



# The Voices of GOAL

## A Note from the Principal Investigators of the GOAL Cohort Study

GOAL Cohort Study

Fall Issue 2013

**Dear GOAL Members,**

We would like to express our gratitude to each of you for continuing to be a part of the GOAL team! As you will learn from our newsletter, your time and input are of great value to our research.

First, we would like to share with you news about the 10<sup>th</sup> International Congress on SLE, which was held in Buenos Aires, Argentina, April 18-21, 2013. More than 1500 physicians and 300 lupus patients attended making this the largest SLE meeting ever held. The congress presented superb quality research with over 400 new studies presented by scientists from all over the world. Our GOAL members' effort was reflected in two scientific abstracts, one on work productivity impairment and the other on organ damage in Georgians living with lupus.

Additionally, a 3-day lupus patients' meeting offered

great opportunities to learn about lupus, exchange experiences living with lupus, and create a worldwide network of patients who are supporting each other and spreading their voices worldwide on what it means to live with lupus. One of our GOAL members, Ms. Kim Schofield, presented her insight on lupus support groups and lupus advocacy in the U.S. A special interview by Ms. Schofield on her experiences at the 10<sup>th</sup> International Congress is offered in this issue. An update of our GOAL surveys with special emphasis on the value of social support is presented as well.

We are also proud to announce that with the amazing effort of our GOAL participants who filled out the 2011-2012 GOAL survey, we published an original study in a prestigious scientific journal. The study entitled "Primary preventive services in patients with

systemic lupus erythematosus: Study from a population-based sample in Southern US" is a report on the quality of preventive care among SLE patients from our GOAL Project, as compared to the general population and to people with diabetes. A brief summary of the study findings is presented in this issue.

Our newsletter concludes with the personal story of Ms. Sandra Roberts, our GOAL member winner of the Mini iPad raffle. Ms. Roberts shares her experiences about social support influences.

We hope that each of you enjoy this issue of the "Voices of GOAL" and continue to be an invaluable member of our GOAL team!

Sincerely,

S. Sam Lim, MD, MPH  
Cristina Drenkard, MD, PhD



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## Social Support Global ACTION by a GOAL Member ~ Kim Schofield



Kim Schofield utilizes her leadership experience and resources to help provide a "voice" for lupus. When she was first diagnosed with lupus in 2000, she was armed with eight prescriptions, a lupus informational brochure, and prayer. She solicited the support of her best friend and together they started their lupus research. Their morbid, scary and negative findings led her on a quest for the "other side of the story". Kim knew there had to be "another way" to live with lupus. Much like a puzzle, she pieced together various social service resources to help her deal with the life events associated with being unable to maintain employment due to the debilitating effects of her fatigue and joint pain. She was stunned by the lack of resources stemming from the lack of disease awareness. Kim attended a Self-Help Management course offered by the Arthritis Foundation that provided "empowerment". In 2003, after battling bouts of depression and feelings of isolation, Kim wrote an article in DeKalb's CrossRoads News sharing her experiences with lupus that resulted in 65 people with lupus attending her first lupus support group meeting. This supportive group provided a safe place to talk about living with lupus and the sharing of re-

sources including panel discussions with physicians. Kim also connected with the Georgia Chapter of the Lupus Foundation of America as a volunteer to raise awareness about lupus. In 2008, Kim embarked on an expansion of the "voice" by engaging GA State Representative Senator Adelman in an initiative that led to the first Lupus Awareness Day in 2009. Kim continues to be a pillar in our GA community especially by serving as the "voice" of lupus.

In 2010, Kim extended her arms further through a global approach as she assisted Dr. Inés Colmegna with support group efforts in Kenya. Kim worked with Sharon Argwings-Kodhek who also had lupus, develop a vibrant resourceful support group in Kenya. The bond was developed further during their in-person meeting at a rheumatology conference in GA. Sharon lost her battle with lupus this year and is dearly missed. But her warm spirit, heartfelt supportive nature, and contributions, especially to the people with lupus in Kenya, are forever engraved in our hearts.

