



RAISING 2021 - 2020 ANNUAL REPORT AWARENESS

Restless Legs Syndrome Foundation is dedicated to improving the lives of the men, women and children who live with this often devastating disease. The organization's goals are to increase awareness, to improve treatments and, through research, to find a cure for RLS.

2021 - 2020

Board of Directors

Carla Rahn Phillips, PhD, Chair
Wimberley, TX

Linda R. Secretan, Secretary
Eagle, ID

Ronald W. Barrett, PhD, Treasurer
Saratoga, CA

Lewis Phelps, Chair Emeritus
Pasadena, CA

Ronald E. Anderson, PhD
St. Paul, MN

Jacquelyn (Jacci) Bainbridge, PharmD
Englewood, CO

Marcia Ball
Grosse Pointe Woods, MI

Jeffery S. Durmer, MD, PhD
Denver, CO

Steve McCann
Atlantic Beach, FL

Greg Oberland
Whitefish Bay, WI

Shalini Paruthi
St. Louis, MO

Paul Rochester
Hillsborough, CA

2021 - 2020

RLS Foundation Scientific and Medical Advisory Board

Christopher J. Earley, MB, BCh, PhD, FRCPI
SMAB Chairman
Baltimore, MD

Ronald W. Barrett, PhD
Board of Directors Liaison
Saratoga, CA

Philip Becker, MD
Dallas, TX

Joseph (Andy) Berkowski, MD
Cleveland, OH

Mark Buchfuhner, MD, FRCP(C), FCCP
Redwood City, CA

Stefan Clemens, PhD, HdR
Greenville, NC

James R. Connor, PhD
Hershey PA

Sergi Ferré, MD, PhD
Baltimore, MD

Jennifer G. Hensley, EdD, CNM, WHNP
Pflugerville, TX

Byron C. Jones, PhD
Memphis, TN

Elias G. Karroum, MD, PhD
Washington, DC

Brian B. Koo, MD
West Haven, CT

Mauro Manconi, MD, PhD
Switzerland

Emmanuel Mignot, MD, PhD
Palo Alto, CA

William Ondo, MD
Houston, TX

Kathy C. Richards, PhD, RN, FAAN
Austin, TX

Denise Sharon, MD, PhD, FAASM
Claremont, CA

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:

10/15-16/20

Telephonic

12/15/20

Telephonic

2/12/21

Telephonic

5/11/2021

Telephonic

2021-20 Highlights | From the Chairman of the Board

This has been a busy and satisfying year for the Foundation's Board of Directors, despite the continuing challenges of the Covid-19 pandemic. We hold several meetings online every year to see how we're doing financially, and those meetings continued on schedule. In ordinary years (can we still remember what ordinary looks like?), we would meet face-to-face for our important annual meeting, which is jam-packed for the better part of two days. However, in 2021 as in 2020 our annual meeting was also held online, to stay on the safe side as the pandemic continued. We all missed being able to meet in person, but we accomplished all of our necessary business, which included approving the budget for the Fiscal Year, which runs from October 1st to September 30. I am pleased to report that the Foundation continues to be financially healthy, thanks to generous support from our members and careful management by Karla Dzienkowski and her staff.

Like many of you, I learned a lot regarding new research about RLS and how to manage my symptoms at the 2018 Patient Symposium in La Jolla, California. I was very much looking forward to another in-person meeting in 2021, but we had to postpone our plans for another year. In the interim, we've learned to take full advantage of the opportunity to meet online. Our Virtual Summit this past Fall 2021, with the online platforms of Zoom and Whova, was a great success, surpassing our hopes for a successful meeting. The Whova chat rooms were lively before, during, and after the formal presentations by scientific and medical experts, so that we could learn from one another as well as from the formal presenters. Even though it would have been great to interact in person with other attendees, there is a bright side to meeting online. Those of us with RLS can participate fully without worrying about having to sit still!

As you may remember, the Foundation conducted an important survey about what it means to live with RLS in September and October of 2020. This Patient Odyssey II survey asked those of us with RLS and our partners to answer lots of questions about our daily activities, our sleep patterns, our medications, and other information that helps to define how RLS affects our quality of life. About half of our members filled out that survey, and it took most of 2021 to compile the statistics from our answers and analyze them. Those of us with RLS know the impact that it has on our lives, and now we can show that impact with impressive statistics. You'll be hearing a lot more about how the Foundation plans to use those statistics to further our goals for better education, awareness, and treatment options for RLS. Stay tuned!

The last point I want to make relates to the wonderful group that keeps us informed about public policy regarding healthcare issues. The Health and Medicine Counsel (HMC) of Washington, D.C., represents non-profits like the RLS Foundation that need to know what Congress and various federal agencies are doing with regard to healthcare. Despite the importance of government healthcare initiatives to our RLS community, we simply don't have the time and expertise to track them ourselves. The HMC, through its dedicated leader, Dale Dirks and partner Philip Goglas, finds out what's going on in committee hearings and legislation in Congress, and in the National Institutes of Health, the Centers for Disease Control and Prevention, and other federal agencies, and makes sure we know about it. In their monthly briefings, weekly summaries, and regular emails in between, the Foundation learns about anything and everything at the federal level that can affect the RLS community. One of the highlights of my duties chairing the Board is participating in these regular briefings. When we ask our members to write to their elected officials in Washington, advocating for the RLS community, you can bet that the alert came from HMC. They also provide opportunities for the Foundation to join with other non-profits supporting legislation and other initiatives that concern us all. The bottom line is that when we send out a Call to Action, please take it seriously. HMC knows that advocacy by constituents, especially when they have a personal story to tell, makes a huge impact.

Best wishes,



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



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

RLS Symposium Reimagined

By Steve Smith, RLS Foundation Volunteer Discussion Board Moderator

On Saturday, October 17, the RLS Foundation conducted its second RLS symposium for patients since this forum was resumed in 2018. Obviously, the previous plans to meet at Johns Hopkins University in Baltimore had to be changed due to COVID-19. So, like many other 2020 activities, the conference went virtual.

Other than being virtual, the conference was similar in format to the one that was held in September 2018 in La Jolla, California. Following an introduction to the use of Zoom, participants were welcomed by the meeting moderator, Dr. Shalini Paruthi, a member of the RLS Foundation's Board of Directors, and the Foundation's executive director, Karla Dzienkowski. Presentations were then given by a variety of RLS experts, with titles such as: "RLS Basics and Treatments," "Dopamine Agonists: Approach with Caution," "Opioids for RLS," "RLS and Hypertension, Heart Disease and Stroke," "Iron and New Treatment Guidelines," "RLS and Genetics," "What's New in RLS Research?" and "RLS Advocacy: Making a Difference – Sharing Your Story." There was a Question & Answer session at the end of the summit to answer questions that participants submitted prior to and during the conference.

There was so much valuable information provided, but three topics really stuck out to me. The first was Dr. David Rye's discussion of the initial work to identify the genes that are associated with RLS – research that continues to this day. The second was a discussion of buprenorphine as a treatment for RLS. Buprenorphine is in a class of medications called opioid partial agonist-antagonists, and its use in the United States was restricted until recently. Now, it provides another option for those of us who suffer from side effects with some of the opioids. And the third topic was the unofficial announcement that an update to the consensus RLS treatment guidelines is expected to be published early in 2021.

Then, there was the presentation of not one, but two Ekblom Awards this year. The awards were given to Dr. John Winkelman and Karla Dzienkowski, which was a surprise to both recipients. The surprised look on Karla's face when her daughter opened the door and walked in with her award was priceless. As for Dr. Winkelman, his award was so unexpected that he received it and said his thank-yous while riding as a passenger in his car.

For me, one of the best parts about attending the conference in 2018 was the opportunity to meet others with RLS so that we could discuss our common challenges, exchange stories and simply get to know one another. There were plenty of opportunities to do this during coffee breaks, at lunch and during the Dine with the Experts portion. As a Foundation volunteer, this provided me with the opportunity to meet people I had been corresponding with for several years but had never actually met. The greatest limitation of the virtual aspect of this year's meeting was that we simply did not have the chance for one-on-one conversations. To compensate for this, a virtual RLS Happy Hour was held after the educational part of the meeting. We were broken up into smaller groups for conversations about the summit—Dr. Art Walters even joined one of the groups. Nevertheless, I missed the opportunity to talk with other participants and with the experts face-to-face about our common interests outside the scope of RLS.

Despite the inability to meet one-on-one, the conference was a highly educational meeting that gave everyone a chance to hear about the latest developments directly from the experts. The silver lining about the conference being virtual was that it would have been terrible to miss the chance to learn about progress during the last two years simply due to travel restrictions. Thanks to the efforts of the RLS Foundation staff and the various presenters, we did the same thing that schools have been doing since last March and made the best of the situation by using Zoom.

