



Lupus Report

NORTHWESTERN UNIVERSITY
RAMSEY-GOLDMAN RESEARCH TEAM

2009-2010 ISSUE

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SPECIAL POINTS OF INTEREST:

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Sleep Well Get the right amount of sleep at the right time

Sleep is a part of our daily life that affects our physical and mental health in many ways. Due to the nature of lupus disease which causes fatigue, it is especially important for lupus patients to obtain plenty of sleep. Many lupus patients believe their flares are triggered by a significant and prolonged lack of sleep. The National Institutes of Health (NIH) suggests lupus patients ensure they have a good amount of sleep at night. For those who are coming out of a flare, it is beneficial to take small naps during the day. Below is some information regarding how to get high quality of sleep. Both the amount and the timing are important.

What is the right amount?

The optimal amount of sleep we need depends on the individual, for example, people at different age requires different amount of sleep. People at a young age need longer sleep than ones at older age. In general, according to the National Sleep Foundation, a typical adult needs an average of 7-9 hours of sleep each day. However, in reality most people especially women can only get an average of 6 hours and 41 minutes of sleep. A study based on experiences done on sleep deprived mice suggests that sleep deprivation may contribute to an early presence of autoimmune diseases like lupus due to the fact that lack of sleep extensively affects endocrine and immune systems. Besides the amount of

sleep, to ensure good quality of sleep also needs to sleep at the right time.

When is the right time?

Some people may sleep for as long as 10 hours. However, the quality of sleep also relies on the time of the sleep. If a person sleeps after 2am, regardless the length, it is not as effective. Our body temperature fluctuates during the day, and it usually reaches its lowest point early in the morning around 4:30am. According to the human biological clock, our body starts to feel sleepy at 9pm, and reaches the deepest sleep at 2am. Therefore, the best time to sleep should be around 9pm, and it should last for ideally 7-9 hours.

Some tips for a good night sleep

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Thank you for supporting our ongoing lupus research at Northwestern University. Due to your help, we are learning more about lupus everyday. We are currently recruiting *people with lupus* for the following research studies:

ESRD-GO

Study patients are being asked to participate in this research study because they have lupus and have been diagnosed with endstage renal disease (ESRD), which occurs when the kidneys are no longer able to function at a necessary level. This study is being done to gain a better understanding of the contribution of genetic and environmental risk factors to the occurrence of ESRD among people with lupus. The doctors involved in this study are working with several institutions to find out more about causes of ESRD among people with lupus as well as why some patients do better than others. There is some evidence that inherited factors (genes) may contribute to the development of ESRD among people with lupus.

NUgene Project at Northwestern

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.

At the Heart of It

Understanding Cardiovascular Disease and Lupus

Over the last year, our research team published a number of papers pertaining to cardiovascular disease and lupus. The work of Dr. Peggy Wu, MD, titled “35-hydroxyvitamin D and Cardiovascular Risk Factors in Women with Systemic Lupus Erythematosus” was published in the October 2009 edition of *Arthritis Care and Research*. The objective of this study was to evaluate the associations between Vitamin D levels and cardiovascular risk in women. The study demonstrated that Vitamin D levels in women with lupus are low. In addition, these low levels exist with increased cardiovascular risks. We are now looking at Vitamin D levels to see if they predict lu-

pus disease progression on imaging tests which look for the presence of atherosclerosis, a condition in which fatty materials collect on artery walls.

Dr. Carly Skamra reviewed current findings in the relationship between cardiovascular disease (CVD) and lupus in a paper titled “Management of Cardiovascular Complications in Lupus Erythematosus.” This was published in the *International Journal of Clinical Rheumatology*. The article reviews current findings in the relationship between cardiovascular disease and lupus. It specifically examines the higher prevalence of subclinical atherosclerosis, early stages of atherosclerosis among women with lupus.



SLICC REGISTRY

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Genetics and Lupus

Through a partnership with the University of Alabama and lupus centers around the world, we are currently engaged in research to examine genetic and environmental risk factors for organ damage in people with lupus. We are now recruiting Caucasian, African-American, and Hispanic men and women at least 19 years of age for this study. Study participation involves three annual visits that include a blood draw, urinalysis, and physical exam.



Spotlight On....

