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 5, No. 2, Winter 2005*

Welcome to www.nolupus.org

The Lupus Foundation of Mid and Northern New York is inviting you to visit our website, www.nolupus.org. Countless hours of volunteer work went into developing the content for our site as well as formatting the pages. Since we are new to this we welcome your comments and input on the website. We will be editing and updating the site ourselves so please share your thoughts with us. It is our hope that if you have lupus or know someone who has lupus you will use this website as a tool to take control and learn to live with lupus. We are here for you as you and your loved ones continue on your lupus journey.

Save The Date

6th Annual
LUPUS
Charity Golf Classic

The 6th Annual Lupus Charity Golf Classic is scheduled for Friday, August 18th, 2006 at Shenendoah Golf Club. Corporate Sponsor packets were just sent out and Golfer invitations will be mailed on May 1st. Priority registration is given to Corporate Sponsors and previous foursomes and then any open spots become available to new teams. Contact the office for information.

The Lupus Communiqué

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www.nolupus.org
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TABLE OF CONTENTS

DISCLAIMER

It is the policy of 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.

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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 notify us of any address change or other corrections to ensure accuracy in the database and 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 new website. Thank you.

Dave Arntsen

President's Message

March came in a like a lion with a typical Nor'easter; winds in excess of 50 miles an hour and snow accumulation measured by the foot instead of inches. If upstate New York weather was predictable, one could bet that the end of the month will bring forth the promise of spring. However, our weather here is ever changing, much like our complex health care system. Since the implementation of Medicare Part D on January 1st, patients, pharmacists, and physicians across the country struggle to make sense of the chaos. New York state has the highest Medicaid costs in the nation as well as the largest number of "dual eligibles", well over 600,000 people. Duals are individuals who receive both Medicare and Medicaid and are the most vulnerable members of our society. Their prescription drug coverage has been in jeopardy and their continuity of care has been threatened since the transition to Medicare Part D began. Both the state and federal agency officials are optimistic that the entire system will be smoothly operating by July 1st. New York State officials have also adopted and will be implementing a Medicaid Preferred Drug Program (PDP), sometime later this year as have approximately 35 other states so far. This plan is a formulary designed to keep health care costs down, but in reality; as many of us advocates pointed out, there are many situations where it may instead, do just the opposite and increase costs. We have become involved in these important public policy advocacy issues; being a voice for those who cannot speak for themselves.

Many of us living with chronic disease have been attempting to navigate this intricate medical system in order to maintain some type of control and balance in our lives for a while now. We have learned to be proactive, educated, empowered, and most importantly, part of our treatment team in order to survive. Who is better suited to manage their own complicated medical picture than oneself, especially those of us with multiple health conditions who take daily drugs in the double digits? For example, one little administrative policy decision to switch mail order drug companies can wreak havoc in one's life for months. When one tries to correct the situation by contacting the customer service toll free line; they become part of the world of automated voice mail hell. Prior to the New Year, the wait time was approximately 6 minutes; it has now reached 20 plus minutes. Once one reaches a live human being, 9 times out of 10 this individual has attitude. The question begging to be asked here is, "Why would anyone work in a customer service department if they do not want to service customers?" At this point the conversation develops into the blame game with the CS Rep blaming the insurance plan, the prescribing physician's office, and the US Postal Service. They have a patented list of excuses in response to one's rebuttals.

I have become proficient at advocating for myself after dealing with lupus for over 2 decades now. Lupus is not a disease that fits neatly into a box. It is not black and white; it requires resourcefulness and thinking outside the box to treat. As each new personal health crisis develops, it becomes a lesson in patience and frustration. Recently I was referred to 4 different specialists within a 7-week period for the same problem, 3 whom did nothing but refer me to another specialist. Each office sent mounds of paperwork to be filled out including personal medical information, etc. Having inflamed joints and eyes at the time, writing was out of the question. With my husband's help I developed tables on the computer to insert or update medical information that can be used by any medical practice. With all of the technology available today, why isn't our health care system utilizing it to standardize and streamline the process?

