of hard and effective work by the dedicated volunteers who serve on our Board of Directors and our Science and Medical Advisory Board, our very capable and professional staff, and the many volunteers who lead support groups or provide phone and online support around the country. Within the past five years we have established eleven Quality Care Centers that are staffed by certified RLS experts who are knowledgeable and experienced in managing the most severe cases of RLS. With your support and extraordinary commitment, we have raised nearly two million dollars to fund medical research that has led to better treatments and is coming closer every day to finding a cure. We have also led the creation of invaluable diagnosis and treatment guidelines, led in the efforts to identify and deal with the phenomenon of augmentation, created resources for children and teens to help them understand and manage their RLS, and are now leading the fight to preserve access to low total daily dose opioids for patients with difficult-to-control cases of RLS.

2017 was a banner year for the Foundation as we certified four of those eleven Quality Care Centers and expanded our member base, now numbering more than 5,000 individuals. We ramped up our presence on social media to increase RLS awareness far beyond our member base and donors. And, we funded two promising research studies: to evaluate a possible treatment for augmentation (a common and devastating side effect of RLS dopamine medications); and to gather data on the long-term use of opioids to treat RLS.

The opioid crisis has affected the RLS community. The Foundation has developed a strategy to respond to this challenge and retained an advocacy organization with extensive experience in nonprofit, healthcare industry and governmental relations to guide and direct our efforts on behalf of the RLS community. The Foundation will continue to support research to understand further issues of tolerance, efficacy and addiction as it relates to use of opioids for management of severe forms of RLS and to distinguish RLS from chronic pain as each has its own distinct pathophysiology.

All of these efforts need your continuing and increased support. Although the Foundation is far stronger financially than it was a few years ago, we need all who are affected by RLS to step forward by supporting us and bringing others into the fold as new members. Please consider increasing your donation to the RLS Foundation to support research, education, advocacy outreach, and the service to the RLS community that our staff and volunteers provide. Equally as valuable, if you know anyone affected by RLS who is not a member of the Foundation, encourage them to join, or pay it forward and buy their first year of membership!

On behalf of the RLS Foundation staff, volunteers and Board of Directors, thank you for all that you do. Together, our voice – and our impact – are powerful.

Lew Phelps
Chair, RLS Foundation Board of Directors

25th
RLS Foundation
1992–2017

2017

Creating a ‘Perfect Experimental Platform’ for RLS

From the seeds of an RLS Foundation grant, researcher Byron Jones, PhD, has grown a genetic reference population of mice that is poised to serve as an animal model for RLS research.

In 2004, the RLS Foundation awarded Byron Jones, PhD, an $8,000 grant for a project to start a mouse colony that could be used in research to help identify RLS-related genes. Over the course of 12 years and many mouse generations, Jones has employed a genetic reference colony that not only has helped unearth three possible RLS genes, but also may provide a model for studying RLS and testing treatments. Jones’s program is summarized in a recent review article in *Sleep Medicine*.[1]

“The human genome informs the mouse genome,” says Jones. “It’s partly tongue in cheek, but also serious. … Genetic information in the mouse is, 90 percent or better, the same as in humans.”

“We need to understand how things happen at the cellular, molecular level,” he says. “The drugs we use are superficial – not cures. I want to go after what is causing RLS, and how we can intervene to prevent this [disease]. You need to know how it works before you can cure it.”

BXD40: A match for RLS iron regulation

In the RLS-funded project, Jones (then at Penn State) set out to find an inbred mouse strain whose genetics, when deprived of iron, produced the same biological characteristics (phenotypes) as RLS. He obtained mice known to be different in all kinds of phenotypes, and tested them for differences in their response to iron deficiency.

Jones’s team studied over 30 strains of mice to identify a strain called BXD40 that met their criteria. When fed an iron-deficient diet, the BXD40 females showed great loss of iron in the substantia nigra region of the brain, but hardly any loss in the periphery – matching the iron deficiency profile of RLS in humans.

