

# Lupus News

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*Lupus Foundation of Southern Arizona, Inc.*

*www.lupus-az.org*

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## Pain Management in Lupus and Connective Tissue Diseases

by Janice Dort RN

*One of the most difficult parts of having lupus is the constant readjustment of our lifestyles. This may be caused by increased disease activity, but more often by discomfort or chronic pain which may not be reflected in laboratory tests.*

Health care professionals get frustrated in their efforts to help relieve this discomfort. After a period of time your doctor or nurse may appear to develop a "Deaf ear" to your complaints of pain. After an assessment looking for a "new" cause of the pain finds nothing significant, we are frequently told it is "just lupus" and to "learn to live with it." This only increases our frustration and feelings that our complaints aren't heard or believed. Interestingly, One of the co-authors of a textbook on pain written for nurses by Margo McCoffery, states "pain is whatever the experiencing person says it is, and exists whenever he says it does."



To help better understand pain, there are two generally accepted components:

**Physiological pain**—the physical feeling of pain with changes in pulse, respiration, blood pressure, etc. And

**Psychological pain**—the emotional response to pain, which has an almost endless list of reactions ranging from depression and withdrawal to hyperactivity and anxiety.

Most bodily pain is a combination of the two components. Recognizing *acute pain* from *chronic pain* is a matter of terms, not a judgment of the severity of pain. Acute pain usually has a recognized specific cause such as, a broken bone, surgery, appendicitis, etc. Acute pain will generally have a specific duration and tend to decrease over time and then end. Chronic pain has been defined as pain that is present for more than six months and may vary in intensity; it may or may not have a specific cause that is easily pinpointed. Chronic pain often becomes a frustration to the health care professional by continuing to cause discomfort despite the efforts of the medical team.

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Like us on Facebook!



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## *From Your President.....*

### **Mission Statement**

To provide information, education and referrals for those affected by lupus; 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 support relevant lupus research, and collaborate with the professional community in improving the standards of diagnosis, care and treatment of lupus patients.

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What a successful Walk-the-Loop-for-Lupus we had in April! I want to take this opportunity to thank our sponsors, especially Miller-Coors and Agero, our Title and Presenting sponsors, respectively. My thanks go out to all of our Board members, dedicated staff, and selfless volunteers, who gave their time and energy to make the 14<sup>th</sup> Annual Walk very special. Most importantly, I want to thank everyone who came out to walk for our mission and our cause.

The Foundation welcomes two new Board members, Sue Thomas and Bill Murphy. We also welcome Luci Ponticelli, our new office team member. Sadly, we say goodbye to Patty Powell, who retired earlier this month after 30 years of service on the LFSA Board. Patty, most notably, orchestrated the Walkathon since its inception 14 years ago.

LFSA is now offering *Coffee Talk* once a month for those individuals who just can't make our daytime support group meetings. *Coffee Talk* is an open forum for Lupus patients and their families, friends, and supporters to come and mingle. Additionally, the Foundation has posted all of the details of our new Limited Scholarship Program to aid Lupus patients of any age, or minors who are supported by a parent or caregiver with Lupus. The LFSA Board understands it is difficult for people living with Lupus to juggle work, family, try to further their education, and STAY WELL. Remember, you are not alone in your journey, so please visit our website [www.lupus-az.org](http://www.lupus-az.org) for all of our support group and scholarship information.

We will also have information on our Camps for Kids, Camps for Families living with Lupus, and Retreats for Women with Lupus, posted on our website very shortly. Our September target date will provide 'free' workshops to bring together our Southern Arizona Lupus community. These camps and retreats are designed to provide support, interaction, and a sense of community, while helping provide the tools and coping skills for patients and their families.

Finally, our very first Annual Gala this year will be held at the Lodge at Ventana Canyon on Sunday, November 15<sup>th</sup>, with Arizona Dental Medicine as our Presenting Sponsor. The evening will include a silent auction, dinner, guest speaker-Dr. Bridget Walsh, and recognition of the lives of Amy and Derrick Ross. Details and registration will be posted August 1<sup>st</sup>.

Please stay in touch with us, either by phone or visit, or through Facebook on our web, as we welcome your input, your journey, your thoughts, and your needs.

