

# Advocating for the RLS Community

**2018** ANNUAL REPORT

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.

## 2017 - 2018

### Board of Directors

**Lewis Phelps, *Chair***  
*Pasadena, CA*

**Ron Barrett, *Treasurer***  
*Saratoga, CA*

**Linda Secretan, *Secretary***  
*Eagle, ID*

**Jacquelyn Bainbridge**  
*Englewood, CO*

**Sandra Katanick**  
*Hollywood, FL*

**Steve McCann**  
*Atlantic Beach, FL*

**Shalini Paruthi**  
*St. Louis, MO*

**Starla Phelps**  
*Alexandria, VA*

**Carla Rahn Phillips**  
*Wimberley, TX*

**Paul Rochester**  
*San Francisco, CA*

**Robert (Bob) Waterman, Jr., *Chair Emeritus***  
*Hillsborough, CA*

## 2017 - 2018

### RLS Foundation Scientific and Medical Advisory Board

**Christopher J. Earley, MB, BCh, PhD, FRCPI**  
***Chair***  
*Baltimore, MD*

**Michael Aschner, PhD**  
*Bronx, NY*

**Philip Becker, MD**  
*Dallas, TX*

**Marie-Françoise Chesselet, MD, PhD**  
*Los Angeles, CA*

**Stefan Clemens, PhD, HDR**  
*Greenville, NC*

**James R. Connor, PhD**  
*Hershey, PA*

**Jeffery S. Durmer, MD, PhD**  
*Johns Creek, GA*

**Sergi Ferré, MD, PhD**  
*Baltimore, MD*

**Jennifer G. Hensley, EdD, CNM, WHNP**  
*Nashville, TN*

**Byron C. Jones, PhD**  
*Memphis, TN*

**Brian B. Koo, MD**  
*West Haven, CT*

**Mauro Manconi, MD, PhD**  
*Lugano, Switzerland*

**Mark P. Mattson, PhD**  
*Baltimore, MD*

**Emmanuel Mignot, MD, PhD**  
*Palo Alto, CA*

**William Ondo, MD**  
*Houston, TX*

**Michael H. Silber, MB, ChB**  
*Rochester, MN*

**Lynn Marie Trotti, MD, MSc**  
*Atlanta, GA*

**George Uhl, MD, PhD**  
*Albuquerque, NM*

**Arthur S. Walters, MD**  
*Nashville, TN*

**John W. Winkelman, MD, PhD**  
*Boston, MA*

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

**November 29, 2017**  
Telephonic Meeting

**February 8, 2018**  
Telephonic Meeting

**August 7, 2018**  
Telephonic Meeting

**September 27 - 28, 2018**  
Annual Meeting

## 2018 Highlights | From the Chairman of the Board

Every year in the quarter-century history of the Restless Legs Syndrome Foundation has been significant, but the last year more so than others.

During 2018, the Foundation took strong strides in a new direction by retaining a public affairs firm in Washington, DC, to represent the interests of RLS patients. This was needed because of the political discussion surrounding the opioid epidemic in the US. Potential legislation creates a serious threat of making it difficult or impossible for some RLS patients to obtain the medications they need. The Foundation's superb staff, our Board of Directors, our Science and Medical Advisory Board, and others have been working intensively to explain to policy-makers that individuals with severe RLS need long-term, unhindered access to low total daily dose opioids, when all other medication classes available to treat their debilitating symptoms have been exhausted. The results of our efforts since this initiative began are positive and heartening, but the issue is far from resolution.



**Lewis Phelps**  
*Chair, RLS Foundation  
Board of Directors*

The Foundation's long and active support of research plays several important roles in the current opioid dialogue. I recall the euphoria in May 2005 when the FDA first approved Ropinirole (Requip®). Our excitement was short-lived because researchers, including Chris Earley (now chair of our Science and Medical Advisory Board (SMAB)) and Richard Allen were already warning the neurology and sleep community about the dangers of augmentation. Thanks to work by the dedicated researchers and clinicians who serve on the SMAB, we now know that augmentation is an almost inevitable consequence of RLS treatment with dopaminergic drugs. Until someone finds a cure, some of us will need opioids.

Ever since British physician Sir Thomas Willis, a founding member of the Royal Society, the world's first national scientific organization, first described restless legs syndrome symptoms in 1672, doctors have known that it could be treated effectively with opioids. However, clinicians have often been hesitant to prescribe opioids for RLS because of concerns about addiction. In the last decade, as augmentation problems have multiplied, we have gained more clinical experience in the use of opioids. In general, (a) low total daily doses of opioids are sufficient to control RLS symptoms and without concerns of tolerance or dose escalation, (b) the risk of addiction for RLS patients is relatively low, and (c) treating RLS with opioids doesn't turn people into addicts.

The Foundation is currently funding a large multi-year study to develop deeper knowledge, with stronger statistical foundations, that will enhance our understanding of the efficacy and safety of opioids to treat RLS. Our stalwart SMAB published a sentinel article, "The Appropriate Use of Opioids in the Treatment of Refractory Restless Legs Syndrome," in the *Mayo Clinic Proceedings* – a highly-regarded peer-reviewed medical journal. These and other efforts will be essential in our ongoing efforts to preserve access to opioids for RLS patients.

All these initiatives cost a lot of money. Although the Foundation is vastly stronger financially than it was a few years ago, we need donors to step forward today to a greater degree than ever before. Please consider increasing your donation to the RLS Foundation to support this essential work and the ongoing service to the RLS community that our marvelous staff and volunteers provide.

A handwritten signature in black ink, appearing to read 'Lew Phelps', with a stylized flourish at the end.

Lew Phelps  
Chairman of the Board



# New Research Identifies Adenosine Role in RLS

If you have RLS, you know the relentless leg discomfort that can drive you out of bed at night.

Chances are, you also have two other symptoms: periodic limb movements in sleep (PLMS) – 80 percent of those suffering from RLS display this symptom; and constant wakefulness or “hyperarousal” – people with RLS typically are not sleepy during the day, even if they don’t sleep well at night.

Now, scientists have gained new insight into what causes these symptoms – and new avenues to investigate for treatment.

In 2014 and 2015, Sergi Ferré, MD, PhD, of the National Institute on Drug Abuse (Intramural Research Program) received grants from the RLS Foundation to more closely examine how dopamine and glutamate work in the brain.

Dr. Ferré has found that low levels of receptors of adenosine, a chemical in the brain that regulates neurochemicals, lead to abnormally high levels of glutamate and dopamine. This may be the underlying cause of both PLMS and hyperarousal in RLS. The researchers have also pinpointed a subtype of receptor in the brain – the dopamine D4 receptor – as a new and better target for dopamine drug development.

These findings are the culmination of a four-year study funded by the RLS Foundation, and were recently published in *Annals of Neurology*<sup>1</sup> and *Frontiers in Neuroscience*.<sup>2</sup>

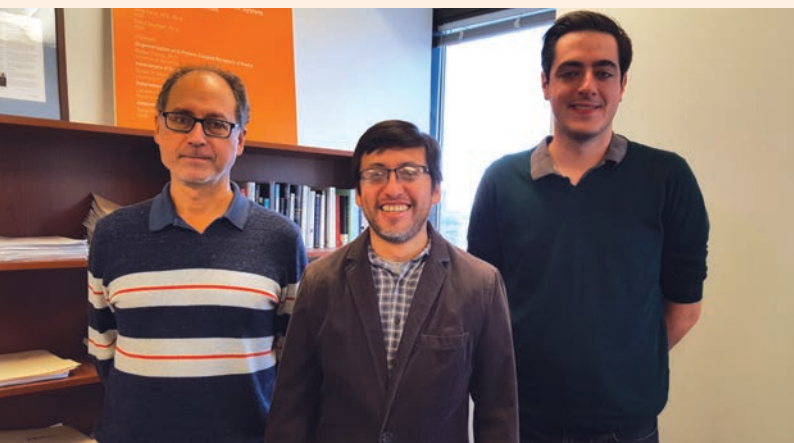
brain chemical that sends messages) associated with muscle activity and movement. Dopamine medications for RLS act by decreasing the amount of dopamine produced by neurons (brain cells). This has the effect of reducing PLMS. However, use of dopamine medications is limited by the serious side effect of augmentation.

In 2013, scientists at Johns Hopkins identified the involvement of another neurotransmitter – glutamate, which is associated with arousal (wakefulness). Researchers found elevated levels of glutamate in the brains of people who had RLS. The extra glutamate is thought to contribute to PLMS – and to hyperarousal. Many RLS patients take alpha-2-delta medications to control their symptoms by reducing glutamate levels.

In the current study, Dr. Ferré’s laboratory used its first RLS Foundation grant to create an animal model that will help develop and test new RLS treatments. A rodent was fed an iron-deficient diet to mirror the brain iron deficiency found in people with RLS.

The researchers invented a method that combines optogenetics and microdialysis. They attached a light-activated protein to specific neurons between the cortex and striatum in the brain of the rodent. When they shone a light on the neurons, this triggered the release of glutamate – which was greater in the animals with iron-deficiency than in animals fed a regular diet.

“The first finding was to show that in the rodent with brain iron deficiency, a well-accepted pathogenetic model of RLS, we were able to show that brain iron deficiency produces increased sensitivity of the cortico-striatal terminals to release glutamate,” says Dr. Ferré. Recently, Dr. Ferré’s team tested this animal model with several RLS drugs: the dopamine agonists pramipexole and ropinirole, and the alpha-2-delta drug gabapentin. The researchers validated that these medications work by counteracting the release of glutamate.

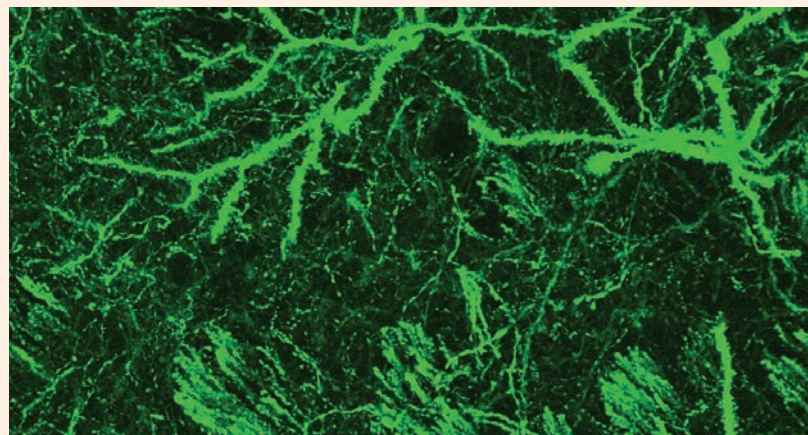


*Pictured, left to right: Research team members Sergi Ferré, MD, PhD; César Quiroz, PhD; and Gabriel Yepes, BS*

### Building on decades of RLS research

Dr. Ferré’s research into RLS builds on decades of science by others on the roles of dopamine and glutamate in the brain for those who suffer from RLS.

