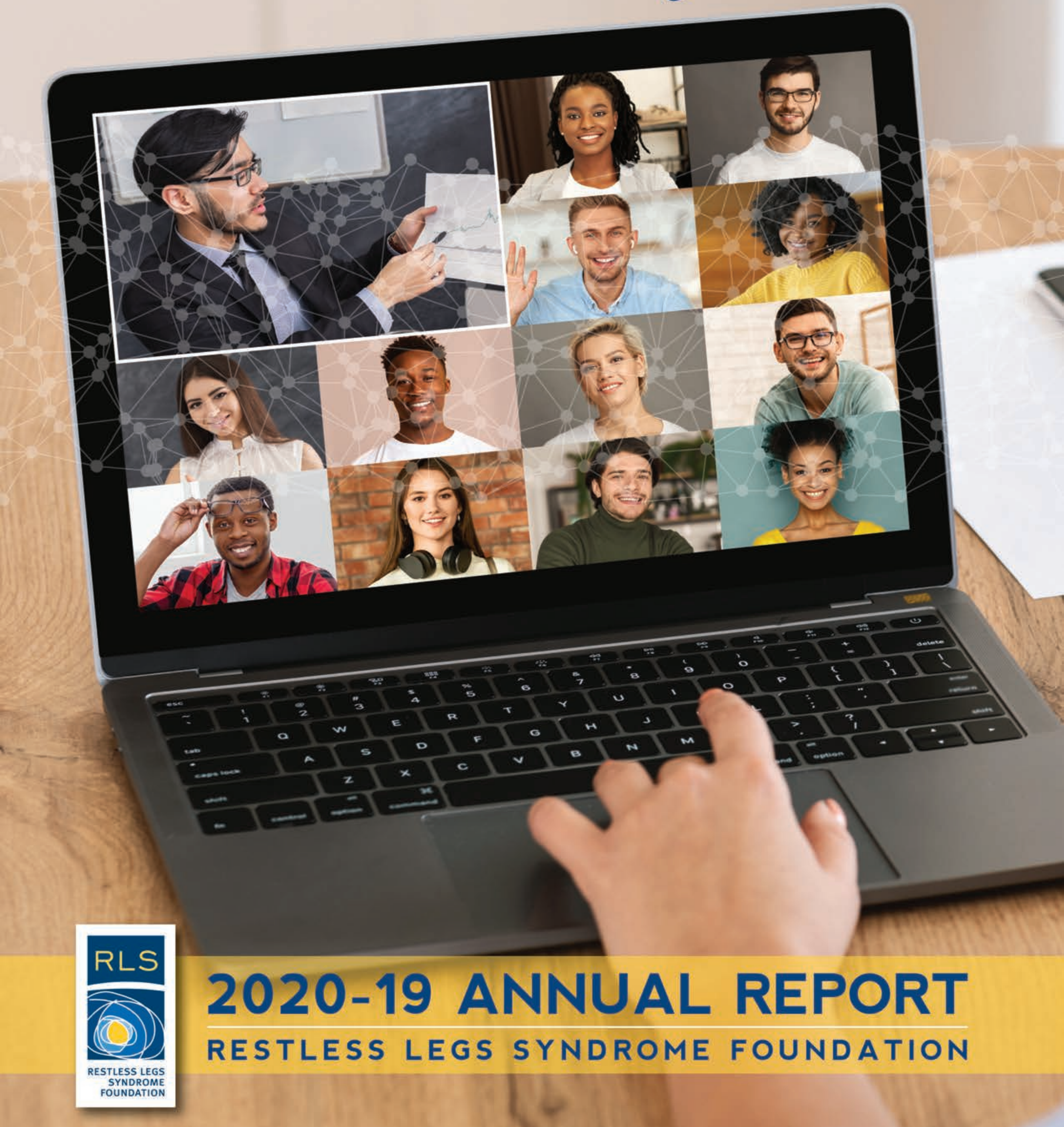
Making Connections *Remotely*



2020-19 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.

2019 - 2020
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John W. Winkelman, MD, PhD
Boston, MA

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

10/26-27/19 Austin, TX 2/6/20 Telephonic 6/9/20 Telephonic

2019-20 Highlights | From the Chairman of the Board

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

This is my first year chairing the Board of Directors of the RLS Foundation, and what a year it's been! No one guessed that a tiny virus would force us to rewrite all of our plans. Covid-19 has changed nearly everything we do and how we do it, but one thing has not changed. The Foundation remains solidly committed to providing support to our members, educating the public and healthcare providers and supporting advanced research about RLS.

We've lived up to those commitments in new ways:

- Our Support Groups, led by a dedicated corps of trained volunteers, have moved from in-person meetings to online sessions. Foundation staff have set up systems and support to make this transition as seamless as possible. To everyone's delight, the online sessions have been enormously popular, bringing in an influx of new members.

