LUPUS
Foundation of Mid and Northern New York, Inc.

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 6, No. 2, Winter 2007*

A Record Breaking $20,000 Research Donation

Lupus Foundation of Mid and Northern New York donated their largest ever annual research grant to the Lupus Research Institute at their Annual Scientific Meeting on October 19, 2006 in support of their novel research program. This $20,000 research donation includes $5,200 from the Hannaford Research Initiative developed by member Danielle Turner and illustrates our commitment to support the best available lupus research. Pictured below is President/ CEO Kathleen Arntsen presenting the check to LRI Chairmen of the Board Jack Lavery (left) and Robert Ravitz (right). Thank you to Hannaford Supermarkets, Danielle Turner and all of our supporters who helped to make this outstanding contribution possible.

The Lupus Communiqué

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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

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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.

Community
Health Charities
of New York
WORKING FOR A HEALTHY AMERICA

CFC
Combined Federal Campaign

sefa
STATE
EMPLOYEES
Federated
Appeal

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 new website. Thank you.

Dave Arntsen

President's Message

Recently, I wrote an editorial entitled *Legacy of a Patient* as an emotional outlet in response to both my personal situation and the untimely death of yet another friend and lupus patient. My situation is not unique, it is a mirrored image of many patients living with lupus who take immune-compromising drugs across this nation. I hope that my sentiment is both shared and echoed by many of you and dedicate this editorial to all of you struggling with this devastating disease.

I am just a patient. I am just a patient who knows firsthand that we need new drugs to treat autoimmune diseases like lupus. I know this with every breath I presently struggle to take. I am an immune-compromised lupus patient. Right now, I have viral bronchitis, accompanied by a sinus and double ear infection. It is my umpteenth infection of this year and caused me to miss Thanksgiving as well as my niece's baptism. I have missed many holiday and family celebrations due to lupus over the years. Both the empty chair at the dinner table and my absence weigh heavily on my husband and parents' hearts. Lupus does not just affect individuals; it strikes the entire family.

I have suffered for three decades from lupus and a quarter of a century from the devastating side effects from the toxic treatments I have endured. I just returned from the American College of Rheumatology's Annual Scientific Conference all pumped up because the pharmaceutical industry is finally showing interest in developing new therapies for lupus. This is a topic I have been passionately vocal about for the past 8 years. While others have been discussing the need for a cure, I have been advocating for better treatments and diagnostic tests to improve the quality of life for our patients now. "We need new drugs for lupus," has become my mantra. Nevertheless, I am just a patient and until now no one has heard my cry.

There is one catch; we need to ensure enough patients are recruited for the clinical research trials so these treatments can become FDA-approved. This may seem like an insurmountable task to others, but to us patients we have to believe it can be done. After all, it is our only hope for safer and more effective treatments that do not ablate the entire immune system. This is the only chance we have and it is right here, right now, before industry loses interest in lupus.

I may be just a patient, but I have been a patient advocate and volunteer leader with our local lupus organization for 20 years now. People like me are down in the trenches with the patients who are battling lupus on a daily basis. We handle their phone calls, e-mail messages, support groups, and education meetings. We continuously interact with individuals affected by lupus and thus have our fingers on the 'lupus pulse.' Being so connected to patients, I also personally feel an obligation to give them hope for a brighter future. As an advocate I am honored to be their voice on public policy issues. They are a constant inspiration for me to continue in my advocacy efforts; their stories become my message. As long as there is breath in my body I will scream from the rooftop for these lupus warriors.

As I move through the stages of grief over the recent death of yet another lupus patient and friend, I reach frustration and anger. My discontent with lupus is channeled into action. I am compelled to write to anyone who will listen to me as a patient. I have been told by some that I am overzealous, too intense, and too passionate about this cause. This is not a job for me; I am not paid or punch a time clock and get to leave my work behind at the office. Lupus struck me down in the prime of my life; I lost my career, my dreams, and my aspirations to lupus years ago. I will never be a mother or a grandmother. This has become my calling; my family and I have accepted that this is where I am supposed to be. This is my legacy; the legacy of a patient.

