



*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 7, No. 1, Autumn/Winter 2008

## Arntsen Receives National ACR Advocacy Award



Pictured Above: Karen Kerr, President of the Association of Rheumatology Health Professionals presenting Lupus Foundation of Mid and Northern New York President/CEO Kathleen Arntsen with the Ann Kunkel Advocacy Award on November 7, 2007 at the Opening session of the American College of Rheumatology's Annual Scientific Meeting in Boston. Arntsen is the first recipient of the award that recognizes an ARHP Member who has provided extraordinary service in advocating for patients with arthritis and related diseases on the local, state, and national levels. All nominated health professional candidates were assessed on sustained advocacy work for patients and/or health professionals in rheumatology and the breadth and impact of their advocacy efforts. Kathleen was nominated by fellow colleagues Sandi Frear, Lupus Foundation of Mid & NNY Secretary, and Peggy Dowd, Lupus Research Institute President/CEO. She is well known for her commitment to improving the health care system and her tremendous dedication to those suffering from autoimmune diseases. All of us here at the Lupus Foundation of Mid and Northern New York congratulate Kathleen on her achievements and thank her for her ongoing passion for this cause.

# *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

National Advocacy Award .....	1
Newsletter Information .....	2
Campaigns .....	3
President's Message .....	4
Upcoming Events .....	5
Fundraising for a Loved One.....	6
Memorials, Tributes & Donations .....	7
ACR & Clinical Trials Photos .....	8 & 9
8th Annual Golf Classic .....	10
Loop for Lupus Bike Run .....	11
Announcements .....	12
Victorian Tea Party .....	13
Clinical Trial Info .....	14
Membership Form .....	15
Education Symposium .....	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*  
**Sarah I. Eastup**

*Treasurer*  
**Helen J. Lenart**

*Secretary*  
**Sandra M. Frear**

*Chairman of the Board*  
**Philip A. Teague**

### *Members*

**David L. Arntsen**

**Stephanie C. Darwak**

**Ellen C. Gloo**

**James E. Mitchell, Jr.**

*Honorary Board Member*  
**Rosemary Franklin**

*Honorary  
Medical Advisory Board*

**Beth Biggee, MD**  
*Rheumatologist*

**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*



*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 empty pages of the blue exam book stare back at me and no matter how hard I concentrate my mind draws a blank. Freezing, I am drenched to the bone with sweat, and my entire body shakes. Something pleasantly familiar and warm presses against my cheek and a small feline chortle awakens me. I roll over in bed, pull myself painfully to a sitting position and gather my cat into my wet, trembling arms. As I soothe him with cooing “mommy” noises I try to calm myself as well. It is another episode of fever with night sweats and nightmare in which I never graduated from college because I did not finish my final exams. It is decades later and I must return to college and retake the tests in order to get my degree. I have this bad dream at least twice a month so I am sure it has psychological significance—something Vonnegutian, but it escapes me. As I come downstairs into the sunlit kitchen to feed the cats I realize it is Valentine’s Day, a day of significance for us. My husband proposed to me on this day 19 years ago with a heart-shaped diamond and the promise of a long and fulfilling life together. He knew then that I had lupus and yet still decided to take the plunge. He has been a blessing and strength during the rough times in my journey with lupus and is definitely a “keeper.” This day is also the anniversary of the new off-label treatment I was given in 2001 during a bad lupus flare. I would never have thought that 7 years later it would still not be FDA-approved for treating lupus. I take my temperature and vital signs, recording them into a journal for my nephrologist, and realize with the fever, aches, and frigid weather we will not be celebrating out tonight at our favorite Italian restaurant. I phone David at work and he improvises; he is accustomed to plans changing and punts well. He brings take out, chocolates, and roses, and we exchange cards and gifts and settle in to watch television while the golden glow of the fireplace envelopes the room.

