LUPUS
Foundation of Mid and
Northern New York, Inc.

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. 4, Summer 2011*

RECORDBREAKING LUPUS CHARITY GOLF CLASSIC

What a beautiful day to break a record. The 11th Annual Lupus Charity Golf Classic was held on August 12th, 2011; a perfect Friday afternoon at Shenendoah Golf Club at The Turning Stone Resort in Verona, NY. More than $42,000 net proceeds were raised to fund our program services. Thank you to all of the golfers, sponsors, volunteers, and supporters who made the event possible! Pictured above left practicing his putting skills is Honorary Chairman Dr. Donald Raddatz, Bassett Healthcare Rheumatologist.

The Lupus Communiqué

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DISCLAIMER

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Community
Health Charities
of New York
WORKING FOR A HEALTHY AMERICA

CFC
Combined Federal Campaign

sefa
STATE
EMPLOYEES
Federated
Appeal

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—

It has been a busy season this summer and I have many things to say but only limited space so here goes. First and foremost, I want to thank the Board of Directors and Dr. Donald Raddatz and Dr. Raquel Rosen for honoring me for a quarter of a century of volunteer services to the lupus community. It was quite a surprise which is not easy to pull off and I am extremely grateful to all involved in this endeavor. The Board's tribute is on page 12. Instead of my usual President's Message I am sharing my remarks from the Golf Classic Awards Dinner this year with all of you, especially since it was such a phenomenal event.

Good evening. I want to thank all of you for being here today and hope you enjoyed the beautiful Shenendoah Golf Course and your round of golf. Wow what a year it has been for Lupus! For the first time in 56 years a drug was approved by the FDA for treating lupus in March. That's a Hoo, Hoo! And yes that definitely deserves a round of applause! I had the extreme honor of being part of the FDA Advisory panel in November that recommended approval as the first lupus patient representative appointed to the Office of Special Health Issues at the FDA. Now, because of this there has been a surge in potential lupus and autoimmune disease treatments being developed and tremendous hope for so many who have waited far too long for safer, targeted therapies in Autoimmune diseases. The draught is finally over! Needless to say it is an exciting time for lupus research as well. I am also delighted to tell you that this is another record breaking year for us here at the Lupus Foundation of Mid & Northern NY. Many of you who supported us from the first Golf Classic 11 years ago 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 income from today's event and a new record for us is approximately $58,000 with a profit of $42,000! This is an increase of $9,000 from last year! We are also on track to make over $100,000 this year for the first time ever! Our income should reach $109,000 which is an increase of $21,000 from last year.

As many Americans struggle to make ends meet with the present economic situation it has been a difficult year 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 very challenging fiscal times. Thank you for recognizing that lupus does not dissipate nor disappear just because the nation is facing a crisis. It may not seem like a big deal to you that you came here today but it certainly means a great deal to all of us personally 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 3rd Lupus Awareness Event and Month in NY State in May in Albany once again. Because of our strong grassroots advocacy efforts we were able to help get 2 key pieces of legislation passed in the Assembly which are still pending in the Senate that could substantially assist New Yorkers with lupus. The Lupus Taxpayer Gifts Bill would list lupus as a checkoff box on the NYS Tax Return and the Lupus Education & Outreach Bill would provide for a lupus advisory panel through the NYS DOH. I would like to thank former Assemblywoman Audrey Pheffer for being a co-sponsor of both of these bills and for always being a strong legislative champion for Health care issues that improve New Yorkers' quality of life. And for the 22nd 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 99% of every dollar we raise goes back to program services. It is amazing what a small group of passionate & dedicated individuals can achieve! Each year I stand up here and tell you none of us are paid; we are an all-volunteer passion driven agency, operated out of my home with little overhead and yet at least once a week someone asks me how much I earn a year running the lupus foundation!