The system needs to be overhauled immediately. The majority of our society is now comprised of aging baby boomers that are being initiated into their elderly parent's medical realities. Several of us attended a presentation last Fall developed by Medical Professionals who were frustrated with the convoluted system that personally failed them and their families. It is ironic for us to see others struggle with the bureaucratic red tape that we have been screaming about since our diagnoses. Living in the most progressive nation in the world, we refuse to submit to this non-caring, impersonal health care delivery system. We want the people involved in our medical care to treat us with respect, dignity, empathy, and patience. We want them to give us their undivided attention and to work with us to solve the current issue. We do not want to be patronized, treated like neurotic hypochondriacs, or passed along like a football from physician to physician or CS Rep to CS Rep. Somewhere along the way we have become disconnected from what is most important—treating and caring for the patient. We want the members of our health care team to be capable of admitting when they do not have the answers, but willing to give a valiant effort to resolve the problem, and welcome to second opinions.

Why have we added advocacy to our organization's mission statement? As long as our health care system remains imperfect and unequal, advocates like us will continue to raise our voices in objection. If we can change the policies of a single clinic, hospital, doctor's office, pharmacy, insurance company, health plan administrator, legislator, or government agency official then our efforts are worthwhile. Like a snowball hurling down a mountainside, gaining momentum with each revolution, we will continue forward on our advocacy campaign to improve the health and well-being of all; not only in the lupus community, but also within our state and nation. We are here for you.

Be Well—Kathleen

Memorials, Tributes, and Donations

Memorials

In Loving Memory of…

Joseph Kipper-
Dominick & Marie Oriolo

James & Mary Alice Mitchell-
Lou & Jill Ann Smith
Jane Williams

Helen Schmelcher-
Julia Damkoehler

Salvatore P. Acquaviva-
Dominick & Marie Oriolo

Isabelle "Belle" Clark-
David & Kathleen Arntsen
James & Patricia Mitchell

Brooke N. Walseman-
Mrs. Doris Walseman

Heide G. Bielby-
Robert E. Bielby

Virginia S. Kulesza-
Purcell Construction Corporation,
Mr. & Mrs. Jack Bansbach,
Mr. & Mrs. Anthony Zach,
Mr. & Mrs. Roger G. Eastman,
Frank & Helen Robbins,
Mr. & Mrs. C. David Hudson
Mr. & Mrs. Thomas Trebi
Van Epps Candies
Karl & Harriet Hockey

Elaine Mazza Carlo-
Tony & Kim Matt
David & Kathleen Arntsen

Nick Kinney-
Dominick & Marie Oriolo

Tributes

In Honor of…

Helen Lenart-
Chester & Jane Trzepacz
Mr. & Mrs. Norman Stanulevich

Ellie Wurz-Mazloom-
BPI

Danielle Turner-
Hannaford Lupus Initiative

Partner Memberships

Roxanne Falitico-
Rocco & Monica Falitico

Danielle Turner-
Trisha Utter & Family

Sandi Frear-
Shelley Sands, John Porter, Jane Porter

Donations

Campaign Donors
IBM, SEFA, CFC, United Way, Merrill Lynch

Unrestricted Educational Grant—Pfizer, Inc.

Jamie Gloo
Viginia Merola
Peter Rogers
Margaret Andrews
Rocco & Monica Falitico
Nancy Eannace
Sharon Rolchigo
Sonya Linakis
Linda Talarico
Bruce & Nancy Griesmer
Linda Joynt
Sharon Santa Maria
Donald Lust

Lupus Foundation of Mid and Northern New York

Spring General Education Meeting

Tuesday, April 4th, 2006 at 7:00 pm

Dr. Allan Smiley, Rheumatologist

From Slocum Dickson Medical Center

"Lupus Treatments"

Faxton-St. Luke's Healthcare Regional Cancer Center
Anderson Auditorium 2nd Floor
Newell St. in Utica, NY

Refreshments will be served. Reservations required by March 30th to 315-829-4272 or e-mail lupusmidny@aol.com

Get into the loop.™

Learn about Lupus

Support Group Information

Utica Area *Facilitator-Helen Lenart* **lupusmidny@aol.com**

The Utica Area Support Group usually meets monthly on the third Thursday at Faxton-St. Luke's Healthcare Regional Cancer Center in Utica in Weaver Lounge, 2nd floor. The next meetings will be at 7:00pm on March 16, 2006 and April 20, 2006.

