Patient Advocates Travel to Capitol Hill

Washington, DC — Lupus Foundation of Mid and Northern New York patient advocates recently traveled to Washington, DC for a Lupus Research Institute National Coalition 2-day event. “Lupus Clinical Trials A Training for the Lupus Community” was held on Tuesday, April 24th and an Advocacy Day & Training was held on April 25th at L'Enfant Plaza Hotel. Our organization was in charge of the Hospitality Suite and Advocacy Day. Kathleen Arntsen & Sandi Frear developed all advocacy materials and conducted the training presentation and coordinated congressional meetings for the entire coalition. The event was a tremendous success as 60 advocates from the major metropolitan areas of the country met with 150 congressional offices delivering a strong message for support of our lupus-related issues. Helen Lenart & Sandi Frear were the hostesses for the hospitality suite where coalition members could gather informally to network and share ideas. Kathleen Arntsen was also a presenter during the Clinical Trials Training giving her patient perspective on trials participation. Shown here in front of the Capitol are Lupus Foundation of Mid & NNY advocates: President/CEO Kathleen Arntsen, Vice President Helen Lenart, Secretary Sandi Frear, and Volunteer Sheila Watts. Thank you to our advocates for bringing their passion and raising their voices on critical lupus issues.
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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.
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 at the Lupus Foundation of Mid and Northern New York. Between our national advocacy events and local education and fundraising events we have barely had time to breathe. Our 3rd Annual Education Symposium “Promise, Progress, and Opportunity” was held on May 19, 2007 at Rossetti Education Center at Madison-Oneida BOCES in Verona, NY. The event was a great success with record breaking attendance, support, and tremendous speakers. Dr. Betty Diamond, renowned lupus researcher and Chief of the Autoimmune Disease Center of the Feinstein Institute for Medical Research spoke on *Lupus and the Nervous System*. Dr. Beth Biggee, Bassett Healthcare Rheumatologist presented on *Endocrine Conditions and Lupus including Thyroid, Diabetes, Osteoporosis, HRT, Menopause, and Pregnancy*. Kathleen Arntsen, President/CEO of the Lupus Foundation of Mid & NNY presented on *Clinical Trials Participation – What to Know* and Rick Deyulio, from Armstrong Communications spoke on *Prescription Assistance Programs*. There were Exhibit Booth Displays, goodie bags, and Lupus Clinical Research Trial Information for all attendees. Here are my remarks from the Awards Luncheon.

We had another stellar year here at the Lupus Foundation of Mid & NNY. Our 6th Annual Lupus Charity Golf Classic was a tremendous success, with profits over $26,000.00, our membership hit 586 members, and our income reached over $68,000.00 net; allowing us to increase our annual research donation to the Lupus Research Institute to $20,000.00 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 Dr. Diamond? The secret to our success is simple, we have HEART! Our chapter volunteers and our supporters have tremendous passion and dedication to the lupus cause. None of us are paid for the endless hours we give to this organization, yet we continue to do so out of a desire to make the world a better place. For some of us volunteering fills a void in our lives after lupus ravaged our dreams of being parents or having a career. For others it shows support for our loved one suffering from this disease. No matter what the motivator is our little organization continues to move forward with optimism and hope for a brighter tomorrow for all in the lupus community. For 2006 we logged over 9,600 volunteer hours which would be equivalent to $220,000 in income! Please give all of our volunteers a big hand. Thank you so very much.

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 furthering our cause.

**Patient Education & Support - David L. Arntsen, Board Member;** David’s input has been instrumental in improving and refining our education programs.

**Fundraising - Stephanie Darwak, Board Member;** Stephanie’s personal efforts have raised thousands of dollars for our organization over the past 2 years. She also has a personal connection to lupus.

**Corporate Award - La Jolla Pharmaceutical Corporation;** LJPC has supported our education programs for the past 4 years. Several of us had the fortunate experience of touring their research facility in San Diego, CA 2 years ago.