Thus, here is my call to action to all in the lupus community. I passionately implore every lupus agency, researcher, patient advocacy group, research entity, clinician, health professional, government official, pharmaceutical representative, and individuals affected by lupus and their loved ones to embrace the opportunity before us now to get new drugs for lupus. We must work collectively to recruit patients for the upcoming trials. In order for these efforts to be successful we must come together and stand united. Like a snowball hurling down a mountainside, gaining momentum with each revolution; this has the potential to be powerful enough to finally give our patients a better quality of life and brighter future. After all, isn't that what all of us want anyways? Lupus ends with Us.

Be well and stay warm —Kathleen

A Tribute to A Friend

All of us here at the Lupus Foundation of Mid and Northern New York are deeply saddened by the recent death of Board Chairman Michael P. Jones. Michael lost his courageous battle with cancer on October 16, 2006. Michael was a very hard worker and good friend to many of us here and his absence has left a void in countless lives. His Mom Elizabeth Jones and his sister Kathleen Cieslak were charter members of our organization and both served as officers as well as played critical roles in its development in the 1980's. Both women suffered from lupus and predeceased Michael.

Michael Jones became a Board Member in 1993 and remained on the Board until his death as an active volunteer. He developed our first electronic database, donated our first computer, and worked on the Utica Professional Firefighters Association Local 32 Charity Golf Tournament Committee for 5 years. Michael served as Treasurer of The Lupus Foundation for one term of 3 years and then became Chairman of the Board for the past 5 years. He did all of the Business Mailings for 6 years and picked up the mail and processed it with President Arntsen weekly. He attended several statewide lupus meetings as a representative of the organization so that he would be better able to understand the big picture of the lupus community. He received the Volunteer of the Year Award in 1996 and the JC Penney Golden Rule Volunteer Group Award in 1998 along with the entire Board of Directors.

Michael helped us develop The Lupus Charity Golf Classic in 2001 and was extremely proud of our achievements in the past 6 years with the event. He even named his foursome "Team Kathy C" after his sister. His team placed 4th in 2005 and he won Closest to the Pin Seniors the same year. He always sold 50 or more raffle tickets for the event, collected door prizes, and recruited golfers. He even managed to sell his 50 tickets this summer with all he was going through. He was missed by many this year at the tournament. Michael has been a voice of reason and common sense on our Board and we knew that we could count on him to do any task he was asked to perform. He always had a smile on his face and a gleam in his eyes along with a bit of wit. Most of all Michael will be remembered for his heart of gold both as a friend and a dedicated volunteer.

DRUG RESOURCES

DRUG INFORMATION

Internet Drug Index
www.rxlist.com/

Kidney Disease drug information
www.kidneydrugcoverage.org

Drug Finder
http://gsm.about.com/compact/monograph.asp

INFORMATION FOR PATIENTS TAKING ORAL ANTICOAGULANTS

Warfarin Institute of America (coumadin)
www.warfarinfo.com/default.htm

The Anticoagulation Forum is a network of healthcare professionals who promote professional development and the enhancement of the quality of anticoagulation care.
www.Acforum.com

DRUG ASSISTANCE PROGRAMS

Needy Meds helps patients find specific programs to fit their needs
www.Needymeds.com

Partnership for Prescription Assistance brings together America's pharmaceutical companies, doctors, other health care providers, patient advocacy organizations and community groups to help qualifying patients who lack prescription coverage get the medicines they need through the public or private program that's right for them. Many will get them free or nearly free. 1-888-4PPA-NOW
www.pparx.org

Together RX has A FREE prescription-savings card for eligible residents of the United States and Puerto Rico who have no prescription drug coverage. A public service program created and sponsored by a group of some of the world's largest pharmaceutical companies. 1-800-444-4106
www.TogetherRxAccess.com

A co-pay relief program (cpr) provides co-payment assistance to insured Americans who financially and medically qualify. 1-866-512-3861 www.copays.org

RxAssist offers a comprehensive database of these patient assistance programs, as well as practical tools, news, and articles so that health care professionals and patients can find the information they need. www.rxassist.org

Programs that assist with medication **co-pays**
www.rxassist.org/patients/res-co-pays.cfm

RxHope is the only patient assistance Internet initiative financially supported by PhRMA (Pharmaceutical and Research Manufacturers of America) and participating pharmaceutical companies. www.rxhope.com