It has long been believed that RLS is related to a malfunction in the way the brain uses dopamine. Dopamine is a neurotransmitter (a



*This photomicrograph of the RLS animal model shows neuronal terminals in the brain that have been genetically altered to emit a green fluorescent protein when glutamate is released.*

In the process, the team also pinpointed a specific type of protein, called the dopamine D4 receptor, that controls the transmission of glutamate in these cells. This protein may be an effective target for future dopamine medications. “Thanks to this mechanism, we were able to find which subtype of dopamine receptor needs to be targeted,” says Dr. Ferré. “I believe that augmentation is acting on other subtypes. That opens up new hope for therapeutic approaches that probably will have less secondary problems like augmentation and will be more successful.”

### Uncovering a new player: Adenosine

If RLS medications work by reversing unusually high dopamine and glutamate levels, how could these high levels be prevented in the first place?

That is the scientific question – and Dr. Ferré feels he may have found an answer in adenosine. Adenosine is a neurotransmitter that regulates the levels of other chemicals; it acts as a brake for the dopamine and glutamate systems in the brain.

Using the animal model, Dr. Ferré’s team found that when there are fewer adenosine receptors (specifically of the A1 subtype), there is increased dopamine and glutamate. This links adenosine to PLMS symptoms.

But there’s more. “Adenosine by the way, regulates the sleepiness associated with prolonged wakefulness,” explains Dr. Ferré. In the cortex, thalamus and other areas of the brain, adenosine modulates homeostatic sleep. Low levels of adenosine receptors could explain the hyperarousal of RLS. “The beauty of the adenosine story is that it connects the hyperarousal symptoms with movement [PLMS],” he says.

“What is really important about our story is that maybe we have found a mechanism – the adenosine system – that links brain iron deficiency to hyperglutamatergic and hyperdopaminergic states.”

This insight can be used to potentially develop RLS treatments that increase the concentration of adenosine to prevent both PLMS and hyperarousal. One such drug is already available clinically: dipyridamole, an antiplatelet drug that protects against stroke and heart attack.

Dr. Ferré’s team validated dipyridamole using the animal model. He also collaborated with Diego García-Borreguero, MD, PhD, director of the Sleep Research Institute in Madrid, to trial the drug in a small group of RLS patients – with promising results. As a next step, Dr. García-Borreguero will coordinate a larger clinical trial in Europe.

Dr. Ferré is also working with several research laboratories to pursue drugs similar to dipyridamole that are more potent and can more easily cross the blood-brain barrier.

“The story now reaches the clinical level,” says Dr. Ferré. “Anything else that could modify the release of glutamate by those terminals could theoretically be good therapeutically for RLS. That’s the case with dipyridamole. We just got results that validate once more our animal model and, in fact, dipyridamole decreases glutamate release by cortico-striatal neuronal terminals.”

### Thanks to the RLS Foundation

Dr. Ferré credits the RLS Foundation with making the last four years of progress in his laboratory possible. “The RLS Foundation research grant has made what we’ve done so far possible. Above all, it has made it possible for a scientist on our team, Gabriel Yepes, to devote his time entirely to this project. And it has been a complete success.”

He also points to the Foundation’s role in cultivating a community of scientists dedicated to solving the mysteries of RLS who support each other’s work. Forty-four researchers have received grants from the RLS Foundation since 1997, and nine have served on the Foundation’s advisory board. Their work spans several continents and many disciplines. “Thanks to the RLS Foundation, I can connect to different specialties quickly and get their input right away,” says Dr. Ferré.

“We are much closer to understanding the mechanisms of RLS. If you understand the mechanisms, that directs your research,” he adds. “We are very close to getting new approaches – not just new molecules that are acting the same way. We are discovering new mechanisms, and that should open a line to new approaches. To hope.”

<sup>1</sup>Yepes G, Guitart X, Rea W, Newman AH, Allen RP, Earley CJ, Quiroz C, Ferré S. Dec 2017. “Targeting hypersensitive corticostriatal terminals in restless legs syndrome.” *Ann Neurol* 82(6): 951–60. doi:10.1002/ana.25104.

<sup>2</sup>Ferré S, Quiroz C, Guitart X, Rea W, Seyedian A, Moreno E, Casadó-Anguera V, Díaz-Ríos M, Casadó V, Clemens S, Allen RP, Earley CJ, García-Borreguero D. 2018. “Pivotal Role of Adenosine Neurotransmission in Restless Legs Syndrome.” *Front Neurosci* 11: 722. doi:10.3389/fnins.2017.00722.

# Researchers Create Model for Anemia-induced RLS

Scientists are one step closer to developing a working animal model of RLS. In a study funded by the RLS Foundation, Yuan-Yang Lai, PhD, and her team at the University of California – Los Angeles (UCLA), researchers manipulated the diet of rats to make them iron deficient, and the animals demonstrated symptoms of RLS. These symptoms improved when the rats were given the drug pramipexole, and when they received more iron in their diets – two therapies known to improve RLS in humans.

“Dopamine drugs are one of two first-line treatments for RLS; however, they can lead to adverse effects, such as augmentation, after use,” says Dr. Lai. “Using our animal model, we should be able to test alternative drugs that are developed for the potential treatment of RLS that is caused by iron-deficiency anemia.”

The model may also enable researchers to identify the specific brain regions, circuits and chemicals involved in RLS and periodic limb movements disorder (PLMD). The study, “Motor Hyperactivity of the Iron-Deficient Rat – An Animal Model of Restless Legs Syndrome,” was published August 2017 in the journal *Movement Disorders*.

Studies have shown that RLS is common in people with iron-deficiency anemia, affecting up to 32 percent of people with this condition. The researchers fed rats an iron deficient diet to create anemia, then recorded their motor activity, or movement, through implanted electrodes – before and after treatment with pramipexole. They also monitored the animals after feeding them a normal diet to restore their iron stores, representing the process of iron therapy in humans.

The researchers found that the iron-deficient animals had symptoms similar to those seen in RLS patients, including motor hyperactivity in quiet wake and in sleep, frequent awakening from sleep, and daytime sleepiness. These symptoms were relieved when the rats received pramipexole, as well as when they received a normal diet containing iron.

These findings build on those of a previous RLS Foundation-funded study in which Dr. Lai found that iron-deficient rats given thioperamide, an H3 receptor antagonist, showed reduced period limb movements (PLMs). As a next step, Dr. Lai’s team is currently using the animal model to study why pramipexole treatment causes augmentation, and which areas and chemicals of the brain are involved in RLS.



*Yuan-Yang Lai, PhD*



## 2018 Highlights | Improve Treatments

# RLS Advocacy in Washington

## *Making Our Collective Voice Heard*

In February 2018, members of the RLS Foundation staff and leadership team traveled to Washington to advocate on behalf of the RLS community.

The delegation met with groups at the National Institutes of Health (NIH), the US Food and Drug Administration (FDA) and Congress. The goals were two-fold: to educate policy makers about the need to ensure that RLS patients continue to have access to opioid therapies; and to promote funding for RLS research.

“We are focused on making our collective voice heard in Washington,” says Karla Dzienkowski, RLS Foundation executive director. “Our meetings were a critical step in growing opportunities for RLS research – and toward making sure that elected officials are informed about the needs of RLS patients in relation to any upcoming legislation or policy on opioids.”

For the millions of people in the US who have chronic, unrelenting, nightly RLS symptoms, opioid medications may offer the only hope for long-term relief when all other treatments have failed.

Dr. Christopher Earley, who is chair of the RLS Foundation’s Scientific and Medical Advisory Board, was part of the delegation. “Our role . . . is to advocate for an open-minded view on the value of opiates in treating RLS,” Dr. Earley says. “It is an important treatment option that needs to be continued and maintained, such that patients with severe RLS, if they need to use these vital medications, are not restricted in any way.”

The meetings in Washington were coordinated by the Health and Medicine Counsel of Washington (HMCW), a government relations organization and RLS Foundation partner that is helping to guide the Foundation’s advocacy initiative.

Led by Dzienkowski, the Foundation’s team included Ronald Barrett, treasurer of the Board of Directors; Dr. Earley; Dr. Michael Silber, head of the Opiate Committee on the Scientific and Medical Advisory Board; Kris Schanilec, RLS Foundation communications consultant; Peter Herzog, HMCW legislative associate; and Dale Dirks, HMCW president.

### Day 1: Meetings with NIH and FDA

On Feb. 22, the RLS Foundation met with leaders of two NIH institutes: the National Heart, Lung, and Blood Institute (NHLBI); and the National Institute of Neurological Disorders and Stroke (NINDS).

The Foundation shared the challenges of RLS patients who face limited treatment options, and the specific areas where research is needed to discover and test new therapies. The team also stressed the

need for both clinical trials of opioid medications and long-term studies on their safety and effectiveness for treating severe RLS.



*RLS Foundation advocacy team in Washington, DC. Pictured, left to right: Peter Herzog, (HMCW); Kris Schanilec, Ronald Barrett, Karla Dzienkowski, Dale Dirks (HMCW), Dr. Michael Silber, Dr. Christopher Earley*

The NIH staff were supportive of the Foundation’s goals and offered many suggestions to explore in follow-up. “The fact that you’ve taken the time to network with us is a powerful statement,” said Dr. Nina Schor, who is deputy director of the NINDS. “The RLS Foundation has provided vital input to NINDS in our efforts to support research that will decrease the burden of neurological illness.”

The RLS Foundation also met with staff at the FDA Center for Drug Evaluation and Research to discuss the importance of low total daily dose opioids as an RLS treatment option.

The Foundation shared stories of RLS patients who have been taking opioid medications for decades and now are having problems accessing their prescriptions. The team highlighted opioid treatment guidelines for patients with RLS that were recently published by members of the Foundation’s Scientific and Medical Advisory Board in *Mayo Clinic Proceedings*.

Ronald Barrett observed, “The FDA members that we met with recognized the possibility of unintended consequences of heavy-handed restrictions on legitimate opioid use and the potential impact on RLS sufferers. Hopefully there will be positive outcomes from our meeting.”

