

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 9, No. 2, Autumn 2010

Record Breaking Annual Research Donation



Lupus Research Institute Chairmen Jack Lavery (left) and Robert Ravitz (right) receive our largest ever Research Donation of \$24,000 from Lupus Foundation of Mid and NNY President/CEO Kathleen Arntsen on October 18th at the LRI Annual Scientific Meeting at the New York Marriott Marquis. This amount represents 1/3 of our annual income for 2010. We have now donated \$151,500 to the LRI in the past 9 years in support of their peer-reviewed novel research. Our donation continues to illustrate our tremendous faith in the ongoing progress and success of The Lupus Research Institute and its scientists. The Lupus Foundation of Mid and Northern New York is honored to be a member of the Lupus Research Institute National Coalition representing the patient voice for lupus research. Lupus ends with Us!

The Lupus Communiqué

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

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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.

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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—

As the howling wind hurls snow against the windowpanes, we are awakened from our slumber by the cacophony of rattling glass. At sunrise the countryside is postcard perfect; transformed into a swirling landscape of confectioners' powdered drifts, crystallized cascades, and frosty glistening furrows. With the outside temperature plummeting to a single digit and the weatherman forecasting snowfall accumulation in feet instead of inches again, we settle in for yet another blizzard. The season has been harsh and relentless so far and doesn't seem to be dissipating. This evening I take refuge in the coziness of my easy chair while basking in the warm amber glow of the fireplace, pausing to reflect on recent accomplishments.

It was a record breaking year for us in membership, overall income, and our annual research donation to the Lupus Research Institute. Although the local economic forecast has remained bleak our supporters have remained loyal and generous far beyond our expectations. On a much broader scale it has been a remarkable year of progress for all in the lupus community. Promising drug development research is taking place that includes safer, more effective therapies in the pipeline. Meaningful partnerships between government agencies, patient advocacy & professional organizations, academia, the medical community, and the pharmaceutical industry have emerged. Bearing witness to these achievements has brought a sense of pride and fulfillment to those of us who work tirelessly for the lupus cause.

Winter symbolizes a period of rest and relaxation for many, as well as a season of self-contemplation, creativity, and collaboration. It is a time for studying, thinking, and planning—a time for completing previously discarded projects and preparing for future ones. Winter is our retreat following an extremely busy Autumn. Like spring flowers waiting to bloom, we emerge from this annual hibernation refreshed, refocused, and ready. In anticipation of a new season of warmth and rebirth, we are powered by determination and once again filled with tremendous hope for the future. Surviving winter here is much like enduring a season of Lupus. It is complex, unpredictable, relentless, and accompanied by good days and bad. In order to survive one requires patience, preparation, tenacity, resourcefulness, motivation, and a sense of humor. We are guided forward by optimism and the possibility that each new day brings us closer to a better tomorrow.

On October 18, 2010 the Lupus Research Institute released results from the organization's first scientific research impact report entitled, "A Decade of Impact in Lupus Research – Driving Discovery through Innovation." With its unconventional approach, the LRI has accelerated the pace of discovery and created a robust platform for scientific innovation that has grown the pool of investigators dedicated to lupus. Forty percent of LRI-funded researchers were brought to the field from other disciplines to work on lupus. The

LRI has also leveraged a \$22 million research investment into \$100 million in follow-on funding and, ultimately, is responsible for several of the most pivotal findings in lupus.

Eighty percent of LRI-funded investigators have published their discoveries in top peer-reviewed journals and/or obtained major follow-on funding, quickly leading to the filing or approval of seven patents for new biomarkers or therapeutic approaches as a result of LRI-funded research. Twenty percent of LRI grant holders already have embarked on pathways translating novel research to the clinic. The report outlines the organization's accomplishments in its first decade and represents an independent review of funded and completed projects to evaluate the success and impact of LRI's unorthodox and vigorous approach to lupus research and is available at www.lupusresearchinstitute.org/driving-discovery. We are proud to support the LRI and honored to be part of its national coalition.

On November 16, 2010 the FDA Arthritis Advisory Committee convened at the Marriott Inn & Conference Center at the University of Maryland in Adelphi, MD to discuss belimumab, proposed trade name BENLYSTA, sponsored by Human Genome Sciences for the proposed indication of reducing disease activity in adult patients with active, autoantibody-positive systemic lupus erythematosus (SLE). I had the privilege of being a voting member of this panel as a Special Government Employee and the first Lupus Patient Representative for the Office of Special Health Issues with the FDA. The panel recommended 13 to 2 for approval of the product with label revisions. The entire lupus community awaits The FDA decision which is expected on March 10, 2011. Experiencing the drug approval process from the other side of the table as a panel member was both exhilarating and exhausting at the same time. I am honored to be a voice for the lupus patient and look forward to participating in future FDA Advisory Meetings.

