



Lupus Report

NORTHWESTERN UNIVERSITY
RAMSEY-GOLDMAN RESEARCH TEAM

2011 ISSUE

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GOOD NEWS!

Thank you for supporting our ongoing lupus research at Northwestern University. Due to your help, we are learning more about lupus everyday. We have received more funds for SLICC Study!

Fitness: Why Is Exercise So Important?

Everyone, not just athletes, should fit exercise into their busy daily schedules. This is especially true for patients with lupus. However, many lupus patients experience various levels of fatigue, which makes exercise quite challenging or seem impossible. This article will help you understand why everyone should exercise, and why lupus patients can and should exercise.

What happens to our body when we exercise?

Sweating, deeper and faster breathing, a quicker heart beat, and muscle toning are some of the obvious changes to your body that you can see and feel, when you are exercising. There are also many other good things happening inside of your body when you exercise that you probably do not know about. For example, as long as you move any part of your body, your muscles will contract. "Flexible, strong muscles will help protect joints," says Rosalind Ramsey Goldman, M.D., DrPH, Solovy/Arthritis Research Society Professor of Medicine at Northwestern University Feinberg School of Medicine. When you contract your muscles, your body

needs oxygen. When you exercise, you breathe deeper and faster. As a result, you breathe in more oxygen into your body. To carry all this extra oxygen to various parts of your body, you will need more red blood cells. So your body generates more blood. The increase in blood volume in turn triggers your body to build more blood vessels which increase the blood supply to your organs and tissues and this increased flow of blood will bring more nutrients to your organs and carry away toxic waste to their destinations. In addition, when you exercise there may be a reduction in your blood pressure as the new blood vessels help do some of the work done by your old blood vessels. As a whole, your body gets healthier.

Another benefit of exercise is a reduction in body fat when you burn calories and this can lower the risk of cardiovascular and chronic diseases. "There is evidence to show that exercise helps prevent and manage chronic illnesses like diabetes, obesity, and depression," according to Dr. Ramsey-Goldman. "Exercise does not only help you physically, but also mentally. Tied up into the fatigue are stress, anxiety, depression, and poor sleep." We talked about how important quality sleep was to lupus patients in our

Fitness: Why Is Exercise So Important? (continued)

(Continued from pg. 1)

previous newsletter; exercise is one of the good ways to help improve the quality of sleep. Exercise will also trigger your brain to release endorphin --a chemical that helps to lift your mood. It is impossible to list all the good things happening to our body during exercise, but hopefully this article has helped you understand some of the benefits of exercise.

How should lupus patients exercise?

Believe in yourself: the first and most important step is to correct your attitude towards exercise. Don't let your fatigue or limitations discourage you. Only compete with and compare your progress to yourself, not the one who can run a marathon. Dr. Ramsey-Goldman says, "If you don't think you can exercise, that's going to be a barrier to being able to do it. Cast off the mindset of, 'I'm sick; I can't do anything.' When you move, you actually feel better."

Set up a plan that fits you: Once you believe in yourself, work with your doctor to set up an exercise plan. Exercise plans vary among individuals, simply because everyone is different. Some can run a marathon, while others can hardly walk a block. Dr. Ramsey-Goldman suggests lupus patients change their perception of "exercise", "Exercise can mean moving, which is OK. It doesn't have to only mean that you have to work out hard at the gym" she says. You should talk to your physician before you start exercise and work your physician to help you tailor the amount of exercise to fit your body. You can try yoga or pilates as fun and new forms of exercise.

Pace yourself: There is an ancient Chinese saying "One stone at a time, you can move a mountain." Once you set up your plan, pace yourself and start slowly and gradually. Dr. Ramsey-Goldman says, "You can't go from 0 to 100 overnight. Don't try to do too much too quickly, because then you will hurt yourself and you won't want to do any more."

Tips for exercise: Here lists some tips to make exercise safely and more fun:

- **Wear good shoes:** wear sturdy shoes so you won't fall.
- **Keep hydrated:** sweating is a way for your body to cool off when you exercise, and also a way of water loss to your body. So keeping your body hydrated during exercise is very important.
- **Multitasking is possible:** depending on what type of exercise you do, you can multitask while exercising. For example, reading, listening to music, watching TV on your treadmill, can not only make exercise more fun, but also help save time.
- **Don't forget sunscreen:** if you like to work out outdoors, don't forget to put sunscreen on. Even in the cloudy days and cold winter, there are still UVA rays that penetrate clouds to damage your skin. Lupus patients especially need to be cautious about the sun. Make sure you always wear sunscreen if you exercise outdoors. The way to apply sunscreen in the winter should be similar to the summer, apply daily and reapply often.

