

# THE M.U.S.C.L.E.



Medical University of South Carolina Lupus Erythematosus Research Group  
Division of Rheumatology & Immunology

## WELCOME

We at the Medical University of South Carolina Lupus Erythematosus Group continue to work hard to identify causes and better treatments for lupus. We are pleased to have had the opportunity of working with patients with lupus, their families, and friends over the years. It is because of you that we are able to do what we do. Many thanks and we hope that this newsletter is both informative and motivating in regards to the fight against lupus.

The past year was full of hope and exciting news in the world of lupus research, treatment and awareness! Several recent announcements bring optimism that better treatments and ultimately a better quality of life will be coming soon for the 1.5 million Americans and the more than 5 million people with lupus worldwide. Trials of promising new therapies, many of which are conducted here at M.U.S.C., continue to be launched – making the dream of effective targeted therapies with fewer side-effects come closer to reality. Watch our website for updates and as always, feel free to give us a call or email with questions about the latest developments in lupus.

**Did you see us at the MLK 5K Unity Race for Lupus Research & Education held at Furman University?**



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## Meet Our M.U.S.C.L.E.S.

### Lupus Investigators

Gary S. Gilkeson, MD

James C. Oates, MD

Diane L. Kamen, MD, MSCR

Holly C. Mitchell, MD

Natasha Ruth, MD, MSCR

Hazel Breland, PhD

Lee Moultrie - Community Research Associate

Melissa Cunningham, MD, PhD - Fellow

Marina Pulini-Franks, MD - Fellow

### Study Coordinators

Liezl de la Cruz-Tracy, CCRC

LoriAnn Ueberroth, CCRC

Anna Meyer, PhD

Brittany Smalls

Barbara Roe

Abigail Powell



## NEWEST M.U.S.C.L.E. GROUP MEMBERS



**Brittany Smalls** joined the M.U.S.C.L.E. group as a Study Coordinator in January, 2010. Originally from the Charleston area, she has a BS in Anthropology and is looking to pursue a PhD in Health and Rehabilitation Science next fall. Brittany got started on her quest for research while an

undergraduate student at College of Charleston, working for the Center of Health Disparities Research.

**Abby Powell** joined the M.U.S.C.L.E. group as a Study Coordinator in January, 2011. Her previous work experience includes a diverse background of telecommunications and IT technologies. She considers herself to have “always had an affinity for healthcare” and is “very excited to start a new career path.”



EAT, DRINK & BE  
HOPEFUL

please join us at our

WINE TASTING FUNDRAISER  
TO BENEFIT  
LUPUS RESEARCH

saturday, march 19, 2011  
6:00 pm - 10:00 pm  
\$20 admission

sponsored by virtuous ladies motorcycle club

WINE TASTING FUNDRAISER

saturday, march 19, 2011  
6:00 pm - 10:00 pm  
st. julian devine center  
1 cooper st., downtown charleston

for more information please contact:  
karen holt 843.364.8150 | tiffany anderson 843.637.1638  
virtuousladiesmcfsc@yahoo.com



**Barbara Roe** started as a Study Coordinator in October, 2010. “My previous position was in pre-clinical testing with a major pharma company. Due to site consolidations, I found myself in a position to begin a new journey. I am excited to be a part of the M.U.S.C.L.E group, this is a new area for me and being a part of such a caring group is a big bonus.



The best part for me so far has been being able to see the positive effects our work has on the participants of the studies – something I never got to experience previously.”

**Question:** Why is the butterfly associated with lupus?

**Answer:** One of the symptoms of lupus is a rash on the nose and cheekbones that appears in a butterfly pattern.

## NEW PEDIATRIC LUPUS STUDY

### The Association of Anti-NMDA Receptor Antibodies and Neurocognitive Dysfunction in Pediatric Patients with Lupus and in the Offspring of Adult Patients with Lupus



**Dr. Natasha Ruth** is the Principal Investigator for a new Pediatric Clinical Study here at MUSC. We are excited for this study as it is our first study here at MUSC that specifically focuses on pediatric patients with lupus.

