

*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. 1, Summer 2010

## 10th Annual Lupus Charity Golf Classic Sets Record



The 10th Annual Lupus Charity Golf Classic was held on August 13, 2010— a gorgeous Friday afternoon at Shenendoah Golf Club a Turning Stone Resort Casino in Verona, NY and a new fundraising record was set with net proceeds just over \$33,000 to support our program services. The weather was superb and the course was in beautiful condition due to the PGA Event practice rounds being held there the week before. Once again Dr. Donald Raddatz, Bassett Healthcare Rheumatologist was Honorary Chairman and Pfizer was Tournament Sponsor. Pictured to the left is Shenendoah Golf Club Tournament Director Andy Myers explaining the rules to the golfers during the shotgun start. Below left is golfer Mike Simonds from Team Maryrose Too practicing his putting. Pictured below right is Team A-NIT-A Cure enjoying the barbecue luncheon on the patio during registration.

The 11th Annual Lupus Charity Golf Classic will be held on Friday, August 12, 2011 at Shenendoah Golf Club. A complete list of sponsors can be found on page 7 and more pictures can be found on pages 8 and 9 and on our website [www.nolupus.org](http://www.nolupus.org). Thank you to Dr. Raddatz, the sponsors, golfers, prize donors, volunteers, golf classic committee, and Turning Stone staff for making this event a success!



# *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**

<b>Golf Classic .....</b>	<b>1</b>
<b>Newsletter Information .....</b>	<b>2</b>
<b>Campaigns .....</b>	<b>3</b>
<b>President's Message .....</b>	<b>4 &amp; 5</b>
<b>Memorials, Tributes &amp; Donations .....</b>	<b>6</b>
<b>Golf Classic Sponsors .....</b>	<b>7</b>
<b>Golf Classic Photos .....</b>	<b>8 &amp; 9</b>
<b>NIAMS Article .....</b>	<b>10 &amp; 11</b>
<b>Flu Article .....</b>	<b>11 &amp; 12</b>
<b>Clinical Trial Info .....</b>	<b>13</b>
<b>Membership Form .....</b>	<b>14</b>
<b>Announcements .....</b>	<b>15</b>
<b>Lupus Booth at the NYS Fair .....</b>	<b>16</b>

## **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*  
**James E. Mitchell Jr.**

*Treasurer*  
**Philip A. Teague**

*Secretary*  
**Stephanie C. Darwak**

*Chairman of the Board*  
**David L. Arntsen**

*Members*  
**Dale R. Bullock**  
**Maryrose T. Bullock**  
**Ellen C. Gloo**  
**Jacqueline L. Taylor**

*Honorary  
Medical Advisory Board*

**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*



Community  
Health Charities  
— of New York —  
WORKING FOR A HEALTHY AMERICA



*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—*

I was completing this issue of the newsletter filled with pride over sharing the news of our successful summer with you while contemplating the theme for my President's Message when a call came in on the lupus line that guided me in the right direction. It was Sharon Ryan, a long time supporter of our Golf Classic calling with the sad news that Mary Becker had passed away. Mary fought a long, courageous battle with her lupus and had defied the odds many times. She always remained positive no matter what was thrown her way and was loved by all who knew her. She enjoyed golf and quilting and was active in her church, helping others. She was able to play in 3 of our golf tournaments, even going up to the hotel room for her dialysis. She never gave up hope that a donor kidney would come along and sure enough it did. She was so proud that her husband Larry and son had played in our event with her. We are extremely saddened by Mary's passing and extend condolences to her family and friends. Since this issue is about the golf event I think it is only fitting to dedicate it to Mary L. Becker in honor of her spirit, her courage and her ability to inspire all of us; she will be missed. Here are my remarks from the Golf Classic Awards Dinner.

