



The Voices of GOAL

A Note from Dr. Sam Lim, Principal Investigator of the GOAL Project

Dear Goal Members,
Another summer is close upon us. In addition to partnering with the Lupus Foundation of America to bring you a free subscription to the information-packed LupusNow Magazine, we periodically will be sending you topical information of interest to our members. In this issue, we discuss sun exposure and tips to protecting yourself. Not all patients with lupus are sensitive to sunlight. But for many who are, this does not mean your life should slow in summer. Like most everything else in lupus with education and planning, you can

be equipped to live the life you deserve.

I would also like to remind you that another important component of our mission is research. The type of research we primarily do is to gather information directly from you through research surveys. Through the generous donation of your time and efforts, we will better inform other researchers as well as policy makers to direct the efforts and support where the lupus community needs it most. Look for our next questionnaires soon.

On behalf of all our staff, we wish you a healthy and rewarding summer!

S. Sam Lim MD, MPH



GOAL Project

Summer Issue 2010

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GOAL Update

Thank you for continuing to be a part of the GOAL family. We are busy making sure that we continue to keep you abreast of the latest happenings related to lupus and fun tidbits for your educational benefit

along the way. We are increasing in ranks and now have a total of 442 participants. THANK YOU!!

This issue is dedicated to summer fun and keeping your skin safe and healthy throughout the hot summer

heat. We hope to continue working with you and let us know of any additional topics that might interest you for further issues.



5 Great Skin Tips for Healthy Skin

1. Protect yourself from the sun.

Avoid the sun between 10 am and 4 pm. Wear protective clothing such as long sleeves, hats and sunglasses. Try to wear sunscreen while in the sun.

2. Don't smoke. Smoking damages the fibers in your skin decreasing its strength and elasticity. It also can make your skin look older and contributes to wrinkles.

3. Treat your skin gently. Its best to limit bath time and try to use warm rather than hot water. Avoid strong soaps that can strip your skin. Look for mild soaps. Shave carefully and always in the direction the hair grows.

Use shaving gels and a sharp razor. After bathing pat your skin dry to leave some moisture on your skin. Moisturize dry skin with a lotion that fits your skin type and leaves skin feeling smooth and soft.

4. Eat a healthy diet

Eat a diet with plenty of fruits and vegetables, whole grains and lean proteins.



Avoid the sun's harmful rays by using protective actions..

5. Manage stress

Stress can cause your skin to be more sensitive and trigger breakouts and acne flares. Its best to reduce stress to maintain not only healthy skin but a healthy state of mind. Try to make time to do the things you enjoy while managing your to-do list, and other strenuous life demands.

-Mayo Foundation for Medical Education November 24, 2009

Protective Clothing Creates Protected Skin

Clothing is a great way and easy way to protect yourself from the sun's harmful rays. Hats usually go a long way to start with. You want a hat that has a good wide brim. 3 inches or better would be perfect. The more skin you are showing, the wider your hat brim should be. A hat can help protect against areas where we cannot apply sunscreen, such as the scalp or places that we often forget, such as the top of our ears or bridge of our nose. Hats can also protect your eyes and help to relieve your eyes from the brightness of the sun.

Sunglasses are also a great way to protect your eyes. Although it can be tough picking out a stylish pair, there are basic rules that can help you when thinking along lines of protection.. For starters, sunglasses should block 99-100% of the sun's UV rays. Check the tag on the package to ensure this. They also should fit comfortably behind your ears and not slide down the bridge of your nose. Meg Mirtallo, a frames designer advises, "Different types of lenses are appropriate for different activities. Polarized lenses are good for driving and water sports since they reduce glare from reflective surfaces like water, increasing visibility. Colored lenses serve a variety of purposes: Brown lenses create greater color contrast, providing better visibility on solid-color surfaces such as ski slopes by highlighting the peaks and valleys, while yellow lenses are good for both contrast and depth perception, making it a good choice for golfers and for bicyclists who need to be wary of debris on the road."

Clothing can also help to protect your skin from the sun. Contrary to popular teachings about wearing light colored loose fabric in the summer time, these fabrics provide little protection from sun burn. Dark clothing is ideally the best when trying to prevent UV rays. It is also important what the fabric is made from. Tighter woven fabric or fabric that you cannot see through works well. Also high luster polyesters and silks can reflect the sun's rays. A laundry detergent called Sun Guard can also help. When added to your regular wash it adds the sunscreen Tinosorb(R)FD, which can increase the protection factor and last for up to 20 washings. Some manufacturers market special sun protective clothing. These specially treated clothing prevent both UVA and UVB rays and are recommended by the Skin Care Foundation.

