



The Voices of GOAL

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

Dear Goal Members,

First, I would like to express my gratitude to each of you for continuing to be a part of the GOAL family! Your time and input have been extremely valuable to our research. By sharing your experiences you will, ultimately, help to improve treatment and health care for Georgians with lupus. Through each and every person's story, together, we are painting a picture to the world of what it means to live with lupus.

Our research team continues its commitment to providing GOAL members

with useful information on managing lupus. This issue of our annual newsletter focuses on the benefits of exercise for improving the physical and mental health of those living with lupus.



Herein, we offer helpful tips for becoming more physically active in order to maintain a healthy weight, manage depression, and fight fatigue. Findings from the GOAL surveys are presented as well. Members' fatigue, anxiety and de-

pression are illustrated and summarized.

This issue concludes with the personal story of one of our GOAL members, Tamera Mixon, who shares her experiences with managing her physical and mental health through exercise.

We hope that you enjoy this issue of "The Voices of GOAL." Please let us know of any topics you would like covered in future issues.

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

Sincerely,
S. Sam Lim, MD, MPH

GOAL Project

Summer Issue 2012



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Upcoming Activities:

- > Follow-up surveys coming out in the fall
- > This year, there will be 3 raffle winners because we will be giving away 3 great prizes!

GOAL Update: Follow-Up Surveys

Attention GOAL Members!

So far, almost 900 Georgians with systemic lupus erythematosus (SLE) are part of the GOAL Project. Of those, over 740 have completed the GOAL baseline survey.

Please be on the look out for another mailing from GOAL this fall. It will contain the

follow-up survey that we need you to complete and return to us. By administering a follow-up, we can track changes that have occurred over time in your quality of life, lupus-related illnesses, and other important aspects of living with lupus. We will be having another raffle, but there will be 3 winners this

year! So, please return your completed survey as soon as possible to be entered into the raffle for a chance to win 1 of 3 prizes and to receive a \$10 gift card.

As always, we sincerely appreciate your input. Just a little bit of your time can have a huge positive impact!



Importance of Physical Fitness for A Healthy Body and Mind



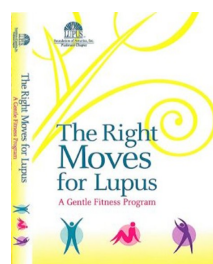
Exercising regularly, maintaining a healthy weight, managing stress, and minimizing fatigue are all essential for overall physical and mental fitness. However,

tiredness, achy joints, and stiffness are common for people living with lupus. So, the mere thought of exercise can be painful for some. Fortunately, research has revealed that low-impact activities can actually relieve these ailments. In addition to building stronger muscles, promoting weight loss, and reducing the risk of certain diseases (Type 2 diabetes, some cancers, heart disease,

etc.), studies have shown that aerobic activities (walking, swimming, cycling) can ease fatigue, decrease depression, reduce anxiety, and increase a sense of wellbeing in people with lupus.

Some exercises that you can try to begin slowly are yoga, tai chi, Pilates, stretching, and walking. But, be sure to talk to your doctor first BEFORE you start exercising!

“The Right Moves for Lupus” is a new low-impact exercise program designed for people with lupus by someone with lupus. It is a gentle fitness



routine that you can practice in the comfort of your own home. The DVD can be purchased at the Lupus Shop on the LFA website (www.shoplupus.org) for \$14.95.

What is your BMI?

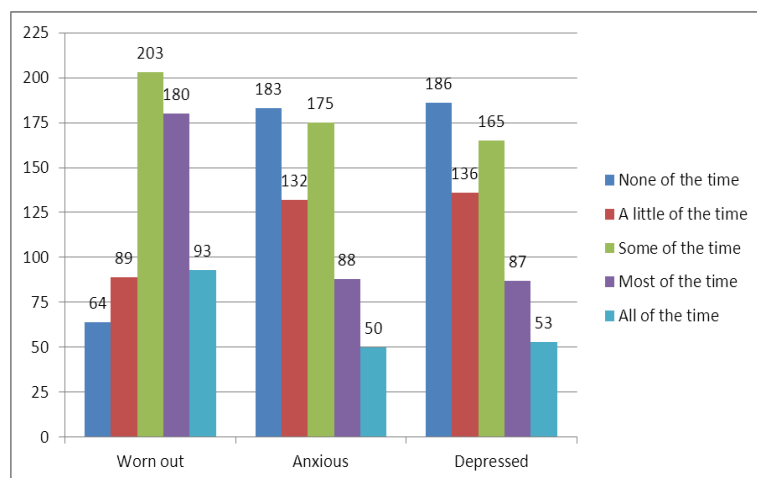
One measure of *general* physical health is body mass index (BMI), which is based on one's height and weight. The BMI is used to screen for weight categories that may lead to health problems. Visit the CDC website at <http://www.cdc.gov/healthyweight/assessing/bmi/index.html> to find out your BMI. A healthy BMI score is between 18.5 and 24.9. Knowing your score can help you determine how much, if any, weight you need to lose (or gain) to reach a healthier weight.

