



# The Voices of GOAL

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

GOAL Cohort Study

Fall Issue 2014

**Dear GOAL Members,**

Over the years we have been making great strides in understanding lupus as well as expanding awareness and support for those affected by the disease. This can only be attributed to the remarkable growth of support and involvement of the GOAL community. Through our efforts to learn more about lupus we hope to identify factors which impact progression of the disease and its effect on quality of life.

As we know, lupus can present itself in various ways which may differ from person to person. However, many can relate to the physical and emotional changes experienced throughout the progression of lupus. Understanding the impact of the stress associated with adjusting to these changes along with other

psychosocial stressors is vital to understanding the role of social support, treatment options, and other aspects of care in regards to symptom management.

In this issue, members of GOAL share how social support has helped them to counter the effects of the psychosocial stressors in their lives which both reflect and impact living with lupus. GOAL member, Natasha David shares her mission to change the perception of lupus through her advocacy work throughout South Georgia. Her drive to work through the ups and downs of living with cutaneous lupus to bring light to the broader picture of all of the lives impacted by the disease is truly empowering.

We also share the story of our Wave 3 iPad

winner, Lenwood Williams, who has pulled through many obstacles by focusing on the positive changes lupus has brought about in his life with the help and support he has found in unexpected areas of his life.

Finally, look out for another newsletter in the next couple of months about exciting new GOAL initiatives. We will tell you about opportunities that have national, if not international, visibility with the potential to take our understanding of lupus to new levels. 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



<b>Empowered Advocacy:</b>	<b>2</b>
<b>Natasha David</b>	
<b>Lupus &amp; Stress</b>	<b>3</b>
<b>GOAL Study Updates</b>	<b>4</b>
<b>Empowered Living:</b>	<b>5</b>
<b>Lenwood Williams</b>	
<b>Acknowledgements</b>	<b>6</b>





Natasha David does not retreat and allow lupus to disrupt her natural liveliness. It has in fact reinforced her relationship and connection with God.

Natasha was diagnosed with lupus in 1996 while she was pregnant with her daughter. Similar to many newly diagnosed people with lupus, she experienced many challenges understanding and coping with the varying effects of this chronic illness. She was also faced with the realization that most people in her community were unaware of lupus. This was especially troublesome for Natasha, who tended to bruise easily as part of her lupus presentation. Many people treated her as if she was contagious, and at times during emergency visits, she was approached as a domestic violence victim. These experiences were very traumatic especially given that her husband, Derek, is a champion supporter in every facet of her life. Derek describes Natasha as committed and unselfish in her lupus advocacy. He adopts her passion and campaigns

to help men become better supporters of their wives with lupus.

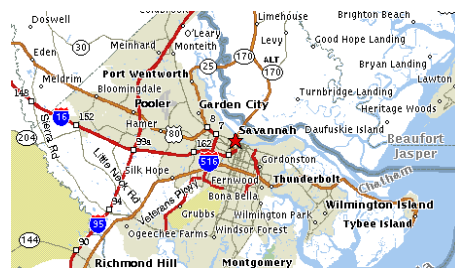
Natasha experiences great challenges with avascular necrosis for which she has had 19 surgeries and utilizes a spinal cord stimulator to treat her pain. However, she celebrates life daily especially serving as a lupus advocate.

Natasha's mission as an advocate for lupus is to change the perceptions of lupus. She openly shares her photo diaries of her cutaneous lupus involvement to advance the awareness of this lupus presentation. Natasha encourages people to "not judge a book by the cover."

The Lupus Foundation of America (LFA) helped Natasha and Tia Walker develop a support group in Savannah (Savannah Love, Faith, Hope Lupus Support Group). On the last day of May, during Lupus Awareness Month, Natasha brings the community together for a celebration



of life. Messages are written on balloons and released in honor of those who passed away. Additionally, Natasha and her team (Team David) has been instrumental in bringing awareness to 9 cities in south Georgia by pushing proclamations declaring Lupus Awareness Month. Team David has blazed a remarkable trail through southeast and middle cities in Georgia, to include Savannah, Pooler, Garden City, Montezuma, Richmond Hill, Warner Robins, Thunderbolt, Port Wentworth, and Fort Valley. Their drive continues as they currently work on 5 more Proclamations!!