We are extremely grateful for the accomplishments of the past year and continuously amazed by the commitment of all in the lupus community. The lupus world has come to the realization that it is only through our united efforts that we can move forward and succeed in the battle against this formidable opponent. Finally there is hope on the horizon for those affected by lupus from a multitude of sources who are connected by this cause. We at The Lupus Foundation of Mid and Northern New York are proud to be a small part of the big picture and honored to represent you during these exciting times. We look forward to the New Year with high expectations for one filled with tremendous promise and progress into the diagnosis, treatment, and research of Lupus Erythematosus. We are successfully enduring both winter and lupus and are ever thankful for your continuing support.

Stay Healthy, Warm and Well— Kathleen

Memorials, Tributes, and Donations

Memorials

In Loving Memory of...

*Mary Becker-
David & Kathleen Arntsen,
Roland & Mary Guinn,
Daymon Worldwide,
Mr. & Mrs. Bartolo Natoli,
Joseph & Jane Concato,
Will & Sharon Ryan,
Rob & Judy Off,
Steve, Melissa & Danika Tworkowsky*

*Sharron Lee Ferris-
Dorothea DeYoung*

*Anthony Maritato, Sr.-
David & Kathleen Arntsen,
Bill & Sandi Frear*

*Jim, Mary Alice & Tom Mitchell-
Jane Williams*

*George Williams-
Jane Williams*

*Isabelle Zeock-
Bill & Sandi Frear,
David & Kathleen Arntsen,
James & Patricia Mitchell*

*Francine Ravitz-
David & Kathleen Arntsen,
Bill & Sandi Frear,
James & Patricia Mitchell,
Ellen Gloo,
Tom & Jackie Taylor,
Dale & Maryrose Bullock,
Philip & Kathy Teague*

*Brooke N. Walseman-
Mrs. Doris Walseman*

*Robert C. Davis-
Coramae Mikitin*

*Christine Marie Smith-
David & Kathleen Arntsen*

Tributes

In Loving Honor of...

*Geri Lemke-
Virginia Merola*

*Roxanne Falitico-
Virginia Merola, Rocco & Monica Falitico*

*David Arntsen's Birthday-
James & Patricia Mitchell*

*Kathleen Arntsen's Birthday-
James & Patricia Mitchell,
Dan & Lois Rumfelt, Tom & Jackie Taylor*

*Rocco & Monica Falitico-
Virginia Merola*

*John Falitico-
Virginia Merola*

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

*Christmas Honors for
Linda Arntsen, Dan & Lois Rumfelt,
James & Patricia Mitchell,
Dan & Lisa Mitchell,
Don & Sue Arntsen-
David & Kathleen Arntsen*

Donations

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

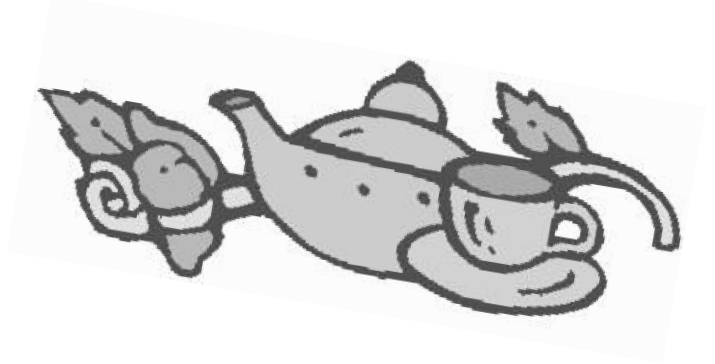
*Astra Zeneca
Beta Sigma Phi Lowville Chapter
Brenda Carnes
Donna Gloo
Sonya Linakis
Joseph & Victoria Jupin
Edward B. Lee, MD
Dominick Ianno
Rocco & Monica Falitico
Jill Anne Smith
Sharon Santa Maria
Tammy Evans
Elizabeth Barley*

AN INVITATION TO CELEBRATE WORLD LUPUS DAY

WHAT: Victorian Tea

WHERE: Your Home

WHEN: May 10, 2011



Recipe for a successful tea party:

1. *Dust off the stove*
2. *Find the teapot (a mug & microwave will also work)*
3. *Cookies Optional*
4. *Take the phone off the hook*
5. *Kick off your shoes*
6. *Put your favorite music on the stereo*
7. *Write out your donation check*

Please consider supporting the Lupus cause this Spring by participating in our World Lupus Day Victorian Tea. Proceeds from this non-event will be used to fund our Organization's Program Services:

Newsletter Printing & Postage

Lupus Awareness and Education Programs

Continued Training to update our leaders on lupus information

Distribution of lupus materials for awareness & education events 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.

