



Our Mission: To improve the quality of life for those affected by lupus through advocacy, education, awareness, empowerment, and research.

Lupus Communiqué

Lupus Foundation of Mid and Northern New York, Inc.

Volume 8, No. 2, Summer 2009

9th Annual Lupus Charity Golf Classic



Over \$26,000 in net proceeds was raised at the 9th Annual Lupus Charity Golf Classic at Shenendoah Golf Club at Turning Stone Resort Casino in Verona on Friday, August 14, 2009. Pictured above right is Honorary Chairman Dr. Donald Raddatz, Bassett Healthcare Rheumatologist with Shenendoah Tournament Director Andy Myers directing golfers during the shotgun start. Thank you to Dr. Raddatz, our golfers, sponsors, prize donors, committee members, and volunteers for making this event possible—we couldn't do it without you!



The Lupus Communiqué

*Is published four times a year by
Lupus Foundation of Mid and
Northern New York, Inc.*

**PO Box 139 Utica, NY 13503 Phone: 315-829-4272
or 1-866-258-7874 Fax: 315-829-4272**

**E-mail: lupusmidny@aol.com
www.nolupus.org**

Editor: David L. Arntsen

TABLE OF CONTENTS

9th Annual Lupus Golf Classic	1
Newsletter Information	2
Campaigns	3
President's Message	4
Golf Classic Sponsors	5
Memorials, Tributes & Donations	6 & 7
Golf Classic Collage	8 & 9
Autoimmune Article	10 & 11
Kidney Article	12
Clinical Trial Info	13
Membership Form	14
Announcements	15
Lupus NYS Fair Booth	16

DISCLAIMER

It is the policy of the Lupus Foundation of Mid and Northern New York, Inc. to publish articles on Lupus and related diseases that have been written by physicians, nurses, and other healthcare providers and medical professionals. The opinions and statements expressed by the authors or contributors to this publication do not necessarily reflect the opinions or positions of The Lupus Communiqué, or Lupus Foundation of Mid and Northern New York, Inc.

The material published herein is provided for informational purposes only and does not imply endorsement of any specific treatment, product, clinical trial, company or organization. We oppose self-diagnosis and self-treatment and urge readers to discuss any concerns they may have regarding diagnosis and treatment with their physicians. All rights reserved. No material in this issue may be copied or published without the express written consent of Lupus Foundation of Mid and Northern New York, Inc. Thank you.

BOARD OF DIRECTORS

President/CEO
Kathleen A. Arntsen

Vice President
James E. Mitchell Jr.

Treasurer
Philip A. Teague

Secretary
Stephanie C. Darwak

Chairman of the Board
David L. Arntsen

Members

Dale R. Bullock

Maryrose T. Bullock

Sandra M. Frear

Ellen C. Gloo

Jacqueline L. Taylor

*Honorary
Medical Advisory Board*

Atul Butala, MD
Hematologist

Gregory Cummings, MD
Neurologist

Victoria Laucello, MSW
Psychotherapist

Edward B. Lee, MD
Dermatologist

Martin Morell, MD
Rheumatologist

Khalid Parvaiz, MD
Nephrologist

Donald Raddatz, MD
Rheumatologist

Raquel Rosen, MD
Nephrologist

Allan Smiley, MD
Rheumatologist



Community
Health Charities
— of New York —
WORKING FOR A HEALTHY AMERICA



Please consider Memorial and Tribute contributions to our organization. It is a wonderful way to honor or remember someone special in your life while also supporting the lupus cause. If you belong to a Service or Fraternal organization, or participate in a workplace-giving program such as: CFC, SEFA, UNITED WAY, IBM or other campaign, please remember to designate our organization.

Lupus Foundation of Mid and Northern New York, Inc. is a tax-exempt charitable organization eligible to receive tax-deductible contributions under IRS Code Section 501(c)(3). Our federal tax identification number is 16-1083229 and a copy of our latest annual report may be obtained upon request from us or The NYS Attorney General's Charities Bureau at 120 Broadway, NY, NY 10271.

EDITOR'S NOTE

Suggestions or comments on the newsletter are always welcome. Please contact us with any address changes or other corrections to ensure accuracy in the database. If an address is incorrect the Post Office will not deliver under their revised policies and the mail piece will be returned and we will be charged a fee. Please notify us immediately of any changes to avoid extra postal fees. As Technical Director I also invite your input and assistance in improving our organization's operations, especially in maintaining our website. Thank you.