During the project, Jones was invited by Johns Hopkins researchers Christopher Earley, MD, PhD, and Richard Allen, PhD, to collaborate on researching genetics and iron regulation in the brain. Allen showed that BXD40 mice had phenotype characteristics the same as people with RLS – namely, altered sleep patterns and problems with their sensory systems.

This team identified three genes seemingly involved in iron regulation that were not previously known to play a role in RLS – among them, the gene BTBD9. “We literally stumbled upon these mice, but it was a planned stumbling,” says Jones. “We struck a homer.” Other scientists like Yuqing Li, PhD, an RLS Foundation grant recipient, at the University of Florida, are using these findings to further explore BTBD9 in genetic models of RLS.

A ‘perfect experimental platform’

Jones subsequently was awarded two R01 grants from the National Institutes of Health – one to continue this work on genetic regulation of iron in the brain, and the other to study the effects of chronic stress on alcohol consumption. His research team (now at the University of Tennessee) has controlled breeding within the colony to create strains with fixed genotype so that all are genetically alike. They have grown the mouse colony, generation by generation, to include over 100 strains of mice.

Byron Jones, PhD

Jones calls this a “perfect experimental platform.” Scientists can now look at the effects of the different genes by going into the colony, choosing mice with a particular genetic profile, and testing them to answer scientific questions. Strains can also be tested in different laboratories to tease out the effects of environmental factors. “We get remarkable replication of experimental results across all laboratories,” says Jones.

Matching RLS behaviors and response to medication

In recent work, Jones and collaborator Erica Unger, PhD (at Lebanon Valley College in Anville, Pennsylvania), matched the BXD40 model with RLS behaviors.

Unger analyzed the 24-hour activity levels of BXD40 mice compared with five other BX strains. The BXD40 showed that with dietary iron deficiency, the BXD40 mice had an increase in activity in the last part of their active cycle and first part of their rest cycle –matching the cycle of RLS symptoms in humans. No other strain showed this circadian change in behavior.

Unger also tested this model with RLS medications. Preliminary data showed that treating the BXD40 animals with levodopa or quinpirole significantly reversed the decreased rest time and increased activity.

The result: a potential RLS animal model in the iron-deficient BXD40 mouse which shows the many characteristics of RLS in humans – iron regulation, behaviors, and response to dopaminergic drugs.

Jones plans to use this animal model to build on his RLS research.

“We were able to find some animal verifications of what was going on with humans, and that’s always cool,” says Jones. “Now, if we find out how the protein BTBD9 operates in the brain in iron management, then instead of treating RLS with a dopamine agonist, we might find some agent that alters the expression of this gene.”

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[1] Allen RP, Donelson NC, Jones BC, Li Y, Manconi M, Rye DB, Sanyal S, Winkelmann J. “Animal models of RLS phenotypes.” *Sleep Medicine* 2016 Sep 2 (Epub ahead of print).

Research Will Evaluate Nighttime Agitation and RLS

For many people who have Alzheimer's disease, evenings are difficult. Right around sundown, uneasy feelings and confusion start to flow. The person may become forgetful, agitated – even aggressive, and start pacing or wandering. These symptoms can last through the night and make it tough for anyone in the household to get a good night's sleep.

Could it be that these behaviors – known as nighttime agitation, or "sundowning" – are caused by RLS? And could treating the RLS lessen the nighttime agitation symptoms?

Researchers led by Kathy Richards, PhD, at the University of Texas at Austin are working to answer these questions. Dr. Richards and co-investigator Christine Kovach, PhD, from the University of Wisconsin-Milwaukee have been awarded a $3.9 million, five-year grant from the National Institute on Aging to evaluate whether there is an association between nighttime agitation and RLS in people who have Alzheimer's disease.

"Nighttime agitation is the No. 1 reason why people with Alzheimer's cannot be cared for at home," says Dr. Richards. "If we can find a better and more precise way to treat nighttime agitation, we can improve the quality of life for many persons who are living with Alzheimer's disease."

Nighttime agitation is often treated with powerful antipsychotic drugs, which are only moderately effective and carry with them serious risks, such as falls, stroke and death.

