



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. 3, Spring 2011

LUPUS AWARENESS IN NEW YORK STATE



Lupus Foundation of Mid & NNY President/CEO Kathleen Arntsen receiving the 2011 NYS Resolution declaring May as Lupus Awareness Month from Senate Prime Resolution Sponsor Senator Joseph Griffo and Assembly Prime Resolution Sponsor Assemblywoman Vanessa Gibson on May 4, 2011. Also pictured is Senator Diane Savino and lupus leaders representing the other 6 Lupus Agencies of New York State. Senator Griffo spoke during the group presentation in the Legislative Office Building Well and on the Senate floor along with Senator Diane Savino, Senator Kemp Hannon, and Senator Betty Little. We thank Senator Griffo for being the Prime Senate Sponsor and all of our legislative supporters for promoting lupus awareness during the month of May. We also thank former Assemblywoman RoAnn Destito for initially coordinating our state event for the past 3 years and wish her well in her new position as Commissioner of Office of General Services under Governor Andrew Cuomo's administration.

The Lupus Communiqué

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

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DISCLAIMER

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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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Health Charities
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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—

Instead of the usual message I am sharing my remarks from the May Symposium regarding our Appreciation Awards.

The purpose of life is not to be happy - but to *matter*, to be productive, to be useful, to have it make some difference that you have lived at all. ~Leo Rosten

That statement pretty much echoes the sentiment we feel about the dedicated volunteers of the Lupus Foundation of Mid and Northern New York. We are an all-volunteer passion-driven organization and have no paid staff so each and every task and activity and event that is completed here is accomplished through volunteer efforts. Most of our volunteers 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 a tremendous asset to our organization.

At this time we would like to honor our volunteers and present our Annual Awards. The Lupus Foundation's mission is to improve the quality of life for those affected by lupus through advocacy, education, awareness, empowerment, and research. Our programs reflect this mission by promoting public awareness, providing patient education, emotional support, & advocacy and funding lupus research. Today we honor 4 individuals and 1 organization that have gone the extra mile in the past year in furthering our cause.

Fundraising—Jaime Venditti, Newly-elected Board Member;

Jaime's efforts have raised thousands of dollars for our organization over the past 2 years, even though her relationship with us was strictly professional as an employee of a corporate sponsor. Jaime is committed to finding supporters and sponsors for our organization.

Promotion of Public Awareness—Jackie Taylor, Board Member;

Jackie's energy good humor, and efforts over the past 4 years have improved our organization tremendously. She has volunteered at the State Fair, attended advocacy events in Washington & Albany, co-chaired our former Loop Ride, volunteered at the Golf Classic and done pretty much any duty she was asked with a smile on her face even traveling from one capital to another in the middle of the night.

Education—Stephanie Darwak, Board Secretary;

Stephanie has been a passionate supporter of our annual education symposium in recruiting sponsors and speakers; helped develop the Annual Lupus Event in Albany, volunteers at the NYS Fair Booth with her family and looks for every opportunity to educate anyone about lupus.

Volunteer of the Year—Molly Snitchler, Volunteer;

Molly's Mom Bridget has lupus so Molly knows firsthand how difficult it is to deal with this disease. Molly has volunteered for the past 5 years at the NYS Fair, 1 year at the Golf Classic and for 3 years now at the Symposium. She always has a smile on her face and is full of energy.

Corporate Award—PhRMA has generously supported our programs for the past 5 years while collaborating with us to improve patient access to therapies. Representing them here today is Jaime Venditti.

There are two ways of spreading light - to be the candle or the mirror that reflects it. ~Edith Wharton, *Vesalius in Zante*

If you think you are too small to be effective, you have never been in bed with a mosquito. ~Betty Reese

Stay Cool, Remember the Sunscreen and Enjoy the Summer— Kathleen

SUN PROTECTION RESOURCES

Clothing

Regular clothing sometimes doesn't offer enough protection for sun-sensitive skin. A special line of clothing with a sun-protective factor of more than thirty is now available through the companies listed below. Fabrics are light-weight, cool and offered in a variety of colors. Additional information is available by calling the companies directly.

Sun Grubbies
1-888-970-1600
www.sungrubbies.com

Sun Precautions
1-800-882-7860
www.sunprecautions.com

Sunveil Sunwear
1-800-565-0585
www.sunveil.com

Solartex Sun gear
1-877-476-5789
www.solartex.com

Splashskins (children)
1-866-947-7946
www.splashskins.com

Coolibar
1-800-926-6509
www.coolibar.com

Laundry Treatment

Rit® Sun Guard™ Laundry Treatment

1-866-794-0800 www.sunguardprotection.com

This treatment washes sun protection into clothing. The protection is invisible and doesn't change the color or comfort of the clothing. One treatment lasts for more than 20 washings.