Autumn 2010 Meetings & Events

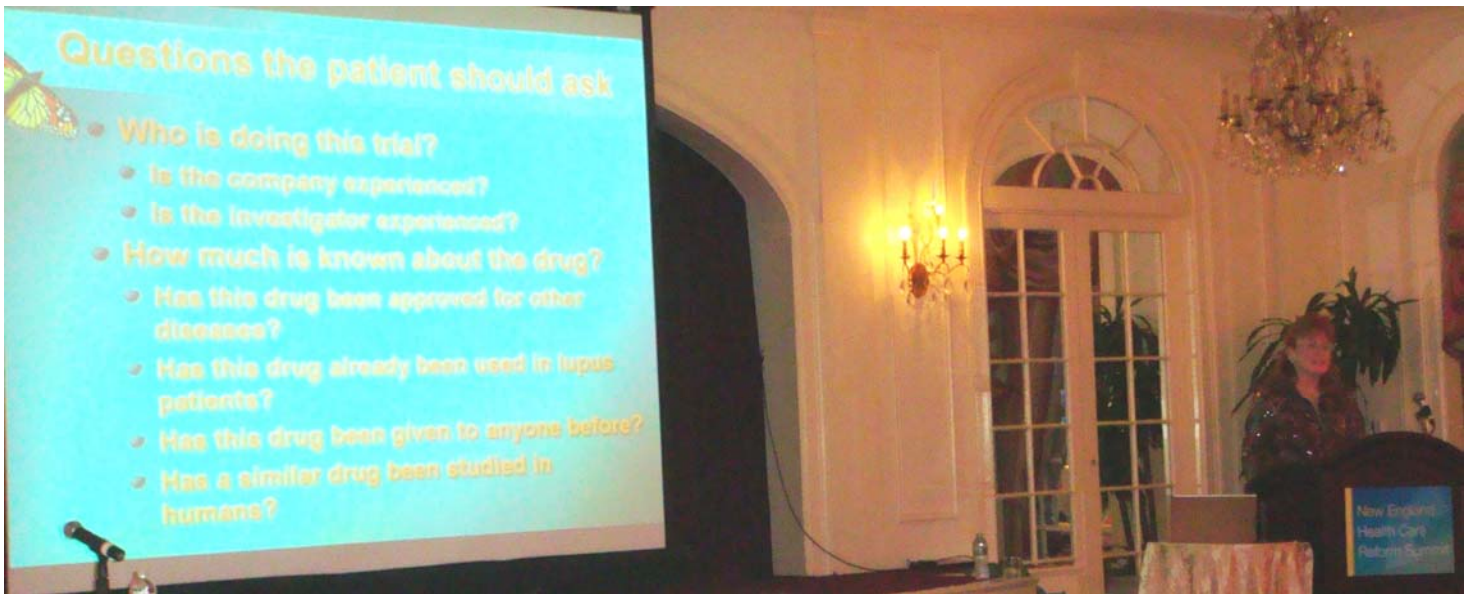


Pictured above: The room was packed for the FDA Arthritis Advisory Committee Meeting held on November 16, 2010 at the Marriott Inn & Conference Center at the University of Maryland in Adelphi, MD to discuss belimumab, proposed trade name BENLYSTA. Pictured to the right: Lupus Patient Representative and FDA Advisory Panelist Kathleen Arntsen asks for clarification on a presentation slide. In the lower left corner of the same picture is the podium where 30 Public Hearing Speakers gave moving testimony to the panel members. The panel recommended 13 to 2 for approval with label revisions. The FDA decision is expected on March 10, 2011.



