Lupus Report

Dr. Ramsey-Goldman Recognized For Achievement in Lupus Research

We are pleased to announce that this November, Dr. Ramsey-Goldman was recognized by The Lupus Foundation of America for exceptional achievement in lupus research during the the American College of Rheumatology (ACR) Annual Scientific Meeting. Dr. Ramsey-Goldman was presented with this year's **Evelyn V. Hess Award**, which is awarded annually to a clinical or basic researcher whose body of work has advanced understanding of the pathophysiology, etiology, epidemiology, diagnosis, or treatment of lupus.

From the Lupus Foundation of America Website:

Dr. Ramsey-Goldman is globally recognized for her clinical skills, diversity of her research efforts and focus on lupus. Over the past 30 years, she has worked at the interface between immunology and rheumatology, and has undertaken several major committee assignments for the American College of Rheumatology (ACR), National Institutes of Health (NIH), and the Systemic Lupus International Collaborating Clinics (SLICC). As chair of SLICC from 2003-2008, Dr. Ramsey-Goldman conducted research on many wide-ranging areas of focus including quality indicators, lupus classification, flare assessments in lupus and guidelines for lupus nephritis.

"I am honored to be the recipient of the Evelyn V. Hess *(Continues on Page 7)*

New Lupus Projects

Two new initiatives being done by the lupus team are looking at ways to impact the awareness and treatment of the disease on a national level

Dr. Rosalind Ramsey-Goldman from the Division of Rheumatology is leading a new project that has been funded by the Department of Health and Human Services, Office of Minority Health (OMH). The funding will initiate the Lupus Conversations project to develop and test successful culturally-competent lupus education interventions that mitigate poor outcomes for health professionals, paraprofessionals and community stakeholders and to replicate these interventions at the national and local levels. The collaborative academic and community partnerships will leverage the adaptation of the Popular Opinion Model (POL), a successful application of a CDC behavioral evidence-based model, with the innovative "Lupus Conversations" videos, to address greater social and emotional support issues voiced by African-American female participants and reduce lupus health disparities outcomes at the community-level. The project will be implemented in Chicago and Boston and is a joint effort with Harvard University to further expand community-based work in African American communities affected by lupus. The National Association of Chronic Disease Directors based in Atlanta, Ga will be assisting in the dissemination of the project nationally.

Dr. Ramsey-Goldman was recently awarded an R21 grant, funded by the National Institute for Arthritis and Musculoskeletal and Skin Diseases, to study more about diagnosing Lupus in large populations.

SLE is often difficult to diagnose because of the diverse manifestations that occur over time and across care sites. Electronic health records (EHR) are now used in a majority of health care settings throughout the country, and present a rich source of information about patients which can be mined for earlier diagnosis and identification to improve quality of care, or enable high throughput clinical studies.

Despite this potential, to date, few algorithms have been developed to identify SLE patients using

EHR data. Construction of an effective algorithm, either by rule-based or machine learning methods, requires access to two data resources not commonly available: 1) a validated "gold standard" patient data set with clear documentation of criteria that are indicative of SLE that can be compared against EHR data and 2) an integrated health record dataset that contains data from multiple

Welcome to the Lupus Team

Danette Ko is from Florida and received her medical degree at the University of Florida. She completed her internal medicine residency at the University of Utah in 2014. After residency she was an academic hospitalist at Northwestern for two years before starting her Rheumatology fellowship at Northwestern in 2016. Her research interest is in quality improvement and utilizing electronic medical records to improve patient outcomes. Her research with Dr. Ramsey-Goldman is studying whether we are appropriately screening and treating lupus patients for glucocorticoid-induced osteoporosis.

Chase Correia is a 2nd year fellow in the Division of Rheumatology at Northwestern and a current NIH T32 appointee. He received his undergraduate education at Yale University majoring in Molecular, Cellular, and Developmental Biology. After completing medical school at University of Nevada School of Medicine, he did his residency at Loyola University in Chicago where he was named Chief Resident. His research interests include medical education research, particularly how to effectively teach fully-trained practicing physicians. In addition, he is also working on machine learning algorithms to predict disease severity in patients with systemic sclerosis. He is currently working on an OMH-supported grant to increase cultural competence in providers who are treating African American patients with SLE.

Lupus and Sleep
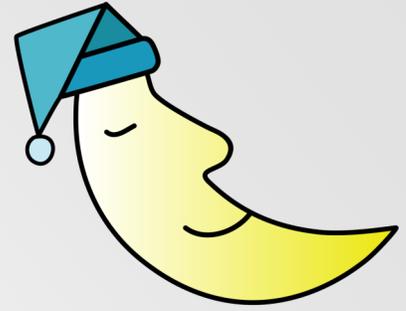
Good sleep habits are important for maintaining your health. Not getting enough sleep can increase inflammation in your body, and for people with lupus, that can worsen symptoms such as fatigue, pain, depressed mood, poor attention and concentration, mental processing speed, and memory. In order to keep yourself well rested, consider these factors in helping to get a good night's sleep:

A Healthy Sleep Environment

Make sure that your bedroom is a good environment for encouraging sleep. Try using curtains or shades that block light. Other things that help are using calming colors for the walls, and using a white noise generator or fan to mask ambient sound. In addition, make sure you have a comfortable mattress, pillow and bedding.

Creating a Bedtime Ritual

You can prepare for sleep by exercising daily, ideally approximately 5-6 hours before you go to sleep. You should also avoid caffeine, nicotine and alcohol, particularly before bed time. Relaxing activities – such as reading or taking a warm bath – can help you fall asleep faster and improve your quality of sleep. Try to avoid distractions such as television or phone use an hour before bed.