(DRUG RESOURCES cont'd)

NeedyMeds provides information for people who need help with the cost of medicine and other healthcare expenses. www.needymeds.com

AARP State-by-State, Plan-by-Plan List of Pharmacy Assistance Programs

CORPORATE ASSISTANCE PROGRAMS

The **Abbott** Patient Assistance Program (PAP) provides Abbott medications, at no cost, to patients in financial need. Abbott Patient Assistance Program

Provides information about **AstraZeneca**'s assistance programs.
AstraZeneca Patient Assistance Program
.
GlaxoSmithKline's patient assistance program for non-oncology medicines, provides GSK prescription medicines to eligible low-income patients without prescription drug benefits.
Bridge to Access

Eli Lilly and Company index of all company programs to assist patients with prescription drug costs.
Lilly Direct Patient Assistance Programs

Merck & Company provides its medicines and adult vaccines for free or at discounts to people who do not have prescription drug or health insurance coverage and who, without our assistance, cannot afford their Merck medicine and vaccines.
MerckHelps

Novartis Pharmaceuticals Corporation's Patient Assistance Program (PAP) provides assistance to patients experiencing financial hardship who have no third party insurance coverage for their medicines.
Novartis Patient Assistance Program

Ortho-McNeil provides assistance to patients who, because of financial burden and lack of prescription drug coverage, may have difficulty paying for their treatment.
Ortho-McNeil, Inc. Patient Assistance Program

An index of patient assistance programs offered by **Pfizer, Inc.**
Pfizer Patient Assistance

Roche program providing company drugs, free, to patients who lack prescription coverage and the means to pay for the medications they need.
Roche U.S. Pharmaceuticals Assistance Program

Schering-Plough assists patients in securing drug reimbursement as well as providing lifesaving drugs at no cost to people with low incomes through our patient assistance programs.
Schering-Plough Patient Assistance Programs

NNY Autumn Education Seminar & Luncheon

Clockwise from top left—LFMNNY President Kathleen Arntsen and Rick Deyulio from PPA; Arthritis Foundation, Upstate NY Chapter, Program Director Genoa Wilson; PPA Exhibit; NNY Program Attendees; Volunteers Wendy Cianfrocco & Amanda Nemcek at the Lupus Display. Thank you to our organizers, our volunteers, and especially our supporters Pfizer Helpful Answers and Partnership for Prescription Assistance.

Lupus Advocacy in Action

Connected by a Cause—Mary Rose Bullock (right) presents a donation check to Secretary Sandi Frear (left) after raising $101 from a Pampered Chef and Beta Sigma Phi Sorority Alpha Chapter Fundraiser in October. Kudos to Mary Rose for her support. Below middle row Board Members Stephanie Darwak, Kathleen Arntsen, & Sandi Frear attend a Health Disparities Conference in Groton, CT at Pfizer Inc.'s Research Facility. Bottom row (left) LRI Development Director Andrea O'Neill and Kathleen Arntsen manning the LRI Exhibit at the ACR's Scientific Conference in November in Washington, DC. (Bottom right) Sandi Frear and Kathleen Arntsen at a Genentech Advocacy Reception at the ACR Meeting.

Memorials, Tributes, and Donations

Memorials

In Loving Memory of…

Michael P. Jones-
James & Patricia Mitchell,
David & Kathleen Arntsen,
Larry & Kathy Scharf,
Gladys Hill,
Philip & Kathleen Teague,
Bill & Sandi Frear,
Ellen Gloo,
Sarah Eastup & Family,
Dick & Helen Lenart,
Jim & Leslie VanWormer,
Stanley & Helen Cieslak,
Domenic Tarnelli,
Steven & Renee Fluty

Kathleen Cieslak-
Stanley & Helen Cieslak

Jim & Mary Alice Mitchell-
Jane Williams

Brooke N. Walseman-
Mrs. Doris Walseman

Heide Bielby-
Robert E. Bielby

Dominick "Pete" Manfredo-
Dominick & Marie Oriolo,
Dan Lo Conti & Thelma Roy

Ida DeGiglio-
Dan Lo Conti & Thelma Roy

Norma Benedetto-
Toni Lo Conti

Alma Oriolo-
Dominick & Marie Oriolo

George Cooker-
Dominick & Marie Oriolo

Richard J. O'Hara-
BW Elliott Manufacturing Co.

