



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. 2, Spring 2008

Annual Appreciation Awards Presented



Pictured to the left is Lupus Foundation of Mid and Northern New York's Volunteer of the Year Stephanie Darwak receiving her award from President/CEO Kathleen Arntsen. Stephanie, who is a Board Member and dedicated volunteer for the past 3 years serves on the fundraising, education, and advocacy committees

Pictured below is the Corporate Appreciation Award recipient Vifor Pharma Aspreva. Receiving the award from President/CEO Arntsen (second from left) are (left to right) Leslie Magnus, VP US Medical Affairs, Rick Goulburn, Head of AI TA Marketing & NA Operations, Dr. Martin Lubell, Director of Medical Education, and Carol McCabe, US Office Management. Aspreva has supported our Education programs for the past 5 years.

Congratulations to all of our Annual Award Recipients. Your efforts and support are appreciated.



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

Appreciation Awards	1
Newsletter Information	2
Campaigns	3
President's Message	4
NYS Fibromyalgia Awareness.....	5
Guest Message	6
Memorials, Tributes & Donations	7
4th Annual Education Symposium.....	8 & 9
8th Annual Golf Classic	10
Sun Protection	11 & 12
Announcements	13
Clinical Trial Info	14
Membership Form	15
Advocacy	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—

We have been very busy here this Spring with our Education, Advocacy, Awareness, and Fundraising Events. Our 4th Annual Education Symposium & Luncheon held on May 3rd was the most successful effort to date with 125 registrants. The *Essence of Wellness* Theme and the Exhibit Booths were well received by all attendees. Thank you to the speakers, supporters, exhibitors, and volunteers who helped to make this event so wonderful. We honored our volunteers and presented our Annual Awards during the delicious luncheon. The following are my brief remarks from the event.

“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 3 individuals and 1 organization that have gone the extra mile in 2008 in furthering our cause.

Fundraising- Ellen Gloor, Board Member; Ellen’s personal efforts have raised thousands of dollars for our organization over the past 2 years. Volunteer of the Year- Stephanie Darwak; Board Member, Her energy and efforts over the past 3 years have improved our organization tremendously. Corporate award- Vifor Pharma Aspreva has supported our education programs for the past 5 years. Promotion of Public Awareness- Maryrose Bullock; She has promoted lupus awareness at health & wellness, fundraising, and sorority events. Congratulations to all of our award recipients and thank you for your efforts.

We had a stellar year for Lupus Foundation of Mid and Northern New York in 2007. Our 7th Annual Lupus Charity Golf Classic was a tremendous success, with profits over \$28,000.00, our membership hit 589 members, and our income reached over \$63,000.00 net; allowing us to increase our annual research donation to The Lupus Research Institute to \$21,000.00 an all time high. Just think if all lupus groups in the nation gave 1/3rd of their income to research; where would we be then? Our administrative costs for 2007 were 1.9% so 98.1% of every dollar raised went to program services. Our little organization continues to move forward with optimism and hope for a brighter tomorrow for all in the lupus community. For 2007 we logged over 9,900 volunteer hours which would be equivalent to \$230,000 in income! Please give all of our volunteers a big hand. Thank you so very much.”

**Unless someone like you cares a whole, awful lot. Things are not going to get better they’re NOT! –
Dr. Seuss, *The Lorax***

Stay Cool, protect yourself from the sun and have fun this Summer—Kathleen



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

- ◆ **National Coalition of Autoimmune Patient Groups**
- ◆ **NIAMS Coalition**
- ◆ **Lupus Agencies of New York State**
- ◆ **Patient-Centered Quality Alliance**



