



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 10, Annual Edition 2012

RECORDBREAKING RESEARCH DONATION



Lupus Research Institute Chairmen Jack Lavery (left) and Robert Ravitz (right) receive our largest ever Research Donation of \$32,000 which represents a little over 1/3 of our annual income for 2012 from Lupus Foundation of Mid and NNY President/CEO Kathleen Arntsen (center) on October 22nd at the LRI Annual Scientific Meeting at the New York Marriott Marquis. We have now donated \$214,500 to the LRI in the past 11 years for novel, innovative lupus research.

The Lupus Communiqué

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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.

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Community
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Since we are no longer collecting membership dues, 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—

As I listen to holiday music hoping to gain inspiration to share with you, I am once again reminded of the chaotic pace of the season. It's 2 weeks before Christmas and like everyone else, we are tying up loose ends before the New Year begins. We are also making some changes within the organization to continue to provide the most optimal services we can to the community. As you may have noticed by now, this is the first newsletter since March. Due to printing and postage costs and in keeping with a green theme, we have decided to go to an annual edition of the Lupus Communiqué. However, our website www.nolupus.org will continue to offer current news and information and be updated regularly. The hotline is still available and we can also be reached by e-mail if you would like information or just to talk to someone with lupus.

With the advancement of technology, we have come to the realization that our current education program needs to be revamped, especially in the way we deliver services. We understand that many of you are just as busy as we are in this complicated, multi-tasking, overwhelming world. So we have decided to move in the direction of holding small chat sessions instead of quarterly education programs. We are also looking into education collaborations with other advocacy groups.

In May the Board of Directors voted unanimously to amend the Bylaws to remove Membership Dues. We realized that during these challenging economic times it has become a hardship for some of our members to pay their dues. Anyone who was on our mailing list will continue to receive mailings and new inquirers will be added to the list. Although we no longer require membership dues, we still need financial support. There are many ways to support us such as Memorials and Tribute donations, the May World Lupus Day Tea, the Annual Charity Golf Classic, and general donations. You may also want to consider making an end of year donation since it is December.

Our awareness, public education, and research programs remain intact, especially since we are the lead NYS Lupus Agency directing the May Lupus Awareness in the State Capital and the Lupus Exhibit Booth at the State Fair and continue to promote and present our "Hope is on the Horizon" program to educate consumers on the importance of clinical research trials in getting new treatments to patients. It is our hope that all drug development and discoveries continue to progress rapidly to improve patient quality of life and we are extremely committed to supporting the best lupus research in the country. As you are all aware, we currently donate one-third of our income each year to support The Lupus Research Institute.

Advocacy initiatives have become a major part of our program services. We not only advocate for people affected by lupus and other autoimmune diseases but also for health care reform and patient access to care issues which affect each and every American. We have been 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. Other initiatives include: health care reform and its implementation; protecting entitlement programs; providing positive patient protections; advancing health information technology; and furthering research programs, both privately and through the NIH. We are also collaborating on national health disparity and autoimmune awareness initiatives as well.

It was another great year for us in overall income, and a record breaking one with regards to our annual Golf Classic proceeds and our research donation to the Lupus Research Institute. Although the local economic forecast has remained bleak our supporters have remained loyal and generous far beyond our expectations. On a much broader scale it has been a remarkable year of progress for all in the lupus community. Promising, innovative research and development is taking place that includes safer, more effective therapies in the pipeline. Meaningful partnerships between government agencies, patient advocacy & professional organizations, academia, the medical community, research entities, and the biopharmaceutical industry have emerged. Bearing witness to these achievements has brought a sense of pride and fulfillment to those of us who work tirelessly for the lupus cause.

We are extremely grateful for the accomplishments of the past year and continuously amazed by the dedication of all in the lupus community. It is only through our united efforts that we can move forward and succeed in the battle against this formidable opponent. Finally there is hope on the horizon for those affected by lupus from a multitude of sources that are connected by this cause. We at The Lupus Foundation of Mid and Northern New York are proud to play a small role and honored to represent you during these thrilling times. We look forward to the New Year with high expectations for one filled with tremendous promise and progress into the diagnosis, treatment, and research of Lupus Erythematosus. We are extremely thankful for your continuing support.

Stay Warm and Well—Kathleen



Season's Greetings!