We have a selection of shows to choose from in the current prime time line up: *Lipstick Jungle*, *Cashmere Mafia*, *Big Shots*, or *Desperate Housewives* where every major character is glamorous, beautiful, and a size 4 or less. They drive luxury vehicles, sport designer everything, belong to exclusive country clubs, and attend posh benefits weekly. Watching them is an escape from Reality. On the other hand, we can watch *Celebrity Apprentice* or *Amazing Race* and see mean, conniving people trying to get the best of each other doing tasks in a NY boardroom or racing around the world. Even the medical shows are unrealistic. In both *Grey's Anatomy* and *House* residents personally escort patients and oversee each medical test themselves. I was hospitalized recently and could not even get a dietician to see me about meal options, much less a resident to conduct my procedures, instead I got a 20-something Goth guy with bright purple/fuchsia hair and multiple facial body piercings bringing me a standard menu. Moreover, I would definitely have to be revived if I ever had a doctor who looked like McDreamy or McSteamy come near me with a stethoscope.

Why can't we have true Reality TV shows that feature everyday people living and dealing with chronic illness? How about a series filled with us doing our normal routines? Standing-order lab draws, uncooperative veins, adhesions, special IV teams, 24-hour urines, x-rays, INR's, dye reactions, central lines, rx refills, cracked catheters, infiltrated IV's, who's on call after hours, technicians who know you by name, and waiting, waiting, waiting in: dialysis centers, clinics, physicians' offices, labs, diagnostic centers, and hospitals or waiting, waiting, waiting for: prior authorizations, test results & treatment options, health professionals to call you back, treatments to work, mail order refills to come, better lupus therapies, and health care solutions. We are called patients for a reason—Patience. Reality is hospitalization can be the gift that keeps on giving. After leaving the hospital recently I developed a UTI and kidney infection from the foley catheter and now after 14 days of an antibiotic it looks like I may have c-diff colitis. Did I mention having a sense of humor helps tremendously with chronic disease?

I can appreciate an escape from Reality and enjoy looking at beautiful, vogue people on occasion. After all, there are pictures of me in this newsletter attending some pretty suave events (I clean up well). However, my Reality is that I spend the majority of my life in jeans, sweats, and pajamas with no makeup but sunscreen and my hair in a braid. When I visit legislators on Capitol Hill they often remark that I look pretty good, considering. I should have had a picture taken of me during my recent hospital stay for future reference. I was a sight—oversized hospital gown with a telemetry unit in the front pocket, huge blue hospital-issued robe, i-pod & ear buds, compression knee-highs, pink ballet slippers, chapped lips, dry flaky, butterfly-rashed skin, carrying a urine bag and dragging an IV infusion unit. Lovely image, eh?

Humor aside though, my recent hospitalization brought home the Realization that after 15 years of fighting to improve our complicated health care system we are not gaining much ground. Insurance and institution formularies can dictate changes in your treatments even if you are stable on a present regimen. I am fortunate because I am a tenacious and knowledgeable advocate and know my rights. But what about the elderly, uneducated, low-income, and comatose patients; who fights for them? As our society grows older, our priorities and focuses shift and responsibilities increase.

Many of us are part of the "Sandwich Generation" taking care of elderly parents, children, grandchildren, as well as our own health care needs. I have been advocating to empower those affected by lupus to maintain their own health records for over a decade now. I have an excel spreadsheet with 25 years of lab results recorded, and a personal health record on my computer that can be easily updated in word format. The files are also saved on a usb-flash drive, my pda, and in a notebook to be shared with any medical professional treating me. Although most of us have increased our productivity and organization with better technology there has also been a negative impact on basic communication skills. Unfortunately, the Reality is that we have become disconnected from each other. Technology and automation have promoted a society fulfilled by pushing telephone keypads, mouse clicks, onscreen taps, and drive-thru orders. Etiquette and courtesy are lacking today both online and via telephone. This is even present in the non-profit community among fellow advocacy groups; a place where one would think that graciousness and good manners would abound. We receive daily e-mail messages here asking for information, resources, contacts, materials, and assistance and yet, when we respond we rarely receive a message back thanking us. Two simple words that do not even need to be capitalized can make a big difference.

