



# Lupus Report

NORTHWESTERN UNIVERSITY  
RAMSEY-GOLDMAN RESEARCH TEAM

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## Lupus Education in the Community

[Dr. Rosalind Ramsey-Goldman](#), has recently been awarded an [Office of Minority Health](#) grant for her project: Addressing Lupus Health Disparities Adapting Culturally-Competent Community-Based Education Models Through Local and National Collaborative Partnerships. The goal of the project is to help eliminate racial and ethnic health disparities in lupus in communities both in the Chicago area and throughout the country.

The intervention, adapted to lupus and designed by Dr. Patricia Canessa uses an endorsed Centers for Disease Control and Prevention (CDC) Popular Opinion Leader (POL) model. It was piloted through a community and grass-roots organization (Casa Michoacán) in the Cook County area, engaging community workers and lupus survivors in the delivery of messages that encourage early screening and care.

As part of the Latin American Weeks event on October 6th, the Consul of Mexico introduced a workshop which included a presentation given by Northwestern Feinberg School of Medicine MD degree candidate Christian Bengtson, who spoke about lupus and the traditional challenges that Latino patients encounter in seeking timely medical care. This background presentation on the disease was followed by an over

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# SLICC Update: Lupus and Quality of Life

A diagnosis of lupus can have a large impact on your quality of life; this includes activities you may do throughout your day, in addition to your ability to work. As a part of the SLICC Registry for Atherosclerosis in Lupus, patients completed a health questionnaire called the SF-36 Health Survey. This survey is used to study the physical, psychological and social impacts of having a chronic disease such as lupus. The study looked at patient responses to this survey in order to determine if a patient's quality of life changes over time in the first 5 years after your diagnosis.

The study found that quality of life improved over time, most notably in the part of the survey that addressed your physical health. Most of the improvement occurred within the first 2 years after diagnosis.

The study also looked at what other factors, such as sex, race, disease activity and age may be linked with the changes seen in survey responses. IT was found that men tended to have larger improvements in vitality, social function and physical activity responses. Being diagnosed with lupus at an older age was linked to slower improvements in physical, social and emotional function. Those who were suffering from a lupus flare at the time of completing the survey showed lower improvement rates in bodily pain and physical, social and emotional function.

This study demonstrates that in early lupus, the SF-36 Health Survey is a good indicator that can be used to test for changes in



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people's quality of life. It also highlights disease activity, especially at diagnosis, is related to the changes in one's quality of life in early disease. This is most likely due to the fact that many patients tend to have active lupus at the time of their diagnosis, and then receive proper treatment. Once the patient's lupus is controlled at years 2-5, the quality of life generally stabilizes or remains unchanged in response to the symptoms levelling off.

This study also highlights the importance of receiving regular healthcare regarding your lupus, instead of seeking help only when symptoms worsen. By maintaining regular medical exams your doctor can note changes to your health and identify and treat your flares early. Proper management of your health can avoid active disease and hopefully improve or maintain a higher quality of life throughout your disease.

Source: *SLICC International Inception Cohort study of SLE 2015 Newsletter*

## New To the Research Team



**Zineb Aouhab, MD** is currently a second year rheumatology fellow at Northwestern University. Zineb is originally from Morocco where she attended Universite Hassan 2 de Medecine et de Pharmacy de Casablanca for her medical education and graduated with honors. She then came to the US and completed her Residency in Internal Medicine at John H. Stroger Hospital of Cook County. She is interested in health disparities associated with SLE. She also participated in fellows project led by the Lupus Initiative and is looking forward to expanding her experience in SLE behavior in underserved communities and act as a patient advocate to help eliminate health disparities in SLE.

**Brenda Herrera BS**, has recently joined Dr. Ramsey-Goldman's group as the new research study coordinator. Brenda graduated from Bradley University with a degree in nutrition and wellness. Prior to her current position, Brenda worked as a research assistant at Northwestern University on a study examining dietary and physical activity changes among patients with type 2 diabetes. Her prior research experience was with the Illinois Caucus for Adolescent Health (ICAH) as a Peer Health Ambassador where she coordinated afterschool wellness programs in the West and South side of Chicago. When she is not working she enjoys long distance cycling, listening to Start Talk Radio, and eating a variety of vegan food!



**Emily Bacalao BS**, is a Research Study Coordinator for the Rheumatology division. Emily graduated from Northwestern University in June of this year with a degree in Communication Sciences and Disorders and a minor in Global Health. During her undergraduate years Emily worked as a research assistant in an endocrinology research lab on a project that searched for genes associated with polycystic ovary syndrome (PCOS).

## Celebrating Lupus Awareness Month

The month of May was Lupus Awareness Month, and the Research Team at Northwestern recently celebrated this by providing information in the rheumatology clinic regarding lupus, and by participating in the Fighting for Lupus campaign created by the Lupus Society of Illinois. We showed our support with a group picture displaying our commitment to helping fight lupus with our research. Below is our picture for lupus awareness month with the statement “We fight for lupus because we want to improve treatment, prevent flares, and minimize complications of lupus.”