Rosalind Ramsey-Goldman, MD, DrPH

Dr. Rosalind Ramsey-Goldman, the Principal Investigator for the Study of Lupus Vascular and Bone Longterm Endpoints (SOLVABLE), has dedicated her research to investigating Systemic Lupus Erythmatosis (SLE) prevention and complications. She is known for her projects pertaining to rheumatic diseases and pregnancy, lupus and pregnancy, epidemiology of SLE, genetics and SLE, bone disease and immuno-suppression, cardiovascular disease and SLE, and SLE clinical trials.

In the last year, Dr. Ramsey-Goldman has been honored for her dedication and contributions to lupus research. This year she received the Medical Service Award from the Lupus Foundation of America, Illinois Chapter in recognition of her research, clinical treatment, and patient education. Starting in 2009, she began serving as a board member on the Board of Directors for the American College of Rheumatology (ACR) and recently became a co-editor of *Arthritis and Rheumatism*. Dr. Ramsey-Goldman will be serving as Vancouver 2010 Poster Discussion Leader for the 9th International Congress on Systemic Lupus Erythematosus, which is an international meeting of patients with lupus, their families, clinicians, and scientists focusing on lupus research.

There is More to Learn

Participating in Lupus Research at Northwestern University

The Lupus Program at Northwestern University is extensive, expanding beyond the Study of Lupus Vascular and Longtern Endpoints (SOLVABLE) that you are generously participating in. Our team understands that women like you in this study are donating their precious time for a number of reasons. Often women participate because they know a friend or relative with the disease, want to contribute to a good cause, or desire to learn more about lupus. For this reason, our team launched a new 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 new website at www.lupus.northwestern.edu.

New to the Lupus Research Team

Juanita Romero-Diaz, MD, is a visiting scholar from the Instituto Nacional de Ciencias Medicas y Nutricion S.Z. in Mexico City, where she is both a part of the Rheumatology Division staff and a Professor. She completed medical school at Benemerita Universidad Autonoma de Puebla, where she specialized in Internal Medicine and Rheumatology. Over the next two years she will be working on clinical research related to the epidemiology of Systemic Lupus Erythematosus. In March of 2010 she will receive a Master's degree in Medical Sciences from the Universidad Nacional Autonoma de Puebla. Outside of the office she enjoys reading poetry, exercising, and spending time with her husband and two sons.

Karen Mancera-Cuevas, MS, CHES, is the Lead Research Coordinator for Dr. Ramsey-Goldman in the Division of Rheumatology. She has an undergraduate degree in Community Health Education, a Master's degree in Health Administration and is a Certified Health Education Specialist. Karen has more than 10 years of experience in clinical/



Dr. Ramsey-Goldman's Research Team

Left to right: Ahn Chung, Andrea Baker, Sue Cunanan, Beth Randall, Rosalind Ramsey-Goldman, Karen Mancera-Cuevas, Patricia Murphy, Christine Hsieh, Carly Skamra, Gwen Dela Cruz, Not pictured: Jeny Lin, Juanita Romero-Diaz

biomedical research. Her most recent position was with Northwestern University in the Department of Preventive Medicine where she was a study coordinator for Multi-Ethnic Study of Atherosclerosis (MESA) and Hispanic Community Health Study/Study of Latinos (HCHS/SOL). Prior positions include research specialist in the Department of Obstetrics and Gynecology at the University of Illinois at Chicago and community health educator at the Epi-

lepsy Foundation of Greater Chicago. She has served as a consultant on projects pertaining to health disparities, minority-based health education programs, capacity building, and community participatory research.

Jiesi Lin, BS, is a research coordinator in Dr. Ramsey-Goldman's group. She earned her BS in mathematics at Northwestern University. Prior to her BS, she studied Chinese medicine in Beijing Capital School of Medicine for three years. While pursuing her degree at Northwestern University,

she worked as a health interviewer in the Department of Preventive Medicine for Multi-Ethnic Study of Atherosclerosis (MESA) and Coronary Artery Risk Development in (Young) Adults (CARDIA). She has also done volunteer work in hospitals, working in the pediatric surgery department at University of Chicago Hospital, IL., and E.R. in Weiss Hospital, IL. In her spare time, she enjoys spending time with her two children, singing, reading, and traveling.



Patti and Education

Patricia Murphy MSN, CNP, CNM is the Nurse Practitioner in the Division of Rheumatology. She works primarily with the Lupus Program. She is the Project Coordinator for the Lupus Inpatient Satisfaction Research Project. The object of the project is to identify area of improvement for the Lupus Program. Patients who were hospitalized from 9/07-3/08 and received a Rheumatology consult were sent a written survey, based on the results of the survey patients were invited to attend a focus group. During the focus group patients discussed their hospital experience. The Lupus Health Passport, a personalized small pocket sized booklet which is

used in Canada was introduced to the group. The group felt this would be a useful tool. Dr. Ramsey-Goldman and Ms. Murphy will share the result of the project the administration. The use of the Lupus Health Passport will continue to be explored.

