

Our Mission: To improve the quality of life for those affected by lupus through advocacy, education, awareness, empowerment, and research.

Lupus Communiqué

Lupus Foundation of Mid and Northern New York, Inc.

Volume 7, No. 4, Autumn 2008

Rosemary Franklin - An Inspiration to Us All





We are deeply saddened by the death of Rosemary Franklin; an inspiration and medical miracle to all of us, who passed away on January 19, 2009 one month before celebrating the 16th anniversary of her double lung transplant. Rosemary was a tremendous individual who defied the odds continuously and survived. She touched the lives of all those who were blessed to know her and tried to make the world a better place through her local volunteerism with the Lupus Foundation of Mid and Northern New York, the Baptist Church, TOPS, Red Hats Society, the American Legion and VFW Auxiliaries of Carthage, and the Black River Valley Fiddlers and nationally through her lupus advocacy efforts. A tribute to Rosemary can be found in the President's Message on page 4 and more photos can be found on page 9. Rosemary is pictured above left at the 2001 NYS Loop for Lupus Awareness Day at the State Capitol in Albany and above right at the 2004 LFA Gala in Washington, DC. Rosemary loved being around other lupus patients and enjoyed participating in lupus events. We extend sincere condolences to her husband Doug, son Ron, and family and friends.

The Lupus Communiqué

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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—

Instead of our regular message we have chosen to share remarks given by me at Rosemary Franklin's funeral on January 24, 2009 in Carthage, NY. Dozens of people who were touched by Rosemary during her amazing life sent their heartfelt expressions to us as inspiration for her tribute. Thank you to all of you who reached out to us during this difficult time. We are all joined together by similar sentiments, impressions, and memories of a great human being.

Helen Keller once said "Character cannot be developed in ease and quiet. Only through experience of trial and suffering can the soul be strengthened, ambition inspired and success achieved."

Rosemary Franklin was a wife, mother, daughter, sister, aunt, cousin and a friend. Rosie was my friend and became part of my family. We made a pact years ago that if anything ever happened to either of us the other one would speak at the funeral service. So I am here today to share my thoughts and celebrate her amazing life and character.

Rosemary lived with lupus since 1981 and despite many critical complications she survived. She was the first lupus patient in the country to undergo a double lung transplant in February of 1993 and was just about to celebrate her 16th anniversary. She had a kidney transplant in 2002 and open heart surgery in 2003. She continually defied the expectations of the medical community and credited her survival to faith, family, friends and her physicians.

When I first met Rosemary in 1994 she weighed close to 200 lbs. and wore a bandana to hide her baldness. She was attending a kickoff luncheon for our Northern New York Support Group and wanted to become more involved in The Lupus Foundation since she was feeling better. Who would have guessed that lying beneath that "cocooned" exterior was a beautiful creature waiting to spread her wings? Having been housebound, dependent on oxygen and severely limited for so many years, she was hungry for life.

Rosemary made a commitment to our organization in 1998 and became the new NNY Support Group leader. She attended the Lupus Foundation's Meetings, absorbing a great deal from the workshops and thriving on interactions with other lupus patients. The NNY support group flour-ished under her guidance and those who attended benefited from her courage, kindness, compassion and unselfish generosity. She served as Vice President of The Board and Membership Chairperson until her kidney failure forced her to retire. She became an Honorary Board member at that time.

Rosemary was a wonderful volunteer. Always willing to lend a hand but wanting to stay in the background, she eventually became a knowledgeable spokesperson on Capitol Hill and to local reporters. She wasn't afraid to tell it like it was and her candor was refreshing. She even carried a picture of herself at her worst and did not hesitate to show it to others as proof of her journey.

Rosemary possessed tremendous faith despite adversities. Her eldest son, Doug was killed in a military jeep accident, yet she remained levelheaded enough to insist his donor organ wishes be carried out so that someone else might benefit. She experienced organ donation from both perspectives and encouraged others to become donors. When asked how she got through this horrible experience without becoming ill, she credited her son and her faith.

(Rosemary Franklin cont'd)

Rosemary's passion and dedication to improving the quality of life for all lupus patients despite her own infirmities was a constant source of inspiration for those of us who were fortunate enough to know her. Like the fragile butterfly's existence in nature, Rosemary's will and spirit to survive was a source of amazement to us all.