*-Rebecca Shields*





## Pain Management in Lupus and Connective Tissue Diseases cont'd from pg 1

Lupus and other connective tissue diseases can be present with multiple manifestations of acute and chronic. The pain of pericarditis, pleurisy, abdominal pain, etc., tends to fall into the acute label with a sudden onset that generally responds to therapy. The joint and muscle pain, nerve pain called neuralgia and neuritis, and headaches can have a sudden or slow onset with lupus patients. Occasionally these conditions parallel the activity of the disease and responds as the disease gets under better control. But it is far more common for these discomforts to become a relentless part of day-to-day life for the lupus patient.

Methods of dealing with pain includes invasive methods such as the use of medication or surgical procedure, and non-invasive methods that do not require the skin to be broken or an organ of the body to be entered. There are many things available to use. Medication, physical therapy, biofeedback and TENS units are useful in some situations, but all require a doctor's prescription and may not be available at 3AM. It helps to have a variety of options to help us hang on until the pain lets go.

**DISTRACTION** can be your number one defense. We can decrease our awareness of pain and increase our tolerance by directing our attention to something other than the discomfort. The distraction can be anything. The most relaxing and enjoyable experiences are music, humor, TV, movies, hobbies and sharing affection. Most people utilize this technique but have been unaware of its role in pain management and do not consciously use it to decrease pain.

**REST** is highly effective and underrated management technique. Although sleep and relaxation are frequently interrupted by musculoskeletal pain, they are most effective in minimizing this discomfort. Occasionally minor tranquilizers and anti-depressants are prescribed to overcome the sleep disturbance and allow a healing rest to take place. We can rest tender muscles and sore joints by decreasing our activity for a short period of time. We must guard against the tendency not to resume our activities such as exercise since it is important to maintain muscle tone and physical conditioning.

**HEAT AND/OR COLD** treatments with or without massage, are beneficial. Cold has a numbing effect from a few minutes to a few hours. Heat is soothing and helps promote muscle relaxation. Safeguards must be taken against frostbite or burns, especially if there are circulatory or sensation deficits.

**IMAGERY** can also help. Imagining the discomfort while relaxed and using thought to destroy the problem is a proven method. An example of imagery is to think of a headache as a spot on a fabric. The spot is attacked by an enzyme detergent and disappears. Do this fifteen or so minutes two or three times a day while listening to relaxing music. It becomes more effective with repetition.

**BIOFEEDBACK**, (a process used to control the physiological functions of the body) has been highly

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## Pain Management in Lupus & Connective Tissue Diseases cont'd from page 3



publicized and has some benefits for pain. It is a learned response where the patient works with a therapist and psychologist.

similar situations and found ways to cope. Increased understanding of lupus will decrease the anxiety associated with having lupus (which contributes to the pain). This may be the first time you are able to meet people who are willing to listen and who understand what you are going thru.

### RELAXATION AND STRESS REDUCTION TECHNIQUES

are similar methods. A restful environment and enjoyable music or even silence can be very healing. There are many self-help books to teach these techniques and how to incorporate them into your daily life. They take you through the step-by-step process of learning some of the methods used to achieve the level of relaxation that is helpful in pain reduction and healing.

All of these methods of pain management can be beneficial to the person with lupus, and they are particularly effective when used in combination. As with many aspects of lupus, each individual needs to find out what works best in his or her particular case.

This may take some practice before you give up on a technique. It is important to be aware of all pain defenses because what may not work today may ease the pain tomorrow. ■

**SUPPORT GROUPS** - Attending Lupus Support Groups is very helpful. These groups provide the opportunity to meet others who are dealing with



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Happy Summer! Please join us at Apple Annie's for their summer harvest. A portion of all proceeds will benefit the Lupus Foundation of Southern Arizona. Take a look and set a date !!