## Day 2: Championing RLS on the Hill

On Feb. 23, the RLS Foundation team met with Congressional staff in the offices of 16 US senators and representatives. The group shared information about RLS, its devastating effects on the lives of millions of Americans, and the limitations of current treatment options. The team discussed issues with access to opioid medications and delivered nearly 100 letters written by concerned members of the RLS community.

The Foundation team visited the offices of Senator Joni Ernst (R-IA), Senator John Cornyn (R-TX), Senator Tina Smith (D-MN), Senator Ted Cruz (R-TX), Representative Rod Blum (R-IA), Representative Tim Walz (D-MN), Representative Roger Williams (R-TX), Representative Michael McCaul (R-TX), Senator Dianne Feinstein (D-CA), Senator Kamala Harris (D-CA), Senator Chris Van Hollen (D-MD), Senator Ben Cardin (D-MD), Representative Judy Chu (D-CA), Representative John Sarbanes (D-MD) and Representative Anna Eshoo (D-CA).

The RLS Foundation asked each representative to:

- Support at least \$36 billion for NIH funding in fiscal year 2018 so that funds will be available for RLS research. This funding was subsequently passed on March 23. This was the second largest increase in funding for medical research in NIH history, bringing total funding up to \$37.1 billion.
- Include “sleep disorders” as a condition eligible for grants from the Department of Defense, so that RLS research can continue to be funded through this channel.
- Include a safe harbor for RLS in opioid-related legislation, regulations and policies, so that people with severe RLS can continue to access these medications.

These talks were a first step in building relationships with members of Congress, and an especially strong connection was sparked with one staffer who has a family member with RLS. The Foundation will continue to contact these representatives in the coming months to update them on the needs of the RLS community.



# New Guidelines Issued on Iron Treatment for RLS

Iron deficiency is a known contributing factor to RLS, and many find some symptom relief from supplemental iron in pill form or by intravenous (IV) infusions.

Healthcare providers have new guidance for treating RLS patients whose iron stores are low. A paper published in the January 2018 issue of *Sleep Medicine* provides information on how to evaluate RLS patients for low iron, when to offer iron therapy as a treatment, and which type of treatment is most likely to be helpful for individual patients, including children.

“Iron treatment, despite its importance, is not well understood,” says co-author Richard P. Allen, PhD, a researcher at the Johns Hopkins Center for Restless Legs Syndrome. “Iron treatment is complicated by current iron status, and the various oral and IV iron treatments available. Understanding the benefits of IV iron in particular for some patients is relatively new, and this paper provides reasonable guidance for its use that is not available elsewhere.”

Past research has shown that iron deficiency in the brain is an underlying abnormality of RLS. “RLS treatments are basically palliative – they reduce symptoms but do not reduce any basic biological abnormality,” Allen says. “Iron treatment differs. It serves to reduce, for some, a biological abnormality in RLS of reduced brain iron.”

The new report was developed on behalf of the International Restless Legs Syndrome Study Group (IRLSSG). In recent years, a number of research studies on iron for RLS and periodic limb movement disorder (PLMD) have been published. To evaluate these findings, the IRLSSG formed a task force of 12 medical experts in RLS, sleep medicine, neuroscience and other fields, to evaluate published research on the topic and develop a set of recommendations for clinical practice.

This group searched the medical literature and examined 299 related articles. The group’s analysis also included clinical recommendations based on expert clinical opinion. The resulting report includes evidence- and consensus-based guidelines that confirm iron should be a first-line treatment option for RLS. The report also recommends treating people with RLS and iron deficiency with oral iron first, unless there is a medical reason why oral iron cannot be used. The article presents updated treatment algorithms for iron use to treat RLS in adults, and both RLS and PLMD in children.

Importantly, the article delves into the differences among five different IV iron formulations available. “Not all IV iron formulations are alike, and some appear to work better than others,” says Dr. Allen. In addition, specific guidance about when and how to

use oral iron is presented, including the recommendation that taking oral supplements once a day is preferable to taking them twice a day.

The article, “Evidence-based and consensus clinical practice guidelines for the iron treatment of restless legs syndrome/Willis-Ekbom disease in adults and children: an IRLSSG task force report,” is available online at [www.sleep-journal.com](http://www.sleep-journal.com). For additional analysis, see In the News on page 16.

This and other clinical publications are the outcome of dedicated work by members of the RLS medical and scientific community to help healthcare providers worldwide offer the best possible medical treatment to RLS patients.

### Iron and RLS: What you need to know

Every individual with RLS should have their blood iron levels (serum ferritin) checked, as keeping ferritin levels mid-range – at 75 micrograms per liter and above – correlates to RLS symptom improvement.

If your iron levels are low, your doctor may recommend ways to replenish your iron stores, including:

- **Increased consumption of iron-rich foods**, especially meat, fish and liver. Leafy green vegetables also contain iron but may not be broken down adequately by your digestive tract to deliver significant amounts of iron to your body.
- **Oral iron supplements**. For best iron absorption, iron pills should be taken at night on an empty stomach with vitamin C. They should not be taken with food, milk, antacids, calcium supplements or medications used to treat acid reflux and thyroid.
- **IV iron therapy**. Your RLS doctor should be aware of the potential for IV iron treatment, and if you are an appropriate candidate, can refer you to a hematology center or RLS program that provides iron treatments for RLS.

Iron supplements should only be taken under the supervision and care of a physician to ensure proper monitoring and help prevent iron overload.

### Learn more

To learn more about iron and RLS, please view the webcast “Iron and RLS” or see the handout *Understanding Iron and Restless Legs Syndrome*, available in the Member Portal at [www.rls.org](http://www.rls.org). You can also order a print copy using the publication order form on page 23 or by sending an email to [info@rls.org](mailto:info@rls.org).

# Foundation Achieves Top Ratings from Charity Navigator, GuideStar

In 2018, the RLS Foundation has been awarded top honors by two independent reporting agencies: the highest 4-star rating from Charity Navigator and the Platinum Seal of Transparency from GuideStar.

“These awards demonstrate our good governance and financial accountability, and assure our supporters that we are making wise use of their investment,” says RLS Foundation Executive Director Karla Dzienkowski. “The majority of our funding is spent in programming that directly benefits the RLS community and supports our goals to raise awareness, improve RLS treatments, and fund research toward a cure.”

Using objective analysis, Charity Navigator awards only the most fiscally responsible organizations a 4-star rating. Ratings show donors how efficiently Charity Navigator expects a charity will use donor contributions today, how well the charity has sustained its programs and services over time, and the charity’s level of commitment to accountability and transparency.

GuideStar collects, organizes and presents key information about nonprofits as a public service. GuideStar does not evaluate charities, but provides information that advances transparency, enables donors to make better decisions, and encourages charitable giving. The Platinum Seal of Transparency is earned by an organization reporting metrics that show the progress the nonprofit is making toward its mission.

Visit [charitynavigator.org](http://charitynavigator.org) and [guidestar.org](http://guidestar.org) and search for Restless Legs Syndrome Foundation to learn more.



# Advancing RLS Awareness in Washington, DC

The RLS Foundation visited Washington, DC, in June for a second round of meetings to advocate for research funding and for continued patient access to opioid medications to treat severe RLS.

Led by Executive Director Karla Dzienkowski, the Foundation team met with members of Congress who are on key legislative committees that have jurisdiction over health policy, and with two groups at the National Institutes of Health (NIH).

“Our meetings at Congress and the NIH were very important to moving our advocacy program forward,” Dzienkowski says. “We had the opportunity to meet with Congressional staff who are directly involved in opioid-related legislation. We are also excited to be deepening our relationships at the NIH and taking meaningful steps to advance RLS research.”

The Foundation team met with staff in the offices of Sen. Sheldon Whitehouse, D (RI); Sen. Bob Casey, D (PA); Sen. Elizabeth Warren, D (MA); Rep. Markwayne Mullin, R (OK); Rep. Conor Lamb, D (PA); Rep. Katherine Clark, D (MA); and Rep. Michael Burgess, R (TX).

The discussions centered on the need for a safe harbor for RLS in any upcoming legislation or policy that might restrict access to opioid medications. “Staffers shared that over 50 opioid bills are under consideration,” says Dzienkowski. For the millions of Americans who have chronic, unrelenting RLS, opioid medications taken in low total daily doses can be very effective for controlling symptoms.

The Foundation team also asked legislators to support two research priorities: \$2 billion in increased funding for the NIH in fiscal year 2019; and continued inclusion of “sleep disorders” as a category eligible for grants by the Department of Defense.

At the NIH, John Winkelman, MD, PhD, gave a presentation on behalf of the Foundation to the Sleep Disorders Research Advisory Board (SDRAB) of the National Heart, Lung, and Blood Institute. Dr. Winkelman is director of the RLS Quality Care Center at Massachusetts General Hospital and a member of the Foundation’s Scientific and Medical Advisory Board.

The SDRAB is a federal advisory committee that sets the strategy for sleep disorders research at the NIH, and the meeting was an opportunity to highlight the unmet needs of RLS patients. RLS Foundation Board member Linda Secretan is one of two patient advocates on the SDRAB.

In his presentation, Dr. Winkelman discussed limitations of RLS treatments and the importance of research, including his current study to evaluate the long-term use of opioids to treat RLS.

“We had a very positive discussion,” Dr. Winkelman says. “It was



*Pictured, left to right: Dr. John Winkelman, Karla Dzienkowski, Kris Schanilec, Peter Herzog, Dale Dirks*

options, particularly as not everyone at the table was fully aware that many people with RLS continue to suffer for a variety of reasons, such as augmentation. It was equally important to raise awareness about the effectiveness of very low total daily doses of opioid medications as a therapy for severe RLS.”

The Foundation also visited the National Institute on Drug Abuse and met with members of the Division of Neuroscience and Behavior, which supports research on drug use and addiction. Dr. Winkelman led a lively discussion on the neuroscience of RLS and how new drug therapies might be developed to treat the disease.

“We’re always looking for new ways to intervene to prevent or treat RLS,” Dr. Winkelman says. “We discussed what we already know about what causes RLS in the brain, and the various ways we might learn more about the neurological pathways involved. We came away with new ideas to explore for research.”

The meetings were coordinated by the Health and Medicine Counsel of Washington (HMCW), a government relations organization with nonprofit and healthcare industry expertise that is partnering with the RLS Foundation to guide its advocacy efforts. In addition to Dzienkowski and Dr. Winkelman, the delegation included Kris Schanilec, RLS Foundation communications; and Dane Christiansen, Dale Dirks and Peter Herzog of HMCW.