The Reality here at the Lupus Foundation of Mid and Northern New York is that although we are all volunteers and providing services to you while attired in our casual wear, we try to maintain professionalism and courtesy at all times. We promise to get back to you within 48 business hours and to follow through on your requests as soon as is reasonably possible. We are asking you to join us, trust us, help us, and support us. Thank you for your support and graciousness, it is appreciated.

*Stay Warm and Be Well—Kathleen*

## **SAVE THE DATES**

**Sunday, March 2, 2008 Lupus Carousel Mall Walk**  
**Wednesday, March 5, 2008 LRI Coalition Advocacy Day**  
**Tuesday, April 1, 2008 Victorian Tea Party**  
**Saturday, May 3, 2008 4th Annual Lupus Education Symposium**  
**Sunday, June 29, 2008 2nd Annual Loop for Lupus Poker Run**  
**Friday, August 15, 2008 8th Annual Lupus Charity Golf Classic**  
**Thursday, August 21—September 1, 2008 Lupus Agencies of NY Exhibit Booth at NY State Fair**

### **First Annual Mall Walk**

Our friends at The Lupus Alliance of America, Upstate New York Affiliate are holding their first annual mall walk on Sunday, March 2, 2008 at the Carousel Center in Syracuse, NY.

Registration is 8:30 AM and the walk begins at 9:30 AM. Minimum donation is \$20 for adults, \$5 for children 5-12, and children under 5 are free.

Call the Lupus Alliance of America Upstate New York Affiliate at 1-800-300-4198 for more information.



Find a clinical trial.  
Talk to your doctor.  
Get involved.

**LUPUS**  
Together  
FOR CLINICAL TRIALS TODAY

Visit [LupusTrials.org](http://LupusTrials.org) »

# FUNDRAISING TO MAKE A DIFFERENCE



All fundraising events no matter how large or small make a difference to those affected by lupus.

Below Melissa Wallis and family Luanne Fry, Rachell Rickits, and Joanne Wallis (not pictured) setting up a fundraiser on August 18, 2007 at Oneonta WalMart in loving memory of her aunt Amy Bryant Mowers who passed away in 2006. Melissa raised \$634 with WalMart's matching donation.

Pictured above Volunteer Maryrose Bullock presents Fundraising Chair Sandi Frear with a donation in the amount of \$387 from a Pampered Chef Party, Beta Sigma Phi Sorority event, community jugs, and a fundraiser at Laurens School that Patrick Bullock held in honor of his mother.



Pictured below are Barry Ravitz, Kathleen & David Arntsen, Annie, Robert, Francine, and John Ravitz at the December SLE Lupus Foundation "Life Without Lupus Gala" at the Marriott Marquis in New York City. Over 3.2 Million Dollars was raised to support lupus research.



LUPUS RESEARCH INSTITUTE  
*National  
Coalition*  
The Patient Voice for Lupus Research



# *Memorials, Tributes, and Donations*

## Memorials

*In Loving Memory of...*

*Janet F. Grimm-  
Charles Grimm*

*James E. Mitchell-  
Jill Smith*

*Mary Alice Mitchell-  
Jill Smith*

*Brooke Nicole Walseman-  
Jack & Marcia Flint & Family  
Mrs. Doris Walseman*

*Bonnie Martin-  
Kay Falcone*

*Richard C. Rogers-  
Peter Rogers*

## Donations

*Ellie Canell*

*Mike & Fran Eck*

*Bruce & Nancy Griesmer*

*William & Julia Mitchell*

*James & Patricia Mitchell*

*Geraldine Conniff*

*Julia Lauber*

*Linda Joynt*

*Barbara Denslow*

*Marion Edick*

*John & Joan Carmody*

*Don & Sharon Lust*

*Donna Gloo*

*Victoria Jupin*

*Anna Maria Maritato*

*Joan Lutz*

*Pfizer Foundation*

*General Electric Foundation*

*Aetna Foundation*

*CFC, SEFA, United Way, IBM and  
Employee Donor Plans*

## Tributes

*In Loving Honor of...*

*James & Patricia Mitchell's  
50th Anniversary-  
Dick & Helen Lenart,  
Bill & Sandi Frear*

