



Lupus Report

NORTHWESTERN UNIVERSITY
RAMSEY-GOLDMAN RESEARCH TEAM

2012-2013 ISSUE

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Winter Health Tips

As we approach the winter season, it is important to be even more aware of how lupus and cold weather can affect your health. Many people with lupus may show signs of Raynaud's phenomenon, which causes tightening of the blood vessels. These circulatory problems can become more acute in the cold weather. Following these tips can help ensure you are staying healthy.

Dress appropriately. Be sure to dress warmly, wearing a hat and scarf. Use mittens instead of gloves to help insulate your fingers.

Maintain good circulation. Try to avoid sitting for long periods of time, making sure to move around every hour, and rotate your ankles when possible. Wear loose-fitting clothes as opposed to tight clothing, which can restrict blood flow. Avoid keeping your legs crossed for long periods of time.

Stay hydrated. Winter can be very dry, so it's important to drink plenty of water. Drink tea if you prefer something warm.

Keep medication at room temperature. Most medications are recommended to be stored at 68 to 77 degrees. Avoid keeping them in extreme temperatures, and check the drug information sheet included with the medicine.

Get regular exercise. Winter can also make it difficult to keep up with your usual fitness routines. The cold temperatures and lack of sun often restrict many people's usual outdoor activities. Be sure to keep your health in mind by following these cold weather exercise tips:

Find indoor fitness activities. There are plenty of exercises that can be done inside, especially if you have access to a gym, such as running, swimming and bicycling. If you want to work out at home, try a fitness DVD. Taking the stairs instead of escalators is another easy way to get some extra exercise inside.

Enjoy the snow! If the weather isn't too chilly, try some outdoor activities such as ice skating or sledding. Be sure to keep aware of the temperature and wind chill while you're outside.

Also remember to stay safe in the winter, keep an emergency kit at home for potential snowfalls, be careful walking and driving in icy areas, and avoid traveling when weather advisories are issued.

"Circulate Yourself" *Lupus Now*, Fall 2011.

"Out of Hibernation" *Lupus Now*, Fall 2011.

WebMd., <http://www.webmd.com/parenting/family-health-12/checklist-winter-fitness>, retrieved 10-20-12.

Thank you for supporting our ongoing lupus research at Northwestern University. Due to your help, we are learning more about lupus everyday.

New to the Chicago Lupus Database?

If you have recently 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.

NUgene Project

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.

For more information, visit the NUgene website: <http://www.nugene.org> or call (312) 695-0700

IRB STU00010003 "NUgene: Gene-Disease Associations and Treatment Outcomes

Recent Findings and Updates

SOLVABLE Update

Dr. Rosalind Ramsey-Goldman's MCRC project, the Study of Lupus Vascular and Bone Long-Term End-points (SOLVABLE), focuses on heart and bone problems in women with and without lupus. Information is collected at three study visits over a period of five years. A new study, expanding on the original SOLVABLE work, investigates a possible blood test that could identify atherosclerosis (narrowed blood vessels) in the heart or other major blood vessels. Women with atherosclerosis are at higher risk for cardiovascular disease, such as heart attacks and strokes. Also, the lupus women in SOLVABLE have more atherosclerosis in the heart, detected by a CT scan, than women without lupus. Earlier identification of lupus patients at risk for atherosclerosis with a blood test would allow earlier treatment of cardiovascular disease before complications arise. In collaboration with Dr. David Ford, PI on the project from St. Louis University, Dr. Mary Mahieu, a medical resident at Northwestern, investigated one such blood test, called alpha-chlorofatty acid (alpha-

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Lupus and Heart Health

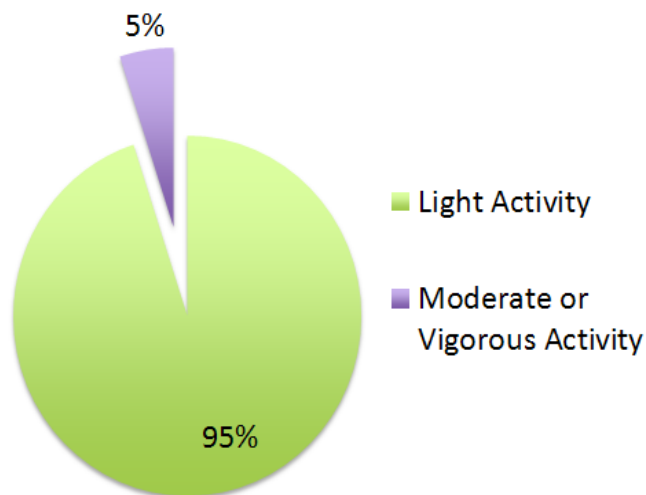
Dr. Apinya Lert is working on investigating risk factors for progression of subclinical cardiovascular disease - cardiovascular disease that is present but not yet showing symptoms -- in women with SLE and in women without SLE. Women with SLE are known to have significant cardiovascular disease at an earlier age than those without SLE, and she is examining traditional risk factors (such as age, body mass index, smoking, cholesterol levels) and other novel risk factors to see if they may be associated with a risk for progression in cardiovascular disease. Because certain types of imaging, such as ultrasound and CT, can show cardiovascular disease in major arteries of the body before patients have outward symptoms, we are using these to measure early cardiovascular disease: ultrasound measurements of the thickness of the carotid artery and the amount of atherosclerotic plaque in the carotid artery, and CT to measure the amount of coronary artery calcium and aorta calcium, which are