As the year comes to a close, we encourage you to take a moment for yourself to pause and reflect on family occasions gone by.

May you once again experience the simple wonderment, joy and blessings of the season surrounded by those you love.

Wishing you a wonderful holiday and a healthy New Year!

Memorials, Tributes, and Donations

Memorials

In Loving Memory of...

*Bernie Carter-
Bob & Cathy Walseman
Isabel Woolshlager
Jeffrey & Susan Virkler & Family
Larry & Karen Woolshlager & Family*

*Ethel Clark-
Isabel Woolshlager*

*Wellington Walseman-
Bob & Cathy Walseman*

*Douglas Kerr-
Bob & Cathy Walseman*

*James McCarthy-
Larry & Karen Woolshlager*

*Eleanore Iglesias-
Lisabeth Iglesias*

*Louis Smith
Christine Marie Smith-
Jill Anne Smith*

*Marguerite Curri
Peter & Dorothy Curri
Angela "Aya" Lo Conti
Michael P. Jones
Elizabeth Jones
Rosemary Franklin
Amy Bryant Mowers-
David & Kathleen Arntsen*

*The Rev. S. Kenneth Arntsen-
David & Kathleen Arntsen
Marian J. Arntsen*

*Richard W. & Penny L. Cassin-
Helen E. Cassin*

*Barbara M. Porter-
Helen E. Cassin
John Zeock
Bill & Sandi Frear*

Memorials

In Loving Memory of...

*Lorna E. Relf
Louis A. Relf
Sam Relf
Elva Fox
Arthur A. Relf
John Bagley
Alberta Bagley
Elmer Bagley
Alice Bagley-
James & Patricia Mitchell
David & Kathleen Arntsen*

*James E. Mitchell
Mary Alice Mitchell
Harold Leach
Catherine Leach
James E. Mitchell
Elizabeth Mitchell
Thomas P. Mitchell-
James & Patricia Mitchell
David & Kathleen Arntsen*

*Isabell Zeock-
John Zeock*

*Harold F. Woolshlager-
Bob & Cathy Walseman
Isabel Woolshlager
Jeffrey & Susan Virkler & Family
Larry & Karen Woolshlager & Family*

*Elwood Virkler-
Jeffrey & Susan Virkler & Family*

*Anita Curtiss-
Larry & Karen Woolshlager & Family*

*Mary A. Caruso-
Phil & Phyl Cittadino*

*Sophie Barbara Dydula-
The Dobies & Zatwarnicki Families*

*Jim, Mary Alice & Tom Mitchell-
Jane Williams*

Memorials, Tributes, and Donations

Memorials

In Loving Memory of...

*Angelo J. "Joe" Marotta-
Frank & Lyn Soja*

*Brooke N. Walseman-
Mrs. Doris Walseman*

*Brooke N. Walseman-
Bob & Cathy Walseman
Isabel Woolshlager*

*Jeffrey & Susan Virkler & Family
Larry & Karen Woolshlager & Family*

*Joseph Jupin-
David & Kathleen Arntsen
James & Patricia Mitchell
Philip & Kathy Teague
Tom & Jackie Taylor
Arthur Fitzpatrick
Mr. & Mrs. Al Kearney*

*Bonnie J. Martin-
Kay J. Falcone*

*World Lupus Day Tea
David & Kathleen Arntsen
Rocco & Monica Falitico
Cynthia Donaldson
Tom & Jackie Taylor
Larry & Kathy Scharf
Bill & Sandi Frear
John Porter & Elisabeth Kaye
Robert & Jennifer Porter
James & Patricia Mitchell
Carol Walker
Joseph & Victoria Jupin
Norman & Arlene Stanulevich
Phil & Kathy Teague
Jaime Venditti
Ellen Gloo
Frank & Stephanie Darwak
Dale & Maryrose Bullock
Jill Anne Smith*

Tributes

In Loving Honor of...