- We had planned to host a Patient Symposium in October 2020, building on the success of our 2018 symposium in La Jolla, California. Although we had already lined up a conference site and a stellar group of presenters, Covid-19 forced us to postpone the gathering until it is safe to meet together in person. Instead, this year we held a Virtual Summit online on October 17, 2020, which was an educational and inspiring experience. The Virtual Summit reached over 100 participants, who told us afterwards that they were deeply satisfied with the day and looked forward to the postponed in-person symposium.

- We also conducted an updated Patient Odyssey survey in September and October of 2020 that produced over 3,000 completed survey responses from RLS patients and their partners. Preliminary analysis of the results shows that RLS has a severe impact on the quality of life, and that knowledgeable healthcare professionals are the key to successful disease management. As these results are further studied and reported to the healthcare community, they will provide statistical evidence in support of better education for healthcare professionals and better treatment options for the RLS community.

- Throughout the year, we've made an extra effort to be in contact with our members, providing them with support to manage their disease. Karla Dzienkowski, our Executive Director, has joined many of you for informal coffee hours online that combine support with a sharing of information and advice.

Behind the scenes, the staff has had to reinvent almost all of their normal work patterns. With Covid-19, keeping the office open was no longer safe, yet phones still had to be answered, new members welcomed and projects kept on schedule. Very quickly, procedures were reorganized to ensure that only one person at a time was in the frequently-sanitized office. Online tools eased collaboration to some extent. Likewise, the Board of Directors was able to meet the requirements of a well-run nonprofit – reviewing programs, providing financial oversight and setting overall directions for the Foundation – by means of frequent online meetings. We were guided by an active Finance Committee, supported by outside accountants and independent auditors, to ensure our financial health.

I want to particularly acknowledge the two recipients of the Foundation's highest award for dedication and service to the RLS community – Dr John Winkleman and Karla Dzienkowski. Each in their own sphere has been a quiet hero. On a sad note, the Board lost a valued member with the death of Ron Anderson, whose deep scholarship on human suffering of all kinds illuminated his compassion for those living with RLS. We will miss his wise counsel.

All things considered, it's been a good year, and I'm pleased to have been able to share it with such a passionate and dedicated group of people: my fellow Board members, Karla Dzienkowski and her staff and all of you, our wonderful members.

Carla Rahn Phillips

Carla Rahn Phillips, PhD
Chairman of the Board

2020 Federal Spending Package Supports RLS Research

The RLS Foundation continues to advocate for the RLS community on Capitol Hill and across federal agencies. 2019 was an active year, and the Foundation was successful in helping to secure recommendations from Congress through the appropriations process.

Notably, the federal funding bill encourages sleep disorders research at the National Institutes of Health (NIH) – and for the first time, specifically lists "restless legs syndrome." In late December, Congress passed its final bills, and the president signed both to fund the government in fiscal year 2020.

Following are some of the key recommendations and funding that were included in this important legislation.

Medical Research

National Institutes of Health (NIH):

- Congress appropriated $41.7 billion for the NIH – an increase of $2.6 billion over the 2019 fiscal year. The RLS Foundation worked alongside the broader patient community to ensure that the NIH received a substantial increase in funding to continue vital research that will benefit patients.
- Congress included the following recommendations:
  - *Sleep and Circadian-Dependent Mechanisms Contributing to Opiate Use Disorder*. The funding bill specifically recognizes work by the National Institute on Drug Abuse (NIDA) and the National Institute of Neurological Disorders and Stroke (NINDS) to address the opioid crisis through innovative research directions. The bill notes "the promise that research on sleep and circadian mechanisms can play in the prevention and treatment of opiate use disorder" and encourages relevant NIH institutes and centers to work collaboratively to "continue the exploration of innovative research pathways."
  - *Sleep Disorders*. The bill commends "the recent expansion and advancement of the sleep and circadian research portfolio under the coordination of the National Center on Sleep Disorders Research (NCSDR)," and "encourages dedicated research activities on specific sleep disorders, such as narcolepsy and **restless legs syndrome**, to ensure scientific progress benefits patients impacted by debilitating conditions disordering their sleep and biological rhythms."
- The fiscal year (FY) 2020 NIH Congressional Justification (a document with detailed estimates and justifications for research activities) also emphasizes that restless legs syndrome research continues to be a promising direction for the NCSDR.

Department of Defense:

- The Peer-Reviewed Medical Research Program has been funded at $360 million for FY2020, and *sleep disorders* has been included again as a category eligible for funding.

Professional Education

Centers for Disease Control and Prevention (CDC):

- Congress budgeted $5 million for the National Neurological Conditions Surveillance System. This initiative aims to expand surveillance of neurological conditions, providing data to increase the understanding of these disorders and to further support neurological research. The system will initially focus on multiple sclerosis and Parkinson's disease, with the goal to eventually expand surveillance of many neurological conditions.