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ALTER Study

We are still actively collecting valuable information about physical activity from our study participants. Initial preliminary analysis of the ALTER study (Activity in Lupus To Energize and Renew), shows that people with SLE tend to be in more pain and feel more fatigued. Public health guidelines on physical activity recommends at least 150 minutes engaged in moderate or vigorous physical activity, with at least 10 minutes of continuous activity at a time. Our preliminary analysis shows only 5% of total physical activity is at a moderate or vigorous level, and a majority of the time engaged in less intense activity. We are currently in the process of finalizing the data collection at this time. We hope to develop an intervention to help improve quality of life in those affected by SLE by utilizing our results.

Average Daily Physical Activity



Staff Announcements

We would like to congratulate several members of our team about the exciting recent events in their lives.

Future Doctors!

Student assistants **Daisy Zhu** and **Patrick Lloyd** both began medical school this fall. Daisy is attending the University of Virginia, and Patrick at Midwestern University. We will miss them both and wish them the best of luck!

New arrivals!



Lily Ahjun

Dr. Grace Ahn, Rheumatology Fellow, gave birth to a baby girl, Lily Ahjin on March 27th, 2012.

Dr. Chrissy Hsieh, Rheumatologist, recently gave birth to baby girl Hana Mei.



Hana Mei

REACH Project

The lupus research group has taken on a new initiative, the Roadmap for Education and Access to Care for Chicago Hispanic Lupus (REACH LUPUS) Disparities Project which is funded by the ACR to work with a targeted Hispanic-Mexican population in Chicago's Pilsen community to increase lupus awareness where individuals diagnosed with conditions such as lupus that have few recourses for care, follow-up and continued treatment using educational materials. The project has been recently funded and is still in early program development. The project design is multifaceted and will include work provided to the community via support group services and to primary providers by engaging in outreach and education.

New to the Lupus Research Team



Luke Barr, BA, graduated in 2008 from The College of the Holy Cross in Worcester, MA with a B.A. in chemistry. Following college, he spent two years working in an immunology research laboratory at the San Francisco Veteran's

Affairs Hospital. Last spring, Luke finished his first year as a medical student at the Northwestern University Feinberg School of Medicine. This summer he is working with the lupus research team to gain experience with clinical research before his second year begins this August.



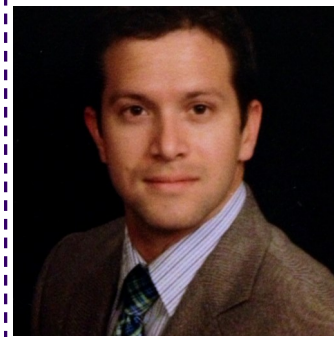
Danielle Lerner, BA, is a Research Study Coordinator for Dr. Ramsey-Goldman's group. Danielle graduated from American University with a degree in Psychology. Prior to her current position, Danielle worked as a project manager

at the University of Chicago on a study examining the effects of social relationships on aging and health, and as a coordinator on the Youth Emotion Project at Northwestern University, which studied the occurrence of emotional disorders in adolescents.



Peter Lloyd, MD is currently completing his residency training in Internal Medicine at the University of Chicago NorthShore program. Peter is a Chicago native and has enjoyed caring for the patients of his hometown and giving back

to the communities he grew up in. Prior to returning to Chicago, he graduated from the University of Vermont College of Medicine and from the University of Colorado, Boulder with a Bachelor of Science degree in Biology and Applied Business. Through his residency he has had the opportunity to work with and learn from Dr. Ramsey-Goldman as a visiting resident. He is very thankful for the patients that have taught him so much through his residency.



Christian Bengtson is a researcher for Dr. Ramsey-Goldman's group. Christian is first year medical student at Feinberg School of Medicine. He graduated from University of South Florida with a degree in Chemistry.

