



The Voices of GOAL

VOLUME 2 MARCH 2009

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

.....
Inside this issue:

Progress of GOAL	2
Quality of Life Research	2
Clinical Trials	2
Health and Well Being	3
GOAL Members Corner	4
Reminders	4

Dear GOAL members,

It has been several months since our last mailing and many of you are probably wondering what has become of our project. Rest assured that much has been going on behind the scenes and we remain committed to improving the lives of those living with lupus. We aim to accomplish this in two main ways: through education and research.

We seek to educate those with lupus on a variety of topics, including coping with the disease in your daily life and learning about treatments and the results of latest research. We are excited to announce that we have partnered with the Lupus Foundation of America (LFA) – Georgia Chapter in helping us get this information out to you. The LFA is the largest organization for lupus patients in the country. It just made sense that we piggy-back on their resources. And as a result of this partnership, we are also excited to offer every GOAL member a FREE LFA membership, including a subscription to the “Lupus Now” magazine. This excellent magazine is published three times a year and contains information on all aspects of lupus, including tips and advice for improving your life with lupus and access to medical information from the top lupus experts throughout the world! We hope you take advantage of this special offer by returning the enclosed postcard. We will also continue to send you other educational material of interest throughout the year.

Our research on lupus is done through you by your responses to our surveys. It is shocking how little the public, including researchers and legislators, knows about the impact lupus has on our community. This is a chance for your voice to be heard, anonymously but effectively. Every six months, we will be sending surveys to our participants. We deeply appreciate your efforts to complete them. We will share some of the results and what we think it may mean in each of our future newsletters. If you are interested in participating in or learning more about our research, please mark the postcard accordingly.

Thank you again for your willingness to participate and contribute. As Georgians Organized Against Lupus, we will have a significant impact in those living with lupus.

Best Wishes,

Dr. Sam Lim

**Our GOAL is to improve the lives of
Georgians with lupus.**



GOAL Project
Division of Rheumatology
Emory School of Medicine
49 Jesse Hill Jr., Dr., SE
Atlanta, GA 30303

Phone: 404-616-0433

E-mail:
info@lupusingeorgia.org

Web:
www.LUPUSINGEORGIA.ORG

The Progress of the GOAL Educational Project

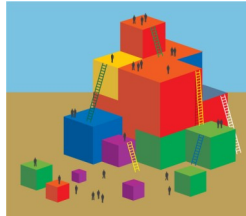
Since the project started in August of 2007, we have a membership of 375! In addition to receiving educational materials, 220 of our members consented to participate in the GOAL study.

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. (See what we have learned on page 3.)

If interested, please mark the interest box on the enclosed postcard.

Thank you for your participation!

We certainly cannot do this without you!



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

There has been no new FDA approved drugs for approximately 50 years!

For more information please contact us:

Telephone: 404-616-0433

E-mail: info@lupusingorgia.org

The importance of Quality of Life Research:

It is important to look at health from the point of view of the patient. Quality of life refers to the affect that a disease and its treatment has on the ability to function. This is determined through surveys of well-being in physical, mental and social aspects of life. This has become increasingly important as new treatments are developed and introduced to patients.

The health and well-being survey you completed allowed us to see how you feel and how well you are able to do your usual activities. We looked at your reported physical functioning, pain, general health, energy level, social functioning, and emotional functioning.

Quality of life is especially useful in clinical trials.



Thank you for letting us learn about your quality of life and health!

The importance of Clinical Trials:

A clinical trial is a process of discovering and proving the effectiveness of medical drugs and substances. Clinical trials are conducted to allow data to be collected for new drugs or devices in a safe manner. These trials can only take place after the necessary approval from health committees are granted.

There are lupus clinical trials conducted through the Grady Lupus Clinic. If you are interested in knowing more on lupus clinical trials, contact us or visit the LFA GA website (www.lfaga.org).



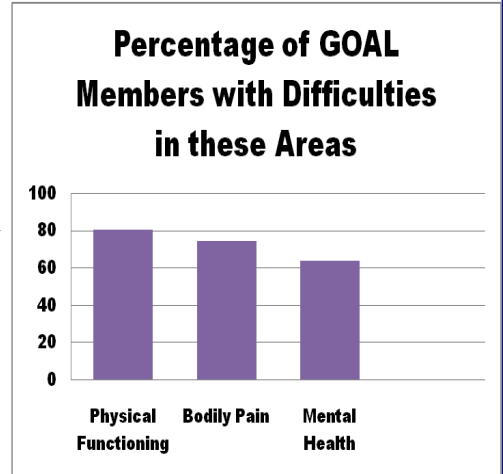
The GOAL Study

What have we learned about your health and well-being?

Thanks to the patients that consented to participate in the GOAL Study!

We have received your surveys and we are learning from you on the impact that lupus has on your health and well-being.

If you feel like you are not doing well and you have lupus, you are not alone. From your surveys, we have learned that GOAL participants, as a group have difficulties in areas such as physical functioning, bodily pain, mood and mental functioning.