Sun Screen

Blue Lizard Australian Sunscreen

www.crownlaboratories.com/bluelizard/products

This product was developed to combat one of the most intense UV environments in the world. All formulas offer more than 30 times your skin's natural protection against UVB rays.

Ultraviolet Shields

There are several ultraviolet screen products available that can be beneficial to individuals with lupus who are sensitive to ultraviolet light from the sun and/or fluorescent bulbs.

North Solar Screen

1-866-230-4700 www.northsolarscreen.com

Fluorescent Bulb Jackets slide over the bulb to provide immediate protection.

Solar Screen Co, Inc.

1-800-347-6527 www.solar-screen.com

Transparent shades are see-through and keep out solar heat, glare and ultraviolet rays.

CAKOON UV

1-888-225-6665 www.raybeth.com

These umbrellas provides excellent protection from the sun & the damaging effects of ultraviolet rays while providing cool & comfortable shade. The special canopy has been laboratory tested for a UPF Rating of 50+. This means CAKOON UV-brella blocks 99.9% of the sun's UVA & UVB rays making it a helpful solution for those suffering from sun-sensitive conditions. CAKOON UV-brellas come in 40" to 60" arcs.

Memorials, Tributes, and Donations

Memorials

In Loving Memory of...

*Bernice Carter-
Bob & Cathy Walseman,
Isabel Woolshlager,
Jeff & Sue Virkler & Family,
Victor & Mary Pat Faduski,
Ms. Mary Ripp,
Billy Sargent,
Central NY DSO Lowville
Office Co-Workers,
John & Pam Lucidi,
NYS DOT Office of Structures*

*John Della Contrada-
Bob & Val Spindler,
Fran Aiello,
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Julius Pirillo,
Ralph & Josephine Agone,
Pat & Peg Corbett,
Jackie Kindler,
Claire & Ralph Mirabelli,
Diane & Vincent Grieco,
Pat & Marlene DelPiano,
Dominick & Donna Tagliaferri,
Richard Lombino,
George DiFabio,
Mr. & Mrs. Dale Rashford
Rocco & Monica Falitico*

Education Symposium Sponsors

*New York Health Works
Human Genome Sciences
FoxKiser
Pfizer Helpful Answers
National Kidney Foundation of NENY
PPA/PhRMA
NYS Epic Program
Excellus BCBS
Fallene, Ltd.
Anne's Wellness
Madison-Oneida BOCES—
Cosmetology, Nursing &
Culinary Arts Students & Instructors*

Tributes

In Loving Honor of...

*Cathy Walseman & WLD Tea—
Mary Ripp, Jack & Marcia Flint & Family*

Donations

*CFC, SEFA, United Way, IBM, GE,
American Express, United Health,
and Pfizer Employee Donor Plans
PhRMA
Human Genome Sciences
FoxKiser
Carnival/Alcalde & Fay
Pfizer, Inc.
Pfizer Helpful Answers*

World Lupus Day Tea

*Rocco & Monica Falitico
Gladys Hill, Larry & Kathy Scharf
Ellen Gloop, Jaime Venditti
David & Kathleen Arntsen
James & Patricia Mitchell
Tom & Jackie Taylor
Phil & Kathy Teague
Frank & Stephanie Darwak
Jaqueline Hummel
Frank & Mary Della Posta
Dale & Maryrose Bullock
Bill & Sandi Frear
Helen Cassin, Jane Porter
John & Elisabeth Porter
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NYS Awareness Sponsors

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International Institute of Human Empowerment
Global Healthy Living Foundation
Sjogren's Syndrome Foundation
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Scleroderma Foundation Tri-State, Inc.
Arthritis Foundation NENY*

11th ANNUAL



LUPUS
Charity Golf Classic

FRIDAY, AUGUST 12, 2011

SHENENDOAH GOLF CLUB
TURNING STONE RESORT CASINO
Verona, N.Y.

REGISTRATION 11:30AM SHOTGUN START 1:00PM
COMPLIMENTARY DRIVING RANGE 11:30AM

ALL PROCEEDS BENEFIT

LUPUS FOUNDATION OF MID
& NORTHERN NEW YORK, INC.