"I want to thank all of you for being here today and hope you enjoyed the course and your round of golf. This is a year of milestones for us here at the Lupus Foundation of Mid & Northern NY. This year is the 10th Anniversary of our Lupus Charity Golf Classic. When we began 10 years ago we were not sure how much we could raise at a golf tournament and were delighted when we hit \$10,000 in profits for the first time ever on any fundraiser. Many of you who supported us then are still coming back year after year and we thank you for being loyal to both the event and to us. I am very pleased to say that our projected profit from today's event and a new record for us is approximately \$33,000! Now that definitely deserves a round of applause.

Since we have more than tripled our net proceeds in a decade I feel compelled to thank you 3 times over this year for your commitment to us because of the current economy. It has been a difficult year for everyone in the nation, especially for charities like us trying to raise funds to support our program services. We were forced to work extra hard in order to reach our fundraising goals this year. Thank you all from the bottom of our hearts for choosing to support us during these challenging fiscal times. Thank you for recognizing that lupus does not diminish nor disappear just because the nation is facing a crisis. It may not seem like a lot to you that you came here today and supported us but it means a great deal to all of us affected by this devastating disease.

The monies raised from this event support our program services including our education, advocacy, and awareness programs. We not only advocate for people affected by lupus and other autoimmune diseases but also for health care reform and patient access issues which affect each and every American. We were the lead agency coordinating the 2nd Lupus Awareness Event and Month in NY State in May in Albany and our resolution is on display here. Because of our strong grassroots advocacy efforts we were able to help get 2 key pieces of legislation passed that can help our patients. The Lupus Taxpayer Gifts Bill was the first lupus legislation ever to be passed in both the NYS Senate and Assembly. This landmark legislation would list lupus as a check-off box on the NYS Tax Return from 2011 on and every local legislator from our service area supported this bill for us. The second key bill we supported is the Specialty Tier Prescription Drug Bill. This legislation also passed in both houses of the NYS Legislature and prohibits commercial insurance plans from creating specialty tiers within their prescription drug formularies based on expense or disease categories. And for the 21st year we are coordinating the Lupus Agencies of NY State Booth at the State Fair in the Science & Industry Building. We are very proud of our accomplishments as a small, all-volunteer non-profit agency in rural, upstate NY. We want you to know that 98.5% of every dollar we raise goes back to program services. It is amazing what a small group of passionate & dedicated individuals can achieve!

This event also funds our Research Program Services. We are proud to say that we give 1/3 of our income to research each year. I would like to share some figures with you on the 10th Anniversary of our Golf Classic. Because of your tremendous support and generosity over the years we have netted \$232,427 from this event that has enabled us to enhance our local program services, and fund \$159,000 in grants to Lupus Research. Because of research, the lupus community is close to having the first lupus drug approved in 55 years. So as you can see it has been a tremendous year for us locally as well as for lupus overall.

In closing, I would like you to help me to pay tribute to everyone who makes this event successful. First I must recognize our Board of Directors, please stand. Not only are all 10 of our Board Members here today working (and 2 traveled from Florida) but each of them also raised at least \$500. Thank you for your strong leadership. Secondly, I invite Dr. Donald Raddatz to stand. Dr. R has been a fixture at all 10 Golf Classics and has served as Honorary Chairman for the past 5 years. Thank you very much for your support and commitment to our organization. He has agreed to continue as Chair as long as we don't give him any embarrassing gifts. Next I ask all of our Volunteers to rise and take a bow or curtsy. This event could not happen without your dedication so thank you so much for your efforts. You may all sit down.