"Contrary to popular teachings about wearing light colored, loose fabric...these will provide little protection..."

Lupus Walk 2010

On Saturday May 8, 2010, the Lupus Foundation of Georgia hosted a Walk for Lupus Now 1.5 mile walk at Piedmont Park. It was a great afternoon for a walk with blue skies and light breezes.



The park was filled with 4000 walkers from over 400 teams, and 160 volunteers. The cheers and chatter of the spirited participants along with the colorful butterfly decorations, balloons, music and refreshments made

this such a festive event. Members of our GOAL Research Team were thrilled to be a part of this event as we especially supported the Grady Lupus Support Team, Laces DeKalb County Support Group Team, and the

Hispanic Support Group "Por Una Nueva Vida".

This quality of life is indeed what we, the GOAL Project, work so hard to maintain as patients continue to grapple with the effects of lupus.

Kudos to the Lupus Foundation of Georgia for a fantastic event!

By: Charmayne Dunlop - Thomas



What have we learned about you? GOAL Sun Statistics

Thank you so much for your continued participation. Up to date we have over 300 patients consented for the GOAL project and we are learning a great deal about you.

According to the data:

- 57 % of you use sunscreen during the summer
- 68 % of you try to avoid the sun during peak times.

sunscreen to keep your skin soft, looking healthy, and lasting for a lifetime.

We hope you will continue to be an active GOAL member!

"57 % of GOAL participants use sunscreen during the summer"

Skin care is very important and we have learned from your survey results that many of you are using sunscreen.

This shows us that we still have a gap to close in relation to sun health. It is important that everyone use

Inside tips on Sunscreen

Sunscreen is an essential tool in helping to protect your skin during the summer. It works by helping to reflect, scatter, and absorb the sun's rays. Sun rays are classified into two main categories, ultraviolet A -UVA and ultraviolet B - UVB rays. Anyone who is going to spend time in the sun should use sunscreen regardless of if you have darker skin tones, tan easily, or can tolerate longer periods in the sun. SPF or sun protection factor, found in sunscreen, measures how much

protection you have from UVB rays. The higher the number the more protection is offered. SPF decreases in effectiveness the longer you stay in the sun, so reapplication is important. You also need to reapply sunscreen after sweating, or swimming. When purchasing sunscreen watch out for extra ingre-



Sunscreen is essential to protect yourself in the summer!

dients that may irritate your skin. Also try to buy a product that protects against both UVA and UVB rays. Apply sunscreen liberally. Usually if you have a 4 ounce bottle you want to use about 1/4 of it to cover all exposed parts. You want to apply at least 30 minutes before going outside and then again every 2 hours.

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Be a Part of GOAL

Research is such an important step toward a better understanding of lupus and the development of a new treatment for people with lupus...

IF YOU ARE NOT A MEMBER OF THE STUDY, WE INVITE YOU TO JOIN! It only requires 15-20 minutes of your time to complete surveys by mail twice per year.

Thank you for your participation!

We certainly cannot do this without you.

Lets Keep Working Together!



GOAL Members Corner - Share Your Story

For our summer issue we would like to spotlight one of our GOAL members who has cutaneous lupus. Ms. Tracey Smith is a 43 year old woman with 5 children currently living in Atlanta, Ga. She has had lupus for 24 years being first diagnosed in 1986. She initially went in to see her physician after hair loss and a skin rash on her face., thinking it was from a recent chemical burn in the hair salon.

After her early diagnosis Ms. Smith was relatively healthy. She had her first serious flare in 1988 where she had severe weight loss, extreme pain, fatigue, and peeling skin. She was able to regain control and had another stable period of almost 20 years with her lupus being very inactive.

Recently, after some traveling, she has been having problems with pain, fatigue and small skin flares. She is hoping to once again control her lupus in order to keep her body healthy. She would like to return to work and school very soon and continue her love for culinary the arts.

When I asked to Ms. Smith about advice for other lupus patients who might be suffering with skin problems her advice was simple—always listen to your doctors and cover your skin. She thinks back on the days when she first got diagnosed and how she did

not take it as seriously as she should. She wants to remind others to please

take the doctors advice to heart. Always wear sunblock while outside, keep on long sleeve clothing to keep your skin cov-



ered, wear wide brim hats and sunshades. This is a simple way to help reduce breakouts and dry itchy skin.