*Rocco & Monica Falitico-  
Virginia Merola*

*Helen Lenart-  
Chester & Jane Trzepacz*

*Amy Bryant Mowers-  
Melissa Wallis & Family*

*Kelly Bunce-  
Sharon Combs*

*Sheila Watts-  
Diane Craig*

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

*David & Kathleen Arntsen for Christmas-  
Marian J. Arntsen, Linda Arntsen,  
Lois & Dan Rumfelt*

*Lois & Dan Rumfelt, Linda Arntsen,  
Don & Sue Arntsen, Jim & Marion Mitchell  
& Family, Dan & Lisa Mitchell,  
Tim & Deb Mitchell, James & Patricia  
Mitchell for Christmas-  
David & Kathleen Arntsen*

*Maryrose Bullock-  
Laurens Central School Key Club,  
Beta Sigma Phi Alpha Iota Chapter,  
Pampered Chef, JP's Restaurant,  
La Tarantella Trattoria*

*Birdies for Charity PGA Event-  
Dr. Donald Raddatz Bill & Sandi Frear,  
David & Kathleen Arntsen, Dan Dischiavio,  
James & Patricia Mitchell*

*Cathy Walseman-  
Glenfield Elementary School Staff  
Beta Sigma Phi Sorority*

# AN AUTUMN TO REMEMBER



R  
E  
S  
E  
A  
R  
C  
H



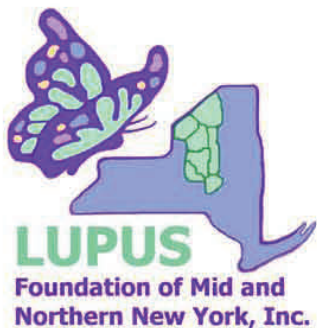
A  
D  
V  
O  
C  
A  
C  
Y

Clockwise from top left LFMNNY Officers Sandi Frear & Kathleen Arntsen present our Annual Research Donation for \$21,000 to Lupus Research Institute Co-Chairs Robert Ravitz (left) & Jack Lavery (right). Our overall research funding since 1990 now totals \$136,000 with \$84,500 going to the LRI in the past 6 years. Top right President Arntsen with FDA Director Dr. Janet Woodcock at the September LRI Scientific Meeting in NYC. Arntsen with LFMNNY Medical Advisory Board Member Dr. Donald Raddatz at the ACR Scientific Meeting in Boston. Ann Kunkel Advocacy Award recipients Kathleen Arntsen & Amy Leong following the ACR Awards Presentation at the Annual Scientific Meeting. Arntsen by her Biography display with fellow advocate and nominator Sandi Frear at the Boston Convention Center. Frear with Dr. John Harley from the Oklahoma Medical Research Foundation.

# LUPUS CLINICAL TRIALS ROAD SHOW



During October Advocates Kathleen Arntsen & Sandi Frear traveled to the west coast and presented the Clinical Trials Campaign they developed on the importance of research trials in discovering new lupus therapies to attendees at 5 education programs. Clockwise top left are LFMNNY President Arntsen (left) and Secretary Frear (right) presenting Dr. Deirdre Gillespie, CEO (center) of La Jolla Pharmaceutical Co. with our Annual Corporate Sponsor Award. Top right Arntsen & Frear with Lupus Foundation of Southern California Staff & Volunteers. Our friends at La Jolla Pharmaceutical Co. with Arntsen following her presentation to LJPC Staff Members. Arntsen signing a waiver for lupus documentary director Charysse Tia Harper (left) while Lupus Foundation of Southern CA Executive Director Hollaine Hopkins (center) looks on. Lupus Foundation of N CA Presenters Kathleen Arntsen & Dr. Melissa McNamara. Presenter Arntsen with Lupus Foundation of Colorado Executive Director Skip Schlenk. Arntsen being introduced by Lupus Foundation of Northern CA Executive Director Jo Dewhirst at the LFNC Fall Seminar.