I was especially thrilled to hear that the Foundation plans to hold the next RLS patient symposium in October 2021 if the pandemic is contained and it is safe to assemble. So, as they say, stay tuned.



Steve Smith

2021 Webinars

September 15, 2021

RLS Medications: Are My Doses Too High?

Speaker: Dr. John Winkelman

August 19, 2021

The Signs of Augmentation: How to Manage It

Speaker: Dr. Mark Buchfuhrer

July 14, 2021

Older Adults and RLS: What's Different?

Speaker: Kathy Richards, PhD, RN, FAAN

June 4, 2021

I've Been Diagnosed with RLS, Now What?

Speaker: Dr. Andy Berkowski

April 23, 2021

The Latest in RLS Research

Speaker: Lynn Marie Trotti, Md, MSc

March 11, 2021

Brain Donor Project

Speaker: Tish Hevel, CEO of The Brain Donor Project

February 19, 2021

Technology, Sleep and RLS

Speaker: Dr. Jeffrey S. Durmer

January 5, 2021

Do My Grandchildren Have RLS?

Speaker: Dr. Shalini Paruthi

November 12, 2020

Genetics & Epigenetics: Their Relationship to RLS

Speaker: Christopher J. Earley, MB, BCh, PhD, FRCPI

October 8, 2020

Using Light to Increase Alertness and Improve Sleep

Speaker: Dr. Mariana G. Figueiro

Progress in RLS Advocacy During 2020

Despite the tension in and around Washington and the current pandemic, the RLS Foundation continues to make strides in advancing the community's perspective and legislative agenda. Highlights this year included the first RLS Virtual Advocacy Day in April, key awareness activities during September's RLS Awareness Month, an advocacy update to members at the October RLS Virtual Summit and participation in the Virtual Sleep Advocacy Forum in early October. The RLS Foundation continues to collaborate with other relevant sleep organizations to advance shared priorities. In October we also completed the RLS Patient Odyssey Survey II and we have begun sending the results to all Capitol Hill offices. We will continue to follow up as we end the 116th Congress and begin the 117th.

At the time of writing, Congress had yet to finalize all of the appropriation bills for Fiscal Year (FY) 2021, but below is a brief summary highlighting key successes from the appropriations process and the Foundation's success on several key initiatives, including opioid policy. Notably, the National Institutes of Health (NIH) and the Department of Veterans Affairs have specifically included a mention of restless legs syndrome in their appropriations bills – a victory for the tireless advocacy efforts of the RLS community.

Appropriations

Centers for Disease Control and Prevention (CDC)

- \$1.31 billion for Chronic Disease Prevention and Health Promotion, a proposed increase of \$66.5 million over FY 2020, including **\$3 million for a new Chronic Disease Education and Awareness Program**. This program will create a competitive process to award grants to expand public health education and awareness of a variety of diseases that do not currently have dedicated resources.
- \$593.5 million for Public Health Scientific Services, a proposed increase of \$38 million over FY 2020, including **\$5,000,000 for the National Neurological Conditions Surveillance System, equal to the level funded in FY 2020**.

National Institute of Health (NIH)

- \$3.89 billion for the National Heart, Lung, and Blood Institute, a proposed increase of \$264.39 million over FY 2020. **National Center on Sleep Disorders Research (NCSDR) is encouraged to continue to reinvigorate circadian and sleep disorders research activities and to further coordinate sleep research across Federal agencies.**
- \$2.62 billion for the National Institute of Neurological Disorders and Stroke (NINDS), a proposed increase of \$177.74 million over FY 2020. **Specific language encourages NINDS to bolster research activities into restless legs syndrome and pursue initiatives that advance scientific understanding of specific sleep disorders impacting patients.**

Department of Veterans Affairs (VA)

www.rls.org

- \$840 million for the VA Medical and Prosthetic Research Program, an increase of \$40 million above the FY 2020 enacted level. **The Director of the Defense Health Agency is encouraged to pursue initiatives that advance scientific understanding of sleep disorders such as restless legs syndrome that impact servicemembers.**

Department of Defense (DOD)

- \$370 million for the DOD Peer-Reviewed Medical Research Program (PRMRP), a proposed increase of \$10 million over FY 2020. **Sleep disorders and conditions that limit sleep are again included.**

Appropriate Patient Access to Treatment

Through outreach to key federal agencies and congressional committees, the Foundation continues to advocate for appropriate access to low total daily dose opioid therapy for patients whose RLS cannot be managed with other therapies. In February we visited the office of, among others, Senator (now Vice President-elect) Kamala Harris to discuss maintaining access to prescriptions for low total daily dose opioids and the importance of the patient perspective in any policy updates or new legislation. The office of Senator Lamar Alexander (R-TN), chair of the Senate Health, Education, Labor and Pensions Committee, which has jurisdiction over opioid policy, is keenly aware of the importance of maintaining access for patients who responsibly use an opioid for therapy. We also visited the office of Senator John Cornyn (R-TX), as the Foundation's headquarters are in Austin, and received continued support for our legislative priorities. Through our outreach, we are working to ensure that the RLS patient voice is heard and that our priorities are considered by policymakers.

On Friday, February 14, RLS Foundation leaders met with key personnel at the NIH, including NINDS, National Institute on Drug Abuse (NIDA) and the National Center on Sleep Disorders Research. Dr. Christopher Earley, Chair of the Foundation's Scientific and Medical Board, also attended these meetings, which focused on ongoing research. In addition to receiving an update of any new studies pertinent to our concerns, the RLS Foundation discussed the needs of our patient and research communities. Important results of the meetings included new collaborative opportunities with NIDA on opioid research and other areas of shared interest. Both NIDA and NINDS recognize the importance of the NIH NeuroBioBank to ensure that a sufficient amount of tissue is available to expand RLS research.

The RLS Foundation followed up with the leaders of the NeuroBioBank, who agreed to place the Johns Hopkins Restless Legs Severity Scale on intake forms to identify donors with diagnosed RLS. In addition, Tish Hevel, CEO of The Brain Donor Project, has agreed to present a webinar to educate the RLS community about The Brain Donor Project and the importance of the NeuroBioBank.

The Management of Restless Legs Syndrome: An Updated Algorithm

Restless legs syndrome (RLS) is a common neurological disorder affecting up to 10% of the population in the United States, with nearly 3% experiencing severe symptoms that require daily medical treatment. An article in the *Journal of Neural Transmission* in 2007 reported that it takes nearly 13 years from the onset of symptoms to the initiation of a treatment plan for RLS.

Much has changed in RLS disease management in the last eight years, which has led to the update of the 2013 RLS treatment algorithm by the Scientific and Medical Advisory Board of the RLS Foundation. The updated algorithm was published in the July 2021 edition of *Mayo Clinic Proceedings*, a leading peer-reviewed clinical journal widely read by physicians and often cited in scientific papers. Publication in this journal will ensure the availability of this information to a broad group of clinicians, including primary care providers.

Scientific discoveries since 2013 have led to the better understanding of RLS and new approaches to disease management that include:

Clinical Advancements

- Untoward side effects of dopaminergic therapy; knowledge and understanding of the long-term risks of augmentation, impulse control disorders and rebound
- Consensus guidelines for the iron treatment of RLS
- Consensus guidelines for RLS diagnosis, treatment and management during pregnancy and lactation
- Appropriate use of opioid therapy in low total daily doses for refractory RLS
- Improved RLS diagnosis, treatment and management in children and adolescents

Research Advancements

- Clinical trials for pregabalin and oxycodone
- Adenosine and RLS relationship
- Identification and replication of 13 new RLS risk genes and confirmation of six previously identified RLS risk genes using GWAS (genome-wide association studies)

These advancements relate to ongoing research into the underlying causes of RLS and the search for durable treatments and potential cures for the disease.*

The 2021 RLS treatment algorithm is divided into sections that outline detailed guidance on clinical best practices in RLS disease management, including:

- General treatment considerations
- Alpha-2-delta ligands and iron treatment as first-line therapies
- Iron treatment guidelines for RLS
- Dopamine agonists as a second-line therapy
- Treatment for intermittent, chronic-persistent, and refractory RLS
- Special patient populations and potential future therapies

The new treatment algorithm describes medication selection, use, dose and side effects. Decision trees and tables provide visual guidance for treatment consideration. Nondrug therapies and other approaches are highlighted, which include activities to stimulate the mind and the avoidance of medications and substances known to worsen symptoms. For example, RLS specialists who practice at certified RLS Quality Care Centers report that augmentation from certain medications is the number one reason that patients seek specialized care from a knowledgeable and experienced provider. The 2021 RLS treatment algorithm pays special attention to the use of combination therapies and the appropriate use of opioids in low total daily doses to treat refractory RLS – a common, yet manageable treatment challenge. For the first time, the new treatment algorithm also discusses RLS management in pregnancy, lactation and childhood.

