

# Lupus News

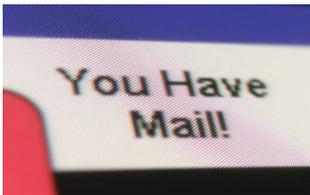
Volume 27, Issue 2

APR - AUG 2012



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## HEALTH CARE REFORM AND THE LUPUS PATIENT

“The Lupus Research Institute Applauds the Supreme Court Ruling on Healthcare Act. *Legislation Maintains Key Critical Principles for People with Lupus and Other Chronic Diseases*”

“The historic decision is greatly welcomed news for the 1.5 million Americans living with lupus. In upholding the Act, the Court supported principles the LRI and its National Coalition of patient organizations had successfully advocated for inclusion to ensure that people with chronic diseases such as lupus are protected. The Supreme Court ruling maintains the following four key principles so critical to people with lupus and other chronic diseases:

Insurance coverage available for all Americans, regardless of pre-existing conditions.

Elimination of lifetime caps on health benefits.

Provisions dedicated to prevention and wellness and educating those with and at risk for chronic disease on best ways to manage and prevent illness.

Dedication to eliminating racial disparities in chronic diseases such as lupus, which disproportionately affects minorities.”

(To see an outline of the Supreme Court decision, please go to page 3.)



*The Lupus Office has handouts on  
Prescription Drug Assistance -  
just call us at 520-622-9006.*

## Mission Statement

To provide information, education and referrals for those affected by lupus and to promote the development and enhancement of health and social welfare services at the local level to assist lupus patients. To promote public education and increase knowledge and understanding of the disease and its ramifications. To encourage support of research programs related to the diagnosis, treatment, cure and prevention of lupus. To promote the exchange of information among health professionals and collaborate with the professional community to improve the standards of diagnosis, care and treatment of lupus patients.

### Board Officers

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Vice-President: Patty Powell  
Secretary: Julie Gates  
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email: lupus12@juno.com



## *From the President....*

*I* love the monsoon season, with all of its excitement and fury. As you know some parts of it have been destructive, but overall it is good to be in Southern Arizona in the summer!

At the last board meeting in May, we said good bye to Jack Dufficy. Jack has retired and we all will miss him. Jack has been our main SLESH class coordinator and a valued board member since 2000. We also have received the resignation of Donna Kidder, due to health issues. Donna joined the board in 2009 but will need to focus now on becoming well. We send our best wishes to Jack and Donna.

We are in the midst of having our board election and the results will be announced at the Annual Meeting which will be on Saturday, September 29th.

We will be having our Annual Meeting Luncheon At Emeritus Catalina Foothills on Saturday, September 29<sup>th</sup>. If you have never made it to this luncheon please consider joining us this year. We will be sending out the details in our membership mailing so make friends with the postman and keep an eye out for it!

We had to withdraw as a charity for the El Tour de Tucson for this year. We are hoping to be a participant for next year. Please contact the office if you know any cyclists who will ride for Lupus or if you are able to work on this committee.

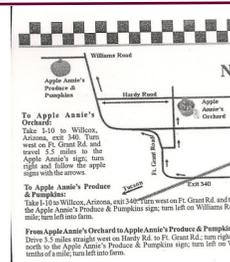
We are asking our members to provide their email addresses to us so we can make contact with them by email instead of just by the U.S. Mail. This will reduce our expenses and even save a tree! We will not solicit donations via email but we will keep you aware of fundraisers, membership events and news. We are hoping to send our quarterly newsletters to you via email in the future if you would prefer to receive it that way. Building our email base is another way we are trying to be good stewards of the Lupus Foundation funds.

Have a great rest of the summer and keep cool!

*Joni Broussard*



Pick your own fruit this summer at  
"Apple Annie's Farm" in Wilcox and don't  
forget the All-You-Can-Eat-Peaches and  
Pancake Breakfast!! A donation will be  
made to the Lupus Foundation!