No matter how ill she was Rosemary rallied for our advocacy events making our road trips down Route 81 to Washington a fun-filled adventure. She scheduled her dialysis around our meetings like it was no big deal. She made an impact on lawmakers like Congressmen Boehlert who told us that he was so overwhelmed with the enormity of her medical costs that he constantly used her as an example when he talked to other legislators about Health Care Reform. Congressman McHugh and his staff always looked forward to their visits with her.

Rosemary was one of those rare beings whose purpose in life was to reach out to those around her, making them better individuals and making the world a better place. She was humble and kind -hearted and accepted people for who they were. Her courage and tenacity were an inspiration to



all lupus patients. She truly was "The Wind Beneath Our Wings." Many of us were able to keep going when confronted with adversity by thinking of the challenges that Rosemary faced daily and yet always with a positive spirit. Her noble and charitable character is a shining example of the determinedness that is needed to conquer devastating diseases like lupus. Let's take comfort in knowing that she is in a better place, finally free from the pain and suffering of lupus and reunited with her son and mother. She will live on in the hearts and minds of all of us whose lives she touched across this country. Her spirit and love continue.

I leave you with the poem I wrote as a tribute to Rosemary and all individuals with lupus when she received the Butterfly of Hope Award from the Lupus Foundation in 2001 (pictured above).

"The butterfly symbolizes heroism in its continued survival against enormous odds. From its incredible transformation and rebirth, to its amazing existence despite facing great opposition, this fragile creature is the embodiment of Hope. Like the butterfly, the Lupus patient continues to survive in a complex world, triumphing over adversity each day with tremendous grace, dignity and courage."

—Kathleen

5th Annual Lupus Education Symposium Keynote Speaker is Donna Jackson Nakazawa

The 5th Annual Lupus Education Symposium & Luncheon "Learning, Linking, and Looking Ahead" will be held on Saturday, May 2, 2009 at the Rossetti Education Center at Madison-Oneida BOCES in Verona. We are honored to have Donna Jackson Nakazawa as our Keynote Speaker. She will be presenting on "The Autoimmune Epidemic: What You Need to Know." Donna, a Johns Hopkins patient and author shares her struggle with Guillain Barre syndrome, one of nearly 100 autoimmune diseases that affect one of every nine women, and unveils the story behind today's growing autoimmune epidemic. She will be speaking about the reasons behind this increasing trend in autoimmune diseases, and what you can do to protect your own immune system by rethinking your daily diet, controlling exposure to everyday chemicals, and eliminating stress.



Donna is a nationally acclaimed researcher, writer and public speaker on health and family issues. She is the author of <u>The</u> <u>Autoimmune Epidemic: Bodies Gone Haywire in a World out of</u>

<u>Balance and the Cutting Edge Science that Promises Hope</u> (Touchstone/Simon and Schuster, 2008), an investigation into the reasons behind today's alarming rise in rates of autoimmune diseases (multiple sclerosis, lupus, type 1 diabetes, thyroiditis, and dozens of other autoimmune diseases) in industrialized countries around the world.

In her book and lectures on the autoimmune epidemic, Ms. Nakazawa lays out the mounting evidence showing how our modern lifestyles, chemical-laden environment and twenty-first century diet have created the "perfect storm" -- the ripest possible conditions -- for this epidemic to take hold. Nakazawa blends personal stories with the latest science to shed light on what we should know and do to halt this epidemic.

Andras Perl, M.D., Ph.D. Professor of Medicine, Microbiology & Immunology and Chief of the Rheumatology Division at SUNY Upstate in Syracuse will be presenting "The Latest on Lupus" including symptoms, diagnosis, treatments and research. A list of local clinical research participation opportunities will be available.

Margarita Perez-Cheron, M.D., F.A.C.E. Internist and Endocrinologist from Mohawk Valley Endocrinology in Utica will be speaking on "The Vitamin D, Calcium, and Osteoporosis Connection" and its importance to those living with chronic conditions such as lupus.

There will be a Buffet Luncheon, Exhibit Display Booths, Therapeutic Massages, Paraffin Hand Waxing, Wellness Checks, Handouts, Raffles, and Goodie Bags available for all attendees. Registration is required by April 25 and is free to all current members. There is a \$20 charge for non-members. Contact the office at 315-829-4272 for a form or more information or visit our website at www.nolupus.org/EducationEvents.asp to download a registration form.

Memorials, Tributes, and Donations

Memorials

In Loving Memory of...