Because nighttime agitation has a strong circadian component and shares symptoms with RLS, Dr. Richards and others have long postulated that for some people, undiagnosed RLS could be the underlying cause. In a previous study led by Dr. Richards, researchers examined symptoms in 59 people who had Alzheimer's disease and nighttime agitation. They found that 24 percent of participants also had RLS.

In the current research, the team will validate this result in a pilot study – an eight-week, double-blind, randomized controlled trial with 136 long-term care residents who have nighttime agitation and RLS. Participants will receive either gabapentin enacarbil (Horizant, an FDA-approved medication for treating RLS) or a placebo. Data from the study will also help discern the effectiveness, safety and optimal dosage of gabapentin enacarbil for treating nighttime agitation, as well as whether the frequency of RLS symptoms may be linked to nighttime agitation.

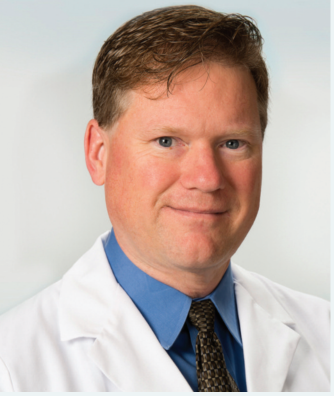
The researchers will use a tool newly developed by Dr. Richards called the Behavioral Indicators Test-Restless Legs. This test includes a brief 20-minute observation and simple set of questions for caregivers. Previous studies have shown the tool to be an effective way to diagnose RLS in people who have Alzheimer's, and one that has potential for future use with children and others who don't have the ability to report their symptoms.

RLS Foundation Executive Director Karla Dzienkowski visited the University of Texas in May, where she gave a presentation about RLS and met with Dr. Richards' team to extend the RLS Foundation's support for the research endeavor. "Cognitively impaired seniors with RLS may have difficulty expressing RLS symptoms causing an inability to sit or lie still during the evening or nighttime hours," says Dzienkowski. "This study will ensure seniors with cognitive impairments are accurately diagnosed and receive proper treatment to manage their RLS symptoms."

Dr. Richards emphasizes that while there is no evidence suggesting that RLS causes Alzheimer's, the study may show that it's important for caregivers of people with any type of dementia to watch for possible signs of RLS that can then be treated to potentially reduce nighttime agitation.

It all comes down to quality of life for people who have dementia, says Richards. "I hope they will be more comfortable, and that they – and their caregivers – can get a good night's sleep."

New Study Will Test Treatment for Augmentation


William Ondo, MD

The RLS Foundation Research Grant Program has awarded $37,000 to William G. Ondo, MD, of Houston Methodist Neurological Institute, to explore a potential treatment for augmentation. The study "Treatment of RLS Augmentation with Ecopipam, a D1 Specific Antagonist" will evaluate the drug ecopipam in reversing the symptoms of augmentation, a common side effect of dopamine medications taken for RLS. 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.

"Dr. Ondo's proposal presents an exciting opportunity to investigate a new approach to treat RLS augmentation," says RLS Foundation Executive Director Karla Dzienkowski, RN, BSN. "As the only organization with a dedicated RLS research grant program, it is our hope that research like Dr. Ondo's will lead to new and better treatments and one day, a cure for patients living with RLS."

Summary: "Treatment of RLS Augmentation with Ecopipam, a D1 Specific Antagonist"

Dopamine and dopamine agonists (medicines that mimic dopamine) can dramatically treat RLS and periodic limb movements in sleep (PLMS). However, chronic use often results in augmentation, a condition manifested by earlier onset and intensification of the original RLS symptoms. Understanding and eliminating augmentation is arguably the greatest practical problem in RLS management.

The mechanisms by which dopaminergics actually treat RLS are not entirely understood. First, dopamine and dopamine agonists react with at least five different dopamine receptors, which can do very different things depending on their type and location. In fact, in several known systems, the D2/3 types seem to do the exact opposite of the D1 type.