Autumn General Education Meeting & Informal Chat Session at Rossetti Center on November 30, 2010





Clinical Trials Presentation at the New England Healthcare Reform Summit on October 14, 2010 at Wentworth By the Sea Marriott in Portsmouth, NH



Our Crew at the SLE Lupus Foundation 40th Anniversary Gala on November 22, 2010 at Avery Fisher Hall Lincoln Center



Essential Benefits Panel at the Empire State Healthcare Reform Summit *What the New Law Means for Patients* held on December 7, 2010 at the Albany NY Marriott

PEOPLE WITH LUPUS MIGHT BE AT A GREATER RISK FOR CANCER

ATLANTA – People with systemic lupus erythematosus are 1.15 times as likely to develop cancer as the general population and more than 2.5 times as likely to develop hematologic malignancies, such as lymphoma and leukemia, according to research presented this week at the American College of Rheumatology Annual Scientific Meeting in Atlanta.

Systemic lupus erythematosus, also called SLE or lupus, is a chronic inflammatory disease that can affect the skin, joints, kidneys, lungs, nervous system, and/or other organs of the body. The most common symptoms include skin rashes and arthritis, often accompanied by fatigue and fever. Lupus occurs mostly in women, typically developing in individuals in their twenties and thirties – prime child-bearing age.

Some studies have shown a link between lupus and cancer risk, and researchers recently aimed to make more precise estimations of this risk. They observed 13,492 people with lupus from 24 medical centers for an average of nine years, for a total of 118,359 patient-years (number of patients multiplied by number of years of observation), and compared these participants to people without lupus.

During the course of this study, 632 cases of cancer were noted, and the data concerning hematological cancers—cancers that affect the bone, blood and lymph nodes—was the most striking: researchers found that people with lupus were 3.2 times more likely to develop lymphomas than the general population and 3.4 times more likely to develop non-Hodgkin's lymphoma, specifically. They also found that people with lupus were 1.7 times greater risk of developing leukemia.

"These results more precisely define cancer risk in SLE [than previous studies], highlighting a higher risk of hematological malignancies – both lymphoma and leukemia," says Sasha R. Bernatsky, MD, assistant professor in the Department of Medicine, Divisions of Rheumatology and Clinical Epidemiology, at McGill University, a medical scientist at the Research Institute of the McGill University Health Centre, and co-principle investigator in the ongoing study along with Ann E. Clarke, MD, and Rosalind Ramsey-Goldman, MD, Dr.PH. "However, the news may not be all that bad, considering that hematological cancers remain a rare event – one in every 1,250 patient-years of follow-up for these patients. Just what is driving the risk of cancer in SLE is still unknown, but we currently suspect that disease activity plays a role, although drug exposures have not been ruled out."

Study participants also demonstrated an increased likelihood of developing lung cancer (1.2 times as likely as the general population), cervical cancer (1.6 times more likely), vulvo-vaginal cancers (2.8 times more likely), and liver cancer (2.2 times more likely). The study also shows that people with lupus who are younger than 40 have a particularly high risk, as they are 1.7 times more likely to develop cancer than the general population.

On the other hand, participants did display a significantly decreased risk of developing hormone-sensitive cancers, including breast cancer (0.7 times as likely as the general population), endometrial cancer (0.49 times the likelihood), and ovarian cancer (0.56 times the likelihood).

"The lower risk of several hormone-sensitive cancers may invoke the possibility of alterations in the metabolism from estrogen and/or other hormones," Dr. Bernatsky explains. "But, because female SLE patients may be at higher risk for cancers and pre-cancerous changes of the uterine cervix, they should try to undergo pap testing regularly once they become sexually active, especially if they take immunosuppressive drugs."

The American College of Rheumatology is an international professional medical society that represents more than 8,000 rheumatologists and rheumatology health professionals around the world. Its mission is to advance rheumatology. The ACR/ARHP Annual Scientific Meeting is the premier meeting in rheumatology. For more information about the meeting, visit www.rheumatology.org/education. Follow the meeting on twitter by using the official hashtag: #ACR2010.

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(Cancer Risk cont'd)

Editor's Notes: Dr. Bernatsky presented this research during the ACR Annual Scientific Meeting at the Georgia World Congress Center at 5:30 PM on Monday, November 8 in Room B 402. Dr. Bernatsky was available for media questions and briefing at 8:30 AM on Tuesday, November 9 in the on-site press conference room, B 212. Learn more about living well with rheumatic disease as well as rheumatologists and the role they play in health care. www.rheumatology.org

Media Contact Suzanne Forte/Erin Latimer Office-(404) 633-3777 Newsroom-(404) 222-5805
sforte@rheumatology.org elatimer@rheumatology.org

Yale Researchers Find A Surprising Culprit in Lupus

Posted: December 16, 2010

Yale University researchers were able to reduce symptoms of lupus in mice by eliminating a key immune system cell and in doing so may have identified a new therapeutic target for a variety of other autoimmune diseases.