At this time I would like to recognize our Sponsors. Just look at the program to see the tremendous support we receive from all of our patients and their families, friends, unions, legions, physicians, and employers. For 10 years the patients have been our inspiration by becoming fully engaged in this event. You see Lupus does not just affect individuals but affects everyone close to us. Your generosity has kept this event and our agency going and growing each year. Special thanks to Anna Maria Maritato & Pfizer as Tournament Sponsor. Thanks to my family the Mitchells as Cart Sponsor and my husband David—for years you have been there for me even carrying me when I could not continue on my own. Thank you to Vic Gazzilli and Lou Demichele from Carbone as our Hole in One Sponsor. Thanks to Geri Lemke, Phil Teague, Ellen Gloor, Sandi Frear, Jane Porter, Cathy Walseman, Lisabeth Iglesias, Maryrose & Dale Bullock & Beta Sigma Phi, Wendy Cianfrocco & NYSCOPBA, Jackie Taylor & UFCW, Anita & Brigid and your team, The Ryans & Mary Becker, Victoria Shepardson, David Snitchler & The Transit Union, George Penree & the Utica Firefighters, and Oliver Santana & WalMart representatives Don Defeo & Penny Watkins for your ongoing support. Bravo to our new Corporate Sponsors, Shannon Graham from PhRMA, Congressman Mike Arcuri, Rick Deyulio, Assemblywoman RoAnn Destito, and Jaime Venditti from JS Strategies for supporting us. And thanks to Tom Francisco from Putnam Pest and others who increased their donations this year. Thank you all so very much from the bottom of our hearts.

Finally, I would be remiss if I did not extend appreciation to all of the Golfers. Thank you for participating in today's event, for being such good sports, and for your extraordinary support. As you can all see fundraising events like this cannot succeed without the collaborative efforts and heart of everyone here today. All of us collectively make it happen; together we are powerful and making a positive difference in the lives of those affected by lupus. Thank you all again for joining us here today, and for keeping our hope and our families' hopes alive that we will conquer this debilitating disease soon."

*Stay Warm and Well— Kathleen*

### **Mary doing what she loved.**



Pictured above left is Mary Becker and Sharon Ryan with their all gals team at the 2003 Golf Classic; above center is Mary with her husband Larry (2nd from left) and her son Larry at the 2004 event; and above right is Mary with her son Larry and her dear friends Sharon & Will Ryan at the 2005 Golf Classic.