FIBROMYALGIA AWARENESS WEEK



**N
Y
S
T
A
T
E** **A
D
V
O
C
A
C
Y**



NYS Legislators passed resolutions in both the Assembly and Senate declaring May 12-18, 2008 to be Fibromyalgia Awareness Week to increase public awareness and misconceptions about the disease. Fibromyalgia Patient Sandi Frear was to emcee the event but became ill and Patient Advocate Kathleen Arntsen filled in. Pictured from the top left clockwise: Dr. Martin Morell, Rheumatologist from Arthritis Specialists presenting on Fibromyalgia; Assemblywoman & Resolution Sponsor Audrey Pheffer presenting the resolution to Advocate Kathleen Arntsen on May 14th; Assembly Members George Lattimer, RoAnn Destito, and Audrey Pheffer with Arntsen; Senator & Resolution Sponsor Betty Little; Mistress of Ceremonies Arntsen welcoming the attendees; Senator Little, Arntsen and Senator Joseph Griffo outside the Senate Chamber right after the resolution

Guest Message

I am an advocate. I advocate professionally and I advocate personally. Each and every one of us advocates for something every single day. We are supporters, backers, promoters, believers, activists, campaigners, and sponsors of various things. We advocate for the poor, for the underserved, for the disabled, and for our rights. We advocate for those we love and for what we are most passionate about.

As an Advocacy Relations Consultant, I work with organizations from all over New York State on health care issues pertinent to their group, cause, or the people they serve. The organizations I work with come in many different shapes and sizes – there are very large organizations, small organizations, rural groups, urban groups, support groups, community based organizations, faith based organizations, all-volunteer organizations, and those with paid staff. Their health care agendas and policies vary from one organization to the next, their priorities may differ and yet many times they are quite alike. No matter what disease state they represent, or the particular barriers they are trying to eliminate, or the valuable knowledge they are trying to be bestowed – these non-profit agencies are all equal and united by one thing - ADVOCACY. They are advocating for better access to healthcare and drugs, for funding, for programs, for more research...and the list goes on. These organizations and individuals are raising monies to help find cures, they are making their voices heard by calling or writing their legislators on issues they care about, they are building coalitions to unite themselves for the betterment of an issue – a worthy cause they are passionate about.

As a board member of the Lupus Foundation of Mid and Northern New York, Inc., I get to advocate on a personal level. My uncle was diagnosed with Lupus long before I even knew what Lupus was and started advocating for this disease. For many years, I have had the pleasure of working with Kathleen Arntsen on various advocacy issues, and I am now honored to serve on her stellar board. Being a board member for a not-for-profit has taught me a lot more about the continued need for advocacy as well as the hurdles that patient advocates must overcome. I have also learned how important it is to be educated and involved in your own healthcare and even more so when you are sick. I am humbled to see how strong patient advocates remain even in the face of adversity. I feel that they are humanity's true champions and I am inspired by their constant quest to improve the quality of their lives and those of others.

As part of my involvement with the Lupus Foundation of Mid and Northern NY, I have written to Congressman C.W. Bill Young thanking him for his commitment towards Lupus and autoimmune research and applauded his support of the Five-Year Trans Institute Lupus Plan at the NIH. I also had the opportunity to go to Washington, D.C. in March with my local Lupus colleagues, and on behalf of the LRI we advocated for an NIH funding increase, an updated progress report on the Trans-Institute Lupus Research 5-Year Plan, and requested language for additional funding for the Office of Minority Health to initiate lupus professional education programs. I experienced first hand how important it is to form personal relationships with your Congressional representatives and how much they will fight with you on your issues once those relationships are formed. It was amazing to see the "red carpet treatment" that our little Lupus agency received while in D.C. and I know that it has evolved from years of relationship building by Kathleen Arntsen and Sandi Frear and the passion and enthusiasm they bring to the hill each year. Amongst all the excitement and successful meetings, I also witnessed the obstacles that my dear friends and colleagues face daily as patients – and yet they persevere as advocates.

Working with the Lupus Foundation of Mid and Northern NY and seeing the dedication and sacrifice that our board members and volunteers display each and every day, continues to fuel my fire for advocacy – professionally and personally. Anyone can be a successful advocate. All it takes is a lot of heart, passion, and the desire to make the world a better place. Don't ever underestimate the power of letting your voice be heard – you can make a difference!

**Stephanie C. Darwak,
Advocacy Relations Consultant
Board Member, Lupus Foundation of Mid and Northern New York, Inc.
July 2008**

Memorials, Tributes, and Donations

Memorials

In Loving Memory of...