We Learned About Your Exercise Habits and Fatigue, Anxiety & Depression

Over 600 GOAL members (lupus patients) have shared with us about their exercise habits and mental health. The good news is that nearly three out of five members (58%) had participated in some form of physical activity (running, gardening, walking, etc.) during the month before completing the GOAL survey. Unfortunately, this means that more than two out of five (42%) had not been physically active. *As a result, many are considered overweight according to their BMI scores. Therefore, GOAL members need to exercise more to maintain a healthy weight.

*** On average, GOAL participants have a BMI score of 28.9.**

The graph below illustrates how lupus has impacted the lives of the 629 GOAL members who answered questions about how often they felt worn out, anxious, and depressed during the 4 weeks before responding to the survey.



The large majority (61%) reported feeling worn out "some" or "most" of the time. In terms of anxiety and depression, nearly half of GOAL members felt anxious or depressed *at least* some of the time (50% and 49%, respectively). Fortunately, about 30% of members had not experienced anxiety or depression.

So, what can/should you do to improve your physical and mental fitness? A healthy body and mind are the result of being physically fit. Begin by talking with your doctor to determine your current fitness level and to avoid risks and possible injury. Together, you

can create a realistic exercise/health plan that is best suited for you personally. Next, you'll need to take those necessary steps to begin making positive changes that can enhance your overall fitness...both physically and mentally. So, grab a friend and get moving!!



A Little Exercise Goes a Long Way: Overcoming Depression

For many SLE patients, the journey after diagnosis can be stressful and frustrating at times. The process of learning how to manage symptoms and push through the challenges brought on by lupus flares and/or medication side effects causes many to lose hope. Studies suggest that up to 60% of people with chronic illness, such as lupus, also experience clinical depression. According to preliminary data from the current GOAL survey, 70% of GOAL members reported feeling depressed *at least* "at little of the time." Unfortunately, entering a state of depression can lead to reduced physical ability, difficulty sleeping and, ultimately, lower quality of life.

Research has found that, over time, lupus patients who routinely participated in physical activity increased their ability to do aerobic activities. Although some may think it will be too difficult, participating in moderate aerobic activities such as swimming, walking and bike riding has been found to decrease depression in patients living with lupus. Even everyday activities such as gardening, walking pets, and doing household chores can lower levels of stress and depression. A 2008 study of 20,000 adults published in the *British Journal of Sports Medicine* showed that just 20 minutes of physical activity a week can boost mental health (although, more is better). Participants who did simple physical activities experienced less depression after exercising. The benefits of regular exercise include improved physical ability, less anxiety, and an enhanced sense of well-being. This, in turn, can minimize how severe and how often SLE patients encounter feelings of depression.

So, talk to your doctor, call a good friend, or join a lupus support group to take a major step towards managing your lupus and curbing depression (support group is held every 2nd and 4th Tuesday at 11:00 am at the Grady Lupus Clinic). Having the support of a knowledgeable doctor and others who understand what people living with lupus go through is extremely important. Whether you get fit by yourself, have a workout partner or exercise with a group, try to incorporate more physical activities into your daily life to maximize the benefits of exercise. (Please remember to speak with your doctor before starting any exercise program.) The end result will be improvements in your mental and physical health!



Fatigue, Exercise and Lupus

Fatigue is one of the most commonly reported symptoms (up to 80%) and most disabling for people with lupus. Among the factors related to lupus fatigue are disease activity, pain, medications, poor physical and mental health, lack of support, depression or anxiety, and lack of exercise. Fatigue has physical aspects (tiredness, weakness), emotional elements (lack of motivation, low mood), and mental aspects (confusion, problems concentrating). Some tips to help with lupus-related fatigue include getting the proper amount of rest, establishing good sleep patterns, quitting smoking, eating healthy, and exercising regularly.