Dave Arntsen

President's Message—

The great coach Vincent T. Lombardi once said, “The achievements of an organization are the results of the combined effort of each individual.” That statement pretty much echoes the sentiment we feel about the dedicated volunteers of the Lupus Foundation of Mid and Northern New York. Since we are an all-volunteer organization and have no paid staff every task and activity and event that is completed here is accomplished through volunteer efforts. Somehow, even with the poor economy we managed to end our fiscal year on September 30th only \$2,000 less in income than last year. Due to unforeseen circumstances we were forced to cancel the July Motorcycle Run that was expected to raise over 2k so we were pretty much on target this year in comparison with the previous year's income. And our Annual Golf Classic netted \$1,000 more than last year's when the final donations were tallied! At the end of the Golf Classic Awards Dinner all of our volunteers received a standing ovation from the golfers and sponsors in recognition of their efforts. It was a proud moment at the end of a very long and tiring but exhilarating day.

The 9th Annual Lupus Charity Golf Classic was held on August 14, 2009—a very sunny and humid Friday at Shenendoah Golf Club at Turning Stone Resort Casino. More than \$26,000.00 net was raised to fund our local programs. 104 golfers enjoyed a great round of golf at a spectacular premier New York State golf club with a delicious meal and awards dinner immediately following at the beautiful Shenendoah Clubhouse. The monies raised from this fundraising event support our ongoing program services including our advocacy, awareness, education, and research programs. We not only advocate for people affected by lupus and other autoimmune diseases but also for health care reform and patient access issues that affect each and every American. This past year we also initiated the first ever Lupus Awareness Month in NY State in May through our own local legislators and received a resolution from Governor Paterson. We were the lead organization on this awareness event and have been coordinating the Lupus Agencies of NY State Booth at the State Fair for the past 20 years. It is amazing what a small group of passionate people can achieve! The golf tournament also funds our Research Program Services. We are proud to say that we give 1/3 of our income to lupus research each year. Because of the tremendous support and generosity over the past 9 years we have netted \$199,274 from this event that has enabled our small all-volunteer organization to enhance our existing program services, and fund \$131,500 in grants to Lupus Research. Next year's event is scheduled for Friday, August 13, 2010 at Shenendoah Golf Club.

Almost all of our volunteers here are personally connected to the lupus cause either because they have lupus themselves or love someone with lupus. Either way they are motivated to give us their time and they are all a tremendous asset to our community. As we begin our new fiscal year with uncertainty about the economy, health care, and weather we can certainly reflect on the year just ended with great pride and satisfaction. Please think of us if you have a little time to donate. The teacher and philosopher Shira Tehrani once said “You can't do anything about the length of your life, but you can do something about its width and depth.” We are here for you.

Stay Healthy, Warm and Well —Kathleen

9th ANNUAL LUPUS CHARITY GOLF CLASSIC CORPORATE SPONSORS

TOURNAMENT SPONSOR

Pfizer, Inc.

PLATINUM SPONSOR

**Hole-In-One sponsored by Carbone Dodge Chrysler Jeep
Family & Friends of Geri Lemke
ΒΣφ Alpha Iota Oneonta Chapter in Honor of Maryrose Bullock
The Mitchell Family and MCORP in honor of Kathleen
NY State Corrections Officers PBA
Utica Professional Fire Fighters IAFF Local 32
Wal Mart Store #1677**

GOLD SPONSOR

**David & Kathleen Arntsen
Ellen Gloo
Jane Porter in Memory of Barbara M. Porter
Teague Accounting Xperts, Inc.**

SILVER SPONSOR

**Amalgamated Transit Union Local 1145
Rick Deyulio
Helen E. Cassin in Memory of Richard W. Cassin
Presto Print, LLC
Raquel Rosen, MD
Ryan Family Real Estate & Investment in Honor of Mary Becker**

BRONZE SPONSOR

**Friends of Congressman Michael Arcuri
Arthritis Health Associates
Fayze Chahfe, MD
Eastup Automotive in honor of Sarah Eastup
Rocco & Monica Falitico in honor of Roxanne Falitico
CPF, Inc. in honor of Sandi Frear's Advocacy Award
Donna Gloo
La Familia de Lisabeth Iglesias
Edward B. Lee, MD
Susan McNaughton in honor of Sandi Frear
Dan & Lisa Mitchell & Family/MCorp
Pierce Auto Parts
Family & Friends in Memory of Barbara M. Porter
Putnam Pest Control
Scharf Plumbing & Heating
Surgical Association of Utica, PC
In Honor of Cathy Walseman: Bob Walseman & Isabel Woolshlager**

Memorials, Tributes, and Donations

Memorials

In Loving Memory of...