It has also been an extremely busy year for us in fighting state and federal policies that negatively impact Americans' ability to get the most appropriate treatments for their medical conditions. Having accessibility to the best therapies prescribed by a healthcare professional familiar with a patient's individuality is extremely important to us. We actually made 2 whirlwind road trips from our nation's capital to our state's capital to voice our concerns to policy makers telling them most emphatically that we will not allow the most vulnerable members of our society to become victims to belt tightening while richer Americans get wealthier! Not on our watch!

This golf event also funds our Research Program Services. We are proud to say that we are the only lupus organization in the nation that gives 1/3 of its income to research each and every year. I would like to share some figures with you on the 11th Anniversary of our Golf Classic. Because of your tremendous support and generosity over the years we have netted $274,600 from this event that has enabled us to enhance our local program services, and fund $235,068 in grants to Lupus Research. 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, who are not only here today working but each of them also raised at least $500. Thank you for your strong leadership. Secondly, I must recognize and thank Dr. Raddatz who has been a fixture at all 11 Golf Classics and has served as Honorary Chairman for the past 6 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 embarrass him. Next, I salute our fantastic volunteers whose efforts help to make this event happen.

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, physicians, and employers. For 11 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 and every year. Special thanks to John O'Conner & PhRMA as Tournamet Sponsor and for the first time we have both a Dinner & Luncheon Sponsor. Thank you to Stephanie Darwak for securing support from Astra Zeneca as the Dinner Sponsor and Adam Miller from Astellas as Luncheon Sponsor. Thanks to my family the Mitchells as Cart Sponsor and my husband David—for decades 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 Gloo, Maryrose & Dale Bullock & Beta Sigma Phi, Wendy Cianfrocco & NYSCOPBA, Jackie Taylor & UFCW, Mark Ambrose & the Utica Firefighters, WalMart representative Don Defeo, Jaime Venditti from J Strategies, Tom Francisco from Putnam Pest, Sandi Frear and her family, and Cathy & Bob Walseman and their friends and family for your ongoing support and Steve Cembrinski and NYCM Insurance as a new Corporate Sponsor 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.

Enjoy the Fall Foliage and Stay Warm — Kathleen

CHARITY GOLF CLASSIC CORPORATE SPONSORS

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

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Ellen Gloo in honor of the Board
Family & Friends of Geri Lemke
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Utica Professional Fire Fighters IAFF Local 32
Wal Mart Store #1677

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David & Kathleen Arntsen
BΣϕ Alpha Iota Oneonta Chapter in Honor of Maryrose Bullock
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NY State Iron Workers
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Surgical Associates of Utica, PC
Family & Friends in honor of Cathy Walseman
"Go Team Cathy" from Eric & Laury

Memorials, Tributes, and Donations

Memorials

In Loving Memory of…

John Della Contrada-
Rocco & Monica Falitico
Florence Miles Barrett

Marianne Lupica-
Mr. Lavergne McMurray
Donna Gentile, Larry Romaine
Jim & Meg Filingeri
Mike & Shirley Brady
Geri Cunningham
John & Paulette Loomis
John & Carol Shannon
Marianne & Karl Hopkins
Deanna Balutis, Judith Hoffman
Charles & Lucille Hand
Susan Lupica, Michael Lupica,
and their Families
Don & Karen White
Joseph & Johann Spadea

