



Rheumatology
A key to proper diagnosis

Clinical studies
Fighting for a cure today

Quality of life
The benefits of a positive outlook

MEDIA PLANET

July 2011

LUPUS AWARENESS



A SHOW OF SUPPORT

If you have lupus, care about someone with lupus, or think you may have lupus, there's **hope** and **help** in your community

PHOTO: PRIVATE

Q: LUPUS A: NORTHWESTERN

If you have questions about lupus, the experts at Northwestern University Feinberg School of Medicine have the answers. Our physicians provide you with comprehensive, individualized and coordinated care. Our scientists conduct patient-oriented research that seeks to increase survival rates and reduce disease complications, and leads to the development of new tests and therapies. We also train the next generation of young researchers driving the cure for the disease.

To learn more, call (312) 695-8628 or visit www.lupus.northwestern.edu.



NORTHWESTERN UNIVERSITY
FEINBERG
SCHOOL OF MEDICINE



CHALLENGES

Imagine after months of suffering with joint pain, unexplained fevers and extreme fatigue you were diagnosed with lupus. **Would you know how to react?**

FACT
1
TWO OUT OF THREE PEOPLE KNOW LITTLE TO NOTHING ABOUT LUPUS

Saving lives, providing hope

didn't. My wife, Shirley, was diagnosed with lupus as we were becoming empty nesters in 2001. In the ten years since her diagnosis, I have learned a lot about lupus—what the disease is, who gets it, and how it impacts not only the individual with the disease but everyone who cares about that individual. I am so committed to improving the state of lupus in Illinois that last year I became the President and CEO of the Lupus Foundation of America, Illinois Chapter.

Lupus can be mild to life-threatening

Lupus is a chronic autoimmune disease in which the immune system becomes unbalanced, causing inflammation and tissue damage to virtually every organ in the body. An estimated 1.5 million Americans are living with lupus every day, and no one is safe from lupus—the disease can develop in anyone regardless of age, race or gender. However, ninety percent of people with lupus are women, and minority women are two to three times more likely

to acquire the disease. Researchers believe individuals with lupus have a genetic predisposition to the disease, and that certain environmental factors play a role in triggering lupus. Unfortunately, there is no single test for lupus, making it a difficult disease to diagnose, but early diagnosis and proper medical care can often keep lupus under control. In addition, despite researchers not knowing the exact cause of the disease, lupus is not contagious.

Increased awareness about lupus is critical

A recent study showed that two out of three people know little to nothing about lupus—and awareness is particularly low among women 18 to 24 years of age—the group most often diagnosed with the disease. The objective of raising awareness about lupus is to improve and save lives. The average lupus diagnosis currently takes four or more years after visiting three or more doctors—too long since early treatment is imperative to improved outcomes. By educating the public about the signs and symptoms of lupus, the



Charles Brummell
President & CEO,
Lupus Foundation
of America,
Illinois Chapter

delay between the onset of lupus symptoms and the diagnosis of the disease will be reduced, resulting in faster treatments and improved outcomes. The lack of lupus awareness contributes to a feeling of isolation for lupus patients, so increasing awareness about lupus will improve lupus patients' quality of life.

Lupus research offers hope

With a disease like lupus, of which there are so many unanswered questions, research is necessary to find answers. This past March, the Federal Drug Administration approved the first new lupus drug (Benlysta) in 56 years. This monumental accomplishment provided hope to those living with the disease.

Getting help now

I know better than anyone how lupus impacts not just the indi-

viduals with the disease but the people who care about them as well. The foundation's mission is to improve the diagnosis and treatment of lupus, support individuals and families affected by the disease, increase awareness of lupus among health professionals and the public, and find the causes and cure.

The Illinois Chapter provides programs and services that provide support and assistance to the estimated 65,000 Illinois residents living with lupus and the thousands more who care about them. The foundation's support includes educational material, support groups, individual peer support, financial assistance and personal assistance. All programs and services the foundation offers are provided at no cost to the individual. If you have lupus, care about someone with lupus, or think you may have lupus, I encourage you to contact the foundation and find out more. The Lupus Foundation of America—Illinois Chapter is here to help now.

CHARLES BRUMMELL
editorial@mediaplanet.com


WE RECOMMEND


Dina Thachet's story
"I am thriving despite the lupus."