*Richard Cassin-
Bill & Sandi Frear,
Jane Porter,
Helen Cassin,
John Porter*

*The Rev. S. Kenneth Arntsen-
David & Kathleen Arntsen*

*Lorna E. Relf, Louis A. Relf, Sam Relf-
James & Patricia Mitchell,
David & Kathleen Arntsen*

*Arthur A. Relf & Elva Fox-
James & Patricia Mitchell,
David & Kathleen Arntsen*

*Angela "Aya" LoConti-
James & Patricia Mitchell,
David & Kathleen Arntsen*

*Michael P. Jones, Elizabeth Jones-
James & Patricia Mitchell,
David & Kathleen Arntsen*

*Peter & Dorothy Curri, Marguerite Curri-
James & Patricia Mitchell,
David & Kathleen Arntsen*

*Sandra Haase-
David & Kathleen Arntsen*

*John H. Dabolt III-
David & Kathleen Arntsen*

*Barbara M. Porter-
Bill & Sandi Frear,
Jane Porter,
Helen Cassin,
John Porter*

*Richard & Rita Rogers-
Peter Rogers*

*Juanna Nitti Pavone-
Philip & Phyl Cittadino*

*Angela Carol LoConti-
Dominick & Marie Oriolo*

Memorials

In Loving Memory of...

*John & Alberta Bagley-
James & Patricia Mitchell*

*Rosemary Franklin-
David & Kathleen Arntsen*

*Bill Acquaviva-
David & Kathleen Arntsen*

*Amy Bryant Mowers-
David & Kathleen Arntsen*

*Harold F. Woolshlager-
Bob & Cathy Walseman, Isabel Woolshlager,
Jeff & Sue Virkler & Family,
Larry & Karen Woolshlager & Family*

*Brooke N. Walseman-
Bob & Cathy Walseman, Isabel Woolshlager,
Jeff & Susan Virkler,
Larry & Karen Woolshlager & Family*

*Douglas C. Kerr-
Bob & Cathy Walseman*

*Wellington Walseman-
Bob & Cathy Walseman*

*Ethel Clark-
Isabel Woolshlager*

*Anita Curtiss-
Isabel Woolshlager,
Jeff & Sue Virkler & Family,
Larry & Karen Woolshlager & Family*

*Elwood Virkler-
Jeff & Sue Virkler & Family*

*James McCarthy-
Larry & Karen Woolshlager & Family*

*Janet F. Grimm-
Charles M. Grimm*

*Julie Firlet-
Larry & Kathy Scharf*

*Beverly G. Clinkscales-
Velma Brisson*

Memorials, Tributes, and Donations

Memorials

In Loving Memory of...

Mary Alice Mitchell-

*Jane Williams, James & Patricia Mitchell,
David & Kathleen Arntsen, Jill Anne Smith*

James E. Mitchell, Sr.-

*Jane Williams, James & Patricia Mitchell,
David & Kathleen Arntsen, Jill Anne Smith*

Thomas P. Mitchell-

*Jane Williams, James & Patricia Mitchell,
David & Kathleen Arntsen, Jill Anne Smith*

Christine Marie Smith-

Jill Anne Smith

Mary Olivadoti, Leonard A. Benedetto,

Antoinette Falbo, Frank Alesandro,

Carlo P. "Carl" De Fazio,

Frank Andrello, Bruno Arcuri,

Sharon A. Faustski, John J. Valletto,

Gasper "Casper" Viti, Philip Latella,

Emily M. Carvelli, Jennie Damico,

John Nussia, Philomena Taurisano,

Dean A. LoConti, Alex Oriolo,

Frances "Butch" Montrose, Claudio Poccio,

Marie "Mary" Christiano, Thelma "TR" Roy,

Marione Eandrello, Sarah Montesanti,

Michael Cataldo, Joseph Elacqua,

Margaret "Peg" Julian, Clara K. Burline,

Carmella DiMeo, Jennie Amado,

Michael J. Mezzanini Jr., Bea Gambino,

Frank Pugliese, Josephine Barbero—

Dan LoConti

Tributes

In Loving Honor of...

Partner Memberships-

Kelly Bunce-

Sandra Combs, Sharon Rolchigo

Cathy Walseman-

Laury Kerr, Peter & Nancy Marshall

Tributes

In Loving Honor of...

Roxanne Falitico-

Rocco & Monica Falitico

Sandi Frear-

*Vikki Vallone, Helen E. Cassin,
Rick & Kathy Voskuil, Susan Fraser, MD,
John Porter & Elisabeth Kaye*

Maryrose Bullock-

*Donna Schultes, Tina Fox, Annie Myers,
Terry Church, Sharon Clute,
Beverly Ballard, Angela Bouchard*

*David & Kathleen Arntsen's Birthdays-
James & Patricia Mitchell*

*Larry & Kathy Scharf's 25th Anniversary-
Katherine Reitinger*

Donations

*CFC, SEFA, United Way, IBM, GE,
American Express, United Health,
and Pfizer Employee Donor Plans
American Postal Workers Union*

Anthony & Kim Matt

Jay-K Independent Lumber Corp.