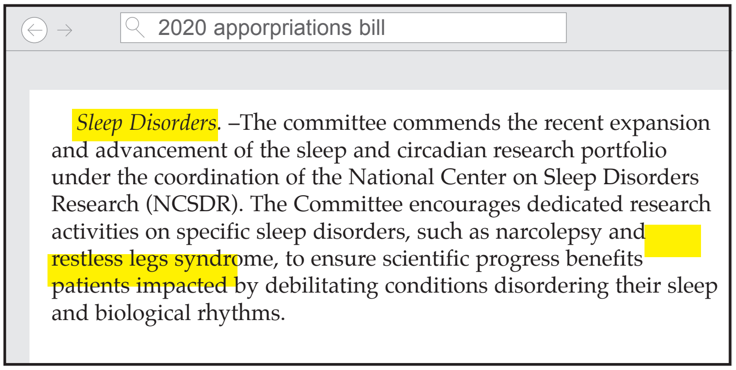
Department of Veteran's Affairs:

- *Sleep Disorders*. The Department of Veteran's Affairs was previously directed by Congress to assign a program manager for sleep disorders. The new funding bill requires that the Department provide an update to Congress by June 30, 2020. This is an important first step in improving coordination of sleep disorders research across federal agencies and in broader activities.

None of this progress would be possible without the many RLS patients and others across the country who have connected with their legislators locally and in Washington to share their personal stories.

While the RLS community has accomplished much, more needs to be done. In 2020, Congress will continue to take legislative action on funding the government, advancing critical research, and addressing the opioid crisis. The RLS Foundation will continue to advocate for appropriate access to opioid therapy at low total daily doses for RLS patients through targeted outreach to federal agencies and key congressional committees.

The RLS Foundation is looking for individuals to get involved in legislative activities and share their experiences with leaders in Washington. Are you ready to step up? To learn more about RLS advocacy and to view free educational webinars, visit the "Get Involved" section of www.rls.org or contact the Foundation at info@rls.org.



Sleep Disorders. –The committee commends the recent expansion and advancement of the sleep and circadian research portfolio under the coordination of the National Center on Sleep Disorders Research (NCSDR). The Committee encourages dedicated research activities on specific sleep disorders, such as narcolepsy and restless legs syndrome, to ensure scientific progress benefits patients impacted by debilitating conditions disordering their sleep and biological rhythms.

Yuqing Li, PhD, 2015 RLS Foundation Grant Recipient, Awarded NIH Funding

The National Advisory Neurological Disorders and Stroke Council (NANDSC), a division of the National Institutes of Health (NIH), has awarded a new grant to Yuqing Li, PhD, a professor of Neurology and Neuroscience at the University of Florida. Dr. Li and his team will further investigate the genetic mechanisms that are involved in the development of restless legs syndrome.

Dr. Li will build on his previous research concerning the role of the MEIS1 gene in RLS, which was made possible with an RLS Foundation grant he received in 2015. Li's work involved exploration of an animal model in which he and his team performed a detailed analysis of MEIS1 mutant mice to determine whether they showed RLS symptoms. They also examined the brain's dopamine system to identify areas affected by the MEIS1 mutation.

"I want to take this opportunity to express my gratitude for the Foundation grant in 2015," said Li, who published three papers on MEIS1. "The funding allowed us to collect the necessary preliminary data to apply for this NIH grant."

Li says the Foundation grant allowed him to identify changes in the dopamine and cholinergic systems in the brains of the mutant animals, which suggests that they could be important in causing RLS.


Yuqing Li, PhD

"With the new NIH grant award, we are going to develop animal models with MEIS1 altered only in dopaminergic or cholinergic systems," said Li, who received the NIH grant in September. "This will allow us to determine the relative importance of the two systems in causing the RLS. We may find out that both systems are important, or one is crucial and leads to the changes in the other. This kind of knowledge will allow us to have a better understanding of how RLS can develop in patients and develop better-targeted therapies for RLS patients."

The support of the Foundation members has led to the funding of 47 grants totaling over $1.8 million in funding. "The RLS Foundation is excited by the news of this NIH award to Dr. Li. This study will help to expand our knowledge and understanding of the disease leading to development of targeted therapies and, hopefully, a cure," said Dzienkowski, RLS Foundation executive director. To support the RLS Foundation Research Grant Program go to **www.rls.org/donate**.

RLS Foundation to Conduct Patient and Partner Survey

Take the RLS Patient Odyssey Survey to help advance RLS research, treatments and awareness!

On Sept. 23, RLS Awareness Day, the RLS Foundation will launch a new research study on the challenges of living with RLS. The RLS Patient Odyssey Survey II will evaluate RLS treatment strategies, emotional well-being, relationships and lifestyle, adding to the body of knowledge about the burden of disease and identifying focus areas for future education and research.

Specifically, the study aims to:

- Understand the experiences of RLS patients with medical treatment and symptom management
- Provide data to researchers on the long-term burden of disease, including impact on spouses and partners
- Promote awareness that RLS is a serious neurological disorder
- Provide resources for RLS patients to help facilitate decision-making with their healthcare providers on medical treatments to manage their disease

RLS Patient Odyssey Survey II is the second survey developed by the RLS Foundation. Findings in the 2013 first survey were published in the the *Journal of Sleep Medicine* and disseminated broadly. RLS Patient Odyssey Survey II will gather updated and expanded data in areas such as symptom management, experience with healthcare providers, and ways in which the disease affects daily life and emotional well-being.