PAGE 5

MEDIA PLANET

 LUPUS AWARENESS,
1ST EDITION, JULY 2011

Publisher: Lindsey Sayles
lindsey.sayles@mediaplanet.com
Business Developer: Terence Cooke
terence.cooke@mediaplanet.com
Designer: Mariel Fitzgerald
mariel.fitzgerald@mediaplanet.com
Managing Director:
Geraldine Delacuesta
geraldine.delacuesta@mediaplanet.com
Editorial Manager: Jackie McDermott
jackie.mcdermott@mediaplanet.com

Contributors: Charles Brummell;
Heather Sayles Gawron; Robert Katz,
MD; Lupus Foundation of America, Inc.;
Lupus Research Institute; Dina Thachet;
The Lupus Initiative

Distributed within:
Chicago Tribune, July 2011
This section was created by
Mediaplanet and did not involve
the Chicago Tribune or its Editorial
Departments.



FOLLOW US ON FACEBOOK & TWITTER!
www.facebook.com/MediaplanetUSA
www.twitter.com/MediaplanetUSA

Mediaplanet's business is to create new customers for our advertisers by providing readers with high-quality editorial content that motivates them to act.



Lupus Research Institute Pioneering Discovery to Cure Lupus



The world's leading private supporter of innovative research in lupus, the Lupus Research Institute champions scientific risk-taking in the hunt for solutions to this complex and dangerous autoimmune disease.

For further information, call 1.800.74.LUPUS (58787) or visit: LupusResearchInstitute.org.

INSIGHT

Answering the question “Do I have lupus?”

Since arriving at Rush University Medical Center in Chicago many years ago, I have seen many patients enter my office asking the same question: “Do I have lupus?”

Unfortunately, the reality is that there is no one test for lupus and the symptoms can be quite difficult to put together if there is nothing concrete or objective at the time of an office visit.

Rheumatologists specialize in the area of internal medicine which includes lupus and other autoimmune disorders. When I first started treating patients, lupus was identified as a serious, threatening disease. Now, with greater research and newly developed treatments, lupus patients are living longer and having more productive lives, but the first step in living longer with



A PROPER DIAGNOSIS
Dr. Robert Katz (left) seeking answers for his patients.
PHOTO: RICHARD SHAY PHOTOGRAPHY

analysis looking primarily for protein spilling into the urine, as well as other antibody tests are conducted. Together the symptoms, physical signs, lab tests, and sometimes a biopsy of skin or the kidney help establish a diagnosis of lupus.

ROBERT KATZ, MD

Professor of Medicine,
Rush University Medical Center, Chicago
editorial@mediaplanet.com

lupus is an accurate diagnosis.

The diagnosing process

To obtain a proper lupus diagnosis, rheumatologists rely on knowledge, experience, and to some extent, the American College of Rheumatology’s lupus diagnostic criteria. This criteria includes: joint pain, a facial butterfly pattern rash

(over the cheeks and forehead), pleurisy (chest pain associated with deep breathing) and other symptoms, including sun sensitivity, blue or white fingertips in the cold, extensive hair loss, mouth sores, fever (over 100 degrees) and fatigue. Additionally, the kidneys, heart, lungs, brain or blood vessels may develop complications, in

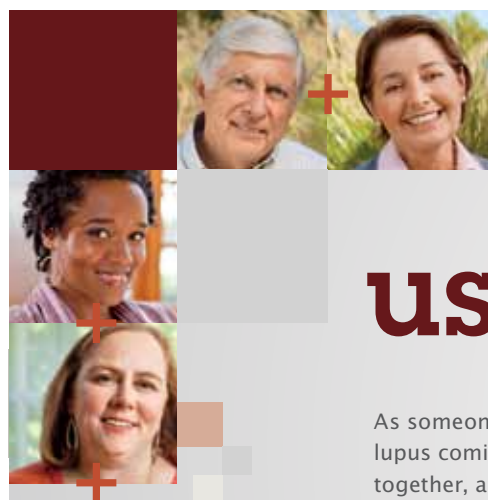
which case a biopsy to determine the diagnosis and proper treatment of lupus may become required.