**EIGHTH ANNUAL  
LUPUS CHARITY GOLF CLASSIC**  
**AUGUST 15, 2008**  
**Shenendoah Golf Club**  
**Turning Stone Resort Casino**



**SPONSORSHIP FORM**

Corp. Name: \_\_\_\_\_

Attention: \_\_\_\_\_

Address: \_\_\_\_\_

City/ State/ Zip: \_\_\_\_\_

Phone: \_\_\_\_\_ E-mail: \_\_\_\_\_

- \$5,000 EVENT Sponsor** – Complimentary Foursome, logo display on event & tee gift, dinner tables, carts, banner display, tee sign, program listing, dinner recognition
- \$3,500 DINNER Sponsor** – Complimentary Foursome, logo display on dinner tables, banner display, tee sign, program listing, dinner recognition
- \$2,000 LUNCHEON Sponsor** – Complimentary Foursome, logo display on luncheon counter, banner display, tee sign, program listing, dinner recognition
- \$1,500 CART Sponsor** – Complimentary Foursome, logo display on carts, banner display, tee sign, program listing, dinner recognition
- \$1,000 PLATINUM Sponsor** – Complimentary Foursome, banner display, tee sign, program listing, dinner recognition
- \$500 GOLD Sponsor**    **\$250 SILVER Sponsor**    **\$100 BRONZE Sponsor**  
Tee sign, program listing
- Other Donation** – Please list \_\_\_\_\_

\*All foursomes include 18 holes of golf w/cart, box lunch, and dinner for four

For additional information call: 315-829-4272 or 1-866-2-LUPUS-4 or E-mail [lupusmidny@aol.com](mailto:lupusmidny@aol.com)

Please make checks payable to:     ***The Lupus Foundation***  
   ***P.O. Box 139***  
   ***Utica, NY 13503***

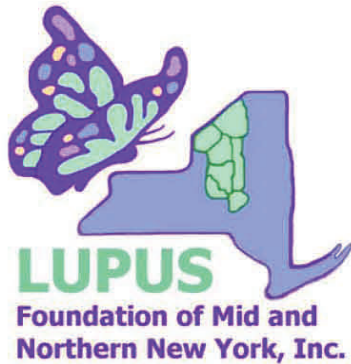
**Thank You!**

# Loop for Lupus

Poker Run and **OUTBACK** STEAKHOUSE® Bar-B-Q

*All Vehicles Welcome*

Sponsored by  
the **Red Knights MC**  
NY Chapter XIX

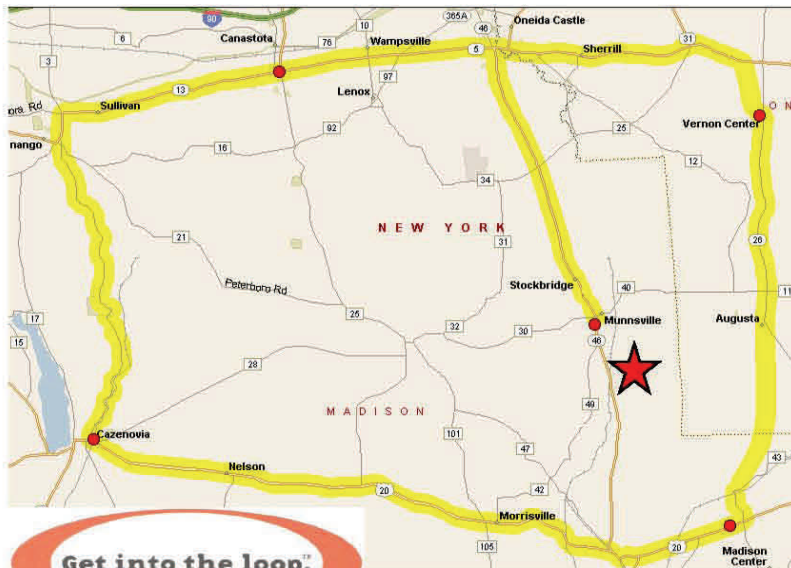


to benefit the

**Lupus Foundation of  
Mid and Northern NY**

**Sunday - June 29, 2008**

Registration 10:00am -12:00 noon  
Munnsville Fire Department Rt. 46, Munnsville, NY