Don & Joan Gloo

Victoria Shepardson

Marian J. Arntsen

Leonardo & Laura Mangiaracina

Marilyn Sousa

Geoffrey, Theodore & Barbara Cobb

William & Julia Mitchell

Edward B. Lee, MD

William P. Hannan, MD

Roxanne Falitico

Mike & Fran Eck

Sonya Linakis

Geraldine Conniff

Christa Anderson

Joseph & Victoria Jupin

Jill Anne Smith

Sharon SantaMaria

Donald & Sharon Lust

9th Annual Lupus Charity Golf Classic



This event would not be possible without the dedicated efforts of our wonderful volunteers who survived the 90 degree weather to help out that day. Special thanks to David & Kathleen Arntsen (above center), Sandi Frear (above left), and Jackie Taylor (above right on the left side of the raffle cage) for organizing the tournament.



OUR VOLUNTEERS ARE THE REASON THIS EVENT IS SUCH A SUCCESS !!!



Shenendoah Golf Club at Turning Stone



Pictured above left Men's Champions Team Burkhard; above center Ladies' Champions Team Lemke; above right Co-ed Champions Team Bush/Myers



Chairman Donald Raddatz, MD



Tournament Sponsor Pfizer



Platinum Sponsor Mitchell Family & MCORP



Platinum Sponsor Family & Friends of Geri Lemke



Utica Professional Firefighters



NYSCOPBA



Wal Mart Store 1677

Thank you to our 2009 sponsors, golfers, prize donors, ticket sellers, volunteers, and supporters for making this event possible.



Platinum Sponsor Team Maryrose & BΣΦ Alpha Iota Oneonta Chapter (left); Hole-in-One Sponsor Carbone Dodge Chrysler Jeep (right)



NIH Podcast Provides Insights on Autoimmune Diseases and their Impact on Women

Your body's immune system protects you from disease and infection. But if you have an autoimmune disease, your immune system attacks healthy cells in your body by mistake. Autoimmune diseases are a category of disorders that can affect just about every organ system in the body--from hair to toenails--and are often chronic diseases that can go on for a lifetime.

The NIH's Office of Research on Women's Health monthly podcast, "Pinn Point on Women's Health," provides updates on women's health research, and is hosted by Vivian W. Pinn, M.D., director of NIH's Office of Research on Women's Health. This month, Dr. Pinn interviewed Dr. Robert Carter, deputy director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases, and an expert in the field of autoimmune diseases.

"Although they don't get the publicity of cancer or sudden heart attack, the burden of these diseases is enormous because they affect a lot of people and go on for a lifetime," said Dr. Carter. "And there is something about being female that leads you to a higher risk for many autoimmune diseases."

An autoimmune disease can be isolated (affecting only the thyroid, for example) or systemic, such as rheumatoid arthritis, lupus and scleroderma. The diseases may also have flare-ups--when they get worse--and remissions, when they seem to disappear. The diseases do not usually go away, but symptoms can be treated. They also tend to run in families, and African-American, Hispanic-American, and Native American women have a higher risk for some autoimmune diseases.

"Looking at sex and gender differences has provided researchers with many clues," said Dr. Carter. "The presence of female hormones as well as the fact that women have two X chromosomes may play a part in contributing to the development of an autoimmune disease."

Lupus can be a particularly devastating and even fatal autoimmune disease that primarily affects women of all ages. It is defined as a constellation of problems that can affect the skin, kidneys, lungs, and gut.

"From a patient care standpoint, lupus is a huge burden for families," said Dr. Carter, "And for the physician it's a real clinical challenge, and from the research side, it's both extremely fascinating disease because of its complexity, and a challenge in terms of developing new therapies. We don't yet understand it well."

Lupus has many symptoms. Some common ones are:

- ◆ Joint pain or swelling
- ◆ Muscle pain
- ◆ Fever with no known cause
- ◆ Red rashes, often on the face (also called the "butterfly rash")

There is no one test to diagnose lupus, and it may take months or years to make the diagnosis. Dr. Carter recommended that although fatigue and joint pain may not be signs of lupus, women--particularly those with a family history of the disease--should talk to their doctor if they have those symptoms. Although there is no cure for lupus, medicines and lifestyle changes can help control it.

Dr. Pinn noted that rheumatoid arthritis (RA) is also an autoimmune disease that occurs more frequently in women, and causes pain, swelling, stiffness and loss of function in the joints, most commonly in the wrist and fingers, and can also affect the eyes and lungs. Rheumatoid arthritis is different from osteoarthritis, the common arthritis that often comes with older age, due to wear and tear on the joints. People can have rheumatoid arthritis for only a short time, or symptoms might come and go. The severe form can last a lifetime.