In 2012, Kim assisted Dr. Cristina Drenkard and the International Congress on Lupus Organizing Council as a patient representative. During the congress in Buenos Aires, Argentina in April 2013, Kim

full-heartedly embraced the opportunity to engage with 14 lupus social support groups from around the world. Although there was a foreign language barrier, the language of lupus was universally understood! Kim was struck instantly by the commonalities surrounding social service needs, advocacy, and the passion toward "finding a cure".



Kim's experiences locally and internationally only serve to fuel her passion to empower people living with lupus! She continues to help people with lupus to maximize their quality of life through the sharing of experiences, resources and supportive efforts. This is truly an exemplary demonstration of leadership and passion for life ~ a courageous and steadfast "voice" of lupus!

Picture:  
Leadership Organizing Committee Members with International Lupus Affiliates from across the Globe ~ Argentina, Alberta, Canada, Malaysia, Republic of Mauritius, Netherlands, Philippines, Trinidad & Tobago, Peru, New Mexico, Indonesia & Chile



# Benefits of Social Support on Health

**"Each patient carries his own doctor inside him." - Albert Schweitzer**

Social interactions, by natural design, influence self-perceptions as well as associated circumstances such as health. The National Institutes of Health reports the importance of maintaining a good support system ~family, friends, medical professionals, community organizations, and support groups. Research studies have found that people who have more support, especially that allowed them to discuss their emotional reactions to lupus and assist with provisions of material resources, reported a better overall health than those with fewer supportive social contacts and resources. There appears to be an association between the quality of social support and stress and coping levels. Positive social support can serve as a stress buffer. There are various types of social support ranging from informational and educational support to emotional support. Stories presented in this newsletter by both Kim Schofield and Sandra Roberts illustrate the impact of social support. You can develop your social support resources based on your interests. The resources below provide you with more information regarding programs and services.

"And when it rains on your parade, look up rather than down. Without the rain, there would be no rainbow."

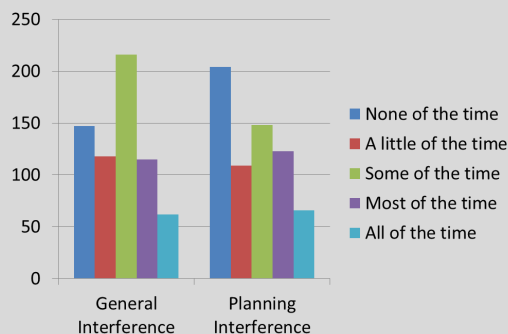
- G.K. Chesterton

## What have we learned about how lupus impacts your socialization?

In general, many of the GOAL members are unemployed (41%). However 10% are maintaining full-time or part-time employment. Based on the variability of lupus disease activity, it is understandable that extra efforts may be required in order to engage in social activities regardless of the level of desire.

As a group, a majority of GOAL members reported generally looking forward to events and enjoying a good laugh. However, many reported that lupus disease activity interfered with social activities (78%) and/or caused difficulties planning and scheduling events (69%).

### Impact of Lupus on Social Activities

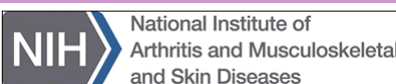


The graph illustrates how lupus impacted the lives of 662 GOAL survey participants who answered the following questions:

- During the past 4 weeks, how much of the time has your physical health or emotional health interfered with your social activities?
- During the past 4 weeks, how often did your lupus interfere with your ability to plan activities and schedule events.?