**Promotion of Public Awareness - Mari-Kristine Neyhart;** Mari-Kristine has run the NYS Lupus Booth with her family for the past 5 years. Her wonderful and vibrant personality is contagious to all who come in contact with her.

**Volunteer of the Year - Sandi Frear;** Board Secretary, Education & Fundraising co-chairperson; Basket maker extraordinaire; my national advocacy partner and wearer of many hats in the lupus community like so many of us. Sandi came out of early retirement from the Lupus Foundation of Greater FL to become active in our organization 4 years ago. Her energy and expertise have benefited many of us here.

To everyone—Thank you again from the bottom of our hearts for your continuing commitment to our organization, we could not exist without your love and support.

*Be well and stay out of the sun —Kathleen*  

4
Memorials, Tributes, and Donations

**Memorials**
*In Loving Memory of…*

- Celia Linkiewicz-
  Kevin, Diane & Teal Siembab
- Lauren Croke-
  Sonya Linakis
- Antoinette Falbo-
  Dominick & Marie Oriolo
- Judy Ruebel-
  John & Colleen Gometz
- Sophie Allbright-
  Greg Hearty & Angela Tomaselli

**Donations**

- Irene Donato
- John & Joan Carmody
- Brian Petrizzo
- John Zagami
- Mary Rose Bullock
- CFC, SEFA, United Way,
  Merrill Lynch, Pfizer, and IBM Donors

**Tributes**
*In Loving Honor of…*

- Sandi Frear-
  Carnival Foundation
  Alcalde & Fay
- Geri Lemke-
  Family & Friends & ACS Co-workers
- Patricia Mitchell for Mother’s Day-
  Kathleen & David Arntsen
- Marian Arntsen for Mother’s Day-
  David & Kathleen Arntsen
- James E. Mitchell, Jr. for Father’s Day-
  Kathleen & David Arntsen
- Cathy Walseman-
  Beta Sigma Phi XI Delta Phi Sorority

**Education Symposium Support through**
**Unrestricted Educational Grants from:**
- Pfizer, Inc.
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- La Jolla Pharmaceutical Co.
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  PhRMA
- Exhibit Material & Other Sponsors-
  Encysive Pharmaceuticals
  Fallene, Ltd.
- ALCiS Health, Inc.
- Lupus Research Institute National Coalition
- Lupus Research Institute
- Lupus Clinical Trials Consortium- LCTC
- NIH; NIAMS; NIDDK; NIAID; NINDS
- NYS DOH Arthritis Program
- Sjogren’s Syndrome Foundation
- Scleroderma Foundation Tri-State Chapter
- Madison-Oneida BOCES
- Turning Stone Resort Casino
Dear Editor-

I am writing this letter to thank the Board of Directors of the Lupus Foundation of Mid & Northern New York and President/CEO Kathleen Arntsen for allowing me the opportunity to attend the Lupus Research Institute National Coalition Clinical Trials Training and Advocacy Day in Washington, DC. I am honored to represent this organization as a volunteer and I have learned a great deal about Patient Advocacy and Clinical Trials under the careful direction of Kathleen.

Kathleen’s dedication, commitment and sincerity are awe-inspiring. She has more knowledge about Lupus and autoimmune disease than any other patient I have ever met. She is the “go to” person for any questions or concerns regarding clinical trials, advocacy, and interacting with health care professionals. She is not afraid to speak up and be heard; making her a strong voice for patient rights and selflessly shares her knowledge and personal self-help tools.

I cannot say enough about how impressed I was with how well The Advocacy Day was put together, especially the resource materials, which were clear, concise, and easy to understand. Kathleen and Sandi Frear did an amazing job of developing the dynamic advocacy training presentation and preparing other coalition members to meet with their legislators fueled with outrage that there have been no Lupus drugs approved in over 40 years, and carrying with them the message that we (Lupus Patients) will not be ignored any longer. The time has come to hold our public officials accountable and to make drastic changes in legislation that affects Lupus Research funding.