The current survey is particularly focused on the RLS patient experience, especially with regard to treatments and medical care. The survey was designed by a work group comprised of RLS Foundation Scientific and Medical Advisory Board members Brian Koo, MD, William Ondo, MD and John Winkelman, MD; Board of Directors member Jeffrey Durmer, MD, PhD; and staff members Karla Dzienkowski, Maddie Lionberger and Zibby Crawford. The survey is made possible thanks to an educational grant from Arbor Pharmaceuticals.

RLS Foundation members and nonmembers alike are encouraged to participate in the study, which will consist of two online surveys: one for RLS patients, and one for partners. To participate, visit **www.rls.org/odyssey** from Sept. 23 to Oct. 23. See below for details.

Survey results will be shared with the RLS community and the public in 2021, prepared for publication in the medical literature, and presented in scientific meetings. Findings will also be shared with health policymakers in Washington, DC in the RLS Foundation legislative agenda and advocacy materials.

"RLS is a serious disease that can have a devastating impact on quality of life," says Karla Dzienkowski, executive director of the RLS Foundation. "We have come a long way to advance treatments and research, but today's treatments are limited, and there is no cure. RLS patients still face significant, daily challenges in managing the disease. This study will provide data to accelerate and focus our efforts to address these challenges and improve quality of life for RLS patients and future generations of their families."

Foundation Board Member Publishes New Research on the Dangers of Dopamine Agonists

New research from John Winkelman, MD, PhD, a member of the RLS Foundation's Scientific and Medical Advisory Board, and director of the Massachusetts General Hospital certified RLS Quality Care Center, was featured in the August issue of *Sleep Review* magazine! The article, "Are Dopamine Agonists Doing More Harm Than Good for Restless Legs Syndrome Patients?" features a study that Winkelman, a researcher at Harvard Medical School, conducted, which found nearly 20% of restless legs syndrome (RLS) patients are prescribed doses above the FDA recommended maximum.

The article notes that while clinicians who prescribe their patients higher doses of dopamine agonists (DAs) may find symptoms quickly disappear, that result is usually temporary and can even lead to worsening RLS, also known as augmentation – or as Winkelman describes it, "putting out fire with gasoline." Research indicates that augmentation occurs in 50% to 70% of patients who use DA medications for 10 years.

"When the dopamine agonists have made the RLS worse, the response of most doctors, unfortunately, is to increase the dose, which just makes it even worse," said Winkelman, whose study was published in the medical journal, *Sleep*. "Then they increase it again and they get into this vicious cycle."

The research found that roughly 20% of RLS patients prescribed dopamine agonists, out of a large data sample, were prescribed doses higher than the upper limit of what the Food and Drug Administration (and RLS expert guidelines) recommend. Even more worrisome is that half of those patients (10% of those given a dopamine agonist) are prescribed these medications at doses greater than 150% of the FDA recommended maximum for RLS.

"This doesn't happen overnight. This happens over years and years," said Winkelman.

Dr. Mark Buchfuhrer, also on the Foundation's Scientific and Medical Advisory Board and the new medical editor for *NightWalkers*, commented on Winkelman's research. "For most doctors this is still first line treatment," said Buchfuhrer, who practices at the Restless Legs Syndrome Clinic at the Stanford Center for Sleep Sciences and Medicine, a certified RLS Quality Care Center.

John Winkelman MD, PhD

Dr. Winkelman concluded that prescriber education on the risks of high-dose DA prescribing for RLS is especially important. The Foundation offers a free twelve-part on-demand educational webinar series to educate healthcare providers about the care of RLS patients. The series is located at **www.rls.org/PhysicianEd.**

Sleep Review

To access the full article online, visit https://www.sleepreviewmag.com/sleeptreatments/pharmaceuticals/prescription-drugs/dopamine-agonists-harm-restless-legs-syndrome-patients/.

United We Stand

RLS Foundation Board of Directors

Is the nation as divided as network anchors and cable news pundits say we are? From the wall-to-wall coverage of today's political landscape, it might seem so – but at the RLS Foundation, we're grateful to say that our membership is a house united!

We all may come from varied backgrounds, faiths and ideologies, but when it comes to the disease we share, we stand firmly on common ground. Thanks to member support, we have begun to make our united voice heard and respected on both sides of the aisle in Washington.

Two years ago, we decided it was time to add a new pillar – public advocacy – to support the efforts that underpin so much of what we do in awareness-building, quality care delivery, and world-class research. In 2019, we learned just how powerful and effective our voices could be.

Our advocacy goals are incisive and laser-focused. We aim to press policy makers and stakeholders to support an increase in RLS research, to clear a path for improved education about RLS within the medical community and with the public, and to ensure patients with severe RLS continue to have access to low total daily dose opioid therapy, an important consideration as our nation grapples with the opioid crisis.

With the springboard of these clear objectives, expert counsel, and dedicated involvement from our staff and members, we set out in a quest to make significant headway.