James R. Hecox-
Rome Teachers Association

Rita L. & Richard C. Rogers-
Peter J. Rogers

Thomas P. Mitchell-
Jane Williams, Jill Anne Smith

Mary Alice & Jim Mitchell-
Jane Williams, Jill Anne Smith

Christine Marie Smith-
Jill Anne Smith

Louis Smith-
Jill Anne Smith

Tributes

In Loving Honor of…

Cathy Walseman-
Laury Kerr & Eric Roderick

Kelly Bunce-
Sandra Combs

Sandi Frear & Kathleen Arntsen-
Helen E. Cassin

David & Kathleen Arntsen's Birthdays-
James & Patricia Mitchell

Rocco & Monica Falitico-
Virginia Merola

Donations

CFC, SEFA, United Way, IBM, GE,
American Express, United Health,
and Pfizer Employee Donor Plans
Rocco & Monica Falitico
WalMart Volunteer Program
Frances Eck
James & Patricia Mitchell
Leonardo & Laura Mangiaracina
Margaret Andrews
JoAnne Klein
Larry & Kathy Scharf
William & Julia Mitchell
LRI National Coalition/GSK
for Fall Education Programs
Elizabeth Barley, Eleanor Canell
Marion F. Edick, Julia Lauber
Donald & Sharon Lust
Norma Christian
Joseph & Victoria Jupin

11th ANNUAL LUPUS CHARITY GOLF CLASSIC

Pictured above left to right: Ladies' Champion Soaring Eagles and Men's Champion NYSCOPBA with Chairman Dr. Donald Raddatz and Co-ed Champion Bush/Myers.

VOLUNTEERS MAKE IT ALL POSSIBLE


















THANK YOU TO ALL OF OUR WONDERFUL VOLUNTEERS

PLEASE TAKE ACTION TO ENSURE COVERAGE OF BENLYSTA® FOR NEW YORKERS

Empire BCBS in NYS is now requiring a SLEDAI (Systemic Lupus Erythematosus Disease Activity Index) disease measurement that is not considered standard of care as part of pre- authorization, and is also requiring patients to fail first on 10 mg of prednisone for at least 30 days before Benlysta® can be approved for treatment. This is a form of step therapy and if we do not stop this now all future treatments could be subjected to the same requirements and this could expand to all NYS Insurance Companies if Empire succeeds with this policy. Max Hamburger, MD, President of the NYS Rheumatology Society and I are asking everyone in the NYS Lupus community to write e-mails and letters to the Medical Director of Empire BCBS voicing your concerns over this "step therapy" practice. Here is the e-mail address for the Empire Medical Director, Scott Breidbart.

scott.breidbart@empireblue.com

First state how lupus has impacted your life or that of someone you know.

Here are some bullet point examples for you to use in your messages.

- It is ridiculous that the lupus community waited over 5 decades for a new lupus treatment and now that Benlysta® is finally approved for SLE we must overcome another barrier before lupus patients can receive the drug.

- Only health care professionals familiar with a patient's personal medical history should be making treating decisions in the best interest of their patient; not insurance companies basing treatment decisions on cost only.

- Lupus is heterogeneous; no two patients are alike. Health providers know best what treatments to use to balance therapeutic & safety concerns in complex lupus patients.

- Forcing patients to take 10 mg of prednisone first and fail as a step before their physician can prescribe Benlysta® is absurd. Anyone who has ever taken prednisone knows the side effects and complications that can arise. Most of us struggle for years to get off prednisone; tapering down even 1 mg at a time requires extreme diligence.

- Not everyone can take prednisone and in some individuals it can do more harm than good.

- The determination of the most appropriate medical treatment is best accomplished by open and transparent communication between health care provider and patient. If a physician prescribes Benlysta® for a patient they should receive it without further delay.

Please share with your friends and relatives and post to your Facebook & Twitter pages. The goal is to get as many e-mails sent to Mr. Breidbart as possible so he understands how upset the NYS lupus community is about the Empire BCBS policy. Thank you for participating in this important campaign. Please contact me if you have any questions.

PLEASE TAKE ACTION TO SUPPORT COVERAGE OF BENLYSTA® IN THE UNITED KINGDOM

As a result of a recommendation by the National Institute for Health and Clinical Excellence (NICE), lupus patients in the United Kingdom may be unable to gain coverage for and afford treatment with Benlysta®. The Lupus Foundation of Mid and Northern NY along with other members of the Lupus Research Institute National Coalition have passionately advocated for newer, safer, and more effective lupus therapies for years. Finally in March, Benlysta® was approved by the U.S. Food and Drug Administration as the first new treatment in over 50 years; therefore we are now in support of global campaigns for all lupus patients to have access to the best treatments available.