The findings, reported in the December 16 issue of the journal *Immunity*, focused on the role the dendritic cell plays in systemic lupus erythematosus or SLE, a chronic inflammatory disease that affects a variety of parts of the body including skin, joints, blood and kidneys. Dendritic cells are important for initiating the immune response to pathogens but it is unclear what role they play in autoimmune diseases, such as SLE.

A team led by [Mark Shlomchik](#), Professor of Laboratory Medicine and of Immunobiology and senior author of the paper, knocked out dendritic cells in lupus-prone mice and found a dramatic reduction in symptoms of lupus. They also discovered another surprise.

Dendritic cells were believed to be crucial in activating T cells, which along with B cells comprise the two main arms of the immune system. However, knocking out the dendritic cells in lupus mice did not reduce the activation of pathogenic T cells as expected. Instead, the cells disappeared from inflamed tissue such as kidneys, causing a reduction in symptoms in lupus mice lacking the dendritic cells. Dendritic cells appear to play a localized role in lupus tissue damage and so might make a good therapeutic target for lupus and possibly other autoimmune diseases as well, the authors say.

Dendritic cells could be having the same effects in a variety of other autoimmune diseases, but we will not know until we do similar experiments in other disease models," Shlomchik said.

Other Yale authors of the paper are Lino Teichmann, Michael Kashgarian, and Michelle Harris-Ols. The work was funded by the National Institute of Arthritis and Musculoskeletal Diseases and the Lupus Research Institute.

Spring General Education Meeting & Informal Chat Session

Wednesday, March 30, 2011

6:45 PM to 8:00 PM

Rossetti Education Center, Madison-Oneida BOCES

4937 Spring Rd. Verona, NY

Reservations required to 315-829-4272 or lupusmidny@aol.com

Refreshments will be served.



ELEVENTH ANNUAL LUPUS CHARITY GOLF CLASSIC

AUGUST 12, 2011
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, lunch, and dinner for four

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

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

Thank You!

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

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

THE LUPUS FAMILY REGISTRY AND REPOSITORY

The LFRR 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
- American Indian Studies
- Asian American Studies
- All Ethnicities
- Families with one lupus patient
 - Families with two or more lupus patients
- Unrelated volunteers also needed

For more information, please visit
<http://lupus.omrf.org> or call a recruiter,
toll-free at 1.888.655.8787 (1.888.OK.LUPUS)



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

LUPUS
Together
FOR CLINICAL TRIALS TODAY

Visit LupusTrials.org »

LUPUS RESEARCH OPPORTUNITIES

The University of Rochester is recruiting patients to participate in a clinical research study on an investigational drug.

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

If you qualify you will receive study medication and study related medical exams at no cost and compensation for your time and travel.

For more information please call:

Maria Allen at (585) 275-7167

University of Rochester
Clinical Immunology Research Center
601 Elmwood Avenue Rochester, NY

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												
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Up-to-date Lupus Foundation of America, Inc. Brochures There is a \$.25 fee per brochure													
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Please remit total payment to: Lupus Foundation PO Box 139 Utica, NY 13503													



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

**3rd Annual Lupus Awareness Day
 Wednesday, May 4, 2011**

Legislative Office Building Well Albany, New York

**7th Annual Lupus Education Symposium & Luncheon
 Saturday, May 14, 2011 9:00am to 2:30pm**

Rossetti Education Center at Madison-Oneida BOCES

**Friday, August 12, 2011 11th Annual Lupus Charity Golf Classic
 11:30am registration, 1:00pm shotgun start, 6:00pm Awards Dinner
 Shenendoah Golf Club at Turning Stone Resort**

Lupus Exhibit NY State Fair

Thursday, August 25, 2011 to Monday, September 5, 2011

**3 Hour Volunteer Shifts available; admission & parking included
 Contact Kathleen at 315-829-4272 or e-mail lupusmidny@aol.com**



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
- ◆ NY Healthworks





**7th Annual Education Symposium & Luncheon
“Decades of Progress, Promise & Possibilities”**

Saturday, May 14, 2011

9:00am to 2:30pm

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

Presenters include:

**Marc R. Chevrier, MD, PhD, FACR
Rheumatologist & Clinical Researcher
*Lupus, Then and Now***

**Raquel M. Rosen, MD
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*Medication Management***

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

**No cost to current 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**

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