- We held the first-ever RLS Advocacy Day on Capitol Hill in Washington on May 3, 2019, organizing a team of 30 participants to meet with 45 congressional offices representing 16 states.
- We educated key legislators, agency officials, and policy makers through a grassroots base of RLS patients and a group of congressional champions both on and off the Hill.
- We mobilized 350 public comments from the RLS community on federal rulemaking regarding the opioid epidemic to press the case for access to low total daily dose therapy.
- We coordinated grassroots meetings with local congressional offices throughout the country during the August recess.

In short order, our efforts began to bear fruit. We secured key congressional appropriations committee recommendations to support RLS research in the 2020 federal budget. We convinced Congress to continue to champion RLS research at the National Institutes of Health. The Senate Defense Appropriations committee once again included "sleep disorders" among the conditions eligible for funding through a Department of Defense medical research program. (For updates in these areas, including news of federally funded RLS research, turn to pages 3 and 6.)

And, at long last, we earned Congressional recognition of RLS Awareness Day on September 23!

Our members made the difference in two important ways. Membership dues and contributions to Foundation fundraisers helped pay for our presence in Washington and for experts who continue to guide us through the bureaucratic thicket and enable our voice to be heard. Moreover, some members strengthened our presence with their own personal voices and stories, through written comments and in-person meetings. To find out how you can make a personal difference, visit www.rls.org/get-involved/advocacy.

We enter a new year and a new decade with palpable optimism that a cure is finally within reach. We stand as a house united – not divided – as we continue to persuade policymakers across the political spectrum to more fully accommodate the needs of RLS patients, and to help deliver our ultimate goal of finding a cure for RLS.

Why Your Voice Matters

Your advocacy efforts have been paying off! In October 2017, the RLS Foundation launched an advocacy initiative to inform federal policy makers about restless legs syndrome (RLS) with three main goals in mind: increasing funding for research, protecting appropriate access to opioid therapy, and expanding physician education and public awareness.

Many members of the RLS community have done their part in pursuing these goals by reaching out to their federal and local representatives via email, letter or phone – as well as joining the Foundation in Washington, DC, last May for RLS Advocacy Day on Capitol Hill. As a result, Congress continues to highlight RLS medical research at the National Institutes of Health (NIH) through report language in annual appropriations bills; and the Department of Defense continues to pursue important research on sleep disorders.

You may be wondering, "How does this affect me?" Educating legislators about the concerns of RLS patients puts necessary pressure on Congress to continue funding major research institutions, which in turn allocate resources to further research on RLS and sleep disorders in general – bringing scientists closer to finding better treatments and ultimately, a cure.

The proof is in the grant allocations that have been awarded to key researchers in the field, including members of the Foundation's very own Scientific and Medical Advisory Board. **Brian B. Koo, MD**, who is the director of the Yale Center for Restless Legs Syndrome (an RLS Quality Care Center), recently received a grant from the Department of Defense for his work on RLS and hormones. Dr. Koo and his team at Yale University are investigating whether the levels of melanocortin hormones are increased in the blood and cerebral spinal fluid of people with RLS. (If you are interested in participating, see page 21.)

Likewise, RLS Foundation advisory board member **James Connor, PhD**, at Penn State University received a grant from the National Institute of Neurological Disorders and Stroke to investigate iron deficiency and the RLS brain, in collaboration with **David Rye, MD, PhD**, and **Lynn Marie Trotti, MD, MSc**, both of Emory University. Dr. Trotti is the director of the Emory Sleep Center – an RLS Quality Care Center. Together, these researchers have developed models that will help to determine how cerebral spinal fluid from RLS patients affects the iron transport at the blood brain barrier.

Also funded by the NIH are RLS Foundation advisory board member **Kathy Richards, PhD, RN, FAAN**, of the University of Texas; and **Christine Kovach, PhD, RN, FAAN**, of the University of Wisconsin. They received a large grant from the National Institute on Aging to improve the treatment of nighttime agitation in people with Alzheimer's disease. The researchers hypothesize that RLS may be a cause for nighttime agitation and sleep disturbance in these individuals.

These experts have made significant advances in the field of RLS research. Dr. Koo is one of the world's foremost experts on the epidemiologic research that links periodic limb movements during sleep and cardiovascular disease. Dr. Connor is a leader in understanding the cellular and molecular mechanisms by which cells regulate iron. Dr. Rye was part of an international team that identified the first gene variant associated with RLS. And, Dr. Trotti is a two-time recipient of the American Academy of Sleep Medicine Foundation Strategic Research Award for her work on central disorders of hypersomnolence, RLS and sleep in neurodegenerative disease. (For more on Dr. Trotti's accomplishments, see page 12.)