Talin Robinson Catalan, BS, graduated from the Rochester Institute of Technology with a degree in biotechnology. She is interested in health disparities associated with SLE, which include socioeconomic, race, gender and genetic risk variants factors. Her experience designing clinical trials for underserved communities and acting as a patient advocate for at-risk volunteers. Community engagement includes recruiting under-represented minorities (URMs) to STEM career fields. In her free time she enjoys traveling, going to live concerts and athletic activities. She also has a loving husband and two beautiful and talented daughters. Research interests include: SLE molecular clinical manifestations and clinical diagnostic design, SLE Patient Advocacy, Pregnancy Immunology, and health Disparities and SLE.



From left: Teresa Dirosa, Dr. Rosalind Ramsey-Goldman, Study Coordinator Karen Mancera Cuevas

Support From the Community

Teresa Dirosa was diagnosed with lupus at the age of 24, and had been a patient in Dr. Ramsey-Goldman's clinic since 2006. This past fall, she helped organize a community fundraiser which donated a portion of their proceeds to the Lupus Program at Northwestern. We interviewed her to ask about her experiences participating in studies at Northwestern, and why contributing to research is important to her.

How did you get started participating in research for Dr. Ramsey-Goldman?

I've been a patient of Dr. Ramsey-Goldman's for about six years now, and have been participating in her studies for probably the last five years. As soon as she asked me to participate I was all for it, because I have lupus, so to find a cure would be great.

How do you feel participating in these studies has helped you?

I get a better understanding of what's going on and what they're looking for to find cures. Dr. Ramsey-Goldman and Patricia Murphy are very good at explaining the procedures and why they need these types of tests.

How did you get involved in fundraising for Northwestern?

My husband is from Italy and I'm a second-generation Italian. We're part of an organization of people from his town in Italy, and we like to get together and try to raise money for a good cause. Because there are five of us within our small organization that have lupus, we thought

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that would be good cause to donate to. They asked if I knew of any place I wanted to donate to, so I asked Patricia Murphy about it at a visit. She told me they have research projects that would be more than willing to accept our donation, so that's how we got together. We may have only made a small donation, but small is better than nothing, because they need all they can get.

What do you hope others will learn from your work?

In life, people that go through health issues, and doctors need this research to in order to help. If there's any little thing that we can do, a few dollars here and there won't hurt our pockets, and it can make a big difference in someone else's life. Having lupus and knowing the struggles and the heartache and the confusion that goes along with it, to find a cure for just one of the little symptoms that we may experience would be a huge help for our lives moving forward.

For others who may be interested in doing more for lupus research, what would you suggest they do?

I feel very comfortable going up to the doctors and asking them. I'm always at the doctor's office, so it's just a matter of asking, and they'll be more than willing to come forward. Also having worked with Maureen Mizwicki, she was amazing at facilitating this and putting this all together. I told them "I don't want you guys going out of your way, because it's not anything huge that we're going to be able to donate". I didn't want to put them out, but they all came to the event and were great about it.

Is there anything else you would like to add?

Just a huge Thank You to Dr. Ramsey-Goldman, because she's an amazing woman. She's done so much, and I think without her help and without her knowledge we wouldn't be where we are today with lupus. I lost my cousin to lupus, and even though it was only ten years ago, ten years ago I think we were in the dark about what this disease could do. We've come so far, and she's a huge contributor to that. She's done great work.

I wish more people would know about lupus, because most don't know what it's all about. It's a hidden disease that people don't talk about, and I wish more people would be open about it.

Interested in donating?

To continue our work with lupus research, education, and patient care, your philanthropic support is welcome. If you would like to find out more about supporting Northwestern University Feinberg School of Medicine, please reach out to:

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Solvable Update (continued)

-CIFA), that is thought to be produced when the blood vessels narrow with atherosclerosis. The lupus women in SOLVABLE had higher blood levels of alpha-CIFA. Higher blood levels of alpha-CIFA at the first study visit, however, were not associated with the presence of atherosclerosis. Further work to examine the relationship between alpha-CIFA and atherosclerosis, as well as identify other blood test markers of atherosclerosis, are still in progress. We look forward to providing updates on future results from SOLVABLE.

Lupus and Heart Health (continued)

signs of early atherosclerosis. Her findings have preliminarily shown that increased SLE disease damage, as measured by the modified American College of Rheumatology/Systemic Lupus International Collaborating Clinics-Damage Index, is associated with a higher risk for progression in coronary artery and aorta calcium scores. These findings were presented at the 2012 American College of Rheumatology meeting in Washington, DC.



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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