Lewis County & Boonville Area, Jefferson County & St. Lawrence County

The Chapter Education Committee conducted a needs assessment in The NNY Counties and based on the input we received we have decided to temporarily suspend these support groups and re-evaluate in one year. We will continue to hold our Annual Autumn Luncheon. Thank you for your patience and support.

HIP HOP ARTIST'S DEATH FROM LUPUS COMPLICATIONS RAISES PROFILE OF DISEASE THAT DISPROPORTIONATELY IMPACTS AFRICAN AMERICANS

CONTACT: Dennis da Costa, ddacosta@lupusny.org, or Liane Stegmaier, lstegmaier@lupusny.org, 212-685-4118

NEW YORK CITY, February 21, 2006—The untimely death of a visionary hip-hop producer on February 10, 2006, just three days after his 32nd birthday, has jolted the music world and shed light on an often-debilitating disease that afflicts 1.5 million Americans.

The cause of death for James Dewitt Yancey—a.k.a. Jay Dee and J Dilla—has been reported as both kidney failure and cardiac arrest, apparently brought on by lupus, from which he suffered for several years. According to the Lupus Research Institute (LRI), lupus is a chronic autoimmune disease in which the body's immune system—normally our natural defense against disease—becomes overactive and forms antibodies that attack and damage different organs and tissues such as the skin, brain, heart, lungs, blood and kidneys. One in three lupus patients has kidney disease, and heart disease is one of the leading causes of death among people with lupus. According to the Lupus Research Institute, nine in ten lupus patients are women—J Dilla had the misfortune of being one of the one in 10 lupus sufferers who are male. Sadly, he only survived for three years past his diagnosis.

J Dilla's tragic death serves as an important opportunity to highlight the widespread incidence and devastating impact of lupus on Americans, in general, and people of color in particular. More Americans have lupus than cerebral palsy, multiple sclerosis, sickle-cell anemia, and cystic fibrosis *combined*, making it one of this country's most prevalent medical problems. And African American, Hispanic/Latina, Asian and Native American women are three times more likely to develop lupus than Caucasian women.

The exact cause of lupus is unknown and, as yet, lupus cannot be prevented or cured. And the last treatment for lupus was approved 40 years ago, which points to the great need for increased research. That's where the Lupus Research Institute comes in. The LRI, the nation's leading sponsor of innovative, novel lupus research, is enabling scientists to make bold, new breakthroughs in our understanding of the disease. Founded and funded by lupus patients and families across America, the LRI's strategic research investment already totals more than $14 million. To learn more about lupus and the Lupus Research Institute, log on to www.lupusresearchinstitute.org.

LUPUS
RESEARCH INSTITUTE

LUPUS RESEARCH INSTITUTE
National
Coalition
The Patient Voice for Lupus Research

Lupus Foundation of Mid and Northern New York is proud to support the Lupus Research Institute and honored to be a member of the Lupus Research Institute National Coalition.

Education

Lupus Foundation of Mid & NNY Leaders Helen Lenart and Sarah Eastup at the 2004 International Lupus Meeting in New York.

Boy Scouts from Troop 23 in Oneida help work on the lupus newsletter as part of their service project hours. By helping the community, they work toward rank advancement. Pictured doing a good turn are Andrew Teague and Brian Tucker. Andrew is the son of Lupus Foundation Board Member Phil Teague and former Board Member Kathy Teague.

Awareness

Lupus Foundation of Mid & NNY Leaders Sandi Frear and Sarah Eastup volunteering at the LRI Booth at the 2005 Annual ACR Scientific Conference In San Diego.

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Research

Sandi Frear and Kathleen Arntsen at The Rheuminations and Lupus Clinical Trials Consortium Dinner with Kit and Arnold Snider co-founders of both organizations.