# *Memorials, Tributes, and Donations*

## Memorials

*In Loving Memory of...*

*Michael Eck-*

*Johanna Zeszutko*

*Fran & Peggy Frantz*

*Garden St. Investment Group*

*The Funshine Girls*

*Camille Jasinski*

*Tuesday's Cards Special Friends*

*Kelly Blake-*

*Beverly Hobbs, Gordon & Gertrude Decker,*

*Frank & Joan Pochobradsky,*

*Alfreda Konik, Ellen Buehler,*

*Dolores Buehler, Debra Male*

*Nicholas D. Ricci-*

*Phil & Phyl Cittadino*

*Bonnie Martin-*

*Kay J. Falcone*

*Mary Becker-*

*David & Kathleen Arntsen,*

*Roland & Mary Guinn, Daymon Worldwide*

## *Golf Classic Memorials-*

*Marguerite Curri, Peter & Dorothy Curri,*

*Angela "Aya" Lo Conti,*

*Michael P. Jones, Elizabeth Jones,*

*The Rev. S. Kenneth Arntsen,*

*Mary Alice Mitchell, Jim Mitchell,*

*Arthur A. Relf, Louis A. Relf,*

*Lorna E. Relf, Sam Relf,*

*Thomas P. Mitchell,*

*Louis Smith, Christine Marie Smith,*

*Elva Fox, John Bagley, Alberta Bagley,*

*John H. Dabolt III,*

*Wellington N. Walseman, Douglas C. Kerr,*

*Anita W. Curtiss, Elwood D. Virkler,*

*Ethel Clark, Brooke N. Walseman,*

*Harold F. Woolshlager, James McCarthy,*

*Richard W. Cassin, John Hudec,*

*Barbara M. Porter, Robert E. Porter,*

*Sandra Haase, Rosemary Franklin,*

*Amy Bryant Mowers, Ethel Clark,*

*Bill Acquaviva, Trudy Morrissey,*

*Eleanore Iglesias*

## Tributes

*In Loving Honor of...*

*Gerri Lemke-*

*Virginia Merola*

*Roxanne Falitico-*

*Virginia Merola, Rocco & Monica Falitico*

*David Arntsen's Birthday-*

*James & Patricia Mitchell,*

*Jill Anne Smith*

*Kathleen Arntsen's Birthday-*

*James & Patricia Mitchell,*

*Dan & Lois Rumpfelt, Jill Anne Smith,*

*Tom & Jackie Taylor*

*Rocco & Monica Falitico-*

*Virginia Merola*

*Lewis County Lupus Patients-*

*Beta Sigma Phi Lowville Chapter*

## Donations

*CFC, SEFA, United Way, IBM, GE,*

*American Express, United Health,*

*and Pfizer Employee Donor Plans*

*Syracuse University SCOPE Members,*

*Frances Eck, JoAnne Klein, Julia Lauber,*

*Virginia Merola, Jim & Connie Coulthart,*

*Anna Maria Maritato, Dan & Lois Rumpfelt,*

*Susan Keller, Cece Flyzik, Sue Foreman,*

*Donald Raddatz, MD, Sarah Sackett,*

*Marilyn Sousa, Ellie Canell, Don & Sharon Lust,*

*Bob & Cathy Walseman, Don & Joan Gloor,*

*Jeffrey & Susan Virkler & Family,*

*Isabel Woolshlager, Angela Bouchard,*

*Jill Anne Smith, Jane Williams,*

*Larry & Karen Woolshlager & Family,*

*Bill & Sandi Frear, Robert & Jennifer Porter,*

*Sheila Arcaro, Tina Fox, Annie Myes,*

*Dale & Maryrose Bullock, Beverly Ballard,*

*John Porter & Elisabeth Kaye, Sue Lundin,*

*Terry Church, Laury Kerr, Sharon Clute,*

*David & Kathleen Arntsen, Sonya Linakis,*

*James & Patricia Mitchell, Dan & Lisa Mitchell,*

*Joseph & Victoria Jupin, Jane Porter*

# ***Golf Classic Sponsors***

## **TOURNAMENT SPONSOR**

**Pfizer, Inc.**

## **CART SPONSOR**

**The Mitchell Family & MCORP/MARY KAY in honor of Kathleen**

## **PLATINUM SPONSOR**

**Hole-In-One sponsored by Carbone Dodge Chrysler Jeep**

**Family & Friends of Geri Lemke**

**Congressman Michael Arcuri**

**ΒΣφ Alpha Iota Oneonta Chapter in Honor of Maryrose Bullock**

**NY State Corrections Officers PBA**

**Pharmaceutical Research & Manufacturers of America**

**Utica Professional Fire Fighters IAFF Local 32**

**Wal Mart Store #1677**

## **GOLD SPONSOR**

**David & Kathleen Arntsen**

**Rick Deyulio**

**Ellen Gloor**

**Teague Accounting Xperts, Inc.**

**UFCW District Union Local ONE in honor of Jackie Taylor**

## **SILVER SPONSOR**

**Amalgamated Transit Union Local 1145**

**Helen E. Cassin in Memory of Richard W. Cassin**

**In Memory of Barbara & Robert Porter: Cassin, Frear & Porter Families**

**Presto Print, LLC**

**Putnam Pest Control**

**Raquel Rosen, MD**

**Ryan Family Real Estate & Investment in Honor of Mary Becker**

**Scharf Plumbing & Heating**

**Surgical Association of Utica, PC**

## **BRONZE SPONSOR**

**Americu Credit Union**

**Marian J. Arntsen in honor of Dave & Kathleen's 20<sup>th</sup> Anniversary**

**Arthritis Health Associates**

**CPF, Inc. in Honor of Sandi Frear**

**Assemblywoman RoAnn Destito**

**Rocco & Monica Falitico in honor of Roxanne Falitico**

**In Memory of Eleanore Iglesias**

**JS Strategies, Inc.**

**Laury Kerr in honor of Cathy Walseman**

**Laurens American Legion Post 1688**

**Edward B. Lee, MD**

**Pierce Auto Parts**

**In Honor of Cathy Walseman: Bob Walseman & Isabel Woolshlager**

# 10th ANNUAL LUPUS CHARITY GOLF CLASSIC



Pictured above left Men's Champions Team NYSCOPBA; above center Ladies' Champions Team Lemke with Honorary Chair Dr. Raddatz; above right Co-ed Champions Team Wal-Mart