> *"The RLS Foundation's presence in Washington, DC, has been very important in enhancing visibility of the name and the disease. This gives us a fighting chance for competitive grant money."*
> – Dr. Christopher Earley

In addition to their work in research, these experts also work directly with the RLS Foundation to increase their impact on the RLS community. Drs. Connor, Koo and Trotti are all members of the RLSF Scientific and Medical Advisory Board. Dr. Koo and Dr. Trotti serve as the directors of the Yale Center for Restless Legs Syndrome and the Emory Sleep Center, respectively. Dr. Rye is a certified RLS provider at the Emory Sleep Center. Finally, Dr. Koo and Dr. Trotti play a significant role in educating the public, as the medical editor of *NightWalkers* and the author of the "In the News" column, respectively.

RLS Foundation Scientific and Medical Advisory Board member **John W. Winkelman, MD, PhD**, of Harvard University; and board member **Jeffrey Durmer, MD, PhD**, of Fusion Health; have attended numerous meetings with policy makers to advocate the needs of RLS patients.

Christopher Earley, MB, BCh, PhD, FRCPI, also adds a powerful voice to RLS advocacy in Washington. Dr. Earley is not only the chair of the RLS Foundation's Scientific and Medical Advisory Board, but also the director of the John's Hopkins Center for Restless Legs Syndrome, an RLS Quality Care Center. He has joined the RLS Foundation in Washington on multiple occasions to advocate for the needs of RLS patients, healthcare providers, and researchers. Dr. Earley is conducting an NIH-funded study to evaluate epigenetic changes in DNA from blood (lymphocytes) and from brain autopsy in individuals with and without RLS.

Here is Dr. Earley's take on the recently funded research projects: "The truth is, restless legs syndrome is something that most people don't know about, and definitely very few people understand. When it comes to competing for grant-based money whether through the National Institutes of Health, National Science Foundation, or Department of Defense, name recognition is important. The RLS Foundation's presence in Washington, DC, has been very important in enhancing visibility of the name and the disease. This gives us a fighting chance for competitive grant money when measured up against heart disease, cancer, and neurological conditions like Alzheimer's disease. Further work is needed. Another visit to Washington is planned in February to address the possibility of giving RLS higher visibility on grant-supported initiatives."

Zooming Ahead to Make Worthwhile Connections

The COVID-19 pandemic has been an unprecedented time and period of adjustment for every one of us. Fortunately, the RLS community has many volunteers across the country who are willing to take time to coordinate support group meetings for anyone interested in learning more about restless legs syndrome (RLS), discuss strategies for coping with RLS, and find relief and hope by coming together to share a common goal—managing RLS.

John Alexanderson leads the Doylestown, PA Support Group and generally holds a meeting every quarter. When stay-at-home orders prevented the group from meeting in person, John was the first to volunteer to serve as our "guinea pig" by holding a virtual meeting on Zoom. Meanwhile, Nick contacted the Foundation looking for a support group in his area. However, no support groups exist in his state of Montana.

Clara Schlemeyer, the Volunteer Coordinator for the RLS Foundation was able to connect Nick with John, who invited him to join their virtual meeting. Thus, we found a wonderful way to help more people reach each other for support, regardless of where they live. Plus, everyone found the virtual meeting to be very helpful! "We liked it so much that we plan to make Zoom a regular meeting, but also hoping for some purely social interaction in between," said Alexanderson.

Bobbie Kittredge, former RLS Board Member and Ekbom Awardee, has led the Seacoast Support Group for 16 years and was eager to try something new. She invited RLS Foundation Executive Director, Karla Dzienkowski, to join her virtual meeting and update the group on what's happening at the Foundation. "I think it was very special for the group to meet you, Karla, and I certainly did appreciate what you brought to our first virtual gathering," said Kittredge. "Clara did a great job making this Zoom meeting so easy for us."

COVID-19 has changed the world in many ways, and for the Foundation, the global pandemic allowed us to realize the potential we have to expand our support throughout the world without leaving the house. During a recent Zoom gathering we enjoyed meeting a gentleman from South America, proving that RLS has no boundaries! When this pandemic comes to an end, the Foundation will continue to offer Virtual Support Group meetings open to everyone in the RLS community, along with their partners and family members. So, please sign up at **www.rls.org/vsg** to join us in a future Virtual Support Group soon. We can't wait to meet you!

Webinars 2020

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

September 9, 2020
Ask Dr. B
Speaker: Dr. Mark Buchfuhrer

August 25, 2020
How You Can Raise RLS Awareness This September
Speaker: Philip Goglas, HMC

August 24, 2020
Painful RLS. Do You Have It?
Speaker: Elias G. Karroum, MD, PhD

July 14, 2020
Cannabis and RLS
Speaker: Jacquelyn Bainbridge, PharmD

June 10, 2020
sIRLS: Self-completed RLS Severity Scale
Speaker: Denise Sharon, MD, PhD, FAASM

May 6, 2020
Safe Treatment of RLS with Opioids
Speaker: John W. Winkelman, MD, PhD

April 8, 2020
Iron and RLS
Speaker: Dr. James R. Connor

February 7, 2020
Basics of RLS
Speaker: Dr. J. Andrew Berkowski

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 Ekbom Heritage Society, an elite group at the Foundation committed to our mission and vision for the future.