# 2018 Highlights | Increase Awareness

## How You Can Take Action

The RLS Foundation is working hard to advocate on behalf of the RLS community. The Foundation needs you, an RLS patient or family member, to amplify these efforts by meeting with your legislators. You can meet with your members of Congress at offices in your home state or in Washington. Elected officials want to hear directly from their constituents, and sharing your personal experiences is the best way to educate them about the needs of RLS patients.

The Foundation has resources to help you get started. Contact Peter Herzog at [herzog@hmcw.org](mailto:herzog@hmcw.org) or visit [www.rls.org](http://www.rls.org) to learn more.

## How You Can Support Our Advocacy Efforts

The RLS Foundation appreciates the continued support of members to make this initiative possible. Your donations are crucial to keep advocacy efforts moving forward as legislation that can affect the RLS community is under consideration. Please consider making a gift in support of our advocacy outreach on behalf of RLS patients.

## RLS Advocacy: Our Progress

Since October 2017, the RLS Foundation and its partners at HMCW have:

- Delivered letters to members of Congress from 200+ individuals who responded to a request for personal stories about opioid medications and RLS.
- Attended Congressional meetings and hand-delivered position letters to committees that are crafting legislation related to opioid medications and/or biomedical research funding. These efforts helped support passage of the FY2018 appropriations bill, securing a \$3 billion increase in funding to the NIH.
- Delivered 40 letters to members of the Senate Defense Appropriations Subcommittee from RLS Foundation members who responded to an Action Alert to support inclusion of “sleep disorders” on the Department of Defense Peer Reviewed Medical Research Program in FY2019.
- Met with 23 Congressional offices, three NIH institutes, the NIH Sleep Disorders Research Advisory Board, and the US Food and Drug Administration (FDA).
- Coordinated or supported meetings by the RLS Foundation team and Foundation members with US senators and representatives of 13 states.



# Over 150 Attend RLS Patient Symposium

Everyone's RLS is different, there are many ways to relieve symptoms, and medical help is available for those who need it.

These themes and more were on the program at the RLS Patient Symposium on Sept. 29–30, 2018. More than 150 RLS patients, spouses, partners, family members and medical experts gathered in La Jolla, California, for two days of learning about a wide range of topics in RLS treatment and research.

Attendees came from 22 US states and Canada to listen and learn from presentations by top RLS clinicians and researchers. “There was a tremendous exchange of information, and also a surge of connectivity. People who attended were able to meet others like them who live with RLS,” says Karla Dzienkowski, executive director of the RLS Foundation. “There is a great need for knowledge regarding RLS diagnosis, treatment and coping strategies. Attendees came away better informed about the spectrum of treatment options available, and learned practical ways to best cope with the disease and not let RLS stand in the way of doing things that they enjoy.”

The symposium included question-and-answer sessions with the speakers, and a “Dine with the Experts” event. Throughout the symposium, attendees used an app on their tablets or smartphones to ask questions, participate in polls, discuss topics, share photos and connect with each other.

### RLS diagnosis and treatment: Every case is different

Many people with RLS share the experience of having suffered for years before receiving a diagnosis. At the conference, J. Steven Poceta, MD, of the Scripps Clinic Viterbi Family Sleep Medicine Center (a certified RLS Quality Care Center) gave an overview of RLS and the process of diagnosing patients. Dr. Poceta explained that about 90 percent of people with RLS also have periodic limb movements in sleep (PLMS). He also noted that for some individuals, RLS has an underlying cause such as low iron stores in the brain, renal failure, pregnancy, medications or neurological lesions.

RLS often starts in childhood, and many adults who have RLS recall having their early symptoms being misdiagnosed as “growing pains” when they were young. “Growing pains is RLS,” explained Shalini Paruthi, MD, of Saint Louis University, in a presentation on RLS in specific populations. RLS in children may also be mistaken for attention deficit hyperactivity disorder, and kids may not have the language to report their symptoms. About 70 percent of children have significant PLMS. Dr. Paruthi outlined the special considerations for diagnosing and treating RLS in children. She also

*“One of the best and most educational and helpful conferences that I’ve ever attended. The speakers were the experts in RLS from around the nation. The information that they shared literally changed the lives of the attendees.”* – Caren

discussed RLS in pregnant women, people with kidney failure, and people who have depression.

Brian Koo, MD, director of the Yale Center for Restless Legs Syndrome (a certified RLS Quality Care Center) gave an overview of the approach for RLS treatment in adults. The first step is to make sure the individual is using good sleep practices (sleep hygiene) and to reduce any obvious RLS triggers. If medication is needed, then providers can follow the step-by-step approach provided in the RLS Medical Bulletin (see page 23). Dr. Koo emphasized the importance of keeping an open mind if a physician suggests trying a medication that wasn’t effective in the past. “Just because you’ve tried a medication before and didn’t get a response, does not mean that this medicine does not work to treat your RLS. Other factors may have changed,” said Dr. Koo.

In a separate talk, Dr. Koo presented information about PLMS, which occurs in 80–90 percent of RLS patients. The good news, said Dr. Koo, is that many RLS medications are likely to effectively treat PLMS at the same time.

When drug treatments are needed, the mainstay are medications in two classes: dopaminergic agents and alpha-2-delta ligands. Mark Buchfuhrer, MD, of Stanford Sleep Medicine Center (a certified RLS Quality Care Center) gave a comprehensive description of how these medications work in the body, recommended dosages, and side effects such as impulse control disorder. In particular, he described how to prevent and diagnose augmentation, a common side effect of dopaminergic drugs. These medications may at first be very effective for treating RLS, but over time they cause symptoms to occur earlier in the day and spread to other body parts. Healthcare providers and patients alike must be aware of this devastating side effect and prepared to adjust treatment immediately if symptoms change. “Whenever a patient who has been on a stable treatment for at least six months requests more medication, it is augmentation unless proven otherwise,” said Dr. Buchfuhrer.

If patients have tried all other RLS medications and their symptoms are severe and uncontrolled, then opioid medications should be considered. Opioids, despite any stigma they may hold, are very effective for RLS when used in small total daily doses. Christopher J. Earley, MB, BCh, PhD, FRCPI, of the Johns Hopkins Center for Restless Legs Syndrome (a certified RLS Quality Care Center), discussed the types of opioid medications available, how they work in the brain, and their appropriate use in very small doses to treat severe RLS.

### Iron therapy, nonmedical treatments, and technology

Several presenters discussed the role of iron in the brain and the importance of addressing low iron stores as a way to improve RLS symptoms. Richard P. Allen, PhD, of the Johns Hopkins Center for Restless Legs Syndrome, walked through the research studies that





*RLS patients and caregivers gather for the two-day educational symposium.*

have demonstrated iron deficiency in the RLS brain. “It is very clear that it is brain iron, not peripheral iron, that is low in RLS patients,” he summarized.

For some people, iron supplements taken orally or by IV infusion can help lessen RLS symptoms. William Ondo, MD, of the Houston Methodist Neurological Institute (a certified RLS Quality Care Center), gave an in-depth presentation on the process of iron regulation in the body. Iron therapy aims to increase iron concentration in the blood so that some iron can be transported to the brain. Dr. Ondo described the types of iron that can be taken for RLS, including a comparison of the different IV iron formulations available.

RLS patients can also look to a variety of alternative therapies. The key is for each individual to identify what triggers their RLS, and what makes their symptoms more tolerable, explained Jacquelyn Bainbridge, PharmD, of the University of Colorado. Examples of triggers include caffeine, nicotine, alcohol, lack of exercise, lack of sleep, extended sitting during long flights or meetings, low iron stores, and certain medications. On the other hand, things that may relieve RLS include stretching, moderate exercise, yoga, massage and other nondrug interventions. Individuals should work with their healthcare providers to explore strategies that may work for them. Dr. Bainbridge emphasized the importance of moderate exercise and nutrition in any RLS treatment strategy. Finally, she provided a comprehensive overview of medical marijuana as a strategy. Her message: more research is needed to optimize the potential use of medical marijuana for RLS.

Jeffrey Durmer, MD, PhD, of Georgia State University, discussed the use of technology to help RLS patients – for example, cognitive behavioral therapy for insomnia (see page 12) and counterstimulation devices. Also, many apps are available that may help improve sleep by calming the mind and relaxing the body. Other technology devices can

*“I come away encouraged that there are providers who care about RLS sufferers, who have decades of experience researching and treating RLS, and who are willing to use the medications available to relieve our symptoms.”*

– Nicholas

*“The RLS Symposium was by far the most life-changing event for me to date. I could never have the ability, time or money to put forth in order to obtain access to the medical professionals, education and information that they afforded me. I will do my best to help the RLS Foundation continue their much needed and appreciated efforts to bring hope and healing for RLS patients around the country. A very heartfelt THANK YOU to the RLS Foundation.”* – Kasey

help create a cool and quiet environment in the bedroom, or enhance circulation in the body. Just as importantly, people must consider the negative effect of technology on sleep. Light-emitting devices reduce melatonin in the body, stimulating wakefulness. These devices should be kept out of the bedroom and should not be used within an hour before sleep, according to Dr. Durmer.

### **Foundational research in brain chemistry and genetics**

Research has shown that several systems in the brain play a role in RLS. Dr. Earley explained the complex interactions that take place in brain cells, or neurons, that involve the neurotransmitters dopamine, glutamate and adenosine. Neurotransmitters are chemicals in the brain that act as messengers to transmit information from one neuron to another, sending the signals to areas of the body. Research has shown that in RLS, these systems are imbalanced. Common RLS medications are designed to work on the dopamine system (ropinirole, pramipexole, rotigotine) or glutamate system (gabapentin, gabapentin enacarbil, pregabalin). Many of these drugs are also used to treat Parkinson’s disease, where these systems are damaged, but the brain chemistry of RLS is different. In RLS, these neurotransmitters systems are imbalanced, and medications aim to correct this imbalance.

In addition, opioid medications such as methadone and hydrocodone act on the morphine system. Recent findings on RLS and the neurotransmitter adenosine has sparked research into a potential new class of drugs to treat RLS by acting on the adenosine system.





*RLS Foundation staff members Kathy Dzienkowski, Zibby Crawford and Karla Dzienkowski (left to right)*

Genetics have been found a significant factor in RLS, according to a presentation by Dr. Ondo. He described what is known about genetic patterns in RLS, and the findings of various research studies. In 2007 an RLS Foundation-funded study by David Rye, MD, PhD, at Emory University School of Medicine uncovered the first genetic variant for RLS; as of today, 19 genes have been identified as associated with RLS. While this information does not currently help with diagnosing or predicting RLS, it has helped scientists better understand RLS and provides information for researchers who are working to develop an RLS animal model that could be used to test new potential RLS medications in the future.