The 2021 RLS treatment algorithm is a comprehensive approach to the management of RLS in the various stages of disease progression and across the life span. Michael Silber, M.B., Ch.B., lead author on the article and director of the Center for Sleep Medicine at Mayo Clinic, says, “This updated algorithm is based on current research, consensus documents and the combined practical experience of a team of practitioners highly experienced in the management of RLS. We hope it will provide practical guidelines for primary care providers and specialists who are needed to treat patients with this common and highly distressing disorder.”

The RLS Foundation has made this an open-access article, available for free download by patients, clinicians and researchers (see below). Executive Director Karla Dzienkowski says, “The publication of the 2021 RLS treatment algorithm is based on the latest scientific knowledge and clinical experience of RLS experts from around the globe who serve on our Scientific and Medical Advisory Board. I thank these members for their service to the Foundation and the RLS community and for their work on this seminal publication that furthers our mission and goals to educate and support RLS research leading to better treatments and a cure.”

*The RLS Foundation funds the only research grant program dedicated to RLS. Member support for the Foundation's Research Grant Program has funded nearly \$2 million for 47 grants to RLS researchers, whose research forms part of these key advancements. A revised RLS Research Grant Program protocol will be announced later this year to further the quest toward a cure.

Thanks to the support of our members, the Foundation is able to make this important article "open access" – freely accessible to the public at no cost. We encourage you to share the article with your family, friends, healthcare providers and all interested individuals who treat and manage your RLS.

Download at www.rls.org/21Algorithm



Leaving a Lasting Legacy Through Brain Tissue Donation

The study of human brain tissue has led to advances in the science of neurologic diseases and disorders. Currently, there is an urgent need for brain tissue donation for a variety of neurological disorders, including RLS.

The use of donated brain tissue in RLS research will advance understanding of the disease and help put RLS to rest for future generations. Although life-and-death matters are never an easy discussion for families, breakthroughs in neuroscience come from individuals who make this ultimate gift to medical research. Now is the time to think through your own wishes and let them be known to your family.

The Brain Donor Project is an innovative not-for-profit group that provides support to the National Institutes of Health (NIH) by making high-quality brain tissue donated by persons whose symptoms and diagnoses are well documented available for neurologic researchers. The Brain Donor Project supports the brain banks of the NIH, called the NeuroBioBank, by simplifying the donation process, coordinating donations and making this tissue widely available to qualified researchers studying specific disorders.

Solving the riddle of highly perplexing disorders like RLS depends on the willingness of those suffering from the disease to donate their brains for scientific study. If you would like to help, here are some basic facts about tissue donation:

- Signing up on a general form to be an organ donor does not mean your brain is included. Separate arrangements need to be made for brain donation in advance.
- Donating your body for anatomical study does not mean your brain will be used for neurological research. Again, separate arrangements must be made in advance.
- People who have not been diagnosed with a neurological disorder can also donate brain tissue. Brain tissues used as a control are needed for medical research studies to compare pathologies to the “normal.”
- Brain donation will not affect or delay funeral services.
- There’s no additional cost to the family for brain donation by a loved one.

Starting the process is easy: Go to www.braindonorproject.org to learn about brain donation. If you have questions that are not answered on the site, visit their “Contact Us” page to get the answers you need. When you’re ready to sign up, click on the “Brain Pre-registration” button at the top-right and complete the online form. You will be asked to provide your contact information and confirmed medical diagnosis for any neurological condition(s); your documented medical history will be critical to verify research findings.

Within 10 business days after submitting the online form, you’ll receive

the next set of registration forms for one of the brain banks within the NIH NeuroBioBank. Consent and release forms will be delivered to you, along with instructions for your family or the person you have appointed as your executor. Upon your passing, your body will be transported to a medical or mortuary location to collect your brain, at no cost to the family (all cost is covered by the NeuroBioBank). Donor preregistration ensures the timely coordination with all parties and delivery of your gift to the NeuroBioBank. Your body, with no disfigurement, is then released to the family for funeral arrangements. Open casket is still an option.

If you would like to make this precious gift to advance RLS research, please visit braindonorproject.org and start the process. Thank you for considering this invaluable gift that will benefit future generations.

Member-Funded RLS Research Grant Program Becomes More Targeted

By Stefan Clemens, PhD, HdR, Chair, Research Committee, RLS Foundation Scientific and Medical Advisory Board



Stefan Clemens, PhD

The RLS Foundation's Research Grant Program is a return-on-investment initiative; member contributions lead to advances in the understanding of RLS and to potential improvements in treatment options. The RLS Foundation established the Research Grant Program in 1997 under the leadership of Bob Waterman (Board of Directors member with two terms as Board Chair, 1995–2005 and 2011–2019). The idea was to award small research grants seed funding to provide the critical data necessary to secure additional research grants from national and international agencies.

The first research grant was awarded in 1999. Since then, an average of about two projects per year have been funded. To date, 48 grants have been supported by the RLS Foundation, totaling nearly \$2 million in research funding. These 48 projects were carried out by 41 clinicians and researchers. Their findings have led to over 25 publications in a wide range of neurological and neurobiological journals and books. More importantly, the seed-funding grants provided by the RLS Foundation have led to over \$10 million in additional grant support from other sources, thereby further strengthening research in the field of RLS.

Research grant applications are first reviewed by the RLS Foundation's Scientific and Medical Advisory Board (SMAB); details about its members can be found at www.rls.org/SMAB. The SMAB consists of both clinicians and basic science researchers who are responsible for monitoring RLS medical and scientific research issues and bringing their respective expertise to the grant review sessions. In addition to reviewing research grant applications, the SMAB reviews all Foundation publications and advises the RLS Foundation's Board of Directors on issues of medical or scientific interest and importance. A group of external specialists approved by the SMAB has agreed to serve as grant reviewers to strengthen the rigor of the research supported by the RLS Foundation and to provide additional guidance. Research grant proposals that receive a favorable decision by the SMAB are then presented to the RLS Foundation's Board of Directors for funding consideration.

Since its inception, the grant program has focused on specific areas of study: genetics, epidemiology, iron regulation, neurophysiology, the development of novel treatment options and RLS animal models. Based on the findings of research in these areas, the SMAB recently developed new guidelines and funding priorities for future grant proposals that are summarized here:

Brain Iron Homeostasis: RLS is regularly associated with changes in brain iron function.

- Research Target: Elucidate the biological factors that contribute to RLS-relevant alterations in iron homeostasis in the nervous system.

Genetic/Epigenetic Factors: Multiple studies have underscored the role of specific genetic and epigenetic factors in the development of RLS. Genetic factors refer to factors that stem from familial heredity or gene mutations; epigenetic factors refer to changes in a person's genome as a function of, for example, exposure to environmental factors.

- Research Target: Identify genetic and epigenetic factors and their interactions in RLS patients and develop animal models in which these interactions can be better explored in mechanistic detail.

Comorbidities: RLS is often associated with a wide range of other neurological and non-neurological diseases. What is the impact of RLS on other ailments such as cardiovascular disease, sleep apnea or Parkinson's disease?

- Research Target: Identify any possible causal links between RLS and these other diseases.

Neurobiological Interactions: A variety of signaling molecules have been identified in the nervous system that are changed with RLS. It is often unclear, however, if the changes in these signaling molecules are themselves causing RLS symptoms or if they are a result of other changes.

- Research Target: Identify RLS-relevant neurotransmitters and neural pathways that may be implicated in RLS.

continued on next page

2021 - 2022 Highlights | Find a Cure

Therapeutics, Pharmacological Treatments and Therapeutic

Responsiveness: A wide range of medications is used to treat RLS, and many of these compounds can lead to unwanted side effects, such as tolerance or augmentation.

- Research Target: Explain the pharmacology of existing RLS medications, develop novel approaches that show better efficacy or fewer side effects, and generally advance knowledge toward development of better treatments of RLS.

Nonpharmacological Treatments: In addition to current pharmacological treatment options, RLS patients may find benefit from nonpharmacological approaches. These include, but are not limited to: transcranial or spinal magnetic or electric stimulation; transcranial direct current stimulation; cognitive behavioral therapy; and intermittent compression of the lower limbs.

- Research Target: Describe the mechanisms in nonpharmacological treatments that lead to the improvement of RLS symptoms.

Novel Diagnostic Markers: Identifying RLS relies on the subjective feedback of a patient to their clinician.

- Research Target: Develop better assessment techniques or devices that will provide improved outcome measures for clinical research.