Memorials

In Loving Memory of...

Barbara Porter-
Dick & Helen Lenart,
David & Kathleen Arntsen,
James & Patricia Mitchell,
Bill & Sandi Frear,
Lawrence & Erma Porter,
Lupus Alliance of America,
Long Island Queens Affiliate,
Scott & Beth Brewster,
US Psychiatric Rehabilitation Association,
Honi Kurzeja,
Shelley Sands,
Dick & Helen Cassin,
John Porter,
Ellen Gloo,
W. Endicott Ladies Auxiliary Unit 1700

Rose C. Palmeri,
Ronald J. Miller,
Joseph "Peppy" Messa,
Frank P. Puleo,
Genevieve "Salerno" Montana,
Gerald Dimitri Herbowy,
Michael J. Nassar,
George Jadhon,
Margaret Polito,
Elaine Carlo
Lawrence "Larry" Gazzilli,
Annette Marraffa,
Evelyn Sacco,
Marilyn Papandrea,
Rosalie Gargon,
Fred "Frank" Prechowicz,
Mary Jane Granata,
George S. La Nave Jr.,
Carmella "Millie" Pardie,
Dominick "Dick" Carlo,
Joan Farney,
Rosemarie Romano,
Flora Elacqua-
Dan Lo Conti

Memorials, Tributes, and Donations

Tributes

In Honor of…

Danielle Turner-
Hannaford Lupus Initiative

Rocco & Monica Falitico-
Virginia Merola

Patricia Mitchell's 70th Birthday-
David & Kathleen Arntsen

James E. Mitchell Jr.'s Birthday-
David & Kathleen Arntsen

James & Marion Mitchell,
Timothy & Deborah Mitchell, and
Daniel & Lisa Mitchell for Christmas-
David & Kathleen Arntsen

Dan & Lois Rumfelt,
Donald & Susan Arntsen,
and Linda Arntsen for Christmas-
David & Kathleen Arntsen

Donations

Thank you to…

Donald & Sharon Lust
Stephanie Darwak
Mary Rose Bullock-Pampered Chef
Frank & Mary Della Posta
Sam & Geri Tocco
Henry & Mary Ann LaRaia
Donna Gloo
BMI Products, Inc.

Mary Rose Bullock and
Beta Sigma Phi Sorority Alpha Iota Chapter

NNY Luncheon Education Meeting-
Partnership for Prescription Assistance,
PhRMA and Pfizer Helpful Answers

CFC, SEFA, United Way,
Merrill Lynch, Pfizer, and IBM Donors

Fall General Education Meeting

On November 7, 2006 the Fall General Education Meeting was held at Faxton-St. Luke's Healthcare in Utica, NY. Attorney John Kalil spoke on Social Security Disability. Mr. Kalil (left) is pictured here with Board Chairman Philip Teague (right).

SPRING GENERAL EDUCATION MEETING

Tuesday, March 20, 2007 at 7:00pm

Anderson Auditorium 2nd floor
Faxton-St. Luke's Healthcare
Regional Cancer Center
Newell St. in Utica, NY

Kim Bloomer, Registered Dietician
Nutrition in Autoimmune Diseases

Dave Schilling, Doctor of Physical Therapy
Management of Soft Tissue Conditions Through Physical Therapy

Refreshments will be served and reservations required by March 16, 2007 to 315-829-4272 or toll free 1-866-258-7874 or e-mail lupusmidny@aol.com

Support Group Information

Utica Area ***Facilitator-Helen Lenart*** **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, 2nd floor. The next meeting will be at 7:00pm on February 15, 2007.

LUPUS
RESEARCH INSTITUTE

LUPUS RESEARCH INSTITUTE
National
Coalition
The Patient Voice for Lupus Research

Lupus Foundation of Mid and Northern New York is proud to support the Lupus Research Institute and honored to be a member of the Lupus Research Institute National Coalition.