What have we learned about your mood?

From the surveys, we have learned, in general, as a group...

54% reported feelings consistent with depression.

59% reported sleep as restless.

50% reported feeling that everything done took an effort.

GETTING HELP:

According to the National Institute of Mental Health (NIMH), if unsure where to go for help, talk to someone you trust who has experience in mental health—for example, a doctor, nurse, social worker, or religious counselor. Ask their advice on where to seek treatment. If there is a university nearby, its departments of psychiatry or psychology may offer private and/or sliding-scale fee clinic treatment options. Otherwise, check the Yellow Pages under "mental health," "health," "social services," "crisis intervention services," "hotlines," "hospitals," or "physicians" for phone numbers and addresses. In times of crisis, the emergency room doctor at a hospital may be able to provide temporary help for a mental health problem, and will be able to tell you where and how to get further help.



It is sometimes difficult for patients with lupus to keep control of feelings and emotions that allow for a more positive and hopeful attitude. Talk about these difficulties with your physician. Additionally, there are various local support groups to help patients develop effective strategies.

The Lupus Foundation of America, Georgia Chapter have volunteer support groups that understand the issues that challenge a person with lupus. They offer support to lupus patients, friends, and family members. These groups provide an opportunity to receive introductory information about lupus, encourage the expression of concerns, share experiences, support positive coping strategies, and emphasize the importance of medical treatment. This chapter also has teen and Hispanic support groups, newly diagnosed patient seminars, and a Living with Lupus symposium with medical experts sharing valuable expertise and information for patients.

(See enclosed listing of Georgia Support Groups.)

LFA contact information

Website: www.lfaga.org

Telephone: 770-333-5930

E-mail: info@lfaga.org

GOAL Members Corner

Imagine traveling along the road of life as a single mom, owning your first home, working for the same company for over 5 years, child in private school, a community and church leader; enjoying a life rich with good friends and good times. Yet in the blink of an eye, imagine everything that seemed so stable unravel right before your eyes.

I am Kim Schofield and in 2000, I was diagnosed with systemic lupus. Having never heard of this disease and having no other family members with it, it was amazing that I would end up becoming a leading advocate for lupus. It was after a routine eye exam that I learned what I thought was conjunctivitis (pink eye) was actually iritis (inflammation of the eye). When I began to lose sight in my left eye I knew there was something seriously wrong. My optometrist suggested that I get a physical and my response was, "I'm not sick; most people don't go to the doctor unless they are sick." Based on the results of my physical, my doctor referred me to a rheumatologist. A blood test, ANA and additional markers confirmed that the diagnosis was lupus. I began taking as many as 30 pills (i.e. Plaquenil and Prednisone) daily until my sight and body began to stabilize. It was during this time that I lost my job, my health benefits and my income. For me, my life had hit a brick wall.

Out of desperation, I began to call state and local community agencies only to discover that many people did not know enough about lupus to consider it a disease that warrants health resources. I called state representatives and ultimately the White House to again be told, "I'm sorry, there is nothing that we can do." It was at one of my lowest points that I began to realize that I was not the only person with lupus and decided to tell my story in a local DeKalb County newspaper. I invited people who were living with or caretakers of those with lupus to meet me at my church just so I could put additional faces to this disease. At this meeting, 65 people showed up. It was at that moment that we became a family...LACES, Lupus and Community Empowering Support. We formed a support group and joined with the Lupus Foundation of America, Inc., Georgia Chapter to raise awareness and support those touched by lupus.

My lupus journey has not been easy. I have had many bouts with flares, unable to work for long periods, left without health insurance, denied social security at least four times and exhausted many resources. Yet throughout the good, bad and ugly side of lupus, there is always hope. As my life is not over, lupus has taught me a new definition of living. Each day in my world is divinely orchestrated, passionately filled and intentionally designed for me to life it to the fullest. In spite of lupus, I have been able to return to school, complete a Bachelor's and Master's degree and I am currently pursuing a Doctorate---with, through and above lupus. Lupus is not the end of the road; it is just a pit-stop on life's journey.

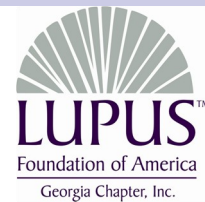


Kim Schofield

Being a Part of GOAL

The Lupus Foundation of America is giving you a free subscription of their Lupus Now magazine! This magazine is published 3 times a year, and offers information on all aspects of lupus, with tips and advice for living your best life.

If interested, please mark the subscription box and complete contact information on the enclosed post-card.



We would like to have our members share their experiences with lupus.

If you would like to share your story in the newsletter and/or on our website for other members to read, please mark the story box and complete contact information on the enclosed postcard.



Lets keep working together!

⇒ **Please don't forget to return the enclosed postcard.**

⇒ **If you are a GOAL Research Member, please plan to complete and return the surveys within one month of receiving them.**

