

Cutaneous Lupus Registry Update

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Cutaneous Lupus Registry Newsletter

By: Benjamin Chong, MD, MSCS (Principal Investigator)



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This is our third annual newsletter for the University of Texas Southwestern Cutaneous Lupus Registry. To date, we have enrolled a total of 388 people and 676 visits!!! On behalf of our research team, I would like to thank all of you for participating in this registry. We are extremely grateful for your enthusiastic participation in the registry. We want to update you with some of our ongoing research projects that have stemmed from the registry. We hope that you will enjoy reading this newsletter, and we look forward to seeing you again in the near future, as we continue to work towards improving our knowledge about the disease. If you would like to schedule a follow-up study visit or if you know of other individuals who may be interested in participating, please e-mail us at skinlupusregistry@utsouthwestern.edu, or call us at 214-648-3427.

UVA1 Clinical Trial For Discoid Lupus Patients By: Patrick Blake, MD

We are conducting an exciting clinical trial determining the effects of UVA1 phototherapy on discoid lupus erythematosus (DLE) patients. Past research on systemic lupus erythematosus (SLE) patients indicates that this treatment may be effective in treating cutaneous lupus with few side effects. The fact that most DLE patients are seen at dermatology clinics also increases the usefulness of this

study because there is a large probability that phototherapy treatment will be accessible for many of the patients that stand to benefit from it.

Study participants are receiving low dose (20 J/cm²) UVA1 phototherapy treatment three times per week for 10 weeks. Each treatment takes less than 30 minutes. This period is followed by an eight week observation phase to assess longer term effects of the treatment. Patients are assessed for disease activity, and blood studies and photos are completed prior to, during, and after phototherapy treat-

ment. Optional skin biopsies of affected and unaffected skin are performed at the beginning and end of the active treatment phase. Participants are compensated for their time during the study. Although the trial is currently underway, we are still recruiting adult patients with at least two areas of active DLE.

If you believe you are an eligible study participant, or would like more information regarding this study, please contact us at skinlupusregistry@utsouthwestern.edu.



Frequency of and Barriers to Sunscreen Use in Cutaneous Lupus Patients

By: Danielle Lin, BA

Past studies have shown that UVA and UVB radiation can cause and worsen skin lupus lesions among cutaneous lupus patients. A 8-week clinical trial revealed that daily use of broad spectrum sunscreen by cutaneous lupus patients significantly diminished the severity of disease. Another study involving 25 cutaneous lupus patients exposed to UVA and UVB radiation demonstrated that pre-treatment with sunscreen could prevent formation of skin lesions. Despite this, cutaneous lupus patients do not consistently use sunscreen, but the reasons for this are unknown.

Thus, we conducted a survey of patients in the University of Texas Southwestern Cutaneous Lupus Registry to determine the frequency of and barriers to sunscreen use. 100 cutaneous lupus patients successfully completed the survey between January 2012 and April 2013. Our results revealed that 40% of cutaneous lupus patients surveyed do not use sunscreen at all, and 32% reported that they used sunscreen daily. When comparing the demographics of patients who did not use sunscreen at all (“non-sunscreen users”) and daily, daily sunscreen users were more likely to be married. There was a significantly higher percentage of patients whose income was less than \$10K among non-

sunscreen users. The most common barrier to sunscreen use among cutaneous lupus patients was forgetfulness (reported by 42% of patients), which was closely followed by the belief that sunscreens are ineffective in preventing lupus flares (41%). Compared with daily users, non-sunscreen users were more likely to agree that forgetfulness, inconvenience, and inefficacy were reasons not to use sunscreen. These findings stress the need for providers to teach cutaneous lupus patients about how sunscreens can prevent lupus flares, and how to properly apply sunscreen. Additional educational media such as videos and pamphlets can be also employed to teach patients about the importance of sunscreen use.

The results of this study will be published in a future issue of British Journal of Dermatology.



Quality of Life in DLE patients

By: Noelle Teske, MSc

Many skin conditions, like cutaneous lupus, are not life-threatening but can still significantly influence patients’ well-being through symptoms, emotional impact, or impairment of daily functioning. Standardized quality of life measures allow physicians and researchers to quantify this impact of skin conditions in order to better study and treat patients with these dis-

orders. Previous studies have shown that patients with cutaneous lupus do have impaired health-related quality of life. However, these studies were done in groups of patients with many different types of cutaneous lupus, which can have very distinct clinical features. Patients with discoid lupus erythematosus (DLE), in particular, experience some unique characteristics, such as dyspigmentation, alopecia and scarring, which may distinctly impact their quality of life.

In a recent study, we examined quality of life specifically in 117 patients with discoid lupus from the University of Texas Southwestern Cutaneous Lupus Registry. We also examined various factors like age, gender, race, smoking status, and disease activity, to see which might correlate with lower quality of life in this patient group. Overall, patients with discoid lupus had worse quality of life than those without skin disease. They also reported more negative more emotional and functional impact on their quality of life than those with other skin diseases including acne, alopecia, rosacea, and non-melanoma skin cancer. Discoid lupus patients also had worse symptom-related quality of life than patients with other types of skin lupus, especially with respect to itching and bleeding of the skin. Female patients and current smokers with discoid lupus were particularly vulnera-



ble to have impaired quality of life. These results help us understand which factors related to discoid lupus seem to impact patients most, and which patients might be particularly in need of additional interventions in order to improve quality of life in this disease.

These findings were presented at the 2014 Rheumatologic Dermatology Society meeting in Boston, MA.



Patient Support Groups and Lupus

By: Tina Michelle Vinoya, MD

Patient support groups are an integral part in the lives of patients with chronic medical conditions. Education and awareness about a disease is one of the main missions of these support groups; patients become knowledgeable about the nature of their condition and gain access to the latest information including the latest therapeutic options available. They hold regular meetings that become effective avenues for patients with similar health conditions to freely exchange their ideas and help them cope better. They help form and foster rela-

tionships among patients, their families and loved ones, and even physicians. One also cannot over-emphasize the role of patient support groups in research by generating much needed interest in a certain disease. The collaborative effort of members of these groups contributes immensely by way of lobbying for funding in research.

For patients with lupus, a number of national support groups abound. This includes the: Lupus Research Institute (www.lupusinstitute.org), Alliance for Lupus Research (www.lupusresearch.org) and Lupus Foundation of America (www.lupus.org).

In the Dallas Fort Worth area, the Lone Star Chapter of the Lupus Foundation of America (www.lupuslonestar.org) sponsors monthly support group meetings. It also organizes events such as the “Dallas Fort Worth Walk to End Lupus Now” to help increase the public’s awareness about lupus, and annual informational conferences to educate and update patients and family members about the disease. They also have Facebook and Twitter pages for patients to express feelings and advice and ask questions about their disease. The Alliance for Lu-

pus Research also holds an annual “Dallas Walks with Us” fundraiser.

The role of patient support groups is invaluable as they encourage patient empowerment. They are an important ally of health care professionals in providing holistic treatment to their patients.

Dr. Chong is a medical advisory board member for the Lone Star Chapter of the Lupus Foundation of America.



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If you would like to schedule a follow-up study visit or if you know of other individuals who may be interested in participating, please email us at skinlupusregistry@utsouthwestern.edu or call 214-648-3427.