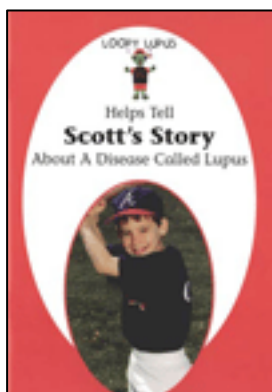
The purpose of the study is to assess whether pediatric patients with lupus and the offspring of adult lupus patients, with anti-NMDA receptor antibodies, will have a higher prevalence of problems with thinking and memory, including depression, learning disabilities, and lower health-related quality of life, compared to juvenile arthritis controls.

#### For More Information Contact:

Anna Meyer  
843-792-8997

#### Recommended Reading:

This book was conceived, created and written by Scott and his 3<sup>rd</sup> grade class with help from their teacher. The book uses the 'Loopy Lupus bug' to explain the technical side of lupus, while home photos of Scott and his family illustrate Scott's life with lupus.



### KIDS WITH LUPUS

At one time lupus was thought to be more severe in children than in adults, but most physicians no longer believe this. Lupus in children is the same disease as lupus in adults; however, children diagnosed with lupus often have been ill for a longer period before the diagnosis is made.

One of the most difficult problems for every parent is how to let their children "grow up" without letting them take unnecessary risks. This is even harder for parents of children with lupus. The key concept must be, "as normal as possible." For every decision you face with your child (school trip permissions, friends, a sleepover, etc.), ask yourself if you would let them go if they didn't have lupus. The only big exception is exposure to excessive sunlight, which may make lupus worse. A child with lupus may not be able to go to the beach for the day, or sit out in the sun by the pool. If you are unsure, ask your physician.

You must understand that your child will have days when they are upset about having lupus. They will be upset about the side effects of their medications and upset about the limitations placed on them because they have lupus. The fact that it's no one's fault doesn't make it better. You must treat your child just as you would if they were angry about anything else. Occasional problems are normal. There is no single solution that will work for everyone.

#### MUSC Pediatric Rheumatology Contact Information:

Charleston, SC office: 843-792-5696  
Columbia, SC office: 803-434-5989  
Drs. Natasha Ruth and Murray Passo

Adapted from Lupus Foundation of America  
([www.lupus.org](http://www.lupus.org))

The MUSCLE Newsletter is available electronically! Help the environment, request the newsletter electronically by sending your e-mail address to: [lupusresearch@musc.edu](mailto:lupusresearch@musc.edu); subject line: newsletter

## LUPUS IN MEN

### Coping with Lupus

The emotional stresses for men with SLE are the same as those experienced by women with the disease. In some ways, it may be even more difficult for men to cope with having lupus because of the cultural and societal expectations of men.

For example, the same incapacitating feelings that a woman with SLE feels may be even more apparent in a male: he may no longer be able to perform or progress in his work environment; he may not be able to continue working to support his family; he may have difficulty in performing duties or activities that involve physical labor.

The inability to work and earn a living, because of disability due to illness, may result in significant emotional and mental stress. The roles and expectations of males and females in today's society are changing, but acceptance of these changes takes a long time. These types of stresses, coupled with the fact that lupus is mistakenly referred to as a "woman's illness," can make it difficult for males to cope with this chronic disease. Although cosmetic changes are usually not as incapacitating for men as they are for women, certain symptoms associated with either the disease or the treatments are of some concern to men with lupus (skin rashes, hair loss, and weight gain).

On the other hand, men may be more concerned than women with other "non-physical" changes: (change of job performance, significant loss of independence, problems with self-esteem, false feelings about a "loss of masculinity").

### Drug-Induced Lupus Erythematosus

More men than women develop drug-induced lupus erythematosus (DILE) because the most common medications to trigger DILE are used more frequently in men: isoniazid (used to treat tuberculosis), procainamide (used to control various types of heart abnormalities), and hydralazine (used to control high blood pressure). The symptoms can appear just like systemic lupus, however with DILE they often resolve once the triggering medication is stopped.

(Adapted from Lupus Foundation of America; [www.lupus.org](http://www.lupus.org))

**Myth:** Lupus won't affect me, I'm a man and it's a "woman's" disease

**Fact:** Men can, and do get lupus. Before puberty, 1 male for every 3 females; teens and adults, 1 male for every 10 females; and after age 50, 1 male for every 8 females will develop systemic lupus.