"The good news is that we've had dramatic success in the development of new treatments and treatment approaches and the very nature of this disease has changed dramatically since I've been involved," said Dr. Carter. "We're getting much better at preventing permanent damage to eyes, lungs and vascular system as well as preventing damage to the joints and the kind of mutilating arthritis that we used to see."

(NIH Podcast continued)

Researchers are exploring the genetics and causes of RA disease as well as seeking to understand how inflammation occurs and what makes it cause damage to the joints.

“With rheumatoid arthritis, we now have a variety of drugs available and we are seeking to understand who will respond best to which drugs, said Dr. Carter. He also stressed the importance of seeing a rheumatologist (a medical doctor who specializes in arthritis and related diseases) and getting early and aggressive treatment if a person is diagnosed with RA. “With lupus, we do not have as many proven treatment options, but early treatment can improve the outcome in severe disease.”

Scleroderma, another autoimmune disease, literally means “hard skin,” and affects approximately 50,000 people in the United States. It is a group of diseases that causes abnormal growth of connective tissue, the proteins that support skin and organs. There are two main types--localized scleroderma affects only skin, and systemic scleroderma affects blood vessels and internal organs such as the digestive tract or kidneys, as well as skin, and can be mild or severe. No one knows what causes scleroderma, and there is no cure, but various treatments can relieve symptoms.

“Our understanding of scleroderma is still pretty rudimentary and what that means is that most of the treatments that we have are not very targeted,” said Dr. Carter. “The important progress that we are making is in identifying these proteins that drive the abnormalities in the cells that cause the thickening and hardness in the skin, but we have not yet been able to translate that progress into treatment.”

Autoimmune diseases are a range of diseases that can attack specific organs or the entire body. Dr. Pinn noted that autoimmune thyroid disease is also more common in women, and one of the major causes of thyroid disease. Other autoimmune diseases include: alopecia (affecting the hair follicles and causing baldness), vitiligo (affecting skin pigmentation), psoriasis (a skin disease that causes itchy or sore patches of thick, red skin), inflammatory bowel disease, and multiple sclerosis.

“This is an exciting time in research,” said Dr. Carter, “We are learning a lot about the immune system and we have made some progress, particularly in rheumatoid arthritis, and we are trying to apply many of the lessons that we’ve learned to other autoimmune diseases.”

This month’s podcast is a two-part program—the first focusing on lupus, and the second on rheumatoid arthritis, scleroderma, and other autoimmune diseases. To hear Dr. Pinn’s podcasts, visit the Office of Research on Women’s Health home page at <http://orwh.od.nih.gov> and click on "Autoimmune Diseases" under "Podcasts."

Information on how to use podcasts, is available at <http://videocast.nih.gov/faq/podcast/default.asp>.

CONTACT: Dorie Hightower, 301-443-8650 e-mail: dorieh@nih.gov

#####

The mission of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), a part of the Department of Health and Human Services' National Institutes of Health (NIH), is to support research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases; the training of basic and clinical scientists to carry out this research; and the dissemination of information on research progress in these diseases. For more information about NIAMS, call the information clearinghouse at 301-495-4484 or 877-22-NIAMS (free call) or visit the NIAMS Web site at <http://www.niams.nih.gov>.

The Office of Research on Women’s Health (ORWH), Office of the Director, National Institutes of Health (NIH) serves as a focal point for women’s health research at the NIH. For more information about NIH’s Office of Research on Women’s Health, visit <http://orwh.od.nih.gov/>.

Antimalarial Drug May Protect Kidneys in Lupus Patients

Systemic lupus erythematosus (SLE), also known simply as “lupus,” is an autoimmune disorder that can affect multiple organs. The kidneys, which are part of the renal system, are often affected and the damage lupus can cause to the kidneys can be severe. Now, scientists funded in part by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) have confirmed that a drug originally developed to fight malaria has the potential to provide a protective effect for the renal system.

According to a study authored by Dr. Graciela S. Alarcón, M.D., M.P.H., at the University of Alabama at Birmingham, along with a geographically diverse group of colleagues, renal symptoms occur in 50 to 70 percent of lupus patients. Despite advances in therapy, the degree of illness and the death rate among lupus patients with inflammation of the kidneys (known as lupus nephritis) remain high. Lupus nephritis leads to the development of end-stage renal disease in 17 to 25 percent of patients.