Thomas Patrick Mitchell-Jill Anne Smith

> Phillip P. Beyer-Isabel Woolshlager

Douglas C. Kerr-Bob & Cathy Walseman

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

> Brooke N. Walseman-Mrs. Doris Walseman

Rosemary L. FranklinJames & Patricia Mitchell
David & Kathleen Arntsen
Marilyn Sousa
Lucinda Durant & Bill Jakobsen
LAA, Long Island Queens Affiliate
Bill & Sandi Frear
Bob & Cathy Walseman

Donations

Geraldine Conniff
Angelo & Angela Nole
Donna Gloo
Sonya Linakis
Rick Deyulio
Our Friends
CFC, SEFA, United Way, IBM and
Employee Donor Plans

Clinical Trials Campaign-Human Genome Sciences

Education Symposium-Coolibar Sun Protective Clothing



Tributes

In Loving Honor of...

Cathy Walseman-Jeff & Debra Nowicki, Peter & Nancy Marshall Lowville Chapter of Beta Sigma Phi Sorority

Maryrose Bullock-Beta Sigma Phi Alpha Iota-Oneonta Chapter

For Christmas

David & Kathleen Arntsen-Linda Arntsen, The Rev. Dan & Lois Rumfelt

Bill & Sandi Frear-Helen Cassin, Jane Porter, Shelley Sands, Mr. & Mrs. Jack Zeock, Mr. & Mrs. John Zeock

James & Patricia Mitchell-David & Kathleen Arntsen

The Rev. Dan & Lois Rumfelt-David & Kathleen Arntsen

Don & Sue Arntsen-David & Kathleen Arntsen

Linda Arntsen-David & Kathleen Arntsen

James & Marion Mitchell-David & Kathleen Arntsen

Tim & Deb Mitchell-David & Kathleen Arntsen

Dan & Lisa Mitchell-David & Kathleen Arntsen

Honor a volunteer, speaker, or loved one by purchasing a Lupus Butterfly of Hope Plate from Angel Pix for \$35 and we receive 10% back as a donation for lupus research. The \$35 includes plate, stand, tribute on back, and priority shipping. If interested please e-mail lupusmidny@aol.com or call us at 315-829-4272.

Another Record Breaking Research Donation



Lupus Foundation of Mid and NNY Representatives attended the Lupus Research Institute's Annual Scientific Dinner and presented our largest annual research donation ever in the amount of \$22,000 on October 6, 2008 at the Yale Club in New York. We are proud to say that we have now donated \$106,500 in 7 years to the LRI and \$158,000 since 1990 to lupus research overall. Pictured to the left are LFMNNY President/ CEO Kathleen Arntsen, LRI Co-Chair Jack Lavery, LRI Co-Chair Robert Ravitz, and LFMNNY Volunteer Jackie Taylor. We have been fortunate to give 1/3 of our income to lupus research for the past 4 years and wish every lupus organization in the nation could do the same.



Pictured above are Vivian Fernandez, Sr. Manager Medical Affairs from Human Genome Sciences; Holly Russell, Director, Product Communications, GlaxoSmithKline; Lora Allemeir, Sr. Director, Marketing US Commercial, GSK; Gregory Dennis, MD, Sr. Director, Medical Affairs, HGS; with Lupus Foundation of Mid and Northern New York Board Members Kathleen & David Arntsen at the SLE Lupus Foundation "Life Without Lupus" Gala on November 20, 2008 at the Marriott Marquis in New York.



Human Genome Sciences Headquarters in Rockville, MD





Board Members Kathleen Arntsen, Sandi Frear & Stephanie Darwak met with NYS Assemblywoman RoAnn Destito (left) and NYS Senator Joe Griffo (right) to discuss lupus—related issues and budget proposals on February 2, 2009 in Albany.

Rosemary "Rosie" Franklin



Rosemary being taped for an advocacy video at the CT Lupus Foundation Walk.



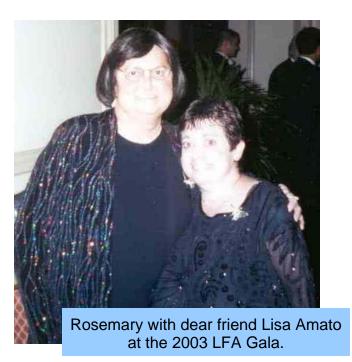
Rosemary at Miami Beach during the LFA Annual Meeting in 2001.



Rosemary with friends Sue Mortier and Kathleen Arntsen at the 2003 LFA Gala.