Inside the lab

A proper lupus diagnosis also requires work inside the laboratory, where tests on the antinuclear antibody, anti-DNA antibodies, the sed rate test for inflammation, uri-

! Don't miss!
Further tips:

On page 8 of this special report you'll find the “Test Yourself For Lupus” questionnaire provided by the Lupus Foundation of America. The Illinois Chapter’s website, lupusil.org, provides additional information about the diagnosis and current treatment of lupus, along with other valuable lupus information.



Where can people living with **lupus** go to find their voice—and many reassuring echoes?

us in lupus.com
together we're stronger

As someone who’s living with lupus, you may sometimes feel alone. But there’s a whole group of people living with lupus coming together. Whether we have lupus or care about someone who does, we are taking on our challenges together, and not giving in to them. We are learning from each other and moving forward. We are **the us in lupus**.

Where can you find us? At the **usinlupus.com**. There you'll find stories for us—inspired by us. You'll get access to information about living well with lupus. Best of all, you'll find the voice of people living with lupus—and a community that embraces it.

Visit the **usinlupus.com/learnmore** today.

Or call **1-855-USINLUPUS** (1-855-874-6587)

Some people featured in the **us in lupus** are paid spokespeople for Human Genome Sciences, Inc. and GlaxoSmithKline.

us in lupus.com
together we're stronger



INSIGHT

Question: Does relief come with the diagnosis of lupus?

Answer: After years of testing, yes.

My lupus, my life

This may sound thoughtless, but when I was first diagnosed with lupus eight years ago, I was actually happy. Why?

Well, imagine visiting several different doctors over the course of a few years, all the while being subjected to various exams and blood tests, only to receive no answer to the question "What is wrong with me?" The diagnosing of my lupus was such a painfully long process that discovering the cause of my various symptoms and illnesses was truly a welcome relief.

Glad to finally know

I was glad to finally know what was

making it so that I couldn't get out of bed most days. I was glad to finally know what it was that was making it so that I could hardly even lift a gallon of milk out of the refrigerator. Once my doctors and I found out the root cause of my many illnesses, we could finally go about making it all better, or at least making it a little better. However, answers don't always solve problems.

Life with lupus

The most frustrating thing about having lupus is maintaining a "normal" life. It's really hard to explain to people why I can't work or why I need help taking care of my four year old son. I've also lost count of how often I have to tell people why it is that they can't see



SISTERLY LOVE Years after her diagnosis, Heather (left) celebrates the birthday of her sister, Publisher Lindsey Sayles (right). PHOTO: PRIVATE

what makes me sick. It's not so obvious this lupus thing, especially when it manifests itself through so many symptoms, such as severe joint pain, chronic fatigue, facial rashes, mouth sores and terrible

headaches. Rising out of bed in the morning, showering, and even getting dressed (things people do every day and take for granted) are things I can't do sometimes. Though I have medications that

often make things easier, sometimes the side effects can be worse than the symptoms themselves.

Hope is ahead

I've tried many different medications since my diagnosis, including pain medication and muscle relaxers, and very soon I will be starting the newest lupus medication on the market called Benlysta. Thanks to the increasing research and discoveries of such new treatments, I'm hopeful that my lupus will go into remission, and thanks to the support of my family and friends, I know I will never run out of hope.

HEATHER SAYLES GAWRON

editorial@mediaplanet.com

If you or a family member have lupus

and want to inquire about appropriate therapy, the latest treatments, proper diagnosis, or ongoing clinical care, please feel free to contact Dr. Katz. Dr. Katz continues to participate in research of new treatments for lupus and has written over 250 academic research papers. He serves as Chairman of the Medical Advisory Board of the Lupus Foundation, Illinois Chapter, and on the board of the Lupus Research Institute.

1725 West Harrison Street
Suite 365
Chicago, Illinois 60612

312-226-8228

www.DrRobertKatz.com

Robert S Katz, MD
Professor of Medicine,
Rush University Medical Center
Adjunct Professor of Medicine,
Northwestern University
Feinberg School of Medicine



Hundreds of Lupus patients recover from pain, depression, anxiety and chronic illness at The Bridge.

www.thebridgerecoverycenter.com

Call now ! 877-885-9567 We can help!

FACT

2

THE AVERAGE
LUPUS
DIAGNOSIS
TAKES FOUR
YEARS OR
MORE

INSIGHT

In 1993, I was a **typical young college student** at the University of Illinois—going to classes, studying all day, and going out dancing on the weekends.