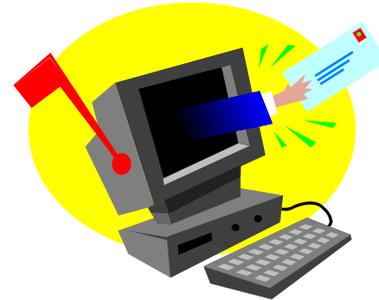
## Health Reform Benefits for Americans

[www.whitehouse.gov](http://www.whitehouse.gov)

The Affordable Care Act gives lupus patients and other Americans the stability and flexibility they need to make informed choices about their health. Some of the benefits are listed below:

- √ Provides Coverage to Americans with Pre-existing Conditions: Patients may be eligible for health coverage under the Pre-Existing Condition Insurance Plan.
- √ Covers Preventive Care at No Cost to You: You may be eligible for recommended preventive health services. No copayment.
- √ Ends Lifetime Limits on Coverage: Lifetime limits on most benefits are banned for all new health insurance plans.
- √ Removes Insurance Company Barriers to Emergency Services: You can seek emergency care at a hospital outside of your health plan's network.
- √ Protects Your choice of Doctors: Choose the primary care doctor you want from your plan's network.
- √ Ends Arbitrary Withdrawals of Insurance Coverage: Insurers can no longer cancel your coverage just because you made an honest mistake.
- √ Keeps Young Adults Covered: If you are under 26 you may be eligible to be covered under your parents health plan.
- √ Ends Pre-Existing Condition Exclusions for Children: Health plans can no longer limit or deny benefits to children under 19 due to a pre-existing condition.
- √ Restricts Annual Dollar Limits on Coverage: Annual limits on your health benefits will be phased out by 2014.
- √ Reviews Premium Increases: Insurance companies must now publicly justify any unreasonable rate hikes.
- √ Helps You Get the Most from Your Premium Dollars: Your premium dollars must be spent primarily on health care --not on administrative costs.
- √ Guarantees Your Right to Appeal: You now have the right to ask that your plan reconsider its denial of payment.

For detailed information: [www.healthcare.gov/law/features/choice](http://www.healthcare.gov/law/features/choice)



## Sign Up for Lupus Updates

*Don't worry we won't flood your inbox with unnecessary communications or solicitations. We'd just like to have a quick and easy way to keep you informed of lupus updates and upcoming Foundation happenings!*

*This will save the Foundation time and money and allow us to keep you up-to-date more efficiently.*

*You can send us an e-mail at:*

**[lupus12@juno.com](mailto:lupus12@juno.com)**

*Join other lupus members and receive notices of special programs, meeting changes and updates, and community opportunities to show your support for the Southern Arizona Lupus Foundation.*

*Thanks for your help!*

**Our Sincere Thanks to  
GlaxoSmithKline for their  
contribution toward the  
printing of LUPUS NEWS**





# Lupus Annual Meeting Luncheon



## You Are Invited To Our Annual Meeting Luncheon.....

**When:** Saturday, September 29, 2012

**Where:** Emeritus at Catalina Foothills

3701 N. Swan Road

**Time:** 10:30am Registration

Guest Speaker, Dr. Hunter Yost, speaking on how

Functional Medicine can help those with Rheumatological Disease

Registration Deadline: Thursday September 27th.

**Ticket Donation** - \$8.00 - light lunch

Mail to: Lupus Foundation of So. Arizona

4602 E. Grant Road

Tucson, AZ 85712



You can call us at 520-622-9006 if you have any questions.

### Lupus Foundation Annual Meeting Luncheon Reservation, September 29, 2012

Donation \$8.00

Please send me \_\_\_\_\_ Luncheon Tickets

I am enclosing check or money order in the amount of \_\_\_\_\_

Please charge my credit card: Name on card: \_\_\_\_\_

My address: \_\_\_\_\_ Card # \_\_\_\_\_

\_\_\_\_\_ Exp. Date \_\_\_\_\_

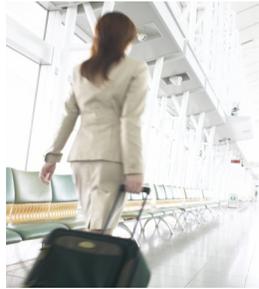
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(e-mail address to receive next day confirmation) \_\_\_\_\_

## Survey Shows the Burden of Lupus on Work and Wallet -

Human Genome Sciences [www.hgsi.com](http://www.hgsi.com) Rockville, MD, and Research Triangle Park, Inc. July 11, 2012



Results of a Roper survey of the lupus community highlight that in addition to the physical burdens of lupus, the disease can contribute to significant economic challenges among patients and caregivers. Patients with systemic lupus Erythematosus (SLE or lupus), caregivers and physicians overwhelmingly agree that career disruptions caused by the challenges of living with lupus often exact a heavy financial and emotional toll, according to the survey.