Tournament Sponsor Pfizer

Cart Sponsor Mitchell Family & MCORP



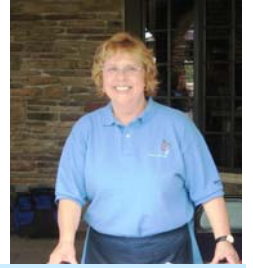
Pictured above left Hole-in-One Sponsor Carbone Dodge, Platinum Sponsors: NYCOPBA, Wal-Mart, UPF Local 32; Platinum Sponsors pictured below: Geri Lemke, and PhRMA



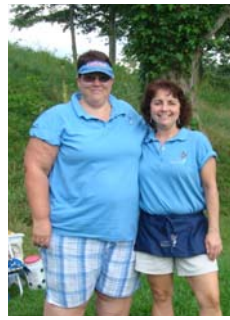
Gold Sponsors UFCW Local One & Teague Accounting

Thank you to our 2010 sponsors, golfers, prize donors, ticket sellers, volunteers, and supporters for making this event possible.

# SHENENDOAH GOLF CLUB



**OUR VOLUNTEERS ARE THE REASON THIS EVENT IS SUCH A SUCCESS !!!**



**Volunteer & Gold Sponsor Ellen Gloor**



# NIH scientists discover secrets of helper T cells involved in autoimmunity

Scientists at the National Institutes of Health have redefined the roles of several cytokines involved in the generation of immune cells implicated in severe autoimmune diseases. The study in mice showed that development of Th17 immune cells can occur without the presence of transforming growth factor (TGF)-beta, a mediator thought to be required for Th17 cell development. The study demonstrates that the interaction of three inflammatory cytokines (proteins that influence the behavior of cells) – interleukin-6 (IL-6), IL-1-beta and IL-23 – is responsible for the creation of Th17 cells that are more active in promoting autoimmunity than Th17 cells generated with IL-6, IL-1-beta and TGF-beta. These findings reemphasize the separate roles of IL-23 and TGF-beta in immunity and autoimmunity, and open up possibilities for the development of new therapies. The study appears in the current issue of the journal *Nature*.

The immune systems of mice and humans mainly consist of B cells and T cells. While B cells fight infections and can induce autoimmunity by producing antibodies that directly target foreign antigens or a person's own tissue, T cells are involved in overall cell-mediated immunity. Importantly, how a T helper (Th) cell differentiates (develops from an immature, unspecialized cell into a mature, specialized cell) determines how it mediates immune responses. Th17 cells produce IL-17, a powerful inflammatory cytokine, and have been implicated in multiple autoimmune diseases, including rheumatoid arthritis, psoriasis and multiple sclerosis. The established belief has been that Th17 cells initially differentiate in response to activation by IL-6 and TGF-beta. However, previous research has shown that TGF-beta is primarily associated with suppressing immune functions and promoting regulatory T cells (Treg), which can produce inhibitory cytokines that dampen inflammatory immune responses.

In the present study, the NIH scientists first looked at the conditions to differentiate Th17 cells from naïve T cells outside of the mouse (in vitro) and tried several different cocktails of cytokines to see which combinations would promote Th17 development. They found two combinations that efficiently induced Th17 differentiation. As previously described, IL-6, IL-1-beta, and TGF-beta-1 together created Th17 cells. Surprisingly, IL-6, IL-1-beta, and IL-23 without TGF-beta also created Th17 cells. Most interestingly, the action of Th17 cells generated with IL-23, designated Th17(23), was different from the action of Th17 cells generated with TGF-beta (Th17(beta)). The researchers compared transcription factors, receptors and mediators of the two Th17 subtypes and looked at the pathogenic activity of both Th17 subtypes in mice during experimental autoimmune encephalomyelitis (EAE), a common model of autoimmunity that mimics some aspects of multiple sclerosis. They found that Th17(23) cells provoked significantly more severe disease than did Th17(beta) cells.