Get into the loop.™

Learn About Lupus

Entry Fee

**\$25 per Motorcycle**



Bar-B-Q  
2:00-4:00

**Families Welcome !**  
**\$10 per additional guest**  
(children under 7 free)

PRIZES  
50/50 RAFFLE  
SILENT AUCTION  
MUSIC

For More Information  
315-336-4117  
315-829-4272  
[www.nolupus.org](http://www.nolupus.org)



## November Education Meeting

Dr. John Cai, Slocum Dickson Medical Group Cardiologist spoke on *Lupus and Heart Disease* at our Autumn General Education Meeting on November 13, 2007. Pictured are Education Co-Chair Helen Lenart, Dr. Cai, and Board Chair Philip Teague.

**What if my favorite charity had a penny for every time I searched the Internet...  
Now it can!**



Search the web with [www.goodsearch.com](http://www.goodsearch.com) and money from our advertisers will go to your favorite charity without you spending a dime!

## Support Group Information

**Utica Area      Facilitator-Helen Lenart**

**[lupusmidny@aol.com](mailto:lupusmidny@aol.com)**

The Utica Area Support Group usually meets monthly on the third Thursday at Faxton-St. Luke's Healthcare Regional Cancer Center in Utica in Weaver Lounge, 2<sup>nd</sup> floor. Please park in the Newell St. parking lot and enter through the Cancer Center main door. The next meeting will be at 7:00pm on February 21, 2008. Please contact the office for more information.

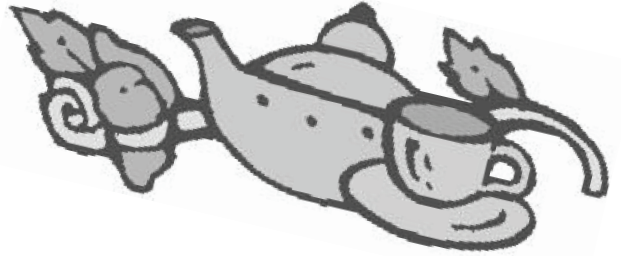
## Butterfly of Hope Tribute Plate



***Honor a volunteer, speaker, or loved one by purchasing a Lupus Butterfly of Hope Plate from Angel Pix for \$35 and we receive 20% back as a \$7 donation for lupus research. The \$35 includes plate, stand, tribute on back, and priority shipping. If interested please e-mail [lupusmidny@aol.com](mailto:lupusmidny@aol.com) or call us at 315-829-4272.***

# An Invitation to Celebrate Spring and Support Lupus

**WHAT:** Tea Party  
**WHERE:** Your Home  
**WHEN:** April 1, 2008



## Recipe for a successful tea party:

1. *Dust off the stove*
2. *Find the teapot (if you can't find the teapot, a mug will do)*
3. *Cookies Optional*
4. *Take the phone off the hook*
5. *Kick off your shoes*
6. *Play your favorite music*
7. *Write out your check*

Please consider supporting the Lupus Foundation of Mid and Northern New York, Inc. on April Fool's Day by participating in our Tea Party. Proceeds from this non-event will be used to fund our Organization's Program Services:

Newsletter Printing & Postage  
Lupus Awareness, Advocacy, and Education Programs  
Continued Training to update our leaders on lupus information  
Distribution of lupus materials for health fairs and inquirer packets  
Telephone Hotline and Website

*Please make checks payable to:*

***Lupus Foundation***

***PO Box 139***

***Utica, New York 13503***



***Thank you for your Consideration and Support!!!***

*The 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. For more information on our event please contact us by phone at 315-829-4272 or e-mail [lupusmidny@aol.com](mailto:lupusmidny@aol.com).*

# Clinical Trial Opportunities

## 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](http://www.ormf.org/?page=aboutlmrr)  
or call 1-888-OK-LUPUS

## Patient Registry SLE

Are you interested in learning about clinical studies and research treatments available to you? There is no cost to you and you get to decide what studies you want to participate in. All information is kept confidential!