The RLS Foundation plans to open a new series of biannual calls for submissions of research grant applications with rotating main themes, in which submissions will be prioritized around the above-listed research areas. The RLS Foundation will also be seeking grant submissions from specialists in these respective areas, to increase the scientific depth and widen the breadth in RLS-related research. Additionally, the RLS Foundation has set aside funds for one predoctoral or postdoctoral fellowship grant per year to attract promising young investigators to the field. To contribute directly to that fund, go to www.rls.org/AllenFund.

These changes to the RLS Foundation's Research Grant Program will improve our understanding of RLS in the clinic, spearhead new approaches and treatments in the lab, identify new and emerging drugs and technologies, and improve patient outcomes by engaging an increasing number of clinicians and researchers dedicated to finding a cure for RLS.

RLS Foundation Levels of Giving

At the RLS Foundation, we rely on private donations to make our work possible. While we do receive some industry grants, our lifeblood is you and your commitment to our mission. We cannot thank you enough for the support you give every year.

Unrestricted gifts give the Foundation the flexibility to target funds for programs and projects that are in the most need of financial support.

Restricted gifts may be designated to three areas: Quality Care Centers, education and research. Donations to these funds are earmarked for special projects that may complement your intentions more closely.

Monthly giving allows you to spread your donation out over the year and enables us to count on a more even stream of gifts. You can also choose to restrict your gifts with this option. Monthly giving can be done by setting up a recurring credit card gift.

Tax-deductible donations are the quickest and easiest way to give to the RLS Foundation. Checks payable to the RLS Foundation or credit card donations completed online are fully tax deductible and provide an immediate source of income for programs.

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

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

If you would like to learn more about planned giving, please contact us at 512-366-9109 or info@rls.org.

Levels

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

Thank you!

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

Leaders**(\$10,000 or more)**

Anonymous
Ronald and Sharon Barrett
Dorothy A. Caudill
The Dzienkowski Family
Dr. Kaye Herth
Laura S. Hoffman
Gregory C. Oberland
Nancy S. Passanante

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

Anonymous
Mr. Louis Adler
Mr. Tim Bailey
Mrs. Marcia Ball
Russ Buschert
Pickett M. Guthrie
E. W. Littlefield, Jr.
Ms. Catherine MacMillan
Mrs. Jill Mitchell
Carolyn Mohn
Carla Rahn Phillips &
William D. Phillips
Mr. and Mrs. Paul Rochester
Mr. & Mrs. E. Randall
Smolik
Mr. Aleksandar Totic
George Uhl, MD, PhD
Dan Vreeland

Patrons**(\$2500 to \$4,999)**

Peter and Incy Brooks
Charles & Ellen Brown
Ms. Felicia M. Cashin
Tom Gardner
Charles C. Gould
George Grandison
Marilyn and Robert Marlette
Mr. Rex E. McCrary
Mr. Peter Nostrand
Mr. Freeman H. Smith III
Jan A. Sogge and Louis
Roberts
Tim & Kristin Thornton
Peggy R. Walker-Conner
Cal & Grace Walstra
Jon Wellinghoff and
Karen Galatz

Sponsors**(\$1,000 to \$2,499)**

Mrs. Gela Altman
Philip M. Becker MD
Inez Boettcher
Mrs. Gail S. Buckley
Brad Burkey
Ms. Caroline Chamales
Ms. Barbara E. Clucas
Lee C. Coates
Ms. Carol Connolly
Dr. and Mrs. James R.
Connor
Miss Heather Cornwell
John Daly
Anne B. Dorsey
Mr. and Mrs. Louis
Echavarria
Mr. James B. Fullerton
Ms. Vera M. Gerhardt
Chip and Margie Gillis
Ms. Elizabeth Grant
Ms. Anne W. Hammond
Mr. Thomas Hartzog
Mr. James Hemak
Mr. Dyke Henderson
Caren Hill
Mr. Dean Houdeshel
Mr. Clyde L. Humphrey
Byron C. Jones PhD
Mrs. Roberta J. Kittredge
Mr. Kevin Kohagen
Mr. James Krall
Colin MacKenzie
Mr. Patrick McIlrath
Pat & Diane McKeague
Mr. Howard McNally
Ms. Jacqueline C. Morby
Mrs. Lindy Munoz RN
Kenneth F. Myszka
Mr. Barry Otterholt
Shalini Paruthi MD
Donna and Randal Peterson
Judy Phillips
Ms. Lisa A. Pugh
Lori Schifrin
Mr. Allen Secrest
Linda Secretan
Mr. and Mrs. Stephen N.
Smith PE
Dr. Craig Snyder
Mr. Robert E. Spangler
Mrs. Richard Steinheider

Mr. Jack Stone
Dr. Gilbert Storms
Helen W. Sutphen
Cindy Taylor
Grant P. & Sharon R.
Thompson
Robin Tost
Eilene Toughy
Mrs. Janet Tschantz
Karen Walborn
Ms. Joy K. Walker
Ms. Margaret Watson
Ms. Helen Wheeler
Ms. Toby Woodhouse

Sustainers**(\$250 to \$999)**

Anonymous (27)
Mr. Jesse Adams
Mrs. Betty Affisco
Mr. and Mrs. Ralph L.
Albright
Ms. Melba Alderman
Stirling Aldrich
Harriet Anani
Mr. Jerry Andersen
Evelyn M Anderson
Guy and Dona Armstrong
Ms. Joan Arsenault
Mrs. Jill Bader
Drs. Jacquelyn and Scott
Bainbridge
John W. & Mary C. Baker
Mary and John Baker
Mr. Rich Barra
Lois E. Belohlavek
Paul H. Bergh
Mr. Richard Billings
George and Linda Bone
Mr. and Mrs. George F.
Bone
Mr. Jeffrey Borofsky
Mr. William Bossenberger
Mrs. Kay Bowers
Mr. Bruce Bredland
Dr. & Mrs. James Breece
Ernie Bruce
Mary R Burns
Mr. Richard C. Burton
Ms. Karen Byrne
Ken Campbell
Susanne Campbell
Dr. Margaret Campbell
Gregory and Carolyn Carter
Anne R. Chalfant
Mr. John Champ, Jr.
Mrs. Kitty Champlin
Bonnie Christensen
Allison Whitney Coleman
Mrs. Rei M. Colling
Mr. Laurence Conley
Sheila C. Connolly
Mr. and Mrs. Clive Cook
Mr. Charles Cooke
Ms. Lorraine F. Coughlan
John Wesley Cox
Mr. Roger Crooks
Ms. Mary Cuseo
Mrs. Patrice Deutsch
Mindy and Joe Dill
Carol T. Edmiston
Mr. David Ellefson
Mary Ann and Jim Emswiler
Mr. and Mrs. Stephen Enk
Mr. Bryan Fagan
Mr. Robert C. Fairly
Mr. Sigo Falk
Barbara A. Faraone
Ms. Lisa Feinstein
Kathryn Figueroa
Ms. Kristi Fillner
Ms. Beth Fischer
Mary Fransen
Ms. Mary Fritz
Mrs. Mehri Frost
Mrs. Louise Furcolo
John D. Gage
Marcella Gallagher
Mr. Jay Gerard
Lucynda "Cindy" Gibbs
Ms. Janna Gies
Mr. Jerry Gilland
Ms. Nina Glasner
Ms. Charlotte B. Goddin
Patricia Golab
Mr. Doren Goldstone
Mr. Neil Greenwood
Diane L Grefer
Ms. Suzan K. Griffin
Rene Guyton
Mr. Carl F. Hagenmaier Jr.
Mrs. Elizabeth M. Haning
Ms. Saira Haq
Dr. and Mrs. Matthew R.
Harmody
Mr. Ali Hashmi

Robert G. Hasty
 Ms. Susanne Havlic
 Dr. Deborah Hayes
 Jim Healey
 Ms. Julie Herbert
 Mr. Gordon Herron
 Mr. Gilbert Heth
 Dr. Arthur M. Hewitt
 Ms. Monica C. Hill
 Ms. Matthew Hill
 Ms. Gail Hill
 Mrs. Tina Hines
 Mr. Lloyd Hittle
 Mr. Stanley Hoernicke
 Dr. and Ms. Dean G.
 Holland
 Mr. Peter K. Hoover
 Ms. Isabella W. Horsky
 Annette & Pat Hunter
 Peter and Marcia Hunter
 Mrs. Annette S. Hunter
 Mr. Peter Hunter
 Stephen H. Iser
 Mrs. Maureen Janda
 Rev. Harold E. Johnson
 Elizabeth R. Jones
 Mrs. Anne Markey Jones
 Dr. Jeffrey Jones
 Mr. and Mrs. Hisashi Juba
 Mr. and Mrs. John Juvinall
 R. Fred Kautz
 Mrs. Linda M. Kawtoski
 Ms. Judith Kaye
 Mrs. Judith Kearney
 Mr. Terry Keiper
 John Kievit
 Michael J. Kikta, MD
 Ms. Doreen Kim
 Ms. Mary King
 Mr. Jeffrey Kloc
 Mrs. Nancy Koch
 Brian B. Koo MD
 Judith Kuenzli
 Mr. Michael Kun
 Mrs. Faye G. Kunze
 Linda LaBerge
 Mrs. Cynthia Landgrebe
 Kim Larrow
 Mr. Michael T. Lavelle
 Amelia Lewellen
 Mr. Robert Lewellen
 David A. Lewis
 Ms. CJ Liang
 Mrs. Jennifer Lindsey