These findings suggest a new model for Th17 generation and the existence of functionally different subtypes of Th17 cells. This study also provides a better understanding of the array of immune components involved in autoimmunity and suggests possibilities for new targeted therapies.

NIH scientists contributing to this study are affiliated with the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), the National Institute of Dental and Craniofacial Research (NIDCR), and the National Institute of Allergy and Infectious Diseases (NIAID). Additional support was provided by Merck Research Laboratories (Schering-Plough Biopharma), Palo Alto, Calif.

## *Reference*

Ghoreschi K, Laurence A, Yang XP, Tato CM, McGeachy MJ, Konkel J, Ramos HL, Wei L, Davidson T, Bouladoux N, Grainger J, Chen Q, Kanno Y, Watford WT, Sun HW, Eberl G, Shevach E, Belkaid Y, Cua DJ, Chen W, O'Shea JJ. Enhanced Pathogenicity of Th17 cells Generated in the Absence of Transforming Growth Factor- $\beta$  Signaling. *Nature*. 2010 October 21;467(7318): 967-971.

The mission of the National Institute of Arthritis and Musculoskeletal and Skin Diseases, a part of the U.S. Department of Health and Human Services' National Institutes of Health, 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 Web site at <http://www.niams.nih.gov>.

The National Institute of Dental and Craniofacial Research (NIDCR) is the Nation's leading funder of research on oral, dental, and craniofacial health. For more information about NIDCR, visit the NIDCR Web site at <http://www.nidcr.nih.gov/>.

The National Institute of Allergy and Infectious Diseases (NIAID) conducts and supports research — at NIH, throughout the United States, and worldwide — to study the causes of infectious and immune-mediated diseases, and to develop better means of preventing, diagnosing and treating these illnesses. News releases, fact sheets and other NIAID-related materials are available on the NIAID Web site at <http://www.niaid.nih.gov>.

The National Institutes of Health (NIH) — *The Nation's Medical Research Agency* — includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. It is the primary federal agency for conducting and supporting basic, clinical and translational medical research, and it investigates the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit [www.nih.gov](http://www.nih.gov)

## Arthritis and the Flu

**People with certain types of arthritis (listed below) have a higher risk of getting flu-related complications, such as pneumonia.**

Rheumatoid arthritis (RA), Systemic lupus erythematosus (SLE), Psoriatic arthritis, Anti-phospholipid syndrome, Polymyalgia rheumatic, Systemic sclerosis/scleroderma, Spondyloarthropathies, Sjögren's syndrome, Polymyositis/dermatomyositis, Vasculitis (e.g giant cell arteritis), Necrotising arteritis, Sarcoidosis, Polyarteritis nodosa

**People with inflammatory arthritis or rheumatic disease should get vaccinated.**

**Persons with inflammatory arthritis should not use the inhaled "FluMist®" vaccine.**

**If you are taking certain medications for your arthritis, they may weaken your immune system, and put you at high risk for getting the flu or complications from the flu.** Note: This list applies to medications that are ingested or injected and does **NOT** include medications that are applied to the skin such as creams and ointments. Your healthcare provider can clarify if the medications that you take weaken the immune system.

### People with Health Conditions

People with certain health conditions such as asthma, arthritis or lupus, diabetes, cancer, HIV/AIDS, heart or kidney disease, or morbid obesity may face special medical challenges during flu season.

### All Health Conditions and the Flu

**If you have one of these health conditions**—asthma, arthritis or lupus, diabetes, cancer, HIV/AIDS, heart or kidney disease, or morbid obesity and you develop flu-like symptoms, contact your health care provider or seek medical care.

## Arthritis and the Flu (cont'd)

**Serious complications** from the flu include pneumonia, ear and sinus infections, dehydration, or even death.

**If you have a chronic medical condition**, during a flu outbreak you should:

**Get a written record of the kind of chronic disease(s) you have** and the treatment you are receiving. Keep this information with you at all times.