(Adapted from Lupus Foundation of America; [www.lupus.org](http://www.lupus.org))

## SPOTLIGHT ON CLINICAL STUDIES in LUPUS at MUSC

### A Randomized, Double-Blind, Controlled, Phase II Multicenter Trial of CTLA4Ig (Abatacept) Plus Cyclophosphamide vs. Cyclophosphamide Alone in the Treatment of Lupus Nephritis

The purpose of this research trial is to determine if the drug Abatacept improves the treatment response rate of Lupus Nephritis (LN) in people (male or female) aged 16 years of age or older.

LN must be confirmed with a kidney biopsy within 12 months from study participation. This study is sponsored by the National Institute of Allergy and Infectious Disease (NIAID) through the Immune Tolerance Network (ITN). The study will be conducted on the MUSC campus at the Clinical and Translational Research Center (CTRC). Each qualified participant will be assigned to one of two investigational medications: Placebo or Abatacept along with routine standard of care medications. Study participation consists of approximately 19 visits over a total of 2 years. Study participants will receive investigational and study-related medications, health examinations and labs at no cost. Compensation for time and travel may also be available.

For More Information Contact:

LoriAnn Ueberroth

843-792-0549

**ADDITIONAL CLINICAL STUDIES in LUPUS at MUSC**

Please see our website for further information

[www.musc.edu/lupus](http://www.musc.edu/lupus) or [www.scresearch.org](http://www.scresearch.org)

**A Randomized, Double-Blind, Parallel-Group, Placebo-Controlled Study to Evaluate the Efficacy and Safety of a 200-mcg Dose of CEP-33457 in Patients with Systemic Lupus Erythematosus**

**Phase IIa, Multicenter, Randomized, Double-Blind, Placebo-Controlled, Study to Evaluate the Safety, Tolerability and Clinical Effect of Laquinimod in Active Lupus Nephritis Patients, in Combination with Standard of Care**

**Environmental Determinants of Autoimmunity among African Americans in Coastal SC (POPAI)**

**A Phase IIa, Multicenter, Randomized, Double-Blind, Placebo-Controlled Study to Evaluate the Safety, Tolerability and Clinical Effect of Laquinimod in Systemic Lupus Erythematosus Patients with Active Lupus Arthritis**

**A National Consortium to Explore the Genotypic Basis for ESRD in Lupus**

**Sisters of Women with Systemic Lupus Erythematosus (SisSLE)**

**CONGRATULATIONS!**

Imani Fickling has left the M.U.S.C.L.E. group for nursing school. We wish her all the best in her new career.

# LUPUS Support Group

Just a friendly reminder (or notification if you've never heard of us)....

**Next Meeting**Date: **March 12, 2011**Place: Holiday Inn Express  
at Elms Plantation

Time: 10:30 am

**“THE IMPORTANT  
RELATIONSHIP WITH  
YOUR RHEUMATOLOGY  
NURSES”**

We will review information that is helpful for you to keep updated in your medical file and discuss with your nurse at each visit, along with advice on phone calls to your doctor.

For additional information, please contact the support group facilitator:

**Alice Burress 843-884-3949**

**Walk for Lupus!**Mark your Calendar for the [28below.org](http://28below.org)**Laps for Lupus Walk**Friday, May 13<sup>th</sup>, 2011

Check in @ 5:45pm

Sumter High School Memorial Stadium  
in Sumter, SC

[www.28below.org](http://www.28below.org) for info

28 Below Foundation



Lupus Awareness



**MUSC Lupus Erythematosus  
(M.U.S.C.L.E.)  
Research Group**

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Email: [lupusresearch@musc.edu](mailto:lupusresearch@musc.edu)  
Website: [www.musc.edu/lupus](http://www.musc.edu/lupus)

## GOT LUPUS? GOT SMILES?

**ARE YOU AN AFRICAN AMERICAN WITH LUPUS  
WHO IS FROM THE SEA ISLANDS?**

**HAVE YOU EVER WONDERED IF YOUR DENTAL  
HEALTH (TEETH) COULD BE AFFECTING YOUR LUPUS?**



**IF YES, PLEASE CALL (843) 792-8997 OR  
TOLL FREE 1-866-859-6107 TO LEARN ABOUT  
A NEW STUDY EXAMINING THE RELATIONSHIP  
BETWEEN DENTAL HEALTH AND LUPUS**



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RETURN SERVICE REQUESTED