Rosemary with Congressman John McHugh during the LRI 2005 Advocacy event.



9

The New Language of Health Care: How's Your HPIQ?

HEALTH POLICY Carol Levine 08/01/2008

What do you call a person admitted to a hospital? If you said "patient," you're hopelessly out of date. The person lying there awaiting surgery or recovering from a heart attack is a "consumer." The person examining the consumer is a "provider." Depending on the situation, she may be a "hospitalist," "intensivist," "proceduralist," "surgicalist," or other "ist." If you're admitted at night, the provider is a "nocturnist." Ordinary doctors, who don't have "ists" after their titles, are seldom seen in hospitals these days. That's just one example of how health care language is changing. It's not enough to know clinical terms; you have to know the lingo of health policy and practice to navigate though the health care system. Here's a little test of commonly used terms to determine your HPIQ (Health Policy Information Quotient). Match the term to the correct definition.

- 1. Medical home
- a. a doctor's office adjacent to a residence
- b. a central medical office that coordinates care
- c. the home of someone who needs oxygen, a wheelchair, and other equipment
- 2. Medically necessary
- a. health care you think you need
- b. health care your doctor says you need
- c. health care your insurance company decides you need
- 3. Medication reconciliation
- a. making sure the little red pill gets along with the big white one
- b. making sure that you leave the hospital with prescriptions for all the medications you came in with and still need
- c. making sure that the generic form of the medication is the same as the prescription form
- 4. POLST
- a. a physician trained in Poland
- b. Post Operative Long Stay
- c. Physician Orders for Life-Sustaining Treatment
- 5. Custodial care
- a. janitorial services in a hospital
- b. health care in a prison
- c. basic care like dressing and feeding

- 6. HIPAA
- a. a federal law to protect the confidentiality of personal medical information
- b. a new procedure for joint replacement
- c. when repeated, a cheer when a troublesome consumer is discharged
- 7. Dual eligibles
- a. consumers old enough for Medicare and poor enough for Medicaid
- b. consumers who need both hips and knees replaced
- c. consumers who see two specialists, both of whom get paid

(Continued on next page)

- 8. Multimorbid
- a. person with obsessive attraction to horror movies
- b. person with several medical problems
- c. person who is sad about several life events
- 9. P4P
- a. a new drug
- b. a method of paying providers on the basis of outcomes
- c. a campaign that promotes provider-patient communication
- 10. Informal supports
- a. grab bars and railings for the home
- b. casual clothing for physical therapy
- c. people who provide most long-term care--in other words, family members

Answers: 1 (b); 2 (c); 3 (b) 4 (c); 5 (c); 6 (a); 7 (a); 8 (b); 9 (b); 10 (c)

Scoring: 8-10 correct: PW (Policy Wonk); 5-7: NR (Needs Remediation); 0-4: HIC (Health Information Challenged)

Carol Levine directs the Families and Health Care Project at the United Hospital Fund in New York City.

SAVE THE DATE

Friday, March 27, 2009 Jazzmatazz Fundraiser Wednesday, April 1, 2009 Lupus Victorian Tea Party **Lupus Awareness Month May 2009** Saturday, May 2, 2009 5th Annual Lupus Education Symposium Sunday, July 12, 2009 3rd Annual Loop for Lupus Motorcycle Run Friday, August 14, 2009 9th Annual Lupus Charity Golf Classic Thursday, August 27, 2009 to Monday, September 7, 2009 Lupus Agencies of NYS Exhibit at the State Fair



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

LUPUS RESEARCH INSTITUTE



The Patient Voice for Lupus Research

SEEKING MEMBER INPUT ON PROGRAMS

Information gathered in our last 2 needs assessments have indicated that our members desire up-to-date information on lupus and related conditions including treatments, physicians, research, and breaking news. Those who responded to the assessment want us to continue with the annual education symposium in May and quarterly education meetings with professional speakers. There was little desire shown for monthly support meetings and since there has been poor attendance at both monthly and then quarterly support group meetings in the past 2 years we have stopped them for now. David & Kathleen Arntsen are considering holding 4-6 support meetings for couples only provided there is enough interest and commitment. Please contact Kathleen at 315-829-4272 or e-mail her at lupusmidny@aol.com if you are interested in a Couples' Group.

Please e-mail Kathleen at lupusmidny@aol.com or call her at 315-829-4272 with your ideas, suggestions, and thoughts on programs you would like to see The Lupus Foundation develop. Your input as members is crucial to creating programs that will benefit all of us and we cannot stress this strongly enough.