**Prepare a typed or printed list of all medications** usually taken and the times of day they are taken. Also include necessary medical supplies or equipment such as syringes, strips, lancets if you have diabetes, or oxygen if you have

**Keep the name, phone number, and office address of your doctor** or health care provider with you at all times.

If you use medications for your condition, **continue taking those medications even if you become sick with the flu**, unless your doctor or health care provider says otherwise

**Be alert to changes in your breathing**, especially if you have heart failure, congestive heart disease or COPD.

Promptly report changes to your doctor or health care provider

**Inform family members** or close friends of your medical condition.

**If you have a chronic medical condition, do the following to prevent from getting sick:**

**Take time to get vaccinated.**

**Get the Seasonal Flu Vaccine:** The seasonal flu vaccine protects against the three most common flu viruses. The 2010-2011 flu vaccine protects against three different flu viruses: an H3N2 virus, an influenza B virus and the H1N1 virus that caused so much illness last season. The Seasonal Flu Vaccine can protect you from getting sick from these

**Take everyday preventive actions.**

- **Wash your hands often with soap and water.** Alcohol-based hand cleaners are also effective.
- **Avoid touching your eyes, nose or mouth.** Germs spread this way.

**Avoid close contact with sick people.**

**If you do get the flu:**

**Cover your nose and mouth with a tissue when you cough or sneeze to keep from spreading flu viruses to others.** Throw the tissue in the trash after you use it.

**Wash your hands often with soap and water**, especially after you cough or sneeze. Alcohol-based hand cleaners are also effective.

**Stay home if you are sick until at least 24 hours after you no longer have a fever (100°F or 37.8°C) or signs of a fever (without the use of a fever-reducing medicine, such as Tylenol®).**

**Take antiviral drugs if your doctor recommends them.** Antiviral drugs may be especially important for people who are sick and have a health condition that places them at greater risk of flu complications. For maximum effectiveness, antiviral drugs should be taken as soon as possible after symptoms begin.

[www.FLU.Gov](http://www.FLU.Gov) Know what to do about the Flu. A federal government Website managed by the [U.S. Department of Health & Human Services](http://www.HHS.gov) - 200 Independence Avenue, S.W. - Washington, D.C. 20201