Dorothy Liston
 Paul Lohrenz
 Ms. Andrea Lowery
 Mr. Barry Lynn
 Tom E. Main
 Ms. Christina Marciniak
 Mr. and Mrs. William
 Marietta
 Mr. Rob Marshall
 Mr. Robert Martindale
 Jerry McCaslin
 M. Lynn McCracken
 Mr. Tim McDonald
 Linda McKenna
 Dr. and Mrs. Joseph
 Messenbaugh III
 Dr. Hiba Mihyar
 Wayne L. Miller
 Mr. and Mrs. Darius Mistry
 Karen Mokrzycki
 Dr. Frits Mooi
 Nellwin E. Moore
 Mrs. Janine Moore
 Mr. David Moulton
 Mrs. Diane P. Moyer
 Roger Mulvihill
 Mr. George Murray
 Ms. Tess Nelson
 Ms. Eloise Nicodemus
 Jim & Barbara North
 Ms. Rebecca OConnell
 Ms. Philomene Offen
 Ms. Nancy K. Olson RN
 William G. Ondo MD
 Mr. Craig Oren
 Ms. Marilyn Parks
 Mrs. Donna Parshalle
 Mr. William Pattinson
 Lorys Penrod
 Professor Robert J. Peroni
 Peggy Peterman
 Dr. G Peters
 Dr. Matthew Petrie
 Starla Phelps
 Mr. Gary Pollatz
 Mrs. Christina M. Price
 Mrs. Carolyn Quick
 Mr. Thomas Rader
 Mr. John Ralston
 Emily Rand Breitner
 Dr. Rollin J. Randall
 Mrs. Joyce Ratkowski
 Mr. Walter H. Rauser
 Ms. Sara Reed

Daryl and Ella Reid
 Shirley Reseck
 Gerald B. Rich, MD
 Kathy Richards PhD, RN,
 FAAN
 Joyce E. Richardson
 Ms. Kathryn W. Roberts
 Mrs. Sue Sabaloni
 Ms. Sonnhilde Saunders
 Mrs. Elizabeth O. Scheben
 Mary M. Schelb
 Ms. JoAnn E. Schoenegge
 Dr. Brian Schrag
 Ms. Jennifer Schultz
 Mr. John Schwager
 Ms. Ursula Scribner
 Mr. Allan Segel
 Mrs. Diane Segel
 Mr. and Mrs. F R. Sekowski
 Mr. Daniel G. Shoaf
 Michael H. Silber, MB, ChB
 Dr. Ronald Silvestri
 Mr. and Mrs. Michael K.
 Smith
 Mr. Duncan M Smith
 Sherry Smith
 Ms. Jacqueline A. Snodgrass
 Michael & Regina Spaulding
 Mrs. Judy M. Staples
 Ms. Virginia Steel
 Mr. Reed Sullivan
 Ms. Alida D. Sullivan
 Nan Suydam
 Susan Theiss
 Mr. Tim M. Tierney
 Mr. Melvin G. Trammell
 Mr. John Trefethen
 Ms. Antonia Trost
 Lynn Marie Trotti, MD,
 MSc
 Mr. Thomas E. Turk Jr.
 Mr. Randall Vermillion
 Mr. Richard Vezza
 Marguerite H. Wagner
 Ms. Luann Wagnon
 Christine Tunison Wait
 Richard Warburton
 Mr. Peter Warren
 Neva M. Warsen
 Judy and Bob Waterman
 Mr. Jeffrey Weill
 Ms. Victoria Welch
 Ms. Sheila Wengert
 Elise & Woody Widlund

Margery Widroe
 Mrs. Diane R. Wilds
 Ms. Marilyn Wilkes
 Larry and Fran Williams
 John W. Winkelman MD,
 PhD
 Mary Lou Wohlhieter
 Mrs. Lucy H. Wong
 Diane W. Wood
 Paul E. Wylie, MD
 Ms. Kathleen Zaback
 Mr. Dean Zarras

Supporters (\$100 to \$249)

Anonymous (38)
 Mr. James Abbott
 Mr. Mark Abramovic
 Mr. James Acheson
 Anne Adams Gorry
 Mr. Jay D. Adkisson
 Mrs. Carol Agnew
 Mr. William Ahern
 Mr. Joseph Albert
 Dr. Allison Aldous
 Mr. John Alexanderson
 Ms. Mary Alexon
 Ms. Paije Alfano
 Serena Alleman
 Ms. Faith Allen
 Mr. Richard Allen, Jr.
 Mrs. Cathleen Allen
 Janet L. Allis
 Mrs. Donna Anastasi
 Mr. & Mrs. Leland E.
 Anderson
 Mrs. Patricia Anderson
 David W Anderson
 Mrs. Mary F. Anderson
 Dr. Ronald E. Anderson
 Ms. Mary Clare Andrews
 Mr. Richard Appleby
 Dr. Don Arbuckle
 Mrs. Susan Arndt
 Dr. Colin Arnold
 Ms. Carole S. Arthur
 Ms. Susan Aspelund
 Ms. Lee Aten
 Ms. Lee Aten
 Richard C Austin MD
 Mr. Michael Austin
 Carmen Ayala
 Mr. Donald N. Babb
 Ms. Mary Bandura