Based on clinical and basic science information, our team and others have speculated that stimulation of dopamine D2/3 receptors in the spinal cord treats RLS symptoms. The main dopaminergic RLS medications (pramipexole, ropinirole, rotigotine and L-dopa) all mostly stimulate D2/3 receptors, but also stimulate D1 receptors to a lesser degree, especially L-dopa.

We previously developed an animal model of RLS in mice and rats. This model consists of iron deprivation, and destruction of the dopaminergic neurons that descend into the spinal cord, where they interact with both D1 subtype and D2/D3 type receptors. These animals showed markedly increased activity consistent with RLS, although they could not tell us if they had RLS sensations. Importantly, the symptoms improved with the D2/3 drugs to treat RLS, such as pramipexole and ropinirole, but also dramatically worsened with a drug that specifically stimulates D1 receptors. No such drug is available for human use.

In later experiments, we tried to identify underlying mechanisms of augmentation by treating some of these modeled mice chronically with the dopamine agonist pramipexole. The main change over time was that treatment increased spinal cord affinity (efficiency) of the D1 receptors (which seem to worsen RLS symptoms in the model). There was also a mild reduction in D3 receptor density over time. Therefore, our hypothesis for augmentation is that over time, the ratio of the "bad" D1 receptors to "good" D2/3 receptors increases, thus causing the chaotic condition where the same drug both treats and worsens the condition. In turn, based on this theory, if you could block the stimulation of the D1 receptors and keep the D2/3 stimulation, you could have benefit similar to when the medicine was first started.

Unfortunately, there are very few medicines that specifically block D1 receptors without also blocking D2/3 receptors. In fact, only one such drug has ever been tested in humans: ecopipam (owned by Psyadon Pharmaceuticals), an investigational D1-specific blocker. The drug has been tested in more than 1,000 people with Tourette's syndrome, obesity, schizophrenia, cocaine dependency, Lesch-Nyhan syndrome, and diabetes mellitus. It is currently undergoing studies in Tourette's. The safety profile has been good, with sedation the most common side effect (potentially desirable in people who have RLS).

We will be conducting a small, short study of ecopipam in RLS patients currently taking only dopamine agonists – pramipexole (Mirapex), ropinirole (Requip) or rotigotine (Neupro) – who initially had good benefit but now have augmentation. Other RLS drugs will not be allowed in the study. Participants will add either ecopipam or placebo for six weeks to their current dopamine drug. Participants will then "cross over" to the other arm (placebo or ecopipam) for another six weeks, so that everyone will get both ecopipam and placebo at some point in the study. Neither the patient nor the physician will know which group they are in, to avoid bias. Overall, there will be six visits in Houston over about 14 weeks. We will assess a number of RLS and augmentation scales to determine if the medicine helps augmented RLS. Based on the results of this "exploratory" study, funded by the RLS Foundation, other larger studies might follow.

RLS Training for Doctors Would Be Cost Effective, Study Shows

Recent research findings make the case for investment in a long-term infrastructure to train primary care providers in the United States to recognize and treat RLS. Currently, doctors do not receive such training in medical schools.

In 2016, the RLS Foundation awarded a research grant to William Padula, PhD, of Johns Hopkins Bloomberg School of Public Health, to conduct an economic study on the value of accurately diagnosing and treating RLS. Padula, in collaboration with Christopher J. Earley, MD, MB, BCh, PhD, FRCPI, at Johns Hopkins Medicine; and Charles E. Phelps, PhD, MBA, at the University of Rochester; concluded that training primary care providers to correctly diagnose RLS would be cost effective. They found that in 65 percent of cases, the cost of training is expected to be lower than costs related to patients' medical care, as well as lost work and time.

Padula and Phelps will co-present their findings at the annual meeting of the International Society of Pharmacoeconomics and Outcomes Research (ISPOR) in May, and are preparing the results for publication in a medical journal.

"We hope that in addition to publishing these findings, headway can be made to incorporate training on RLS treatment into standard postgraduate medical curriculum for many of the primary and secondary medical disciplines," says Padula. "This scientific evidence on value is sure to help."

