



Lupus Report

NORTHWESTERN UNIVERSITY
RAMSEY-GOLDMAN RESEARCH TEAM

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Awards and Presentations

During the past year, the Lupus team has had the opportunity to present the findings of our recent lupus research at several different events and conferences. In addition, the Lupus program, led by Rosalind Ramsey-Goldman, MD, DrPh, has been awarded the Lawren H. Daltroy Award for Excellence in Health Communication

at the recent LUPUS 2016 international (Americas) meeting in New York. This award recognized our educational efforts in the community to facilitate patient-provider communication. The lupus research team also met with Congresswoman Honorable Jan Schakowsky to discuss lupus research at Northwestern including our community work and

shared this award announcement with her. We were accompanied by Jennifer Kunde, Executive Director, Government Relations, Northwestern University who organized this meeting. Thanks to the contribution of participants in the Chicago Lupus Database, our research can continue to be recognized by other physicians and researchers across the country.



Members of the MONARCAS Project presented at the American College of Rheumatology Popular Opinion Leaders workshop in Atlanta on May 26th

Lupus and Fragmented Care

A paper entitled “Disease Outcomes and Care Fragmentation among Patients with Systemic Lupus Erythematosus” examines the effects of fragmented lupus care in different populations. Care fragmentation occurs when a patient is seen at more than one different institution for their health. Because care for lupus spans multiple specialties, lupus patients can often end up with fragmented care. The coordination between providers can be very complex and expensive, thus leading to significant challenges for the patient, especially those without adequate insurance. Receiving care at multiple institutions often creates difficulties in creating a clear picture of overall care of a patient, which can be associated with poorer health outcomes.

Using the Chicago HealthLNK Data Repository (HDR), an assembly of electronic health records (EHRs) from six institutions, we identified patients with SLE whose care was delivered at more than one organization. The HDR provides a unique opportunity to understand the role of care fragmentation and health data exchange without compromising patient confidentiality. With this dataset, we were able to estimate the frequency of severe infections and common

comorbidities for SLE that are indicators of damage due to disease or treatment for disease. Through this database we could assess the frequency and location of care of patients that cannot be assessed using only the single site Chicago Lupus Database.

When examining the relationship of fragmentation to indicators of complications in SLE, it was determined that fragmentation is correlated with increased frequency of severe infections requiring hospitalization (particularly bacterial infections), increased frequency of kidney disease (kidney inflammation and kidney function failure requiring dialysis or transplant), and cardiovascular disease (heart attacks and strokes). The data showed that care fragmentation could have a long term negative impact on the health and severity of disease in SLE patients. In addition, for patients with SLE, care fragmentation had a relationship with race and insurance use, particularly for African American patients and those who are public insurance beneficiaries.

The paper demonstrated that care fragmentation in SLE patients can be identified using a city-wide database of integrated EHR data. Combined with previous research suggesting that existing damage is a predictor of future damage for SLE patients, our study suggests that improving care coordination and access to a more complete set of medical record data may be a key strategy for improving health outcomes for SLE patients.



Lupus Team News



Dr. Mary Mahieu, MD, recently graduated from the Northwestern Rheumatology Advanced Fellow Training Program, and has taken on the position of Assistant Professor this summer. She will be building a Phase I clinical trials program, and will also have a very active clinical practice.



Erica Littman joined our group this summer as a research volunteer, and had the opportunity to work with our staff assisting in day to day activities and attending team meetings. She is currently a freshman at Northwestern University majoring in Biochemistry. She is interested in going into a career in medicine, and hopes to become a rheumatologist.

Lupus in the Heartland

Members of the lupus team recently presented at the Lupus in the Heartland Symposium in Springfield, IL

The goal of the symposium was to Increase the capacity of health professionals and front line providers to master skills to diagnose lupus signs and symptoms, and manage the evolution and treatment of a complex auto-immune disease. In addition, we hoped to educate people about the burden of the disease among vulnerable population groups, and increase skills addressing challenges of complex disease management in less resourceful areas of the state of Illinois.

Participating in Lupus Research at Northwestern University

A new research study is currently looking for volunteers

Right now, the XSEL clinical research study is inviting volunteers to test a new investigational treatment for lupus that's unlike anything previously tested. "Investigational" means that the medication is not approved for use by the public but is currently being studied.

If you qualify for and participate in this study, you may receive the investigational medication or placebo (inactive) treatment. There is no cost to you for participating in the study.

Those who volunteer will immediately receive steroid injections and stop some of the medication that's not currently working for them. When and if the improvement from the steroid injections wears off, patients and their doctors can choose any standard of care treatment and receive it immediately.

Participation in research is a personal decision

A clinical research study is a research project done with human volunteers to learn more about new treatments for diseases like lupus. Being in a study means that you're volunteering to be given a new kind of treatment or randomly assigned to inactive treatment. Some people volunteer to gain access to investigational drugs or treatments. Others volunteer to help advance science. Whatever your reason for participating, we'll closely monitor your health and protect your privacy. You always have the right to stop participating at any time and for any reason.