Ms. Christine Barbour	Lucy L. Brown	Mrs. Debbie Costa	Mr. Peter Edwards
Bob Barker	Mr. Robert Brown	DeElda L. Cotanche	Mrs. Dorrit W. Edwards
Ms. Shari Barker	Mr. Susan R. Brown	Ms. Suzanne Covert	Ms. Sherryl Eldridge
Mr. G H Kipp Barkley	Ms. Mary W Brown	Mrs. Barbara Cox	Roberta Elliott
Ms. Cynthia M. Barnard	Mrs. Gwen Bruington	Mrs. April Cox	Mrs. Sylvia Ely
Ms. Agnes R. Barrett	Mr. Alexander Bruner	Ms. Barbara Crain	Ms. Kathryn Endo
Mr. David Barrett	Mr. Terry Bruton	Elizabeth Crawford	Mr. Randall Engel
Mr. Robert Barry	Mr. Jeffrey Bryan	Mr. William S. Creveling	Linda Engfer
Mrs. Peggy Beach-	Ms. Jeffrey Bryan	Mr. Richard Cronin	Mr. Marv Enslin
McLaughlin	Mrs. Julie Bryant	Mr. Dennis Crouch	Mr. Fredric J. Entin
Ms. Susan Beachler	Ms. Jody Bucci	Ms. Isaac Crouch	Mary Jo Enyeart
Rev. Wendy Beasley	Mr. Allen Bucknam	Kathleen B. Crowley	Mrs. Laurel Euler
Mr. Tim Beech	Katherine Bufanio	Mr. John Crowley	Mr. Robert Ewart
Ms. Misty Beeler	Mrs. Janice Buffler	Mr. Harry Cummings	Ms. Susie M. Fagen-Wirges
Ms. Phyllis Beery	Mrs. Judy Bunkall	Mary D. Cushman	Mrs. Renee Farmer
C. Beil	Mr. William Burch	Ms. Yvon Dacayana	Mrs. Julia Farrell
Betty Lee Bell	Ms. Linda A. Burk	Jonelle & Tom Darr	Ms. Barbara Farrell
Mrs. Cynthia B. Belyeu	Margee Burke	Mr. and Mrs. Thomas Darr	Ms. Marla Feldmar
Darleen Bennett	Ms. Eden Buron	Ms. Dale David	Mr. Larry Felix
Diane E. Bennett	Dr. Sherrill Busboom PA-C	Mr. Bruce H. Davidson	Ms. Margaret Felton
Mrs. Patricia Benton	Margaret Butkereit	Ms. Linda Davies	Mr. Gary Ferguson
Mr. Gerry Berglin	Ms. Deborah Cahn	Mrs. Elaine F. Davis	Mr. Eugene L. Ferries
Mrs. Juliet Bergner	Mr. Dave W. Candler	Mrs. Delores Davis	Mrs. Christa Fineshriber
Dr. Joseph Andrew A.	Mr. Edward Cantrall	Carol A. Decker	Ms. Lori Finger
Berkowski MD	Mr. Al Capitanini	Ms. Veda I. Decof	Ms. Margaret Finnegan
Richard and Cathy Berman	Mr. John Carney	Dr. Edward T. Dehan	Rick and Barbara Firmine
Lola Bermudez	Mr. Paul A. Carney	William W. Denton, III	Lee J. Fischer
Barbara Berrier	Laura Case	Mr. Ronald DeRuiter	Don and Carol Flammer
Mrs. Janet Berrill	Mr. Bill Cassen	Ms. Helle K. DeSimone	Mrs. Sue Fletcher
Anne and Don Berschback	Mrs. Patricia A. Cerny	Mr. Charles Dickinson	Susan Flintom
Don R. Berschback	Mr. Paul Chalkis	Ms. Kathy Dimiduk	Emmett T. Florea
Ms. Nataliya Bettis	Mr. Robert Chambers	Dr. Maureen Dinges	Mr. Mark Foglesong
Mrs. Phyllis Bevivino	Mark Chase	Elizabeth Dirkx	Dr. Harriet Forman
Elizabeth L. Bewley	Mrs. Doria Chege	Mr. Don DiRusso	Janet M. Forni
Ms. Margareta Bjorkegren	Mrs. Rochelle Cheifetz	Mr. John Dobrinski	Dr. Sara Frampton
Ms. Sybil J. Blankenship	Ms. Sandy Chockla	Dr. Robert C. Doekel MD	Ms. Karin Frederick
Ms. Marianne Bliley	Sudhansu Chokroverty, MD	Mrs. Denise Dolge	Mrs. Penelope Frederickson
David Bloomberg	Ms. Susan Christiance	Mr. Bruce C. Dolin	Mrs. Catherine Freeman
Ms. Susan Boehme	Ms. Donna Chronic	Mr. James Dougherty	Mr. Robert Freese
Ms. Linda Boly RN	Mr. Ron Cicchini	Andrea C. Dragon	Mrs. Andrea Friede
Mr. Thomas Boris	Mrs. Sue Ellen Claggett	Mr. Ron Draxler	Ms. Linda R. Fuehrer
Carolyn P. Bower	Mrs. Dawna M. Clark	Mr. Richard Ducotey	Mr. & Mrs. Mastern Fuller
Dr. Agnes Bowling	Ms. Donna Clark	Paul H. Dudek	Mark T. Gabr MD PC
Ms. Linda Bowman	Caro Claus Artz	Paul B. Dudley	Ms. Sylvia R. Gallagher
Dr. Kenneth H. Bradt	Ms. Mary Ann Coldwell	Mr. John T. Dumas Sr	Ms. Marilyn M. Gampel
Thelma Bradt	Ben Cole	Dr. Jean Liming Dundas	Mr. Cesar Garcia
Mrs. Julie V. Brady	Mrs. Danielle Carole	Mrs. Sue Dunn	Art Garman
Ms. Carol Bretta	Comeau	Mr. Bill Durako	Jeannine Garrett
Mr. Clarence Brink	Mrs. Karen Compton	Mrs. Judy Durant	Mrs. Albert Gaskill
Betty M. Brockington	Mr. George Connell	Mrs. Toni Dwyer	Mr. Robert Gatanis
Mr. Willard Bronson	Mr. George Connell	Ms. Deborah Early	Mr. James Gaynor
Joel M. Brooks DDS	Susan Cooley	Ms. Barbara Earnest	Carolyn Geduld
Jane E. Brown	Mr. Buddy Coronado	Ms. Diane Edell	Mr. John Geisler

Mrs. Kay Gent
Mr. Peter Gerame
Ms. Judy L. Gerardi
Ms. Kenneth German
David Gilbertson
Ms. Patricia Gillan
Ms. Margaret Gillis
Mr. William Gilster
Ms. Sheilah Glover
Mrs. Ruth A. Goats
Ms. Judy Goebel
Kenneth Golden
Mrs. Dorothy D. Goldstick
Ms. Violet Gong
Mr. Earl Goodwin
Mrs. Ruth K. Gordon
Ms. Charla Gordon
Mr. Robert L. Gorecki
Ms. Wilma J. Gormley
Jane Gorski
Ms. Mary Gossett
Ms. Ruth Graber
Ms. Patricia Grady
Erica Grantmyre
Mrs. Jasmin Grautstück
Ms. Jane B. Green
Sharon J Green-Hennessy
PhD
Judith Greff
Dr. Courtney Griffin
Ms. Nina Griffith
Mr. Donald Griggs
Ms. Valerie L. Grosch
Ms. Frances Gruen
Mrs. Shiras Guion
James A. Guldan
Ms. Janet Gunther
Mr. Brandon Gustafson
Douglas and Marcia Haas
Mrs. Judy Haase
Susan W Carey
Mrs. Carolyn M. Hahne
Mrs. Richard Hallock
Debby
Mr. Charles Hamilton
Donald and Mary Ann
Hamman
Mrs. Cheryl Hanselmann
Mrs. Sharon Hansen
Mrs. Patricia Hansen
Ms. Elizabeth H. Hardison
Mrs. Nancy C. Hardy
Mrs. Ren Harman

Mr. Ralph Harmon
Mr. Gordon Hartshorn
Dr. and Mrs. Victor Hauser
Mr. Jaime Hazan
Jeannette and Wilson Heath
Mrs. Marguerite Heaton-
Colella
Mr. Paul Heiman
Mr. Carl Heintzelman
Eleanor Heinz
James Heinz
Mr. William Heinz
Mr. and Mrs. Jay Heitman
Mr. Randolph J. Helms
B. Kay Henderson
Dr. Stephen Henderson
Dr. Kevin D. Hennessy
Ms. Sheila Herman
Mrs. Dolores Hermann
Ms. Donna Heroux-Everson
Ms. Michelle C. Hester
Dr. Susan Hetherington
Ms. Sara L. Heydari
Mrs. Katherine A. Higgins
Mr. Greg Hill
Sue Hille
Mr. John D. Himmelfarb
Ms. Connie Hodge
Patty Hodgins
Judith Hoffman
Mr. Douglas Holden
Mrs. Mabel E. Hollender
Ms. Karen R. Hollingsworth
Mrs. Irma Hornbeck
Ms. Julia S. Horowitz
Jim Horton
Mrs. Charlene M. Houghton
Ms. Rachel Hovne
Ms. Stephanie Howell RN
Mr. Jonathan Hoyt
John T. Hubbard Jr.
Joan Hudgins
Mr. James S. Huffman
Mr. Doug Hull
Sr. Sr. Phyllis Hunhoff
Ms. Virginia Hurdon
Mr. Mickey C. Hurry
Mr. Ronald Hutter
Lucille L. Hynes
Ms. Willemien Insinger
Susanne Isbill
Mrs. Gail Jackson
Mr. Ed Jacobsen

Mrs. Patricia Jankelson
Glenn W. Jeffrey
Ms. Margie Jetter
Ms. Carol Johns
Mr. Thomas Johnson
Mrs. Audrey Johnson
Ms. Catherine Johnson
Ms. Erica Joiner
James and Ellie Jones
Ms. Judy Jongsma
Mr. Norihisa Juba
Mr. Edward Kalinowski
Mrs. Kathleen Karmy
Ms. Leslie Kean
Garry Kearns
Ms. Peggy R. Keith
Mrs. Sarah P. Kellen
Mrs. Virginia Kelly
Mr. Jayson Kendrick
Allan R. Kerze
Mrs. Randy Keyne
Nancy Kindness
Ms. Mary King
Ms. Kelly Kipkalov
Mrs. Anita Kirby
Mrs. Susan M. Kirkland
Mr. Jeffrey Kirsch
Ms. Lucy Klocksinn
Ms. Kim Korringa
Rosemary Kosmak
Kathleen Kotchi
Dr. Mark Kozlowski
Mrs. Brenda Kraetz
Dr. Laurence Krieg
Phil Kroeker
Ms. Birgitte Krogh
Ms. Gary Krueger
Mr. Ta-hsia Kuo
Mrs. Jorjann Kuypers
Yuan-Yang Lai PhD
Ms. Susan S. Laidlaw
Ms. Kathleen Land
Mr. Brian Landsberg
Mr. John Lane
Mr. Charles Langelier
Betty Lapham
Mr. Larry Larson
Mr. Lang Larson
Ms. Nancy Lauby
Ms. Edith Lavin
Gee Lawton
Mary Leach
Mr. Lane Leckerman

