

# Lupus News

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*Lupus Foundation of Southern Arizona, Inc.*

*www.lupus-az.org*

4602 E. Grant Road  
Tucson, Arizona, 85712  
Ph. 520-622-9006  
Toll-Free 1-877-822-9006  
Fax 798-0972

## Lupus and Your Thinking, Memory & Behavior



Questions about how lupus affects the brain? We hope the following articles are helpful.

*Meggan Mackay, MD, Columbia University Medical Center, New York, NY 2012*

In about half of people with lupus, the disease attacks the brain and spinal cord. Lupus can also affect the peripheral nervous system, which is made up of the nerve fibers that give skin and muscle the power for feeling and movement. These developments can be very frightening and frustrating. Thankfully, there are steps a person can take to make things easier. Doctors who specialize in these complications are called “neurologists.”

Many lupus patients—at least one in five—have trouble thinking clearly at some point and experience memory problems, confusion, fatigue or difficulty expressing thoughts, called cognitive dysfunction. Cognitive dysfunction likely occurs because blood stops flowing as smoothly to the brain as it should. This also can happen when lupus antibodies cross the “blood-brain barrier,” directly damaging brain cells in areas that store memories and other important information. Cognitive dysfunction may come and go but often steadily worsens over time.

“Lupus Fog” can be a part of cognitive dysfunction. For example, they may read the same sentence over and over again. Or struggle with some patients. They will get spells of “fogginess” when, for several seconds or minutes, they cannot get to information that they know is in their with a normally easy task like balancing a checkbook or dialing a familiar number.

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**Annual Walkathon April 25, 2015**

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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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Well, so far 2015 has been a whirlwind! The Foundation set out to achieve some big goals for 2015, and I am happy to report we are working hard to achieve them, one goal at a time. First, we have given Lupus Foundation on Grant Road a makeover and we have a whole new look. Please come by, as we have extended our hours to Monday through Friday 9:00 am to 2:00 pm to serve the Lupus community five days per week. We have also completely redesigned our website which should prove to be more user friendly, providing more information and guidance. The website links out to Facebook, provides easy access for registering for our events, links up to the latest research and awareness videos on Lupus, and so much more.

In addition to the services we currently provide, we are also working diligently on getting our new programs underway. We will be providing limited scholarships to Lupus patients, or youths who are financially impacted by a parent/caregiver with Lupus, to attend a community college/technical school. Applications will be posted online April 1<sup>st</sup>. Camps for kids, women, and entire families impacted by Lupus are also in the works at the Foundation. If you want to take part, please contact our office at 622-9006.

In my 29 years as a Lupus patient, I am still amazed at how many people still don't know what Lupus is. So, we are 'making it our mission' to create a higher level of awareness of Lupus in our community. Several business and entities in our community have joined our cause this year and the Foundation is honored to recognize our new 'Community Partners' on our website [www.lupus-az.org](http://www.lupus-az.org).

Our Walk-the-Loop for Lupus Walk is April 25<sup>th</sup> this year. We are trying to break the 1,000 walker mark, so please come and join us. I hope to see faces from last year as well as new faces. I will be one of many in a 'purple' shirt walking for the fight against Lupus.

Again, 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*

*Memorials*

A memorial gift to the Lupus Foundation is a loving and lasting tribute. This can be a gift in memory of a deceased relative or friend or can be given as a tribute in the name of a friend or relative to commemorate occasions such as birthdays, anniversaries or special events. These thoughtful gifts serve the living by supporting lupus education and lupus research.

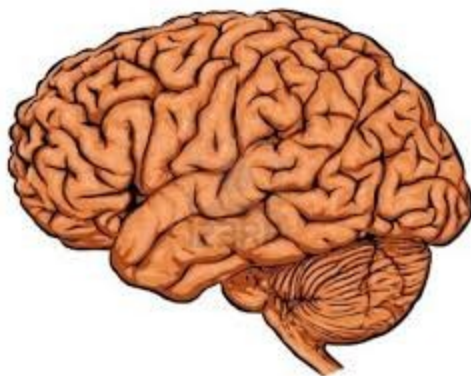
Acknowledgements of memorials and tribute acknowledgements are mailed to the family with no reference made as to the amount of the gift. The donor receives a tax receipt from the Foundation.