Honorary Chairperson—Dr. Donald Raddatz

\$150 per golfer Early Registration by July 15, 2011

\$175 per golfer Registration after July 15, 2011

Includes: greens fee, cart, lunch, awards dinner

Team Categories

Men

Women

Senior (all over 55)

Co-ed (min. 1 female)

RESERVATIONS LIMITED TO FIRST 128 GOLFERS PAID IN FULL !!

Deadline for Early Registration is July 15, 2011 then fee increases

TEAM NAME _____ CATEGORY _____

CAPTAIN _____

ADDRESS _____

PHONE _____ E-MAIL _____

GOLFER 2 _____ ADDRESS _____

GOLFER 3 _____ ADDRESS _____

GOLFER 4 _____ ADDRESS _____

Golfer Registration Fees \$ _____

Dinner Guest(s) \$35 each \$ _____

Other Monetary Donation \$ _____

TOTAL Amount Enclosed \$ _____

For more Information: 315-829-4272 or 1-866-2-LUPUS-4 (toll free) or e-mail lupusmidny@aol.com

Please Mail Registration Form and Payment to: LUPUS FOUNDATION
P.O. BOX 139
UTICA, N.Y. 13503

Visit our website www.nolupus.org

7th ANNUAL LUPUS EDUCATION SYMPOSIUM



Pictured above left to right: David & Kathleen Arntsen with Keynote Speaker Dr. Marc Chevrier; Speaker Dr. Raquel Rosen; and Speaker Dr. Nicole Pagano. Pictured below left to right are Annual Volunteer Award Winners receiving congratulations from President Kathleen Arntsen: Jaime Venditti for Fundraising; Jackie Taylor for Awareness; and Stephanie Darwak for Education.



Pictured below left to right: Volunteer of the Year Award Winner Molly Snitchler; Corporate Award Winner PhRMA represented by Jaime Venditti and Ashley Ennis; and the Lupus Foundation of Mid and NNY Board of Directors receiving a round of applause for their volunteerism and efforts on behalf of the local lupus community.



CONGRATULATIONS TO AWARD RECIPIENTS !

DECADES OF PROGRESS, PROMISE & POSSIBILITIES



Our 7th Annual Lupus Education Symposium & Luncheon was held on Saturday, May 14, 2011 with nearly 100 attendees at Rossetti Education Center at Madison-Oneida BOCES in Verona, NY. Presenters included Dr. Marc Chevrier, a Rheumatologist with longstanding research and clinical interest in lupus and its mimics speaking on Lupus, Then & Now; Dr. Raquel Rosen, Bassett Healthcare Nephrologist speaking on Hypertension; and Dr. Nicole Pagano a Pharmacist from Palmer Pharmacy speaking on Medication Management. We are honored to have such knowledgeable presenters at our education forum. Once again the Cosmetology, Culinary Arts, Secondary & Adult Nursing Students showed off their skills and interacted with attendees at their exhibit booths. Massages, paraffin hand waxing, scalp massages, wellness & blood pressure checks, prescription assistance, clinical trial, lupus and autoimmune resources were also available at display tables and a delicious breakfast & luncheon catered by the students was enjoyed by all.

Scientists Find Clues to Role of Neutrophils in Lupus

Scientists have long suspected that immune system cells called neutrophils play a role in lupus, a disease that occurs when the body's immune system attacks and damages its own tissues, including the skin, joints, heart, lungs, kidneys and brain. More than a half-century ago, scientists found that the blood serum from patients with lupus triggered alterations in the nuclei of these abundant immune system cells. This finding was used to diagnose patients with lupus for many years, but the role of neutrophils in the disease remained elusive. Scientists supported by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) have now found a new role for these cells in lupus. Their discovery, published in the journal *Science Translational Medicine*, could potentially lead to the identification of new therapeutic targets for the disease.

Following the discovery of an abnormal neutrophil gene expression pattern in the blood of children with lupus, Virginia Pascual, M.D., and her colleagues at the Baylor Institute for Immunology Research found that exposing neutrophils from children with lupus to anti-ribonucleoprotein (anti-RNP) autoantibodies (a type of antibody commonly made by people with lupus) caused the neutrophils to die rapidly, similar to the way neutrophils from healthy children die in response to bacterial and fungal infections. But, perhaps more importantly, they found that in the process of dying, the neutrophils from children with lupus released material from cell nuclei, which did not happen with the neutrophils of healthy children exposed to the same autoantibodies. The release of this material led to the activation of other immune system cells, particularly those that produce interferon-alpha (IFN- α), one of a family of potent immune proteins. Earlier research by Dr. Pascual and her colleagues showed IFN- α to be highly elevated in patients with lupus, and likely to be involved in the immune system alteration and damage in the disease.