Don't stay in bed if you're awake and restless

If possible, have set a schedule to give yourself sufficient time for sleeping and remember that if you have trouble sleeping, the best approach is to get out of bed and do something relaxing until you feel tired. Continuing to toss and turn in bed when you are unable to sleep may create anxiety and further contribute to insomnia.

Use of Natural Light

Ideally, it is best to wake up with the sun, as it can help the body's internal biological clock reset itself each day. If you have a schedule that prevents you from waking up with the sun, there are products on the market that mimic the sunlight coming up in place of an alarm sound, which may be worth exploring.

Source: https://resources.lupus.org/entry/sleep-and-lupus

New Research Opportunities at Northwestern

New clinical trials in the lupus clinic are looking for volunteers to test new investigational treatments for SLE. If you would like to learn more about these studies, check our website at lupus.northwestern.edu, or contact Study Coordinator Danielle Lerner at 312-503-1919.

The NUgene Project

NUgene is a clinical research project currently being conducted at NMH and NMFF. The goal of this project is to collect and store genetic samples (DNA) along with associated healthcare information to form a gene bank. This large bank of samples, currently at 9,600 and growing, is available to researchers who are working to identify genetic contributions to human disease. This allows the researchers to more easily obtain many samples at one time, facilitating genetic research so it can more quickly impact healthcare in the future. All samples and information are de-identified before distribution for research. Participants in this study have the opportunity to provide Dr. Ramsey-Goldman with access to the information collected from participants through NUgene for research purposes. This will allow her to do additional research in the future on the role that genes play in lupus.

health care institutions and reflects that SLE patients often seek and receive healthcare at multiple institutions and from a diverse collection of healthcare providers given their chronic, progressive disease. Over the past several years, our team has created both key resources: the Chicago Lupus Database (CLD), a physician-validated registry of 880 patients and gold standard data set and the Chicago Health-LNK Data Repository (HDR), a unique regional data resource which includes integrated medical records for 2.3 million patients across multiple institutions. Together, these two important datasets, in addition to the Northwestern Medicine single health system medical record database, enable the creation, testing and validation of algorithms for the identification of SLE in EHR data and thus will help provide a more comprehensive picture of a patient population at risk for lupus. The ultimate goal of this study is to develop algorithms to identify patients with lupus in medical record data and determine whether there are clinically distinct subpopulations of patients with SLE based on differences in clinical criteria for describing the disease.

Keep up with the latest Northwestern Lupus Research news

Lupus team members from left to right: (bottom) Dr. Linda Elrich-Jones and Dr. Rosalind Ramsey-Goldman; (middle) Danielle Lerner and Anh Chung; (top) Patricia Murphy and Karen Mancera Cuevas.

Our team understands that participants like you in this study are donating their precious time for a number of reasons. For this reason, our team launched a website that provides links to recent publications, the most up to date information about the disease, and our latest research projects. You will also be able to find information about our most recently published articles and spotlights on members of the Lupus Research Team.

We encourage you to learn more about the disease and cutting edge research in the field. Your participation makes an enormous difference in our understanding of this very complicated disease. You can visit our website at **www.lupus.northwestern.edu.**

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Award from the Lupus Foundation of America," said Dr. Ramsey-Goldman. "I remember being in awe of Dr. Hess when I interviewed with her for a rheumatology fellowship, and am humbled to be recognized by this award in her name for the work of my research teams and collaborators which have focused on improving the lives of those who suffer from lupus. Our studies of disease outcomes and health disparities, development of assessment tools and biomarkers, advances in management and new therapeutics, and the opportunities to mentor junior investigators have enriched not only my career but have also given hope to those with lupus."

Source: https://www.lupus.org/research-news/entry/lupus-investigators-receive-prestigious-awards-for-contributions

Top: OMH Research Team: (left to right) Karen Mancera Cuevas, Dr. Candace Feldman, Dr. Linda Ehrlich Jones, Dr. Elizabeth Ferucci, Dr. Ciana Leatherwood, Dr. Ramsey-Goldman, and Dr. Chase Correia at a breakfast meeting during ACR.

Bottom: Dr. Patricia Canessa (far right) presenting the MONARCAS project at the American Public Health Association meeting. This presentation described the impact of lupus information spread in Chicagoland Latino communities through the use of Popular Opinion Leaders. (POLs).

Support the Lupus Program at Northwestern University

The Lupus Program at Northwestern University is supported by funds from private philanthropy, government and institutional grants, and patient service revenue. While every source of funding is important, private philanthropic support is especially vital to the success of our activities. Over the years, the generosity of friends and patients has enabled us to initiate important projects that have the potential to contribute to lupus breakthroughs.

We invite your philanthropic partnership in helping us achieve our patient care, research, and teaching aspirations each day. Your commitment could help us to advance a promising research study, develop a new educational program for our trainees, or purchase a key piece of equipment or technology. Each gift truly makes a difference.

For your convenience, a number of giving options are available, including outright gifts of cash, appreciated assets such as securities, or pledges payable over a three-to-five-year period. We greatly appreciate your interest and support of our efforts. Thank you!

Northwestern University

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We hope you have enjoyed the latest issue of the *Lupus Report*. If you have any questions, comments, or suggestions for topics you would like us to cover in the next newsletter, please send us your feedback.

Want more information about our research? Visit **www.lupus.northwestern.edu** for more information or email solvable@northwestern.edu.

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