



Lupus Report

NORTHWESTERN UNIVERSITY
RAMSEY-GOLDMAN RESEARCH TEAM

2013-2014 ISSUE

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REACH LUPUS in the Community

The Lupus Research Group at Northwestern University's "Road map for Education and Access to Care for Chicago Hispanic Lupus" (REACH LUPUS) is partnering with the American College of Rheumatology's "Eliminating Health Disparities in Lupus Initiative" (EHLDI). REACH LUPUS is working in an Hispanic-Mexican population in Chicago's Pilsen community to increase lupus awareness where individuals diagnosed with conditions such as lupus have few recourses for care, follow-up and continued treatment. The project design is multifaceted



(From left to right: Sheryl McCalla - American College of Rheumatology, Dr. Graciela Alarcón-University of Alabama-Birmingham, Karen Mancera-Cuevas – Northwestern University, Dr. Patricia Canessa – Salud Latina, Dr. Rosalind Ramsey-Goldman – Northwestern University, Lisa Amaker - American College of Rheumatology, Dr. Daniel Vicencio - Mercy Hospital

and includes work provided to the community via popular opinion leaders (POLs), support group services and to primary providers by engaging in outreach and education.

As part of the REACH LUPUS initiative, the Lupus Research Group welcomed the arrival of Dr. Graciela Alarcón,

Professor Emeritus of Rheumatology at the University of Alabama-Birmingham on June 5, 2013. The day included two presentations, one directed to primary providers working in the Pilsen community, and the other for community members. As part of her visit, she met meet with members of

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Tips for Healthy Living



EATING WELL WITH LUPUS

There is no specific diet for a person with lupus. To improve heart disease risk, reduce inflammation, and lower blood pressure -- all of which are very important for people with lupus. Try to make sure to follow these general guidelines for healthy eating:

- Eat plenty of fresh fruits and vegetables. Fruits and veggies add color, flavor and texture plus vitamins, minerals and fiber to your plate. Don't let winter stop you from enjoying produce. It may be harder to find fresh options, but frozen and canned are great alternatives.
- Eat whole grains, and moderate amounts of freshly cooked meats and poultry. Try to use half your plate for fruits and vegetables and the other half for grains and lean meat, poultry, seafood or beans
- Avoid or limit foods containing saturated fat, hydrogenated or partially hydrogenated fats, or trans fats. Limit daily sodium intake, especially from processed and "fast" foods.
- Drink plenty of water (if there is no fluid restriction). Our bodies depend on water to regulate temperature, transport nutrients and oxygen to cells, carry away

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FIGHTING OFF INFECTIONS

For people living with lupus, the risk of infection is often greater than in the general population. Both lupus and some of the medications commonly used to treat it, especially immunosuppressant's such as prednisone and Cytoxan, can leave people vulnerable to many types of infections. The common cold and strains of influenza are a regular threat, as well as opportunistic infections that occur after bacterial contact, such as pneumonia, urinary tract infections and strep throat. People with lupus may also be more susceptible to infections that develop from minor cuts and sores.

In addition to the greater risk of infection, people with higher lupus disease activity, lupus kidney disease, or other related health complications often take a longer time to recover from their infections. This is partly because lupus causes the hyperactivity of certain immune cells, creating antibodies that are destructive to the immune system itself.

In order to ensure you keep your infection risks at a minimum, it is important to take proper steps to protect yourself. One way this can be done is to through immunizations against viruses such as the flu shot. But it is important to note, that if you do get the flu shot, you should not get vaccinations that contain the live virus.

A healthy lifestyle is also important. Eating a good diet, reducing junk food, getting enough sleep, and reducing stress all contribute to healthy living. Vitamin D supplements are helpful to counteract limited sun exposure.

Lupus and Headaches



The SLICC Study has recently completed a study of headaches in people with SLE. This studied what types of headaches people had, and how often they had them to better understand how SLE and headaches are related. Their findings included:

- Headaches are common in SLE patients but probably not more frequent than in the general population of similar age and gender.
- The occurrence of headache is not related to overall SLE disease activity and is not associated with changes in lupus medications.
- The majority of headaches in SLE patients are probably not due to a direct effect of lupus affecting the nervous system
- Regardless of the cause, SLE patients with headaches report a lower quality of life.
- Most headaches in SLE patients get better and resolve over time.

"Headaches and Lupus." *SLICC International Inception Cohort Study of SLE* (2 Apr. 2013)



Going Purple!

Staff members from Dr. Ramsey-Goldman's group wearing purple in support of Lupus Awareness Month this past May.

Solvable Update

Dr. Rosalind Ramsey-Goldman's MCRC project, SOLVABLE (Study of Lupus Vascular and Bone Long-Term Endpoints), focuses on heart and bone problems in women with and without lupus. Premature atherosclerotic cardiovascular disease (CVD) has been recognized as a major cause of morbidity and mortality in patients with systemic lupus erythematosus (SLE). We have received recent acceptance of the combined Chicago and Pittsburgh study showing the carotid ultrasound examinations predicted cardiovascular events in SLE (uses SOLVABLE and HEARTS) data, independent of traditional CVD risk factors and medication use. This study was planned over 10 years ago by Dr. Susan Manzi and Dr. Ramsey-Goldman, and was recently accepted for publication.