The scientists hope that recognizing and better understanding the process of neutrophil death, and the subsequent immune cell activation, will lead to the identification of targets to block this type of cell death and intervene in the process that ultimately leads to tissue damage in lupus.

The mission of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), a part of the U.S. 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 website at <http://www.niams.nih.gov>.

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Garcia-Romo GS, Caielli S, Vega B, Connolly J, Allantaz F, Xu Z, Punaro M, Baisch J, Guiducci C, Coffman RL, Barrat FJ, Banchereau J, Pascual V. Netting neutrophils are major inducers of type I IFN production in pediatric systemic lupus erythematosus. *Sci Transl Med*. 2011 Mar 9; 3(73):73ra20. PubMed PMID: 21389264.

Study Shows Unexpected Role of Immune Cell in Lupus

A new study by NIAMS-supported researchers provides surprising insights into the immune process involved in lupus, a chronic inflammatory disease that can damage many parts of the body including the joints, skin, kidneys, heart, lungs, blood and brain. The study's findings, which focus on an immune system cell called a dendritic cell, could potentially lead to the development of new treatments for the disease, the researchers say.

In infectious disease models, dendritic cells are important for activating two other types of immune system cells, T cells and B cells, as part of the response to invaders such as viruses and bacteria. But the role they play in autoimmune diseases such as lupus is unclear.

To better understand that role, researchers led by Mark Shlomchik, M.D., Ph.D., professor of laboratory medicine and of immunology at Yale University School of Medicine in New Haven, CT, developed and used a mouse model of lupus genetically manipulated to lack dendritic cells. Without dendritic cells, the investigators demonstrated that overall disease in the lupus prone-mice was reduced dramatically. Furthermore, they showed that mice lacking dendritic cells were less likely to develop characteristic kidney and skin disease.

While this finding confirmed that dendritic cells do play an important part in disease progression, the scientists were surprised that the removal of the dendritic cells did not hinder the initial activation of the other immune system cells, says Dr. Shlomchik. Instead, dendritic cells were essential for the invasion of target organs by inflammatory cells, including T cells, and responsible for tissue damage. In other words, instead of initiating the immune response, the dendritic cells amplified it, says Dr. Shlomchik.

While current lupus therapies are directed largely toward T cells and B cells, the new research, published in the journal *Immunity*, suggests therapies targeted at blocking dendritic cells may be effective at reducing or preventing tissue damage in lupus and perhaps other autoimmune diseases.

The mission of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), a part of the U.S. 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 website at <http://www.niams.nih.gov>.

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Teichmann LL, Ols ML, Kashgarian M, Reizis B, Kaplan DH, Shlomchik MJ. Dendritic cells in lupus are not required for activation of T and B cells but promote their expansion, resulting in tissue damage. *Immunity*. 2010 Dec 14; 33(6): 967-78.



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

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\$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

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

Best Ball; Captain & Crew
\$150 per golfer; \$600 foursome
Sponsorship opportunities available

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



**Lupus
 Research
 Institute**



LUPUS Agencies of NYS



**Lupus
 Research
 Institute**
 National Coalition

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 Health Works

LUPUS AWARENESS IN THE STATE CAPITAL



On Wednesday, May 4, 2011 all 7 Lupus Agencies of New York State sponsored the 3rd Annual Lupus Awareness Event in Albany at the Legislative Office Building (LOB) Well to kick off Lupus Awareness Month. Senator Joseph Griffo was Prime Senate Sponsor and Assemblywoman Vanessa Gibson was Prime Assembly Sponsor. A presentation in the Well was followed by a Senate Floor Presentation led by Senator Griffo. Pictured above are lupus leaders and advocates from all over the state with Senator Roy McDonald, Senator Betty Little, Senator Diane Savino, Senator Joseph Griffo, Senator Kemp Hannon, and Senator David Valesky on the Million Dollar Staircase in the NYS Capitol Building. Pictured below are lupus advocates JoAnn Quinn, Kate Anastasia, Ashley Ennis, Stephanie Darwak, Kathleen Arntsen, Violet Regan, Jaime Venditti, Jessica Rowshandel, Jackie Taylor and Honi Kurzeja with Senator Kemp Hannon a co-Prime Sponsor of the NYS Lupus Resolution.