Dr. Alarcón and her colleagues knew from previous studies that the drug hydroxychloroquine, an antimalarial also used in the treatment of lupus and other autoimmune diseases, was associated with a reduced risk of overall tissue damage. The team wanted to more precisely define whether the drug could delay the development of kidney damage. They used several tools in their inquiry.

First, they tapped an existing database of lupus patients called LUMINA, which is an acronym for LUpus in MInorities, NAture versus Nurture. LUMINA, an NIAMS-funded project begun in 1994, was designed to study lupus patients of Hispanic, African American and Caucasian descent, over time. Dr. Alarcón and her colleagues at the University of Alabama at Birmingham, the University of Texas Health Science Center at Houston, and the University of Puerto Rico Medical Sciences Campus, measured renal damage in LUMINA patients by using a standard index called the Systemic Lupus International Collaborative Clinics/American College of Rheumatology Damage Index (also known as the SLICC/ACR Damage Index, or simply the SDI). Participating patients enrolled in this study had lupus nephritis – kidney inflammation – but had not developed actual kidney damage. After controlling for other variables and performing exhaustive statistical analyses of the results, the researchers determined that participants from LUMINA’s three ethnic groups who had been on hydroxychloroquine had a diminished probability of renal damage in comparison with those who did not take hydroxychloroquine. The results indicate a high likelihood that hydroxychloroquine retards the development of renal damage in lupus nephritis patients. The researchers published their study in the journal *Arthritis & Rheumatism*.

###

The mission of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), a part of the Department of Health and Human Services’ National Institutes of Health, is to support research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases; the training of basic and clinical scientists to carry out this research; and the dissemination of information on research progress in these diseases. For more information about NIAMS, call the information clearinghouse at 301-495-4484 or 877-22-NIAMS (free call) or visit the NIAMS Web site at <http://www.niams.nih.gov>.

Reference: Pons-Estel GJ, Alarcón GS, McGwin G, Danila MI, Zhang J, Bastian HM, Reveille JD, Vilá LM. Protective Effect of Hydroxychloroquine on Renal Damage in Patients with Lupus Nephritis: LXV, Data From a Multiethnic US Cohort. *Arthritis & Rheumatism*. 2009 Jun 15;61(6):830-9. PMID: 19479701.

Clinical Trial Opportunities

LUPUS TRIALS

The SUNY Upstate Medical University
Syracuse, NY

is conducting clinical research studies on

Basic research

Metabolic control of systemic autoimmunity

Role of the HRES-1/Rab4 Locus in SLE

Mitochondrial Hyperpolarization in Lupus T cells

Clinical studies

Study of abatacept for lupus nephritis

Treatment of SLE with N-acetylcysteine

Prospective study of Rapamycin for SLE treatment

For more information please call:

Andras Perl, MD PhD at (315) 464-4194

Irene Ramos at (315) 464-5247

A CLINICAL RESEARCH STUDY FOR SYSTEMIC LUPUS

Have you been diagnosed with systemic lupus?

Have you had kidney problems due to lupus?

Are you between the ages of 12 and 70?

If you answered **YES** to these questions, you may qualify to take part in a research study with a new investigational medication that may decrease kidney problems due to lupus

Qualified Participants Will Receive:

Study medication

Study related medical care for your lupus

Monetary payment in compensation for time and travel expenses

For More Information Call:

(585) 442-1980

AAIR Research Center

300 Meridian Centre Suite 305

Rochester, NY 14618

LUPUS RESEARCH OPPORTUNITIES

If you are interested in learning about
upcoming Clinical studies and

Research treatments call us to enter our

LUPUS PATIENT REGISTRY

You'll be the first to hear about an exciting future
using investigational treatments.

For more information please call:

(585) 275-7167

University of Rochester

Clinical Immunology Research Center

601 Elmwood Avenue

Rochester, NY

The Lupus Multiplex Registry

The LMRR is actively researching the
different ways in which SLE affects
various ethnic groups.

Families with one or more living members
diagnosed with lupus may be eligible for
one of the following studies:

Minorities and Lupus, African American
Studies, Hispanic American Studies,
Native American Studies, Asian American
Studies, All Ethnicities, Families with 1 Lupus
Patient, Families with 2 Lupus Patients