Sarah Eastup and Kathleen Arntsen with Aspreva Pharmaceuticals President Noel Hall and Lupus Research Institute President Peggy Dowd at the LRI's Reception at the San Diego Yacht Club.

Empowerment

Lupus Foundation of Mid & NNY Leaders Sarah Eastup, Kathleen Arntsen , and Sandi Frear with La Jolla Pharmaceutical Friends Faith Manesis, Steve Engle, and Andrew Wiseman and Hollaine Hopkins, Executive Director of the Lupus Foundation of San Diego. Our group gave a patient presentation to staffers and then had a guided tour of LJPC's Corporate Headquarters in California.

Advocacy

Not even a February blizzard could stop Lupus Foundation of Mid & NNY members Carl and Pat Scavello, Danielle and Frank Turner (in back), Jamie Gloo and Kathleen Arntsen from participating in the 2nd Stem Cell Advocacy Event at the Empire State Plaza in Albany, NY. They were joined by 150 other New Yorkers for the Advancement of Medical Research.

SAVE THE DATE

Lupus Foundation of Mid and Northern New York

invites CNY Health Agency Leaders to attend:

NYS Health Policy Update 2006

Tuesday, April 4th
10:30am – 3:00pm

Turning Stone Casino Resort and Conference Center
Cayuga Room

in Verona, NY (Thruway Exit 33)

Topics to be addressed:

- Medicare Part D – Update
- NYS Medicaid - Overview and Update on the implementation of the Preferred Drug Program (PDP)
- Advocacy - How you can be a better advocate for yourself and the patients you serve
- Evidence Based Medicine
- Patient Assistance Programs – Pharmaceutical coverage for the uninsured

Seating is limited so pre-register early by e-mailing your reservation to Kathleen Arntsen at lupusmidny@aol.com. If you need a hotel room on April 3rd or 4th, contact Charlene Edwards at 315-361-7717 and mention the Lupus Foundation Meeting to get the special rate of $110. Thank you.

Registration is free and a buffet lunch will be included.
Final agenda will be sent to you after pre-registration.

Supported through an unrestricted educational grant from Pfizer

6th Annual Lupus Charity Golf Classic
Wish List

160 snack packs: Turkey breast for 80 people, Ham for 80 people, Cheese for 160 people, 160 Rolls, 160 Mayonnaise packets, 160 Mustard packets, 160 Bags of chips, 160 Packages of cookies, 160 Lunch paper bags, 160 Sandwich bags

Beverages: 10 cases of soda, 10 cases of beer, 20 cases of water

Door Prizes & Auction Prizes

Please contact us at 315-829-4272 or e-mail us at lupusmidny@aol.com if you are willing to sponsor the Snack packs handed out at registration to all golfers and volunteers or if you would like to donate any of the above items. Perhaps you have connections in the community that may be willing to donate some of the items.

We also need volunteers who are current members of the organization, willing to work from 9:30am to 8:00pm on Friday, August 18, 2006, and willing to attend a training session in early August. Please contact the office for more information.

Sixth Annual LUPUS Charity Golf Classic Raffle

Drawing to be held August 18, 2006 at Shenendoah Golf Club

1st Prize – 1 Week Lake Tahoe Condo

2nd Prize – Set of PING Irons or $500.00 Cash

3rd Prize – Shenendoah Windshirt

All proceeds benefit:

Lupus Foundation of Mid and Northern New York, Inc.

** Need not be present to win*

Donation $5.00 each or 3 for $10.00

Please contact us at 315-829-4272 or e-mail lupusmidny@aol.com if you want to sell or purchase tickets. Thank you.

Stress Hormone Enables Lupus Antibodies to Alter Behavior, Damage Cognition

Lupus Research Institute (LRI) Funds Initial Findings

A major breakthrough in lupus research—one that may fundamentally change thinking on how the disease affects behavior and cognition—was reported in the January 17, 2006 *Proceedings of the National Academy of Sciences* (*PNAS*). Entitled *Immunity and behavior: Antibodies alter emotion,* the research builds upon a framework of findings supported by LRI funds from 2001 to 2004.