I was diagnosed with Lupus in 1993 but it was not until recently when my daughter Alexis was also diagnosed with Lupus that I felt hopeless and filled with despair. As I walked around at Christmas time and saw all the displays by companies representing their charity of choice I became angry that so many lives are affected by this disease and yet even in 2007 physicians are still baffled and patients still go so long without being diagnosed because there is not enough awareness about the disease even within the medical community. I decided I had to do something. I had to take action.

In my quest for knowledge, answers, and someone to connect with; my path crossed Kathleen’s. She appeared in my life at just the right time. I was searching for an outlet for my emotions as the frustration of being on disability for the past two years and Alexis’s recent diagnosis had left me hopeless when Kathleen provided a much-needed outlet. I was able to deal with my own condition and diagnosis much better than I was with my daughter’s. Kathleen and I talked endlessly for hours…connected both by the devastation of this disease and by this cause. She has turned out to be an amazing and supportive friend and confidant. I know from attending The 3rd Annual Education Symposium and Luncheon "Promise, Progress, and Opportunity" that took place on May 19th in Verona, NY that there are many others who feel the same way about her. I was welcomed warmly by the outstanding, caring, and compassionate Board of Directors and Volunteers of the Lupus Foundation of Mid and Northern New York. Collectively they are an awesome team….

To Kathleen I say you are not “just a patient” but a remarkable person with the best intentions, most sincere and generous heart and lungs that allow you to be the voice for lupus patients and we need more patient advocates like you. I congratulate you on your very well deserved ACR/ARHP 2007 ANN KUNKEL ADVOCACY AWARD and look forward to collaborating with you on future projects and advocacy efforts.

Sincerely,

Sheila R. Watts, Patient Advocate & Volunteer
June 2007

Editor’s Note: Kathleen A. Arntsen is the first recipient of the ACR/ARHP ANN KUNKEL ADVOCACY AWARD nominated by Peggy Dowd, Lupus Research Institute President and Sandra Frear, Lupus Foundation of Mid & NNY Secretary to be presented at the ACR/ARHP Annual Scientific Meeting in Boston, MA in November. We are very proud of Kathleen and honored to have her as our President/CEO.
Clockwise from below: LFMNNY President Kathleen Arntsen with Keynote Speaker Dr. Betty Diamond. Registration Table. PhRMA Presenter Rick Deyulio with the PPA display. Key Volunteers Wendy & Pat Cianfrocco, Amanda Nemcek, and Sheila Watts. Presenter Dr. Beth Biggee, second from left with LFMNNY Vice President Helen Lenart, President Kathleen Arntsen, and Secretary Sandi Frear.

“PROMISE, PROGRESS, AND OPPORTUNITY”
Thank You Corporate Sponsors & Volunteers

Pfizer, Inc.

Volunteer of the Year Sandi Frear

Education Award David Arntsen

Fundraising Award Stephanie Darwak

Volunteer & Corporate Appreciation Awards

Clockwise from top right—LFMNNY President/CEO Kathleen Arntsen, Secretary Sandi Frear, and Vice President Helen Lenart. Officers Lenart, and K. Arntsen with Education Award Recipient David Arntsen. Officers Lenart, Arntsen, and Frear with Fundraising Award Recipient Stephanie Darwak. Officers Lenart, Frear & Arntsen with Syracuse.com Sponsors Melissa McEnaney & Troy Hogue. Rick Deyulio from PPA with President Arntsen. Board Member Stephanie Darwak with Pfizer Sponsor Appreciation Award.
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 (SPF) of more than 30 is now available. Fabrics are lightweight, cool and offered in a variety of colors. Additional information is available by calling the companies.