**Kudos to this amazing team!**

### Messages to Heaven - Balloon Key:

- ◆ White for those passed with lupus
- ◆ Purple for those with lupus
- ◆ Orange for those with cutaneous lupus.

## Lupus Expressions

*“The more you praise and celebrate your life, the more there is in life to celebrate.” - Oprah Winfrey*

Lupus is expressed very differently in each body. Some people with lupus have outward appearances associated with skin (cutaneous) and other physical features. Majority of people with lupus develop different cutaneous symptoms at some time during the course of the disease. These symptoms include rashes/lesions, hair loss and ulcers. Recurrent episodes of these inflammations can cause different levels of disfigurement. Additionally, some of the medications used to treat lupus may cause individuals to gain weight. The various expressions of lupus in addition to stressful life events impacts the mind’s ability to consciously or unconsciously adjust and relate the body to the social environment. Without the appropriate social and/or psychological resources, these events lead to psychosocial stress.

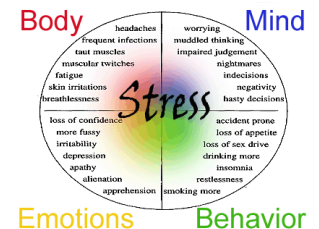


**During the next few years, our lupus team at Emory University will be focusing on studying more about the impact of psychosocial stress on lupus outcomes. We will be sending you more information regarding these studies.**

## Stressful Life Events

The Mayo Clinic describes stress as a normal aspect of living. With the busyness and constant demands from family, work, and personal concerns, stress will affect everyone at some point. It is easy to get worried, anxious, and even concerned when confronted with hard situations. At times, stress can be unavoidable because there are always things that we have no control over. The challenge is to learn ways to manage how we internalize and perceive stress. Especially with Lupus, stress can have negative effects. The CDC (Center for Disease Control and Prevention) reports that stress can cause increased muscle aches, sleep problems, sadness, decrease your immune system, and tension, among other adverse effects.

According to the American Psychological Association, in addition to daily stressors, perceived racial discrimination negatively affects emotional wellbeing. Often, people who are discriminated against based on their race may not realize the long-term physical impact. Since lupus primarily affects people of color, this is especially important in the study of this disease. In such stressful encounters, the body releases a stress hormone called cortisol which is helpful in life or death situations because it releases adrenaline. However, on a daily basis cortisol decreases the immune system, affects digestion, and impacts mood. The Mayo Clinic reports that the long-term effects of different stressors can create digestive problems, depression, anxiety, and lowered immune system functioning.



## Stress Reduction

- **Physical Activity**—any small aspect of movement and activity that slightly raises your heart rate above a normal pace will have a tremendous effect. A simple change can supply your brain with “feel-good-hormones” or endorphins that assist in stress relief and mental wellbeing.
- **Prayer and Meditation**—promote relaxation and calming.
- **Journaling**—simply writing down thoughts, feelings, ideas, fears, and joys can release emotions.

Ultimately, each person knows the stress relief method that works best. It is important to find a healthy stress relief method and start using it.

## 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.

Currently we have more than 900 Georgians with lupus enrolled in our GOAL Study! Of those, approximately 682 of the 2013 surveys have been returned. And most of the GOAL members have completed 3 waves of surveys since 2011! 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 2014 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.**



**GOAL Research Publications:** We recently published 2 articles focused on data from GOAL members. One article regarding the burden of lupus on employment and work productivity identified major factors that negatively impacted work outcomes as fatigue, disease activity and organ damage. More effective coping strategies at the workplace are needed to reduce the burden of lupus on work outcomes. Another article published data that validated a patient-reported measure of organ damage in lupus. It is important to support the use of cost-effective tools for collecting this data that is essential to better understand the burden of lupus.

## 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 about 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 (Cytoxan) 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.**



## Lupus Expressions & Empowered Living by a GOAL Member ~ Lenwood Williams



CONGRATULATIONS TO OUR  
GOAL WAVE 3 IPAD RAFFLE  
WINNER!!!

Lenwood Williams' lupus story begins with a doctor's visit to understand why he frequently felt tired and not like himself. His doctor performed several tests to rule out any illnesses and in 2010 Lenwood's doctor confirmed he had lupus. Alarmed and anxious after receiving this news, he immediately did research to learn more about this new disease, but more importantly, to educate himself on how to live well.