A third primary area of focus for RLS research is the role of iron in the brain. James Connor, PhD, of The Pennsylvania College of Medicine took a deep dive into the topic. According to Dr. Connor, it is believed that the RLS brain has plenty of dopaminergic cells, but they are not storing iron as they should. He described what is currently known about how the body transports iron from the blood into the brain, which occurs during iron therapy, and questions that scientists are exploring to better understand this process.

Dr. Earley summarized that the three primary areas of RLS research – neurotransmitter, genetics and iron deficiency – are a starting point for future research. “We’ve made major strides in understanding the pathophysiology of RLS,” said Dr. Earley. “We’ve come an awful long way, and we’ve generated some good foundations for future research.”

### **Stepping up: The ‘magic secret’ of continuing the RLS Foundation’s progress**

The symposium opened with Dzienkowski sharing the organization’s history – from its origins around a kitchen table in 1989, to the 5,000+ membership of today.

*“Oh. My. Goodness! ... My head is swimming, my heart is full, and I know for sure I am NOT alone.” – Christa*



*Shalini Paruthi, MD, delivers a presentation on RLS in children and other special populations.*

Lew Phelps, chair of the Board of Directors, closed by stressing the importance of ongoing support for the RLS Foundation’s work in education, treatments and research. “This is a membership organization, and membership is the life-blood of the Foundation,” said Phelps. He encouraged attendees to reach out to anyone with RLS who is not yet a member of the Foundation to invite them to join. The annual fee is only \$35 (“a trip to McDonald’s,” he said), and the Foundation offers scholarships to those who need financial assistance.

Phelps described the Foundation’s advocacy initiative to increase federal funding for RLS research and ensure that people with severe RLS continue to have access to opioid medications for treatment. The Foundation has held two series of meetings this year with members of Congress, the National Institutes of Health and the US Food and

Drug Administration. The Foundation has also mobilized a grassroots campaign of letters and visits with elected officials; and in partnership with the Health and Medical Council of Washington, provided input on key legislation.

Phelps noted that additional support is needed for this work to continue in the next fiscal year; the “magic secret” of the Foundation’s overall budget is members who step up and make additional contributions. “If you have the means, now is the time,” said Phelps. To make a gift to the RLS Foundation, visit [www.rls.org](http://www.rls.org) or call 512-366-9109.



*RLS medical experts answer questions from the audience.*

# Webinars

## 2017 – 2018

### Ask Dr. B - Live Q&A

Mark Buchfuhrer, MD, FRCP(C), FCCP, FAASM  
October 11, 2017

### RLS in Dementia

Donald Bliwise, PhD | November 17, 2017

### Advocacy and Policy Implications from the Opioid Crisis

Dane Christiansen, MBA | December 5, 2017

### Iron and RLS

Christopher Earley, MB, BCh, PhD, FRCPI  
January 25, 2018

### RLS and Kids

Suresh Kotagal, MD | February 19, 2018

### Medications for RLS

Michael Silber, MD, ChB | March 13, 2018

### Legislative Update and Opportunity for Congressional Outreach

Dane Christiansen, MBA | April 16, 2018

### What's New in RLS Research

Lynn Marie Trotti, MD, MSc | May 11, 2018

### Marijuana and RLS

Jacquelyn Bainbridge, PharmD | June 19, 2018

### The Essential Role of Adenosine in RLS

Sergi Ferré, MD, PhD | July 18, 2018

### RLS Triggers

Brian Koo, MD | August 16, 2018



## 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 deductible and provide an immediate source of income for programs.

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

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

If you would like to learn more about planned giving, please request our *Giving Avenues* brochure or contact us at 512-366-9109 or [info@rls.org](mailto:info@rls.org).

### Levels

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

*Thank you!*

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

### Leaders

#### (\$10,000 or more)

Ronald and Sharon Barrett  
Mr. and Mrs. Tom Dunagan  
The Dzienkowski Family  
Ms. Catherine MacMillan  
Carolyn Mohn  
Lewis M. Phelps  
The Portmann Family  
Charitable Fund  
Mr. and Mrs. Paul Rochester  
Judy and Bob Waterman

### Benefactors

#### (\$5,000 to \$9,999)

Anonymous (1)  
James and Sandra Aberer  
Ms. Ann S. Alspaugh  
Peter and Incy Brooks  
Michael Brownstein, MD PhD  
Dennis and Linda Fenton  
Mrs. Rhondda L. Grant  
Ms. Goldie P. Gross  
Pickett and Bob Guthrie  
E. W. Littlefield, Jr.  
M. Lynn McCracken  
Ms. Carla Rahn Phillips  
Mr. Freeman H. Smith III  
Ms. Jan A. Sogge  
Peggy R. Walker-Conner  
Mr. Frank M. Wilson III

### Patrons

#### (\$2500 to \$4,999)

Mrs. Barbara Bere  
Russ Buschert  
Ms. Sue DiCristofaro  
Christopher J. Earley,  
MB, BCh, PhD, FRCPI  
Janice and Larry Hoffmann  
Mrs. Roberta J. Kittredge  
Marilyn and Robert Marlette  
Ms. Lynda Sakraida  
Jack Stone  
Mr. and Mrs. Cal Walstra

### Sponsors

#### (\$1,000 to \$2,499)

Anonymous (3)  
Carolyn C. Achee  
Roger and Loree Austin

Drs. Jacquelyn and Scott  
Bainbridge  
Ms. Barbara E. Clucas  
Elizabeth Crawford  
Nonda Donovan  
J. Hunt Downing  
Maureen Duane  
Mr. Pierre Dupont  
Mary Ann and Jim Emswiler  
Dr. John Freund  
Mr. Jim B. Fullerton  
Ms. Vera M. Gerhardt  
Vanessa and Seth Glogower  
Charles C. Gould  
Ms. Elizabeth Grant  
Mrs. Gail Grim  
Mrs. Laurie Hirst  
Mrs. Delpha A. Hirth  
Mr. Donald Hirth  
Laura Scott Hoffman  
Ms. Marguerite Holden  
Ms. Isabella W. Horsky  
Ms. Aubyn B. Howe  
Mr. Terry Keiper  
Leon and Dina Krain  
Don and Alison Lovell  
Dr. and Mrs. Neil A. MacKenzie  
Mr. and Mrs. J Terry Manning  
Dr. Joseph Martin, MD, PhD  
Pat & Diane McKeague  
Ms. Maureen Murphy  
Shalini Paruthi, MD  
Nancy S. Passanante  
Mrs. Randal Peterson  
Gail L. Pickering  
Ms. Lisa A. Pugh  
Mr. Rex E. McCrary  
Mr. Robert H. Ritterbush  
Lori Schiffrin  
Ms. Charlotte Slack  
Mr. & Mrs. E. Randall Smolik  
Mrs. Constance Stoner  
Cindy Taylor  
Grant P. & Sharon R. Thompson  
Tim & Kristin Thornton  
Robin Tost  
Mr. Aleksandar Totic  
Elise & Woody Widlund  
Naomi and Michael Zigmund  
**Sustainers**  
**(\$250 to \$999)**



Anonymous (24)  
 Mr. and Mrs. Ralph L. Albright  
 Mr. John Alexanderson  
 Mrs. Gela Altman  
 Evelyn M Anderson  
 Ms. Paula Anderson  
 Prof. Ronald E. Anderson  
 Mr. Greg Arling  
 Guy and Dona Armstrong  
 Richard C. Austin, MD  
 John W. & Mary C. Baker  
 Mrs. Marcia Ball  
 C. F. Beil  
 Ms. Barbara Bellamy  
 Elizabeth L. Bewley  
 Ms. Amy Jean Boebel  
 Inez Boettcher  
 George and Linda Bone  
 Ms. Ruthann Bonzi  
 Mr. George Borowsky  
 Mr. William Bossenberger  
 Ms. Betty M. Brockington  
 Ms. and Mr. Lenore Brugger  
 Mrs. Gail S. Buckley  
 Mary R Burns  
 Mrs. Erica Campanello  
 Susanne Campbell  
 Ms. Felicia M. Cashin  
 Ms. Caroline Chamales  
 Lee C. Coates  
 Ms. Allison W. Coleman  
 Mrs. Rei M. Colling  
 Mr. Charles Cooke  
 Mrs. Susan E. Cooley  
 Mrs. Lois M. Crouch  
 Ms. Mary Cuseo  
 Mrs. Kathryn Davis  
 Dr. Edward T. Dehan  
 Mr. Ivan DeJong  
 Elizabeth Dirkx  
 Anne Breckenridge Dorsey  
 Mrs. Katharine Downham  
 Helen Drewett  
 Heyward L. Drummond, Jr.  
 Mr. and Mrs. Louis Echavarria  
 Mr. Peter Edwards  
 Mr. Bryan Fagan  
 Barbara A. Faraone  
 Ms. Beth Fischer

Tom Flanders  
 Dr. Harriet Forman  
 Evelyn France  
 Mr. John Gage  
 Tom Gardner  
 Mr. Joseph S. Gass  
 Irma Gawboy  
 Ms. Nina Glasner  
 Ms. Catherine Glowacky  
 Ms. Charlotte B. Goddin  
 Mr. Doren Goldstone  
 John Grafenauer  
 Mr. David L. Gray  
 Nancy Griffin  
 Mrs. Shiras Guion  
 Mr. Carl F. Hagenmaier, Jr.  
 Mr. Stephen L. Handley  
 Mr. Thomas Hartzog  
 Ms. Susanne Havlic  
 Mr. James Hawthorne  
 Mrs. Julie Herbert  
 Mr. Gilbert Heth  
 Dr. Arthur M. Hewitt  
 Ms. Barbara Hirschy  
 Patty Hodgins  
 Mr. David Hoge  
 Mr. Clyde L. Humphrey  
 Stephen H Iser  
 Mr. and Mrs. Max E. Jester  
 Ms. Dianne Kanzler  
 Ms. Sandra Katanick  
 R. Fred Kautz  
 Garry Kearns  
 Mrs. Sarah P. Kellen  
 Mr. Darrin Kelley  
 Dr. Marvin Kleinau  
 Kathleen Kotchi  
 Bob Landauer  
 Mrs. Cynthia Landgrebe  
 Régis Langelier, PhD  
 Ms. Patricia A. Leighfield  
 David A. Lewis  
 Mr. William Lewis, Jr  
 Mrs. Lee Lipman  
 Dorothy Liston  
 Ms. Andrea Lowery  
 Lorinna W. Lowrance  
 Ms. Linda L. Macey  
 Mrs. Barbara Mack  
 Colin MacKenzie