A number of people with systemic lupus erythematosus (S.L.E.) experience subtle but insidious changes in behavior (affect), such as unusual feelings of fear (or lack of fear) and loss of interest or curiosity. And an estimated 8 in 10 at some point experience progressive cognitive impairment characterized by headache, confusion, fatigue, memory loss, difficulty expressing thoughts, and (occasionally) seizures or strokes.

Aside from actual inflammation in the brain, a grave but relatively uncommon lupus complication, the causes of these behavioral and cognition issues in people with lupus have been elusive. Now answers to the mystery are starting to surface, thanks to the bold and novel research of Betty Diamond, M.D., Chief of the Division of Rheumatology and Professor of Medicine at Columbia University College of Physicians and Surgeons, and lead author of the *PNAS* study.

The LRI— the leading nonprofit sponsor of research into lupus—awarded Dr. Diamond the Novel Research Grant that enabled her to first explore the channels responsible for brain damage in lupus. “Our initial grant from LRI allowed us to test our hypothesis,” said Dr. Diamond, “linking lupus antibodies and stress to cognitive impairment. I am convinced that, without Lupus Research Institute funding, our research would not have gotten off the ground.”

Problem Identified, Solution Proposed

With the LRI grant, Dr. Diamond and colleagues made three, core discoveries. Using mice, they concluded that lupus antibodies can destroy nerve cells in the brain, causing serious cognitive impairment. They also found that infection can pave the way for these damaging antibodies to penetrate into the brain, which is normally protected from various antibodies by a “wall” called the blood-brain barrier. Finally, they identified the Alzheimer’s medicine, memantine, as a potential drug model for inhibiting lupus brain damage.

With the *PNAS* study, Dr. Diamond and colleagues report that the penetration of toxic antibodies into the brain likely leads not just to thinking (cognition) problems, but also to changes in behavior. Specifically, the disease’s anti-DNA antibodies leak not only into the brain and damage neurons in an area called the hippocampus, which houses memories and the ability to navigate (among other things). They can also make their way into the amygdala, a brain region that governs fear and emotional responses, and cause damage there.

The researchers identify the stress hormone, epinephrine, as the agent responsible for letting the lupus antibodies gain access to the amygdale. These antibodies cause damage by binding to neurons and activating a receptor on the surface of the cell. Overstimulation of the receptor can lead to cell death. Epinephrine, which is also known as adrenaline, is produced by the adrenal glands in reaction to stress. Increased levels of the hormone can raise blood flow to the brain and cause leaks in the normally well-sealed barriers to this precious organ.

The *PNAS* authors identified two potential therapies for protecting the brain. The Alzheimer's drug (memantine) blocks glutamate, and may prevent the death of cells in parts of the brain such as the amygdala. Given this drug’s various undesirable side effects, the authors also propose investigating the therapeutic potential of a small molecule (a peptide) that they identified. The peptide may be able to protect brain cells from the anti-DNA antibodies as well.

LRI: Giving New Ideas Room to Grow

“The LRI’s decision to fund Dr. Diamond’s brilliant research clearly demonstrates its acumen in selecting novel ideas of real merit that ultimately pay off in a very big way,” said William Paul, M.D., Chairman of the LRI Scientific Advisory Board, upon hearing of the new research. Dr. Paul is Chief of the

Stress Hormone, (cont'd from page 12)

Laboratory of Immunology at the NIH's National Institute of Allergy and Infectious Diseases.

"The LRI is a catalyst. It brings innovative work to the fore, allowing investigators to make important discoveries that are essential to command greater funding from the NIH and the pharmaceutical industry."

Adds Margaret G. Dowd, LRI President: "By supporting scientists who are willing to defy conventional thinking, we are helping to change the face of lupus research. The strategy behind the Lupus Research Institute is clearly working, and the more than 1.5 million Americans with the disease will directly benefit."

About Lupus

Lupus is a chronic autoimmune disease in which the body's immune system, which normally functions to protect against foreign invaders, becomes hyperactive, forming antibodies that attack normally healthy tissues, including the heart, kidneys, lungs, liver, blood and skin. Complications from lupus can lead to heart attack, stroke and kidney failure.