*Richard Cassin-
David & Kathleen Arntsen, James & Patricia
Mitchell, Sarah Eastup & Family*

*Peter Kurgan-
The Kurgan Family*

Donations

*Victoria Jupin
Sonya Linakis
Rocco & Monica Falitico
Pfizer, Inc.
Pfizer Helpful Answers
General Electric Foundation
CFC, SEFA, United Way, IBM and
Employee Donor Plans*

*Education Symposium Sponsors-
Pfizer, Inc.*

*La Jolla Pharmaceutical Company
Genentech Biogen/Idec
Vifor Pharma Aspreva
Partnership for Prescription Assistance/PhRMA
Our Friends*

*Exhibitors, Materials & Giveaways-
Abbott Laboratories
ALCiS Health, Inc.
Anne's Wellness Center
Eli Lilly
Fallene, Ltd.*

*Helen Sarandrea, PT
Human Genome Sciences, Inc.
Inspire Pharmaceuticals
Lupus Research Institute National Coalition
Lupus Clinical Trials Consortium
Madison-Oneida BOCES
Cosmetology, & Nursing Students & Instructors
Mediquest Therapeutics
NIH; NIAMS; NIDDK; NIAID; NINDS
Okamoto Industries
Mary Wallingford, LMT
NYS Epic Program
Sitrin Home*

Tributes

In Loving Honor of...

*Roxanne Falitico & Geri Lemke-
Virginia Merola*

*Geri Lemke-
Family & Friends*

*Amy Bryant Mowers-
Melissa Wallis & Family*

*The June 14th, 2008 Wedding of
Jennifer Alberico & Sean Temple-
A donation to lupus research*

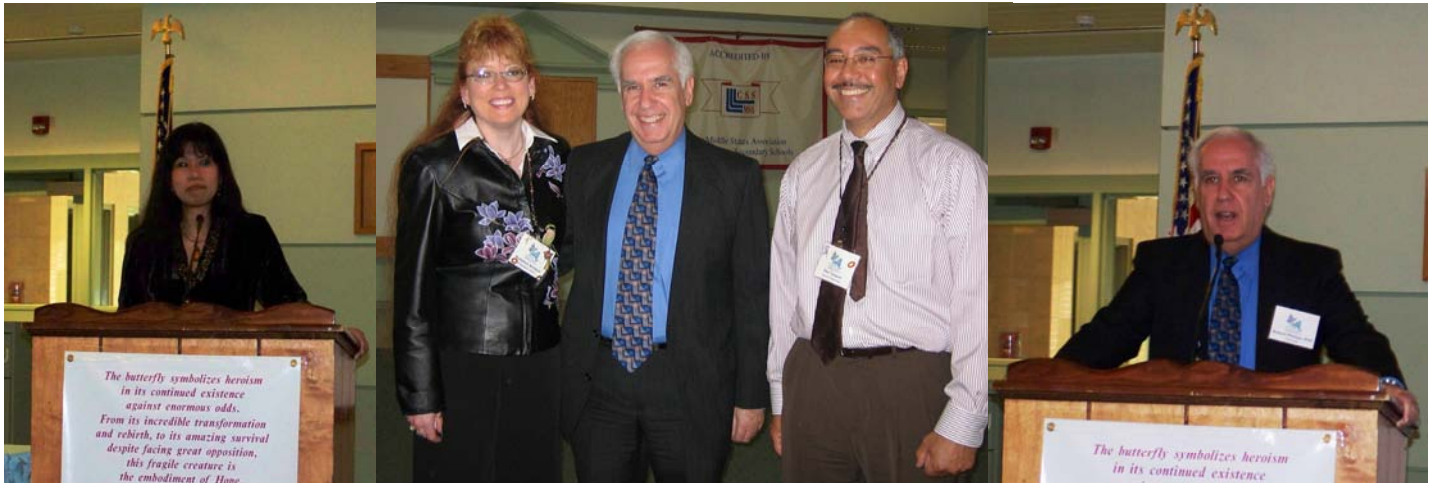
*Cathy Walseman-
Jack & Marcia Flint & Family*