Tom E Main  
 Rev. James & Jean Matthews  
 Mr. Steven McCann  
 Jerry McCaslin  
 Linda McKenna  
 Marney Mesch  
 Mrs. Dixie Messner  
 Mr. Douglas Miller  
 Mr. David Moulton  
 Mrs. Diane P. Moyer  
 Dr. Daniel J. Murphy  
 Walter W. Murrell, PhD  
 Mr. Arlo R. Nord  
 Jim & Barbara North  
 Mr. Peter Nostrand  
 Ms. Rebecca OConnell  
 Mr. William Pattinson  
 Ms. Cynthia Pearson  
 Prof. Robert J. Peroni  
 Joyce Perry  
 Dr. Matthew Petrie  
 Starla Phelps  
 Judy Phillips  
 Mr. Doug Poad  
 Mrs. Betty J. Quist  
 Mrs. Jackie Ramseyer  
 Dr. Rollin J. Randall  
 Ms. Mara Rasure  
 Ms. Patricia Rathke  
 Mrs. Joyce Ratkowski  
 Ms. Dorothy Reddy  
 Joyce E. Richardson  
 Mr. and Ms. Patrick Riley  
 Ms. L. Andrea C. Roope  
 Ellen and Merrill Roth  
 Mr. Mark Rusley  
 Brenda Sallee  
 Mr. David T. Sands  
 Ms. Jane Sauther  
 Ms. Helen T. Schauer  
 Mrs. Elizabeth O. Scheben  
 Ms. Isabel Sonia Schneider  
 Mr. Aaron Scholl  
 Mr. John Schwager  
 Linda Secretan  
 Donald Semrau  
 Louise Sharp  
 Mr. Dennis Sienicki  
 Michael H. Silber, MB, ChB  
 Delores Slawik

Frances Cain Slote  
 Mr. James F. Smith  
 Mr. and Mrs. Stephen N. Smith, PE  
 Mr. William J. Smith  
 Ms. Jacqueline A. Snodgrass  
 Mr. Mark Sofianek  
 Mr. Robert E. Spangler  
 Ms. Mary Stompe  
 Ms. Doris B. Stretch  
 Mr. Stephen L. Tate  
 Suzanne Tennies  
 Mr. James Thompson  
 Mrs. Shirley S. Toothman  
 Mr. Thomas E. Turk, Jr.  
 Ms. Elizabeth K. Usina  
 Mrs. Wendy Veiga  
 Mr. Richard Vezza  
 Dan Vreeland  
 Kate Wagner  
 Christine Tunison Wait  
 Karen Walborn  
 Ms. Joy K. Walker  
 Laura Walker  
 Mr. George Weeks  
 Mr. Jon Wellinghoff  
 Mr. Bill Wendt  
 Mr. John J. White  
 Leah R. Wickham  
 Ms. Carolyn Wilcox  
 Judy Willoughby  
 Ms. Naomi Wilson  
 Diane W. Wood  
 Ms. Toby Woodhouse  
 Mr. William W. Young, Jr  
 Mr. Dean Zarras

## Supporters (\$100 to \$249)

Anonymous (48)  
 Ms. Carol Abboud Connolly  
 Mr. Mark Abramovic  
 Debbie Murdock  
 Mr. Kenneth Achiron  
 Anne Adams Gorry  
 Mr. Joseph Adrignola  
 Ms. Betty Affisco  
 Ms. Mary Alexon  
 Ms. Paije Alfano  
 Jean A. Allee

Janet L. Allis	Carolyn P. Bower	Ms. Lorraine F. Coughlan	Mr. Lorne L. Ebel
Mrs. Mary F. Anderson	Dr. Dolores A. Bower	Ms. Suzanne Covert	Mrs. Susan Eckers
Mr. & Mrs. Leland E. Anderson	Mr. John Bowman	Mrs. Dorothy B. Cowles	Carol T. Edmiston
Dr. Donald Arbuckle	Ms. Edith Bozman	Ms. Edith Cozzi	Mr. Doug Ell
Dorothy Armstrong	Mr. Bruce Bredland	Ms. Barbara Crain	Vashti P. Elliott
Ms. Joan Arsenault	Mr. Clark Breeze	Mr. Jim Cronkhite	Ms. Phylis Elsing
Ms. Carole S. Arthur	Mr. Arnold A. Brewer	Mr. Roger Crooks	Larry L. English
Ms. Carol C. Ault	Hannah and Sydney Britt	Dr. Leo Crowley	Mr. Marvin Enslin
Ms. Carmen Ayala	Ms. Julie Brook	Patrick Crowley	Mrs. Diane M. Evasick
Mr. Donald N. Babb	Mr. and Mrs. Peter K. Brooks, Jr.	Ms. Terri Cunliffe	Richard Ezell
Mr. Wilmer Bahe	Jane E. Brown	Ms. Kita Curry	Dr. Joe Fagan
Mrs. Janet Bailey	Ms. Susan Brown	Ms. Arwilda Cushman	Alan K. Fairchild, MD
Ms. Ann Baker	Ernst B.	Ms. Yvon Dacayana	Mrs. Pam and Rob Fairly
Mr. Glenn Baker	Ms. Susanne A. Brzakowski	Jo Daly	Fausto and Carlene Falcone
Mrs. and Mr. Mary C. Baker	Dr. Fred Burbank	Ms. Barbara L. Dammann	Mr. Sigo Falk
Ms. Mary Ellen Baker	Margee Burke	Ms. Trudy K. Dana	Win Farquhar
Ms. Nancy Baker	Dr. John R. Burns	Jonelle Prether Darr	Ms. Lisa Feinstein
Ms. Betty Ball	Mr. Thomas W. Burns	Mr. Bruce H. Davidson	Ms. Toni Fennessy
Mr. William Ball	Colleen A. Burroughs	Ms. Claire Davidson	Mr. Stefan Feyen
Ms. Mary Bandura	Ms. Cate Campbell	Mr. Chris Davis	Mr. Eugene Firmine
Ms. Christie Barbour	Mr. Al Capitanini	Mrs. Patricia Davis	Lee J. Fischer
Ms. Agnes R. Barrett	Mr. John Carney	Ms. Suzayne W. Davis	Mrs. Diane Flatley
Mr. Thomas M. Barry	Ms. Lillian Carroll	Wilma De Jong	Mr. Eugene Fleishman
Ms. Ann Battenfield	Ms. Stephanie Carty	Mr. Don R. Deabenderfer, Jr	Mrs. Sue Fletcher
Elizabeth A. Bauer	Ms. Mary Lou Case	Ms. Barbara Dean	Emmett T. Florea
Phyllis Bazzano	Mr. Bill Cassen	Ms. Veda I. Decof	Pauline T. Flynn
Mr. Donald T. Becker	Gerard Castry	Mr. Paul Delaney	Elmer G. Foley
Ms. Phyllis Beery	Ms. Janet Catlow	Mr. William Deloach	Mr. Ted Foreman
Mr. Kent Bell	Anne R. Chalfant	Mr. Peter DeMeyer	Janet M. Forni
Mrs. Carrie Bellah	Mr. Paul Chalkis	Mr. Thomas P. DeMund	Ms. Jacquie Foss
Lois E. Belohlavek	Mrs. Kitty Champlin	Ms. and Mr. Jean Derheim	Mr. Robert Fowler
Mr. Robert Benedick	Ms. Peggy Chappell	Ms. Helle K. DeSimone	Ms. Maryanne Fox
Ms. Caroline Benkendorf	Ms. Vera Chernoff	David J. Dickoff,, MD	Ms. Sara Frampton
Mr. Bruce Berlent	Sudhansu Chokroverty, MD	Mindy and Joe Dill	Ms. Mary Fransen
Lola Bermudez	Mr. Thomas Churchill	Mrs. Diane DiPascale	Mr. Robert Freese
Dr. Lawrence Bernstein	Mr. Ron Cicchini	Mr. Bruce C. Dolin	Ms. Linda Frideres
Barbara Berrier	Ms. Renee Cline	Diana Domeier	Mrs. Andrea Friede
Anne and Don Berschback	Mrs. Janet E. Clisch	Ms. Freda Donica	Mr. John Frieden
Ms. Victoria Biggs-Anderson	Arnold and Annebelle Cohen	Ms. Carmen Dorman	Janice H. Frizzell
Mr. Richard Billings	Mr. Herb Cohen	Dr. Jeffrey Dorman	Ms. Karen S. Fulks
Mr. Myron Blackman	Dr. Carol L. Colby	Mr. James Dougherty	Mr. & Mrs. Mastern Fuller
Ms. Sybil J. Blankenship	Dr. Jack Cole	F. Edward Dudek	Mrs. Judith A. Funk-Bailey
Ms. Catherine M. Boehme	Ms. Betsy Collins	Paul H. Dudek	Ms. Marilyn R. Gage
Ms. Susan Boehme	Mrs. Janet M. Coltman	Laura Dunlop	Marcella Gallagher
Edwina H. Bogdan	Ms. Barbara Conits	Ms. Mary Dunn	Ms. Sylvia R. Gallagher
Mrs. and Mr. Linda Bone	Mr. Laurence Conley	Mrs. Judy Durant	Mrs. Norma Galusha
Jane L. Bourn	Sheila C. Connolly	Ms. Ali Dzienkowski	Jeannine Garrett
Mr. Bruce Bowden	Dr. and Mrs. James R. Connor	Mrs. Deborah Early	Mr. James Gaynor
Mrs. Sally H. Bowen	Mr. Nick Cooper	Mr. James Early	Carolyn Geduld
	Thomas J. Corcoran	Ms. Barbara Earnest	Mr. Peter Gerame

Mr. Jay Gerard Gerard  
Kenneth E. German  
Miss Lucynda Gibbs  
Mr. Jerry Gilland  
Ms. Marion E. Gillen  
Mrs. Ruth H. Gillis  
Mr. William Gilster  
Mr. George M. Gingerelli  
Beverly and Murray Ginsberg  
Ms. Ellen Glatter  
Mr. Jonathan Glazier  
Mr. John Godfrey  
Ms. Pat Golab  
Mrs. Dorothy D. Goldstick  
Mr. Kenneth Goodson, Jr  
Mr. Earl Goodwin  
Mr. Robert Gorecki  
Ms. Mary Gossett  
Mr. Kenneth Graber  
Ms. Ruth Graber  
Mr. Neil Greenwood  
Judy Greff  
Ms. Suzan K. Griffin  
Mr. Everett J. Grindstaff  
Mr. Robert F. Groman  
Mr. John Grummitt  
James A. Guldan  
Ms. Janet Gunther  
Ms. Wanda R. Guyton  
Douglas E. & Marcia S. Haas  
Mr. Ron Haedt  
Mrs. Carolyn M. Hahne  
Susan F. Haigler  
David J. Hall,, MD  
Mrs. Richard Hallock  
Mr. Charles Hamilton  
Mr. David Hamilton  
Mr. Peter Hammond  
Annelies E. Hampel  
Mr. John Hampel  
Mrs. Elizabeth M. Haning  
Evelyn Harper  
Mrs. Sheryl Harris  
Mr. Steven Harris  
Ms. Barb J. Harrison  
Mr. Burlin C. Harrison  
Ms. Barbara Hasty  
Robert G. Hasty  
Mr. James Hatcher  
Dr. Jerald Hatton