For more information please call:  
**Emily Cushing at 585-275-7167**  
**Debbie Campbell at 585-275-1635**

## LUPUS NEPHRITIS

The **University of Rochester** is recruiting participants for a clinical research study on an **investigational** drug.

If you are 18 years of age or older and have been diagnosed with **LUPUS NEPHRITIS** you may qualify.

If you qualify you will receive study drug, medical exams and modest compensation for your time and travel.

For more information please call:  
**Emily Cushing at (585) 275-7167**



Approximately 1.5 million Americans have lupus, a disease that occurs three times more often in African Americans when compared to the Caucasian population. One of the most common complications of lupus is inflammation of the kidneys, or lupus nephritis. Lupus nephritis affects approximately one-third of men and women with lupus. **African Americans tend to develop lupus earlier in life and experience greater disease activity, such as kidney problems, than other patients.**

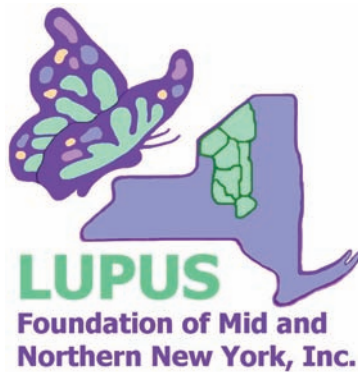
The LUNAR Study is seeking men and women between 16 and 75 with active lupus-related kidney disease. **Because lupus nephritis is most common among minorities, African Americans need treatment options. The LUNAR Study is part of our search for one.**

**To learn more about the study and if you may qualify, call toll free 1-888-68LUPUS or visit [www.lupusclinicalstudy.com](http://www.lupusclinicalstudy.com).**