The study sheds light on a vexing problem: Since RLS is not covered in the medical school curriculum, patients who have RLS are commonly misdiagnosed by inexperienced or undertrained providers as having other chronic conditions with similar symptoms, such as Parkinson's disease (PD), attention deficit hyperactivity disorder (ADHD) or sleep deprivation. Some evidence shows that the misdiagnosis and subsequent treatment for the wrong condition leads to worsening patient outcomes and high accumulated costs of care.

For example, a patient who is misdiagnosed with ADHD may take medications that actually worsen RLS symptoms, and subsequently be misdiagnosed with PD. The period of misdiagnosis commonly persists for years, taking a significant toll on sleep and quality of life.

William Padula, PhD

The researchers collaborated on the design of a cost-effectiveness analysis to model scenarios of costly misdiagnoses leading to poor patient outcomes, as opposed to properly treating RLS. They applied their model using information from a comprehensive review of medical literature.

Padula's economic analysis on the costs of RLS is the first of its kind in the United States and will support the Foundation's efforts to expand provider education.

"Understanding the underlying factors – such as lack of provider education – that delay access to treatment and addressing them will ultimately improve patient outcomes," says Karla Dzienkowski, RN, BSN, executive director of the RLS Foundation.

She adds, "Dr. Padula's study underscores the economic impact of RLS and burden of disease for individuals living with RLS. It is our hope that this research provides RLS researchers valuable information to secure future funding from the National Institutes of Health, Department of Defense, and other sources."

The First 25 Years …

1990

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

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 25 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)

1995

First RLS support group formed
Juanita Therrell leads the first meeting of the group "Sleepless in Seattle."

RLS Support Group Network established
Thelma Bradt volunteers to coordinate the program.

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.

1997

Foundation moves to Rochester, Minnesota

Foundation launches research grant program
Over the next two decades, the Foundation will fund nearly $1.6 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 provides RLS diagnosis and treatment recommendations.

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 and Dr. Christopher Earley.

2000

Foundation establishes RLS Brain Bank at Harvard Brain Tissue Resource Center
The Foundation maintains this collection for tissue distribution to RLS researchers.

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.

2005

National patient meeting held in Orlando, Florida

2006

National patient meeting held in San Antonio, Texas

Medical Advisory Board publishes first RLS treatment algorithm

Success Built on Many Milestones

2007

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

2008

Foundation establishes volunteer 'contact' role
"RLS contacts" are experienced support group leaders who provide support by phone and email.

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.

2012

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

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 Johns Hopkins, Houston Methodist, Mayo Clinic, Innsbruck Medical University, Stanford, Emory, Yale, Vanderbilt, Scripps, Neurocenter of Southern Switzerland, and Mass General.

2014

Foundation conducts 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.

RLS word cloud created
A collection of words used to describe RLS, this collage expresses the shared struggles of people with RLS and serves as a powerful awareness tool.

2015

Foundation relocates to Austin, Texas

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

Foundation conducts Year of Augmentation campaign
The Foundation conducts extensive outreach to educate patients and healthcare providers about augmentation. The RLS Foundation, IRLSSG and European RLS Study Group co-publish an article on augmentation prevention and treatment.

2016

Foundation expands research grant program
Funding is increased to $200,000 annually for up to eight pilot studies. A merged Scientific and Medical Advisory Board is established to best leverage combined expertise.

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

Foundation introduces redesigned, mobile-friendly website

TURN *RESTLESS* INTO *RELIEVED*

Are you experiencing symptoms linked to restless legs syndrome (RLS)? Find tools and support to help get your life back.

Symptoms & Diagnosis

For Healthcare Providers

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.

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RLS Foundation Launches Advocacy Initiative on Opioids

In the midst of a nationwide abuse crisis, access to opioids in the US is tightening. Healthcare providers are increasingly hesitant to prescribe opioids, health insurers may not cover them, and pharmacies are creating policies to limit their use.

While these measures may help prevent abuse, they also have the unintended consequence of making it difficult for people with chronic conditions such as RLS to obtain opioids for legitimate medical treatment.