# 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](http://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																								
<table style="width: 100%; border: none;"> <tr> <td style="border: none;"><input type="checkbox"/> LUPUS BOOK Revised by Daniel J. Wallace, MD</td> <td style="border: none; text-align: right;">\$ 24.00 plus \$4.00 S &amp; H</td> </tr> <tr> <td style="border: none;"><input type="checkbox"/> COPING WITH LUPUS by Robert H. Phillips, PhD</td> <td style="border: none; text-align: right;">\$ 15.00 plus \$3.00 S &amp; H</td> </tr> <tr> <td style="border: none;"><input type="checkbox"/> COOLIBAR SUN PROTECTIVE CLOTHING</td> <td style="border: none; text-align: right;">\$ 20.00 plus \$5.00 S &amp; H</td> </tr> <tr> <td style="border: none;"><input type="checkbox"/> THE AUTOIMMUNE EPIDEMIC by Donna Jackson Nakazawa</td> <td style="border: none; text-align: right;">\$ 15.00 plus \$4.00 S &amp; H</td> </tr> <tr> <td style="border: none;"><input type="checkbox"/> AWARENESS WRISTBANDS <i>Orange or Purple</i></td> <td style="border: none; text-align: right;">\$ 1.00 plus .25 per 3 S &amp; H</td> </tr> <tr> <td style="border: none;"><input type="checkbox"/> BEANIE BEARS</td> <td style="border: none; text-align: right;">\$ 10.00 plus \$3.00 S &amp; 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 \$3.00 S & H	<input type="checkbox"/> COOLIBAR SUN PROTECTIVE CLOTHING	\$ 20.00 plus \$5.00 S & H	<input type="checkbox"/> THE AUTOIMMUNE EPIDEMIC by Donna Jackson Nakazawa	\$ 15.00 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 \$3.00 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 \$3.00 S & H																								
<input type="checkbox"/> COOLIBAR SUN PROTECTIVE CLOTHING	\$ 20.00 plus \$5.00 S & H																								
<input type="checkbox"/> THE AUTOIMMUNE EPIDEMIC by Donna Jackson Nakazawa	\$ 15.00 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 \$3.00 S & H																								
<b>Up-to-date Lupus Foundation of America, Inc. Brochures      There is a \$.25 fee per brochure</b> <table style="width: 100%; border: none; margin-top: 5px;"> <tr> <td style="border: none;">___ What is Lupus?</td> <td style="border: none;">___ Anti-Phospholipid Antibodies</td> <td style="border: none;">___ Lupus &amp; Vasculitis</td> </tr> <tr> <td style="border: none;">___ Kidney Disease &amp; Lupus</td> <td style="border: none;">___ Pregnancy &amp; Lupus</td> <td style="border: none;">___ Childhood Lupus</td> </tr> <tr> <td style="border: none;">___ Skin Disease</td> <td style="border: none;">___ Blood Disorders in SLE</td> <td style="border: none;">___ Lupus in Men</td> </tr> <tr> <td style="border: none;">___ Sjogren's Syndrome</td> <td style="border: none;">___ SLE &amp; The Nervous System</td> <td style="border: none;">___ Depression</td> </tr> <tr> <td style="border: none;">___ Medications</td> <td style="border: none;">___ Steroids Used in Treatment of Lupus</td> <td style="border: none;">___ Drug-Induced Lupus</td> </tr> <tr> <td style="border: none;">___ Lupus &amp; Infections</td> <td style="border: none;">___ Laboratory Tests Used in Diagnosis</td> <td style="border: none;">___ Basics for Better Living</td> </tr> <tr> <td style="border: none;">___ Cardiopulmonary Disease</td> <td style="border: none;">___ Non-Steroidal Anti-Inflammatory Drugs</td> <td style="border: none;">___ Photosensitivity</td> </tr> <tr> <td style="border: none;">___ Joint &amp; Muscle Pain</td> <td style="border: none;">___ Lupus in Overlap w/ Connective Tissue Disease</td> <td></td> </tr> </table> <p style="text-align: center; margin-top: 10px;"><b>Please remit total payment to: Lupus Foundation PO Box 139 Utica, NY 13503</b></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 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

### Fall General Meeting & Informal Chat Session

Tuesday, November 30, 2010

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

### 3rd Annual Lupus Awareness Day

Wednesday, May 4, 2011

Legislative Office Building Well Albany, New York

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  
 Research  
 Institute**



**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

# Autumn is our Annual Membership Drive

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

Have a Blessed Thanksgiving!



## LUPUS AWARENESS AT THE NY STATE FAIR

For the 20th consecutive year volunteers from the Lupus Foundation of Mid and Northern New York manned the Lupus Agencies of NY State Exhibit at the NYS Fair in Syracuse during late August. The booth gives us the opportunity to promote lupus awareness and disseminate information to a much larger population within the state. Pictured below left are LFMNNY volunteers Molly, Bridget & David Snitchler, Tom & Jackie Taylor and Lisabeth Iglesias. Below right is LFMNNY Board Chairman David Arntsen volunteering a shift during the fair. Thank you to all of our volunteers who donate their time and endure the crowds and heat to support the exhibit. Also volunteering but not pictured were: Nathan & Lauryn Mitchell, Kathleen Arntsen, Maryrose Bullock, Joyce Bouchard, Jaime Venditti, Rick Deyulio, Mark O'Rourke, and Mari-Kristine & Jeff Neyhart and their family. After many years of dedicated service the Neyharts have decided to retire as the Directors of the Lupus Exhibit. We owe a debt of gratitude to them for their support and service in promoting and organizing this event for all of us in the New York State Lupus community.