If you would like to learn more about planned giving, please request our *Giving Avenues* brochure or 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**

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continued from page 12

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continued from page 16

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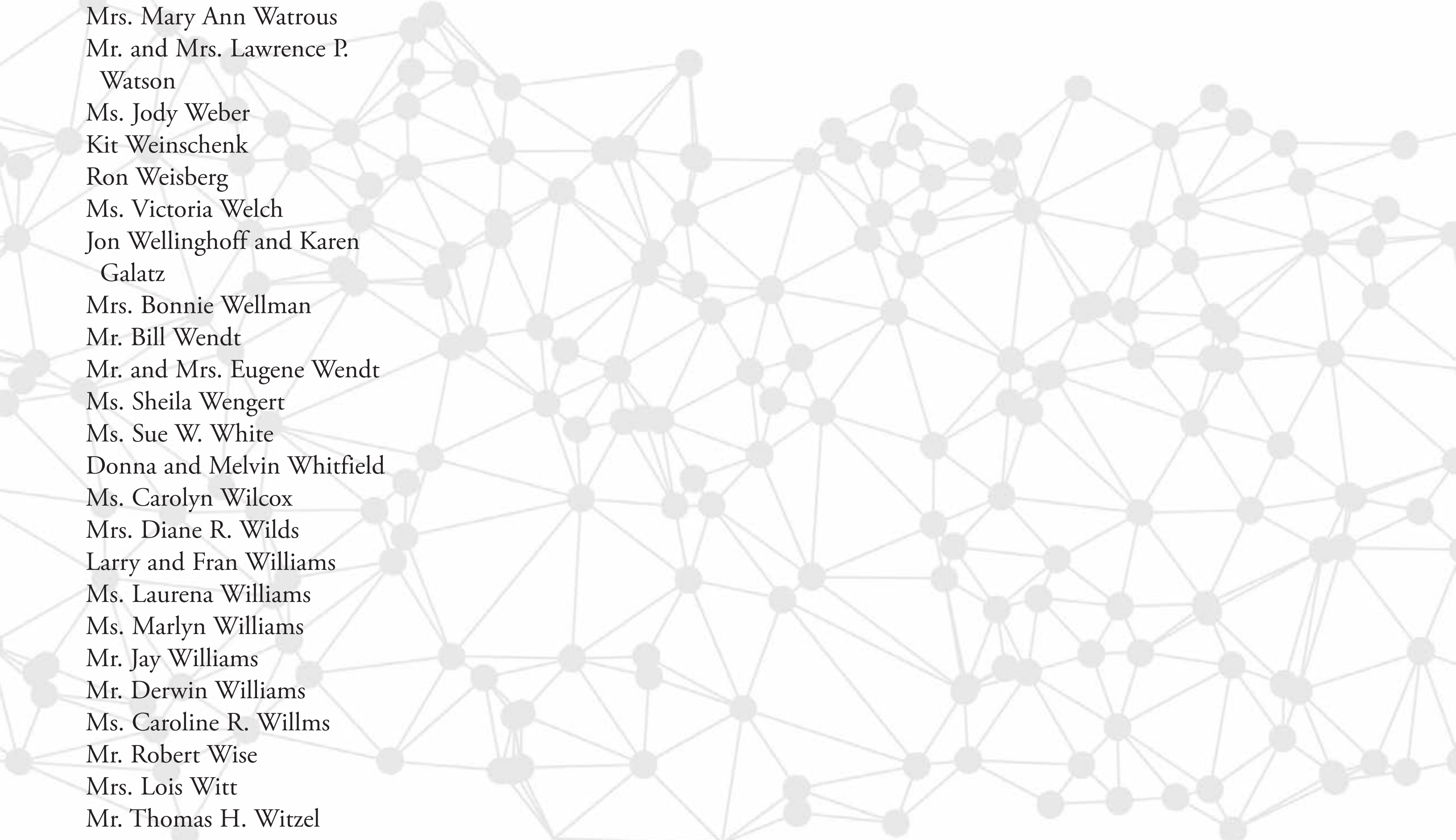


Treasurer Report

Ron Barrett, PhD
Treasurer, RLS Foundation
Board of Directors

I would like to thank the members of the RLS Foundation for their continued support and commitment to the RLS Foundation during our 2019 fiscal year. Individual donations comprise most of the financial support for Foundation programs and activities, representing 82% of total revenue to the organization.