This is the first time anyone has shown that subclinical imaging, i.e. carotid ultrasound, predicts an increased risk of cardiovascular events in women with SLE. This had previously only been reported as a predictor in the general population. These data suggest that carotid ultrasound measurement of the carotid artery may provide an additional tool for CVD risk stratification in the clinical management of women with SLE.

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 Longterm Endpoints (SOLVABLE) that many of you are generously participating in. 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 new website at www.lupus.northwestern.edu.

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.

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waste products and more.

- **Eat Breakfast.** There's no better way to start your morning than with a healthy breakfast. Include lean protein, whole grains, fruits and vegetables. Try oatmeal cooked with low-fat milk, sliced almonds and berries, or top a toaster waffle with low-fat yogurt and fruit.
- **Watch Portion Sizes.** To find out if you're eating the proper portion size, use measuring cups and see how close your portions are to the recommended serving size. Using smaller plates and bowls can help you keep portions under control.
- **Fix Healthy Snacks.** Healthy snacks can sustain your energy level between meals. Try low-fat yogurt with fruit, whole-grain crackers with low-fat cheese, or a small portion of nuts with an apple or banana. Avoid or limit sugary foods and drinks.
- **Follow food safety guidelines.** Centers for Disease Control and Prevention estimates that roughly one in six Americans gets sick from foodborne disease each year. Reduce your chances of getting sick by practicing proper hand washing. Separate raw meat, poultry and seafood from ready-to-eat foods like bread and vegetables. Use a food thermometer to make sure food is properly cooked. Refrigerate food quickly at a proper temperature to slow bacteria growth.

Source: "13 Health Tips for 2013." *Eatright.org*

SLICC Update

The Systemic Lupus Erythematosus International Collaborating Clinics (SLICC) is an international group of rheumatologists and lupologists who have been working together on lupus research since 1991. The SLICC group has developed the Registry for Atherosclerosis with the goals to study the prevalence, risk factors, and possible interventions of early atherosclerotic coronary artery disease in lupus patients.

Now that a large number of patients in the SLICC study have been enrolled for over 10 years of follow-up visits, this has allowed them to look at long term outcomes associated with heart disease. It is known that women with lupus develop coronary artery disease at a higher rate and earlier age than the general public, and women with SLE are up to five times more likely to develop vascular conditions such as heart attack and angina.

Since 2000, a total of 157 vascular events, including heart attack, heart failure, stroke, pacemaker insertion, and peripheral vascular disease have been reported in patients enrolled in the study. Approximately 40% of these events were due to active lupus, while 30% were due to atherosclerosis.

Their analysis indicated that over the first 10 years, vascular events that occurred in patients and were attributable to heart disease, and increased by 0.5% per year, reaching a total of 4.4% at the 10 year mark. This study reaffirms the necessity of long-term outcome studies to track the increased risk of vascular events in SLE patients. The information gained from this research will help physicians better manage and follow heart disease risk factors in SLE patients.

SLICC International Inception Cohort Study of SLE (2 Apr. 2013)

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the Lupus Research Group at Northwestern including fellows Apinya Lertratanakul, MD, and Grace Ahn, MD, and faculty members, Christine Hsieh, MD, and Linda Ehrlich-Jones, PhD, RN, to discuss a variety of emerging lupus research issues. In addition, visitors from the American College of Rheumatology, EHLDI program came to Chicago to participate in the discussion and the day's events.

Dr. Alarcón presented Grand Rounds at Mercy Hospital, emphasizing health disparities and the treatment of lupus in her lecture. Mercy Hospital has clinics located in the Pilsen community. Approximately 50 clinicians attended this event representing primary care and subspecialties at Mercy. Additionally, those in attendance were provided clinical materials from the ACR as well as referral resources from the local chapter of the Lupus Foundation of America.

The day culminated with the Spanish-language community presentation and graduation of the POLs who facilitate dissemination of information to members of the community and are trained to provide appropriate referrals to the Lower West Mercy Community Clinic and other support systems for individuals identified with lupus. Dr. Alarcón provided a very engaging presentation and interacted with the audience during the question and answer session which followed her formal presentation. The POLs were also thankful for Dr. Rosalind Ramsey-Goldman's contribution to the community and implementation of the project in the Pilsen area. As a consequence of the intervention, POLs have been able to refer uninsured patients to the Mercy clinic, as well as educate the community of the signs and symptoms of lupus.



From left to right (back row): Katrina Schwab, Liliana Medina, Dr. Christine Hsieh, Gwen Dela Cruz, Karen Mancera Cuevas, Patricia Murphy, Anh Chung, Danielle Lerner (middle row): Christian Bengston, Dr. Linda Elrich-Jones, Dr. Grace Ahn, Dr. Apinya Lert (Front row): Sheryl McCalla, Dr. Graciela Alarcón, Lisa Amaker, Dr. Rosalind Ramsey-Goldman

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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