LUPUS FOUNDATION OF MID AND NORTHERN NEW YORK
MEMBERSHIP APPLICATION & ORDER FORM

Name:	Date:
Address:	Phone #:
City, State, Zip:	Work #:
E-mail address:	Fax #:

☐ Single ($10.00)
☐ Renewal
☐ Family ($15.00)
☐ New
☐ Professional ($25.00)
☐ Patron ($50.00)
☐ Courtesy

Other Donation (please list)

____

☐ Interested in Support Groups

☐ LUPUS BOOK Revised by Daniel J. Wallace, MD	*$ 20.00 plus $3.50 S & H*
☐ COPING WITH LUPUS by Robert H. Phillips, PhD	*$ 15.00 plus $2.00 S & H*
☐ LUPUS WELLNESS JOURNAL	*$ 8.00 plus $2.00 S & H*
☐ AWARENESS WRISTBANDS *Orange or Purple*	*$ 1.00 plus .25 per 3 S & H*
☐ BEANIE BEARS	*$ 10.00 plus $2.00 S & H*

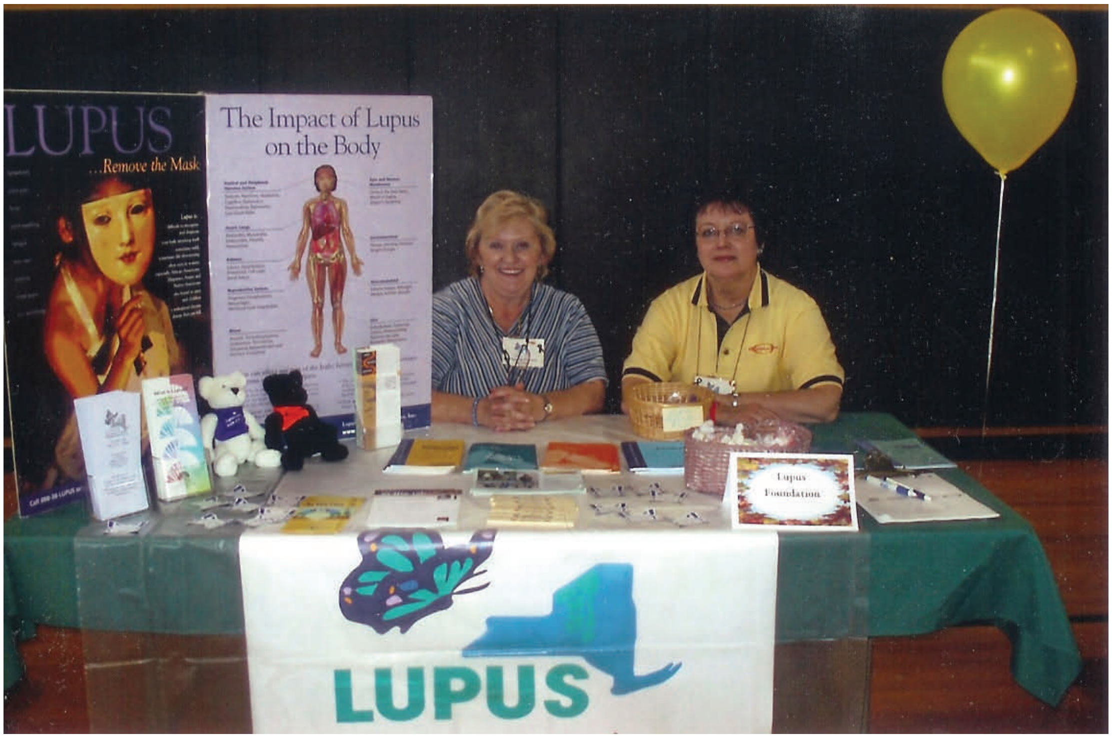
Up-to-date Lupus Foundation of America, Inc. Brochures **There is a $.25 fee per brochure**

___ What is Lupus?
___ Kidney Disease & Lupus
___ Skin Disease
___ Sjogren's Syndrome
___ Medications
___ Lupus & Infections
___ Cardiopulmonary Disease
___ Joint & Muscle Pain
___ Anti-Phospholipid Antibodies
___ Pregnancy & Lupus
___ Blood Disorders in SLE
___ SLE & The Nervous System
___ Steroids Used in Treatment of Lupus
___ Laboratory Tests Used in Diagnosis
___ Non-Steroidal Anti-Inflammatory Drugs
___ Lupus in Overlap w/ Connective Tissue Disease
___ Lupus & Vasculitis
___ Childhood Lupus
___ Lupus in Men
___ Depression
___ Drug-Induced Lupus
___ Basics for Better Living
___ Photosensitivity

Please remit total payment to: Lupus Foundation PO Box 139 Utica, NY 13503

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 and money from our advertisers will go to your favorite charity without you spending a dime!