Mr. John Lehmann
Mr. & Mrs. Leon Levy
Mr. William Lewis Jr
Mrs. Maureen A. Lightbody
Gary and Barbara Lind
Ms. Martha P. Littlefield
Eileen S. Lorenz
Mrs. Patricia Loveland
Lorinna W. Lowrance
Mrs. Ellen L. Luedtke
Lois H. Lummer
Mrs. Martha Lussenhop
Mr. Rick Lybbert
Mr. Ronald Lyon
Barbara B Mack
Tom Mack
Dr. and Mrs. Neil A.
MacKenzie
Dr. Loganathan Mahadeva
Mrs. Saida S. Malarney
Ms. Marisa Maldonado
Ms. Brenda Malewitz
Mrs. Betty Malone
Mrs. Tove Mandigo
Terry and Jan Manning
Mrs. Joan Marett
Mr. and Dr. William
Marietta
Albert W. Marshall
Carol Mayer Marshall
Mr. P Severin Marsted
Mr. David Martens
Mrs. Debra Martin
Mr. Keith Martindale
Mrs. Cheryl Masters
Paul S. Mattheiss
Rev. James & Jean Matthews
Alice J. Maxin
Mr. Steven McCann
Mrs. Pauline McCharen
Ms. Jeanne M. McDonald
Peter and Caroline McElroy
Ms. Susan McGrath
Ms. Suzanne McIntire
Mr. Robert McIntyre
Ms. Angel McMorrow
Ms. Lisa L. McPherson
Dr. Barbara Melamed
Ms. George Mell
Ms. Karen L. Mendonca
Mrs. Beth Menefee
Charlene R. Mentink
Ms. Emily G. Messier

Ms. Ingrid Meyer	Mr. Timothy Olson	Mrs. Sharon Rigdon	Dr. Dee Shepherd-Look
Mr. Larry Michals	Ms. Louise Olson	Mr. Jay Riojas	William D. Shiels
Elsa Michitsch	Frederick K Orebaugh	Ms. Barbara Riser	Ms. Marcia Sholty
Mr. Gerald Migely	Mr. Hamilton Osborne	Nancy Ritchie	Dr. Louis Siegel
Mr. Douglas Miller	Mr. Ronald W. Panter	Carol Roberts	Dr. Frederick Siem
Mr. Douglas C. Miller	Ms. Kathleen Parker	Mr. J David Roberts	Dennis J Sienicki
Sally Mills	Mr. Ted Parrish	Mr. Paul Rockwell	Mr. Jonathan Sigall
Dr. Craig Mills	Dr. Susan Partridge	Mr. Lawrence Rockwood	Ms. Patricia Skillman
Ms. Sarah Milmet	Ms. Carolyn K. Pater	Ms. Leigh Anne Rogoski	Mr. Kevin Skipper
Mrs. Ida R. Minor	Robert J. Patterson	Ms. Cheryl Roman	Mr. David Slay
Mrs. Carmel Mitchell	Mr. Craig Payken	Thomas A. Romig	Frances Cain Slote
Mr. Eric Moen	Ms. Sharon Pearce	Mr. Harvey P. Root	Ms. Annette Slovic
Ms. Donna Moffat	Mr. Thomas N. Pearson Sr	Dr. Christopher Ross	Mr. Terry Smedley
Mrs. Mary Jane Monahan	Dr. Jac Pedersen	Mr. and Mrs. Jim and Anne Ross	Dennis and Kagari Smith
Ms. Katherine Moore	Ms. Maureen Pedzwater	Mrs. Janice Rottman	Mr. James F. Smith
Mrs. Karen Moorhead	Mrs. Vera Penick	Richard Roullard	Mr. Gregory E Smith
Robert A. Moran, PhD	Donald L. Perry	Mrs. Joanne Royal	Mr. Ronald J. Smith
Mr. Tom Morgan	Mrs. Cornelia Perry	Claudia A. Ruzanic	Mrs. Sherrie Smith
Robert L. Morissette, PhD	Carolyn Phillips	Kei Sakita	Dwain L. Smith DVM
Ms. Karl Morris	Ms. Maureen Phillips	Mr. Curtis Sanders	Ms. Lise Soukup
Mr. Kent Mortensen	Ms. Barbara Phillips	Dr. Mark Sanders	Charlotte Spada
Ms. Linda Morton	Jim W. Phipps	Mr. Eric Sanderson	Mrs. Patricia Spampinato
Mr. Charles Moyer	Mr. Robert Michael Pickel	Ms. Joanne Sawadsky	Mr. John Sparrow
Mr. Leo Muldowney	Dan Pike	Mrs. Linda R. Schaeffer	Mr. William Spear
Mrs. Jean Muller	Mr. Ivan Pinkul	Ms. Helen T. Schauer	Dr. Jeffrey Spector
Mrs. Patricia L. Mullins	Mr. Doug Poad	Dr. Kimberly Schimmel	Ms. Beula J. Spell
Mrs. Dorothy Muonio	Mrs. Patricia A. Poelker	Mr. Tony Schlegel	Mrs. Hannelore M. Spence
Dr. Daniel J. Murphy	Mr. Robert L. Poff	Ms. Susan Schlichting	Mr. Marvin Spencer
Mr. Edward Murphy	Jacquie Powell	Ms. Karen Schmidt	Mrs. Joyce C. Spivey
Ms. Jan M. Murphy	Debra B. Price	Mrs. Isabel Sonia Schneider	Mr. Thomas Spradley
Mr. Steven Murphy	Dr. Stephen N. Price	Mr. David G Schneider	Ms. Joyce Spriggs
Mr. Douglas Murray	Mrs. Claudia Pugh	Jan Schneider	Kermit Spruill
Stan Myers	Betty Quist	Mr. Aaron Scholl	Mr. John Starke
Mrs. Tracy Myers	Mr. Bruce Raemisch	Ms. Donna M. Schroeder	Mr. Eric Steeg
Mr. and Mrs. Larry D. Nelson	Ms. Barbara J. Ragland	Patty Schuetz	Ms. Jacqueline N. Steensma
Mr. Dean Nelson	Ms. Marilyn Ralston	Mr. and Mrs. Roger C. Schulte	Mr. Jim Stein
Mrs. Pamela Newberry	Janice A. Ramsay	Mr. and Mrs. Lowell E. Schultz	Steven B. Stein
Mr. Mark Nickell	Mr. Harold Ramsey	Ms. Karen Schwager	Mr. Albert Steiner
Ms. Mary Nolan	Ms. Rosemary Ramsey	Susan Scott	Mr. Walter Stevens Jr
Ms. Katherine Nolte	Mrs. Marilyn Rawson	Mr. Lee Scullin	Rebecca Loehr Stifflemire
Mary Payne Norcross	Mr. Douglas Rea	Carol J. Seely	Ms. Marilyn Stoll
Ms. Margaret H. Northey	Mr. Martin Redman	Mrs. Annette E. Seibel	Mrs. Peggy Storey
Karl W Northwall MD	Marcia Reed	Mrs. Christina Seif	Mr. and Mrs. Peter and Marilee Sturmer
David S. Nourok, MD	Mr. Robert Reese Jr	Mr. Joseph J. Seifried	Mr. James Surface
Mr. Peter A. Nussbaum	Ms. Cindy Reinhart	Donald Semrau	Mr. Wayne Swanson
Ms. Theresa Nygren	Mrs. Karen Remick	Ms. Thea Shallenberg	Mr. Timothy Swanson
Mr. Brendan O'Connell	Mr. William Reny	Louise Sharp	Marian W. Sweeney
Ms. Barbara O'Connell	Ms. Heather Reynolds	Ms. Bonnie Shear	Ms. Dale Talley
Ms. Sharyn O'Hare	Mr. Steve Rhynard	Mr. Billy L Sheats	Harry C. Taylor
Ms. Brenda C. C. O'Brien	L. Jerome Richard	Ms. Carmen Shell	Ms. Claire Taylor
Mrs. Barbara Odenkirk	Chris & Sheila Richards		Ms. Doug Taylor
Dr. Shirley Ogletree	Roberta M. Richardson, MD		Mr. Andrew T. Tershak
	Mr. Johnnie Ricketts		