A survivor: Beating the odds

All of a sudden, never having been sick before, I began having random medical symptoms—achiness, anemia, fatigue, rashes, etc.

For a year, I saw numerous doctors, but was either misdiagnosed or told there was nothing wrong. But then, in the spring of 1994, my life turned upside down when I was hospitalized for a month. My initial symptoms were meningitis and an intestinal infection, but I was eventually diagnosed with Systemic Lupus Erythematosus (SLE) and Stage IV Nephritis.

When I was first diagnosed with lupus, I was given a five year

prognosis. My kidneys were functioning at only about 10 percent, and every possible organ system that could have been affected by inflammation was—I had pleurisy, pericarditis, central nervous system swelling, etc. I was told that I needed to immediately start on Cytoxan therapy, which is a type of chemotherapy, in order to reduce the inflammation in my kidneys and prevent kidney failure.

Thriving and surviving

That was 17 years ago, and not only did I surpass the five year prognosis, I am thriving despite the lupus. Today, though management of my disease is a full-time job, I am in clinical remission, and I'm lucky



UNCONDITIONAL SUPPORT Dina (R) with her parents during last year's Walk For Lupus Now event in Illinois. PHOTO: PRIVATE

“They are there for me when the lupus is threatening to break my spirit, and they are there to help remind me of the fact that I have survived so much worse.”

to have the unconditional love and support of my incredibly supportive parents, brothers, other relatives, friends, and most importantly, my amazing husband. They are there for me when the lupus is threatening to break my spirit, and they are there to help remind me of the fact that I have survived so much worse.

I actively educate others about lupus and the symptoms, offer guidance and support to newly diagnosed lupus patients, and I am involved with the Lupus Research Institute of Chicago (www.lrichicago.org). Each spring, I travel to Washington D.C. along with numerous other people with lupus to educate lawmakers about lupus

and to seek much needed funding for the research and discovery of better treatments.

Because I survived, I am determined to do whatever I can to advocate for others. Having been through all that I experienced, I have a unique perspective and insight into what others deal with and what they need to survive physically, mentally and spiritually. I am not only blessed and fortunate to be alive, I have been able to maintain a relatively high quality of life despite the lupus, and that is my wish for all others who have been diagnosed with lupus as well.

DINA THACHET

editorial@mediaplanet.com



Unpredictable events do occur, and MedicAlert® IDs provide crucial information that can speed appropriate treatment when you or your loved one can't give the necessary information. A MedicAlert ID and emergency wallet card include vital information about your lupus diagnosis and your emergency contact information.

Always There For YouSM

MedicAlert membership benefits for lupus patients:

- Live 24/7 emergency response services
- Live 24/7 family notification services
- Personal health emergency record
- Personalized MedicAlert ID and emergency wallet card
- Access to health/wellness articles and online communities related to lupus

*New MedicAlert styles available!
Shop today at www.medicalert.org/shop*



www.medicalert.org | 1.800.ID.ALERT™



NEWS



Question: How can we expand novel research?
Answer: By driving scientific discovery, identifying new drug targets, and accelerating clinical trials.

THE PATH TO NEW TREATMENTS

The Lupus Research Institute (LRI) was founded in 2000 to encourage scientific innovation by funding creative, novel, and often unorthodox approaches to solve the complexities of lupus and autoimmunity.

Ten years later with over \$36-million invested in more than 120 studies nationwide, the LRI is now the leading private supporter of innovative research in lupus.

A tapestry of knowledge Lupus Research Institute novel research grants, including almost \$2-million awarded to the University of Chicago, have helped to create a tapestry of knowledge not previously available in lupus. New genetic factors have been identified and we better understand the ways in which different organs can be attacked and damaged in lupus. Novel advances have gener-



SUPPORT THROUGH RESEARCH Increased funding of clinical research will lead to more answers and more smiles in the lupus community. PHOTO: PAUL LITKE

ated a core of new knowledge of human lupus biology, allowing scientific discoveries to be explored in human systems. Thirty percent of LRI-funded investigators are on the road to moving their research discoveries into patent applications and biomarkers—the path to new treatments. And finally, after more than 50

years of inaction, the first new drug for lupus (Benlysta) received FDA-approval in March of this year, documenting the transformative power of innovative science to drive clinical success, and proving that sound investment in lupus clinical trials can be worth the time and effort involved.