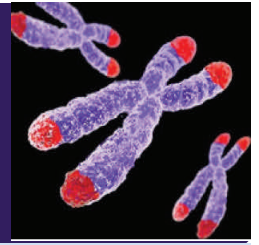
Stephanie Watson, "The Inside Story—what so great about working up a sweat?" *Lupus Now*, Spring 2011 p.g. 16-20.

Kathleen Doheny, "Winter Sun Warrants Sunscreen", *Bloomberg Businessweek*, <http://www.businessweek.com/lifestyle/content/healthday/634271.html> Retrieved on 7/12/2011.



TELOMERE

— The New Finding from SOLVABLE —



Dr. Rosalind Ramsey-Goldman's MCRC project, SOLVABLE (Study of Lupus Vascular and Bone Long-Term Endpoints) has a new manuscript in preparation to describe a study estimating the association between an increased risk of cardiovascular disease and the size of the telomere, a specialized structure inside almost all of the body's cells. The telomere protects the end of chromosomes (genes) in cells. We have found that women with lupus have significantly shorter telomere length than women without lupus. In addition, women with lupus had shorter telomere length at a younger age. We also found that telomere length may be related to the presence of cardiovascular disease, measured by the presence of plaque on carotid ultrasound testing compared to women without lupus. The next step is to evaluate the relationship between telomere length and bone mineral density as an early marker for osteoporosis in women with and without lupus.

Profile —Reviews and Updates

The PROFILE cohort is a nationally-sponsored, multi-center study that is designed to examine the causes of lupus as well as factors associated with disease severity, progression and clinical course. Currently, PROFILE includes lupus patients from eight study sites from the continental US and the island of Puerto Rico as well as from Mexico and Argentina.

The PROFILE study was established in 1997 with support from the National Institute of Arthritis and Musculoskeletal Diseases (NIAMS). Because of your participation, PROFILE provides a unique and valuable resource of demographic and clinical information as well as biospecimens from participants of diverse economic and race/ethnicity back-

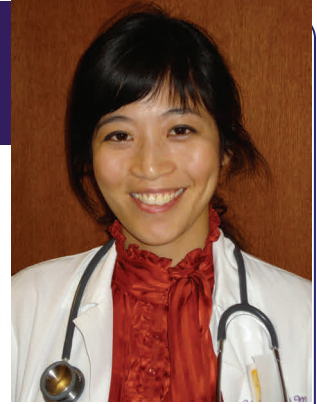
grounds to facilitate an improved understanding of factors that not only influence SLE susceptibility but also disease progression. By capturing a PROFILE of lupus, medical researchers and physicians can work together to advance treatment options, improve clinical management of the disease and ultimately, prevent this autoimmune disease.

This important landmark study is an international effort to examine the effects of biological, chemical, physical, social and genetic influences on the development and progression of lupus. Currently there are over 2,700 participants enrolled in PROFILE of which, the majority are women (92%) with an average age of 34 years and average disease duration of 8

years. Although the majority of participants are of European descent (43%), large proportions of African Americans (35%) and Hispanics (15%) are also included to help improve our understanding of the lupus prevalence and severity, which strikingly differs by race/ethnicity.

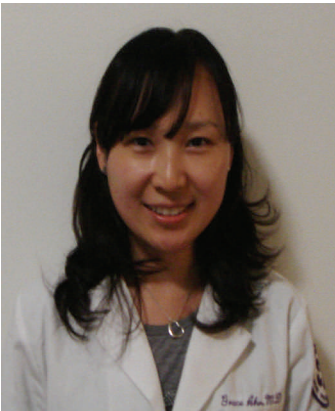
Thanks to your participation and the participation of thousands of other lupus patients from around the world, we have made significant advances in the last few years in identifying over 35 genes that appear to influence the risk of lupus. Among these genes, those responsible for influencing inflammation, antibody complex formation and deposition and cellular trafficking via an alpha-interferon pathway are notable. Currently, our genomics work is focused on un-

Meet Christine Hsieh



Christine Hsieh, MD is an Assistant Professor in the Division of Rheumatology. She completed her undergraduate training at Stanford University and graduated from medical school at Upstate Medical, Syracuse, NY in 2003. She completed her internal medicine residency at the McGaw Medical Center of Northwestern University and completed her clinical rheumatology fellowship at UCSF. She then completed her post-doctorate research at the University of Chicago where she studied the predictive value of interstitial nephritis in lupus nephritis as well as finding better ways to predict prognosis in the disease. Since July 2009, she has been involved with establishing clinical trials in SLE at Northwestern University and has recently completed a trial evaluating new biomarkers in the blood to improve the accuracy of SLE diagnosis. Her Major research interests:

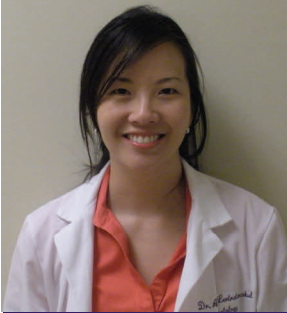
- SLE clinical trials
- CTD and pregnancy
- Inflammatory myopathies
- Dermatologic manifestations of CTD



Meet Grace Ahn

Grace Ahn, MD, joined the Division of Rheumatology in 2010 after completing her Residency in Internal Medicine at Northwestern University in Evanston, Illinois, where she was named chief resident for the 2009-2010 academic year. She completed her internship in Internal Medicine at Drexel University College of Medicine in Philadelphia, Pennsylvania after completing medical school at the Virginia Commonwealth University School of Medicine in Richmond, Virginia. She is looking forward to beginning a research project with Dr. Rowland Chang and Dr. Rosalind Ramsey-Goldman this year. Dr. Ahn is a musician and completed a Bachelors of Arts with Distinction in music at the University of Virginia in Charlottesville. Dr. Ahn focused on piano, and still plays intermittently, especially for friends and family weddings.

New to the Lupus Research Team



Apinya Lert, MD. had received her undergraduate and graduate degrees in Biomedical Engineering. She was involved in physiologic signal processing work at the Margret and H.A. Rey

Institute for Nonlinear Dynamics in Medicine and at the University of Utah. After graduate school, she worked as a scientific consultant at Pharsight Corporation, using pharmacokinetic/pharmacodynamic modeling and clinical trial simulations to assist pharmaceutical companies in decision-making. She then went on to attend medical school at the University of Pittsburgh and completed her residency at the University of Chicago NorthShore campus. She enjoys applying her love of numbers and data to the exploration of the complexities of lupus.



Daisy Zhu is graduating from Northwestern University in December 2011 with a Bachelor of Science in Biomedical Engineering and International Studies. In her three years at Northwestern, Daisy has implemented a

nutrition project with St. Francis Health Care Center in rural Uganda, conducted research on the effects of fluctuations in hormonal levels on the viscoelasticity of knee ligaments at the Rehabilitation Institute of Chicago, and worked as a student instructor for the Global Engagement Summer Institute. In her free time, she enjoys traveling, learning new cultures, and collecting stories from people she meets. Daisy has a keen interest in healthcare, and cherishes this opportunity to volunteer with the Lupus Research Group.



Mary Mahieu, MD.; is a second year Internal Medicine Resident at Northwestern and plans to pursue a fellowship in Rheumatology. She completed her medical school training at Loyola University. During college, she spent three years working in a biophysics lab

investigating molecular signaling mechanisms that promote bone growth. Her current research focuses on identifying novel markers of cardiovascular disease in patients with lupus using SOLVABLE data. Specifically, alpha-chlorofatty acid that is one chlorinated byproduct of myeloperoxidase, an enzyme that is thought to play an important role in the development of atherosclerotic plaque or hardening of the arteries.



Liliana Medina, is a Research Study Coordinator for Dr. Ramsey-Goldman. She graduated from the University of Rhode Island with a Bachelor of Science in Dietetics. Prior to working in the Division of Rheumatology

at Northwestern, she worked in the Department of Preventive Medicine for the Hispanic Community Health Study/Study of Latinos (HCHS/SOL), where she worked as a Research Nutritionist. Her prior research experience was with the National Health and Examination Survey (NHANES) as a Dietary Interviewer. Liliana has also worked in community settings completing nutritional assessments and designing intervention plans for low income families. When she is not working she enjoys long walks with her dog, curling up with a good book and indulging and exploring the culi-

Sharing Experience

— Research Participants Interview —

To help people look at research studies from patient perspective, we interviewed a few patients who participate in multiple lupus studies in our clinic.

Q1: How were you approached and introduced to the studies?

Patient 1: After I was diagnosed with SLE, Dr. Ramsey-Goldman introduced her studies during my clinic visits. When I showed interest, Sue Cunanan, one of Dr. Ramsey-Goldman's research coordinators contacted me for participation during my clinic visits.

Patient 2: Dr. Ramsey-Goldman mentioned the studies and I told her I was interested, and that was how Sue Cunanan got in touch with me.

Patient 3: I came from New York and I was pregnant with my first son. I was doing a study in New York with another doctor. We decided to move back to Chicago, and my doctor in New York knows Dr. Ramsey-Goldman, so she (Dr. Ramsey-Goldman) said she was willing to finish the study for me.

Q2: What made you decide to participate in research?

Patient 1: It was something I was interested in. It was a bone density study, so I got my first bone density screening. I felt I was getting a lot of good information about my own health from participating.

Patient 2: I can be helpful to someone else who don't know what

lupus is, and also to get to know different people who are experiencing different symptoms, it will make me more aware what to look for.