*Geri Lemke-
Friends & Family
Diane Wright, Virginia Merola*

*Cassandra Colon-
Friends & Family*

*David Arntsen's Birthday-
James & Patricia Mitchell*

*Kathleen Arntsen's Birthday-
James & Patricia Mitchell*

*Monica & Rocco Falitico-
Virginia Merola*

*Patricia Mitchell's Birthday-
David & Kathleen Arntsen*

*Marian Arntsen, Linda Arntsen,
James & Patricia Mitchell, Dan & Lisa Mitchell,
Dan & Lois Rumpfelt, Don & Sue Arntsen
For Christmas- David & Kathleen Arntsen*

Donations

*CFC, SEFA, United Way, IBM, GE,
American Express, United Health,
and Pfizer Employee Donor Plans
Joseph & Victoria Jupin
Brigiette Williams
Rocco & Monica Falitico
Ann Lasher
U.S. Pain Foundation
PhRMA
Pfizer, Inc., Pfizer Foundation
Pfizer Helpful Answers
Wal Mart Foundation
Astra Zeneca
Human Genome Sciences
LRI National Coalition
Astellas
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4th ANNUAL LUPUS AWARENESS EVENT



On Wednesday, May 9, 2012 all 6 Lupus Agencies of NYS sponsored the 4th Annual Lupus Awareness Event in Albany at the Legislative Office Building (LOB) Well to kick off Lupus Awareness Month. Senator Joseph Griffo was Prime Senate Sponsor and Assemblywoman Vanessa Gibson was Prime Assembly Sponsor of the 2012 Event. A presentation in the Well was followed by a Senate Floor Presentation led by Senator Griffo and an Assembly Chamber presentation by Assemblywoman Gibson.



12th ANNUAL LUPUS CHARITY GOLF CLASSIC



What a day to break a record! The 12th Annual Lupus Charity Golf Classic was held on August 10th, 2012 -- a rainy morning that turned into a perfect Friday afternoon at Shenendoah Golf Club at Turning Stone Resort in Verona, NY. More than \$48,000 net and a new fundraising record was 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 is our Tournament Sponsor PhRMA with John O'Connor receiving the appreciation plaque and above right is Luncheon Sponsor Astellas with Paul Miller receiving the appreciation plaque from Board President Kathleen Armtsen and Board Member Jaime Venditti.



Pictured above are the 2012 Tournament Champions—Ladies' with a score of 73 was Anita Cure (left) and Men's with a score of 56 was Team Riddell (right).



Pivotal Findings on Autoimmune Disease Shared at Lupus Research Institute “Forum for Discovery”

60+ Leading Scientists Participate in Premier U.S. Research Meeting Dedicated to Lupus

NEW YORK, NY – October 25, 2012 – The 12th annual Lupus Research Institute (LRI) Scientific Conference “Forum for Discovery” brought together more than 60 of the country’s top experts in the field to focus their talent on addressing the critical questions in the autoimmune disease lupus. LRI-funded investigators presented new findings on a broad range of topics including genetic factors that predispose certain individuals to lupus, how the lupus immune system turns against the body, and novel approaches to treat the disease.

A focal question of this year’s two-day think tank was how to stem the destructive cycle of inflammation and organ damage in lupus. In lupus, inflammation is one of the most common causes of damage to vital organs such as the heart, brain, and kidneys. It results from the immune system attacking the body’s own tissues as if there were an infection to fight off. Two guest speakers, Drs. Eric Pamer at Memorial Sloan-Kettering Cancer Center and Charles Serhan at Harvard Medical School, shared pivotal advances in inflammation, stimulating an exchange on how their discoveries can influence lupus research.

LRI-funded investigators reported breakthrough results that have implications not only in lupus but also for the autoimmune diseases affecting 23.5 million Americans. Findings include:

- New insight into how the brain talks to the immune system to suppress inflammation in lupus was shared by Dr. Jane Salmon at Hospital for Special Surgery. Dr. Salmon’s discovery may lead to a whole new approach to lupus treatment.
- Dr. Carla Rothlin at Yale University reported that a blood protein (protein S) known to be low in lupus patients helps to turn off inflammation. This discovery could lead to new drugs that harness the power of protein S to treat lupus and other autoimmune diseases.
- Dr. Anne Davidson, The Feinstein Institute, is using a new approach to find out why an existing rheumatoid arthritis drug anti-TNF can be protective in lupus kidney disease but also induces potentially harmful autoantibodies. Her findings suggest it may be possible to develop improved anti-TNF drugs that eliminate negative effects.
- The “hot” new topic in lupus, epigenetics, was the focus of a presentation by Dr. Amr Sawalha at University of Michigan. Epigenetics tells us how the environment may activate a gene that triggers lupus; importantly this change can also be passed on to the next generation. Dr. Sawalha’s work brings a long-sought missing piece to the puzzle of how lupus is inherited.