## Social Support Resources



Handout on Health: Systemic Lupus Erythematosus:  
[http://www.niams.nih.gov/Health\\_Info/Lupus/default.asp#Lupus\\_11](http://www.niams.nih.gov/Health_Info/Lupus/default.asp#Lupus_11)



Lupus Foundation of America, Georgia Chapter

Support and Services provides information and programs in communities to help people with lupus and their families:

<http://www.lfaga.org>



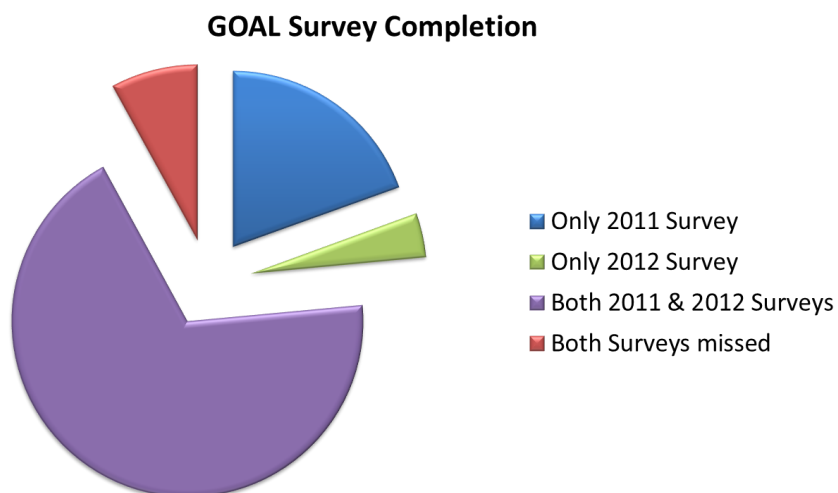
Information about services and programs for older adults and people with disabilities:

<http://www.agewiseconnection.com/>

## GOAL General Updates

Currently we have more than 900 Georgians with lupus enrolled in our GOAL Study! Of those, approximately 669 of the 2012 surveys have been returned. And most of the GOAL members have completed both the 2011 and 2012 surveys. It is especially important to this study to see how GOAL members are doing from year to year.

**Thank you for your participation! We will be sending out the 2013 survey later in the fall. Please look out for this survey in your emails or mailboxes. Please let us know of any contact information changes.**



The following table illustrates the descriptive characteristics of the GOAL cohort based on data from the 2012 surveys:

2012 Survey Participants	662
Female (%)	624 (94.3%)
Average Age	33.1
<u>Race (%)</u>	
Black	510 (77%)
White	142 (21.5%)
Asian	8 (1.2%)
Pacific Indian	2 (0.3%)
Hispanic	47 (7%)
Average years of disease	15.0
<u>Current work status</u>	
Full-Time	18 (2.7%)
Part-Time	47 (7.1%)
Retired	74 (11.2%)
Homemaker	57 (8.6%)
Student	31 (4.7%)
Unemployed	268 (40.5%)



## GOAL General Updates

The purpose of the GOAL Study is to learn more about lupus and how it impacts the lives of people with lupus over time. Your survey data continues to provide us with a voice regarding your disease characteristics, behaviors, and concerns. This data offers further advancement efforts toward refining and redefining lupus treatment options and approaches, as well as lupus awareness.

During a poster presentation at the International Congress, we presented findings regarding work productivity impairment based on the GOAL study surveys. 35% of GOAL members between the ages of 18 and 65 were working. Work impairment for this age group was based on severe symptoms of forgetfulness or depression, muscle pain or weakness, or joint pain.



We recently published an article regarding the use of healthcare preventive services by our GOAL members. People with lupus are at risk for health problems that can be lessened by appropriate preventive care. Depending on gender, age, family history, and other risk factors, these services include vaccinations, cancer screenings, and heart health screenings. In general only 23% of survey responders received all the preventive care services that were appropriate for them. Based on these findings, people with lupus received lower preventive care services than people with diabetes or the general population. This suggests a need to increase healthcare providers' awareness of lupus risks and current preventive recommendation. **Please ask your health care provider for more information about preventive services that are best for you.**

## Other Research Engagement Opportunities



If you are interested, clinical research studies are being done at the Emory University and Grady Health Systems. These research studies are especially important in determining which medical approaches (strategy or treatment) work best for people with lupus. This ultimately helps to improve future lupus patient care.