Who qualifies for this study?

You may qualify for this study if you:

Are 18 to 65 years old

Have been diagnosed with systemic lupus erythematosus (SLE) (If you're not sure if this is you, contact the study coordinator with the information on the back to find out if you qualify.)

Have active symptoms not fully controlled by your medications

The study doctor will evaluate additional information about you to see if you meet all of the criteria

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.

Lupus in the Hispanic Community

The poster “A Community-University Partnership Addressing Hispanic/Latino Lupus Health Disparities” was recently presented at the 2016 Latina Researchers Conference, to address lupus disparities in the Hispanic/Latino Chicagoland community.

Due to a lack of early detection, diagnosis, and care, Lupus significantly impacts Latino Communities. A partnership was developed between Northwestern University and the Illinois Public Health Association to educate Latino communities on the Popular Opinion Leader (POL) Lupus Model. This system uses social networks and opinion leaders of social networks spread lupus education throughout their communities.

Youth were provided training sessions based on a curriculum incorporation POL, lupus basics, community research methods, and practical integration of the skills necessary to go out of the community. This was done in three communities in the Chicagoland area. The POLs consisted of 1) High School Students, 2) Community Health Workers, and 3) Parent Leaders. To measure the effectiveness of the project, questionnaires were used to evaluate lupus knowledge improvement after the educational sessions. Overall. There was evidence of lupus knowledge improvement. Possible limitations included language difficulty, health literacy, and education although interpreters could assist with clarifying questionnaire content.

SOLVABLE Update

A recent paper titled “Depression and Progression of Subclinical Cardiovascular Disease in Systemic Lupus Erythematosus” uses data collected from the SOLVABLE research study to examine the connection between depression and the progression of atherosclerosis in women with SLE.



Because women with lupus have an increased incidence of premature cardiovascular disease, it is important to look at ways to prevent increased inflammation leading to CVD. In the study, assessment of CVD risk factors, depression screening, ultrasound evaluations of carotid plaque, and assessment of lupus activity were evaluated. The results showed that the lupus group had a higher rate of depression, at 29% compared with 11% in the control group. When controlling for traditional CVD risk factors, depression correlated with increased progression of thickening of the carotid artery in the lupus group, but not the control.

The conclusions made from the study were that women with lupus and depression have an increased risk of developing atherosclerosis, which can lead to heart disease. Finding ways to reduce depression in your life can help with one’s physical health.

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What are ways to combat depression? A recent article in Lupus now explores the ways that social support can have a positive effect on your health:

Research has shown that for people with lupus, mental and physical health are closely tied to the amount of social support they receive: Those who receive more support from their family, friends, co-workers, and others tend to have better mental and physical outcomes.

Now, new research headed by Stacey E. Morrison, BSc., Division of Rheumatology at Toronto

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Western Hospital, Ontario, Canada, finds that, rather than the total amount of support provided, it is the type of support provided that was most valued and best associated with well-being.

Morrison explains that the study examined perceived support needs and support received for five domains (work/school, family, recreation, finance, and household); three types of support (instrumental, emotional, and informational); perceived concordant and discordant support; and the relationship between support satisfaction and well-being (depression, life satisfaction, meaning of illness, illness intrusiveness).

Instrumental support is physical, practical support or material aid, such as assisting someone with completing tasks or providing financial support.

Emotional support is providing sympathy and reassurance and discussing feelings.

Informational support is providing information or advice to increase knowledge and access to informal support resources from family and friends, as opposed to formal/professional resources or paid help resources and services.

The responses from the 163 women who participated in the survey revealed that those who felt they were receiving the right amount of support in all areas of their life showed the highest levels of well-being. However, they often reported being under-supported in at least one domain of life; and in the work/school domain, depression and illness intrusiveness scores were significantly greater for those who viewed any type of social support as unsatisfactory, compared with those receiving satisfactory support.

Yet the differences in well-being didn't seem to be associated with lupus activity or how long a woman has been living with the illness. "In fact, some of the women in our sample who were the healthiest still reported needing some kind of help in some area of their life," Morrison says.

And while we tend to think of independence and dependence as opposites, Morrison says those who didn't want support and didn't receive it (independent) and those who wanted support and received support to match their need (dependent) were very similar in terms of well-being. "What seems to matter is not whether or not you need support but whether or not your needs match what you are receiving."

Morrison hopes to build on this information by looking at how support needs and the support women receive—or don't receive—change over time and then try to create a support intervention for women with lupus and their close friends and family to try and improve the "matching" of support resources to support needs.

Source: "Know how to help: New research reveals type of support is key in lupus" *Lupus Now*, Jul 2016.

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 Contact Information

MaryPat Mauro
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:

marypat.mauro@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