A majority of patients, supporters and doctors report that people with lupus change career plans because of lupus, a chronic and potentially disabling disease. More than half (63 percent) of respondents with lupus quit working or retired earlier than planned, about two-thirds (67 percent) reduced the number hours worked and 51 percent of patients changed to a less strenuous job.

Lupus can occur at any age, but appears mostly in young people aged 15 to 44 - prime working years. Inability to work seems to weigh heavily on patients, emotionally and financially. For example, 82 percent of patients reported that not working makes them feel they are not contributing their fair share to the household, and 83 percent found it devastating to leave their jobs due to lupus.

Many people with lupus say the disease impacts their productivity and has an undesirable effect on their relationships with co-workers. In fact:

- 72 percent of patients admit they are not as productive as they could be at work as a direct result of lupus
- Approximately 80 percent of lupus patients say that their condition has caused them to take more sick days
- 59 percent of lupus patients surveyed say that other people think that lupus affects their reliability and dependability
- About two-thirds (69 percent) of patients say they only tell a few co-workers about having lupus

"It is important to reinvent ourselves in meaningful ways when a chronic illness limits your original life plans," said Joan Merrill, M.D., chair of the Clinical Pharmacology Research Program at Oklahoma Medical Research Foundation and consultant to Human Genome Sciences and GlaxoSmithKline. "However, this is hard to do. Friends and family can help by valuing and supporting a new direction or modified goals."

Some people living with lupus have had to think differently about their jobs or careers because they found it difficult to fulfill their responsibilities due to lupus. As disappointing as this may be, many people living with lupus have been able to find jobs in different or related fields that are more suitable to their situations. There are resources and tips to help you better manage your career, available at [UsinLupus.com](http://UsinLupus.com).

About the National Burden of Lupus Survey ---The national survey was conducted by GfK Roper Public Affairs and Communications (GfK Roper North America or Roper) from July through September 2011. It was designed to evaluate the daily and long-term impact of lupus on health, family relationships, career and quality of life, and identify potential gaps in communication. Results were drawn from more than 950 people in the lupus community - 502 people who reported being diagnosed with SLE, 204 supporters (family members or friends) of people with lupus and 251 rheumatologists (physicians who specialize in treating lupus). The survey was funded and developed by Human Genome Sciences and GlaxoSmithKline. This release is the second in a series of reports on the National Burden of Disease Survey. For previous releases please visit: [New Survey Reveals Lupus Communication Gap as Many Patients Remain Silent on True Impact of the Disease](http://NewSurveyRevealsLupusCommunicationGapasManyPatientsRemainSilentonTrueImpactoftheDisease) [www.multivu.com](http://www.multivu.com)

# Events & Potpourri !



A lovely fashion show has been arranged to benefit the Lupus Foundation of Southern Arizona! Come by and see great fashions as you enjoy dinner at Sir Veza's Taco Garage, Swan & Speedway.

Held: Weds, September 26th  
Time: 5pm - 7pm.

If you have any questions just call us at 622-9006 or contact Lindsey Watson at 331-2997

Make sure you send in your reservation for the **Annual Meeting Luncheon** held Saturday September 29th. Seating is limited. Hunter Yost, MD., will be discussing how Functional Medicine can benefit those with lupus and other rheumatological illnesses. Listen and ask questions, while enjoying a light lunch at Emeritus! Deadline for Registrations is Thursday September 27th.

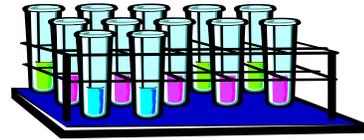


Time for Annual Dues Membership Renewal - new year starts October 1st - \$20.00

You can designate your **United Way donation** to go directly to our Foundation. Write in the Lupus Foundation of Southern Arizona, and use our **CFC Code #69190**. Thank you for your support!