In December Ms. Murphy began one on one patient education visits. New patient's initial visit is with Dr. Ramsey-Goldman. The following visit is an education visit with Ms. Murphy. This visit is tailored to the needs of the patient. The initial visit is at times overwhelming. Information provided the first visit is reinforced and questions and concerns are addressed. The lab results are reviewed. Patients re-

ceive education regarding the disease, medication and monitoring. Plans for follow up visits are discussed. Patients receive written handouts as well as internet resources. This program has been positively received.

Ms. Murphy also provides education visits to established patients. The topics may include but are not limited to exercise, nutrition, stress reduction, bone health, cardiovascular risks, pregnancy and lactation.

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SOLVABLE

(Continued from page 1)

During the day :Avoid

caffeine, nicotine, and alcohol. Wine or other alcoholic beverages do not help our body fall asleep, but causes awakenings at night. Exercise, but pace yourself, do not over stress your body by having too much exercise. Try to go to bed at the same time each day, so your body will be trained to feel tired when you are ready to sleep.

Before bed: Avoid any exciting activities at least 2 hours before bed. Activities like reading, watching calm TV programs, taking a warm bath can help your body relax and set your brain to a ready-to-bed mode. Your bed is for sleeping. If you have a hard time falling asleep, do not just lie in bed. You should train your body to know your bed is for sleeping. The more you feel anxious to fall asleep, the less chance you will be able to.

At night: Control your room temperature. If it is too cold or hot it will keep you from falling asleep. Set a comfortable room temperature. It will not only help you fall asleep, it also helps you to remain asleep.

Keep the room quiet and dark. Bright light may trick your body in thinking it is day time, which makes it hard to remain asleep.

Lastly, consult a doctor if you keep having trouble to fall asleep.

Jenny Thorn Palter, "Sleep Easy", *Lupus Now*. Summer 2010, pg. 6-7.

"*Sleep, Sex Differences and Women's Health*" Information from the Institute for Women's Health at Northwestern University

Michael Smolensky and Lynne Lamberg, "*The Body Clock Guide to Better Health*"; Henry Holt and Company, Publishers (2000).

National Sleep Foundation, <http://www.sleepfoundation.org/sleep-facts-information/debunking-sleep-myths>, Retrieved 8-13-2010.

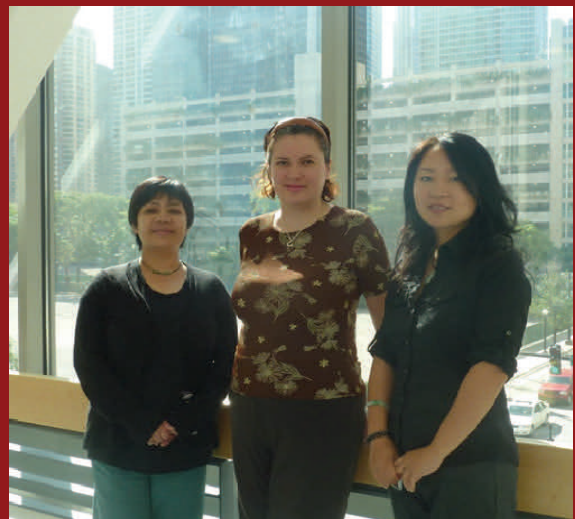
Meet the Coordinators What to Expect in the Clinic

If you have been enrolled in CLD (Chicago Lupus Database), you will have the opportunity to participate in a number of exciting studies. What to expect during your clinic visit:

When you come to your rheumatology appointment, one of our study coordinators from Dr. Ramsey-Goldman's lupus research group will, with your permission, discuss research studies that you are eligible for and ask whether you are interested in participating. Studies that are currently open for recruitment are:

- ESRD GO (endstage renal disease)
- GENETICS and Lupus
- SLICC Registry
- NUGene

If you are interested in any of the studies above, please contact our study coordinator Sue Cunanan by phone 312-503-7211, or email her at s-cunanan@northwestern.edu.



Meet our Research Coordinators. You can contact them to get involved in lupus research studies.

Sue Cunana, Karen Mancera-Cuevas, Jiesi Jeny Lin

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!

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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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