*Partner Memberships-
Sandi Frear-
Dawn Gaeta, Roe Hudec, Sarah Sackett*

*Victorian Tea Party-
Rocco & Monica Falitico
Dick & Helen Lenart
Sarah Eastup & Family
David & Kathleen Arntsen
Carol Walker
James & Patricia Mitchell
Donald & Joan Gloo
Philip & Kathy Teague
Bob & Cathy Walseman
Chester & Jane Trzepacz
William & Patricia Zaleski
Norman & Arlene Stanulevich
Laurens Central School
Dale & Maryrose Bullock
Pasquale Grasso
Bill & Sandi Frear
Frank & Stephanie Darwak
Larry & Kathy Scharf*

*Clinical Trials Campaign-
Pfizer, Inc.
PPA/PhRMA
Our Friends*

4TH ANNUAL EDUCATION SYMPOSIUM



Pictured above: 2008 Education Symposium Speaker Dr. Raquel Rosen, Bassett Healthcare Nephrologist; LFMNNY President Kathleen Arntsen, Dr. Robert Phillips, and LFMNNY Board Chairman Philip Teague; Symposium Presenter Dr. Robert Phillips from the Center of Coping.



**THANK YOU
TO OUR
SYMPOSIUM
SPEAKERS
AND 2008
SPONSORS**



Pictured above left: Raffle Drawing Winner Isabel Woolshlager; to the right: LFMNNY Secretary Sandi Frear, Awareness Appreciation Award Recipient Maryrose Bullock and President Kathleen Arntsen



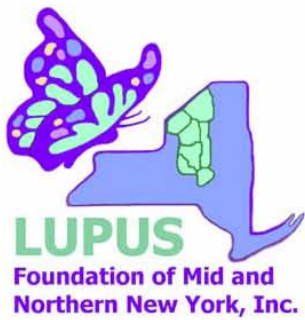
Pictured above left to right: Symposium Sponsors Rick Deyulio and Scott Armstrong from PPA/PhRMA with President Arntsen; Our Friends with President Arntsen & Secretary Sandi Frear; Board Member and NYS Alliance Development Consultant Stephanie Darwak, President Arntsen and Anna Maria Maritato from Pfizer.

ESSENCE OF WELLNESS — May 3, 2008



EDUCATION & AWARENESS





**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

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

Thank You!

Sunburn Protection Factor (SPF)

SPF is a measure of how much solar energy (UV radiation) is required to produce sunburn on protected skin (i.e., in the presence of sunscreen) relative to the amount of solar energy required to produce sunburn on unprotected skin. As the SPF value increases, sunburn protection increases.

There is a popular misconception that SPF relates to time of solar exposure. For example, many consumers believe that, if they normally get sunburn in one hour, then an SPF 15 sunscreen allows them to stay in the sun 15 hours (i.e., 15 times longer) without getting sunburn. This is not true because SPF is not directly related to *time* of solar exposure but to *amount* of solar exposure. Although solar energy amount is related to solar exposure time, there are other factors that impact the amount of solar energy. For example, the intensity of the solar energy impacts the amount. The following exposures may result in the same amount of solar energy: one hour at 9:00 a.m. and 15 minutes at 1:00 p.m.

Generally, it takes less time to be exposed to the same amount of solar energy at midday compared to early morning or late evening because the sun is more intense at midday relative to the other times. Solar intensity is also related to geographic location, with greater solar intensity occurring at lower latitudes. Because clouds absorb solar energy, solar intensity is generally greater on clear days than cloudy days.

In addition to solar intensity, there are a number of other factors that influence the amount of solar energy that a consumer is exposed to: skin type, amount of sunscreen applied, and reapplication frequency.

Fair-skinned consumers are likely to absorb more solar energy than dark-skinned consumers under the same conditions. The amount of sunscreen applied also impacts the amount of solar radiation absorbed, because more sunscreen results in less solar energy absorption. Because sunscreens wear off and become less effective with time, the frequency with which they are reapplied is critical to limiting absorption of solar radiation. The reapplication frequency is also impacted by the activities that consumers are involved in. For example, consumers who swim while wearing sunscreen need to reapply the sunscreen more frequently because water may wash the sunscreen from the body. In addition, high levels of physical activity require more frequent reapplication because the activity may physically rub off the sunscreen and heavy sweating may wash off the sunscreen. In general, more frequent reapplication is associated with decreased absorption of solar radiation.