This landmark approval of the first new treatment for lupus is giving industry as a whole the confidence to move forward with over 100 new lupus trials now advancing to enroll participants. See LupusTrials.org for clinical trial listings, information and enrollment options.

As we actively participate in delivering new hope to patients, the LRI remains steadfast in its determination to take risks, think outside the box, and bring only the best new ideas and imaginative new science to lupus.

LUPUS RESEARCH INSTITUTE

editorial@mediaplanet.com



SisSLE

*Sisters of Women
with Systemic Lupus
Erythematosus
Research Study*

Scientists at the Feinstein Institute for Medical Research are looking for sisters to participate in the SisSLE: Lupus Sister Research Study.



Visit our website at
www.SisSLE.org
or call
1-877-698-9467

Principal Investigators Betty Diamond, MD and Peter K. Gregersen, MD invite physician investigators nationwide to join in this effort.

Are you one of the 5 million¹ individuals living with lupus?

If you are one of these individuals, we invite you to consider participating in the ILLUMINATE Research Study Program. The ILLUMINATE Program is evaluating a new investigational medication for systemic lupus erythematosus (SLE), the most common form of lupus.

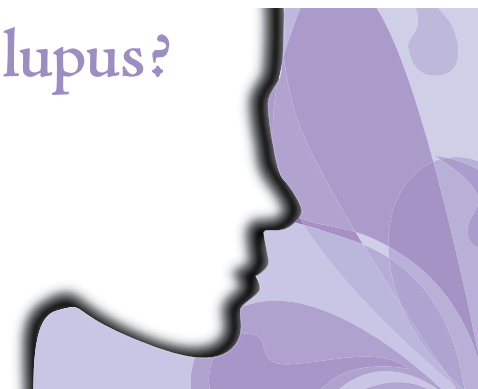
If you or someone you know is **18 years of age or older** and has been **diagnosed with SLE**, then participation in this clinical research program could be an option for you. To determine if you may qualify to take part, our doctors and nurses will perform additional tests and health assessments.

Individuals who qualify will receive study medication and all study-related care at no charge. Reimbursement for study-related travel and time will be provided. Some standard lupus medications will also be permitted during study participation.

For further information, please feel free to contact us:

www.illuminatestudy.com

Contacting us does not mean that you have to participate in this clinical research program and participation is completely voluntary.
¹Lupus Foundation of America, Inc. (2010). Statistics on Lupus. Retrieved from http://www.lupus.org/webmodules/webarticlesnet/templates/new_newsroomreporters.aspx?articleid=247&zoid=60



INSIGHT

Teamwork: Patient-provider partnership

Lupus is a vivid example that Americans of different races and ethnicities do not lead equally healthy lives.

But for all who are touched by lupus, active management can make a difference.

Provider awareness is critical

For some patients, the first sign of lupus is profound fatigue, while for others it's a rash, joint pain, trouble thinking or hair loss. Because lupus can affect virtually any part of the body, it is important for health professionals to recognize its many symptoms, as well as sources of stress in patients' lives that lead to symptom flares. Depending on symptoms, family physicians, pediatricians, rheumatologists, psychiatrists and other key caregivers must learn to work as a team, of which the patient is an essential member.

Know the signs and partner

“Depending on symptoms, family physicians, pediatricians, rheumatologists, psychiatrists and other key caregivers must learn to work as a team, of which the patient is an essential member.”

with providers to take action

Empowered patients have better outcomes. Get educated; partner with your provider to find the most effective treatment for you; stay active; reduce stress; create

a support network; eat a balanced diet. For additional resources, visit www.thelupusinitiative.org/content/organizations.

The Lupus Initiative

The Lupus Initiative provides resources to assist healthcare professionals in treating and managing patients with lupus and eliminating the persistent gaps between the health status of minorities and non-minorities, and women and men—because better treatment improves quality of life and saves lives.

The Lupus Initiative is a division of The American College of Rheumatology. It was conceived by Garth Graham, MD, MPH, Deputy Assistant Secretary Office of Minority Health (OMH) and spearheaded by OMH, with the Office on Women's Health and the Office of the Surgeon General of the US Department of Health and Human Services.

