

Regional Meetings: Learning More One Location at a Time

Chicago

It was a rainy morning in Chicago, Illinois when RLS Foundation staff and volunteers arrived for the first Regional Meeting in July. Bustling throughout the morning, they prepared a conference room at the DePaul University for between 70 and 80 individuals hungry for information on RLS.

By the time the meeting began at 1:00pm, the room was nearly filled. The program began with Dr. Daniel Picchietti* giving an introduction to the disorder most in the audience dealt with on a daily basis. Dr. Picchietti's introduction segued into the presentation on treatment options. Knowledgeable Board member, Jacqueline Bainbridge, PharmD* went into great detail on the pros and cons of many pharmaceutical drugs on the market. The audience participated in the presentations with questions for the speakers.

After the short break, everyone resumed to hear an inspirational talk on "Coping Methods" from public speaker and author, Ann Battenfield.* The audience participated by coming up with coping methods for various life situations such as work, relationships, sleeping, and traveling.

The Regional Meeting in Chicago concluded with Picchietti, Battenfield, and Support Group Advisory Board Chair, Kathy Page, participating in a panel discussion. Attendees had the chance to ask open and specific questions to our sympathetic and knowledgeable panel.

Comments from attendees included things like: "Thank you! I needed to see real people who were afflicted, who understand," and "I do not have RLS, but this seminar was very educational and helps me understand what my wife is going through. This seminar is beneficial to anyone!"



Jacci Bainbridge, PharmD discusses pharmaceutical treatments with those who attended the Chicago Regional Meeting.



Dr. Mark Buchfuhrer provides an overview of RLS to San Francisco attendees.

San Francisco

San Francisco meeting attendees met at the West Bay Conference Center in August for the second of three Regional Meetings. Staff and volunteers again prepared for a group of around 80 individuals but were surprised when they had over 90 register!

The first speaker was Dr. Mark Buchfuhrer* with his version of "An Introduction to RLS." Dr. Buchfuhrer won over the audience with his compassionate yet clearly educated approach. His talk was followed by Dr. Clete Kushida's* presentation on current treatment options. The audience learned specific details on drug interactions, pharmaceutical treatments versus homeopathic methods, and what medications may be helpful to them.

After a short break, Dr. Kushida resumed with a talk on "Sleep Disorders" associated with RLS. By the time Dr. Buchfuhrer came back to close the meeting with his suggestions on working with your healthcare provider, the attendees were energized by the new ideas and information they had learned. By knowing how to address their doctor, many felt new doors of communication were opened. Some direct comments from attendees included: "I love the Foundation's work. I have learned most of what I know about RLS from the Foundation and feel even better educated after this meeting," and "Excellent program all around! Superb speakers, good ideas, good flip-charts – not to mention great value for price of admission."

Like in Chicago, the San Francisco meeting concluded with a panel discussion. Drs. Buchfuhrer and Kushida were joined by Support Group Leader Sherry Dagnall for a question and answer session with the audience. Participants were able to leave the meeting with new perspective on RLS and how to live with the disorder.

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Atlanta

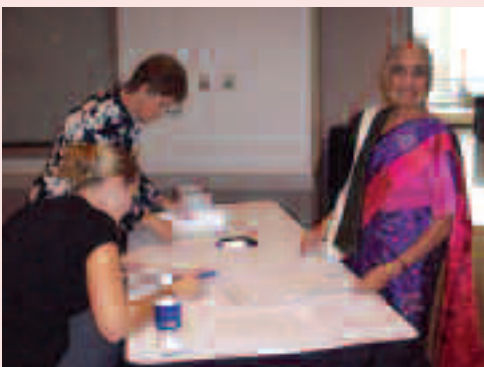
By September, the final Regional Meeting of the year was prepared and ready to take place. Staff flew to sunny Georgia to meet attendees at Georgia State University.

The meeting came to order with Roberta “Bobbie” Kittredge, RLSF Board member and Support Group Leader, welcoming the attendees. She was followed by two knowledgeable physicians, anxious to share what they knew with the audience. Unfortunately, a gas shortage in the area had cut the nearly 80 registered attendees in half, but those who were there were eager to receive education on RLS.

The first presentation was an “RLS Introduction” by Dr. Jeffrey Durmer*. Dr. David Rye* followed up with a presentation on “Treatment and RLS.” After a brief break, Dr. Durmer continued with a talk on “Children and RLS” and Dr. Rye on “Genetics and RLS.” Each of the lectures was met with a very receptive audience, who eagerly passed their questions to the center aisle for a question and answer session at the end of each lecture.

The afternoon concluded with a panel discussion with Drs. Durmer and Rye, Support Group Leader and Regional Liaison Ed Murfin, and Bobbie Kittredge.

The meeting was well received by all who attended. Comments included, “The program was well coordinated and addressed so many of our concerns,” and “The RLS Foundation is a wonderful support system. You don’t feel like you are alone!”



Board member and Support Group Leader Roberta “Bobbie” Kittredge and staff member Wendi Kitsteiner work to register an Atlanta attendee.

Regional Meetings Panel of Speakers

*Daniel L. Picchietti, MD

Dr. Picchietti is an Associate Clinical Professor at the University of Illinois College of Medicine at Urbana-Champaign and Medical Director of the Carle Regional Sleep Disorders Center, based in Urbana, Illinois. He has served on the board of directors of the American Board of Sleep Medicine and is a former member of the RLS Foundation Medical Advisory Board (MAB). He is board certified in sleep disorders, neurology, and pediatrics. Dr. Picchietti’s research interests include RLS in children, RLS and depression, the genetics of RLS, and sleep in ADHD.