Because of the various factors that impact the amount of solar radiation, SPF does not reflect time in the sun. In other words, SPF does not inform consumers about the time that can be spent in the sun without getting sunburn. Rather, SPF is a relative measure of the amount of sunburn protection provided by sunscreens. It allows consumers to compare the level of sunburn protection provided by different sunscreens. For example, consumers know that SPF 30 sunscreens provide more sunburn protection than SPF 8 sunscreens.

Source: Dept. of HHS, US FDA CDER October 6, 2006

Protection from Direct Sunlight

An abnormal reaction to the ultraviolet (UV) rays of the sun, photosensitivity results in the development or exacerbation of a rash that is sometimes accompanied by systemic symptoms. Photosensitivity is common in Caucasian patients. All people with lupus should avoid direct, prolonged exposure to the sun. Sun-sensitive patients should frequently apply a sunscreen. The best sunscreen is one that protects against both UVA and UVB rays. To get adequate protection, patients should be advised to select either a “broad-spectrum protection” sunscreen with an SPF of at least 15, or one that contains micronized zinc oxide or titanium dioxide, both of which block UVA and UVB light. Sun-sensitive patients should also avoid unprotected exposure between 10 a.m. and 4 p.m., and wear protective clothing, such as wide-brimmed hats and long sleeves. In severe cases, patients may wish to purchase special UV-blocking clothing. People with lupus should be aware that UV rays are reflected off water and snow, and that glass, such as car windows, does not provide total protection from UV rays.

People with lupus should also know that fluorescent and halogen lights may emit UV rays and can aggravate lupus. This may be an issue for patients who work indoors, in places with these kinds of lights. Sunscreen and protective clothing can help minimize exposure, and plastic devices are available that block UV emissions from fluorescent or halogen light bulbs.

Lupus: A Patient Care Guide for Nurses and Other Health Professionals 3rd Edition

SUN PROTECTION RESOURCES

Clothing

Regular clothing sometimes doesn't offer enough protection for sun-sensitive skin. Fabrics are lightweight, cool and offered in a variety of colors. A special line of clothing with a sun-protective factor of more than thirty is now available through:

Sun Grubbies
1-888-970-1600

www.sungrubbies.com

Sun Precautions
1-800-882-7860

www.sunprecautions.com

Sun Solutions
1-800-895-0010

www.sunsolutionsclothing.com

Splashskins (children)
1-866-947-7946

www.splashskins.com

Sunveil Sunwear
1-800-565-0585

www.sunveil.com

Laundry Treatment

Rit® Sun Guard™ Laundry 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. If you are unable to find this product in your local supermarket or drug store contact www.seriouslyshady.com (1-800-867-4239) or www.dermadoctor.com (1-877-337-6237)

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.

Concord Window Films – An adhesive system that is factory coated onto the film and contains additional UV block materials. It is easily installed in cars or other windows and it is available in several widths. 203-798-0343 or www.buytint.net

Fluorescent Bulb Jackets – These jackets are open on three sides and easily slide over the bulb providing immediate protection. It is not even necessary to remove the bulb from the fixture. Fax: 1-800-271-0891

Solar-Screen Transparent Shades – These see-through shades keep out solar heat and glare, as well as ultraviolet rays. They are manufactured to fit windows and are available in a variety of colors.

For additional information about ultraviolet shields, contact your local branch office or order directly from Solar Screen Company, Inc., 53-11 105th Street, Corona, New York 11368, 1-800-347-6527. Their web page is: www.solar-screen.com

CAKOON UV-brella – 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 and are priced from \$25 to \$49. Great for rain, too! To order the CAKOON UV-brella call toll-free 1-888-225-6665 or visit www.raybeth.com to view all CAKOON UV products. Mention the Lupus Foundation of Pennsylvania and a donation will be made from sale proceeds.