(Forum cont'd)

“The work presented at this Forum demonstrates the tremendous success of the LRI’s strategic approach of funding the most novel scientific ideas in lupus,” noted world-leading immunologist Dr. William Paul, LRI Scientific Advisory Board Chairman and National Academy of Sciences member. “The LRI continues to thrive on the union of scientists with the passion to pursue the most innovative scientific ideas with the patients and families who share that same passion to find new treatments and a cure for the disease.”

Advancing new lupus treatments

Overcoming the many serious challenges impeding lupus drug development was the focus of an industry forum bringing together government, academia, and industry. One particularly well-received suggestion was to reduce the higher failure rate of drugs at late stage clinical trials by using biological tests (biomarkers) to show much earlier in development whether a drug is safe and has the expected biological effect.

Also featured at the Forum were presentations by Drs. Ann Marshak-Rothstein at University of Massachusetts Medical School and Greg Barton at University of California, Berkeley, the two outstanding recipients of LRI’s new Distinguished Innovators Award. The first \$1 million privately funded international award for academic lupus research, the Distinguished Innovators initiative was created to find the basic causes of lupus that can drive towards a cure.

LRI Awards First \$1 Million Private Sector Research Grants to Uncover the Root Causes of Lupus That Can Drive to a Cure

Distinguished Innovators Initiative Investigates Fundamental Causes of Autoimmunity in Lupus Bringing Broad Application for Other Diseases

NEW YORK, NY – October 16, 2012 – The [Lupus Research Institute \(LRI\)](#) today announced the first \$1 million research grants given to lupus investigators by a private research organization. The LRI Distinguished Innovator Initiative was created to address the current lack of treatments in development that could arrest or reverse the disease. The first privately funded awards of this scale in lupus, it challenges the international scientific community to pursue highly promising new ideas on the fundamental causes of lupus that can lead to a cure.

The two Distinguished Innovator recipients, Drs. Ann Marshak-Rothstein at University of Massachusetts Medical School and Greg Barton at University of California, Berkeley, independently zeroed in on one family of proteins called Toll-like receptors as key triggers of the body’s devastating autoimmune attack on itself that characterizes lupus. Because TLR proteins are essential in fighting any infection, how the body loses control over their activity is a fundamental question in immunology. Finding the causes of lupus, the prototype for autoimmune disease research, could have broad implications across a wide range of illnesses affecting millions.

Which Toll-like receptor is responsible?

Dr. Marshak-Rothstein's research group was the first to propose that the TLRs could have a primary role in lupus by turning on the immune system to attack the body. Recent animal studies found that one TLR, TLR7, has a harmful role, while another, TLR9, has the opposite effect helping to protect against lupus.

Building on that work, Dr. Marshak-Rothstein is developing a highly innovative experimental approach to pinpoint which specific TLR is mainly to blame for causing lupus in humans. This experimental approach also promises to reveal new targets for therapies that could prevent or arrest lupus.

Dr. Marshak-Rothstein noted, "Support from the LRI will enable us to extend our analysis of the cell components recognized by TLRs in mice to TLR activation in human cell populations, and allow us to identify those patients most likely to respond to therapies directed at blocking specific TLRs."

Why Don't TLRs Harm Healthy People?

Also focusing on TLRs as prime suspects, Dr. Barton seeks to solve why TLRs cause a problem in people with lupus but not in healthy people. His work will determine if the reason the lupus immune system begins to attack its own DNA might lie with proteins inside immune cells whose job is to control TLR activity. Dr. Barton anticipates proving that lupus patients have defects in these control proteins that allow TLRs to mistakenly switch into action.

Dr. Barton's study seeks to pinpoint the earliest errors made by the lupus immune system and suggest new treatments to correct them. His investigations also have broad implications for autoimmune disease, infectious disease and beyond. The new knowledge generated by his work could even inform vaccine design against infectious diseases or cancer.

"In the last few years, we have started to learn how the immune system regulates TLRs," said Dr. Barton. "The next challenge, and the focus of our work, is to determine whether differences in these processes can explain why certain people develop lupus while others do not."