The RLS Foundation's Board of Directors has launched an advocacy initiative to help ensure that RLS patients are not denied access to opioids as a treatment option. The Foundation will develop and implement a campaign to lobby policymakers and educate the RLS community and the public on the urgent need for protections for RLS patients.

"Opioids are an important strategy in the fight against RLS," says Lew Phelps, chair of the Board of Directors. "We know from clinical experience and scientific research that the drugs that are FDA approved to treat RLS don't work for some RLS patients and over time actually make the disease worse for many others. If opioids are taken away as a reaction to concerns about opioid abuse, for many people who have RLS, no effective treatment will be available. We can't let that happen."

The Foundation has engaged a public policy firm as its partner to provide input to federal agencies and organizations that are considering creating rules (the White House, Congress, the US Food and Drug Administration (FDA), and the Centers for Disease Control and Prevention (CDC)), as well as to professional societies and other influential groups.

In addition to lobbying at the federal level, the Foundation will work to build a grassroots network of people who can help identify issues at the state and local levels and advocate to decision-makers on behalf of the RLS community.

This initiative has been funded by designated gifts from generous members of the Board of Directors and concerned Foundation members in support of continued access to opioids as a critical RLS treatment option.

Through the initiative, the Foundation also will reach out to the National Institutes of Health (NIH) and Department of Defense to promote funding for RLS research.

"We are working to reestablish our strong voice in Washington," says Phelps. "We anticipate benefits from working with our new public affairs partner that will extend far beyond the immediate 'opioid crisis' issue."

As a next step, over the next several months the Foundation will develop a position statement and strategy for advocacy on opioids. Watch for updates in upcoming issues of *NightWalkers* and *eFriends*, and on the Foundation's website at www.rls.org. To subscribe to *eFriends*, the Foundation's monthly e-newsletter, visit www.rls.org/subscribe.

Why are opioids needed for RLS?

The FDA has approved drugs in two classes of medications for treating RLS, and both types can have major shortcomings. *Dopamine-type drugs* (pramipexole, ropinirole and rotigotine patch) will frequently cause augmentation, a devastating side effect characterized by worsening of RLS symptoms. *Alpha-2-delta ligand medications* (gabapentin, pregabalin and gabapentin enacarbil) can also have significant side effects that limit their use, and in some clinical studies only about 60 percent of RLS patients appear to respond to the medication. When these medications become ineffective, what choices of treatment remain?

The first known description of RLS in the medical literature appears in a treatise by Dr. Thomas Willis published in 1672. In that treatise, the first potential treatment for RLS was also described: opioids. Since then, clinical trials, longitudinal case studies and substantial clinical experience among experts in the field have supported Dr. Willis' observation: Opioids are a very effective treatment for RLS. Some longitudinal studies covering three to 10 years of patient care have shown long-term, sustained benefits when compared to dopamine-type drugs. These longitudinal studies have not shown a significant problem with tolerance or addiction. Based on all data and experience, opioids are considered the next best line of treatment for those in whom the other two classes of medications appear no longer effective.

The RLS Foundation recently awarded a research grant to John Winkelman, MD, PhD, of Harvard Medical School for a study on the efficacy and tolerability of opioids for long-term treatment of RLS. This study was highlighted in the summer 2017 issue of *NightWalkers*.

If you are looking for a healthcare provider, visit **www.rls.org** or contact the Foundation at **info@rls.org** for information about RLS Quality Care Centers and other providers knowledgeable about RLS.

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[1] Garcia-Borreguero D, Patrick J, DuBrava S, Becker PM, Lankford A, Chen C, Miceli J, Knapp L, Allen RP. 2014. "Pregabalin versus pramipexole: effects on sleep disturbance in restless legs syndrome." *Sleep* 37(4): 635–43.

Webinars
2016 – 2017

Iron, Hypoxia & RLS

James Connor, PhD, and Stephanie Patton, PhD
October 14, 2016

RLS Research Review: Then & Now

David Rye, MD, PhD
November 9, 2016

The Prevention & Treatment of Augmentation

Mark Buchfuhrer, MD, FRCP(C), FCCP, FAASM
January 17, 2017

Neurostimulation & RLS

John Winkelman, MD, PhD
February 10, 2017

Coping with RLS

Philip Becker, MD
March 9, 2017

Basics of Advocacy

Linda Secretan
April 19, 2017

What is RLS?