With the successful approval of Benlysta® here in the United States came a source of renewed hope for the 1.5 Americans with lupus, and we are extremely proud to have played a role in this effort. Now is the time to bring that same aspiration to the millions affected by lupus throughout the world that may also benefit from this treatment.

Please take a moment and click here http://www.thepetitionsite.com/1/cover-Benlysta/ to add your voice to the thousands petitioning NICE to recommend that the United Kingdom's National Health Service provide coverage of Benlysta®. Help us extend our lupus loop all the way across the "pond!" Thank you very much for your continued support.

Kathleen A. Arntsen
President/CEO
Lupus Foundation of Mid and Northern New York, Inc.

25 Years of Volunteerism

When one looks in the dictionary for the word “volunteer”, the following definitions are found: [vol-*uh* n-**teer] -** *a person who voluntarily offers himself or herself for a service or undertaking, and a person who performs a service willingly and without pay.* For most, this might mean helping at their church or school with occasional activities and functions, or perhaps providing a day or two of their time at a local hospital or nursing home, but in the case of Kathleen Arntsen, it means committing countless hours each day with no compensation to the needs of those affected by lupus and other related diseases. The equivalent of what many would consider a full time job has been maintained by Kathleen for an incredible twenty-five years. During that entire time, she has passionately dedicated herself to providing our area with programs in patient support, public education and awareness, promotion of research, and most importantly advocacy at the local, state, and national level.

Kathleen’s efforts have taken the meaning of volunteerism to an entirely new level, something that we recognized as a Board of Directors, and wanted to celebrate at this year’s Charity Golf Classic. When trying to differentiate the level of volunteerism that we were attempting to honor, we realized that her work had been extraordinary, and the “Volunteer Extraordinaire” award was born. As we recognized her incredible dedication, we also realized that not only was she an extraordinary volunteer, but also a gifted leader. Commitment without action is merely interest, but through Kathleen’s actions, she turned her dedication into results, which also became her hallmark. Dr. Donald Raddatz gave remarks from both himself and Dr. Raquel Rosen thanking Kathleen for her incredible contributions to the medical community as a patient advocate, and then spoke of how honored he was to be present when she was awarded the first “Anne Kunkel Advocacy Award” from the American College of Rheumatology. He added that “If Kathleen gets an idea, look out, because she will chew your leg off to make it happen, but always with a smile on her face.” Although a light hearted analogy to her tenacity, it resonated in our ears, because as a Board of Directors, we realized that her ability to follow through and complete the task or mission is second to none; perhaps only the Navy Seals. Kathleen has been the driving force behind the incredible growth and success of the Lupus Foundation of Mid and Northern NY for the past twenty-five years, and although she will be the first to give credit to the volunteers that support this organization, we all know that without her leadership, little of what we have achieved would have happened. This has been her life’s work, giving freely of her time, hours on end, months at a time, critical issue after issue, year after year. If you are a volunteer, but want to be a “Volunteer Extraordinaire”, you will need to get back to us in about twenty-five years. From the Board of Directors to our extraordinary leader, congratulations Kathleen we are all honored to work with you!

Pictured above President/CEO Kathleen Arntsen receiving her award from the Board of Directors; above right is Honorary Golf Classic Chair Dr. Donald Raddatz presenting Kathleen with flowers and bottom right is Kathleen with Board Chair and Husband David Arntsen.

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)

LUPUS RESEARCH OPPORTUNITIES

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

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

<u>If</u> 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, Inc.

MEMBERSHIP APPLICATION

Name:	Date:
Address:	Phone #:
City, State, Zip:	Work #:
E-mail address:	Fax #:
☐ Single ($10.00) ☐ Family ($15.00) ☐ Medical Professional ($25.00) ☐ Patron ($50.00) ☐ Courtesy (Contact us to request)	☐ Other Donation (please list below) ____________________ ____________________
☐ Renewal ☐ New ☐ Partner in honor of current member ____________________________	☐ I would like to become a volunteer

Please remit payment and completed form to:

Lupus Foundation
P.O. Box 139
Utica, N.Y. 13503

We appreciate your support!