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

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

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

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

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

Sincerely

Ronald W. Barrett, PhD

2019-20 Highlights | Financials

Revenues and Support

Contributions	$739,314
Membership Dues	$149,822
Other	$11,300
Total revenues and support	**900,436**

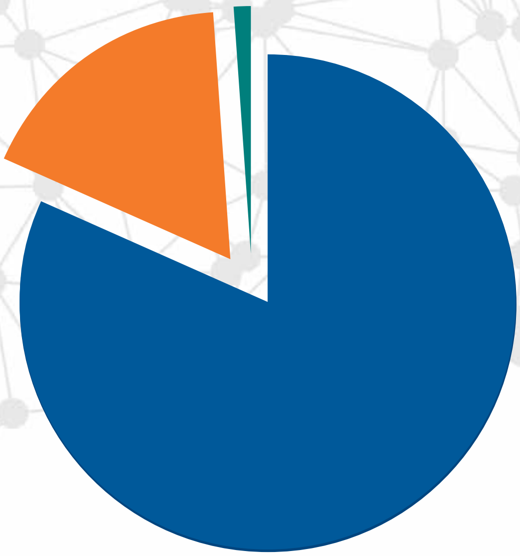
Expenses

Program Services	
Education	$352,888
Membership	$198,623
Research	$46,873
Support Groups	$33,933
Total program services	$632,318
Fundraising	$72,351
Management and general	$76,134
Total expenses	**$780,802**

Statements of Activities For the Fiscal Year Ended September 30, 2020

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

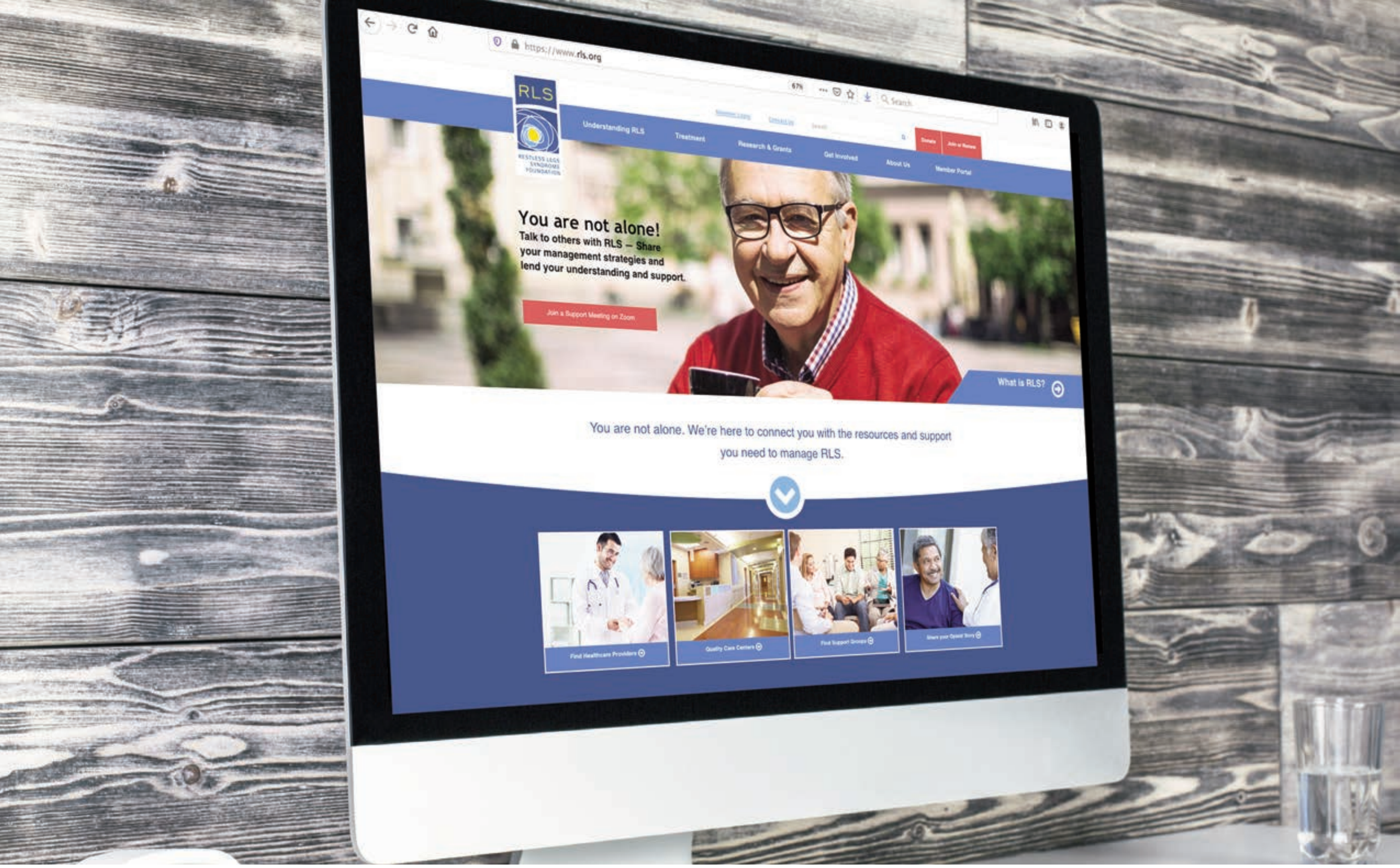
2020 Where Our Funds Come From



●	Contributions	82%
●	Membership Dues	17%
●	Other	1%

2020 Where We Use Our Funds

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



You are not alone!
Talk to others with RLS — Share your management strategies and lend your understanding and support.

You are not alone. We're here to connect you with the resources and support you need to manage RLS.

RLS

RESTLESS LEGS
SYNDROME
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