March is Kidney Month, (cont'd from page 14)

Funding Research on How and Why Lupus Damages the Kidneys

Lupus Research Institute grant recipient **Marcus Clark**, M.D., at the University of Chicago has found activated immune system "B cells" in lupus kidney biopsy tissue. Dr. Clark is asking whether these B cells are promoting inflammation by secreting abnormal antibodies directly in the kidney, or possibly by helping to trigger autoreactive T cells (another type of immune system cell). Dr. Clark will piece together a potentially revealing picture—a molecular profile—of the kidney B cells in lupus.

Other researchers suspect T cells rather than B cells are to blame in lupus kidney disease. With Lupus Research Institute funding, **Peter Mundel,** M.D., at the Mount Sinai School of Medicine in New York City is working on an intriguing concept that the specialized kidney cells that perform blood filtering functions may be the target of autoreactive T cells that get into the organ and start reorganize the cell structure there. He is looking at the contribution of the molecule (known as B7-1) to kidney damage in lupus-prone mice.

Grant recipient **Neil Greenspan,** M.D., Ph.D., at Case Western Reserve University in Cleveland has bred lupus-prone mice that lack a certain type of functional antibody he suspects is involved in the kidney inflammation of lupus. If he is on track, testing for ways to block the antibody in humans is just a few steps away.

In Boston, **Elahna Paul**, M.D., Ph.D, at Massachusetts General Hospital is exploring the novel idea that once kidney inflammation has been triggered, kidney cells contribute to their own eventual destruction by multiplying and secreting inflammatory factors. Her findings could lead to new treatments that block kidney cell activation and prevent kidney failure in lupus—even in the presence of an ongoing autoimmune response.

And at the University of Virginia in Charlottesville, **Umesh Deshmukh**, Ph.D, is similarly challenging the idea that abnormal antibodies are the lone players in causing lupus kidney damage. Using lupus-prone mice, Deshmukh is investigating whether it is antibodies alone that form the basis for kidney disease in lupus, as well as where, when, and how T cells come into play.

About the Lupus Research Institute

The Lupus Research Institute (LRI) is the nation's preeminent sponsor of innovative, novel research into lupus. Established in 2000, this nonprofit organization is headquartered at 149 Madison Avenue, Suite 205, New York, NY 10016; telephone: 212-685-4118, fax: 212-545-1843. To learn more about lupus and the Lupus Research Institute and its research in kidney disease and other areas, log on to www.LupusResearchInstitute.org

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March is National Kidney Month

Lupus Research Institute Funds Innovative Studies on Kidney Disease— A Major Complication for Americans with Lupus

March 13, 2006, New York, NY – The nation observes Kidney Month in March, drawing attention to the importance of keeping these crucial fist-sized organs as healthy as possible. For the many Americans with well-established risk factors for kidney disease such as diabetes and obesity, the month will be a time to reflect on lifestyle and other health changes they can make.

But for the 1.5 million Americans with the chronic autoimmune disease, systemic lupus erythematosus (lupus), the month is a painful reminder that no matter what healthy living habits they follow, they are still at risk for developing potentially life-threatening kidney inflammation called nephritis. About a third of people with lupus suffer this complication, with some eventually requiring renal dialysis because the kidneys, which are crucial among other things for filtering wastes and balancing body fluids, essentially stop working.

The Lupus Research Institute: Pursuing a Cure

Currently, people with lupus kidney involvement have few options. “Lupus nephritis is potentially life-threatening and the medications that we use to treat it have significant and often debilitating side effects," says Lupus Research Institute President Margaret Dowd. “We need some answers, and we need them soon.”

The Lupus Research Institute is working to make that happen. Over the past five years, the Institute has funded more than 55 cutting-edge, 3-year novel research projects in lupus. Much about this devastating disease, in which the body's immune system forms antibodies that attacks various tissues and organs, remains a mystery.

Nearly all of the research grants shed light on the autoimmune response that causes kidney problems in lupus, and eight currently funded studies focus directly on this topic. The grants pursue ideas that look at lupus nephritis in a new way. They represent the kind of bold, out-of-the-box thinking that characterizes the genius and promise of novel research.