For more information call:
315-829-4272
or toll free
1-866-2-LUPUS-4
e-mail - lupusmidny@aol.com
website - www.nolupus.org

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

GENERAL EDUCATION MEETING
Informal Chat for those affected by lupus
Wednesday, November 30, 2011
6:30 PM to 8:30 PM
Rosetti Education Center at
Madison-Oneida BOCES
4937 Spring Rd. Verona, NY 13478

4th ANNUAL NYS LUPUS AWARENES EVENT
Wednesday, May 10, 2012
LOB WELL in Albany, NY
9:00 AM to 2:30 PM

Lupus Research Institute

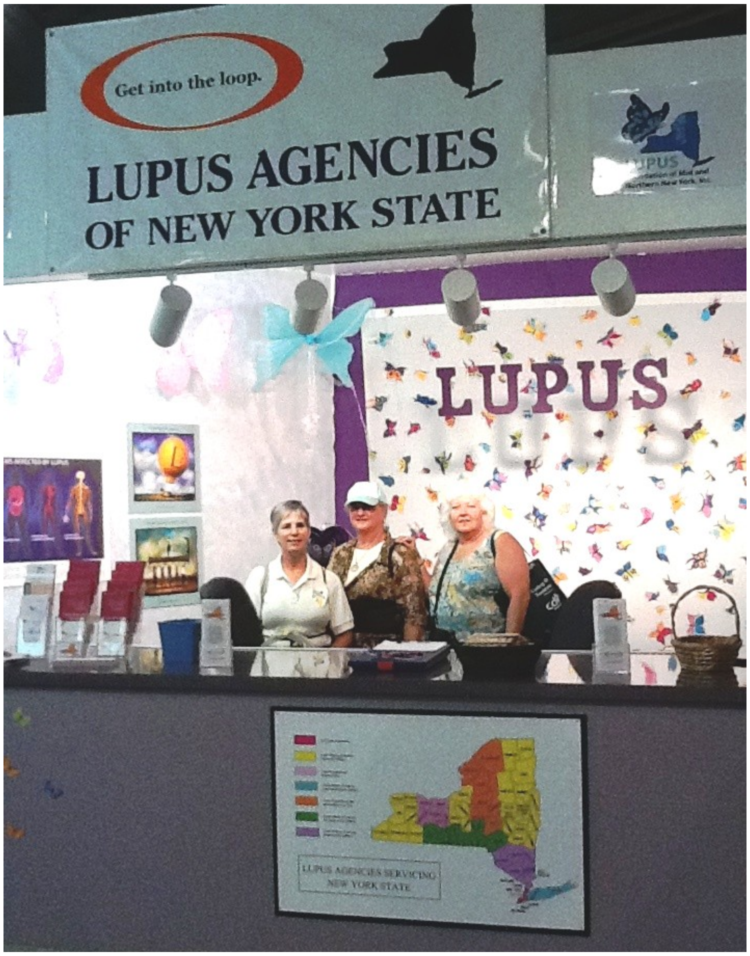
LUPUS Agencies of NYS

Lupus Research Institute National Coalition

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

- **National Coalition of Autoimmune Patient Groups**
- **Lupus Research Institute National Coalition**
- **NIAMS Coalition**
- **Lupus Agencies of New York State**
- **NIAMS Lupus Federal Working Group**
- **NY Health Works**

LUPUS AWARENESS AT THE NYS FAIR



For the 22nd year the Lupus Agencies of NYS had its exhibit at the NYS Fair in the Science and Industry Building in Syracuse. Over 120 volunteers manned the booth for 12 days in late August. Pictured in the booth are Lupus Foundation of Mid and NNY volunteers. Thank you to all our supporters