Patient 3: I felt like whatever I can do to help out any lupus patient or if it would help with someone with other autoimmune conditions, I would definitely be willing to help. Research isn't scary and it is actually kind of fun to meet new people. Just really basically to help, anything I can do to help.

Q3: Is there anything in doing research studies that makes you feel uncomfortable?

Patient 1: No. I feel comfortable. Sue's been great. It is actually kind of fun.

Patient 2: No, I am always comfortable. The person who does the study (study coordinator), she's always polite. They always tell me what to expect ahead of time, never no surprises, no nothing hidden. Everything is just cut-and-dry.

Patient 3: She (Dr. Ramsey-Goldman) has a really good team. It is actually fun (doing research).

Q4: What's the benefit you get from participating in research studies?

Patient 1: More information about my own health, and hopefully I'll have better understanding of lupus.

Patient 2: I am learning more about the illness itself, the possible

side effects and the possibility of other things that can go wrong with lupus other than my usual symptoms.

Patient 3: Personally, it just makes me feel positive and hopeful. That's the direct benefit.

Q5: What would you tell people who hesitate in participating in research studies?

Patient 1: First of all, it is painless. They try to schedule while you are already here for your appointment anyway. You learn so much about your own health from the information shared back with you. It's a win-win situation.

Patient 2: I would tell them not to think of it as you being a guinea pig, but think of it as you being a help to someone else. You can also benefit from it yourself, because there is something new you can learn about it (lupus). It is all about helping others and educating yourself.

Patient 3: I would tell them not to be intimidated by research. If it doesn't help you, somewhere down the line it will help someone else. There is always potential to come up with new information, new data, and maybe even new medicine that could help at some point down the line. I show up at my appointment and am able to take care of the research part either before or after the appointment. It was never a burden.

Lupus Impact Tracker (LIT)

- **What is LIT?** LIT is a tool developed to help patients communicate effectively about their lupus with their physicians.
- **Purpose:** to evaluate how well the LIT measures the construct of interest in a clinical setting; as well as the acceptability and feasibility of the LIT from perspectives of the patient and physician.
- **Components:** Blood Draw, Urinalysis, Vitals, Medical History, Physical Exam, and Questionnaires will be done twice over a 3 month cohort, and each visit will last one and a half hour. A questionnaire to complete at home 7 days after the first visit.
- **Eligibility:** at least 18 years old adults who have lupus. **NOT diagnosed with Rheumatoid Arthritis or other connective tissue disease.**
- **Interested?**
Call Sue Cunanan: 312-503-7211, or email her at s-cunanan@northwestern.edu

Physical Activity Monitor

- **Purpose :** To determine how fatigue or tiredness is impacted by physical activities in lupus patients. A non-invasive device called the accelerometer (as picture shown) is worn at the waist to measure daily physical activities.
- **Components:**
 - A study coordinator will meet with you at the Clinical Research Unit.
 - A urine pregnancy test (for women) will be performed to assess your menopausal status.
 - A nurse will take your vital signs, draw blood (about 1 3/4 tbs) and collect a urine sample.
 - A physician will perform a physical examination on you to assess the status of your lupus.
 - You will complete 7 questionnaires.
 - You will wear an accelerometer around your waist for 1 week and record the times of use on a timesheet. An envelope will be provided for return.
- **Eligibility:** at least 18 years old. **Have not been hospitalized with acute medical illness, or are currently pregnant.**



PROFILE Study Reviews and Updates (continued)

derstanding how these genes work independently and together, which can ultimately be used as therapeutic targets or as a prognostic index to minimize disease progression. In a separate non-genetic evaluation, PROFILE investigators concluded that familial lupus, defined as a patient with a first degree relative with lupus, was not associated with greater disease burden including cumulative organ damage and overall survival, than sporadic (or non-familial) lupus.

Your participation in the PROFILE study offers us the advantage of an unbiased account of exposures and multiple lupus-related clinical manifestations defined over time, which will improve our understanding of the severity, progression and clinical course of this very complex disease. Your continued participation in the PROFILE study will allow us to learn more about this devastating disease. We greatly appreciate your time and efforts. Without your continued participation, our research would not be possible.—*Written by E. Brown, MD, PI of the PROFILE Study, Univ. of Alabama, Birmingham*

Northwestern University Gifts Contact Information

Maureen A. Mizwicki
Senior Associate Director, Gifts
Feinberg School of Medicine
Office of Development
Rubloff Building, 9th floor
750 N. Lake Shore Dr.
Chicago, IL 60611
e-mail:
m-mizwicki@northwestern.edu
Phone: (312) 503-1090
Fax: (312) 503-6743



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.

Dr. Rosalind Ramsey-Goldman
Northwestern University
Division of Rheumatology
240 E. Huron, Suite M300
Chicago, IL 60611