Stellar First Year for New Distinguished Innovator Award Initiative

The LRI received applications for the first privately funded \$1 million grants from many of the world's most renowned scientists as well as rising young investigators with great promise for contributing their talent to uncovering the causes of lupus. Rigorous peer-review was conducted by a team of LRI's scientific advisors and 12 of the world's leading lupus experts.

"We were enormously impressed by the quality of the submissions and the two from Drs. Barton and Marshak-Rothstein stood out as offering the best possibilities for key insights," noted world-leading immunologist Dr. William Paul, LRI Scientific Advisory Board Chairman and National Academy of Sciences member. "With these Distinguished Innovator awards and existing annual Novel Research Grants, the LRI continues to pursue a strategy of funding the most innovative and novel research that has had unprecedented success in driving new answers in a complex disease state. Their work over the past decade has provided the basis for this transformative research initiative to look for the fundamental causes of lupus that can drive to a cure and the means to prevent lupus."

ARNTSEN RECEIVES NATIONAL SERVICE AWARD



On Saturday, November 10, 2012 Lupus Foundation of Mid and Northern NY President/CEO Kathleen A. Arntsen received the Association of Rheumatology Health Professionals' Addie Thomas Service Award in Washington, DC at the American College of Rheumatology's Annual Scientific Meeting. This award is given to an ARHP Member who has a long and outstanding history of volunteer service to the Rheumatology community on the local, regional, and national level. Kathleen previously won ARHP's Ann Kunkel Advocacy Award in 2007. We extend our congratulations to Kathleen on her accomplishments and are honored to have her serve as our President. Pictured to the left is LFMNNY Board Chairman David L. Arntsen

(left), President Kathleen A. Arntsen (center), and Program Director Sandra M. Frear (right) at the convention center award display. Pictured above right is Kathleen with ARHP President Ben Smith, PA-C, during the awards ceremony. Pictured below are LRI National Coalition members with Kathleen and Sandi at the ACR Meeting.





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

EDUCATION PROGRAMS

If you have been diagnosed with lupus and/or another related autoimmune condition and want to be part of a mini chat group please contact Kathleen at 315-829-4272

WEBINAR

Webinar: Living Well, Despite Lupus: Listen Up, Doc!
Tuesday, January 8, 2013 Presented by S.L.E. Lupus Foundation
Time 12:30 p.m. EST

For more information

<https://lupusny.peachnewmedia.com/store/seminar/seminar.php?seminar=1561>.



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
- ◆ NY Biotech Association
- ◆ Health Care for all NY
- ◆ New Yorkers for Accessible Health Coverage

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

Molecular Biology and Pathology of Transaldolase

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

IRebecca Borsuk at (315) 464-2117

THE BUTTERFLY STUDY

- ◆ Are you between the ages of 18 and 75?
- ◆ Do you have active systemic lupus erythematosus (SLE)?
- ◆ Are you currently receiving treatment for SLE?

... You may be eligible for a clinical study in SLE if you meet all the above requirements as well as additional requirements at the study site.

**TO FIND OUT MORE, PLEASE
CONTACT THE STUDY TEAM AT:
585-275-1635**

Contacting us does not mean you have to participate and not everyone will qualify.

Thank you for your interest in the BUTTERFLY Study



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

LUPUS
Together
FOR CLINICAL TRIALS TODAY

Visit LupusTrials.org »

LUPUS RESEARCH OPPORTUNITIES

If you are interested in learning about upcoming Clinical studies and Research Treatments call us to enter our **LUPUS PATIENT REGISTRY**

You will be the first to hear about an exciting future using investigational treatments.

**FOR MORE INFORMATION CALL:
585-275-7167**

University of Rochester
Clinical Immunology Research Center
601 Elmwood Avenue Rochester, NY

LUPUS EXHIBIT AT NEW YORK STATE FAIR



For the 23rd year the Lupus Agencies of New York State sponsored the Lupus Exhibit at the Hall of Health at the New York State Fair in Syracuse. The exhibit ran from August 23rd to September 3rd for 12 days from 10:00am to 10:00pm. Many volunteers from all over the state man the booth for 3-hour shifts distributing information to fairgoers and promoting lupus awareness to the public. Thank you to all of our dedicated volunteers especially Sandy & Ernie Loveland, Jackie & Tom Taylor, David & Kathleen Arntsen and Lisabeth Iglesias.