Mrs. Linda Theis	Leah R. Wickham
Mr. Dennis Thiel	Mrs. Linda Widmer
Mrs. Yvonne Thomas	Ms. Deborah Wilcox
J H Thomas	Mr. John B. Williams
Mrs. Janice Thomas	Mr. Kent Williams
Mr. James Thompson	Mr. Jay Williams
Joe and Susie Thurman	Mr. Roy Willman
Ms. Lynda Tish	Ms. Caroline R. Willms
Ms. Victoria Tool	Mr. Thomas Windmiller
Barbara Torell	Dr. Elva Winter
Ms. Alejandrina Torrens	Jerome P. Witek
Dr. Leslie Townsend	Ms. Lila Witt
Ms. Janet L. Trent	Mr. Gordon Woodard
Ms. Michelle Troutman	Mr. Von Woods
Ms. Diane M. True	Ms. Helen Wornik
Mr. Frank M. Trunkey	Mrs. Lillian M. Worthan
Ms. Simone Tseng	Mr. Mark Wu
Mr. David A. Tuomala	Ms. Pam Wuichet
Ms. Helen M. Turek	Mr. Des Wytmans
Ms. Carol Turkaly	Ms. Lois Yarbor
Mr. James Turner	Mr. Ted Yednock
Michael Ulwelling	Dr. Hugh Young
Ms. Elizabeth K. Usina	Ms. Lora Younts
Lee Van Valkenburg	Ms. Ann L. Zimmerman
Mrs. Wendy Veiga	Barbara Zizka
Ann Veronelli	Mr. Mel Zoerb
Ms. Patricia Veuve	Mrs. Joy D. Zumbrunn
Ms. Gladys Vitz	
Mrs. Ellie Vogel	
Ms. Joan Voigtlander	
Mrs. Hedi Voloshen	
Ms. Cornelia Vooys	
Ms. Paul Vugteveen	
John M. Wadahara	
Kate Wagner	
Ms. Davida C. Wagner	
Gordon Waldron	
Mrs. Nancy A. Walkenford	
Mrs. Claudette F.	
Walschlager	
Dr. Joyce Walsleben	
Nora L. Walter	
Ms. Kay-Frances Wardrope	
Mrs. Shirley M. Ware	
Mr. Joseph Wataha	
Mrs. Mary Ann Watrous	
Mr. Jim Watts	
Ron Weisberg	
Mrs. Bonnie Wellman	
Mr. and Mrs. Eugene Wendt	
Mr. William Wenner	
Mr. David Whelpton	
Mr. Stephen White	

Treasurer Report



Greg Oberland

*Treasurer, RLS Foundation
Board of Directors*

I want to thank the members of the RLS Foundation for your continued financial support and unwavering commitment during our 2020 fiscal year. The last two years have been challenging for all of us, but your support of the Foundation has remained constant. In 2020, individual donors provided the majority of support for Foundation programs and activities, representing 73% of gifts to the organization.

The mission and organizational goals of awareness, education and research leading to better treatments and a cure served as our guideposts in the fiscal year 2020. Members of the Scientific and Medical Advisory Board began to draft the new RLS treatment algorithm and updates to our library of educational materials aimed at educating the general public and medical community. As part of their volunteer service to the RLS community, these experts served as presenters for our popular free monthly webinar series and physician-only webinar series, focusing on educating healthcare providers about the diagnosis, treatment, and management of RLS. Volunteers that lead our support groups, virtual support groups, and discussion board provide individuals with RLS the opportunity to connect, exchange information, and share coping strategies with others in the RLS community who share the daily challenges of RLS. Our education outreach is expanded through the broad power of the Foundation's website and social media channels, including Facebook, Twitter, Instagram, YouTube and LinkedIn, to reach the RLS and healthcare communities. The RLS Foundation's acclaimed quarterly magazine, *NightWalkers*, continues to delight our members with in-depth stories about the most promising research and treatments available today. Communicating through these many channels, we reach a more extensive and younger audience, fulfilling our mission to raise awareness and education about RLS.

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

The RLS Foundation conducted its second RLS Advocacy Day on Capitol Hill. The Foundation met with key legislative offices to discuss the need for additional research funding, seek a safe harbor for RLS in any policy or legislation, and expand RLS awareness and education for healthcare providers. Generous support by RLS Foundation members makes our Public Policy Initiative possible.

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

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

I am pleased to serve on the RLS Foundation's Board of Directors and as the organization's treasurer. I hope that my experience as a corporate executive with more than 30 years experience will be a great asset to the organization. I look forward to the Foundation's continued success in 2021 and our continued work together!

Sincerely

A handwritten signature in black ink that reads "Greg Oberland". The signature is fluid and cursive, with a large, stylized "G" and "O".

Greg Oberland
Treasurer, RLS Foundation Board of Directors

2021 - 2022 Highlights | Financials

Revenues and Support

Contributions	\$634,778
Membership Dues	\$157,381
Other	\$76,966
Total revenues and support	<u>869,125</u>

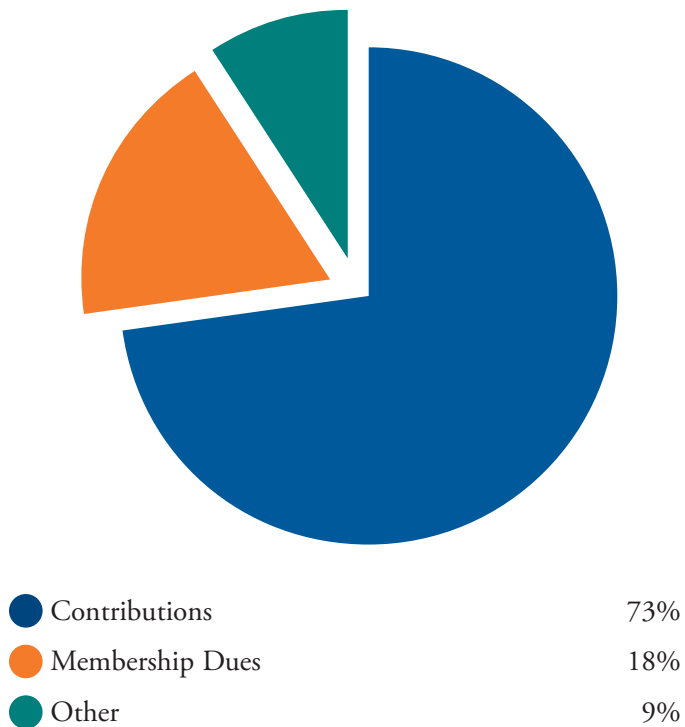
Expenses

Program Services	
Education	\$328,299
Membership	\$180,476
Research	\$32,546
Support Groups	\$26,338
Total program services	\$567,659
Fundraising	\$75,553
Management and general	\$74,222
Total expenses	<u>\$717,434</u>

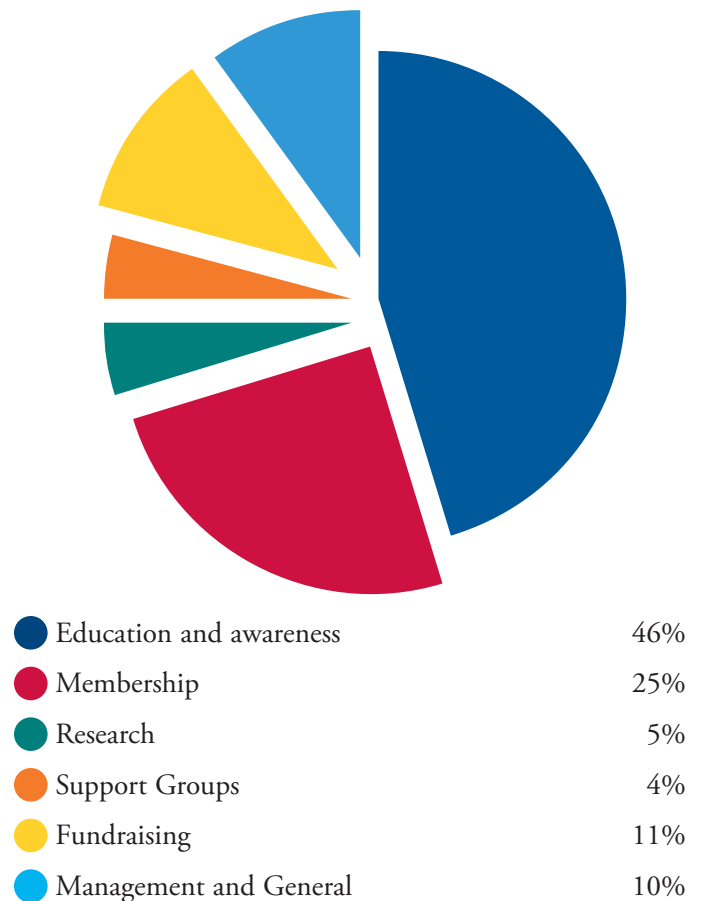
Statements of Activities For the Fiscal Year Ended September 30, 2021

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

2021 Where Our Funds Come From



2021 Where We Use Our Funds





BE HEARD



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**