Volunteers Marlene Faroni (left) and Vice President Helen Lenart (right) manning the Lupus Foundation of Mid and Northern New York display at the NY State DDSO Employee Awareness Day on November 16, 2006. Please let us know if your work-site or employer holds Health & Wellness Events or if you would like to volunteer to sit at our booth at an upcoming event.

Our Annual Membership Drive began on October 1st, 2006

Please renew your membership dues and urge others to partner with us in the lupus cause

Happy Valentine's Day

Let's hope spring comes early this year!

Clinical Trial Opportunities

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
or
Debbie Campbell at 585-275-1635

Research Study Available

If you are 18 years or older and have been diagnosed with **Lupus** you may qualify for a clinical research study on an **<u>Investigational</u>** drug for your condition. <u>If</u> you qualify you will receive free study drug and study-related medical care, and you may be reimbursed for travel expenses.

*Contact **Emily Cushing** at **<u>585-275-7167</u>***
For more information

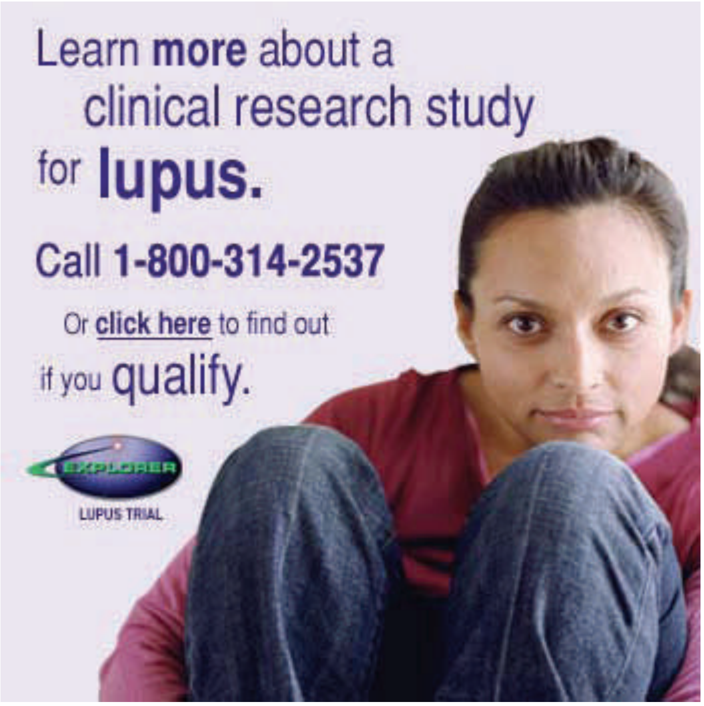
LUPUS NEPHRITIS

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

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

<u>If</u> 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



LUPUS
Foundation of Mid and Northern New York, Inc.

3rd Annual Education Symposium & Luncheon

“Promise, Progress and Opportunity”

Saturday, May 19th, 2007 from 9:30am to 3:00pm

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

Presenters include:
Betty Diamond, MD Columbia University Rheumatologist
Professor of Medicine & Microbiology
Lupus and the Nervous System
Beth Biggee, MD Bassett Healthcare Rheumatologist
Endocrine Conditions and Lupus
Thyroid, Osteoporosis, HRT, Diabetes, Pregnancy, Menopause
Rick Deyulio, Armstrong Communications
Prescription Assistance Programs
Kathleen Arntsen, Lupus Foundation of Mid & NNY
Clinical Trial Participation – What to Know

Clinical Trial Information, Exhibit Booth Displays and Handouts

$10 fee to current members; $25 fee to non-members
For more information or to receive a registration form
please call 315-829-4272 or e-mail lupusmidny@aol.com

Supported through unrestricted educational grants from

Pfizer

LAJOLLA
PHARMACEUTICAL COMPANY

Partnership for Prescription Assistance
NEW YORK