Ms. Marianne Haug  
Vic & Bettye Hauser  
Mrs. Susan Havelock  
Miss Terri Haydon  
Ms. Patricia Hays  
Mr. Jaime Hazan  
Jim Healey  
Ms. Judy Heath  
Ms. Sybil Ann Heim  
Mr. Carl Heintzelman  
Mr. William Heinz  
Ms. Julianne Hennings  
Mrs. Dolores Hermann  
Ms. Donna Heroux-Everson  
Ms. Michelle C. Hester  
Mrs. Lee B. Hickman  
Mrs. Katherine A. Higgins  
Mrs. Caren Hill  
Mrs. Tina Hines  
Mr. Lloyd Hittle  
Mr. Duncan Hodge  
Judith Hoffman  
Dr. and Mrs. Dean G.  
Holland  
Mr. Peter K. Hoover  
Mr. Ron R. Hopperton  
Ms. Julia S. Horowitz  
Ms. Bette Huckabee  
Ms. Margaret T. Huddy  
Mr. James S. Huffman  
Mrs. Annette S. Hunter  
Mr. Peter Hunter  
Mr. Mickey C. Hurry  
Thomas D Hurwitz, MD  
Mr. Michael Hussey  
Marjorie G. Hutchison  
Lucille L. Hynes  
Dr. Wayne Ingmire  
Mrs. Maureen Janda  
Glenn W. Jeffrey  
Ms. Catherine Johnson  
Mrs. Deanna Johnson  
Mr. Eric Johnson  
Ms. Julia Johnson  
Ms. Susan R. Johnson  
Mr. David J. Johnston  
Byron C. Jones, PhD  
Elizabeth R. Jones  
Mr. Evan Jones  
Ms. Marilyn M. Jones

Ms. Mary A. Jordan  
Mr. and Mrs. Hisashi Juba  
Mrs. Georgia Kahler  
Mr. Dave Kaiser  
Mr. Edward Kalinowski  
Mr. Tom Kaper  
Dr. Anoop Karippot, MD,  
DABSM  
Mr. Ken Kaser  
Mrs. Linda M. Kawtoski  
Donnie and Darlene Kee  
Mary C. Kehlhem  
Ms. Mary Louise Keitel  
Ms. Patricia Keller  
Ms. Shirley Kelly  
Allan R. Kerze  
Mrs. Randy Keyne  
Mr. John Kievit  
Michael J. Kikta, MD  
Ms. Doreen Kim  
Nancy Kindness  
Mrs. Jean B. King  
Mr. Patrick J. King  
Mrs. Rachel Haigh Kinney  
Mr. Mike Kirby  
LTC (Ret) Marypat A. Klee  
Mr. Jeffrey M. Kloc  
Mr. Rollin Knecht  
Leo A. Kominek  
Ms. Judith A. Kotar  
Molli Krausz  
Mrs. Susan Kress  
Dr. Laurence Krieg  
Diane Kuehn  
Judith Kuenzli  
Mrs. Nancy C. Kuhn  
Rajeev Kumar, MD  
Mr. Michael Kun  
Sandra Kussin  
Ms. Juliana Kuyk  
Linda LaBerge  
Robert La Fontaine  
Ms. Anne Lampe  
Linda K. Landis  
Mr. Joel Landsberg  
Mr. John Lane  
Mrs. Sharon Langis  
Betty Lapham  
Mrs. Rae Lapides  
Ms. Kim Larrow

Ms. Elisabeth Laura  
Mrs. Catherine Lawson  
Mr. Nick Lawson  
Mr. Roger Leflour  
Dr. Corrie Leisen  
Mrs. Carolyn Lenhard  
Mr. Scott R. Levad  
Amelia Lewellen  
Mr. Roy E. Licklider  
Ms. Vivien Lindsey  
Mr. & Mrs. Charles F.  
Lipscomb  
Dr. Elizabeth Littell  
Ms. Martha P. Littlefield  
Nancy B. Livermore  
Janis Lopes  
Mr. David Loskutoff, PhD  
Dr. Betty Louise Lumby  
Andrea M. Lutz  
Ms. Vicki Lyons  
Ms. Jean L. Mabie  
Mr. Kenneth F. MacKay  
Mr. Bill Makinson  
Cmdr. John O. Makinson  
Mr. Frank Malacane  
Ms. Saida S. Malarney  
Ms. Brenda Malewitz  
Mr. Edward Malewitz  
Frank E. Manchester  
Mrs. Tove Mandigo  
Ms. Mary H. Manning  
Ms. Christina Marciniak  
Mr. Anne Marietta, PhD, RD  
Mr. and Ms. William Marietta  
Ms. Susan Marshall  
Mr. David Martens  
Mr. Keith Martindale  
Ms. Jackie Massaro  
Mr. Mark Mathes  
Lloyd Mathis  
Paul S. Mattheiss  
Marcia Matthieu  
Mr. Kevin B. May  
Mrs. Grace McCartin  
Mr. Murray McDole  
Dr. Gary Mcfadden  
Ms. Molly McGarvey  
Steve and Kris McGaw  
Dorothy McGinnis  
Ms. Marilyn A. McGowan



Mr. Robert McIntyre  
Ms. Lisa L. McPherson  
Mrs. Alexandra McReynolds  
Mrs. Joan M. Meginniss  
Mr. Alf Mell  
Michael T Mendelson  
Dr. and Mrs. Stuart J. Menn  
Charlene R. Mentink  
M. Marjorie Meredith  
Elsa Michitsch  
Mr. Charles J. Miller  
Mr. Gene Miller  
Sally Mills  
Mrs. Ida R. Minor  
Ms. Jenifer Misiaszek  
Mr. Darius Mistry  
Mrs. Jill Mitchell  
Stephen W. Mixon  
Ms. Karen Mokrzycki  
Ms. Clydeen Moller  
Judy C. Monostory  
Ms. Valerie Montoya  
Mrs. Solveig Moore  
Ms. Silver Moore-Leamon  
Dr. Robert L. Morissette  
Donna M. Morrill  
Mr. Robert E. Morris  
Mr. Kent Mortensen  
Steve Morton  
Sue Moss  
Ann Mullinix  
Roger Mulvihill  
Ms. Gale Munson  
Mrs. Dorothy Muonio  
Rita R. Murphy  
Mr. George Murray  
Ms. Dixie Myrick  
Ms. Patricia Nee  
Mr. Karl Neeb  
Ms. Linda R. Nelson  
Mr. Kent Newmark  
Keith and Bonnie Noyes  
Gregory C. Oberland  
Ms. Philomene Offen  
Rev. James B. & Linda M. Olson  
Ms. Nancy K. Olson, RN  
Ms. Roberta Owen  
Dr. Walt Owens  
Mr. Eric Owston  
Mr. James Painter

Mr. Stephen Panoras  
Mr. Ron W. Panter  
Ms. Susan Partridge  
Mrs. Carolyn K. Pater  
Mr. Robert Patterson  
Robert J. Patterson  
Ms. Anne Patton  
Ms. Maria Paul  
Donna S. Peckinpough  
Donald L. Perry  
Mrs. Peggy R. Peterman  
Mr. Frank C. Peterson  
Mrs. Jill Peterson  
Carolyn Phillips  
Mrs. Cynthia Phillips  
Mr. Donald Phillips  
Karen Plate  
Mr. Stephen Plattus  
Mrs. Patricia A. Poelker  
Mr. Robert L. Poff  
Mr. Peter B. Polatin  
Mr. Gary Pollatz  
Dr. Erika Pollner  
Ms. Yvonne Posner  
Jacquie Powell  
Mrs. Elizabeth Purcell  
Mr. Joe Purvis  
Mr and Mrs Stan Quade  
Mrs. Carolyn Quick  
Mr. Mark Quinton  
Ms. Norma L. Raines, RN  
Ms. Marilyn Ralston  
Emily Rand Breitner  
Mrs. Peter L. Randlev  
Dr. Mukunda Rao  
Mark Rasmus, MD  
Mr. Walter H. Rauser  
Mrs. Marilyn Rawson  
Mr. Martin Redman  
Daryl and Ella Reid  
Mrs. Diane M. Reinhart  
Ms. Buena M. Rhodes  
Mr. Kenneth Rholl  
Mrs. Sheila Richards  
Ms. Susan C. Richards  
Mr. Paul Richardson  
Mr. Johnnie Ricketts  
Ms. Norma Rider  
Laura and Patrick Riley, MD  
Ms. Barbara Riser

Ms. Donna Rivers  
Mrs. Ellen Roberson  
Carol Roberts  
Mr. J David Roberts  
Ms. Kathryn W. Roberts  
Ann Robertson  
Jean Robertson  
Mrs. Susan Robertson  
Ms. Leigh Anne Rogoski  
Thomas A. Romig  
Dr. Geoffrey Rose  
Mr. Monte Rosen  
Dr. Ellin Rosenthal  
Dr. Christopher Ross  
Jim and Anne Ross  
Jay and Maija Rothenberg  
Mrs. Janice Rottman  
Ms. Christa Rotz  
Mr. John Ryan  
Ms. Sue Sabaloni  
Ms. Carol Saccomonto  
Kei Sakita  
Mrs. Anne Marie Samway  
May Sanders  
Mr. Richard Sandoval  
Ms. Sonnhilde Saunders  
Ms. Joanne Sawadsky  
Mr. LeRoy Saylor  
Dr. Peter Scardino  
Mr. Ronald Schaeffer & Priscilla Millen  
Mrs. Linda R. Schaeffer  
Mrs. Shirley L. Schapler  
Mr. Paul Schlichting  
Ms. Susan Schlichting  
Jan Schneider  
Ms. Sidney Scholl  
Ms. Donna M. Schroeder  
Ms. Patty Schuetz  
Mr. and Mrs. Roger C. Schulte  
Ms. Mary Schwartz  
Ms. Joyce Secondo  
Mr. Allen Secrest  
Mrs. Joan Seeberger  
Carol J. Seely  
Mr. and Mrs. F R. Sekowski  
Ms. Judy Sewell  
Shirley I. Seymour  
Harry Shaia  
Denise Sharon, MD, PhD  
Ms. Sandy Shaw