|                           |   |   |                                       |
|---------------------------|---|---|---------------------------------------|
| Sweet Corn Festival       | July 11-12, 18-19                                 | Peach Mania                               | July 18,19,25,26<br>Aug 1,2,8,9,15,16 |
| Watermelon Weekend        | July 25,26, Aug 1,2                               | Salsa Fiesta                              | Aug 8,9, 15, 16                       |
| Apple Harvest Celebration | Aug 29,30, Sep 5,7,<br>12,13                      | Apple Pie Weekend<br>& Country Craft Fair | Sep 19,20                             |
| Green Chili Roast         | Sep 5,6,7,12,13                                   |   |                                       |
| Fall Pumpkin Celebration  | Sep 19,20,26,27<br>Oct 3,4,10,11,17,18,24,25,31st |   |                                       |



# Lupus Support Group

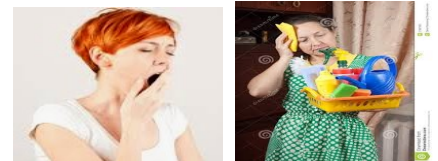
*with Helen Butler, R.N.*

3rd Wednesday of Month—Lupus Office 10AM—NOON

"My goal as your Facilitator is to inform, update and educate our Group on various healthcare topics and resources. Each person is encouraged to share their concerns and question. Remember, this Group is YOUR sounding board. It's a time to express yourself in a supportive surrounding," Helen 299-6895

## SCHEDULE

|            |  |
|------------|--|
| July 15th  | Organic Food Standards                                 |
| Aug. 19th  | Building Blocks to Healthy Living                      |
| Sept. 16th | Prioritizing & Organizing                              |
| Oct. 21st  | Safety In Your Home                                    |
| Nov. 18th  | A change in living arrangements, "Is it time to move?" |
| Dec. 16th  | "Round up" - Bring the Year to an End                  |



**Can't Make An Early Support Group, no worries! Join Our Evening Support Group!**



## WHO

**ANYONE WHO HAS LUPUS OR KNOWS SOMEONE WITH LUPUS**

## WHAT

**JOIN US FOR AN OPEN-FORUM, CASUAL DISCUSSION OF LUPUS-RELATED TOPICS**

## WHEN

**6PM AUGUST 5, 2015**

## WHERE

**LUPUS FOUNDATION OF SO. AZ.  
4602 EAST GRANT ROAD, TUCSON, AZ. 85712**

## REFRESHMENTS

**SNACKS & BEVERAGES**

## QUESTIONS?

**CALL: 520-256-7286**

## EMAIL:

**tucsonlani@gmail.com**

## News Notes & Quotes



The Lupus Camp for Kids & Families and the Lupus Retreat for Women Living with Lupus, are scheduled

for August 22nd, September 29th, and October 10th. These programs offer relaxation and a break from the stresses of living with a chronic illness. Contact Valarie Light at 271-6325 for more information.



The **Lupus Foundation of Southern Arizona Limited Scholarship Program** offers Lupus patients or those financially impacted by Lupus to continue a higher level of education. LFSA is offering \$3000 annual scholarship awards to those candidates who qualify. For details, please go to our website at [www.lupus-az.org](http://www.lupus-az.org)



**Board Nominations**—Time to nominate a candidate you feel will represent your interest as a lupus patient for our 2015 Lupus Board of Directors Elections. You will be receiving the nomination form in your mail the week of July 20th!

*"Education is when you read the fine print.*

*Experience is what you get if you don't. "*

PETE SEEGER Singer & composer



**LESS PREDNISONE!** A small study in Spain is raising hopes that Lupus Nephritis patients can be treated with a dosage of the corticosteroid Prednisone that is less than half the current standard and still be just as effective with few or no side effects. The Lupus Research Institute reports:

LN is typically treated with a combination of immunosuppressants and high-dose prednisone (50-60 mg a day). But the cost of remission over time at that dose is often bone loss, osteonecrosis, cataracts, and cardiovascular disease.

However, researchers at the BioCruces Health Research Institute in Spain report that half or even less than half that amount of prednisone produced complete or partial remission in a majority of patients in as quickly as six months, with few or no side effects.

The new regimen, which they call the "Cruces Protocol," consists of starting doses of 15-30 mg/day given with pulses of methyl-prednisolone, hydroxychloroquine, and cyclophosphamide, rapidly tapering the prednisone to a maintenance dose of 2.5-5 mg/day within 16 weeks, and maintaining azathioprine and/or mycophenolate mofetil for up to two years.