Rather than focus on the negative effects of lupus as shared by others, Lenwood decided that he would not allow this new diagnosis to steal his joy and happiness for life. Despite his positive outlook, he was immediately tested in maintaining a healthy outlook on life. Residing in Albany, GA he could not find a rheumatologist who did not discriminate against him, valued and respected his perspectives. To his surprise,

Lenwood found a "wonderful" rheumatologist in Atlanta, who helped him not to feel alone and find ways to change some aspects of his lifestyle to reduce stress. This was especially meaningful since as a man he felt as if he had to be "strong, a hard worker, and a provider" and could not be "sickly or need help". His rheumatologist helped him to adjust, and not feel depressed or overwhelmed by the effects of lupus. Encouraged and empowered with his new outlook on life, Lenwood realized that it was up to him to determine how lupus would affect him and he had the ability to create negative or positive thoughts.

Prior to his lupus diagnosis, Lenwood lived a fast paced life and often made wrong choices regarding his health and lifestyle. He had little regard to the value of life and believed that life was a constant challenge filled with frustrations. Lupus forced him to change his behavior and thinking, and he has learned to enjoy everyday by slowing down and focusing on what matters most, which is his health. One of the best things that have helped him overcome obstacles is the social support he receives from his co-workers at Miller Coors Brewing Company and their union. His colleagues constantly express how proud they are of his journey living with lupus and it is "so important to find people who support and encourage you when you're up and when you feel low." Although he tries not to make people feel sorry for him about lupus, he appreciates his friends supporting him.



Currently, Lenwood focuses on living a healthy life by making lupus his priority, but not "something to hold him back." By changing his thoughts about his chronic disease, he changed lupus from being a negative aspect of his life, to a positive result by sharing his experience with those who are newly diagnosed and struggling with changing their lifestyle.

In terms of his health, Lenwood's job keeps him walking and active and he utilizes the gym at his job to ride the stationary bicycle and lift weights. However, he constantly listens to his body to make sure he is not overdoing it. In the summer, he wears a white hat that reminds him of Gilligan's Island and if it's too hot, he carries an umbrella. While in the winter, he especially keeps his hand warm and dresses appropriately.

As a social person who enjoys laughing with friends, Lenwood shares his perspective in choosing to see the positive in how lupus has changed his life. Of course he has bad days, and this story is not to overlook the challenges people with lupus face on a daily basis, but to provide encouragement that there is hope after receiving a lupus diagnosis. "Lupus saved my life by helping get my life back. I now look at life differently from a new perspective of appreciating life, valuing myself and helping others. I appear to be different because I am different.

**I am a new ME!"**

## GOAL Cohort Study

Division of Rheumatology  
Emory University School of  
Medicine

49 Jesse Hill Jr. Drive  
Atlanta, GA 30303



Phone: 404-251-8907  
Email: [info@lupusingeorgia.org](mailto:info@lupusingeorgia.org)  
Web: [www.lupusingeorgia.org](http://www.lupusingeorgia.org)

Become our Facebook Friend:



Georgians Organized Against  
Lupus



## 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!!

Let's keep working together!



Help Us Solve  
The Cruel Mystery  
**LUPUS**<sup>TM</sup>  
FOUNDATION OF AMERICA  
GEORGIA CHAPTER

The Lupus Foundation of America (LFA) Georgia Chapter continues to provide our GOAL members with LFA Memberships filled with educational and social support resources. We applaud LFA for their extraordinary efforts as the nation's leading nonprofit voluntary health organization dedicated to finding the cause of and cure for lupus in addition to their exemplary supportive services to all people affected by lupus!

### The Heart of South DeKalb Annual Festival and Community Walk Supports Lupus Research at Emory

Special thanks to Commissioner Larry Johnson, District 3, DeKalb County, Macy's at South DeKalb and HOSD Planning Committee for their donation supporting lupus research at Emory. The Heart of South DeKalb Annual Festival and Community Walk was held on September 27<sup>th</sup> at South DeKalb Mall. GOAL members Betty McPherson, Kim Schofield and Tresa Cullins educated the community about lupus and discussed the exciting research initiatives of GOAL and the continuing Lupus Research at Emory.