For more information visit the website

www.ormf.org/?page=aboutlmrr

or call 1-888-OK-LUPUS



LUPUS FOUNDATION OF MID AND NORTHERN NEW YORK

MEMBERSHIP APPLICATION & ORDER FORM

Name:	Date:												
Address:	Phone #:												
City, State, Zip:	Work #:												
E-mail address:	Fax #:												
<input type="checkbox"/> Single (\$10.00) <input type="checkbox"/> Renewal <input type="checkbox"/> Family (\$15.00) <input type="checkbox"/> New <input type="checkbox"/> Professional (\$25.00) <input type="checkbox"/> Patron (\$50.00) <input type="checkbox"/> Courtesy	Other Donation (please list) <hr style="width: 80%; margin: 5px auto;"/> <input type="checkbox"/> Interested in Support Groups												
<table style="width: 100%; border: none;"> <tr> <td style="border: none;"><input type="checkbox"/> LUPUS BOOK Revised by Daniel J. Wallace, MD</td> <td style="border: none; text-align: right;">\$ 24.00 plus \$4.00 S & H</td> </tr> <tr> <td style="border: none;"><input type="checkbox"/> COPING WITH LUPUS by Robert H. Phillips, PhD</td> <td style="border: none; text-align: right;">\$ 15.00 plus \$3.00 S & H</td> </tr> <tr> <td style="border: none;"><input type="checkbox"/> COOLIBAR SUN PROTECTIVE CLOTHING</td> <td style="border: none; text-align: right;">\$ 20.00 plus \$5.00 S & H</td> </tr> <tr> <td style="border: none;"><input type="checkbox"/> THE AUTOIMMUNE EPIDEMIC by Donna Jackson Nakazawa</td> <td style="border: none; text-align: right;">\$ 15.00 plus \$4.00 S & H</td> </tr> <tr> <td style="border: none;"><input type="checkbox"/> AWARENESS WRISTBANDS <i>Orange or Purple</i></td> <td style="border: none; text-align: right;">\$ 1.00 plus .25 per 3 S & H</td> </tr> <tr> <td style="border: none;"><input type="checkbox"/> BEANIE BEARS</td> <td style="border: none; text-align: right;">\$ 10.00 plus \$3.00 S & H</td> </tr> </table>		<input type="checkbox"/> LUPUS BOOK Revised by Daniel J. Wallace, MD	\$ 24.00 plus \$4.00 S & H	<input type="checkbox"/> COPING WITH LUPUS by Robert H. Phillips, PhD	\$ 15.00 plus \$3.00 S & H	<input type="checkbox"/> COOLIBAR SUN PROTECTIVE CLOTHING	\$ 20.00 plus \$5.00 S & H	<input type="checkbox"/> THE AUTOIMMUNE EPIDEMIC by Donna Jackson Nakazawa	\$ 15.00 plus \$4.00 S & H	<input type="checkbox"/> AWARENESS WRISTBANDS <i>Orange or Purple</i>	\$ 1.00 plus .25 per 3 S & H	<input type="checkbox"/> BEANIE BEARS	\$ 10.00 plus \$3.00 S & H
<input type="checkbox"/> LUPUS BOOK Revised by Daniel J. Wallace, MD	\$ 24.00 plus \$4.00 S & H												
<input type="checkbox"/> COPING WITH LUPUS by Robert H. Phillips, PhD	\$ 15.00 plus \$3.00 S & H												
<input type="checkbox"/> COOLIBAR SUN PROTECTIVE CLOTHING	\$ 20.00 plus \$5.00 S & H												
<input type="checkbox"/> THE AUTOIMMUNE EPIDEMIC by Donna Jackson Nakazawa	\$ 15.00 plus \$4.00 S & H												
<input type="checkbox"/> AWARENESS WRISTBANDS <i>Orange or Purple</i>	\$ 1.00 plus .25 per 3 S & H												
<input type="checkbox"/> BEANIE BEARS	\$ 10.00 plus \$3.00 S & H												
Up-to-date Lupus Foundation of America, Inc. Brochures There is a \$.25 fee per brochure													
<input type="checkbox"/> What is Lupus? <input type="checkbox"/> Kidney Disease & Lupus <input type="checkbox"/> Skin Disease <input type="checkbox"/> Sjogren's Syndrome <input type="checkbox"/> Medications <input type="checkbox"/> Lupus & Infections <input type="checkbox"/> Cardiopulmonary Disease <input type="checkbox"/> Joint & Muscle Pain	<input type="checkbox"/> Anti-Phospholipid Antibodies <input type="checkbox"/> Pregnancy & Lupus <input type="checkbox"/> Blood Disorders in SLE <input type="checkbox"/> SLE & The Nervous System <input type="checkbox"/> Steroids Used in Treatment of Lupus <input type="checkbox"/> Laboratory Tests Used in Diagnosis <input type="checkbox"/> Non-Steroidal Anti-Inflammatory Drugs <input type="checkbox"/> Lupus in Overlap w/ Connective Tissue Disease	<input type="checkbox"/> Lupus & Vasculitis <input type="checkbox"/> Childhood Lupus <input type="checkbox"/> Lupus in Men <input type="checkbox"/> Depression <input type="checkbox"/> Drug-Induced Lupus <input type="checkbox"/> Basics for Better Living <input type="checkbox"/> Photosensitivity											
Please remit total payment to: Lupus Foundation PO Box 139 Utica, NY 13503													

OCTOBER IS OUR MEMBERSHIP DRIVE

PLEASE RENEW YOUR DUES AND URGE OTHERS TO JOIN WITH US IN OUR CAUSE



A limited number of pieces of Coolibar Sun Protective Clothing are available for a discounted price of \$20 per item. Please call the office for more information on styles and sizes.