## Lupus and Your Brain *cont'd from page 1*

Do other brain problems occur in people with lupus? Yes, although they are not as common as cognitive dysfunction. Strokes occur when blood flow to the brain is interrupted and brain cells die from lack of oxygen, causing symptoms such as tingling sensations and problems with vision, speech and movement. Lupus patients have a higher risk for stroke, especially the third of patients who have “antiphospholipid antibodies” that make blood “sticky” and more likely to clot and stop or slow blood flow to the brain.

Can lupus change emotions and behavior? Some individuals with lupus have mild but noticeable changes in behavior such as unusual feelings of fear or lack of fear, or loss of interest or curiosity. More commonly, the fatigue and pain of lupus is draining to the point that a person changes his or her outlook on life. Corticosteroids and other lupus medicines sometime make matters worse by causing weepiness or other strong feelings. The “emotional rollercoaster” of lupus is something that always should be discussed with a doctor.



What can a person with lupus do about brain involvement? Diagnosis is challenging, with the cause of the problem often unclear and complex. Often made difficult because infection and side effects from medicines can lead to the same signs and symptoms as active brain lupus and no single test can show without question that lupus is the cause. A doctor can do a physical examination, test blood and spinal fluid or take imaging tests or electrical studies of the brain. Sometimes this helps to figure out what is going on.

No matter whether the problem is mild or severe, there often are effective and surprising ways of handling lupus thinking problems, memory difficulties, and behavior issues. Counseling and anti-depressant medicines help many people. Support groups are a good place to hear about ideas on concentrating better, remember important things and thinking more clearly. Knowing that others live with the scariness and unknowns of lupus can make having the disease less lonely. With time and luck, the researchers hard at work figuring out what can be done to stop lupus from damaging the brain will have some solid answers.

## Psychological Effects of Lupus

*Our thanks to the Lupus Foundation of Delaware “Learning About Lupus, A User Friendly Guide”*

Systemic Lupus often causes psychological symptoms. These include feelings of anxiety, sadness, depression and confusion. Usually the symptoms are mild and do not interfere with normal daily functioning. Such symptoms are similar to those experienced by any patient with a chronic medical condition such as diabetes or heart disease. Sometimes these symptoms become more severe and cause patients real emotional distress by interfering in their daily activities or in their relationships with others. When this occurs it is important that patients discuss the problems with their doctors. The doctor can do some investigation to find out what may be causing the problem and suggest appropriate treatment

**Thank you Community Partners - Agero \*\* Finley Distributing\*\***

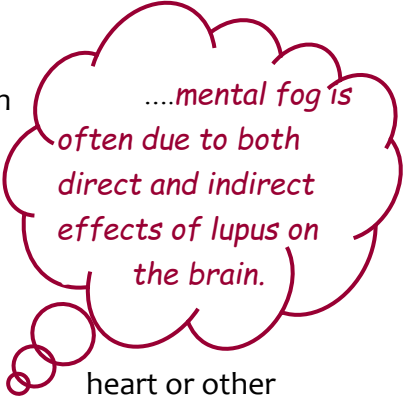
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## Psychological Effects.....cont'd from page 4

### Direct Effects on the Brain

Systemic lupus has many direct effects on the brain. Typically these take the form of problems with memory, slowing of thinking, confusion or hallucinations. They may, however, show up as anxiety or depression. Then neuropsychological testing, and blood tests may be useful to sort out whether active lupus is playing a role in the mental and emotional problems.



....mental fog is often due to both direct and indirect effects of lupus on the brain.

### Indirect Effects on the Brain

Just as in other chronic diseases, when lupus affects the kidneys, the lungs, the heart or other organs, there may be indirect effects on the brain. Disease of the kidneys can cause high blood pressure, allow waste products to accumulate in the blood and change the normal balance of chemicals in the body. Heart and lung disease can affect the amount of oxygen the brain receives and can also affect chemical balance. Thus, when a person has lupus affecting these organs and also have psychological symptoms, it is important to try to treat the organ disease before attributing the psychological problems to other causes.