Ms. Bonnie Shear  
S. J. Shedenhelm  
Eleanor Mary Doherty  
    Sheridan  
Ms. Leila Sheriff  
Ms. Sylvia Shields  
William D. Shiels  
Mr. Daniel G. Shoaf  
Dr. Ronald Silvestri  
Kay Simmons  
Mr. David Singer  
Mrs. Mary E. Sloan  
Mr. Terry Smedley  
Mrs. Cory Smith  
Mr. Edward Smith  
Mrs. Patricia Smith  
Mr. Ronald J. Smith  
Stephen D. Smith, MD  
Donna L. Sons  
Mrs. Patricia Spampinato  
Michael & Regina Spaulding  
Mrs. Hannelore M. Spence  
Ms. Susan Spengler  
Mrs. Joyce C. Spivey  
Ms. Suzanne Spizz  
Kermit Spruill  
Mrs. Rosemary Stader  
Sheila A. Stankus  
Mr. Eric Steeg  
Ms. Jacqueline N. Steensma  
Mrs. Deborah Stefan de  
    Contreras  
Mrs. Faye M. Stephen  
Ms. Elizabeth Stepro  
Mr. Daru Stevens  
Mr. Chris Steward  
Dr. Gilbert Storms  
Joe M. Stovall  
Mr. Richard Straub  
Mr. Joseph Suchecki  
Mr. Jerry Sussman  
Nan Suydam  
Mr. Timothy Swanson  
Marian W. Sweeney  
Ms. Susan Swigart  
Mr. Carl Swindle  
Mr. John Sykes  
Harry C. Taylor  
Mr. Andrew T. Tershak  
Susan Theiss

Mrs. Clara Thomas  
Mrs. Janice Thomas  
Mr. Michael Thompson  
Ms. Jeanette Thoreson  
Ms. Lynda Tish  
Mr. David Tobias  
Mrs. Janice M. Toles  
Helena Tompkins  
Mrs. Ruby Townsend  
Mr. Melvin G. Trammell  
Ms. Janet L. Trent  
Ms. Antonia Trost  
Mr. Richard Tunstall  
H. M. Turek  
T. Michael Ulwelling  
Dr. Gary Utz  
Mr. Charles B. Vail  
Mr. and Mrs. Robert  
    Van Etten  
Mrs. Cynthia M. Van Horne  
Lee Van Valkenburg  
Ms. Elizabeth VanderBurg  
Ms. Shirley Veach  
Mrs. Eileen Vermillion  
Mr. Robert Visser  
John M. Wadahara  
Mrs. Lorene Wagner  
Ms. Luann Wagnon  
Gordon Waldron  
Mr. Roger Wallace  
Mr. Kevin Walsh  
Peggy Walters  
Ms. Kay-Frances Wardrope  
Mrs. Shirley M. Ware  
Ms. Helga M. Warner  
Mr. Peter Warren  
Mr. Joseph Wataha  
Mr. and Mrs. Lawrence P.  
    Watson  
Mr. Rupert Watson  
Mrs. Sallie Waugh  
Mr. James Weatherson  
Mrs. Janet Weiden  
Mr. Alfred Weiler  
Kit Weinschenk  
Ron Weisberg  
Ms. Victoria Welch  
Mr. and Mrs. Eugene Wendt  
Robert J. Werra, MD  
Mr. Rick Westbrock

Lucille Westervelt  
Mr. Barry Weston  
Ms. Helen Wheeler  
Ms. Kristin Whitehead  
Donna and Melvin Whitfield  
Mr. Thomas Wicker  
Mrs. Diane R. Wilds  
Ms. Roseanne Wilhelm  
Ms. Marilyn Wilkes  
Dr. Judy Willard  
Mr. John B. Williams  
Mr. Kent Williams  
Ms. Laurena Williams  
Mr. Jeffrey Willis  
Mrs. Kathleen Willis  
Ms. Caroline R. Willms  
Jo Wilson  
Ms. Jean Wimer  
Jerome P. Witek  
Mr. Thomas H. Witzel  
Mary Lou Wohlhieter  
Mr. Eduard Wojczynski  
Ms. Pam Wuichet  
Ms. Martha Wunderli  
Mr. Des Wytmans  
Ms. Lois Yarbor  
Mr. Ted Yednock  
Mrs. Sharon Zambon  
Mr. & Mrs. Robert J. Zaruba  
Trudy H. Zimmerman  
Barbara Zizka

# Financial Report



**Ron Barrett, PhD**  
*Treasurer*

I would like to thank you, our members, for your continued support and commitment to the RLS Foundation during our 2018 fiscal year. Donations from individuals constitute the majority of the financial support for Foundation programs and activities, representing eighty-one percent of total revenue to the organization.

In fiscal year 2018, the Foundation continued its important educational efforts. 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. They also served as presenters in our free physician only and patient webinar series. Our website and social media channels including Facebook, Twitter, Instagram, YouTube, and LinkedIn continue to expand our reach to RLS sufferers and their physicians. Support groups and the discussion board provide individuals with RLS the opportunity to exchange information and coping strategies with others living with RLS. Our acclaimed quarterly magazine, *NightWalkers*, continues to provide members with in-depth stories about the most promising research and treatments available today. Communicating through these diverse channels provides access to a larger and younger audience, fulfilling our mission to enhance education and awareness about RLS.

A second component of our mission is to support the development of improved treatments and a cure for RLS. As an example of this effort, we are in the second 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 already had an impact on the Foundation's advocacy efforts to assure that legislative and regulatory efforts to address the opioid epidemic do not negatively impact the medically necessary use of opioids by individuals with refractory 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 serve as Treasurer during fiscal year 2018. I look forward to continued success of the Foundation in 2019!

Sincerely,

A handwritten signature in red ink, appearing to read "RW Barrett", with a long horizontal flourish extending to the right.

Ronald W. Barrett, PhD



# 2018 Highlights | Financials

## Revenues and Support

Contributions	\$641,810
Membership Dues	\$137,352
Investment Earnings	\$11,631
Other	\$262
<b>Total revenues and support</b>	<b>\$791,055</b>

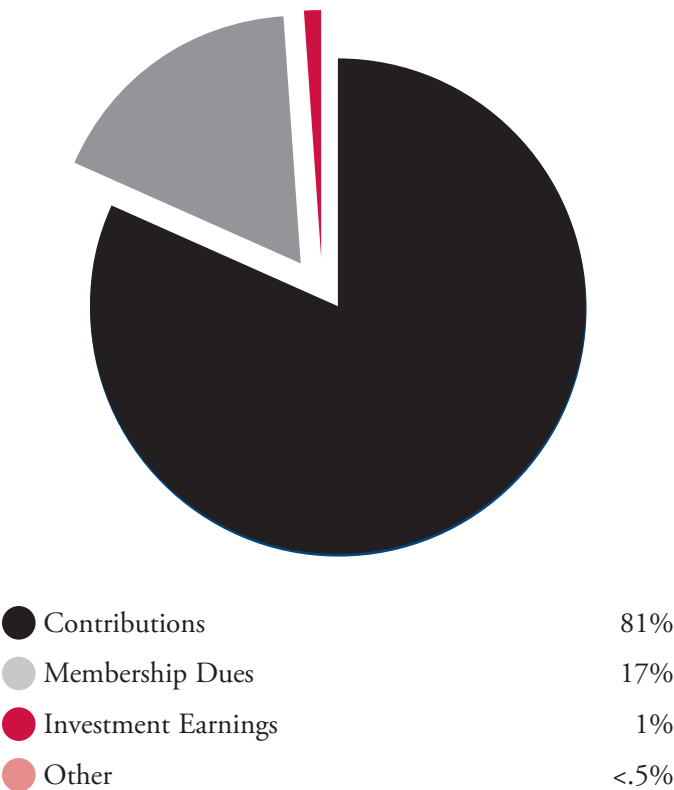
## Expenses

Program Services	
Education	\$493,624
Membership	\$159,124
Research	\$9,668
Support Groups	\$29,711
<b>Total program services</b>	<b>\$692,127</b>
Fundraising	\$65,237
Management and general	\$73,052
<b>Total expenses</b>	<b>\$830,416</b>

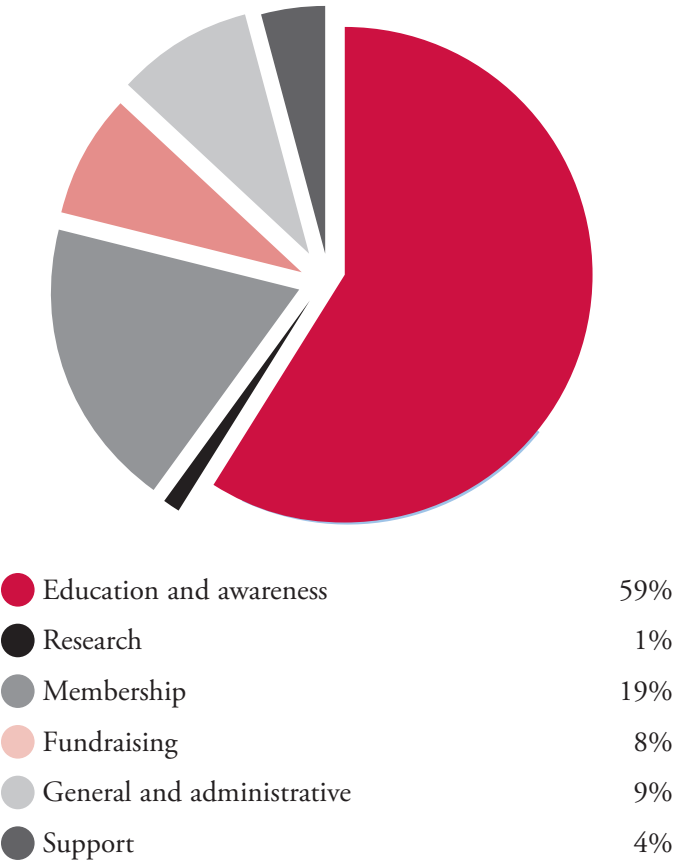
Statements of Activities For the Fiscal Year Ended September 30, 2017

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](http://www.rls.org)

## 2018 Where Our Funds Come From



## 2018 Where We Use Our Funds





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**