Thank You to the Lupus Foundation of Pennsylvania for giving us permission to use this resource page from their newsletter.





LFMNNY Advocates and ARHP Members Kathleen Arntsen and Sandi Frear attended the ACR/ARHP Advocacy Event on February 24-25, 2008 and the LFA Gala on May 7, 2008. Pictured above left: Arntsen & Frear with ARHP Member Ann Kunkel. Arntsen received the ARHP Ann Kunkel Advocacy Award in 2007. The next 2 photos show Arntsen & Frear with Dr. Stephen Katz, Director of NIAMS at both the ACR Event and the LFA Event. Bottom right: Arntsen is pictured with Dr. Jeffrey Siegel, Supervisory Medical Officer at the US FDA CDER and his wife Dianne McCutcheon at the LFA Gala.



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. 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 September 11, 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 10% back as a donation for lupus research. The \$35 includes plate, stand, tribute on back, and priority shipping. If interested please e-mail lupusmidny@aol.com or call us at 315-829-4272.

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
or call 1-888-OK-LUPUS

RESEARCH

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 gene locus in SLE

Clinical studies:

Treatment of lupus nephritis with abatacept

Trials in the planning phase:

Treatment of lupus with N-acetyl cysteine

Prospective study of rapamycin treatment

For more information please call:
Irene Ramos at (315) 464-3836

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



The advertisement features a woman in a pink shirt and blue jeans walking a large grey wolf on a leash along a paved path lined with trees. In the top left corner, there is a logo for 'BLISS' (Baltimore International SLE Study) with a butterfly icon. At the bottom, there is a large orange banner with the text 'TO TAME LUPUS WE NEED YOUR STRENGTH' in white, bold, sans-serif font.

Lupus is the Latin word for wolf, but for many lupus patients it also means constant fatigue and a range of other symptoms that can affect daily life. We are studying an investigational treatment to see if it can help tame the disease.

If you are 18 years of age or older and have been diagnosed with lupus, you may be eligible to participate in this research study. For more information, call the number below or go to www.bliss-study.com

1056_PrintAdvert_2014/07_3amendment00

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



Visit LupusTrials.org »

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 & 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 & H</td> </tr> <tr> <td><input type="checkbox"/> LUPUS WELLNESS JOURNAL</td> <td style="text-align: right;">\$ 8.00 plus \$2.00 S & 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 & 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 & H</td> </tr> <tr> <td><input type="checkbox"/> BEANIE BEARS</td> <td style="text-align: right;">\$ 10.00 plus \$2.00 S & H</td> </tr> </table>		<input type="checkbox"/> LUPUS BOOK Revised by Daniel J. Wallace, MD	\$ 24.00 plus \$4.00 S & H	<input type="checkbox"/> COPING WITH LUPUS by Robert H. Phillips, PhD	\$ 15.00 plus \$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																								
Up-to-date Lupus Foundation of America, Inc. Brochures There is a \$.25 fee per brochure <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 & Vasculitis</td> </tr> <tr> <td>___ Kidney Disease & Lupus</td> <td>___ Pregnancy & 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 & 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 & 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 & Muscle Pain</td> <td>___ Lupus in Overlap w/ Connective Tissue Disease</td> <td></td> </tr> </table> <p style="text-align: center; margin-top: 10px;">Please remit total payment to: Lupus Foundation PO Box 139 Utica, NY 13503</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																								



**A
D
V
O
C
A
C
Y**



Pictured from the top left clockwise: LFMNNY Advocates with FL Congressman CW Bill Young; NY Congressman Michael Arcuri; FL Congressman John Mica; NY Congressman Maurice Hinchey; IL Congressman Donald Manzullo; and NY Congressman James Walsh's Legislative Staffer Ron Anderson during the LRI National Coalition Advocacy Day on March 5, 2008. To the right is Congressman CW Bill Young receiving a Butterfly of Hope Appreciation Award from LFMNNY Secretary Sandi Frear & President Kathleen Arntsen on May 8, 2008 in appreciation of his support of lupus and health care issues.