William Ondo, MD
May 17, 2017

Technology's Impact on Healthy Sleep

Jeffrey Durmer, MD, PhD
June 15, 2017

RLS & the Dopaminergic System

Stefan Clemens, PhD
July 13, 2017

Animal Models in RLS Research

Byron Jones, PhD
August 15, 2017

Cardiovascular Health & RLS

Lynn Marie Trotti, MD, MSc
September 9, 2017

RLS Foundation Levels of Giving

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Thank you for your continued commitment and financial support of the RLS Foundation during our 2017 fiscal year. Again, this year, individuals provided the majority of support for Foundation programs and activities, representing seventy-nine percent of total donations.

Our popular free monthly webinar series, support group meetings held all across the US, the large library of educational materials reviewed and updated by members of our Scientific and Medical Advisory Board, serve to educate the general public and medical community about RLS. Our website and social media channels including Facebook, Twitter, Instagram, YouTube, LinkedIn and +Google continue to expand our reach. Our much-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 are reaching a larger and younger audience, fulfilling our mission to bring greater education and awareness about RLS.

Furthermore, this year we funded two grants through the RLS Foundation Research Grant Program. One grant is a multi-center longitudinal pilot observational study of the efficacy and tolerability of long-term treatment of RLS using opioids, and the second to study a new medicine for the treatment of RLS in patients with augmentation. Together, these two grants will hopefully help the Foundation achieve its goal of finding better treatments, and ultimately a cure for RLS.

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 was my pleasure to join the RLS Foundation's Board of Directors in the fall of 2016 and serve as Treasurer during fiscal year 2017. I hope that my experience as a scientist involved in new drug discovery and prior responsibility as CEO of a publicly-traded company have been be an asset to the Foundation. I look forward to the Foundation's continued success in 2018!

Sincerely,

Ronald W. Barrett, PhD

2017 Highlights | Financials

Revenues and Support

Contributions	$625,489
Membership Dues	$126,178
Investment Earnings	$39,390
Other	$1,707
Total revenues and support	**$792,764**

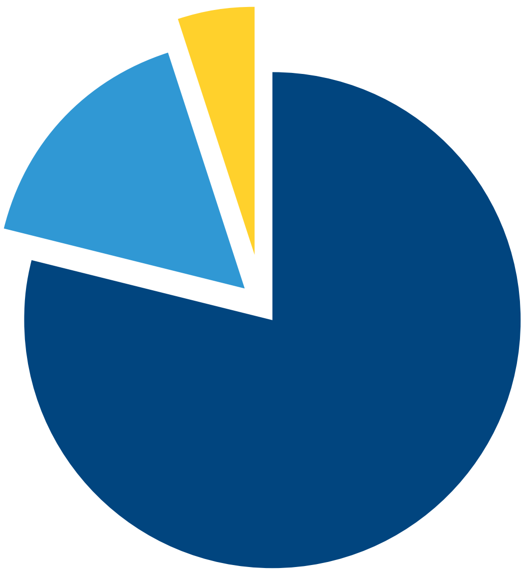
Expenses

Program Services	
Education	$322,987
Membership	$174,970
Research	$190,740
Support Groups	$30,841
Total program services	$719,538
Fundraising	$115,761
Management and general	$72,149
Total expenses	**$907,448**

Statements of Activities For the Fiscal Year Ended September 30, 2017

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

2017 Where Our Funds Come From



●	Contributions	79%
●	Membership Dues	16%
●	Investment Earnings	5%
●	Other	<.5%

2017 Where We Use Our Funds

●	Education and awareness	36%
●	Research	21%
●	Membership	19%
●	Fundraising	13%
●	General and administrative	8%
●	Support	3%

RLS
RESTLESS LEGS
SYNDROME
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RESTLESS LEGS SYNDROME FOUNDATION

25 YEARS OF PROGRESS

1992-2017