We want you to know of some exciting developments in lupus research from our area. The Division of Rheumatology at Emory University is recognized internationally for its research in lupus epidemiology and outcomes. The GOAL project is one of the centerpieces of the program, focusing on what happens in the "real world" in people who live with lupus. We look forward to continuing to share with you our findings and hearing back as to what is most important to you. After all, GOAL could not exist without your commitment and invaluable information. We also recognize that lupus must be conquered on several fronts, which is why we are so excited to share additional opportunities for those who are looking to be even more involved.

First, we know that many with lupus will have kidney involvement. Though current therapies, including cyclophosphamide (Cytosan) and mycophenolate mofetil (Cellcept), are effective and have given renewed hope to many, there is still a clear need for even more effective and safer therapies for lupus nephritis. If you have had a kidney biopsy in the past year and your doctor is considering or you are already on mycophenolate mofetil (Cellcept), you may qualify for an important clinical trial. Please call Research Nurse Karla Caylor @ 404-616-7553 for more information.

Second, Emory researchers are studying cells in the bone marrow to get a better understanding regarding the development of lupus. The bone marrow is a key component in the body's immune system and is where most of the immune cells develop and learn to do what they do. Studying the bone marrow in those with lupus may give us important information as to why cells react the way they do in lupus. If you are interested in learning more about this study, please call Research Nurse Jennifer Scantlin @ 404-712-2943.

## GOAL Cohort Study

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## Next Steps

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

Follow-up survey will be sent this fall. This survey allows us to track changes that have occurred over time in your quality of life, lupus-related illness, and other important aspects of living with lupus.

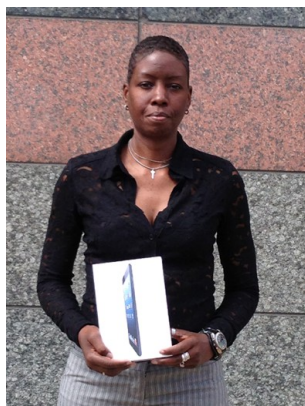
Throughout the year, we will also send you information regarding other lupus-related studies that we are conducting.

Thank you for your participation!

We certainly cannot do this without you!!



## GOAL Members' Corner ~ Sandra Roberts Mini iPad Raffle Winner



### Congratulations to our GOAL Raffle Winner...Sandra Roberts!

Sandra is generally quite resourceful with finding information, especially pertaining to lupus and health, on the World Wide Web (WWW), but this Mini iPad is her introduction to more mobile resource applications. These applications can especially enhance her capacity to better journal her health activities as well as keep in touch with her social network. She certainly looks forward to this new technology exploration!

Sandra's 13-year lupus story started with denial but was changed by a determination to be her "own health advocate". Sandra was born and raised in Brooklyn, New York and is the youngest of eight children. She relocated to Georgia in 1991. In 2000, Sandra noticed that her hair was falling out and a skin biopsy performed by her dermatologist revealed that she had lupus and scleroderma. She was familiar with scleroderma since her mother was also diagnosed with this disease. However, she was unfamiliar with lupus. Her lupus exploration began with the WWW, described by Sandra as the "window to the world", along with the steadfast support of her sister, Brenda. Compounded by a stressful job transition, Brenda helped her through the especially harsh times by being available for supportive and disease-distracting talks, accompanying her to health appointments, and taking care of her when she was too sick to care for herself. Her sister "went through the process" and they "explored" lupus

together. Sandra also attended LFA support group meetings and found it helpful to talk to other people with lupus. After she recognized that lupus presents itself so uniquely in each body, she sought to find out what was "best" for her. She was typically a junk food eater and decided to eat healthier with the addition of a lot of fruits and vegetables. She maintains a healthy practice of juicing. She does not require any lupus medications at this time. However, she reported an especially difficult 1.5-year period of dealing with lupus nephritis. As is typical for those living with lupus, Sandra has some down moments filled with fatigue and difficulties from vascular necrosis as she continues to manage her disease.

However, her knowledge of the disease and medical support from her rheumatologist, as well as her painting and active social life (including her dog Khloe), keep her motivated and inspired.

According to Sandra ~