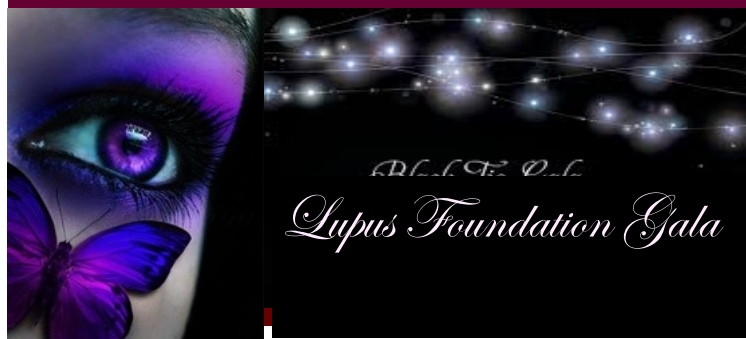
**LEGISLATION** - The Senate passed and President Obama is expected to sign the Consolidated and Further Continuing Appropriations Act of 2015 which provides funding for vital lupus research and education programs.

The federal government and industry are the largest sources of funding for lupus research. That's why our advocacy efforts are a key component to our national research program. Our thousands of lupus activists have four reasons to celebrate because the bill includes funding for:

The National Lupus Patient Registry at the [Centers for Disease Control and Prevention \(CDC\)](http://www.cdc.gov) will receive the largest appropriation in the program's history: \$5.75 million, bringing the total for the program to \$37.8 million. This is the largest lupus research study to determine the number of people in the United States who have lupus. The [Department of Defense's \(DoD\) Peer-Reviewed Medical Research Program's \(PRMRP\)](http://www.defense.gov) funding will increase from \$200 million to \$247.5 million. In 2005, the Lupus Foundation of America was instrumental in having lupus included in the program, and we will encourage the research community to apply for these vital funds. The [National Institutes of Health \(NIH\)](http://www.nih.gov), from where the majority of all lupus research is funded, will receive \$30.1 billion representing a \$150 million increase.

[The Lupus Initiative](http://www.hhs.gov), within the Office of Minority Health, is aimed at educating physicians and other health professionals about lupus will be funded at \$2 million bringing total funding to date to \$8.6 million.





## Memorials

The Lupus Foundation is saddened by the death of long-time member, volunteer and Support Group Facilitator for the Douglas area, **Carol Huddleston**.

Carol died May 1st in her home. Despite having no direct connection with lupus Carol admirably took up the cause and spear-headed investigation into the high incidence of lupus in southern Arizona and became instrumental in the findings of the CDC in 1990's. Since that time Carol facilitated the Autoimmune

Support Group in Douglas , Arizona. Her calming and sympathetic support impacted everyone who attended. Carol will be missed by everyone who ever met her.

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### Memorial Gifts & Tributes....

A memorial gift to the Lupus Foundation is loving and lasting tribute. This can be a gift in memory of a deceased relative or friend or it can be given as a tribute in the name of a friend or relative to commemorate special occasions such as birthdays, anniversaries or graduations. These thoughtful gifts serve the living by supporting lupus education and research. Acknowledgements of memorials and tributes are mailed to the family with no reference made to the amount of the gift, and the donor receives a tax receipt. Thank you for caring.

*Lupus Foundation of Southern Arizona, Inc.*

FOUNDATION

RESOURCES

After- Hours Telephone Support Line - 520-622-9006

Bi-Lingual Information & Support - Lilly 296-7773, Alicia 327-0727

Support Group—Our office, 3rd Weds. 10AM—Helen Butler, RN

Personal & Youth Support - Call Office

Lupus Scholarship Program

Coffee Talk- Evening Support Group - Call Office

Community Speakers

Emergency Medical Need Assistance

Information and Referral Services

Information for Visually Impaired

Lending Library

Lupus Camps & Retreats

Quarterly Newsletter & A Newsletter for the Newly Diagnosed

Website - [www.lupus-az.org](http://www.lupus-az.org) and Toll free = 1-877-822-9006



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