**f** Friend us on **Facebook**. Look for Lupus Foundation of Southern Arizona. We are hoping to have 300 friends by the Annual Meeting on September 29th!!!



Research funded by the Lupus Foundation of America has been instrumental in advancing a promising area of research. Recently the company Exagen announced a new test using C4d to help physicians make a faster and more accurate diagnosis of lupus. Lupus is a complex disease and it is unlikely that one blood test will serve all of the patients all of the time. However, research suggests that a more refined way of looking for clues from the complement proteins might be an improvement over tests that are commonly used today.

ALBUQUERQUE, N.M., Jan 9, 2012/PRNEEWSWIRE/Exagen Diagnostics, Inc. a specialty focused molecular diagnostics laboratory that discovers, develops and markets proprietary tests for rheumatologists and gastroenterologists, announced the launch of **Avise SLE**, which aids in the diagnosis of lupus (Systemic Lupus Erythematosus).

**Avise SLE** is a 5-marker panel designed to Rule-in SLE and Rule-out other rheumatic diseases to help establish the most accurate SLE diagnosis. **Avise SLE** is most impactful when ordered as a first step in patient treatment to help physicians with diagnosis by providing:

Efficiency - 5 individual markers, 1 blood draw

Confidence in Diagnosis - From a panel that rules-in SLE and rules-out other rheumatic diseases

Increased Accuracy - Using CB-CAPs technology to achieve 78% sensitivity and 87% specificity for other diseases/97% specificity for normal/healthy patients

Convenience - Providing kits, pay shipping costs and return test results in 7 business days.

"Exagen is excited to offer a breakthrough diagnostic that uses CB-CAPs technology to help accurately determine if a patient has lupus," said Ron Rocca, President and CEO. "Because diagnosing lupus is so difficult and early diagnosis is critical in avoiding major organ damage, developing an accurate diagnostic to fill the unmet need for rheumatologists was a top priority. We have been able to do that with **Avise SLE** and are pleased to take part in helping physicians gain control over this serious disease."

## Lupus Support Group Schedule

September    Illness & Depression by  
Licensed Massage Therapist &  
Yoga Instructor

October        Stress

November     Holiday Helpful Hints

December     Relaxing Potluck

**Tucson Support Groups are held the 3rd Wednesday each  
Month, 10AM at our office**

Weds Sep 19th    Weds Oct 17th

Weds Nov 21     Weds Dec 19th

For additional details call 622-9006 or email us at [lupus12@juno.com](mailto:lupus12@juno.com)

*Past subjects discussed in Support Group:*

*February - Diagnosis & It's Impact on You*

*March    - Understanding Lab Tests*

*April     - Red Flags!*

*May      - Helpful Hints*

*June     - Stress & Lupus*

*July      - Benlysta Guest Speaker*

# Our Services

**SPECIAL NEWSLETTER** For Newly Diagnosed Patients - tips on flares, doctor-patient relationships, medication problems and a list of lupus publications

**WEBSITE:**

[www.lupus-az.org](http://www.lupus-az.org)

**MEDICAL ARTICLES LIBRARY**

**QUARTERLY NEWSLETTER**

**TUCSON SUPPORT GROUPS**

Held 3rd Wednesday

**DOUGLAS AREA SUPPORT GROUP**

Held Monthly - 520-364-5028

**YOUTH SUPPORT**

**LUPUS SELF HELP CLASSES (SLESH)**

**INFORMATION & REFERRAL SERVICES**

## PUBLICATIONS ON LUPUS FOR PURCHASE

**LENDING LIBRARY**

Books, audio tapes, video tapes, reference material on lupus, along with Regional Lupus Newsletters

**BILINGUAL INFORMATION & SUPPORT**

**INFORMATION FOR VISUALLY IMPAIRED**

**COMMUNITY SPEAKERS**

**SOCIAL SECURITY DISABILITY COUNSELING**

**EMERGENCY MEDICAL NEEDS ASSISTANCE**

**AFTER-HOURS TELEPHONE SUPPORT**

**ONE-ON-ONE SUPPORT**

**VOLUNTEER OPPORTUNITIES**

**TOLL-FREE NUMBER: 1-877-822-9006**

[www.lupus-az.org](http://www.lupus-az.org)

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