# 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="width: 60%;"><input type="checkbox"/> LUPUS BOOK Revised by Daniel J. Wallace, MD</td> <td style="width: 40%; text-align: right;">\$ 24.00 plus \$4.00 S &amp; H</td> </tr> <tr> <td><input type="checkbox"/> COPING WITH LUPUS by Robert H. Phillips, PhD</td> <td style="text-align: right;">\$ 15.00 plus \$2.00 S &amp; H</td> </tr> <tr> <td><input type="checkbox"/> LUPUS WELLNESS JOURNAL</td> <td style="text-align: right;">\$ 8.00 plus \$2.00 S &amp; H</td> </tr> <tr> <td><input type="checkbox"/> THE AUTOIMMUNE EPIDEMIC by Donna Jackson Nakazawa</td> <td style="text-align: right;">\$ 20.00 plus \$4.00 S &amp; H</td> </tr> <tr> <td><input type="checkbox"/> AWARENESS WRISTBANDS <i>Orange or Purple</i></td> <td style="text-align: right;">\$ 1.00 plus .25 per 3 S &amp; H</td> </tr> <tr> <td><input type="checkbox"/> BEANIE BEARS</td> <td style="text-align: right;">\$ 10.00 plus \$2.00 S &amp; 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 \$2.00 S & H	<input type="checkbox"/> LUPUS WELLNESS JOURNAL	\$ 8.00 plus \$2.00 S & H	<input type="checkbox"/> THE AUTOIMMUNE EPIDEMIC by Donna Jackson Nakazawa	\$ 20.00 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 \$2.00 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 \$2.00 S & H																								
<input type="checkbox"/> LUPUS WELLNESS JOURNAL	\$ 8.00 plus \$2.00 S & H																								
<input type="checkbox"/> THE AUTOIMMUNE EPIDEMIC by Donna Jackson Nakazawa	\$ 20.00 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 \$2.00 S & H																								
<b>Up-to-date Lupus Foundation of America, Inc. Brochures      There is a \$.25 fee per brochure</b> <table style="width: 100%; border: none;"> <tr> <td style="width: 33%;">___ What is Lupus?</td> <td style="width: 33%;">___ Anti-Phospholipid Antibodies</td> <td style="width: 33%;">___ Lupus &amp; Vasculitis</td> </tr> <tr> <td>___ Kidney Disease &amp; Lupus</td> <td>___ Pregnancy &amp; Lupus</td> <td>___ Childhood Lupus</td> </tr> <tr> <td>___ Skin Disease</td> <td>___ Blood Disorders in SLE</td> <td>___ Lupus in Men</td> </tr> <tr> <td>___ Sjogren's Syndrome</td> <td>___ SLE &amp; The Nervous System</td> <td>___ Depression</td> </tr> <tr> <td>___ Medications</td> <td>___ Steroids Used in Treatment of Lupus</td> <td>___ Drug-Induced Lupus</td> </tr> <tr> <td>___ Lupus &amp; Infections</td> <td>___ Laboratory Tests Used in Diagnosis</td> <td>___ Basics for Better Living</td> </tr> <tr> <td>___ Cardiopulmonary Disease</td> <td>___ Non-Steroidal Anti-Inflammatory Drugs</td> <td>___ Photosensitivity</td> </tr> <tr> <td>___ Joint &amp; Muscle Pain</td> <td>___ Lupus in Overlap w/ Connective Tissue Disease</td> <td></td> </tr> </table> <p style="text-align: center; margin-top: 10px;"><b>Please remit total payment to: Lupus Foundation PO Box 139 Utica, NY 13503</b></p>		___ What is Lupus?	___ Anti-Phospholipid Antibodies	___ Lupus & Vasculitis	___ Kidney Disease & Lupus	___ Pregnancy & Lupus	___ Childhood Lupus	___ Skin Disease	___ Blood Disorders in SLE	___ Lupus in Men	___ Sjogren's Syndrome	___ SLE & The Nervous System	___ Depression	___ Medications	___ Steroids Used in Treatment of Lupus	___ Drug-Induced Lupus	___ Lupus & Infections	___ Laboratory Tests Used in Diagnosis	___ Basics for Better Living	___ Cardiopulmonary Disease	___ Non-Steroidal Anti-Inflammatory Drugs	___ Photosensitivity	___ Joint & Muscle Pain	___ Lupus in Overlap w/ Connective Tissue Disease	
___ What is Lupus?	___ Anti-Phospholipid Antibodies	___ Lupus & Vasculitis																							
___ Kidney Disease & Lupus	___ Pregnancy & Lupus	___ Childhood Lupus																							
___ Skin Disease	___ Blood Disorders in SLE	___ Lupus in Men																							
___ Sjogren's Syndrome	___ SLE & The Nervous System	___ Depression																							
___ Medications	___ Steroids Used in Treatment of Lupus	___ Drug-Induced Lupus																							
___ Lupus & Infections	___ Laboratory Tests Used in Diagnosis	___ Basics for Better Living																							
___ Cardiopulmonary Disease	___ Non-Steroidal Anti-Inflammatory Drugs	___ Photosensitivity																							
___ Joint & Muscle Pain	___ Lupus in Overlap w/ Connective Tissue Disease																								



**4th Annual Education Symposium & Luncheon**  
**“The Essence of Wellness”**

**Saturday, May 3, 2008**

**9:30am to 2:00pm**

**Rossetti Education Center at Madison-Oneida BOCES  
in Verona, NY (Exit 33 NYS Thruway)**

**Hand Waxing &  
Massages**

**Presenters include:  
Robert Phillips, PhD**

**Wellness Checks**

**Internationally Renowned Psychologist & Author  
from the Center for Coping  
*Coping with Chronic Illness: Bringing Wellness to Illness***

**Raquel Rosen, MD Bassett Healthcare Nephrologist  
*Empowering Patients***

**Kim Thompson, Certified Lifestyle Educator**

**Clinical Trial & RX  
Assistance Resources**

**Metagenics, Inc.  
*Nutrition and Well-Being***

**Neck Massages &  
Reflexology**

**Clinical Trial & Prescription Assistance Information  
Exhibit Booth Displays and Handouts**

**No cost to current members: \$20 fee to non-members  
limited to 150 attendees, registration required**

**For more information or to receive a registration form please  
call 315-829-4272 or e-mail [lupusmidny@aol.com](mailto:lupusmidny@aol.com)**

**Supported through unrestricted educational grants from**