*Jacquelyn Bainbridge, PharmD, FCCP

Dr. Bainbridge is an Associate Professor in the Department of Clinical Pharmacy and Neurology at the University of Colorado in Denver. She has been teaching and running research trials at the university for approximately 12 years. She has served on the RLS Foundation’s Board of Directors since 2006.

*Ann E. Battenfield, CPT

Ms. Battenfield is a partner in a consulting firm that focuses on helping businesses identify solutions to workplace performance issues. She is a certified mediator and volunteers both as a mediator and as a trainer for the Chicago Center for Conflict Resolution. RLS runs in her family, and almost all of her close family members have it. In 2006, she contributed a chapter to *Restless Legs Syndrome: Coping with Your Sleepless Nights* written by Drs. Buchfuhrer, Hening, and Kushida. She has been a volunteer moderator on the RLS Foundation’s online message board for several years.

*Mark J. Buchfuhrer, MD, FRCP(C), FCCP

Dr. Buchfuhrer was born in Montreal, Canada and graduated from McGill University. He went to medical school at the University of Ottawa and finished his internal medicine residency in Toronto. Dr. Buchfuhrer became interested in RLS around 1992 and has developed a large outpatient RLS practice. Since then he has served as a medical advisor to the Southern California RLS Support Group, has developed and maintains a website on RLS (www.rls-help.org), and is on the MAB of the RLS Foundation. He has written several publications on RLS including a patient book (*Restless Legs Syndrome: Coping with Your Sleepless Nights* sponsored by the AAN), a handbook for doctors on RLS, and a third book *Clinical Management of RLS*.

*Clete A. Kushida, MD, PhD, RPSGT

Dr. Kushida received his BAS and MS degrees from Stanford University, and PhD and MD degrees from the University of Chicago. He is an Associate Professor in the Department of Psychiatry and Behavioral Sciences at the Stanford University Medical Center, acting medical director of the Stanford Sleep Disorders Clinic, and director of the Stanford Center for Human Sleep Research. He is president-elect of the American Academy of Sleep Medicine, founding president of the California Sleep Society, and a member of the Restless Legs Syndrome Foundation’s MAB and several other editorial and scientific boards. Dr. Kushida has conducted sleep research since 1977, and he has authored or edited over 100 publications, including six books.

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RLS kept me up at night. Sometimes I was so tired I couldn't play with my kids. I didn't have the energy to do the things I love.

- Joseph, 36
Living with RLS

Joe refused to sit idly by and watch RLS ruin his life or the lives of those he loved. “So much progress has been made since I was diagnosed in 2001, and we now know more about RLS than we did then. My goal is to continue to raise as much awareness for RLS as possible, so that others don't have to suffer like I did. Last year, I ran 50+ miles in one night to bring attention to RLS. This year I'm going to run 75 miles, and my son has asked me to run 100 miles next year. If my body will let me, I will do it! RLS is a genetic condition, so I don't yet know if my children will have RLS like I do. I hope not, but in the meantime, I'm going to do everything in my power to help people understand about this life-altering condition.”

Lynne Kaiser was another participant in this PSA campaign. Lynne is a Support Group Leader in Dallas. Lynne lives with severe RLS and the impacts it has on herself and her family are tremendous. You get just a glimpse into the frustrations of RLS when you see Lynne in the PSA campaigns and hear her voice. “Before I found the best way for me to manage my symptoms, I missed out on a lot. I would be up pacing at night while my family was sleeping. By the time my symptoms subsided and I could fall asleep, it was time for my family to get up. I felt like I lived alone, living on the sidelines of my own life. And RLS affects everything – the lack of sleep turns you into a different person, and you end up changing your behaviors and your habits. It really changes the person you thought you were going to be.”

But like Joe, Lynne is determined to make a difference for future generations. “Thinking of my future grandchildren, I want to do everything possible to help other people suffering from RLS. I want people to know that there are many faces of RLS, and that it is a controllable condition.” We hope you have already gotten the opportunity to witness one of these campaigns for yourself. However, if you haven't seen any of them yet, you can get a first glimpse by visiting YouTube at <http://www.youtube.com/watch?v=kCJP4Sqh0ZQ>.



I have painful, tight, tugging feelings deep within my legs – almost like a deep toothache. For me, these RLS sensations are unbearable and keep me up most of the night.

- Lynne, 44
Living with RLS

Please help us create even more awareness of RLS by sharing this link with your friends and family and encouraging them to visit the RLS Foundation's website (www.rls.org) as well as the website of the initiative (www.WhatIsRLS.org). ■

*This initiative is sponsored by Boehringer Ingelheim Pharmaceuticals, Inc.

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***Jeffrey Durmer, MD, PhD**

Dr. Durmer is a neurologist and neuroscientist by training who first learned about the science of RLS by participating in RLS research in a working group as a sleep medicine fellow at the University of Pennsylvania. He also trained with pediatric sleep medicine physicians and psychologists at the Children's Hospital of Philadelphia. After his sleep medicine fellowship, he became the director of the Emory University Sleep Laboratory and the Pediatric Sleep Medicine Program. Currently, Dr. Durmer is the Medical Director and chief medical officer for the Fusion Sleep Medicine Program in the Atlanta area. He is also a past RLS Foundation grant recipient.

***David Rye, MD, PhD**

A past chair of the Foundation's MAB, Dr. David Rye is the head physician at the Emory Clinic Sleep Disorders Center in Atlanta Georgia, one of the country's leading diagnosis and treatment centers for all forms of sleep disorders, including RLS. A professor of neurology, Dr. Rye is one of the leaders in RLS research and has been the recipient of past RLS Foundation grants while also mentoring many young research scientists at Emory in the study of RLS. ■