There is growing scientific evidence that **physical/aerobic exercise** can significantly reduce fatigue levels in people with SLE. Specifically, **low-impact, low-to-moderate intensity**

exercise programs are considered most beneficial for those with lupus. Some activities to undertake are walking, elliptical machine, stationary cycling, swimming, water aerobics, light weights, yoga, tai chi, and stretching. All of these are a combination of 3 major types of exercises that have specific health benefits:

Cardiovascular - shown to prevent premature coronary heart disease, stroke, type 2 diabetes, osteoporosis, some cancers, and depression. **Muscle strengthening** - helps to create stronger muscles to protect the joints and reduce joint pain; slows muscle loss common in patients with lupus due to inactivity or use of steroid medications. **Flexibility** - improves the range of motion of your joints and decreases the pain and stiffness often observed in lupus, and lowers the risk of inju-

ries. For example, a low impact water aerobics class puts less stress on the joints and helps to activate and build muscles, improve range of motion, core stability, balance, and posture. **The Arthritis Foundation Aquatic Program** is great for people with arthritis and lupus. So, check your local office for classes in your area. If you prefer working out in your own home, you might want to try the LFA's "**The Right Moves for Lupus**" DVD mentioned earlier in this newsletter.

Obesity is another common problem in SLE, which leads to poor functional capacity, higher fatigue levels, pain, and inflammation. Cardiovascular activities like walking, swimming, and cycling are great ways to burn calories and, together with eating right, are very important for weight loss.

Start slow, small, and be consistent!

We know you can do it!

GOAL Project

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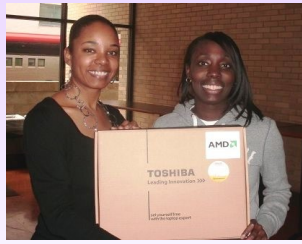
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The 2011 GOAL Raffle Winner is...



...Trinetta Johnson-Langford! She is pictured (on the right) with GOAL Study staff member, Natasha Brown. The GOAL Research Team would like to congratulate her again for winning a brand new laptop computer in the GOAL raffle held in December 2011.

Another raffle will be held this year, but 3 prizes will be awarded this time! So, be sure to complete and return your follow-up survey to us to be entered into the drawing.



Become our Facebook friend: Emory Rheumatology GOAL

GOAL Members' Corner - Tamera Mixon's "My Lupus Story"



My lupus story has been similar to a roller-coaster ride...filled with bad and good throughout. While in my second year

of college at Indiana University, I decided I should see a doctor after swelling in my feet and ankles kept getting worse and eventually moved to my legs. After many tests, I was told that I had lupus.

During the week I spent in the hospital after my diagnosis, there were many lonely nights spent questioning "what am I going to do with my life now; will I die soon from this; what next?" Countless nights of these unexpressed thoughts and days of trying to be strong for family and friends were starting to take their toll on me. Fortunately, I got a new nurse who revealed that she had lupus. She helped me understand what I could face and that everyone has different struggles,

but, most importantly, that it was not a death sentence and that I could still have a good quality of life.

One summer, my doctor reported that we should use a more aggressive approach in my treatment: chemotherapy. After three weeks of treatment, I couldn't take the sickness any longer and asked my doctor for other options. He suggested a drug called Cellcept. Within a few months, I was feeling much better and starting to go into remission. My follow up medical appointments went from a few weeks apart to every three months.

Later, an opportunity to manage my sister's business arose, but the stress of moving to Atlanta brought my lupus out of remission. I didn't know any doctors and didn't have insurance. So, I quickly fell into a depression...I was supposed to be starting a new chapter in my life and, instead of taking steps forward, I felt I was taking huge steps backwards.

Within the first year of being in Atlanta, I had undergone a kidney biopsy, my second round of chemotherapy, and filed for disability. It was one thing after the next, which sent me further

into depression. I felt like I couldn't get a break and decided to seek treatment for my depression. Drug after drug was prescribed, but nothing was really helping and I felt the therapist was more interested in writing prescriptions than helping me. I soon got tired of just taking a pill here and there for depression. So, after some searching, I found a professional I could talk to, which was the best decision I made. I learned how to manage my lupus in and out of remission, both mentally and physically.

When I am feeling my "best," I choose a further parking spot to walk a further distance or take the stairs instead of the elevator.

It has been 11 years since I was diagnosed with lupus, and I am thankful now for every struggle I have gone through as they have made me a better person today. I have learned not to "sweat the small stuff" as I remember the things that I have gone through. Life is too short and, even with limitations, we must strive to be the best we can each day!

If you would like to share your story in the newsletter and/or on our website for other members to read, please contact us either by telephone or email.