Please take a moment and share your thoughts with us. Thank you very much.

We have formed a collaboration with The Sitrin Medical Rehabilitation Center on Tilden Ave. in New Hartford and held our November 2008 meeting there with 22 members attending. We have also joined their committee for Jazzmatazz, a local event sponsored by the Sitrin Medical Rehabilitation Center along with Dr. Martin Morell, Arthritis Specialists. Proceeds from this fundraiser are used to develop programs for people with arthritis, and arthritis related conditions including lupus, fibromyalgia, osteoporosis, etc. Current programs at Sitrin include aquatic therapy, pain management, wellness center, hand therapy, and many more. For more information regarding the programs at Sitrin please visit their website at www.sitrin.com



Director of Clinical & Rehabilitative Services at the Sitrin Medical Rehabilitation Center Jackie Warmuth, LNHA, MS, OTR/L at our November Education Mtg.

Officers Retire

Lupus Foundation of Mid and Northern New York Officers Helen Lenart and Sarah Eastup recently retired from the Board of Directors in November. Both Helen and Sarah have been instrumental in helping to enrich our programs and events. Their wisdom, wit, and generosity will be greatly missed by all in the foundation. We thank them both for their hard work; dedication to the organization, its members, and the lupus cause; and wish them well in their retirement.

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

Study of abatacept for lupus nephritis

Treatment of SLE with N-acetylcysteine

Prospective study of Rapamycin for SLE treatment

Study of abetimus sodium in

SLE patients with renal disease

For more information please call:

Andras Perl, MD PhD at (315) 464-4194 Irene Ramos at (315) 464-5247

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'll be the first to hear about an exciting future using investigational treatments.

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

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

A CLINICAL RESEARCH STUDY FOR SYSTEMIC LUPUS

Have you been diagnosed with systemic lupus? Have you had kidney problems due to lupus? Are you between the ages of 12 and 70?

If you answered <u>YES</u> to these questions, you may qualify to take part in a research study with a new investigational medication that may decrease kidney problems due to lupus

Qualified Participants Will Receive:

Study medication
Study related medical care for your lupus
Monetary payment in compensation for time
and travel expenses

For More Information Call:

(585) 442-1980
AAIR Research Center
300 Meridian Centre Suite 305
Rochester, NY 14618

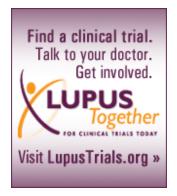
The Lupus Multiplex Registry

The LMRR is actively researching the different ways in which SLE affects various ethnic groups.

Families with one or more living members diagnosed with lupus may be eligible for one of the following studies:

Minorities and Lupus, African American Studies, Hispanic American Studies, Native American Studies, Asian American Studies, All Ethnicities, Families with 1 Lupus Patient, Families with 2 Lupus Patients

For more information visit the website www.ormf.org/?page=aboutlmrr or call 1-888-OK-LUPUS



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Please remit total payment to: Lupus Foundation PO Box 139 Utica, NY 13503		

Loop for Lupus Poker Run

Sunday - July 12, 2009 Verona Volunteer Fire Department

Sponsored By





\$25 per RIDER
(Passengers \$10 extra)
"Once Around the Lake"



Registration 11:00 am - 12:00 noon



Barbecue

2:00 - 4:00 p.m. Families Welcome!

\$10 for meal only (children under 7 free)

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5th Annual Education Symposium & Luncheon "Learning, Linking and Looking Ahead

Saturday, May 2, 2009

9:00am to 2:30pm

Rossetti Education Center at Madison-Oneida BOCES in Verona, NY (Exit 33 NYS Thruway)

Presenters Include:

Donna Jackson Nakazawa Author & Researcher

The Autoimmune Epidemic: What You Need to Know

Andras Perl, MD, PhD
SUNY Upstate Chief of Rheumatology
The Latest on Lupus

Margarita Perez-Cheron, MD, FACE
Mohawk Valley Endocrinology
The Vitamin D, Calcium and Osteoporosis Connection

Local Clinical Trial & Prescription Assistance Information Exhibit Booth Displays and Handouts

No cost to current members: \$20 fee to non-members Limited to 150 attendees, Registration Required

For more information or to receive a registration form please call 315-829-4272 or e-mail lupusmidny@aol.com

Supported through unrestricted educational grants from