“The Lupus Research Institute is willing to take a gamble on ideas which have the potential to really cut new ground,” notes William E. Paul, MD, chief of the Laboratory of Immunology, NIAID-NIH.

Adds grant recipient **Elahna Paul**, M.D., Ph.D., at Massachusetts General Hospital in Boston, “The state of the art now is unfortunately a catch-up game. We start treating someone after they have the disease, but if we can diagnose it earlier, we can test therapeutic modalities that are less toxic and more likely to have an effect earlier in the disease process.”

Hunting for New Ways to Track Kidney Problems

Three studies are looking at early markers (called “biomarkers”) that signal the development or worsening of kidney disease in people with lupus. Biomarkers are urgently needed, as people with lupus often undergo grueling biopsies in which a small piece of their actual kidney is taken for analysis. Unfortunately these tests often give false or misleading results, have to be done repeatedly, and are not always safe.

Lupus Research Institute grant recipient **Anne Davidson**, M.D., at Columbia University in New York City, is examining whether inflammatory molecules in the urine of mice can similarly indicate nephritis onset or remission in humans. Her team has found a drug that reverses lupus nephritis in mice by blocking the activation of damage-inducing T and B cells. "We are already at the bedside," Dr. Davidson says. “If the [drug] combination works, it may be available to treat kidney involvement in lupus in three to five years.”

Also at Columbia University, **Robert Winchester**, M.D., is using his grant to see if a particular pattern of gene activity in immune system cells he has identified as indicators of injury in kidney tissue, taken through biopsy, also appears in the blood. Hopes are high that he is on track, so that a blood test for these biomarkers can be developed to watch for kidney problems, rather than subjecting people with lupus to repeated biopsies. Grant recipient **Hanno Richards**, M.D., at the University of Florida in Gainesville is also testing for an “early indicator” of lupus kidney damage that can be measured through blood and urine tests. His study looks at certain molecules produced by immune system cells that lead to kidney damage.

(continued on page 13)

LUPUS FOUNDATION OF MID AND NORTHERN NEW YORK
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Name:	Date:
Address:	Phone #:
City, State, Zip:	Work #:
E-mail address:	Fax #:
☐ Single ($10.00) ☐ Renewal ☐ Family ($15.00) ☐ New ☐ Professional ($25.00) ☐ Patron ($50.00) ☐ Courtesy	Other Donation (please list) ______________________________________ ☐ Interested in Support Groups

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☐ COPING WITH LUPUS by Robert H. Phillips, PhD	*$ 15.00 plus $2.00 S & H*
☐ LUPUS WELLNESS JOURNAL	*$ 8.00 plus $2.00 S & H*
☐ AWARENESS WRISTBANDS *Orange or Purple*	*$ 1.00 plus .25 per 3 S & H*
☐ BEANIE BEARS	*$ 10.00 plus $2.00 S & H*

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___ SLE & The Nervous System
___ Steroids Used in Treatment of Lupus
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___ Lupus in Overlap w/ Connective Tissue Disease
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___ Basics for Better Living
___ Photosensitivity

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

LUPUS
Foundation of Mid and
Northern New York, Inc.

Annual Education Symposium & Luncheon

"Hope is on the Horizon"

Saturday, May 6th, 2006

9:30am to 3:30pm

Turning Stone Casino Resort & Conference Center
in Verona, NY (Exit 33 NYS Thruway)

Presenters include:

Dr. Ann Parke, MD University of Connecticut Rheumatologist

Phospholipid Antibody Syndrome A Lupus Like Disease?

Dr. Raquel Rosen, MD Bassett Healthcare Nephrologist

Update on Lupus Nephritis

Dr. Beth Biggee, MD Bassett Healthcare Rheumatologist

Updates in Connective Tissue Disease Treatments

Dr. R. John Looney, MD University of Rochester Rheumatologist

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Exhibit Booth Displays and Handouts

No charge to first 100 current members that register

$20 fee to non-members; limited to 150 attendees

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

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