### Side Effects of Medication

Many medications used to treat systemic lupus and its associated problems such as high blood pressure, have psychological effects. Most outstanding in this regard are corticosteroids. Psychological effects appear related to the steroid dose, higher doses causing more emotional problems than lower doses. Steroids often cause a kind of “high.” The patient is more energetic, has a greater appetite, and becomes more elated and outgoing. Higher doses may cause insomnia, nervousness and irritability. Emotions may become labile (mood switches rapidly; the patient laughs one time and cries the next.) Hallucinations and confusion are rarely, not often, caused by corticosteroids. Besides corticosteroids, many other medications have been reported to have psychological effects on some people. Thus, when a patient reports this kind of problem to the doctor, one of the first things the doctor thinks about is whether the patient might be experiencing the side effects of a medication, particularly one that has recently been started or increased.

### Cognitive Dysfunction

Cognitive dysfunction is confused thinking or mental “fog” or “clouding.” It is often caused by physical illness and is part of what is called organic brain syndrome. In lupus, it can be due both to the direct and indirect effects of lupus on the brain. These confused thought processes can be expressed in being disoriented—the patient being unable to recognize time or place; or unable to tell what he or she is doing or even who they are. There may also be problems of attention span—being easily distracted and forgetting your place in a book or a conversation. Even simple calculation becomes difficult. Following a familiar route may be tricky and memory—especially for recent events—is poor. Treatment for cognitive dysfunction usually centers on treatment of the underlying physical cause, although patients may benefit to some extent from retraining or the use of devices to aid memory.

In summary, emotional problems are common in systemic lupus. Not all are due to the disease itself. Many are normal responses to illness and most patients respond well to treatment ■





# COFFEE TALK

## WHO

Anyone who has lupus or knows someone with lupus

## WHAT

Join us for an open-forum, casual discussion of lupus-related topics

## WHEN

Saturday, April 18th, 2015  
10am-Noon

## WHERE

Lupus Foundation of So. AZ  
4602 East Grant Road, Tucson, AZ 85712

## REFRESHMENTS

Snacks and beverages will be provided

## VISIT US AT

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

## QUESTIONS?

Call: 520.256.7286

Email:

[tucsonlani@gmail.com](mailto:tucsonlani@gmail.com)

Lupus.  
Learn about it.

## 2015 Support Group Schedule



### Central Tucson (3rd Wednesday of Month) 10AM

My goal as your Facilitator is to inform, update and educate the group on various healthcare topics. These topics have a direct correlation with expanding our discussions during group. Remember the group is your sounding board. It's a time to express yourself.

Helen Butler, RN Support Facilitator, 299- 6895

#### DATES & TOPICS

<u>May 20th</u>	Research & studies (updates)
<u>June 17th</u>	GMO's fact or fiction
<u>July 15th</u>	Organic food standards
<u>August 19th</u>	Building blocks to healthy living
<u>Sept. 16th</u>	Prioritizing & organizing
<u>October 21st</u>	Safety in your home
<u>Nov. 18th</u>	A change in living arrangements, "Is It Time to Move?"

## Why Attend Support Groups?"

*If you are a newly diagnosed lupus patient, you should go because you will meet people who have gone through the same thing as you—people who understand! You can learn about your choices for medical treatment, and you can learn what others have done to cope with this illness.*

*If you have had lupus for years and know all there is to know about it, you should go. Just think of all the new members who could benefit from your wisdom and expertise?*

*If you aren't feeling well, you should go because you'll probably find someone who has experienced the same thing. They may be able to give you suggestions on how to make things easier.*

*If you feel great, you should go. Share some of the great feeling and optimism with others who aren't so fortunate. Knowing that people with lupus can lead normal lives can be incredibly encouraging. Someone else's good health is good news and beneficial to all of us.*

*If you are not sure about your treatments, or if you have questions about symptoms you are experiencing, you should go. You can compare notes with others in the same boat.*

*If you think the meeting will be depressing, you should go because you will meet people who, although they may be worse off than you are physically, continue to remain upbeat and positive in their attitude—and they can help you to learn to do the same.*

*If you think the meetings are boring, you should go. Of course they are—without fresh faces and fresh ideas to make the meeting exciting. Bring yours to the next one!*

*Lupus Foundation of Southern Arizona, Inc.*

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← 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 Support - Call Office →

← Youth Support - Call Office →

← Douglas Support - 364-5028—Carol Huddleston →

← Community Speakers →

← Emergency Medical Need Assistance →

← Information and Referral Services →

← Information for Visually Impaired →

← Lending Library →

← Medical Articles Library including Research Articles →

← 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 →