Beanie Bears are also available for \$10 each
Lupus ends with US in white
Someone I Love has LUPUS in dark brown

SAVE THE DATE

Wednesday, November 18, 2009 General Education Meeting
6:45pm to 8:00pm at Rossetti Education Center
Madison-Oneida BOCES in Verona, NY
“Being Proactive in Your Health Care”
Informal Chat & Support Session
Open to the Public
Reservations Required to 315-829-4272

Wednesday, April 28, 2010 Lupus Awareness & Advocacy Day in Albany

May is Lupus Awareness Month

Saturday, May 15, 2010 6th Annual Lupus Education Symposium

Friday, August 13, 2010 10th Annual Lupus Charity Golf Classic

The Lupus Foundation of Mid & Northern NY, Inc.
is proud to be a member of the



- ◆ National Coalition of Autoimmune Patient Groups
- ◆ Lupus Research Institute National Coalition
- ◆ NIAMS Coalition
- ◆ Lupus Agencies of New York State
- ◆ NIAMS Lupus Federal Working Group

LUPUS RESEARCH INSTITUTE

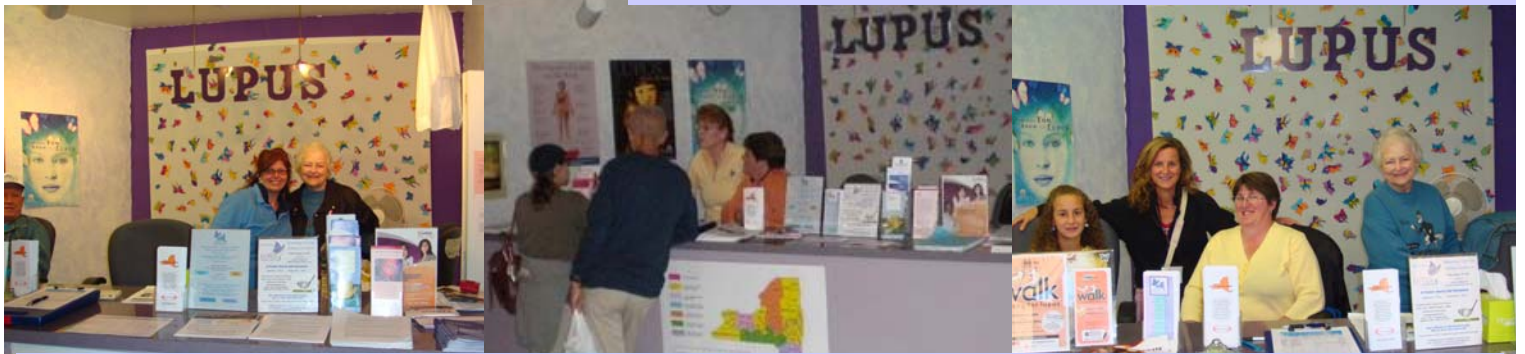
*National
Coalition*

The Patient Voice for Lupus Research

LUPUS AWARENESS AT THE 2009 NEW YORK STATE FAIR



Volunteers manning the Lupus Agencies of NYS Booth— Tom & Jackie Taylor, Dale & Maryrose Bullock & Angela Bouchard (left photo); Dave Arntsen & Jackie Taylor (above center).



Volunteers Lisabeth Iglesias & Patricia Mitchell (above left); Kathleen Arntsen & Jackie Taylor (center); Valerie & Stephanie Darwak, Jackie Taylor & Patricia Mitchell (above right) providing information and lupus awareness to fairgoers. It was the 20th year The Lupus Agencies of NYS had an exhibit display at the fair.



Volunteers Jackie Taylor, Keith & Judy Routson, Patricia & James Mitchell at the LANYS Exhibit on Senior Citizen Day. Thank you to all of our volunteers especially Mari-Kristine & Jeff Neyhart for setting up the booth and coordinating volunteers for the 12 days of the fair. The exhibit is in the Science & Industry Building at the NYS Fair in Syracuse and runs from the end of August through Labor Day each year.

For more information and additional photos on the Lupus Agencies of NYS Booth, or to volunteer for next year please visit our website www.nolupus.org