THE LUPUS INITIATIVE
editorial@mediaplanet.com



A SPECIAL THANKS

Rosalind Ramsey-Goldman, MD, DrPH, is the principal investigator for the Patient-Oriented Clinical Research Program in Systemic Lupus Erythematosus (SLE) at Northwestern University.

The program focuses on improving the quality of life for lupus patients and providing state of the art care for patients.

In addition, her research program includes the investigation of prevention strategies to minimize complications related to SLE, including osteoporosis, cancer and cardiovascular disease. The program is also studying genetic risk factors for disease susceptibility and severity in SLE.

Dr. Ramsey-Goldman is also active in designing, monitoring, and performing clinical trials identifying novel biomarkers and testing innovative therapies for patients with SLE, and has authored over 150 peer reviewed invited publications.

Dr. Ramsey-Goldman is an

active volunteer for multiple professional and lay organizations. She completed a three year term as the Chair of the Committee on Education for the American College of Rheumatology and she is currently serving a three-year term on the Board of Directors of this organization. She is on the editorial board of Arthritis and Rheumatism, and she recently completed a five year term as the Chair of the Systemic Lupus Collaborating Clinics group. She has served on the Medical Advisory Board for Lupus Foundation of America Illinois Chapter for almost 20 years.

“I have devoted my entire professional career to working with patients with lupus, since my first lupus clinic during my rheumatology fellowship. My goal is to improve the lives of those who suffer from the complications of lupus and its treatments.”

SOCIAL SECURITY DISABILITY

BENEFITS DENIED?

Selected By Peers As





JEFFREY A. RABIN
&
ASSOCIATES, LTD.

Providing Effective, Aggressive Legal Service.
Our Lawyers Have Over 40 Years Combined Experience
In Social Security Law. **No Fees Until You Win!**

www.RabinSSlaw.com

847-299-0008

Des Plaines • Chicago • Libertyville • Winfield • Joliet



Jeffrey A. Rabin

Attorney At Law

NEWS

TEST YOURSELF

■ Have you ever had achy, painful and/or swollen joints for more than three months?

■ Do your fingers and/or toes become pale, numb or uncomfortable in the cold?

■ Have you had any sores in your mouth for more than two weeks?

■ Have you ever been told that you have a low blood count(s)—anemia, low white cell count or a low platelet count?

■ Have you ever had a prominent redness or color change in the shape of a butterfly across the bridge of your nose and cheeks?

■ Have you ever had an unexplained fever over 100 degrees for more than a few days?

■ Have you ever had a sensitivity to the sun where your skin “breaks out” after being in the sun (not a sunburn)?

■ Have you ever had chest pain with breathing for more than a few days (pleurisy)?

■ Have you ever been told you have protein in your urine?

■ Have you ever experienced persistent, extreme fatigue and weakness for days or even weeks at a time even after six-hours of restful nighttime sleep?

■ Have you ever had a seizure or convulsion?

! If you answer “yes” to three or more of these questions, talk to your doctor about lupus. Early diagnosis and proper medical care can often keep lupus under control.

LUPUS FOUNDATION OF AMERICA, INC.

**Western Suburbs**

- Saturday, August 20, 2011
- Naperville Riverwalk, Naperville
- 9 AM to Noon

Downtown Chicago

- Sunday, September 18, 2011
- Grant Park (Columbus & Balbo) Chicago
- 9 AM to Noon

www.2011lupuswalk.kintera.org
www.lupusil.org
 (312) 542-0002
 800-2-LUPUS-2

Physicians are researching a new investigational medication for people with skin lupus

Researchers across the country are seeking clinical study participants who are diagnosed with skin lupus (Subacute Cutaneous Lupus Erythematosus (SCLE) and/or Discoid Lupus Erythematosus (DLE)). SCLE is characterized by red raised lesions that worsen when exposed to sunlight or other ultraviolet light. DLE is characterized by sores with inflammation and scarring primarily on the face, ears, and scalp.

People who have been diagnosed with skin lupus for at least 18 months and who are struggling to control their symptoms may be eligible to participate in this study. All study related care is provided at no cost to those who qualify for the study. This study is being conducted by a leading dermatologist in the Chicago area who specializes in complex dermatologic disease including lupus DLE and SCLE. To learn more visit www.LupusSkin.org or call 1-877-674-6317.