Sun Grubbies Sun Precautions Sunveil Sunwear
1-888-970-1600 1-800-882-7860 1-800-565-0585

Sun Solutions Splashskins (children)
1-800-895-0010 1-866-947-7946
www.sunthesesclothing.com www.splashskins.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 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.


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.
PGA TOUR EVENT FUNDRAISING OPPORTUNITY

The Oneida Nation has established the Upstate New York Empowerment Fund as a regionwide charitable–community partnership to promote fund-raising opportunities in conjunction with their PGA TOUR Event. You can help us to raise funds for Lupus Foundation of Mid and Northern New York by participating in Birdies for Charity through a minimum pledge of one cent per birdie or $5.00 flat donation or by purchasing tickets from us for the PGA Tour Event to be held at Atunyote Golf Course on September 17-23, 2007. We receive 100% of Birdies for Charities Pledges and 100% of the PGA Ticket Sales we make. Please contact us at 315-829-4272 for more information.

STATE FAIR VOLUNTEERS NEEDED

State Fair Volunteers are needed to man the Lupus Agencies of New York State Booth in the Science & Industry Building during the NY State Fair. Each volunteer works a 3-hour shift with another person and receives admission to the fair and a parking pass for the Orange lot. The fair runs from Thursday August 23, 2007 to Monday, September 3, 2007. If you are interested in volunteering please contact Mari-Kristine Neyhart at 315-454-0034.

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 June 21, 2007. Due to summer vacations and busy schedules we will not meet during the months of July & August. Meetings will resume in September.

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

LUPUS NEPHRITIS

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

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

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

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

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

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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

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Patient Registry SLE

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

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

To learn more about the study and if you may qualify, call toll free 1-888-68LUPUS or visit www.lupusclinicalstudy.com.
**LUPUS FOUNDATION OF MID AND NORTHERN NEW YORK**  
**MEMBERSHIP APPLICATION & ORDER FORM**

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- [ ] 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 $4.50 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 $1.00 plus .25 per 3 S & H  
- [ ] Orange or Purple  
- [ ] 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  

**Please remit total payment to:** Lupus Foundation PO Box 139 Utica, NY 13503
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LUPUS CHARITY GOLF CLASSIC
AUGUST 10, 2007
Shenendoah Golf Club
Turning Stone Casino Resort

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☐ Other Donation – Please list _______________________________

*All foursomes include 18 holes of golf w/cart, dinner, gift, and prizes 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!
7th Annual 
LUPUS Charity Golf Classic

Shenendoah Golf Club 
at Turning Stone 
Friday, August 10, 2007

Sponsored by: 
LUPUS FOUNDATION 
of Mid and Northern New York, Inc.

A Premier Charity Golf Tournament

Registration - 11:30AM            Shotgun Start - 1:00PM

Tournament Format: Captain & Crew "Best Ball"

GOLF - AWARDS BANQUET - PRIZES

Complimentary Practice Range

Accepting Registrations for:

Teams - Pairs - Individual Golfers

Men, Women, Senior, and Mixed Categories

Enjoy a great round of golf and help to Make a Difference locally for those affected by Lupus

Honorary Chairman - Donald A. Raddatz, MD
Bassett Healthcare Rheumatologist

To Register, Become a Sponsor, or to Donate a Prize
Please Call 315-829-4272 or
e-mail lupusmidny@aol.com or visit our website www.nolupus.org
Loop for Lupus

Poker Run and OUTBACK Bar-B-Q

All Vehicles Welcome

Sponsored by the Red Knights MC NY Chapter XIX
to benefit the Lupus Foundation of Mid and Northern NY

Sunday July 1, 2007
Registration 11:00 - 12:00 noon
Munnsville Fire Department  Rt. 46, Munnsville, NY

Entry Fee $20 per Motorcycle

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

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

PRIZES - 50/50 RAFFLE
Silent Auction

Music by BILAL

For More Information
315-336-4117
315-829-4272
www.nolupus.org

Learn About Lupus
Get into the loop.