## Announcements

Congratulations to Rheumatology fellow Mary Maheiu on the birth on her son, Daniel on September 8th, 2015.

# Solvable Study Update

The recent paper **Adverse pregnancy outcomes and subsequent risk of cardiovascular disease in women with systemic lupus erythematosus** looks at the connection between pregnancy complications and a future risk of cardiovascular disease (CVD) in women with lupus using data from the SOLVABLE research study. Women with lupus tend to experience CVD events at a higher rate, and at earlier ages than the general population. Additionally, compared with the non-lupus population, women with lupus are more likely to have certain types of pregnancy complications.

One of these complications is pre-eclampsia, a pregnancy condition marked by high blood pressure and potential kidney damage. Studies in patients without lupus have shown cardiovascular problems are higher among women who have previously experienced pre-eclampsia, as well as other pregnancy complications, such as preterm delivery and delivery of low birthweight infants. What is not known is whether a relationship exists between pregnancy complications and CVD in women with lupus.

One factor that may underlie the relationship between these pregnancy complications and cardiovascular disease is that the pregnancy complications share several common risk factors with CVD, including obesity, cigarette smoking, hypertension, diabetes and high cholesterol. These traditional CVD risk factors are associated with an increased risk of developing pregnancy complications, just as pregnancy complications are also associated with an increased chance of developing CVD risk factors.

The study found that patients with both lupus and a history of pre-eclampsia had an almost fourfold increase in the rate of cardiovascular disease in the future. A possible reason for this is that in women with lupus, there may be separate, lupus-related factors that creates a risk for developing pre-eclampsia and CVD. Since inflammation plays a role in both atherosclerosis (build-up in the arteries) and pre-eclampsia, it could potentially create a detrimental combination for the future risk of CVD in women 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.

# Lupus and Mood

Mood disorders such as anxiety or depression are frequently found in patients with SLE. In a 2015 article in the medical journal *Arthritis and Rheumatology*, it reports the findings of a study on mood disorders in lupus.

As part of the SLICC study, patients are assessed annually for mood disorders and other neuropsychiatric (NP) events. Of the 1827 patients enrolled in the study worldwide, 47.2% were found to have had at least one NP event over an average of 4.7 years. Mood disorders occurred in 12.7% of the total study patients, and 38.3% of these mood disorders were attributed to SLE.



Points of interest from the study were the fact that patients taking immunosuppressant drugs were found to have a lower risk of a mood disorder, and that there was a greater risk of a mood disorder in those patients who were currently experiencing an NP event.

The study also found that mood disorders were associated with a lower self-reported Health Related Quality of Life (HRQoL) but was not associated with active lupus, or specific lupus antibodies. Antidepressants were used in 72.4% patients with depression which resolved in 50.4% patients and improved in additional patients over the period of follow-up.

The study demonstrates that mood disorders, the second most frequent NP event in SLE patients, can have a negative impact on how one views their quality of life in relation to health. However, this improves over time in the majority of cases. The lack of association with active lupus and lupus autoantibodies shows that multiple factors contribute to depression in SLE patients, and that there is a role for non-lupus specific therapies.

Source: *SLICC International Inception Cohort study of SLE 2015 Newsletter*

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view of cultural competency and a description of population-related health disparities by Dr. Patricia Canessa. The second segment of the workshop was highlighted by testimonials given by two Lupus survivors who described their experience as community educators. The outcome of their community work resulted in key community changes that ultimately improved health-seeking norms among community residents in the Pilsen community. The workshop concluded with lupus patients telling about their experiences with having this disease.

Pictured at right: Christian Bengston and Dr. Patricia Canessa



## Winter Health Tips: Protection from the Flu

When you have lupus, you have to be careful to protect yourself from viruses because they have the potential to not only make you feel horrible from the illness itself, but to cause a flare or increased activity of your lupus. Additionally, the use of strong immune suppressants often prescribed to lupus patients put you at a higher risk for contracting a virus.

In addition to getting your annual flu vaccine, keep these tips in mind to help prevent the possibility of getting a cold, flu, or other virus this winter season:

Wash your hands (tops, palms, and fingers) frequently with hot, soapy water for at least 15 seconds.

Remember that surfaces—especially in bathrooms, on shared office equipment, on store countertops, gas pump handles, any surface of the car, and in restaurants—can expose you to germs. Keep alcohol-based gel or wipes handy, both out in public and at home.

Avoid touching your eyes, nose, or mouth. Germs spread this way.

Use the crook of your arm to shield coughs and sneezing. Do not use your hands or handkerchiefs as they carry moisture that spread viruses.

Please remember that you should never discontinue medications used to treat your lupus without first consulting with your doctor.

## 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](http://www.lupus.northwestern.edu) for more information or email [solvable@northwestern.edu](mailto:solvable@northwestern.edu).

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